

Sexuality and intimacy in cancer and palliative care in The Netherlands: A hermeneutic study

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Abstract

Health care professionals are increasingly aware of the impact of cancer and cancer treatment on sexuality and intimacy, which are important components of quality of life until death. However, professionals are struggling with addressing these issues with cancer patients and their partners (clients). One of the reasons is lack of in-depth knowledge of clients' experiences.

Aims of the study

- To increase understanding of how cancer and cancer treatment impact upon the experience of sexuality and intimacy of patients and their partners
- To increase understanding of how cancer patients and their partners experience the way health care professionals address sexuality and intimacy
- To gain insight into health care professional's perceptions of their role regarding sexuality and intimacy for cancer patients and their partners
- To develop patient driven models, tools and recommendations to acknowledge sexuality and intimacy in cancer and palliative care

Methodology

Using a hermeneutic phenomenological approach, data were collected in the Netherlands through interviewing 8 patients, 7 couples and 6 partners of patients affected by cancer, and 20 health care professionals working in cancer and palliative care. Analysis was based on the hermeneutic circle, moving from the whole to the parts and back, and was enhanced by the use of ATLAS.ti, by peer debriefing and by expert consultation.

Findings

Findings are based on multiple perspectives and are presented in a storyline using vignettes. The core theme of the findings is 'worlds apart', manifesting itself on several levels: between clients and professionals, between partners and on the intra-psychic level of the patient. Cancer and cancer treatment impact on sexual function, sexual relationship and sexual identity, resulting in a unique outcome for every client or couple. Most participants reported that health care professionals did not address sexuality and intimacy, and attempts made often did not match participants' preferences. Most participants said they would value discussing the impact of cancer on their sexuality and intimacy. This does require a 'personalized' approach from the health care professional from the start of the interaction with the patient onwards. Based on the findings of this study and the available literature, a systemic client driven model (the BLISS communication model) and an integral team approach (model of stepped skills) were developed.

Conclusions and recommendations

All types of cancer and cancer treatment potentially have an enormous adverse and enduring impact on sexuality and intimacy. Therefore, sexuality and intimacy should be put on the agenda of health care education and of every cancer and palliative care team.

Both personal factors and lack of guidance hinder professionals in addressing sexuality and intimacy. Using the stepped skills team approach, team members can develop clear and complementing roles in order to properly address sexuality and intimacy issues, resulting in adequate support for clients in all sexual domains: sexual functioning, sexual relationship and sexual identity. Team members should be trained to develop the competencies matching their role.

Contents

Acknowledgements	3
Abstract	5
1. INTRODUCTION	11
2. SUPPORTING LITERATURE	17
<i>Defining the literature search</i>	17
<i>The impact of cancer on sexuality and intimacy</i>	19
<i>Defining sexuality, intimacy and sexual health</i>	19
<i>Impact of cancer and cancer treatment on sexual function</i>	21
<i>Impact of cancer and cancer treatment on sexual identity and sexual relationship</i>	25
<i>The clients' perspective on the impact of cancer and cancer treatment on sexuality</i>	27
<i>Communication about sexuality and intimacy in cancer and palliative care</i>	34
<i>Carrier theories and philosophical perspectives</i>	42
<i>Terror Management Theory</i>	42
<i>Heidegger on being-in-the-world and (in)authenticity</i>	46
<i>System Theory</i>	47
<i>Summary</i>	49
3. METHODS SECTION	51
<i>Paradigmatic stance of the researcher</i>	51
<i>Paradigmatic stance for a hermeneutic approach</i>	55
<i>A hermeneutic approach in studying lived experience</i>	60
<i>Quality criteria for a hermeneutic approach</i>	64
<i>Reflexivity / pre-understanding</i>	66
<i>Transferability of study findings</i>	67
<i>Limitations of a hermeneutic approach</i>	70
<i>Rationale for choosing a hermeneutic approach</i>	71
<i>Ethical considerations</i>	73
<i>Sampling</i>	74
<i>Rationale for including patients, partners, couples and professionals</i>	75
<i>Sampling of patients</i>	76
<i>Sampling of partners and couples</i>	77
<i>Sampling of professionals working in cancer and palliative care</i>	77
<i>Informed consent</i>	78
<i>Data collection</i>	79
<i>Data collection method</i>	79
<i>Interview context and structure</i>	79
<i>Interview process</i>	80
<i>Analysis</i>	81
<i>Processing the data and thematic analysis</i>	83

4. BEGINNING THE DIALOGUE: FINDINGS AND DISCUSSION	87
Setting the scene: the format for the discussion	87
<i>Structuring the story and the core of the study: worlds apart</i>	90
Interview and participant details	95
The clients' story	100
<i>Diagnosis</i>	100
<i>Preparation for treatment</i>	104
<i>Treatment</i>	109
<i>End of treatment: remission</i>	129
<i>End of treatment: death</i>	157
Reflections of the lived experience: on worlds apart	167
<i>Worlds apart: the professionals' world versus the patients' and partners' world</i>	167
<i>Worlds apart: the patients' world versus the partners' world</i>	168
<i>Worlds apart: the patients' authentic world versus the patients' inauthentic world</i>	169
Fusing horizons: lifting the veil	171
Lifting another veil: sexuality and intimacy	176
<i>TMT and sexuality for patients and partners</i>	180
5. CONTINUING THE DIALOGUE: IMPLICATIONS FOR PRACTICE	183
Bridging the gap on all levels of 'worlds apart'	183
<i>Level of patients and partners communicating with health care professionals: healing</i>	184
<i>Level of patient and partner interacting: mutual consolation</i>	188
<i>Intra-psychic level of the patients: wholeness</i>	189
Bridging the theory – practice gap: implications for health care practice and education	193
<i>Competency description and contextual prerequisites</i>	194
<i>Sexual identity, sexual relationship and sexual functioning</i>	195
<i>Person oriented approach</i>	196
<i>Before treatment: professional driven communication</i>	199
<i>During/after treatment: client centred communication: BLISS model</i>	200
<i>Stepped skills</i>	204
<i>Make a difference in 10 minutes</i>	206
Dialogue about the implications for practice with health care professionals	207
<i>Validating and testing out the implications with different target audiences</i>	207
<i>Developing a one-day training programme</i>	208
<i>Piloting the one-day training programme</i>	210
6. COMPLETING THE CYCLE: CRITIQUE AND HERMENEUTIC REFLECTIONS	211
Critique	211
Reflections	219
<i>Reflexivity</i>	219
<i>Personal reflections</i>	223
7. CONCLUSION AND RECOMMENDATIONS	231
<i>The way forward</i>	239

References

Appendices

List of tables, boxes and figures:

Table 1:	Overview of possible side effects of cancer treatment on sexual function and possible remedies	23
Table 2:	Framework showing the vignettes in relation to the timeline and the different levels of the theme 'worlds apart'	94
Table 3:	Overview of number and duration of interviews and resulting number of transcript pages per participant group	95
Table 4:	Demographic and illness related characteristics of the couples	96
Table 5:	Demographic and illness related characteristics of the patients	97
Table 6:	Demographic and (patient) illness related characteristics of the partners	98
Table 7:	Overview of characteristics of professionals	99
Table 8:	Overview of gaps, aims of bridging the gaps and relevance for sexuality and intimacy on the three levels of 'worlds apart'	184
Box 1:	Example of the application of the PLISSIT model in patients with breast cancer	36
Box 2:	Overview of types of generalisation	68
Box 3:	Competence: Addressing sexuality and intimacy in cancer and palliative care	194
Box 4:	BLISS communication model	201
Box 5:	Minimal requirements for 'spotters'	207
Figure 1:	Three concentric levels of 'being-in-the-world'; <u>underlining</u> indicating the perspective(s) taken at each level	91
Figure 2:	Looking in the mirror to see a dying person	172
Figure 3:	Four types of care	197
Figure 4:	Stepped skills model: Team approach for cancer and palliative care teams using complementing skills in acknowledging the importance of sexuality and intimacy	205
Figure 5:	Example taken from the card game 'happy families'	209

1. INTRODUCTION

This was a hermeneutic study of sexuality and intimacy in cancer and palliative care, which was undertaken in 2007 – 2011 in the Netherlands. Therefore, to facilitate implementation in the Dutch context, the terminology used has to reflect current practice in the Netherlands. However, there has been considerable interest in the findings from other countries across Europe and the USA, and currently discussions are under way to adapt the models developed for implementation in these other countries.

The study arose out of a combination of factors. Firstly, working as a lecturer in nursing education, it became evident that students were hesitant to bring up sexuality in practice, for example when exploring Gordon's (1994) functional health pattern on sexuality and reproduction with patients. Secondly, when carrying out two studies based around the problems and needs of patients in palliative terminal care¹ (De Vocht and Notter, 2006, De Vocht, 2007), the findings revealed that apparently neither professionals nor clients took the initiative to discuss sexuality. This raised questions regarding what was happening to these identified patients' needs. Searches for research and materials found limited information from the clients'² perspective and there seemed to be few studies focused on this subject with a view to improving care, a gap acknowledged in a Dutch national report on lacunae in palliative care (ZonMw, 2005) and by the Dutch Comprehensive Cancer Centres (De Graeff et al., 2006). Therefore, this study was originally designed to explore the clients' world, using in-depth interviews focusing on the impact of cancer on the experience of sexuality and intimacy and on related communication with health care professionals. Bitzer (2010) described the 'oncologist's world' and the 'sexologist's world', illuminating fundamental differences, but, fascinating as his presentation was, the client's perspective was missing. Apart from professionals improving understanding between professional disciplines, it is key that they strive to understand their clients' world as best they can, so they can enhance their communication style with their clients.

¹ Although in the UK the term 'end-of-life care' is increasingly being used, this is not the case in the Netherlands

² 'Clients' refers to both patients and partners

The consequence of choosing to explore the clients' world is that it is by definition a holistic endeavour. Clients do not think in terms of separate variables that they can then neatly report on. A lived experience is an experience of the whole, of the Gestalt, in which everything is related to everything, or it could be said: in which everything IS (Heidegger, 1953/2010). As a result of this, the scope of the current study needed to be a broad one. In contrast, a review of publications on sexuality and intimacy in the domain of cancer and palliative care demonstrated the increasingly specialised and fragmented character of modern science. In science overall, the latest estimation is that the total number of journal articles published now amounts to about 50 million (Jinha, 2010), with in the biomedical domain alone, PubMed has an index of more than 19 million articles³ with around one paper per minute added. PubMed includes only humanities publications with biomedical relevance, which means that most articles do not meet their criteria and therefore the total number of articles in the biomedical and humanities domain is (much) higher than 19 million. The result of this mass of materials is that it becomes impossible to meaningfully integrate all relevant information. The most obvious solution is to concentrate on only a small aspect of the phenomenon one is interested in, but whilst this may give initial clarity, in turn it too makes science even more fragmented. Nevertheless, it is a very useful approach if the aim is to develop theoretical knowledge or to provide highly specialised people with evidence to base their decisions on.

By choosing to focus on the clients' world this study went a more holistic way. This has to do with the ambition to make clients' voices heard and to provide aids and resources for health care professionals working in cancer and palliative care. In their daily practice, these professionals meet living patients and have to deal with the 'whole' patient. Studies by De Vocht and Notter (2006) and De Vocht (2007) revealed that professionals were struggling with the topics relating to sexuality and intimacy. This is regrettable, as the literature shows that the majority of patients in cancer and palliative care experience significant changes regarding their sexuality and intimacy as a result of diagnosis and treatment.

³ Reference date July 15th 2010

Therefore, there was a clear need for a study capturing clients' experiences regarding these issues, to identify what support they would like from their health care professionals, and then to convey their message to these professionals. As a result of the holistic approach chosen, during the initial literature search when reviewing the studies to include, choices had to be made, as it was impossible to include every article that had any relevance to the study. The guiding light was which information would be most relevant for professionals in order to meet the needs of both patients (with all types of cancer and in varying stages of the illness and treatment trajectory) and their partners, so the emphasis was on identifying client focused research and literature.

However, repeated searches made it evident that only to look at the clients' perspective was inappropriate, as their perspective on communication with health care professionals cannot be studied in isolation. Professionals are part of the hermeneutic circle in which this communication takes place, and therefore the professionals' perspective was also crucial. As the final aim of the study was to make recommendations for practice, the expertise from professionals was essential to complement clients' experiences, as only then could both perspectives be put together to develop practical applications that were acceptable to both groups⁴. This meant the sample had to expand to include professionals. This resulted in the following aims for the current study:

- To increase understanding of how cancer and cancer treatment impact upon the experience of sexuality and intimacy of patients and their partners
- To increase understanding of how cancer patients and their partners experience the way health care professionals address sexuality and intimacy
- To gain insight into health care professional's perceptions of their role regarding sexuality and intimacy for cancer patients and their partners
- To develop patient driven models, tools and recommendations to acknowledge sexuality and intimacy in cancer and palliative care

⁴ In reality the professionals interviewed appeared to exist along a continuum with some openly stating they had no interest in or a wish to discuss these areas and others totally committed to share their expertise, supporting the aims of the study

In view of these aims, a broad scope from both the clients and the professionals was needed; therefore maximum variation sampling was used in both groups, resulting in a very large sample for a hermeneutic study. As Smith et al. (2009 p. 51) point out “there is no right answer to the question of the sample size” in interpretative phenomenological studies. Whilst ideally a smaller sample would have been preferable in view of the depth needed in the cycle of analysis, this study had to have practical application and therefore a compromise was reached between the theory chosen for the study and its practical application. It was recognized that, as a consequence of this, processing the data would take a considerably longer time if sufficient depth during analysis and interpretation was to be achieved.

Within a hermeneutic approach it is also relevant to consider the perspective of the researcher. Although this study is not about the researcher being or becoming aware of personal norms, values and worldview, it is relevant to address these as within a hermeneutic approach it is deemed impossible and undesirable to leave behind (‘bracket’) one’s preconceptions. Fusing horizons, which is the hermeneutic view of coming to an understanding, involves both the horizon of the researcher and the participant. What follows is a brief characterization of the researcher’s horizon: female, middle class, white, born and raised in the Netherlands, a psychologist, well-travelled, with a professional career in research and nursing education, interested in existential aspects and palliative care, married, with no cancer experience herself but familiar with (terminal) cancer in personal life, and a positive view on sexuality (as something to be enjoyed). However, it should be realised that it is impossible to describe one’s horizon or preconceptions completely, as many of these preconceptions are not accessible to the conscious awareness of the researcher. Therefore, at this stage, the description of the researcher’s horizon is intended merely to give the reader some idea of influences that have shaped the researcher’s worldview.

Searching the literature was an on-going activity because during data collection, analysis and interpretation, new themes came up and had to be pursued in the literature. Various theories and philosophical perspectives offered suitable conceptual frameworks for interpreting the findings and to serve as carrier theories and philosophies for the study. There appeared to be no end to the

paths that these fascinating glimpses of clients' and professionals' perspectives were leading to. It proved challenging to remain within the concepts on which the study was based and repeated refocusing was needed. Inevitably this meant that some issues could not be exhaustively researched.

Guided by the aims of the study and using the hermeneutic cycle, together with data from the interviews and the available literature, it has been possible to develop practical tools and models which provide clear signposts towards a way forward to enhance communication on sexuality and intimacy between clients and professionals in cancer and palliative care. These resources will better help health care professionals to meet their clients' needs in relation to sexuality and intimacy, thus providing a more holistic approach to living with a diagnosis of cancer.

2. SUPPORTING LITERATURE

Defining the literature search

The initial search of the literature was performed before data collection started, using a wide range of databases. It soon became clear that 'palliative' was conceptualized in different ways in the literature, varying from 'terminal' to 'incurable' to 'life-limiting' to 'life-threatening' and 'end of life', making it impossible to clearly distinguish between cancer care and palliative care.

According to the World Health Organization (WHO) (2002), palliative care is:

an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (WHO, 2002a)

Although other life-threatening illnesses were not initially excluded, all participants in the client group turned out to be cancer patients or partners of cancer patients, therefore the focus of the literature included had to be on this group. The WHO (2002a) definition of palliative care does apply to these cancer patients, for all of their cancer is potentially life threatening. Even if hypothetically there was a 100% guarantee that a cancer patient would be cured, the literature suggests that patients themselves often associate a cancer diagnosis with a death sentence (Tritter and Calnan, 2002, Vargens and Bertero, 2007) and therefore experience their cancer as a (potentially) life-threatening illness. In line with this, in the initial interviews with partners and patients it emerged that participants themselves do not make a clear distinction between cancer and palliative care. This is very understandable, as often there is no clear point in time where curative care stops and palliative care starts, as many aspects of palliative care are also applicable early in the course of the illness, in conjunction with anticancer treatment (WHO, 1990, De Graeff et al., 2010). Conversely, palliative care may be combined with therapies aimed at reducing or curing the illness, or it may be the total focus of care (WHO, 1990, De Graeff et al., 2010). So while the concept of palliative care might be distinguishable from other forms of care, in practice no clear line can be drawn

that sets palliative care apart from cancer care. Rice (2000), using the arguments of Lowden 1998 and Macdonald 1998, quite strongly argues that the transition from acute care to palliative care is rarely well defined and therefore the artificial distinction between acute cancer care and palliative care is inappropriate. Consequently, in this study, no clear boundary has been drawn between these domains, reflecting the lack of an absolute boundary between cancer care and palliative care in health care practice. As pointed out by Billings (1998), many elements of definitions of palliative care apply to other fields in health care as well, for example the focus on quality. Therefore, when searching the literature, the search term 'cancer' was used instead of 'palliative' to demarcate the population.

The database search strategy was complemented by snowballing the references found in recent publications and with specific searches for publications of authors that the database search showed to be key authors in the field and by searching the most recent volumes (10 years back) of the journals that came up in the data base search as key journals.

This preliminary search of the literature informed the basis of the study and was helpful in providing an overview of the field and in identifying gaps and inconsistencies in the literature. As this was a hermeneutic study, and therefore inductive, searching the literature did not stop after the preliminary search. Thus, the initial literature study revealed useful background information to consider throughout the study, however, when analysing data, following the inductive principle of the hermeneutic circle, it became evident that the initial literature search did not cover all the topics that turned out to be relevant. Therefore, during the entire research period, more supporting literature was sought, following the directions pointed out by the major findings of the study. As there appeared to be deeper layers of meaning and interpretation, this included philosophies and theories that could serve as carrier frameworks.

Although this chapter offers an overview both of the literature related to the scope of the study and of the carrier philosophies and theories, for clarity, literature that is more pertinent to the findings needed to be included in the discussion chapter.

The impact of cancer on sexuality and intimacy

Defining sexuality, intimacy and sexual health

'Sexuality' and 'intimacy' are elusive concepts to grasp. Many definitions of sexuality have been offered, with Taylor (1983 p. 54) suggesting sexuality "refers to the constellation of physical and psychological traits that make us male or female". This simple definition elucidates the important point that every person, including terminally ill persons, is a sexual being, as everybody has a gender. However, this gives little guidance for those working in practice of how this concept impacts on life. Similarly, Howlett et al. (1997 p. 218) describe sexuality as "encompassing the essence of self, what makes a person who they are" but again this is somewhat vague and needed further consideration. Gamlin (2005) states that the many meanings of sexuality are shaped and influenced by life experiences, which results in "sexuality meaning different things to different people at different stages of their lives" (Hordern and Street, 2007a p. E14). Therefore, sexuality is a highly personalized concept, which has different connotations for different persons. Wilmoth (2006) illustrates this view on sexuality by suggesting that "in many ways, sexuality is like pain or fatigue: It is what a person says that it is" (Wilmoth, 1998p. 905).

A key point, however, is that the concept of sexuality should not be narrowed down to sex or sexual activity (Howlett et al., 1997, Gamlin, 2005, Redelman, 2008, Mercadante et al., 2010). As Girts (1990) succinctly states, sex is something we do and sexuality is something we are. Sexuality is a broad concept, and (potentially) encompasses many aspects as described in the following, somewhat lengthy, working definition by the World Health Organization (WHO):

Sexuality is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical and religious and spiritual factors. (WHO, 2002b)

That a shorter, more succinct definition was not possible, gives a good indication both of the complexity of the subject and of the difficulties encountered by those trying to find a simple way to incorporate sexuality into their work.

It is important to point out that in this broad view on sexuality 'intimacy' is included. Gilley (1988) captures the relationship between sexuality and physical intimacy by stating that sexuality is "the capacity of the individual to link emotional needs with physical intimacy – the ability to give and receive physical intimacy at all levels, from the simplest to the most profound" (Gilley, 1988 p. 121). More recently, Williams' (2001a) review on the concept of intimacy concludes that intimacy encompasses physical, psychological and emotional aspects. Although it is acknowledged that physical intimacy cannot be regarded in isolation from emotional intimacy, intimacy in this study is defined as physical intimacy. The scope of the current study is therefore the whole range of affectionate touching, as expressed in the definition of sexuality provided by Gianotten (2007p. 301): "the full range of physical contact, physical intimacy, eroticism, sensuality, sexual release and the consciousness of being a woman or a man". As physical intimacy is a (potential) component of sexuality it would technically have been sufficient to state that the current study is on the impact of cancer on sexuality (without explicitly mentioning intimacy). However, in order to stress the point that sexuality should be regarded in its broadest sense, 'intimacy' was included in the title of this study.

Interestingly, despite the range of research in this field even the WHO working definition of 'sexual health' seems to exclude cancer patients, as the absence of disease and dysfunction are required:

Sexual health is a state of physical, emotional, mental and social well being related to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled. (WHO, 2002)

This may be due to the use of the term 'health', as early definitions of health preclude those with acute or chronic health problems. Yet it is now recognized that the word health too is relative, and needs to be seen from the individual's perspective. Thus for some the presence of on-going disease does not preclude them from feeling 'healthy' (Kagawa-Singer, 1993).

Sexuality and sexual health are multidimensional concepts, so is sexual dysfunction a multifaceted issue. This is not surprising, as every aspect that sexuality encompasses can be affected and can therefore play a role in sexual dysfunction, with numerous variables potentially contributing. The prevalence of sexual dysfunction can be substantial in non-cancer populations, with Shifren et al. (2008) finding that 43% of the women (from a total of 31,581 United States women) reported some form of sexual dysfunction. However, only 22% experienced any sex-related distress, leading Hughes (2009) to the conclusion that professionals should always assess whether or not sexual changes are affecting patients. Despite the acceptance of the multidimensionality of sexuality, much of the literature on the impact of cancer and cancer treatment focuses on physical sexual function.

Impact of cancer and cancer treatment on sexual function

There is increasing evidence that all types of cancer, and not just cancers that involve sexual organs, can impact on sexuality and intimacy (Rice, 2000, Ananth et al., 2003, Mercadante et al., 2010, Flynn et al., 2011b). However, it is rarely the case that cancer itself leads to sexual dysfunction; it is mainly cancer treatments that interfere with sexual function (Tan et al., 2002). Estimates of sexual dysfunction after cancer treatment vary from 40% to 100% across the range of cancers (NCI, 2004). Cancer treatment can involve surgery, chemotherapy, hormone therapy, radiotherapy and opioid treatment (Schover, 2005), all of which can impact on sexuality and intimacy.

The physical domain per se is not the focus of the current study. However, in order to provide a context for the lived experience of cancer patients and partners, table 1 offers an overview of possible side effects of cancer treatment on sexual function and of some possible remedies (Rice, 2000, Hughes, 2008, Galbraith and Crighton, 2008). It is important to point out that typically different

underlying physiological substrates are damaged in men and women. Schover (2005), talking about men stated that “men frequently have erectile dysfunction (ED) related to damage to the autonomic nervous system and/or reduced circulation of blood to the penis. Hormonal impairment of sexual function is less common” (Schover, 2005 p. 523). She then goes on to discuss women, who “in contrast, are able to overcome damage to autonomic nerves if genital tissues remain structurally intact and estrogenized. Female sexual dysfunction is frequently associated with sudden premature ovarian failure or direct effects of radiation fibrosis or scar tissue causing pain with sexual activity” (Schover, 2005 p. 523). Schover (2005) also points out that the lack of validated interventions for sexual dysfunction following cancer treatment is a major problem. This means that the evidence base for the possible remedies included in table 1 is limited. Shell’s (2002) systematic review of evidence-based interventions for sexual dysfunction in cancer patients concluded that many reported interventions are based on expert opinion and case studies, with only few results based on randomised controlled trials (RCT’s). The Cochrane database holds only one systematic RCT-based review on interventions for sexual dysfunction following treatments for cancer (Miles et al., 2007). Of the eleven RCT’s identified, ten focused on the treatment of sexual dysfunction in men with non-metastatic prostate cancer and only one RCT assessed the effectiveness of a vaginal lubricant. Although the overall quality of the trials was poor, it was concluded that for treatment of erectile dysfunction following treatments for prostate cancer, PDE5 inhibitors are effective.

An overview of the impact of diverse cancer treatments on sexuality and possible remedies is provided by Eeltink et al. (2006). For possible solutions to various physical problems related to sexuality in the palliative-terminal phase, Gianotten and Hordern (2010) provide helpful suggestions. Brandenburg et al. (2010) have provided a booklet with useful tips and ideas regarding intimacy and sexuality for cancer patients and their partners.

Table 1: Overview of possible side effects of cancer treatment on sexual function and possible remedies based on Rice (2000), Hughes (2008) and Galbraith and Crighton (2008).

Treatment	Impact on sexual function	Possible remedies
Surgery involving genital organs or structures near them (neurological or vascular damage), mastectomy	<p>Women:</p> <p>Foreshortening of vagina (hysterectomy)</p> <p>Narrowing of entrance of the vagina (vulvectomy)</p> <p>Vaginal dryness & menopause (oophorectomy)</p> <p>No vagina (pelvic exenteration)</p> <p>Loss of erogenous zone (mastectomy)</p> <p>Men:</p> <p>Erectile dysfunction and loss of semen production (prostatectomy)</p> <p>Diminished libido and erectile dysfunction (bilateral orchiectomy)</p> <p>No penis (penectomy)</p>	<p>Vaginal dilators</p> <p>Prosthesis (breast, penile)</p> <p>Reconstruction (breast, vagina, penis)</p> <p>Lubricants</p> <p>Erection enhancing medication, injection, pomp, constriction ring</p>
Radiotherapy to the pelvis (neurological or vascular damage)	<p>Women:</p> <p>Delayed arousal and orgasm</p> <p>Vaginal dryness</p> <p>Vaginal stenosis and fibrosis</p> <p>Foreshortening of the vagina due to adhesions</p> <p>Loss of ovarian function (resulting in infertility & menopause)</p> <p>Men:</p> <p>Decreased testosterone secretion, diminished blood supply and damage to nerve supply, resulting in a degree of sexual dysfunction</p>	<p>Vaginal lubricants</p> <p>Vaginal dilators</p> <p>(Topical) oestrogen</p>
Chemotherapy	<p>Women:</p> <p>(Temporary) infertility</p> <p>Menopause with vaginal thinning and dryness</p> <p>Neuropathy (clitoris)</p> <p>Loss of (pubic) hair</p> <p>Men:</p> <p>(Temporary) infertility</p> <p>Loss of (pubic) hair</p>	<p>Vaginal lubricants</p> <p>Vibrator</p> <p>Local or general estrogens (if not contra-indicated)</p>
Hormone therapy	<p>Women:</p> <p>Loss of libido</p> <p>Men:</p> <p>Loss of libido</p> <p>Erectile dysfunction</p>	
General treatment side-effects	<p>Pain</p> <p>Nausea</p> <p>Fatigue</p>	<p>Analgesia</p> <p>Antiemetic therapy</p> <p>Energy conserving techniques and rescheduling activities</p>

The emphasis in the literature on the impact of cancer treatment on sexual function is such that most studies focus on acute cancer care, and not so much on those with advanced cancer. When Ananth et al. (2003) undertook their controlled study, they found no previous data available regarding sexual

function on unselected groups of cancer patients in different stages of illness. Their quantitative study used a set of self-completing questionnaires. Patients attending an oncology clinic were compared with patients with advanced cancer and with a group of general practice attendees without cancer, matched for sex and age. Results showed that sexual function was significantly impaired in both groups of cancer patients compared to the general practice attendees, with the most serious impact for the patients with advanced cancer. However, there was little difference in sexual satisfaction between the patients attending the oncology clinic and the general practice attendees. Thus, sexual dysfunction does not necessarily result in sexual dissatisfaction, but where serious sexual dissatisfaction did occur it tended to be in the group with advanced cancer.

The intended focus of a recent review by Mercadante et al. (2010) was sexuality in advanced cancer patients. Despite this focus, and defining sexuality as a broad concept, the majority of their review is about physical changes as a result of cancer and cancer treatment. The authors do acknowledge that in advanced cancer populations “physical and emotional symptoms affect sexuality” (Mercadante et al., 2010 p. 663) but do not address this issue in detail. Mercadante’s (2010) review endorses that the earlier point, about the emphasis being on the physical aspects of sexuality in cancer patients with little attention focused on psychological or relational aspects, is still valid, even where advanced cancer patients are the official focus. In the case of the Mercadante et al. (2010) review, this may (partly) be because they restricted their search to PubMed, which limited the range of literature they could access.

Tan et al. (2002) do include more issues, distinguishing between primary and secondary causative factors in sexual dysfunction, with primary factors including physical or organic changes and secondary factors being primarily psychosocial in nature. The labels ‘primary’ and ‘secondary’ seem to be somewhat arbitrary, as these factors will be impinging upon one another, resulting in a web of inextricably linked and interacting factors. However, as for example a study by Bredart et al. (2010) including 378 breast cancer survivors made clear, the impact of cancer and cancer treatment goes clearly beyond the physical, and

therefore the impact on sexual identity and sexual relationship must be taken into account.

Impact of cancer and cancer treatment on sexual identity and sexual relationship

Since the 1980's there has been recognition and stress on the relevance of adopting a broad scope on sexuality, including sexual identity and sexual relationships based on the literature and / or clinical experience (Taylor, 1983, Gilley, 1988, Howlett et al., 1997, Rice, 2000, Stausmire, 2004, Huber et al., 2006, Redelman, 2008, Shell, 2008, Hughes, 2009).

However, studying the impact of cancer on sexual identity and sexual relationship is challenging, as it fully reveals the complex interactions between numerous relevant variables, most of which are highly personalised and determined by even more unique factors such as personality, upbringing and experiences with sexuality and intimacy in past and current life. Also, sexual identity and sexual relationship are relevant aspects throughout the cancer trajectory, from diagnosis to eventual death, challenging researchers to include patients with advanced cancer in their studies instead of focusing on acute cancer care.

Tan et al. (2002) illustrate the complexity of factors involved through the example of a woman who is no longer able to have an orgasm after her gynaecological cancer treatment. Physiological factors at play could include the decrease in oestrogen level due to her surgery, which results in vaginal dryness and hot flushes. Psychologically this woman is anxious about her femininity and she also has a history of phobia. Socially, she feels a failure towards her family because she gave birth to just one child before having her hysterectomy. Her partner believes that her surgery has affected her sexuality, and she has found out that he is having an extramarital affair. Her sense of attractiveness is further undermined by the media's on-going message that it is the young and beautiful who are sexually desirable. Tan et al. (2002) point out that all these factors can contribute to this woman's inorgasmia, and that being inorgasmic can inversely impact on social, psychological and physiological aspects. It could also be added that there will be an interplay between these social, psychological and

physical factors, resulting in a web of factors that are all interacting in circular and inextricable ways.

The highly complex nature of potential causes of sexual dysfunction has led Pool et al. (2008) to the cardinal conclusion that “after a diagnosis of cancer, there is great diversity in potential (physical and psychological) hindrances regarding sexual functioning. Consequently, there is no uniform, causal model to explain for a certain patient having certain problems regarding sexual functioning” (Pool et al., 2008 p. 327). Despite this, attempts to quantify these variables have been made, although it is debatable how meaningful the outcomes are. For example, Zimmermann et al. (2010) focused on predictors of body image in women with breast cancer. The aim was to determine to what degree body image in these woman was determined by individual variables, how much by dyadic factors and by individual variables from the partner. It has to be noted that body image itself is only one out of the many factors impacting on the experience of sexuality; therefore focusing on this variable is a limitation to begin with. In order to meet the aim of the study, couples completed an extensive questionnaire package. The results were presented in a huge table of 18 by 19 entries, showing the correlations between all variables. Findings from this type of study raise the question of what the **meaning** of these outcomes is. In Zimmermann et al.’s study (2010), hierarchical regression was performed in order to find the smallest possible set of predictor variables in their model. This resulted in a ‘model’ for variables predicting self-acceptance of body image in women with breast cancer, explaining for 24% of the variance by including women’s depression score, women’s age, and male relationship satisfaction. A model based on variables predicting partner-acceptance of body image in women with breast cancer reveals that including the variables ‘women’s age’, ‘women’s relationship satisfaction’ and ‘common dyadic coping-female’, explains for 44% of the variance. Although statistically correct, it does not seem very helpful to professionals to determine which smallest possible set of predictor variables explains for a certain amount of variation, knowing that in the ‘unexplained’ variation numerous factors can play a role. Even factors that make a smaller contribution to explaining for the variance may have great relevance to the outcomes in real life. The clinical implications mentioned by

Zimmermann et al. (2010) (to focus on women's depressive symptoms, on couples' relationship satisfaction and on dyadic coping efforts in order to enhance women's body image) are necessarily addressing only a fragment of the total picture.

Moving the focus from sexual function, which can to some extent be objectified, to more subjective concepts such as sexual identity and sexual relationship, also moves the methodological approach from quantified to qualifying. Studies like those of Zimmermann et al. (2010) demonstrate the limits of quantifying approaches when studying highly personalized and complex concepts. Numbers regarding these personal variables can be generated, but they become less meaningful the more subjective and therefore unique the object of study is, and the less it has of the client's perspective.

The clients' perspective on the impact of cancer on sexuality and intimacy

The term 'clients' in this study refers to both patients and their partners, as they are both seen as 'clients' of the health care system. Nursing models explicitly acknowledge important 'others' as people deserving their care, and the definition of palliative care (WHO, 2002a) clearly states that it is quality of life of patients and their families that is the focus. Despite this, most qualitative studies exploring clients' perspectives focus on the patient's perspective.

- The patient's perspective

Most studies qualitatively exploring the patient's perspective regarding the impact of cancer on sexuality focus on specific types of cancer. Butler et al.'s (1998) qualitative study was one of the first in this field focusing on women with gynaecological cancer. These women made clear that for them sexual functioning was not an isolated component but was intertwined with changes in their lives as a result of cancer and cancer treatment. The findings from this study support Fugate Woods (1987) view on the interrelatedness of sexual self concept, sexual relationships and sexual function. Bruner and Boyd's (1999) focus group findings confirmed the interrelatedness of sexuality of women with gynaecologic and breast cancer. Bruner and Boyd (1999) further drew attention

to the point that questionnaires used to assess sexual functioning may lack important areas of concern for these women.

Shifting the focus to male cancer patients, an interpretive phenomenological study by Bertero (2001) aimed at capturing the impact of prostate cancer on male sexuality and intimacy. As a result of their cancer and cancer treatment, the sexual patterns of these men were altered with participants reporting sexual problems related to urinary incontinence and being unable to achieve an erection. For some men, losing potency not only meant loss of quality of life but could result in losing their sense of manliness and life itself losing its meaning (Westman et al., 2006), and inevitably changed their roles as a sexual partner. These findings illustrate that the interrelatedness of sexual relationships, sexual self concept and sexual function (Woods, 1987) does not only apply to women. However, in contrast to other areas of study (e.g. sexual dysfunction) that mainly focused on men, most of the qualitative research is studying the female perspective. Wilmoth (2001) was among the first authors to study the impact of cancer on sexuality from the perspective of women with breast cancer, after Hordern (2000) provided a literature review addressing the topic. Based on a grounded theory approach, Wilmoth (2001) identified 'an altered sexual self' as the core concept. As Gilbert et al.'s (2010a) review reveals, the information available shows that there is irrefutable evidence that breast cancer can have a substantial impact on physical and psychological aspects of women's sexuality, in the context of their relationships and constructs of 'normal' femininity and sexuality. Gilbert et al. (2010a) state that these aspects are inextricably linked and that, in order to highlight the complex and multifactorial repercussions cancer has on the sexuality of both patients and partners, future research acknowledging this inter-relatedness is needed. Similarly, Stead et al. (2002), interviewing women with ovarian cancer, found that the illness affected sexual desire, raised fears about being sexually active and of being rejected by the partner. This study was complemented by Juraskova et al.'s (2003) study, focusing on long-term post-treatment sexual adjustment of cervical and endometrial cancer patients. They conclude that women's sexual adjustment is the result from an interaction between three main factors: personal factors (coping style and quality of the relationship); self-concept (femininity and body

image) and factors related to the health care provider (support and quality of information).

Interestingly, in some qualitative studies where aspects of sexuality could be expected to be included, they are not. For example in Roing et al.'s (2009) study on making new meanings after treatment for oral cancer, neither kissing nor oral sex was mentioned, despite the study's Heideggerian focus on being in the world and existing with others.

Looking across cancer types, not many qualitative studies have been undertaken in diverse cancer populations, as Flynn et al. (2011b) point out. Lemieux et al.'s (2004) qualitative study was amongst the first to illuminate the meaning of sexuality for patients with diverse types of cancer receiving care in a palliative unit. The study demonstrated that sexuality was important at all stages of life, although the expression might change, with less emphasis on intercourse and more emphasis on intimacy. She concludes that being connected with others, for example by affectionate touch, is an important source of validation. Hordern and Street (2007a) also looked at diverse cancer populations. Using a reflexive study approach they aimed for an in-depth exploration of patients' beliefs regarding the impact of cancer on their sexuality and intimacy and their preferences regarding communication with health care professionals. Hordern and Street (2007a) report fascinating findings regarding communication with health care professionals (as will be discussed further on in this chapter), however, their exploration of the patients' perspective regarding the impact of cancer on sexuality and intimacy lacks depth. The reason for this might be that in their exploratory study they ended up using semi-structured interviews, comprising of 16 open ended questions with interviews lasting approximately 45 minutes in total, resulting in just under three minutes per question. Whilst their study has given very useful insights, further in-depth exploration of this issue is needed.

Gianotten (2007) and Rothenberg and Dupras (2010) provide qualitative information on sexuality in the end-of life stage based on sexology consultations. Their case histories demonstrate the often emotional context in which sexual activities take place at the end of life stages, with Gianotten (2007)

describing various sexual patterns in the palliative-terminal phase, ranging from quitting sex completely to intense and sometimes even aggressive sex.

Flynn et al.'s (2011b) study included patients with diverse cancer diagnoses in order to identify themes regarding sexual functioning across all cancers. Based on 16 focus group meetings (including 109 cancer patients in all), they found that enduring sexual problems were prevalent, regardless of type of cancer or treatment. However, there was no straightforward link with overall satisfaction regarding patients' sexuality and intimacy, so confirming the quantitative findings generated by Ananth et al. (2003). There appeared to be a complex relationship between sexual function, intimacy and satisfaction with sex life. Weijmar Schultz and Van de Wiel (1991, 2003) explain this by pointing out that there is not just a negative impact from the cancer experience on sexual satisfaction but that there can be positive influences as well, such as partners sharing more intimacy, and that the balance between positive and negative aspects determines the outcome on sexual satisfaction. Flynn et al. (2011b) conclude that health care professionals should explore the sexual concerns of cancer patients directly, instead of assuming that satisfaction with sex life is determined by the level of sexual functioning.

Exploring sexual issues might reveal that there are differences between men and women regarding the experience of sexuality, a point noted by D'Ardenne (2004). She describes how illness affects the sexuality of men and women differently, stating that men typically retain the same sexual interest and drive but suffer from loss of performance and as a result avoid all affectionate touching because that might lead to an expectation to perform. Conversely, women more often report that their illness interferes with sexual arousal and interest in sex and they may suffer from feeling less attractive. Flynn et al. (2011b) found that for the women participating in their focus groups feeling sexually attractive was more important than frequency of being sexually active, whereas comments from men on their decreasing sexual activity and loss of sexual function ranged from 'disappointing' to 'frustrating' to 'devastating' (Flynn et al., 2011bp. 381), although some men appreciated the raised level of intimacy that grew out of sexual dysfunction.

These examples demonstrate the complexity of the issue at hand, and as Hordern (2008) in her review pointed out, exploration of the lived experience of patients in cancer and palliative care is a gap in the literature. However, where there is a gap for the patients, there is inevitably a gap for the partners.

- The partner's perspective

Carlson et al. (2000a, 2000b) provide a comprehensive and useful overview of the impact, adjustment and coping of partners of cancer patients, complemented with psychosocial interventions for these partners and suggestions for improvement. Although they acknowledge that the impact of cancer on sexuality is relevant, it is beyond the scope of their review, and they refer to the review by Manne (1998). However, in Manne's 1998 review sexuality was not discussed. Manne (1998) did find that patients value emotional support from their partners and that the increased distress for both partners does not result in a decline of the quality of the relationship for most couples. She does however suggest that health care professionals should try to identify couples that may have difficulties and use interventions that include the partner in order to optimize quality of life for both parties during and after cancer treatment.

In contrast, in Rolland's (1994) introduction on the impact of illness on couples' relationships, sexuality was discussed. Rolland (1994) draws attention to the importance of cultural issues, for example pointing out that in western culture, the breasts of a woman are symbols of attractiveness and femininity, therefore loss or change due to breast cancer treatment can affect her feelings of self-worth. Relevant as these cultural issues may be when interpreting findings, this does not necessarily mean that they are consciously represented within an emic perspective. Holmberg et al. (2001) report that, despite the emphasis on the female breast in adverts, movies and women's fashion, not one woman directly mentioned that her psychological response to breast cancer treatment might reflect the importance our culture places on the breast as part of her female identity.

Rolland (1994) also provides a poignant but clear example which illustrates not only how lack of open communication between partners can be detrimental but also the differences in sexuality between men and women. In her example of a

female cancer patient, the husband wanted to stay sexually active after her operation as a way to stay in close touch with her at a time of uncertainty. This pattern of expressing intimate feelings mainly through sexuality is common amongst men (Rolland, 1994). The female partner complies, but for her sexual activity is painful and she silently resents her husband for his insensitivity. She therefore responds in a distant manner, which in turn only makes her husband feel more desperate. His response is to increase his sexual demands, resulting in further damaging the relationship and widening the distance between them. This cycle of misunderstanding can have long term detrimental effects, as, going through the recovery phase, partners might not have resolved the issues that occurred in the acute phase, leading Schover (2005) to conclude that despite recovery in the physical domain, negative impact on sexuality is enduring. It is essential that a way is found through such misunderstandings, as findings coming from research on the lived experience of closeness in partners of patients with advanced cancer (Palm and Friedrichsen, 2008) demonstrate the importance of experiencing closeness for these partners in case of incurable illness. Closeness encompasses sexuality, intimacy and privacy, and participating partners expressed the importance of physical closeness, including sexuality.

Amongst the limited research a detailed account of the perspective of the partners is given by Gilbert et al. (2009, 2010b). Here, the reasons given by partners for the impact on the sexual relationship were the impact of cancer treatments, often resulting in an absence of libido in the patient; stress and exhaustion due to caring for the patient; repositioning of the partner as an asexual patient; and the partner's views on 'acceptable' conduct in the context of caring for a spouse with cancer. Partners accepted the impact on the sexual relationship and do appreciate the increased closeness and intimacy, but nevertheless experienced anger, sadness, feelings of rejection, self-blame and lack of sexual satisfaction. Of the 20 partners interviewed, 11 reported that they had not found an alternative for sexual intercourse to be sexually intimate. Nine partners did succeed in renegotiating sexual intimacy to include kissing and hugging, massage, mutual and self-masturbation, manual stimulation, oral sex and the use of vibrators (Gilbert et al., 2010b).

The study by Hawkins et al. (2009), studying the partners' perspective using questionnaires with two open ended items (N=156) in combination with semi structured interviews (N=20), found that there was little difference in the impact on sexuality whether or not the cancer involved sexual organs (84% vs. 76%), supporting from the partner's perspective the earlier point that all cancers potentially impact on sexuality.

Other studies made clear that how a couple deals with cancer is partly influenced by coping styles and roles within the relationship prior to diagnosis. Psychological and sexual functioning and the duration and quality of the partnership before the cancer diagnosis are predictors of sexual functioning after the diagnosis (Weijmar Schultz et al., 1992). D'Ardenne (2004) suggests that established relationships are less vulnerable than less stable or newer ones. However, Holmberg et al. (2001) point out that, although coping with cancer may strengthen the relationship, negative changes occurred in strong, caring relationships as well. Sormanti and Kayser's (2000) study showed that, from the woman's perspective, the mutuality of the relationship and the provision of emotional support by the partner contribute to women's coping. Conversely, a diagnosis of cancer may well enlarge existing problems, sometimes resulting in separation (Holmberg et al., 2001).

In summing up this section on supporting literature regarding the impact of cancer on sexuality and intimacy, it can be concluded that most of the studies reviewed focused solely on the impact of cancer treatment on sexual function and therefore mostly on the acute treatment phase of cancer. However, cancer and cancer treatment may and often do have a major impact on sexual function, sexual sense of self and sexual relationship at all stages of the illness. A minority of the literature aims to explore the impact on sexual identity and sexual relationship by focusing on the clients' perspective. However, when studying the clients' perspective, more researchers focus on patients than on their partners, and most studies were limited to one type of cancer. These studies revealed that all types of cancer (be it sexual or non-sexual) could have a major impact on sexual identity and sexual relationships, both for the patient and the partner. Manne (1998) reported that both partners experience similar levels of distress if one of them is diagnosed with cancer, and D'Ardenne (2004)

suggested that the 'unaffected partner' may suffer even more than the patient does. Hordern (2008) identified exploration of the lived experience of the patients as a gap in the literature and Palm and Friedrichsen (2008) point out that future research on closeness (including sexuality and intimacy) should use system theory as a framework which could lead to interviewing couples jointly. In this review, no phenomenological studies were found that look at the impact of cancer in general on the experience of sexuality and intimacy of both patients and their partners and in which joint interviews with couples were included. It is clear that the lived experience of patients and their partners need further exploration as there is a gap in the literature. Therefore, the first aim of the current study was to address this issue, in order to provide in-depth information on how patients, partners and couples experience the impact of cancer and cancer treatment on sexuality and intimacy.

Communication about sexuality and intimacy in cancer and palliative care

Increasingly in the literature the importance of discussing issues related to sexuality and intimacy with patients and partners in cancer and palliative care is being stressed (Gamel, 2000, Evans, 2000, Williams, 2001b, Stead et al., 2003, Quinn, 2003, Katz, 2005, Schover, 2005, Newson, 2007, Carr, 2007, Stilos et al., 2008, Sengupta et al., 2008, Woodhouse and Baldwin, 2008, De Vocht et al., 2010a, De Vocht et al., 2010b). As Taylor and Davis (2006) pointed out, the only way to find out which patients feel the need to discuss sexual health issues is by checking for this on an individual basis. Varying types of sexual assessment are suggested. Some state that the assessment should be tailored to the issue and needs at hand, for example Tan et al. (2002) suggested that a minimal sexual assessment consists of one question, with more comprehensive questioning covering all areas affecting sexual functioning, including pre-morbid sexual status, if needed. According to Krebs (2008), the strategy to follow is to begin with direct questions, followed with open-ended questions for more in-depth exploration. She does acknowledge that sexual assessment should take the patient's gender, sexual orientation, age and cultural beliefs into account; however, it should not be the professional's limitations that interfere with sexual assessment.

Others promote a very direct type of sexual assessment, for example Hughes (2009 p. E244) suggests asking firstly "Sexually, how have things changed?" followed by a second question about the ability to have and keep an erection or to experience vaginal engorgement and lubrication (Hughes, 2009). Katz (2007) incorporates in her book a lengthy sexual history questionnaire based on information from Kaschuk and Tiefer (2001) to be used by nurses. This includes detailed questions about masturbation (e.g. do you masturbate at work during the day, do you masturbate to have an orgasm as quickly as possible or do you take your time) and a question asking the patient to describe the sexual relationships he / she is currently involved in (long-term and casual) (Katz, 2007 p. 25-26). Katz (2007) does point out that this rather long list may be modified in order to elicit basic information. However, as no recommendations for how to use the questionnaire are given, it is hard to see how professionals who already struggle with the subject will cope with such detailed intimate questions, and the same point could very well be raised regarding clients.

In a large number of publications (Wilmoth, 1998, RCN, 2000, Dune et al., 2001, McInnes, 2003, Cort et al., 2004, Stausmire, 2004, Gamlin, 2005, Krebs, 2008, Stilos et al., 2008, Cagle and Bolte, 2009) the use of the PLISSIT model is suggested. Originally devised by Annon (1976) for behavioural treatment of general sexual problems, PLISSIT is an acronym of Permission, Limited Information, Specific Suggestions and Intensive Therapy. By 'permission' Annon (1976) refers to the suggestion that what people want to know is that nothing is wrong with them, that they are okay, that they are normal. He goes on to explain that most people are not overly concerned by their behaviour but by the thought that something is 'wrong' with what they are doing. What these people want from an interested health care professional is that they act as a sounding board to validate their behaviour. Katz (2005) seems to interpret the 'permission' stage a little differently, by limiting it to the somewhat paternalistic permission for clients to discuss sexuality with professionals. She transformed Annon's (1976) quite liberal approach to a rather protocolised way of dealing with issues in the domain of sexuality and intimacy, resulting in a mainly professional driven approach. For example, Katz (2007 p. 41) gives an example of the PLISSIT model in patients with breast cancer, clearly positioning the

professional as the expert (to convey the tone and style of the way PLISSIT is applied the example is quoted in box 1).

Box 1: Example of the application of the PLISSIT model in patients with breast cancer (Katz, 2007 p. 41)

Permission: An example of this level would be to include a general statement that normalizes the topic: "Many couples are concerned about making love after the woman has had a mastectomy. Do you have any concerns that I can help you with?"

Limited information: If the woman has had a mastectomy, the nurse should be able to give the couple some general information about resuming intercourse. "Once the sutures have been removed and you are no longer in pain, gentle love making is fine. You will need to tell your partner when you are uncomfortable, and in the beginning, you may want to protect that side of your body, as you are probably anxious that any pressure will cause you pain.

Specific suggestions: Information at this level includes anticipatory guidance related to possible sexual consequences and other treatments. "Taking tamoxifen for the prevention of breast cancer recurrence may have the side affect of reducing desire or libido. Often, women state that even when they do not feel the desire to have sex, gentle sexual stimulation can sometimes be exciting and cause you to become aroused and interested".

Intensive therapy: Nurses should know when to refer patients with problems or issues are disclosed that are beyond the scope or practice or expertise of the nurse. "It seems to me that you are struggling with the side effects of chemotherapy, and perhaps a visit to a sexuality counsellor would be helpful. We have one on staff. Would you like to have a name and number so that you can call to schedule an appointment?".

Apart from conforming to the 'coital imperative' (Gilbert et al., 2010b), this example displays a lack of exploration of the client's perspective, potentially resulting in secondary victimization of the breast cancer patient by assuming 'norms' that may be appreciated differently by the post-operative breast cancer patient. Perhaps some of the problems arise because Annon (1976) did not develop PLISSIT with cancer patients in mind and, in view of his own writing about PLISSIT, would probably not have subscribed to a professional driven and protocolised way of applying his model. To use his own words: "Many sexual dysfunctions of longstanding concern need only understanding and a common-sense approach for their resolution" (Annon, 1976 p. xi). He emphasizes the importance of listening without jumping to conclusions and his writing is pervaded with accounts of validating clients' sexual behaviour and boosting clients' sexual confidence.

In the PLISSIT model, the idea of stepped care is captured, with fewer people needing increasing levels of care. Most patients and couples need no more than the level of permission and limited information, with Tan et al. (2002) reporting that 80% to 90% of patients need no more than information and brief sexual advice without the need to consult a sexologist, concluding that brief counselling is the core of sexual rehabilitation. Schover and Evans (1987) found that out of 384 cancer patients referred for sexual consultation, 73% were seen just once or twice, with only a minority needing consultation by a medical specialist. Rivas and Chancellor (1997) estimated that no more than 10% to 20% of cancer patients require referral to a sexologist, and that most of the time these referred patients had had pre-morbid sexual problems, sexual problems related to relationship problems and / or sexual problems related to coping with the illness. From conducting detailed interviews with ovarian cancer patients Stead et al. (2001) concluded that these women did not seek extensive information, but were in need of someone to discuss their concerns with and of some reassurance about the safeness of resuming sexual intercourse and about not being the only one dealing with sexual issues after cancer.

Taylor and Davis (2006, 2007) extended the PLISSIT model into the ex-PLISSIT model, emphasising the need to include permission giving at each level of the PLISSIT model and the need to review one's interventions and reflect on the interaction with patients. Other models that have been proposed for sexual assessment are the PLEASURE model (Schain, 1988), the ALARM model (Andersen, 1990) and the BETTER model (Mick et al., 2004). The PLEASURE model is used to assess and develop interventions related to the following areas: Partner, Lovemaking, Emotions, Attitudes, Symptoms, Understanding, Reproduction and Energy. The acronym ALARM stands for Activity, Libido, Arousal / orgasm, Resolution / release and Medical history. ALARM is based on the sexual response cycle (Masters and Johnson, 1966) and has been critiqued for being rather biomedical in its approach (Katz, 2007). BETTER stands for "Bring up the topic, Explain that 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 patients 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 p. 85).

In her critical review of the literature Hordern (2008) argued that the PLISSIT model, although innovative in its original era, is now out-dated because it does not reflect the changed interrelationship between clients and health care professionals, as it does not offer shared opportunities for negotiation and reflection. In contrast, according to Hordern (2008), the BETTER model signifies a step forward by providing a quality-of-life framework, by basing timing and resources on individual needs and by recording discussions on sexuality to stimulate open communication.

Regardless of which communication model or strategy is advocated, the literature also shows that this plethora of advice is mostly not put into practice. Urging professionals to discuss issues related to sexuality means that it is implicitly assumed that they feel confident to discuss these issues with clients and that they know which sexual problems might arise in the context of cancer (Gamlin, 2005). However, most health care professionals either do not broach the subject, or are nervous and hurried when they do, and are apparently hardly likely to encourage a discussion of a subject seen as private, despite them being more aware of the impact cancer and cancer treatment has on patient's sexuality and despite the relevance for patients and their partners (Stead et al., 2002, Stead et al., 2003). Lindau et al.'s (2007) survey including 221 vaginal and cervical cancer patients illustrates the lack of communication about sexual issues, with 62% of the women reporting that they never had any physician-initiated information about the impact of cancer and cancer treatment on sexuality. A recent study by Flynn et al. (2011a) of 819 cancer patients, revealed that the percentage of patients that had ever received any information in cancer care on sexual function depended on the type of cancer, with 79% of the prostate cancer patients, 39% of the colorectal cancer patients, 29% of the breast cancer patients and 23% of the lung cancer patients having had any information. Summarizing the figures showed that over all cancers only 45% received any information or support (Flynn et al., 2011a). It should be noted that both studies (Lindau et al., 2007, Flynn et al., 2011a) only asked about patient education related to the impact of treatment, and not about the actual impact of treatment and how to deal with this, a topic that is even less likely to be

discussed. Therefore, Flynn et al. (2011a first page of early view article) conclude that “sexual health has yet to be fully integrated into oncology care, even for cancers involving sex organs”, demonstrating the need for further work in this domain. A Dutch study showed that with 52% of young (female) breast cancer patients changing sexual function was discussed during treatment (Kedde and Haastrecht, 2008), demonstrating that for this group progress has been made and at the same time revealing that further steps need to be taken to improve care.

Many reasons are suggested for the reluctance of health care professionals regarding discussing sexuality and intimacy issues (Peate, 1997, Stead et al., 2001, Stead et al., 2002, Stead et al., 2003, Gott et al., 2004, Cort et al., 2004, Hordern and Street, 2007b, Hordern and Street, 2007c, Hordern and Street, 2007d, Redelman, 2008, Hughes, 2009, Fobair and Spiegel, 2009) (with the Hordern and Street studies being the most profound ones in this domain). Perhaps one of the most realistic is that put forward by Hordern and Street (2007d), who argued that the majority of health care professionals (coming from a range of disciplinary backgrounds) employ a medicalized approach, assuming that their clients’ main concern is to fight the cancer, with some of them consciously avoiding any discussion expanding beyond medical based communication. Slightly more reflexive professionals recognised the relationship between being able to discuss sexual issues with patients and their own life experiences regarding sexuality (Hordern and Street, 2007d). Professionals try to avoid ‘risky’ exchanges and display a fear of being misinterpreted by their clients and colleagues when they initiate a discussion on sexuality (Hordern and Street, 2007c, Hordern and Street, 2007d) and only few professionals in Hordern and Street’s (2007d) study acknowledged how their private views on sexuality and intimacy might impact on their professional behaviour. Health care professionals adopting a patient-centred communication style based on respect and trust were the exception to the rule (Hordern and Street, 2007d). Hordern and Street (2007b, 2007d) also found that health care professionals make many unchecked assumptions about sexuality of their patients, for example based on type and stage of cancer, age, partnership status and culture. Cort et al. (2004) state that one of the barriers for health care

professionals to address sexuality are fears about invading on clients' privacy and fears of being too intrusive or causing offence. Professionals may not want to 'rub sexual issues in their patients' face', especially not in case of single people (Hordern and Street, 2007c). In addition, organisational structures and the existing culture in cancer and palliative care can make it difficult for professionals to discuss sexuality and to show their vulnerable side (Hordern and Street, 2007b, Hordern and Street, 2007c, Hordern and Street, 2007d). From this it is clear that it is not sufficient to just point out to health care professionals that they should discuss sexuality and intimacy with their clients. It now seems to be the case that professionals in cancer and palliative care know, or at least should know, that it is relevant to discuss these issues, but apparently a combination of personal characteristics and a lack of knowledge and skills are hindering them (Cort et al., 2004). For example Saunamaki et al.'s study (2010) showed that more than 90% of the nurses in their sample (n = 88) were aware of how their patients' illnesses and treatments could affect sexuality. However, 60% were not confident about their ability to address sexuality issues, and 80% did not discuss these issues with patients at all. Similar results were found in an USA-based study (Magnan et al., 2005), with nearly 50% of the nurses not confident in their ability to address sexual issues and 70% not making time for such a discussion.

Focusing on the clients' perspective, Redelman (2008) (based on Hordern and Currow (2003), Lemieux et al. (2004) and Terry et al. (2006)) concludes that research overwhelmingly shows that patients value sexuality and want opportunities to discuss it. The outcomes of the recent study by Flynn et al. (2011a) quantify this conclusion by finding that 78% of their sample of cancer patients (n=819) find it important that health care professionals discuss how cancer and cancer treatment affects their sex lives. In view of the above it is not surprising that Hordern and Street (2007c) found that "there were mismatched expectations between patients and health professionals and unmet patient needs in communication about sexuality and intimacy" (Hordern and Street, 2007c p. 224). Most patients in Hordern and Street's (2007a) study want negotiated, patient-centred communication when it comes to issues of intimacy

and sexuality, tailored to their individual needs, and this did not match the medicalized communication style employed by most professionals.

Assessing the sexual health needs of breast and gynaecology cancer survivors, Hill et al. (2011) found that women in the age group of 18-47 were significantly more interested in receiving care regarding sexual issues than women above the age of 65. Also, women who received their last treatment more than 12 months ago were more significantly interested in receiving such care. However, despite the significant differences, it should be noted that in every group of participants there was a substantial interest in receiving care to address sexual issues. Therefore, Hill et al. (2011) conclude that no individual patient should be excluded from being offered care regarding sexual issues. Rasmussen and Thome's qualitative study (2008) showed variations regarding the point in time when discussing sexual issues felt right for the women included in their study, confirming similar findings by Bruner and Boyd (1999). Therefore, professionals should tailor and time their care to varying individual needs, including varying needs based on gender, as Wessels-Wynia (2010) showed that on average women value psychosocial support more than men do.

Summarizing these findings, it seems that most health care professionals are not sure how and when best to address sexual issues, and therefore, do not do it at all. Or as Redelman (2008) puts it, health care professionals do acknowledge the relevance of sexuality for their patients but find it difficult to act on their beliefs. It is clear that there is a gap between clients' needs and expectations and what health care professionals are offering (Hordern and Street, 2007c). Clients want health care professionals to bring up sexuality issues, and when they do not, clients tend to assume that these issues are not important or that they are the only one's struggling with changes in the sexual domain (Hordern and Street, 2007c). Most patients do not ask health care providers about sexual problems, although the ones with more serious sexual dysfunctions are more likely to overcome their hesitation (Flynn et al., 2011a). However, as patients may not be aware of the impact of treatment on sexuality, health care providers have the responsibility to pro-actively inform patients about these side effects. All cancer types and treatments may have a profound and enduring impact on sexuality and clients who have not had the opportunity

to discuss sexual issues with a health care professional are significantly more prone to complex sexual dysfunction (Lindau et al., 2007).

To the knowledge of Flynn et al. (2011a), their USA-based study and Hordern and Street's Australian study (2007c) are the only studies that explored communication about sexuality including both sexes across a variety of cancer types. None of these studies included partners of cancer patients. Therefore, the second aim of the current European based study was to increase understanding of how a variety of cancer patients and their partners experience the way in which health care professionals address sexuality and intimacy. This was complemented with the third aim of the study, which was to gain insight into health care professional's perceptions of their role regarding sexuality for cancer patients and their partners.

Carrier theories and philosophical perspectives

Terror Management Theory, Heidegger's hermeneutic philosophy and System Theory served as conceptual frameworks for interpreting the findings of this study, and are now briefly introduced in order to avoid lengthy explanations in the discussion.

Terror Management Theory

Terror Management Theory (TMT) was developed within the context of Experimental Existential Psychology (XEP) (Greenberg et al., 2004, Pyszczynski et al., 2010). XEP applies rigorous (experimental) research methods to existential issues, such as how people shield themselves from their knowledge of their mortality, isolation and their deficits in meaning. TMT posits that humans have a biological inclination to continue existence, that human intellectual abilities make them aware of their inevitable death and that the combination of these two aspects creates the potential for paralyzing terror (Greenberg et al., 2004), with TMT explaining how people are trying to cope with the terror resulting from the awareness of their mortality (Greenberg et al., 2004, Pyszczynski et al., 2010). In the literature, this terror is often referred to as death anxiety, with some authors acknowledging the existential characteristic of death anxiety, see for example Nyatanga and De Vocht (2006). According to

TMT (Goldenberg et al., 1999, Greenberg et al., 2004), people manage death anxiety through the mechanism of self-esteem, consisting of the belief that one is a valuable contributor to a meaningful world. In order to achieve this, a symbolic construction of reality (culture) needs to be adopted. Meeting the standards prescribed by one's culture thereupon results in attaining self-esteem. This elevates human beings above animal existence and offers a sense of symbolic immortality by making the individual part of something larger, less temporary and therefore more meaningful than the life of the individual. This is captured in TMT's concept of 'a cultural worldview'. Pyszczynski et al. (2010) highlight that culture provides two types of immortality: literal immortality, which is typically religion based and involves forms of life after physical death; and symbolic immortality, entailing 'living on' as part of something that lasts longer than oneself, e.g. a (family) group one is part of or an achievement that will exceed one's death.

According to TMT, the human body is a constant reminder of our creatureliness, including our mortality (Goldenberg et al., 2001). It might therefore be slightly problematic to fit the creatureliness of the human body into a cultural worldview. Becker (1973/1997), whose ideas heavily influenced TMT, stated that there is a paradox in man having a symbolic identity yet at the same time being food for worms. In order to cope with this paradox, people try to 'flee' their body by distancing themselves from its functions (Goldenberg et al., 2000b). Reminders of animal like behaviour, such as defecating, menstruating, breast feeding and copulating are too confronting and therefore are denounced as taboo. They remind us too much of people being animals and therefore mortal. The body will die, and because people don't like the idea of dying they transform their bodily functions into something 'civilized' so they are not reminded of their creatureliness (including the inevitability of creatures dying). 'Civilization' can mean restricting bodily functions to private domains, such as urinating, defecating, copulating, breaking wind, belching (although cultural differences exist). For the outside world we present ourselves as civilised beings that seemingly do not engage in that type of activities. Activities like eating and drinking are transformed into civilised behaviour; through the use of cutlery, glasses, napkins, waiting until everybody is served before starting to eat and not talking with full mouths. External bodily aspects are transformed into something

presentable: hairs are removed from places where they might appear too animal like, nails and remaining hair are being groomed, bodies are washed and smartly dressed and natural odours are disguised by deodorants and replaced with fragrances. Women (mainly) use jewellery, make-up and high heels to look even more elegant. All sorts of underwear help to look slim and firm, and the aim is to present a clean, groomed, nice smelling body, which looks as perfect as can be. In case of need, plastic surgery can help to remove imperfections and keep the presentation of a young, perfect body within reach. Who would ever guess that people are aging creatures, that bodies are sagging, that the clock is ticking towards death every single second? Who would dare to say that all these bodies will decay in a grave, burn in an oven or left to rot in a river or a wood within a 100 years time? Who would ever think that people are animals now that we have this perfect disguise? People have dealt with that by denying their creaturely aspects and investing in beautifying their bodies (Goldenberg et al., 2001). Of course, there are always people who do not conform to this cultural norm, but this is not well received; why can't they behave or at least make an effort?

TMT would predict that a higher mortality salience increases the need for protection provided by the cultural worldview. Related to the impact of mortality salience on intimacy, in general, the human needs for belonging, togetherness and intimacy are components of the fundamental need for self-preservation and can serve as protective devices against the terror of death awareness. This would predict that death reminders increase a person's striving for intimate and committed romantic relationships. There is experimental proof for this: mortality salience induction led to higher reports of desire for romantic intimacy than did the control condition (Greenberg et al., 2004). However, for people who hold insecure styles of attachment this might not be the case, as these persons do not rely on close relationships in order to cope with death anxiety, and as a result will look for other ways to adhere to a cultural worldview to protect them from death awareness (Mikulincer et al., 2004). Similarly, the impact of mortality salience on sexuality per se is not straightforward either. Based on TMT, Goldenberg et al. (2002) propose that for human beings there is a taboo aspect about sex (partly) because it reminds us of being a mortal creature. Becker (1973/1997) captures the idea that sex is an activity that reminds us of our

animal nature by remarking, “sex and death are twins ... animals who procreate die” (Becker, 1973/1997 p. 163). For people who successfully separated human sex from animal mating by integrating sex into a romanticized (cultural) worldview and its expression through intimate behaviour (resulting in vocabulary such as ‘making love’), this should not be a problem. For them reminders of death might even increase the desire for sex because sex may be part of their cultural system based on meaning and self-esteem (Goldenberg et al., 1999), which can include a high body esteem (Goldenberg et al., 2000a). However, there is evidence for different impacts of death reminders related to gender, showing low survivability cues leading men, but not women, to demonstrate increased sexual arousal and stronger approach-oriented behaviour in response to sexual images (Gillath et al., 2011). Also, there is evidence that for more neurotic people (who have less effective cultural anxiety buffers) raised levels of mortality serve as a reminder of their animal nature, making physical aspects of sex (but not necessarily physical intimacy) less appealing (Goldenberg et al., 1999). Goldenberg et al. (1999) further hypothesized that it is unlikely that individuals low in neuroticism are fundamentally different from highly neurotic individuals, suspecting that for individuals high in neuroticism the connection between sex and creatureliness and subsequently between creatureliness and mortality is just more manifest. In another experiment, reminding a mixed group of 118 participants of their animal nature combined with increased mortality awareness indeed resulted in a decreased appeal to physical aspects of sex (but not to romantic aspects of sex) (Goldenberg et al., 2002). Conversely, reinforcing thoughts about how human beings differ from animals eliminated this effect (Goldenberg et al., 2002), thus providing evidence for the buffer a cultural worldview provides in de-associating sex and death (with creatureliness as the intermediating concept).

In sum, perspectives from TMT reinforce the earlier point that there is no uniform, causal explanation of the impact of cancer (including death anxiety evoked by the diagnosis) on the experience of sexuality and intimacy. TMT also demonstrates that the scope to study this phenomenon should be broader than a focus on sexual function, as existential aspects, impacting on sexual identity and sexual relationship, play an important role. TMT offers a fruitful

psychodynamic framework to consider these vital human concerns (Goldenberg et al., 1999).

Heidegger on being-in-the-world and (in)authenticity

The focus of the current study is not the 'isolated' individual experience, but the experience of Dasein's⁵ being-in-the world. As Heidegger (1953/2010) explains, being-in-the-world refers to three inextricably linked aspects of dasein: the world, the self and the relation between the self and the world. The self is related to animate and inanimate entities (Seiendes) in the world. These entities have no meaning in isolation. A pillow is a pillow because of its meaning: a thing to rest your head on or a thing to put under your hips to change your sexual position or a thing to put between your knees in order to prevent pressure ulcers. The pillow has meaning because of its relation to a bed or a settee, which in turn are understood with reference to the interior of a house and so on. Entities are understood with reference to inter-related systems of meaningfulness (Heidegger, 1953/2010, Sembera, 2007); understanding of being is always embedded in a broader context (Heidegger, 1953/2010). Similarly, Dasein is always with others, all experience is in relation to other people, and we construct our meanings in relation with others, even if these other people are not present in the actual situation. Basically everything Dasein is or does, is explicitly or implicitly related to others (Heidegger, 1953/2010). People therefore do not exist as separate entities but are integral parts of a shared world with the world and individuals coconstituting meanings and understandings. Our meanings do not arise out of individuals in isolation; we are always linked to and in relation with others (Conroy, 2003).

One of the cornerstones of Heidegger's (1953/2010) philosophy is the concept of (in)authenticity. In everyday life we are in what Heidegger called our 'inauthentic mode' (Uneigentlichkeit). We identify ourselves with 'the they' (das Man) and we therefore lack a genuine sense of individuality, although in a numerical sense we are separate individuals. 'The they' absorbs Dasein as one

⁵ Heidegger uses 'Dasein / dasein' both for 'the entity being' (e.g. a human being) and for this entity's 'being there'. In German, nouns are capitalized and verbs are not, therefore 'Dasein' refers to the 'entity being' and 'dasein' refers to 'being there'.

of the many Daseins with the possibility of replacing one Dasein for another (Heidegger, 1953/2010, Sembera, 2007). However, a (silent) call of conscience (Ruf des Gewissens) can make Dasein aware that it is 'being unto death' (Sein zum Tode), evoking angst and resulting in the realisation that Dasein is non-substitutable, as it is not possible to die **as** another (Heidegger, 1953/2010, Sembera, 2007). By acknowledging its being unto death, Dasein for the first time recognizes something as genuinely its own and is 'liberated' from its substitutability as part of 'the they' and therefore in a position to be authentic (Eigentlich) (Heidegger, 1953/2010, Cerbone, 2006). By facing that it has a death to die, Dasein realises that it has one (finite) life to live and that it has to take its own individual responsibility. No directions are provided for that, hence the 'silence' of the call of conscience; the importance lies in the fact **that** the call is heard, so that Dasein is called upon to become the authentic self (Heidegger, 1953/2010). As Cerborne (2006) explained "a resolute, authentic Dasein chooses to choose", and as long as people are looking for somebody else to tell them what to do, they have not reached the point of authentic resoluteness. However, being authentic does not imply that Dasein is no longer "being-in-the-world": "as *authentic being a self*, resoluteness does not detach Dasein from its world, nor does it isolate it as free-floating ego. How could it, if resoluteness as authentic disclosedness is, after all, nothing other than authentically being-in-the-world?" (Heidegger, 1953/2010 p. 298) (Italics in original)

It is important to realize that, for Heidegger (1953/2010), both authenticity and inauthenticity are fundamental modes of Dasein. Heidegger argued that neither authenticity nor inauthenticity is better or worse than the other. Inauthenticity is the normal condition of most of us for most of the time, with the ever-present possibility of authenticity (Heidegger, 1953/2010). As Inwood (1997) explained, the 'they' are others but it also includes Dasein in so far as Dasein conforms to the 'they', without which 'being-in-the-world' is not possible, as everything is (implicitly) linked to others.

System Theory

System Theory is a meta-theory, in that it is applicable to many domains, regardless the focus of study of these domains. General System Theory was originally described by von Bertalanffy (1950). The foundation for the application

of System Theory in social science was laid by Bateson et al. (1956). A major contribution to disseminating System Theory in the USA and Europe was made by Watzlawick (1967). Although System Theory goes back more than 60 years, Willemse (2006) argues that System Theory is not a 'hype' of the seventies in the last century, the relevance of which now has evaporated. He claims that System Theory still is a shrewd and clarifying theory that is applicable to and relevant for a range of practices.

Five basic premises of System Theory are (Watzlawick et al., 1967, Willemse, 2006):

- the whole is more than the sum of its parts
- within a system, parts are interdependent
- the system determines to a great extent the behaviour of the parts
- the system adapts to changing circumstances in order to survive
- a system is characterised by its tendency to maintain itself and to continue to exist

System Theory adheres to a circular view on causality, as opposed to a linear view adopted by physical science. Circular causality excludes the concepts of 'cause' and 'effect' as interactions within systems can be both 'causes' and be 'effected'. Tan et al. (2002) provide examples demonstrating the 'systemic' nature of couples. If a husband's partner is managing her illness well, this may be a relief for him and help him to perform well, which in turn will have an impact on her. Conversely, believing his wife is not coping very well may have repercussions for his functioning that may have repercussions for her. Braun et al. (2011) point out that caregiving is dyadic in nature and that there is a complex interaction between the attachment orientation of the cancer patient and of the caregiver. Also, married cancer patients have better survival rates than single ones (Manne, 1998, Hong et al., 1999), demonstrating that survival rates are not related just to patient characteristics but are influenced by systemic aspects as well.

System Theory adopts a detached stance, as it focuses on how actors are influenced by the systems they are part of, instead of focusing on internal driving forces and the lived experience of actors. System Theory is therefore complementing the insider's perspective with an outsider's perspective. These

complementing views fit well with a hermeneutic approach. In a hermeneutic approach, the lived experience of participants is key but not sacrosanct. The lived experience is not just described but interpreted, based on the context of the experience. 'Being' is always 'being-in-the world' and therefore the context of the systems participants are part of need to be taken into account when interpreting their subjective experience.

Summary

As demonstrated by the literature, potentially numerous factors can impact on the experience of sexuality and intimacy. With all these factors interacting, the combination of all the circular causality may well result in what to the outsider appears to be a 'chaotic' system. Some of the factors may play a tiny role from a statistical point of view; however, from a system and chaos theory point of view they may have great relevance on 'real' life (Kellert, 1993). The complexity of the interacting factors could be compared with the factors determining the weather. In both cases, a delicate interplay between variables determines the outcome, which, taking the weather report as an example, cannot be forecast reliably, sometimes not even for the next day. Despite the fact that the weather system is deterministic, it turns out to be a chaotic system, with no way of predicting the long-term outcome, as very small differences in initial conditions can result in major effects on the 'outcome' (Kellert, 1993). Pool et al. (2008) suggest this seems to be the case with the cancer patient's experience of sexuality and intimacy and, similar to the weather, it can be studied in a reductionist way, but cannot be predicted as a result. The impact of a life threatening diagnosis is so great that often it is only in retrospect, in the light of all other factors, including the disease process, that the individual response can be understood. Nevertheless, patients and partners need to be given the opportunity to consider these important issues at key stages of the cancer journey. Professionals can play a crucial role in helping them understand the implications and outcomes both of diagnosis and treatment. However, to do this they need the appropriate knowledge, communication skills and confidence to address such sensitive issues. The literature also demonstrates that not only was much of the literature focusing on cancer treatment and its outcomes, but

that much of the work was quantitative in nature and therefore not designated to give the in-depth information that the professionals actually need. In consequence, the design for this study had to be one that would provide rich and detailed data that could form the basis for the development of practical tools for professionals to use, hence the choice for a hermeneutic approach.

3. METHODS SECTION

Paradigmatic stance of the researcher

Stress has been placed on the importance of clarity on the paradigmatic position of the researcher, as this is essential in appreciating the perspective taken in a particular study and in evaluating research by appropriate standards (Madill et al., 2000, Lyons and Coyle, 2007). Accepting that a paradigm is “a basic set of beliefs that guides action” (Guba, 1990 p. 17), Koch (1996) argues that all research should be based on assumptions that have their roots in the philosophical underpinnings of a research approach. However, this does not mean that the logic of a piece of research or school of researchers is always made explicit, as it can be based on unstated methodological assumptions (Hart, 1998).

For some the paradigmatic position of the researcher is a consequence of the general orientation to life of that person (Mills et al., 2006). Schwandt (2000) declares: “What we face is not a choice of which label – interpretivist, constructivist, hermeneuticist, or something else – best suits us. Rather, we are confronted with choices about how each of us wants to live the life of a social inquirer” (Schwandt, 2000 p. 205). Following this line of reasoning, researchers should adopt a research method that is compatible with their fundamental assumptions. Some researchers, such as Holton (2007), do identify themselves with the approach they have adopted. It is however debatable whether a paradigmatic stance is a fixed characteristic of the researcher, as others appear to relate the philosophy behind the method to the research process; suggesting that “Methodology is the theory behind the method. The methodology describes the process by which insights about the world and the human condition are generated, interpreted and communicated” (Koch, 1996 p. 174).

The question at stake here is whether or not the philosophical framework is a property/quality of the researcher or, alternatively, of the research. Interestingly, both points of view are compatible with the pragmatic paradigm in which the research question dictates the research method (Armitage, 2007). The difference is that Mills (2006) and Schwandt (2000) would probably recommend different researchers for conducting studies with different philosophical

frameworks, in order to match the general orientation to life of the researcher with the framework of the study. In contrast, based on Koch's (1996) definition, it would be possible for the same researcher to conduct studies based on different philosophical frameworks, because the philosophical framework is linked to the research at hand and not necessarily to the researcher.

In order to conduct different types of studies, the researcher has to be capable of 'adopting' different philosophical frameworks, even in the case of conflicting assumptions between these frameworks. For example, in one study the methodology could be based on an objectivist paradigm with a realist orientation, whereas in another study a constructivist approach based on an anti-realist or relativist orientation needs to be adopted.

For a researcher to adopt 'conflicting' philosophical frameworks and to conduct studies guided by 'incompatible' methodologies, the relativity of any paradigm has to be accepted. With this relativity of any paradigm as a starting point it is conceivable that perception, understanding and knowledge of the world and the human condition is partial at best and of a kaleidoscopic nature. No worldview or paradigm can exclusively claim to be the 'right' one and therefore be capable of determining an absolute truth. Consequently, there is not one big truth but there are many co-existing smaller 'truths', highlighting different aspects of the world and not necessarily pointing in the same direction. This matches a pluralistic view, characterised by inclusive thinking in terms of 'and-and' instead of exclusive thinking in dichotomies of 'either-or'.

As Hart (1998) argues, there is no such thing as one absolute logic by which universal truths can be determined. It is inherently embedded in scientific reasoning and the epistemology of science that any theory may be false (Fay, 1996). There is no Archimedean point; no fixed foundation that can be used as a departure point from which it is possible to arrive at absolute certainty.

Certainty is not something that science can provide, and this notion is at the heart of fallibilism. All our beliefs are fallible, as any of them may be false (Fay, 1996 p. 208). It may be challenging to think (and live) along these lines, because it necessarily implies tolerating a great amount of uncertainty and acceptance of the limits of understanding of the world. It is challenging at an intellectual level, because it can collide with what seems 'logic'. Natural scientists face the challenge of accepting that light is a wave and a particle,

although this by itself seems incompatible. But some qualities of light can only be explained by assuming light is a wave, whereas others can only be explained by assuming light is a particle, and both qualities have been 'scientifically determined'. It is also challenging at an emotional level because there is no certainty in anything, there is no firm ground to set foot on in order to once and for all have a solid foundation. Knowledge and understanding are fluid and ever changing with individuals as little ants trying to work out something that is bigger than themselves and that they will never fully grasp. Or as Fay (1996 p. 211) puts it: "all we have is ourselves scratching around trying to make our experience and our world as comprehensible to ourselves as we can, given the profound epistemic limitations under which we operate". Green (1969 p. 75) succinctly but sceptically captures this point by stating that ".. it is impossible to be certain of anything". This ultimate relativity of human knowledge is imposed on humans by their restricted access to 'reality'. We tend to assume that what we see (or perceive otherwise) **is** reality, forgetting that all we see is all we see, and that we do not have such a thing as a God's eye view, giving direct, full and undistorted access to reality.

It is important though, to point out that acceptance of relativity does not necessarily lead to a position of nihilism. Useful theories and models can be developed to make the experience of the world as comprehensible to us as possible. Fay (1996) uses the metaphor of mapmaking to explain that, depending on what is to be represented and for what purposes, the same area can yield topographical maps, vegetation maps and road maps (just to mention a few). None of these maps is the 'right' (or wrong) map, but nevertheless they are all useful in view of a given purpose. Similarly, acceptance of the relativity of our knowledge and understanding does not mean that no distinction can be made between a good and a bad map or between good and bad research. To avoid nihilism, we need to adopt a set of suitable quality criteria for our research and strive to meet them, despite the fact that we know there are no absolute standards.

According to Fay (1996 p. 212), the overall criterion distinguishing good studies from bad studies is procedural adequacy in arriving at conclusions. The process of inquiry should be fair in the sense that its procedures and the judgements made on the basis of these procedures are responsive to the evidence as best

as can be determined. In order for others to be able to assess whether research procedures were adequate, the research report should be explicit and transparent. Explicitness and transparency by themselves do not guarantee quality, but without them the quality of a study cannot be determined.

More specifically, criteria to assess the quality of qualitative studies have to be in accordance with the qualitative paradigm adopted. Patton (2002) makes this clear by stating that “particular philosophical underpinnings or theoretical orientations and special purposes for qualitative inquiry will generate different criteria for judging quality and credibility” (Patton, 2002 p. 542). This means that preferably criteria are tailored to the purpose and the epistemological / ontological stance that is guiding the research. A study aiming at finding an objective truth should be evaluated with this as the criterion in mind. A study aiming at deepening understanding of a lived experience should be evaluated with that criterion in mind. Assessing the quality of a banana using criteria to evaluate the ‘goodness’ of an orange would not do justice to the banana.

As there is no such thing as an Archimedean point, nobody can claim the right to having the absolute and indisputable, assumption-free and for once and for all correct criteria that studies are to be evaluated with. As Burnard et al. (2008) stated, “unfortunately, despite perpetual debate, there is no definite answer to the issue of the validity of qualitative analysis” (Burnard et al., 2008 p. 431), and therefore no definite answer to the quality of qualitative studies, nor will there ever be. The point to make is that the dispute is endless, because there is no absolute foundation on which absolute ‘proof’ of what is the ‘right’ set of criteria can be based. It is like disputing over which are THE norms to adhere to: whether or not it is acceptable to drink a bottle of wine, to walk around naked, to summon a meeting, to organise individual performance reviews? The answer of course depends on the context: whether it is the home or the work situation.

So acceptability of norms or criteria for ‘goodness’ are dependent on the context. Thus, a great number of sets of criteria have been (and are being) developed, to address the many types of qualitative studies. Already by 1990, Tesch distinguished 27 types of qualitative research, and by 2003 the list was even longer, with Russel and Gregory (2003) identifying more than 40 qualitative approaches in the literature. An alternative is to use more general criteria, that do justice to the assumptions that underlie all or at least most

qualitative studies, for example the four criteria described by Crossly (2007): the primacy of subjective meaning; evidence of sustained integration between theoretical and empirical material; reflexivity and impact. For the current study, quality criteria have been adopted that are in line with philosophical hermeneutics, as will be discussed further on in this chapter.

Paradigmatic stance for a hermeneutic approach

It is not easy to describe which paradigmatic stance fits best with a hermeneutic approach. This is partly due to the different existing conceptualisations of paradigmatic issues. Holton (2007 p. 239) argues that “much of this confusion can be attributed to particularized terminology used by various scholars to set out the boundaries and distinctions between and among the espoused research paradigms and associated issues of ontology, epistemology and methodology”. Holton (2007 p. 239) refers to positivist, interpretivist and postmodern as established research paradigms, whereas Kuper (2008) links positivism with objectivism and links interactionism, phenomenology, hermeneutics, critical theory, feminism and postmodernism with constructivism, referring to the latter as ‘the qualitative paradigm’. Schwandt (2000) makes a distinction between interpretivism, hermeneutics and social constructivism by arguing for them to be seen as three different epistemological stances. In contrast, Coffey and Atkinson (1996 p. 12) strongly object to the view that qualitative research constitutes its own paradigm, and do not distinguish between qualitative and quantitative approaches, stating that “paradigmatic statements are muddled and try to erect barriers and oppositions where none exist, or try to make differences of emphasis into insurmountable epistemological clashes” (Coffey and Atkinson, 1996 p. 12). In line with the position taken by Coffey and Atkinson (1996), it could be argued that the diversity of paradigmatic stances represents a continuum, with, ontologically speaking, naive realism at one end and extreme relativism at the other (Willig, 2008), with stances gradually changing in ontological and epistemological ‘colour’ moving from one end to the other. However, this does not exclude the possibility that the ends of the continuum **do** represent very different paradigms with incommensurable assumptions, just as

black and white, as the tail ends of a continuum of grey tones, are as contrasting as any two shades can be.

In considering the philosophical basis of a hermeneutic phenomenological approach, it is important to make a distinction between different types of phenomenology. There are major distinctions between Husserlian and Heideggerian phenomenological approaches.

Husserl's phenomenology is grounded in the Cartesian tradition, and studies phenomena as they appear through consciousness (Lavery, 2003). Husserlian phenomenological research studies the meaning of human lived experience (Koch, 1996). This phenomenological approach entails three interrelated steps (Giorgi, 1994): reduction, description and search for essences. The researcher has to bracket all past knowledge regarding the phenomenon, in order to arrive at a description of the phenomenon that matches the phenomenon as it presents itself. After this, aspects of the phenomenon are varied imaginatively until its essential features become clear. The researcher then describes the phenomenon by outlining its invariant features and how they relate to each other. Such a description would make the phenomenon identifiable and unique. An important point to consider here is whether bracketing is possible or even desirable. In his seminal work 'Being and Time' (1953/2010), Heidegger explores the notion of 'understanding' in an ontological way. He argues that every encounter entails an interpretation based on the individual's background understanding. For him there is no Cartesian split between the person and the experience, as they are coconstituting and are unable to exist without each other (Schmidt, 2006). The self is not an uninvolved entity. Heidegger believes bracketing to be impossible, as individuals cannot step out of their pre-understandings (Heidegger, 1953/2010).

As in descriptive phenomenology, the lived experience can be studied in hermeneutic research, with data collected in similar ways, for example through interviewing and studying narratives. However, in hermeneutic studies, data are put in context and fused with pre-understandings of the researcher. The interpretation is a blend of various data sources, or a construction (Koch, 1996). Gadamer (1960/1982), a student of Heidegger, subscribes to Heidegger's rejection of the split between subject and object and underlines the

indispensability of pre-understandings (that he calls prejudices) as conditions of understanding (Taylor, 1993). Gadamer (1960/1982) emphasises the crucial role of language when it comes to understanding, stressing that interpretation and understanding are inextricably linked. Martin and Dawda (1999) agree, suggesting that understanding indeed goes beyond empathic attunement because it also includes an intellectual reasoning process. Experiences have meaning for the other person, and to understand these involves making sense of that meaning. In the process of trying to understand, the researcher is an active participant rather than an uninvolved observer.

In view of the initial exploration of philosophical hermeneutics, 'the hermeneutic net' would appear in the part of the continuum covering the constructivist area. However, the label 'constructivism' does not represent one paradigmatic unity, once again demonstrating the continuous nature of paradigms. Schwandt (2000) for example describes an 'everyday, uncontroversial, garden-variety constructivism' (Schwandt, 2000 p. 197). This 'mild' form of constructivism claims that we construct interpretations and knowledge, based on a shared horizon of language and understandings, as opposed to our minds simply reflecting what is 'out there'. In contrast, radical or extreme forms of constructivism adhere to a radical relativist ontological position which implies that there is a non-reducible plurality of individual realities (Mills et al., 2006). A hermeneutic approach, based on Heideggerian and Gadamerian philosophies, is best placed on this paradigmatic continuum in the domain of weak or mild (as opposed to strong or radical) constructivism. This position would ontologically coincide with mild relativism or with 'perspectivism' where "knowledge of the world is a function of the linguistic and conceptual framework within which particular knowers and agents live and operate" (Fay, 1996 p. 76). Most qualitative researchers today share a constructivist belief about knowledge, which holds that the reality perceived is constructed and depends on the context. According to Kuper et al. (2008 p. 405) "this does not usually imply the lack of the real physical world around us, just that our interpretations of that world can differ depending on our social, historical and individual contexts". Paley (1998) makes it clear that 'Being and time' (Heidegger, 1953/2010) presupposes a form of realism (not to be equated with positivism)

and not (radical) relativism. In Dasein, being and the world are inextricably linked, so without the worldliness of the world Dasein could not be. The idea that individuals (co)constitute meaning does not result in individualistic relativism, as the 'experience' of Dasein is the experience 'of' (being-in) the world. Interpretation does not **create** meaning, but it **reveals**, in a more or less appropriate way, "the independently existing meaning of the entity in question", (Sembera, 2007 p. 139). What realism proposes is that certain structures are real, albeit not necessarily visible, and that these structures influence visible events and actions. According to Paley (1998 p. 822), Heidegger's form of realism would be inclined to a fragmentary and ad hoc (time and context dependent) perspective, and would be "a realism of practices rather than a realism of objects".

Epistemologically, hermeneutics could be characterised as subjective transactional, as meaning is coconstituted based on a subjective interrelationship (Mills et al., 2006). If the interest is in phenomena that are not directly observable or quantifiable but that require the collection of linguistic data, for example to understand the way another person experiences something, 'neutral' measurement instruments cannot be used. A voice recorder or CAQDAS-software cannot understand. To understand the lived experience of a human being, another human being is required. Thus, hermeneutic research is (and has to be) subjective. The study object is the (subjective) lived experience, and to study this, the researcher's (subjective) capability of understanding is required. Understanding comes from interpreting linguistic data, and the only entity capable of doing this is a human being. The downside (from an objectivist point of view) from using human beings to do this is that they don't come value free. From a hermeneutic point of view, attempting to interpret 'value free' with all one's preconceptions neatly bracketed is not only impossible but manifestly absurd (Annells, 1996), as this would exterminate the very thing that makes interpretation possible to begin with.

Guba and Lincoln (1994) point out that in constructivism the distinction between ontology and epistemology is challenged, as this distinction is itself the result of a Cartesian worldview. In hermeneutics, but not in Husserlian phenomenology, the ontology coincides with the epistemology, leading to the conclusion that the key difference between these two approaches is that descriptive

phenomenology is epistemologically based, while hermeneutics is ontologically based (Notter, 2002). Interestingly, this ontologically based stance makes the point whether there is such a thing as an objective reality irrelevant, making the discussion on whether people are interpreting reality or constructing their reality irrelevant as well. If, as fallibilism dictates, nothing can be said about 'reality' with certainty, the whole concept of 'objective reality' becomes otiose. If you cannot open a package that was sent to you because it got lost, you can speculate endlessly about what might have been in it but what was actually in it becomes irrelevant, as you will never unpack it. Similarly, Heidegger argues that "the question whether there is a world at all and whether its being can be demonstrated, makes no sense at all if it is raised by Dasein as being-in-the-world – and who else should ask it?" (1953/2010 p. 195). He goes on to explain that the demand for a proof for the existence of things outside us (as made for example by Kant) grows out of a way of positioning that from which an independent world is to be proven as objectively present; a conceptualisation that is not compatible with 'being-in-the-world'. According to Heidegger (1953/2010), if Dasein does not exist, then it can no longer be said that entities are, nor that they are not, but as long as the understanding of Being exists, it can be said that entities will still continue to be.

In this hermeneutic approach the view of radical constructivism, implying that, because there is no 'objective' reality, there is nothing referential about research (Coffey and Atkinson, 1996), is rejected. As Leonard (1994) points out, personal meanings are not completely relative, as they are limited by shared linguistic and cultural meanings. The point that the existence of things outside us cannot be proven does not mean that there is nothing referential about the experience of being-in-the-world. Although 'the world' cannot be separated from being-in-the-world, it is a fundamental structure of Dasein (Sembera, 2007p. 63). As Guba and Lincoln argue (2005):

Templates of truth and knowledge can be defined in a variety of ways – as the end product of rational processes, as the result of experiential sensing, as the result of empirical observation, and others. In all cases, however, the referent is the physical or empirical world: rational engagement with it, experience of it, empirical observations of it. (Guba and Lincoln, 2005 p. 203)

A hermeneutic approach in studying lived experience

A hermeneutic approach is of a dialectical nature as it is in the dialogue that understanding can arise. However, both Heidegger and Gadamer have stressed that they have not developed or described a 'research method' that can be deployed as a technique in order to arrive at understanding. Instead, their philosophies are ontological: understanding is a condition of **being** human. This blurs the line between the epistemological and the methodological premises, just as no clear distinction can be made between the ontological and epistemological premises, as was argued earlier on. To be human is to understand and to understand is to interpret. For Heidegger, understanding is not a way we know the world, but rather the way we are (Lavery, 2003). It is the way we try to make sense of our life world all the time, not just when undertaking a hermeneutic study; it is the only way to make sense. Coming from our own horizon of pre-understandings, we enter in a dialogue, trying to find out what the other person's horizon looks like. Gadamer (1960/1982) supports Heidegger's (1953/2010) view that language and understanding are inseparable structural aspects of 'Dasein', stating that perception of the outside world always means interpretation of the outside world and that language is the universal medium of understanding.

Gadamer (1960/1982) views interpretation as a fusion of horizons, a dialectical interaction between the expectation of the interpreter and the meaning of the text. Coming from the 'whole' of one's own horizon, the researcher 'risks' his or her own understandings of being modified or rejected (Phillips, 2007). Following the principle of the hermeneutic circle, iteratively checking parts against the whole and the whole against the parts, the researcher adjusts both his or her understanding of the whole and the parts until there is harmony, free of inner contradictions (Kvale, 1996). The hermeneutic circle represents the dialectical movement between the parts and the whole, in which a process of reciprocal sense making expands understanding further and further.

Understanding in this sense is not reproduction of knowledge, nor is it taking the perspective of the other in order to discover what the other 'meant'. Gadamer (1960/1982) argues that it is impossible to put oneself in the position of the other person, because the other person has a different pre-understanding due

to a different historical awareness. To come to an understanding of a lived experience of the other is to come to understand oneself in a kind of dialogue, by means of a process that involves 'translating' this experience so that it can express itself in the researcher's own language. It is a way of understanding that is open to the lived experience through bringing oneself into question along with the lived experience of the participant (Malpas, 2009). The experience of the participant is being assimilated in the horizon of the researcher that is therefore changed, in order to integrate the understanding of the lived experience of the other person (Gadamer, 1960/1982). Understanding is a process based on the gradual fusing of the researcher's and the participant's horizon, expanding in concentric circles the harmony between the parts and the whole. This gradual fusing can be envisaged as the integrative combination of many 'mini-fusions' resulting in a 'fusion of horizons' characterized by a meaningful unity between the parts and the whole (Butler, 1998).

The indispensable change of horizon of the researcher does not imply that the researcher's interpretive process per se is the object of study, rather, it is the vehicle to come to an understanding of what it is the researcher is trying to understand: the experience of the participants. Jankowski et al. (2000) use the concept of a 'not knowing stance' to explain that the aim of the researcher is to learn in an on-going way from and about a participant's experience. The dialogue enables the 'not-knowing' researcher to enhance his or her understanding of this experience of the other. This does not mean that the researcher has no prior knowledge of the matter at hand, but that he or she is guided by curiosity about what is as yet unknown and what can be learned from participants.

A not knowing stance firmly classifies a hermeneutic approach as a 'big Q' method. Big Q (Qualitative) methods aim to inductively find new insights into the ways participants experience their world whereas small q (qualitative) methods start with a conceptual framework against which qualitative data are then (deductively) checked (Willig, 2008 p. 9). Researchers who are used to a logico-empirical approach first specify a criterion and then deduce whether the criterion was or was not met. In this way, it is only possible to confirm or disconfirm what was previously posited. In contrast, a phenomenological

approach strives for discovery of meanings in the data, and therefore an attitude that is open enough for unexpected meanings to emerge is required (Giorgi, 1997). In big Q approaches, the researcher avoids asking questions or giving responses that would lead participants to simply confirm the researcher's existing conceptual framework. Instead the focus is on making the participant's experience known in the dialogue with the researcher.

Understanding the lived experience involves fusion of the horizons of both the researcher and the participant, but what the understanding is about is one-sided: the lived experience of the participant. The 'harvest' of the study is the adjusted horizon of the researcher through assimilating the lived experience of the participant, not the changing horizon of the participant as a result of participating in the study. Although in the research process the horizon of the participant might change as well, if participants allow themselves to be challenged by the differentness of the horizon of the researcher (Phillips, 2007), this is not the object of study. This 'one-sidedness' is not to imply that the researcher can come to an understanding in an 'objective' way, unaffected by and external to the process. It also does not justify the 'accusation' of vacillating between constructivism and postpositivism (Mills et al., 2006), as the 'reality' that is referred to here is not a 'fixed' reality that can be 'discovered', but the fluid, constructed and subjective 'reality' of the lived experience, the 'realism of practices' (Paley, 1998).

It is important to understand that for Gadamer (1960/1982) interpreting is not a static activity. Horizons are constantly evolving, both for the researcher and the participants (Pascoe, 1996). Therefore, understanding is always 'under construction', completion of understanding is an impossibility (Gadamer, 1987). In this process of striving towards understanding of the phenomenon, several data sources are merged. The historicity of the researcher's horizon encompasses his or her personal and professional background and theoretical knowledge coming from the literature that the researcher continues to read in order to enhance understanding of the subject of study. This fusing of the researcher's understanding of the lived experience with the extant literature is another loop of the hermeneutic circle, out of which a construction of the phenomenon will emerge (Koch, 1996). Understanding is not merely reproductive, but always productive as well (Gadamer, 1960/1982 p. 264). The

researcher tries to make sense of participants trying to make sense of their experience. Smith (2009 p. 3) typifies this as 'a double hermeneutic' that the researcher is engaged in, and including the reader trying to make sense of the study would result in a 'triple hermeneutic'. The interpretation of a transcript goes beyond the participant (Gadamer, 1960/1982). The idea is to convey the **meaning** of what participants intended to say, not to literally reproduce what was said. A hermeneutic study is not just about describing the 'lived experience' of participants, nor is this lived experience as expressed by participants sacrosanct. In much of the lived experience research it is implicitly assumed that the experience of participants, and their interpretations of the world, cannot be wrong or misguided (Paley, 1998). Paley (1998) goes on to explain that in this assumption two different ideas are confused. The true idea is: the participant's experience is the participant's experience, and must therefore be what the participant says it is. The false idea is that the sense making of the participants experience of the world by these participants faithfully reflects their world and that no one else could challenge the participant's worldview. This false idea results in a newly invented Cartesian split between 'experience' and 'reality' that is not compatible with Heidegger's idea about 'being-in-the-world, (Paley, 1998). Description of 'what an experience is like', fits the aim of descriptive phenomenology, but is not commensurable with a hermeneutic approach. A description of the lived experience of anorexia nervosa could be 'I am overweight' (offering a 'correct' description of the lived experience), whereas in a hermeneutic study the interpretation of this lived experience (coming from a 21st century Western perspective) could be that the person thinks of herself as overweight, with family members and doctors thinking differently, and the (for the moment) agreed on standard of the Body Mass Index actually showing underweight.

To sum up, in a hermeneutic study, the pre-requisite is pre-understanding, the means is dialogue, the process is the hermeneutic circle, and the aim is fusion of horizons in order to come to an understanding of the experience of the other person, and this coming to an understanding inevitably involves interpretation.

Quality criteria for a hermeneutic approach

There is no such thing as a single, correct interpretation within a hermeneutic study. The search for such a conclusive interpretation does not fit with a hermeneutic understanding of multiplicity and plurality (Geanellos, 2000). As there is no 'interpretation-free' truth, hermeneutic studies should not be evaluated with 'objectivity' as the standard. Trying to understand other people's (subjective) experiences requires the (subjective) pre-understanding of the person who is to interpret the data. If this were accepted, it would be illogical to say that the criterion to assess the 'goodness' of such a study should be 'objectivity'. For Gadamer (1988), the criterion of correct understanding at each stage is harmonising all the parts with the whole. Absence of this 'harmony' would be failure to understand.

Witt and Ploeg (2006) propose a framework suitable for evaluating rigour in interpretative phenomenological research. The framework encompasses the following five expressions: balanced integration, openness, concreteness, resonance and actualisation. In the current study these criteria are complemented with criteria for catalytic and educative authenticity as proposed by Guba and Lincoln (1994). According to Witt and Ploeg (2006 p. 224), balanced integration refers to "the articulation of the general philosophical theme and its fit with the researcher and the research topic, in-depth intertwining of philosophical concepts within the study methods and findings and a balance between the voice of study participants and the philosophical explanation". This is similar to Drauckner's (1999 p. 361) concept of convergence, meaning "the extent to which the perspectives of the participants, the researchers and other data sources are merged in the interpretation". Balanced integration can be enhanced by the reflexivity of the researcher on his/her pre-understandings and the research process in combination with peer debriefing, the latter helping to shed light on the researcher's blind spots (Manning, 1997). Balanced integration involves credibility of the study findings that can be maximised by representing the perspectives of participants as clearly as possible. Credibility is based on the extent that the findings match the evidence and are convincing (Finlay, 2006). Using direct quotations can help the reader to judge whether the lived experience has been represented in a fair

way (Fleming et al., 2003). Openness is related to the open orientation of hermeneutic researchers, willing to put their pre-understandings at risk when exploring the issue at hand. It is also related to opening up the study to scrutiny through a systematic and explicit accounting for decisions made throughout the study process (Witt and Ploeg, 2006). Concreteness relates to the usefulness for practice of study findings, to connecting readers to a phenomenon in the context of everyday life, for example the life world of health care practice (Witt and Ploeg, 2006). Because in the current study one of the aims is to provide tools for practice, catalytic authenticity (Guba and Lincoln, 1994) is taken into account, which enables those who can most obviously benefit from the research findings to make use of them. Therefore, findings should not just be disseminated within a scholarly elite (Manning, 1997). Resonance encompasses the experiential or felt effect of reading study findings upon the reader (Witt and Ploeg, 2006). Resonance is changing the horizon and therefore the understanding of the reader when reading the text and is related to educative authenticity which refers to the ability to help people appreciate the experiences and viewpoints of others (Tobin and Begley, 2004). Actualisation refers to the future realisation of the resonance of the study findings (Witt and Ploeg, 2006). Interpretation does not finish when a study is finished. However, as Witt and Ploeg (2006) highlight, there is at present no way to assess the actualization of a study.

These expressions provide a balance between representations of the research process and the outcome of the study, with balanced integration and openness reflecting the research process and the other three expressions addressing the research outcome (Witt and Ploeg, 2006). This is compatible with the 'light constructivist' stance of hermeneutics, finding middle ground between Heideggerian realism and a mild form of relativism. The focus on the research process should make clear whether a study was performed in a 'fair' way (Fay, 1996). This does not and cannot be proof of a 'truthful' outcome (as there is no such thing) but it can show that maximum care has been taken to do 'justice to the object of study' and therefore resulting in a fair representation of a perspective on (an aspect of) the phenomenon. This representation is then open for discussion and for intersubjective evaluation, as part of the on-going

dialogue between scholars, in order to gain the maximum amount of an ever-changing understanding of what 'being-in-the-world' means.

Accordingly, the criteria addressing the outcome of the study do not focus on 'truth' either. There is no final 'truth', but it is possible to strive for horizons to fuse as much as possible, realising and acknowledging that they are constantly changing. This leads to a deeper understanding of the phenomenon that can inform practice.

Reflexivity / pre-understanding

As a hermeneutic researcher it is important to be aware of the explicit and implicit frames of reference in one's own horizon as much as possible, as they can result in tunnel vision. This does not mean the researcher has to be a blank slate. Firstly, this would be an impossible state to achieve. Secondly, it would result in an embryo like state of complete ignorance without any idea of language, empathy or knowledge about the topics to be studied. What it does mean is that researchers should realise that they are guided by their own horizons (as there is nothing else to depart from). It is only with changing backgrounds that it is possible to see what the foreground is. Therefore, the researcher's horizon should be stretched and broadened as much as possible before conducting the interviews. Reflection on previous travelling, experiences of different cultures, literature read, engagement with people coming from differing backgrounds, movies seen, and journal articles read on the topic of study all helps. All this preparatory work is not to close options down to just a few accepted views as published in scientific literature, but to add views. The result of this is that a researcher becomes aware that there is no one single truth to be found. This enables the researcher to be open to and appreciate the richness of multiple (subjective) 'realities', that all add to the richness in the exploration of human experience.

The researcher tunes him- or herself towards 'understanding' the other, making this the (temporal) aim of his or her being, using his or her full range of cognitive and non-cognitive capabilities to act as a resonance body to make the music of participants heard. It is their music; they play the (cognitive and non-cognitive) strings of the researcher, they make the researcher's strings resonate, and

therefore the researcher is the research instrument. No researcher is the same, maybe one resembles a violin and another is more like a piano. The researcher as the instrument is not neutral; the type of instrument will influence the timbre of the sound, and contextual factors like temperature and humidity can slightly change the timbre from day to day. It is impossible to be a 'neutral' instrument or to avoid using an instrument at all, because no music would be heard.

Through the combined action of the participant and the researcher as instrument the sound of the music is revealed, but the themes played are the ones 'composed' by the participant.

Reflexivity regarding the type of instrument one is, sheds light on the way the instrument contributes to the sound of the music. By (re)playing the same data on different instruments (as in peer debriefing) researchers can become more aware of the timbre of their own instrument (that might emphasize certain frequencies over others) and might as a result take complementing timbres on board. In this sense, peer debriefing complements reflexivity, making researchers aware of their blind spots.

Transferability of study findings

Representativeness based on random sampling and statistical generalizability of study findings are not aims of qualitative studies. In line with the philosophy behind the method, a hermeneutic study is not aiming at discovering a truth that is generalizable in a statistical way. Rather, the goal is to highlight commonalities and differences (Benner, 1994b). Looking for similarities is based on the idea that, although people in ways differ from all other people (and are therefore unique), they also share some characteristics with other people (for example a cultural background) and some characteristics with all people (for example the 'condition humaine': we were all born and we all will die) (Newell and Burnard, 2011). Based on the findings of this study implications and recommendations for practice will be generated, suggesting a form of generalizability of the study findings that might by some be considered illegitimate (Paley, 2005).

In answer to this viewpoint, firstly, it should be realised that statistical generalisation is but one form of inductive generalisation (box 2).

Box 2: Overview of types of generalisation (types applicable to a hermeneutic approach in bold)

INDUCTIVE GENERALISATION

- statistical
- **variation-based**
- **theory carried**

ANALOGICAL GENERALISATION

COMMUNICATIVE GENERALISATION

- **responsive**
- **receptive**
 - **transferability**
 - **utilisation value**

Other forms include variation-based generalization and theory-carried generalization, and both forms are applicable to a hermeneutic approach. Striving for maximum variation in the sample is a way to approximate to representativeness of the sample (Fridah, 2009), opening possibilities for non-statistical forms of inductive generalisation (Smaling, 2003). However, it should be acknowledged that it might be problematic to determine exactly which factors represent relevant dimensions to vary in an explorative study, and to indeed vary for all these factors systematically within a qualitative research design. Paley (2005) points out that a large correlation study would be required to determine which participant characteristics are related to the phenomenon under study, and if such a study would reveal a great amount of relevant factors (as would be the case for the issue at hand in the current study) they would be impossible to cover completely within the sample size restraints of a hermeneutic study. Therefore, a supplementing inductive way of generalising can be employed in a hermeneutic study by means of theory-carried generalization. In this type of generalization, research results are generalized by putting them in the context of an existing theory. The existing theory, supported by sufficient evidence, acts as a carrier for the study results (Coffey and Atkinson, 1996, Smaling, 2003).

Secondly, inductive generalisation can be reinforced by analogical (case-to-case) generalization of study findings. Analogical reasoning is made plausible

by addressing the following point: “when do two situations compare with each other sufficiently to make it plausible that research results in one situation will also hold in another?” (Smaling, 2003 p. 12). Smaling (2003) provides six canons that make analogical generalizability more acceptable: the relative degree of similarity; the relevance for the conclusion; support by other, similar cases; support by means of variation; the relative plausibility of the conclusion on its own; empirical and theoretical support. As Morse (1999) pointed out, the knowledge gained in a study is not limited to subjects with similar demographic variables. It is the comparability of the problem or fit of the topic that is relevant when it comes to qualitative generalization, as “it is the knowledge that is generalized” (Morse, 1999 p. 6)

Thirdly, there are two forms of communicative generalization, responsive and receptive generalization, and they both are applicable to a hermeneutic study. Responsive generalisation is interactive by nature, as the researcher and potential users of the study findings communicate interactively before the publication of the final research report (Smaling, 2003). Responsive generalization is related to the criteria of authenticity as posited by Guba and Lincoln (1989). Receptive generalizability is not interactive by nature, as it is the readers generalising study findings based on the practical experience they have in mind. Transferability and utilisation value can both be seen as examples of receptive generalisation. Transferability is implicitly based on analogical argumentation and is most relevant towards participants and settings with similar characteristics as participants and settings included in the study. Utilisation value is especially relevant in practice-oriented research.

Fourthly, it should be realised that the limitations regarding generalisation are relevant for any study addressing sensitive topics, as they depend on voluntary samples or are prone to high non-response rates. In Butler et al.’s (1998) qualitative study, out of the 48 women with gynaecological cancer that were approached, only 17 agreed to participate. In a qualitative study by Brown et al. (2011), women with cervical cancer were interviewed. Out of the 61 women that were invited to participate, only 19 took part. The researchers explain this by the sensitive nature of the illness of the women and do acknowledge that the resulting (white, ethnic homogenous) sample is a limitation of the study. A similar self-selecting mechanism can be at work in quantitative studies. In the

Zimmermann et al. study (2010) on predictors of body image, out of the 231 eligible couples, 120 couples declined participation, the main reason being that these couples felt they were not in need of psychological intervention. In a quantitative study on breast reconstruction by Rowland et al. (2000), 6364 potentially eligible women were identified. Only 1957 were included in the final sample, with older, non-white and unmarried women less likely to be represented. In both cases it is clear that the non-response group is substantial and may very well differ from the participating group on relevant points, restricting statistical generalizability to the population.

Flynn et al. (2011b) conclude that “when discussing sensitive issues, such as sexuality, no single method is likely to elicit frank discussion from all types of people” (Flynn et al., 2011b p. 386). From reviewing the literature it can be seen that different types of studies will always be needed in order to highlight sensitive topics from many different angles and through many different lenses, complementing one another in order to arrive at a picture that is as complete and rich as possible.

Because statistical generalisation is not feasible, recommendations coming from a hermeneutic study should be given in a way that does not illegitimately suppose statistical generalizability, generalising an ‘average truth’ to the population. Instead, in order to do justice to the diversity within the target population, it should be highlighted what variety may be encountered within the population rather than positing how often something will be encountered. In studies aimed at making recommendations for practice at the level of individual patient care, the former might be considered more relevant than the latter.

Limitations of a hermeneutic approach

In a hermeneutic approach, it is only possible to include a limited number of participants, because a greater number of participants would jeopardize the depth of analysis. There are limits to the amount of data that can be mentally processed and conceptualized by the researcher, no matter the amount of software available to support the analysis. Therefore, no large statistically representative samples can be included in a hermeneutic study and as a result outcomes are not statistically generalizable (nor is this the aim of a hermeneutic

study), although findings may be otherwise generalizable and transferable as was discussed in the previous section. However, there is no end point to a hermeneutic interpretation, so no final truth is provided. Hermeneutics offers a view coming from a certain perspective within a certain context at a certain moment in time. As the paradigmatic discussion made clear, from a hermeneutic perspective this is not a pitfall of hermeneutic research, but this is the case for all research, as to understand is to interpret, and every interpretation is an interpretation of an ever-changing world and is based on the context, part of which is formed by the researcher's horizon and pre-understandings. Patton (2002) points out that, although this has not always been the case, these ideas are now commonplace in much contemporary social science and are fundamental in qualitative research.

Rationale for choosing a hermeneutic approach

The choice of a research approach is related to the aims of a study (Willig, 2008). The aims of the current study are:

- To increase understanding of how cancer and cancer treatment impact upon the experience of sexuality and intimacy of patients and their partners
- To increase understanding of how cancer patients and their partners experience the way health care professionals address sexuality and intimacy
- To gain insight into health care professional's perceptions of their role regarding sexuality and intimacy for cancer patients and their partners
- To develop patient driven models, tools and recommendations to acknowledge sexuality and intimacy in cancer and palliative care

In view of the range of factors identified in the literature that are potentially relevant in view of the scope of this study and in view of the interaction between these factors, system theory was adopted as a meta-theory for this study, with a circular view on causality. This was not compatible with a reductionist, quantifying approach, as this approach would be based on a linear model of causality.

Furthermore, as stated previously, there turned out to be a paucity of research data on the lived experience of cancer patients and partners regarding the impact on their sexuality and intimacy and regarding the way health care professionals address sexuality and intimacy. Therefore, the approach chosen had to be consistent with the exploratory nature of the study, further necessitating the need to adopt a qualitative approach.

As the aim was to study the lived experience of participants (as opposed to theory development for which grounded theory would have been a more likely candidate), a phenomenological approach was chosen. As 'phenomenology' is a label that covers a range of qualitative methods, a distinction had to be made between descriptive (Husserlian) and interpretive / hermeneutic (Heideggerian / Gadamerian) phenomenology. The adoption of terms for use in this study had to be clarified before the methodology section could be formalized. The detailed debate that underpins this clarification can be found in appendix 1.

For the current study, a hermeneutic approach was adopted because the aim was to come to a deeper understanding of the lived experience of the participants and not just a description of the essence of these experiences. The choice for a Heideggerian / Gadamerian research approach is based on wanting to achieve a deep understanding of a phenomenon (Fleming et al., 2003). Hermeneutics attempts to deepen understanding in a circular way, as opposed to describing cause and effect when trying to make sense of phenomena (Bauman, 1978). It is a different way of trying to make sense of data and in practical terms, seeking the participant's perspective may be a useful way of complementing quantitative approaches to the issue under study. The reason behind the need to come to a deeper understanding was that resonance was strived for, both in the researcher and the readers of this study. Like Hermes, the researcher has to understand and interpret for herself what the participants want to communicate before she can translate, articulate and communicate this to health care professionals (Mueller-Vollmer, 1986). Although it is appreciated that 'an emic perspective' is unattainable and therefore an oxymoron (Manning, 1997 p. 107), it is at the same time the goal to strive for, as the aim is to deepen understanding as much as possible.

Also, a variety in the response to the research question was expected (in view of the great number of potential ‘variables’ at play as identified in the literature), and it was seen as relevant to map this variety of responses, and not just the essence of the phenomenon, as this might not give health care professionals enough ‘handles’ to deal with the various experiences of the patients and partners they meet in health care practice. This is especially relevant in view of the 4th aim of the current study (to develop tools for practice), as health care professionals do not deal with ‘average’ patients or partners but with a whole range of different or unique clients, displaying endless variety.

This last aim of the study (the development of practical models and tools) meant it was deemed important to make use of relevant literature and expertise, to arrive at the best possible informed tools for practice. A hermeneutic approach allows for such a merging of sources, interpreting and ‘translating’ the accounts of participants even further in developing models and tools that are informed by participant’s and professional’s perspectives but that were developed drawing on other sources as well. A hermeneutic approach fits with this practical aim of the current study, because all understanding has a practical orientation as it is ‘shaped’ by the contemporary horizon of the researcher (Malpas, 2009), with Gadamer (1960/1982 p. 274) considering “application to be as integral a part of the hermeneutical act as are understanding and interpretation”.

Ethical considerations

The study complies with current laws in the Netherlands. The principles of informed consent, confidentiality and anonymity were adhered to. Because participants were approached outside health care institutions with no involvement of health care professionals, no formal ethical approval was needed under the Dutch law. However, in view of the sensitive nature of the study and the vulnerability of the clients participating, advice from a medical ethical committee was sought.

Apart from procedural ethics, it is important to be aware of situational ethical aspects. The psychological impact of cancer is profound and creates enduring uncertainty (Little et al., 1998). Therefore, every care should be taken to protect vulnerable participants, but at the same time it should be realised that excluding

participants based on assumed vulnerability is denying them a voice. Palliative care patients are willing to participate in research, even the ones very close to death (Terry et al., 2006).

Price (2002) identified that questions concerning deeply held feelings can be invasive, as they touch the core of an individual's identity. Researchers should be aware that questioning and probing could result in realization and discomfort in their participants, therefore they should conscientiously consider participant comfort and privacy against the aim of obtaining rich data (Price, 2002).

Researchers should be extra cautious when doing joint interviews, because one participant may reveal information that is potentially discomforting for the other participant, as may be the case in joint interviews with couples, especially when personal topics such as sexuality are discussed (Taylor and De Vocht, 2011).

Because it was anticipated that interviews could potentially be distressing to both the participating clients and the researcher, the second (Dutch) supervisor acted as a safeguard. He is a qualified clinical psychologist, psychotherapist and sexologist and he agreed to counsel clients and / or the researcher if there would be a need for this as a result of participating in the interviews.

Sampling

In quantitative studies the requirement of the sample representing the population is key in view of the desired statistical generalizability of study findings. 'Sampling' in qualitative studies is different, as the principal aim of qualitative studies is not (statistical) generalization but to illuminate and understand complex psychosocial issues (Marshall, 1996). Samples have to be small if in-depth analysis of the data is to be achieved (Smith et al., 2009).

Therefore, the sampling process should actively select participants that are expected to be the most productive in view of answering the research question, a strategy known as purposeful sampling (Marshall, 1996). The meaningfulness generated from a qualitative study has to do more with the information-richness of the participants that were purposefully included in the study and with the analytical qualities of the researcher than with the size of the sample (Fridah, 2009).

Rationale for including patients, partners, couples and professionals

The first aim of this study was to increase understanding of the impact of cancer and cancer treatment on the experience of sexuality and intimacy. It is not possible to study the human way of being-in-the-world in isolation from the world (including animate entities). So although it is the patient who is being diagnosed with the life threatening illness, this patient will not experience the impact of the illness alone. He or she will coconstitute meanings with others, and regarding the meaning and experience of sexuality and intimacy the focus of this coconstitution will be in the relationship with the (sexual) partner.

Therefore, individual interviews included not just patients but also partners of patients with cancer, something further necessitated by the underrepresentation of the partner's perspective in the literature. In addition, interviews with couples were included, as it was considered important to explore joint accounts in which partners were not removed from the 'system' that is key to the research topic: their coupled relationship. In this way, it was feasible to listen to people's experiences from different perspectives in order to get a broader view of the phenomenon under study. These different perspectives are complementary. Individual patients and partners may disclose information they would not share if the partner were present. On the other hand, in joint interviews partners can probe, prompt, correct, question, supplement, challenge or introduce new themes that can result in further disclosure and can enrich the contributions each partner makes. Furthermore, the researcher gains a first-hand impression of the interaction between partners while they coconstitute their 'story' regarding the experience of sexuality and intimacy and communication with health care professionals (Taylor and De Vocht, 2011).

Professionals working in cancer and palliative care were included in the study to complement the picture even further. Communication is a two-way process, and professionals are part of the hermeneutic circle in which exchanges with clients take place. As the final aim of the study was to make recommendations for practice, the expertise from professionals was deemed crucial to complement clients' experiences, as only then could both perspectives be combined to develop practical applications that were acceptable to both groups. In view of this aim, a broad scope from both the clients and the professionals was needed; therefore maximum variation sampling was used in both groups, resulting in a

very large sample for a hermeneutic study. It was anticipated that, as a consequence, processing the data would take a considerable amount of time if sufficient depth in the analysis and interpretation was to be achieved. This was accepted, as it was seen as paramount to strive for both a hermeneutic approach and a broad perspective in this exploratory study aspiring to develop tools for practice.

Sampling of patients

Participants in this study were purposefully selected, based on the scope, aims and rationale for the current study. Maximum variation in the sample was sought for. However, maximum variation could not be completely attained in view of the great number of influencing factors that are potentially relevant for the phenomenon under study and in view of the need to keep the sample small enough to allow for the in-depth analysis that is required within a hermeneutic approach (Kam and Midgley, 2006). Dimensions for variation that could be applied within the patient and partner group of potential participants were: gender; type and stage of cancer; type of treatment; age and time elapsed since diagnosis. Partly, the dimensions that were and were not varied in the sample of the current study were determined by the availability of individuals willing to participate. In view of the highly personal nature of the interview topics the sample needed to be a voluntary one. As Carspecken (1996) points out, lived experiences are part of a domain with 'privileged access', and "we depend on honest and accurate self-reports to learn about the subjective state of the others" (Carspecken, 1996 p. 165).

It was anticipated that it would not be easy to find participants for this study, given the highly personal character of the topics to address and the presumed great impact of a cancer diagnosis and cancer treatment on life. Ways of recruiting anonymously by leaving leaflets at places where cancer patients frequented did not result in any applications. Having discussed the study with cancer support centres and the leaders of the local cancer rehabilitation support groups, an alternative strategy arose. The researcher was invited to give presentations about the project to the local groups. At the end of the presentations she mentioned that she was currently undertaking a study in this domain and left behind a list for people potentially interested in participating in

the study to fill in their details. This approach, in combination with participants coming from the personal network of the researcher, yielded more than enough potential participants.

Sampling of partners and couples

Potential participants were asked whether their partner (if applicable) wanted to participate as well and of course it was for this partner to accept the invitation or not. If the partner was willing to participate, couples were given the choice to be interviewed jointly or separately. If they indicated no preference, a joint interview was carried out. Of the eight couples participating in this study, seven agreed to being interviewed jointly. One couple preferred individual interviews. These two partners were included in the patient group and partner group. Of the eight participating patients, four were single but all had had long term relationships. The other four did have partners at the time of the interview, but as said before one preferred to be interviewed separately. The other three were not in favour of including their partners in the study. They anticipated that their partners would not feel comfortable, mainly because of them 'not being very talkative / communicative'. One reported: "*he even refuses to talk about it with me*" and another:

"I am sure he would clam up. He is not a talker; he is a thinker. If you were to ask him something he would not be able to respond; it would be days later before he would be ready to come back to it, so I don't think you would do him a favour by interviewing him".

Of the six participants in the partner group, four participants had already lost their partner due to a cancer death at the time of the interview. Two partners were in a coupled relationship but one preferred to be interviewed individually and the other was originally approached as a patient (with heart failure) but chose to participate from a partner's perspective (her partner being a cancer patient). Interviews were held at the place of preference of the participant(s); in all but one case for clients the preferred place was the participant's house.

Sampling of professionals working in cancer and palliative care

Professionals working in cancer and palliative care were invited to participate in the study on a personal basis. They were not asked to represent an official point of view from the institution they work for but offered their own professional view

on their role regarding sexuality and intimacy for patients facing a life-threatening illness and their partners. As the aim was a maximally varied sample, care was taken to include doctors, nurses and psychosocial workers, working in different cancer and palliative care settings. It was deemed relevant to interview professionals representing a range of disciplinary backgrounds and working environments in order to strive for representativeness by variation in a small sample. Professionals were interviewed at their work place, with the exception of professionals working in community care who were either interviewed at home or at the university where the researcher was based. The data from the interviews with professionals served two purposes. Firstly, several professionals, coming from all three professional backgrounds, confirmed the picture sketched by patients and partners (reporting that very often sexuality and intimacy were not or hardly discussed), thus contributing to reaching the point of descriptive saturation (Smaling, 2003 p. 7) regarding this aspect. Secondly, expert health care professionals were purposefully sampled, resulting in the inclusion of professionals who do address these topics with their clients and were willing to share their expertise. This expertise informed the development of practical models and tools for care.

Informed consent

Potential participants were sent written information (appendix 2) and were asked to reply by mail or phone if they were willing to participate. The same procedure was followed with candidates that showed an interest in participating through other channels (for example through the personal network of the researcher). After receiving the confirmation of the willingness to participate, the researcher called the research candidates to ask if they had any further queries regarding the study and to make an appointment for the interview. Before the start of the interview the researcher explained in person the research aims and procedures and probed for any further questions. After all queries had been satisfactorily addressed, the participant(s) then signed the informed consent form(s) (appendix 3) before starting the interview.

Data collection

Data collection method

To collect data, in-depth interviews, all in Dutch, were held in the Netherlands between January 2008 and December 2009. All participants consented to being interviewed on one occasion. The rationale behind asking for a single interview was that participating patients were (or had been) facing a life threatening illness, with some of them seriously ill. Repeated exposure to interviewing was seen as too demanding. It was anticipated that considerable emotional elements could come up during the interviews, adding to the sense that it would be unethical to revisit participants. It is the experience of a colleague researcher who is studying similar topics that a second interview does not add much useful information (Taylor, 2010, personal communication). In hermeneutics it is acknowledged that a second interview with the same participant(s) may reveal (slightly) different information, without this leading to the conclusion that this information is more or less correct than the information provided in the first interview (Rubin and Rubin, 2005). In the second interview the participant is not the same anymore, as time has passed, and the same applies to the researcher, therefore different data may be coconstructed during a follow-up interview. From this methodological point of view, repeatedly revisiting the same participants would on the one hand not result in validating earlier findings, and would on the other hand not generate as much new information as an interview with a different participant would, thus supporting the main (ethical) reason for deciding for one-time interviews.

Interview context and structure

At the start of the interview, clients were asked (as part of the conversation) some demographic details and were invited to tell their cancer history. The interview topics were based on the aims of the study, resulting in two main topics for clients: the impact of the cancer diagnosis and treatment on the experience of sexuality and intimacy and how the way health care professionals address sexuality and intimacy was experienced. The interview topic for the professionals was how they perceive their role regarding sexuality and intimacy for cancer patients and their partners. All interviews were concluded by asking participants how they experienced the interview. Immediately after each

interview (or no later than the next day) the researcher recorded field notes, which produced impressions of non-verbal behaviour, relevant contextual information and first reflections on the interviews, including reflections on the role as an interviewer.

Interview process

From the very first contact it was deemed important to be transparent about the motives of doing the study and to build rapport with participants. Care was taken to make participants sense that the researcher was grateful for their time and trust, was respectful, was willing to listen to and to learn from them, was non-judgmental, was careful with what appeared discomforting to them, was sensitive in responding to what was said and was to be trusted. The aim was to make participants feel safe and that they need to fear no harm; the well being of participants always prevailed over the researchers' drive to obtain rich data. This did not exclude the expression of emotions during the interviews, as long as it was the well-considered choice of the participant to continue with the interview.

Interviews had an open structure and were recorded using a digital voice recorder. After introducing the topic(s), the main responses of the researcher were asking further questions (based on information from the participants), paraphrasing and reflecting, constantly checking whether understanding was achieved, resulting in a dialogue focusing on participants' experiences and aiming for a fusion of horizons between researcher and participant. The researcher adopted a 'not knowing stance' (Jankowski et al., 2000) as the aim was to learn from participants what their experience was like, fitting with an inductive approach.

All participants evaluated the interview experience as a positive one. Indeed many clients reported that they valued the opportunity to share their experience with someone showing a sincere interest. This supports the point made by Friedrichsen (2002) that palliative patients and their partners appreciate qualitative interviews as they provide an opportunity to talk about their situation. For some, especially for some of the couples, the interview experience was positive but very intense, due to the highly personal content of the interviews. In

the research information provided beforehand, participants had been given all the contact details of the researcher, but after the interviews these were only used to thank the researcher for the interview and / or for the token gift that was always sent to the interviewees afterwards, thanking them once more for their contribution. Sending the gift was the researcher's way of 'rounding off' the often very authentic contact that had been established during the interview situation. None of the participants needed counselling from the second supervisor to deal with the impact of the interview. The interviews with professionals were understandably not as personal, as it was their professional view that was discussed. Interviews were held during working hours and after asking for some demographic details, the interview topic was introduced, followed by further probing, paraphrasing and reflecting. Again this resulted in an open dialogue aimed at increasing understanding of the perspective of the professional.

Analysis

Neither Heidegger (1953/2010) nor Gadamer (1960/1982) has developed a 'method to analyse'. For them, 'analysing' is coming to an understanding by interpreting. Other researchers have described analysis within an interpretive or hermeneutic phenomenological study. Diekelmann et al. (1989, Diekelmann, 1992) described an interpretive team approach for analysis including seven stages: a) reading the interviews to obtain an overall understanding; b) writing interpretive summaries and coding for possible themes; c) analysing selected transcripts as a group in order to identify themes; d) returning to the text or to the participants for clarification of disagreements in interpretation and writing a composite analysis of each text; e) comparing and contrasting texts to identify and describe shared practices and common meanings; f) identifying constitutive patterns that link the themes; and g) eliciting responses and suggestions on a final draft from the interpretive team and from others who are familiar with the content and or the methods of the study. Diekelmann's approach has been criticized by Fleming (2003) for trying to control 'bias' in a way that is not compatible with Gadamer's ideas. Alternatively, Benner (1994a) described the analytical process as consisting of three interrelated processes: thematic

analysis, analysis of exemplars and the search for paradigm cases. Spichiger (2009) provided a clear example of the application of Benner's approach towards analysing in an interpretive phenomenological study.

Although suggestions for analysing a hermeneutic study can be found in the literature, Patton (2002 p. 433) made clear that "no absolute rules exist except perhaps this: do your very best with your full intellect to fairly represent the data and communicate what the data reveal given the purpose of the study".

However, some general principles can be helpful when analysing qualitative data. Firstly, the overall challenge is to make sense of large amounts of data. Inevitably this involves reduction of the data. Therefore, the most significant information and patterns need to be identified, and a framework needs to be constructed to communicate the most essential information that the data reveal (Patton, 2002 p. 432). Secondly, Burnard (2008) pointed out that a process of thematic content analysis is used in very similar ways in all types of inductive qualitative research, including phenomenological studies. Researchers such as Burnard et al. (2008) and Smith et al. (2009) have provided guidelines on how to perform a thematic content analysis, thus giving clear directions on how to identify the most significant information and patterns out of the massive amounts of data. Thirdly, more specific for a hermeneutic approach, both Heidegger (1953/2010) and Gadamer (Gadamer, 1960/1982) have illuminated the principle of the hermeneutic circle, that can be used as a guiding light in hermeneutic analysis.

Using the hermeneutic circle involves moving from the parts to the whole and back again to deepen understanding, linking the unknown whole with the known parts. Moving through the hermeneutic circle takes place at several levels: a sentence is understood out of understanding the words that make up the sentence, while the words are understood out of the context of the sentence (as becomes perfectly clear when transcribing); the transcripts concerning lived experiences are understood based on the sentences they are composed of, whereas the sentences derive their meaning out of the context of the whole transcripts; the understanding of the phenomenon is nourished by the information coming from the lived experiences, with the lived experiences making sense in the 'Gestalt' of the phenomenon; the existing body of

knowledge provides a context for further interpreting the meaning of the phenomenon, with the meaning of the phenomenon impacting on and contributing to the existing body of knowledge. In this way the unity of the understood sense is expanded in concentric circles (Gadamer, 1960/1982). As was pointed out before, the goal of this analytical process is convergence of participant-generated data and the researcher's understanding of the phenomenon under study. The end of this going through the hermeneutic circle occurs when one has reached a place of sensible meaning, free of inner contradictions (for the moment) (Kvale, 1996).

It is important to bear in mind that the same set of data would not result in the same 'place of sensible meaning' if different persons would perform the analysis, even if those analyses were just as 'good' in terms of being systematic and fair. A nurse or a doctor would emphasize slightly other aspects than a psychologist would, just like an architect would 'analyse' a university building differently from the way a cleaner or a lecturer would. As Fay (1996) points out, evidence may be interpreted in many acceptable ways and may even support quite incompatible theories.

Processing the data and thematic analysis

Transcribing was a first step of immersion in the data. Interviews were transcribed as soon as possible after they were conducted. To support the transcription process, transcription software was used (f4)⁶. Listening to the interview recordings, including all the non-verbal cues related to speech, was very useful as it provided the opportunity to 're-live' the interviews. While transcribing, the researcher was able to focus on what was said and how it was said, without having to pay attention to actually doing the interview. Because of these advantageous effects, nearly all of the client interviews and some of the interviews with the professionals were transcribed by the researcher. Initial observations, especially those (partly) based on audible non-verbal cues, were jotted down during transcription. In case of interviews transcribed by others, the researcher listened to every audio recording while reading the transcript

6 See <http://www.audiotranskription.de/english/f4.htm>

provided. This again resulted in immersion in the data and the generation of initial ideas regarding analysis, but also resulted in the correction of mistakes in the transcripts. Next, transcripts were read and reread to get a first impression of 'the whole' of the interview. Sometimes the researcher went back to the audio recording to re-hear the way things were said. Time stamps provided by the transcription software made it easy to find specific parts of the interview back. From this reading of transcripts, firstly patient characteristics were extracted and put into tables. Then every transcript was summarized, including the field notes made immediately after the interviews, so that the researcher had a 'Gestalt' of the interview and the participant(s) involved. Based on the reading and summarizing of the transcripts, a very rough initial coding framework was developed that could be used as a starting point of the coding process. The coding framework consisted of the codes and the 'definitions' of these codes, identifying the scope of the codes in order to maximise consistent use of the codes.

At the heart of the analysis was the thematic analysis (Burnard et al., 2008) that was supported by the use of the Computer Assisted Qualitative Data Analysis Software (CAQDAS) programme ATLAS.ti. Although experts agree that CAQDAS cannot do the analysis, as it is for the researcher to give meaning to qualitative data (Lewins and Silver, 2007), ATLAS.ti was extremely helpful for organising and handling large amounts of data from the current study. Also, CAQDAS supports a systematic approach to analysis, complementing the more intuitive way of extracting themes and meaning, by forcing the researcher to check and consider every interview fragment, instead of foreclosing interpretations by focusing on those fragments that appear most meaningful at first sight.

The initial thematic analysis was done per group of interviews (couples, patients, partners, doctors, nurses, psycho-social workers). The first group of interviews that was analysed were the interviews with the couples. The coupled interviews are at the heart of this study as they represent the view captured in 'being-in-the-world means being-with' and system theory (including the circular view on causality) that was adopted for this study. Therefore, the coupled

interviews are used in the following section to demonstrate the steps in the thematic analysis using ATLAS.ti. Other groups were analysed in a similar way. For ATLAS.ti transcripts are primary documents (PDs) and a certain group (for example the couples) is a 'family'. Families are organised within a hermeneutic unit (HU). Two HUs were set up: the HU 'clients' housing the three client groups and the HU 'professionals' accommodating the three professional groups. The seven transcripts from the coupled interviews were uploaded as PDs in the PD-family 'couples' in HU 'clients'. After that, all relevant fragments⁷ were coded, using the inductively developed coding framework. While coding, the iterative process used meant that this framework was constantly refined, especially for the first few transcripts that contained many fragments for which no suitable label was available in the initial coding framework. Therefore, codes and/or the 'definitions' of the codes had to be refined, sometimes by making their scope bigger in order to encompass similar fragments, but more often codes had to be split in order to do justice to fine nuances in the data. After changing the coding framework, previous transcripts were revisited to match the coding of these transcripts with the adjusted coding scheme. In this iterative way, all seven transcripts of the coupled interviews were eventually coded, based on the same (final) coding scheme⁸. For an overview of the final 22 codes of the PD-family 'couples' and the grouping of these codes into 'code families' see appendix 4. The next step was to create and print output files in ATLAS.ti that would combine all fragments that were related to one code. This resulted in 22 'thematic' documents. These thematic documents were then analysed to arrive at an interpretive description for every 'code'. Writing these interpretive descriptions per code involved going back and forth from the fragments to the transcripts and 'Gestalts' that the fragments originated from. Without the 'wholes' the parts were meaningless and vice versa. The use of ATLAS.ti was very helpful in finding back fragments in the context of the original transcripts.

⁷ In principle every fragment is relevant, as the interviewee brings up the things that are relevant from his or her perspective. However, some fragments were not relevant in view of the aims of the study, as they related to the building of rapport, which is a means to the ends of this study.

⁸ The final coding scheme of the coupled interviews was used as the initial coding scheme for the thematic analysis of the interviews with patients and with partners and proved to have a good 'fit' with these data, making the coding process of these two groups much more straightforward than the analysis of the first group.

Summaries were useful tools for the researcher to bring back the 'Gestalt' of the interviews, although before too long these 'Gestalts' were so much internalized that the summaries became superfluous.

For all six groups this procedure was carried out, resulting in six analyses consisting of interpretive, thematic descriptions of the most relevant findings for each group, leaving the researcher facing the challenge of tying all the information together to form a meaningful and communicable whole. Issues related to this challenge, that arose during the remainder of the analysis process, were more pertinent to the results and the format for presenting the results and are therefore discussed at the start of the findings and discussion chapter.

4. BEGINNING THE DIALOGUE: FINDINGS AND DISCUSSION

The overall purpose is for this study to make a contribution to client-centred cancer and palliative care in the domains of sexuality and intimacy. Its purpose is to convey the understanding reached, as a result of undertaking this study, in a manner that creates resonance in the reader as Van der Zalm et al. (2000) succinctly argue:

Knowledge, resulting from phenomenological inquiry, becomes practically relevant in its possibilities of changing the manner in which a professional communicates with and acts towards another individual in the very next situation he/she may encounter. Phenomenological knowledge reforms understanding, does something to us, it affects us, and leads to more thoughtful action. (Van der Zalm et al., 2000 p. 213)

For health care professionals, findings from this study provide an invaluable tool as they provide added insights, from a clients' perspective, which have implications for practice.

Setting the scene: the format for the discussion

According to Cohen et al. (2000 p. 4) "themes that go across patients are the outcome of phenomenological research". This does not by definition mean that findings need to be presented as themes. Patton (2002) makes clear that qualitative researchers should use all their intellectual capacities to fairly represent data and to communicate what the data reveal in view of the purpose of the study, and that no absolute rules exist on how researchers should do this. Munhall (2007) argues quite strongly against researchers presenting lists of themes as outcomes of phenomenological research, as she perceives this as a reductionistic categorization of human experience. According to Munhall (2007) these researchers fail to inquire into the meaning of these themes for particular individuals. She advocates a narrative synthesis of data instead of presenting data in a fragmented way and further states that researchers should use their imagination for their creative activity, inspired by their subject and content. Colley (2010) too concludes that there is no such thing as a 'golden key' to unlock qualitative data. She encourages qualitative researchers to think for

themselves when it comes to finding the most appropriate methods to make sense of their data. Methods should not restrict qualitative researchers but guide them; there is therefore no single formula for presenting phenomenological findings.

In view of the aim and intended audience of the current study, a presentation format based on summarizing themes did not seem the most effective way to inform readers or provide the opportunity for increased understanding. Although a thematic analysis was an essential component of the analysis process, this alone did not seem to meet all hermeneutic requirements. Themes going across participants' stories are by definition not ideographic but abstracted from the lived experiences of these participants. They are a way of summarizing an experience, however, without any further contextual information they can give only a decontextualized and fragmented picture of the 'real life' experience as a whole. Thus, they were not the optimal way to enable readers to 'walk in the steps' of patients and partners (to the amount possible) and gain in some small way an indication of the magnitude of the journey for patients and their partners. Van Manen (1997) supports this perception and although lengthy, it is worth reading his statement in its entirety because it encapsulates key points about creating a dialogue between the reader and the person who lived the experience:

People who do phenomenological research like to discover and list themes. But thesis-like or thematic types of statements communicate primarily conceptual meaning, and this conceptual meaning does not need to involve a felt or more deeply sensed understanding. Therefore, these themes must constantly be "mantically massaged," as it were. We must discover the nodal points and the nerve endings of sensory sense; we must discern where a certain pressure or compressure may suddenly bring about linguistic liveliness. This working of the text with experiential accounts, evocative constructions, intensified language, and thoughtful reflections embeds and converts thematic claims into a narrative text that contains and safeguards phenomenological meaning. (Van Manen, 1997 p. 358)

The general aim of a hermeneutic study is to come to a deeper understanding of an experience. This should affect not just cognition; to create resonance, there should be impact on a noncognitive level as well. Therefore, instead of a thematic presentation, a more coherent and contextualized way of presenting

the findings, aimed at creating more resonance in the reader, was needed. To achieve coherence, the findings and themes coming from the analyses of interviews with couples, patients and partners were drawn together. This is methodologically justifiable, as these analyses do illuminate the same phenomenon, albeit from different perspectives. According to Butt & Chesla (2007) and Taylor & De Vocht (2011), combining these perspectives results in richer understanding of the phenomenon.

In order to place themes in the context, condensed versions of the findings are presented as vignettes, or 'snapshots of life'. Vignettes provide examples of how themes manifest themselves in real life. They are stories to read, but are not fiction, as every one is based on findings from the study. They are composites, a collage of the experiences participants shared during the interviews. They were composed to give the reader an indication of and some insight in the significant aspects of participants' experiences, to invite the reader to identify with participants through reading a discussion based on their perspective. For clarity, the vignettes are written in the second person singular, are in colour, are in boxes, and included at significant points and changes in context.

The vignettes are presented in the context of a chronological story, inviting the reader to experience the journey through the cancer process in the same order as the patients and their partners do. The 'story' was created inductively by going back and forth from the transcripts to the analysis to the story line, weaving multiple sources of data and layers of context into the story (Colley, 2010). Participants differed regarding the length of time that had passed since their or their partners' cancer diagnosis and this helped the creation of the chronological storyline, using perspectives from people in the midst of an experience combined with perspectives from people reflecting on similar experiences in a recent or more distant past. Patients also differed regarding their prognosis: some were very uncertain about whether their cancer could be cured or not, others were cured and the remainder were sure they would not be cured or were already terminally ill. The first part of the story is based on perspectives coming from all participants, as they all experienced, directly or indirectly, being diagnosed with cancer and undergoing some form of treatment, be it curative or palliative. At the end of the story there is a bifurcation, with one

branch exploring the experience of participants who are in remission or cured and the other branch exploring the experience of participants until death, and from the partner's perspective what followed the loss of a partner. Where appropriate, findings from the interviews with health care professionals are interwoven to illustrate the story line.

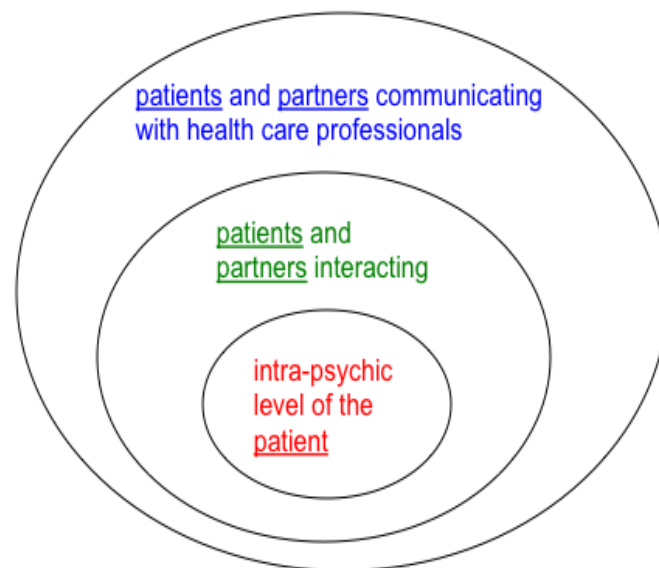
Through the narration, quotes from interviews are provided to illustrate key points and where appropriate the differences between individuals. These allow readers to follow the journey and interpretation of the experiences, grounded in the information and experiences participants shared during the interviews. The length of each quote is determined by how much information is needed to preserve sufficient contextual information to give 'real life' meaning. In translating the quotes, originating from transcripts in Dutch, care has been taken to preserve the 'tone' of expression as much as possible.

Structuring the story and the core of the study: worlds apart

As participants in this study were patients, partners and professionals, in the initial thematic analysis, the focus was on the perspectives of these three groups in isolation (the patients' experience, the partners' experience and the professionals' perceptions of their role). Logically, this was the starting point of analysis as the aim of the current study was to come to a deeper understanding of these perspectives. While working on the analysis and trying to develop a story line, the unitary focus turned out not to fully grasp the dynamics of the experiences of the patients and partners. In order to capture these dynamics, trying to create a conceptual 'whole', on-going cycles of reflection on the 'parts' were needed. Listening to what the data were telling, a shift towards focusing on interactive aspects was required in order to get to the core of the lived experiences. During this process of repeatedly going through the hermeneutic circle, it became evident there were three relevant 'interactive' levels: firstly patients and partners interacting with health care professionals, secondly patients and partners interacting with one another and thirdly the intra-psychic level (the 'intra-action') of the patient. Listening to the data from these perspectives, not all data became concurrent, but a model began to materialise in which all data could be placed. In this model, three concentric levels of 'being-in-the-world' were schematized (figure 1). The patient is at the heart of

these circles, as it is the life-threatening illness of the patient that is the trigger of the experience under study, thus the patient is the epicentre from which ripples emanate. This model was actually developed during the analysis, and was only completed when the process of analysis was finished. However, it informs the whole process, and for the reader to follow the clients' story they need to know the context in which to place what they are reading. To withhold the model to the end of the discussion would be to withhold the context and in consequence it is presented before the findings to prepare readers for their immersion into the lived experience of the participants.

Figure 1: Three concentric levels of 'being-in-the-world; underlining indicating the perspective(s) taken at each level



To avoid confusion, it should be noted at this point that it is not the interaction per se that is the focus of the current study. It is only when determined by the research goal that interactions between participants become the focus of analysis (Morgan, 2010). The research goal of the current study is not to study interactions per se, but to come to a deeper understanding of lived experiences. In order to enhance this understanding, it turned out to be relevant to focus on interactions with others and on intra-action within the patient as key elements of their lived experiences.

This 'interactive' focus is in line with the theoretical framework of the study. On the existential level of 'being', Heidegger (1953/2010) made clear that 'being-in-the-world' (Dasein) is always 'being-with' (Mitsein). Relations to others are a fundamental aspect of being-in-the world, and 'Dasein' cannot be understood without considering the on-going interactions with other people (Langdridge, 2007, Taylor and De Vocht, 2011). Heidegger (1953/2010) further argued that for the individual, different 'modes of being' exist, resulting in the possibility of oscillating between an inauthentic and an authentic mode on the intra-psychic level, thereby partly explaining the dynamics at the intra-psychic level of the patient.

The focus on patients, partners and professionals interacting is in line with the principles as laid out in System Theory (Watzlawick et al., 1967). System Theory stresses the interdependency of the 'parts' that the system consists of. The 'parts' of a system will mutually influence one another, with changes in one 'part' resulting in changes in the other 'parts' and the system as a whole as well. System theory also subscribes to the methodological principle of circular causality (Willemse, 2006) that was adopted for this study, mirroring and matching the circular process of reaching understanding that occurs in the hermeneutic circle when performing the analysis.

A crucial element of the analysis was reflecting on conceptual threads in the study findings. Conceptual threads help to give findings conceptual integrity and clarity and to bind them into a conceptual whole (Su et al., 2010). The principle of the hermeneutic circle with its repeated reflection on the experiences expressed by participants was combined with insights from philosophical and psychological existential literature. It emerged that on all three levels of 'being-in-the world' participants identified existential gaps (and ways to bridge these gaps). Pondering on a suitable label for this experience, direction came from Munhall's (2007) stance that such a label should not reflect a reaction to the experience but the (meaning of) the experience itself. This resulted in a conceptual focus expressed in the core theme: 'worlds apart'. This core element of the findings: 'worlds apart', manifests itself on all three levels of 'being-in-the-world' and this shaped the presentation of the findings.

To illustrate the lived experiences of participants in relation to the three levels of 'worlds apart', the vignettes had to be carefully considered and developed. They are the linking pins between the lived experiences (as embodied in the quotes from the interviews) and the core of the study. They are the heart of the framework (table 2) that was constructed to communicate the essence of what the data reveal (Patton, 2002) and all go back to one of the three levels of 'worlds apart'. For clarity, in the text vignettes are presented in different colours corresponding to these three levels. An overview of the vignettes, their relation to the three levels of 'worlds apart' and their placement in a chronological story line, is given in the framework presented in table 2. The numbering of the vignettes is based on the order in which they appear in the chronological story line. The fact that there is no 'linear' order in the vignettes in the framework presented in table 2 demonstrates the circular interplay between the three levels, with the clients' perspective dictating which levels emerge first at which point in the chronological story. This illustrates the circular and complex nature of human experience, and which poses a challenge for health care professionals who are trying to support patients and partners as best they can.

Only once a dialogue has been created can the implications for practitioners be considered. To interweave these disrupts and runs the risk of breaking the story, therefore the more interpretive discussion and the implications for practice follow the story, as the reader can then see them in the light of the whole discussion.

Table 2: Framework showing the vignettes in relation to the timeline and the different levels of the theme ‘worlds apart’

Worlds apart: <i>Timeline:</i>	Level of patients and partners communicating with health care professionals	Level of patient and partner interacting	Intra-psychic level of the patient
Diagnosis	Vignette 1: Moment of truth	Vignette 3: Unshareable	Vignette 2: No longer taking for granted
Preparation for treatment	Vignette 4: What to expect...	Vignette 6: Goodbye to your sex life (for now)	Vignette 5: Changes in the bedroom
Treatment	Vignette 8: Room 212 bed 4 Vignette 10: Explosion	Vignette 11: Multitasking Vignette 12: See me, feel me, touch me, heal me...	Vignette 7: Unwanted friend Vignette 9: Whose body is it anyway?
End of treatment: remission / cure	Vignette 15: Little pains... Vignette 16: Bring it up	Vignette 14: Fog is lifting	Vignette 13: Back to normal?
End of treatment: death	Vignette 18: There is still something we can do...	Vignette 19: Never again Vignette 20: The consolation of intimacy	Vignette 17: To know or not to know

Interview and participant details

The researcher conducted all interviews. Interviews with clients lasted between 61 and 126 minutes, with an average of 81 minutes. Interviews with professionals lasted on average 52 minutes (with a minimum of 36 minutes and a maximum of 80 minutes). In total, 45 hours and 38 minutes of interviewing were recorded, resulting in 888 pages of transcript (see table 3 for further details). The duration of the interviews is given because it illustrates how the use of the hermeneutic cycle, with only a few topics, led to rich in-depth exploration.

Table 3: Overview of number and duration of interviews and resulting number of transcript pages per participant group

Participant groups	Number of interviews	Duration of the interviews (minutes)	Number of transcript pages
CLIENTS			
Couples	7	592	278
Patients	8	703	202
Partners	6	398	112
Total	21	1693 (28h 13 min)	592
PROFESSIONALS			
Doctors	7	317	98
Nurses	8	424	117
Psycho-social workers	5	304	81
Total	20	1045 (17 h 25 min)	296
GRAND TOTAL	41	2738 (45 h 38 min)	888

Although it is acknowledged that the number of participants was high for a hermeneutic study, the mixed group of patients, partners and couples was helpful in providing a variety of views on the impact of a life threatening illness on the experience of sexuality and intimacy and on discussing these issues with health care professionals. In total, 7 couples, 8 patients and 6 partners participated, resulting in 28 participants representing the clients' perspective. A mixed group of professionals provided valuable insights in perceptions of their role regarding sexuality and intimacy and professionals shared their expertise in addressing these topics. In total, 20 professionals took part, 7 of them doctors, 8 nurses and 5 psychosocial workers. In order not to break the story line, a short summary of all participants is given in table 4-7. In table 4, 5 and 6, using

pseudonyms, demographic and illness related characteristics are presented separately for couples, patients and partners. In table 7 an overview of participating professionals is given.

Table 4: Demographic and illness related characteristics of the couples
(patients in bold; all time periods calculated from time of interview)

Couple (patient & partner)	Age	Relationship, children	Medical diagnosis/diagnoses, made how long ago	Treatment
Wilbert & Gemma (C1pat/par)	71 / 71	married for 50 years 3 grown up sons	intestinal cancer 3 years	bowel surgery, stoma
			metastases 1 years	chemotherapy
Mia & Ryan (C2pat/par)	32 / 28	living together for 4,5 years no children (yet)	breast cancer 4 years	lumpectomy, radiotherapy hormone treatment
Emma & Richard (C3pat/par)	42 / 47	married for 17 years 2 daughters, 15 and 11 years old	mucosa cancer 2 years	Wertheim's hysterectomy, radiotherapy
			mucosa cancer 6 months	chemotherapy
Rose & Jacob (C4pat/par)	71 / 72	married for 46 years 3 grown up children	breast cancer 20 years	lumpectomy, mastectomy
Joyce & Dennis (C5pat/par)	49 / 52	married for 30 years 2 grown up children, 2nd one is about to move out	Hodgkin's disease 4 years	chemotherapy, radiotherapy
			Hodgkin's disease 1 year	autologous stem cell transplantation
Joan & Walter (C6pat/par)	47 / 51	married for 12,5 years 1 daughter, 10 years old	breast cancer 16 months	double mastectomy with immediate reconstruction, chemotherapy, radiotherapy, hormone therapy
			ovarian cancer 1 year	hysterectomy with oophorectomy
Edith & Mike (C7pat/par)	47 / 47	living together for 20 years 1 son and 1 daughter, 13 and 11 years old	breast cancer 1 year	mastectomy
			breast cancer 2 months	mastectomy, chemotherapy

Table 5: Demographic and illness related characteristics of the patients
(all time periods calculated from time of interview)

Patient	Age	Relationship, children	Medical diagnosis/diagnoses, made how long ago	Treatment
Judith (Pat1)	39	married for 4 years, no children	breast cancer 7 years	lumpectomy, radiotherapy, hysterectomy with oophorectomy
			metastases 5 years	chemotherapy
Anna (Pat2)	44	divorced, 1 son 12 years old, 1 daughter 10 years old	breast cancer 3,5 years	lumpectomy, chemotherapy, hormone therapy
Chantal (Pat3)	51	divorced, no children	cervical cancer 16 years	hysterectomy with oophorectomy
			breast cancer 4 years	lumpectomy, mastectomy
Grace (Pat4)	52	married for 28 years, 2 grown up children	breast cancer 9 years	lumpectomy, chemotherapy, radiotherapy, hormone therapy
			breast cancer 6 years	mastectomy
Iris (Pat5)	45	single after cohabitation for 20 years, 1 son 14 years old	breast cancer 14 years	breast conservation therapy, radiotherapy, chemotherapy
			breast cancer 6 years	double mastectomy, oophorectomy
			metastases 1 year	chemotherapy & medication trial
Helen (Pat6)	48	married for 10 years, before that 9 years cohabitation with the same partner, 1 son 12 years old	cervical cancer 9 years	hysterectomy
Alice (Pat7)	44	single after three long term relationships, no children	cervical cancer 3 years	Wertheim's hysterectomy, chemotherapy, radiotherapy
Tristan (Pat8)	60	cohabiting for 30 years, 2 grown up children	stomach cancer (metastasised at time of diagnosis) 4 months	chemotherapy

Table 6: Demographic and (patient) illness related characteristics of the partners (all time periods calculated from time of interview)

Partner	Age	Relationship, children	Medical diagnosis/diagnoses of patient, made how long ago	Treatment of patient	Length of time since patient's death
Nancy (Par1)	52	been married for 32 years, 2 grown children	lung cancer, 4,5 years	chemotherapy, radiotherapy	3,5 years
Bruno (Par2)	55	been married twice, both partners died	second partner: lung cancer 1 year	chemotherapy	half a year ago
Diana (Par3)	60	married for 36 years, 2 grown up children	non Hodgkin's disease 2 years	chemotherapy	dna
Maureen (Par4)	57	13 years cohabitation, grown up children from former marriage	non Hodgkin's disease 2 years	chemotherapy	1,5 year ago
Heidi (Par5)	57	cohabiting for 30 years, 2 grown up children	stomach cancer (with metastases) 4 months	chemotherapy	dna
James (Par6)	60	been married for 12 years	cancer of the ovaries, breast cancer 13 years	oophorectomy, double mastectomy	3,5 years ago

Table 7: Overview of characteristics of professionals

Disciplinary background	Age	Sex	Years of experience with cancer and / or palliative patients
General practitioner (Prof1)	60	M	33
Medical social worker (Prof2)	49	F	5
General practitioner (Prof3)	53	M	19
Nurse working in heart failure clinic (Prof4)	43	F	7
Lung specialist in training phase (Prof 5)	36	F	7
Cardiologist running a heart failure clinic (Prof 6)	59	F	24
Oncology hospital nurse (Prof7)	53	F	10
Community nurse (Prof8)	50	F	3
Auxiliary community nurse (Prof9)	54	F	39
Specialist elderly care and hospice physician (Prof10)	40	F	12
Psycho-social therapist (Prof11)	44	F	2
Specialist oncology nurse (Prof12)	34	M	18
Breast care nurse (Prof13)	34	F	14
Sexologist (Prof14)	44	M	1,5
Sexologist (Prof15)	50	M	14
General practitioner (Prof16)	60	M	31
Community nurse and nurse in low care hospice (Prof17)	54	F	23
Oncologist (Prof18)	65	M	33
Spiritual carer (Prof19)	42	F	16
Nurse in high care hospice (Prof20)	59	F	9

The clients' story

The 'story' begins with the meeting with the physician who officially communicates the cancer diagnosis. From this moment on patients know for sure that they have cancer, and although they may not be aware at this stage, this may very well have an impact on their experience of sexuality and intimacy. Focusing on communication with health care professionals it is relevant to illuminate clients' experiences from this initial phase of interaction. Clients will mentally judge the quality of the interaction, although the topic of sexuality is unlikely to be raised during the meeting where the diagnosis is discussed. The outcome of such an appraisal will determine whether clients will trust their professionals enough to make disclosure of personal issues such as sexuality and intimacy possible in the future. Therefore, also from a communication perspective, the story needs to start even before sexuality and intimacy are on the agenda.

Diagnosis

A cancer diagnosis is always a life-changing event. Some people may have had pre-warnings or indicators that something might be wrong, but for others, the diagnosis comes out of the blue, for example when routine screening gives a positive result. Whichever, many people have lived between hope and fear for some time, awaiting official tests and conclusive results, but at some point, the moment of truth has arrived.

Vignette 1: Moment of truth

You have an appointment with your oncologist today. You have some symptoms that have caused you concern and you have had some tests. Today your oncologist is to tell you the results. The days between the tests and today were the longest and most difficult of your life. Last night you did not sleep at all. You are now sitting in the waiting room and you are very nervous. The nurse comes to call you in. You scan her face to see what it tells you but it is neutral. You feel lost and afraid. Then you meet your oncologist. The appointment lasts for 10 minutes but your whole world revolves around those 10 minutes. This is what happens.....

Grace (Pat4): I remember him telling me the bad news. He sat down beside me, avoiding looking me in the eye, or he stood in front of me looking over my head; he did not look me in the face once.

Nearly a decade later Grace still feels hurt, distressed and angry when she talks about this. She feels abandoned and ignored as a living and feeling human being.

Similarly, although the context was different, Edith too felt frightened and unsupported:

Edith (C7pat): she [the oncologist] treated us so coldly, she didn't smile at us when we came in and most of the time all we saw was the left side of her face as she was looking at her screen while talking to us. She did not spend one minute acknowledging that it must be pretty tough to be diagnosed with breast cancer for the second time in one year. She asked me why I did not have chemo after my first surgery, as if she was blaming me for it, when all I did was do what my doctor said. This made me really scared. We were also afraid that my cancer might be hereditary and we asked about possible consequences for my daughter, but she did not even go into that.

Edith needs all the support she can get, given her situation and her fears for her own well being and that of her 11 year old daughter. Instead, this behaviour demonstrates an unconscious (on the oncologist's part) example of secondary victimization (Williams, 1984). By making Edith and her partner Mike feel a degree of blame for accepting the other oncologist's decision, this second oncologist is making the situation for this couple even more difficult and painful than it already is. Mike could blame himself for not having persisted while Edith could feel guilt that she acceded what was suggested to her. Such self-blame is difficult to cope with and can impact adversely on the relationships of all those involved. Kuhl (1999) calls this 'iatrogenic suffering', explaining that the manner in which health care professionals speak to patients can add to their suffering, as with Kuhl's (1999) participants who stated that the way in which they were told their diagnosis was more emotionally painful than the diagnosis itself. Edith and Mike were so distressed as a result of their experience that they felt they could not maintain their relationship with the same oncologist. Their way of resolving their anxiety was to seek further help with someone else. However, others in their situation may not be so assertive and may then be left with guilt, anxiety and a lack of emotional support.

Edith and Mike were very pleased with the way their new oncologist treated them:

Mike (C7par): He is such a nice man, decisive, but he senses perfectly when you may need more time. Particularly as she had got it for the second time, which came as a

shock of course, he kept the whole waiting room waiting while talking with us for an hour. I think that was tremendous. At some point he said, well, that he needed to carry on. But in a nice way, exactly right.

The public as a whole still associates cancer with a death sentence (Tritter and Calnan, 2002) and therefore a cancer diagnosis often feels like a death warrant (Vargens and Bertero, 2007). Consequently, survival often becomes (initially) the main focus and the body may be experienced differently.

Vignette 2: No longer taking for granted

The cancer diagnosis felt like a real blow. From that moment on, the way you experience your body has changed. Before your diagnosis, you never really thought about your body as a 'functioning body', it simply **was**. The diagnosis of cancer has disrupted the self-evident character of this 'perfectly functioning body'. You now feel like you **have** a body and you feel betrayed by it, because it is now problematic and defective. Nevertheless, this is the one body you have, and this is the body you will have to 'deal' with; there is no alternative. All you want now is to restore the healthy body again. Your focus is on getting rid of the cancer, on treatment, on survival.

It was evident in this study that for many participants the cancer diagnosis came as a shock, but despite this shock effect, more often than not, quick decisions needed to be made, with far reaching consequences, for example with regard to body image.

Edith (C7pat): The strange thing was, and I remember it perfectly, the oncologist said "well it's either breast conserving or it has to be removed" and another patient was just leaving so it never entered my mind that this was about me. I thought well this must be awful for the person concerned. I thought he was referring to something related to a later stage. I never realised that I had to choose between a lumpectomy and mastectomy. "No" he says, "this is about you, so you have to, within a week we would like to hear your decision if possible". Well I jumped, really I did.

Edith literally could not believe this had happened to her. The information was shocking for her and too difficult to take in there and then. She was not immediately capable of making well-considered choices, because of the mutilating nature of the surgery being offered. For some women, the thought that 'whatever I do is going to mutilate me' is just so much they cannot take in anything else. This is a crucial point because patients having to undergo mastectomy may be offered the option of immediate breast reconstruction. The mastectomy has to be done as soon as possible, therefore clients don't have much time to decide whether or not they opt for immediate reconstruction and

most of them make quick, instant decisions (Harcourt and Rumsey, 2004). Instant decisions have far reaching consequences, as will emerge as the story progresses.

Trying to help patients come to terms with their diagnosis, professionals may feel it is helpful to offer clients some statistical data on their prognosis. If this shows their prognosis is relatively good, they (the professionals) think it might help to make the diagnosis feel less threatening which in turn will contribute to helping the patient make informed decisions, even on a short term basis. Survival percentages make perfect sense from an evidence based medicine point of view, however, from the client's perspective, the experience might well appear different. Asked about her prognosis Anna replies:

Anna (Pat2): My prognosis is good...yes. But it doesn't really mean that much to me. I mean, it may sound peculiar, but being confronted with cancer out of the blue for the second time, well, percentages just don't mean much to me you see?

For clients, percentages represent statistical information that on the individual level is confusing. For the individual only two options are open: either you survive your cancer or you die. So for you as the patient it does not really make a difference whether you came from the 10 % chance of survival group or from the 90% chance of survival group if you turn out to be incurably ill. Furthermore, patients do not always seem to understand the meaning of the percentages in relation to treatment options and prognosis (Kellehear, 1992, Stehouwer, 2005). A 10% better chance of survival as a result of treatment is something most patients will accept, without fully realising that this means that 90% of the people are going to have treatment with no effect (but possibly with serious side effects). Similarly, a 10% better chance of survival as a result of chemotherapy combined with a 10% better chance of survival due to radiotherapy does not, as many patients assume, result in a total of 20% better chance of survival. This confusion does not help patients to make well-informed decisions. Potential beneficial effects of treatment are often smaller than patients believe they are, whereas side effects can have major consequences for quality of life. Not surprisingly, The (1999) found that the few people in her study refusing chemotherapy treatment when they were seriously ill were mainly hospital

employees who had seen numerous examples of the effects of chemotherapy treatment.

In the mean time, patients back home are struggling to come to terms with the impact of the cancer diagnosis and may be going through the estranging experience of being unable to communicate what the effects of the diagnosis are for them, resulting in a feeling of unshareability of the experience.

Vignette 3: Unshareable

It is now one week since you got your cancer diagnosis and you have told your relatives and closest friends about it. Some of them say to you: 'I can imagine what you must be going through' but you don't think they can. You remember saying this yourself to other people who got cancer before you, and you now realise you had no idea what you were talking about. Now you know from your own experience what it is like to be diagnosed with cancer, but you cannot really explain this to other people. When you try to communicate how you are feeling, you hear yourself say 'it is **as if** my world is upside down' or 'it is **as if** everything is out of perspective' so you can tell what it is like but not how it **is**. It is like your whole existence is completely lacerated, whereas in the rest of the world, somewhat to your surprise, it is business as usual. Your closest friends, although very sympathetic, rush back to their own lives, leaving you behind with this feeling of being on your own. It's you and nobody else who experiences what this cancer diagnosis means to you. Even to your partner, who is trying to support you the best he can, you cannot convey the enormous impact of knowing you have cancer has for you. He is trying to stay calm and reassuring and although you know this is what you need, you would sometimes like to hit him really hard and shout '**I have got cancer for godsake**' to disrupt his calm and make him feel the intensity of your emotions.

Preparation for treatment

It was evident in this study that, in some cases, when health care professionals prepared patients for treatment, possible side effects of treatment affecting the domain of sexuality were not mentioned at all. In other cases, information was given in a way that did not acknowledge what these side effects would mean in 'real life'.

Vignette 4: What to expect.....

You are anxious; this is a very important day for you, you are about to find out what is going to happen now the oncologist has decided on your treatment. He is discussing it with you, so you will know what to expect. He has a long list of possible side effects to go through, and briefly mentions 'dryness of the mucosa'. You have no idea what this

means, but you don't really pay much attention to this one point; there is so much information to take in, you need to remember it all but are finding it hard to concentrate, there is so much going on inside your head. You want him to stop, but at the same time you think you should know everything.

After this appointment with the oncologist you see the nurse. She seems a nice person so you are hoping for a 'human touch' and some consolation, as you feel very confused and slightly panicky about everything that is happening to you; it feels like a bad dream that you can't get out of. This is what happened next.....

From nurses, people seem to expect more than merely medical information, but it appears that this expectation is not always met.

Mike (C7par): What the nurse does is take you on a guided tour: pay attention to this pay attention to that, the whole works. So she also mentions sexuality but actually she only gives information.

Some nurses seen as the 'supporter' are like other health care professionals who talk about side effects impacting on sexuality in a technical way, fitting a typical one-way patient education style.

Heidi (Par5): The next day we spoke with an oncology nurse, she had another go at it [explaining the side effects], and I thought, oh my, is that how you do your job; I was expecting something entirely different: that she would talk about us. But she was just ticking the boxes: a fingertip may be bothering you, or the soles of your feet; but the consequences of that were never discussed.

The same happens regarding consequences of treatment for the partner:

Maureen (Par 4): In preparation for the first chemo we had a talk with a nurse for about one and a half hours and she told us you are not to have sex 24 to 48 hours after that treatment, because it's in all bodily fluids including his sperm... erm...that was the only time it was mentioned. Just like that: it's in your saliva, and in your sweat and in your sperm and well...that's how she went ... quickly through the list. Nothing more.

In a way, Maureen was 'lucky' to have been given this information at all, because the facts about the potentially aversive side effects of chemotherapy for the partner was not always offered. On a practical note, there is no evidence available on whether and for how long sperm and vaginal fluid contains traces of cytostatics. Unfortunately, there are no evidence-based guidelines on the use of a condom during and shortly after chemo treatment (www.kwfkankerbestrijding.nl). Nevertheless, it is important to discuss these issues, so partners have an idea what the limitations are and, just as importantly, what they are not.

A balance needs to be found regarding the amount of information given at this stage. More information is not always better (Lindop and Cannon, 2001). Edith suggested that professionals should try to find a balance between describing all possible side effects and ‘not scaring off people too much’:

Edith (C7pat): Of course you may encounter lots of things, but not everybody encounters everything and when you hear you may have this or that you start thinking: “Oh my God, I have been through so much and now all that’s still ahead of me”.

So from a clients’ perspective, health care professionals should not strive to be exhaustive in mentioning all possible side effects, but mention the ones that are most likely to be experienced by this patient (including side effects impacting on sexual function), and encourage patients to report any other side effects that might appear⁹. Patients should be encouraged to bring up every worry they might have along the cancer trajectory, be it in the sexual domain or not. The art is to create an atmosphere where people feel truly welcome and safe to discuss their anxieties and concerns. A prerequisite for this is that professionals appear comfortable addressing potential side effects impacting on sexual functioning. In some instances this was clearly not the case (Hordern and Street, 2007b), as the example of Mia demonstrates:

Mia (C2pat): Prior to the chemo treatment the oncology nurse quite sheepishly came to tell us “well erm yes erm sex”, and she spoke so fast, whoosh, that’s that sorted then.

Addressing sexuality as part of patient education is not enough to make the patient willing to talk about it:

*Tristan (Pat8): Before my chemo the oncology nurse gave us a plain purely informative story. The way we experienced it ... was never discussed. Not even “how do you feel about all this”; not a single question. That was wrong, because this is a process that concerns the whole of a human being. Whether you trust the nurse depends on her communication style. We had only information, and I would **never** have felt the urge to share details of my personal life with her, but a good nurse who acknowledges the whole of a human being, yes, I would certainly have welcomed that.*

Professionals should show real interest in how patients and partners are doing. Asking “how are you” out of politeness when clients come in to see the

⁹ In some countries the law might not permit for this, obliging health care professionals to mention all possible side effects.

professional is not an adequate way to do this. It creates the impression that the professional really would like to know whereas the question is merely rhetorical.

Heidi (Par5): Well, of course that question [how are you] was asked, as soon as we came in, but then we weren't ready to answer it, that's the point.

In this study, patients and partners were unanimous in stating that in order to make communication about personal topics possible, a person-oriented communication style from the professional was paramount. They had clear ideas of how they envisaged such a person-oriented approach:

Emma (C3pat): It all boils down to the person I think, is he open? It's in the eyes, body language, is someone sitting like this [arms and legs crossed] or is it someone with a truly open attitude, that's very important to me.

Ryan (C2par): It should be someone really interested, who dares to look straight into your eyes, and there has to be some sort of click.

Anna (Pat2): It all boils down to human interest. You as a whole. Because I truly believe that if they show a real interest, this other subject, sexuality, will more or less come up automatically.

Tristan (Pat8): I think it has to do with whether they're sincere; that people should be able to do this as a person and not because they are adopting a professional role. They should just be open, and that opens up a lot of possibilities.

Perhaps James gave the best summary:

James (Par6): Professionals should just be human...

As the examples make clear, a person-oriented approach requires attention from the very first time onwards that professionals and clients meet.

Vignette 5: Changes in the bedroom

In the privacy of your home, you are still locked in your nightmare, so in the bedroom things have changed as well. The thought of sex has not once crossed your mind since you got your diagnosis. Sexuality is just not in your mind, despite the fact that you and your partner used to have a pleasant and satisfying sexual relationship. You are focused on survival, you are mentally trying to prepare for the treatments you are facing and this requires all the energy you've got. Thinking about what the loss of sexuality means to your partner is even further out of mind and you simply assume (s)he is thinking the same way you are.

Joan made this clear when she describes how she assumed that her partner felt the same:

Joan (C6pat): When you hear you've got cancer, making love isn't on your mind at all. You are only thinking of the operation and that it has to be cut out ... and I've got cancer and oh my and...we didn't feel like making love.

In reality it's different. Even at this early stage, the roads that patients and their partners travel seem to be bifurcating. From the partner's perspective, things look and feel different.

Vignette 6: Goodbye to your sex life (for now)

Your partner has been diagnosed with cancer and is waiting for her treatment to start. Like her, you were shocked to find out that she is seriously ill. Of course, her health and well being is your first concern, but on the other hand you are still a healthy person with a 'healthy' sexual interest. You miss the warmth and the feeling of 'merging' with her, and you feel that making love would help you to cope better. You're in a bit of a dilemma and you feel guilty and ashamed about this, here is your partner seriously ill and you are thinking about sex; why can't you get rid of these thoughts? And of course you don't want to ask anything from your partner that he or she feels not ready for, but for you it feels as if a pleasant, comforting and exciting sex life has very abruptly been cut off, at least for now. It might take some time before she is ready for it again and you will wait patiently for that moment to arrive, but you are looking forward to it already...

As Joan's partner Walter put it:

Walter (C6par): We didn't have the time to adapt ourselves in any way. There was no time because surgery had to be performed as soon as possible, we both agreed that. But overnight, intimacy, sexuality was ... erm, cut off.

For other couples, the impact of the illness on sexuality was more gradual, where patients hadn't been feeling too well for some time prior to diagnosis and as a result of that, had lost interest in sexuality. In these instances, in retrospect, the diagnosis helped to explain what was going on.

Heidi (Par5): That's why it never occurred to me I think, because XXX [partner] hadn't been really fit since last September; he wasn't very active, and that included not being sexually active. He'd stopped all sexual activity, but I didn't notice until December. Well had there been some sort of rhythm with sexuality coming to a sudden halt then I would have noticed. But between us nothing stopped abruptly. Things changed very gradually. In retrospect I would say we could have woken up to it a little earlier. But probably because things had been slowing down for some time it went unnoticed, at least I never noticed and XXX never mentioned it.

For some couples, sexual activity had already come at a standstill before the cancer diagnosis and the cancer diagnosis was not the reason sexuality was no longer on the agenda.

Wilbert (C1pat): We have come to an age where our hormones don't run rampant anymore [☺]¹⁰. Our sexual life gradually disappeared.

Gemma (C1par): Already before Wilbert turned ill neither of us felt the need anymore, I don't know why but we just didn't consider it that important anymore.

So to summarize, in the first period after a cancer diagnosis, for a variety of reasons, for most couples sexuality is not in the foreground of their relationship. For them, the focus is on coping with treatment. It is important to realise that losing sexuality also means losing a major source of potential intimacy and sharing. However, it seemed that in this phase, participants didn't tend to see sexuality as a suitable way to help them cope, even if it might have helped some partners.

Treatment

For many patients, especially for those for whom there was a possibility of survival, an operation, aimed at removing the tumour, was part of treatment. This means the self of these patients was affected in different ways. Not only is there an impact on their independent existence, they also emerged from this process with a surgically altered body, resulting in an altered body image and sense of self that inevitably impacted on the sense of (sexual) identity (Mercadante et al. (2010).

Vignette 7: Unwanted friend

You have woken up from your surgery with a stoma. The nurse said you have to 'make friends' with it, but even now that you are back home you still don't feel like 'making friends'. For you the stoma is an unwanted friend and you find living with it neither easy nor pleasant. At first you avoided going out altogether, as you were afraid other people might perceive noises or smells coming from your stoma. Just the thought of that made you very anxious and insecure. For you, this stoma is an obstacle that is always in the way, especially when you want to be intimate with your partner. You don't like this new 'friend' at all; it's like an intrusive and uninvited visitor who is always on your tail and that you can't shake off. Your GP tries to put things in perspective by reminding you that if you had not had the operation including the stoma, you would have been dead by now.... You know this is the case, and you **are** grateful to be alive, but that doesn't make living with a stoma any better...

¹⁰ [☺] indicates audible laughter

The change of body image is obvious when the appearance of the body is changed, as is the case for example for breast cancer patients who undergo surgery:

Edith (C7pat): The first time I saw my body without my breast I cried and cried, it looked horrible. The very first time oh my god... this is just awful, but that does wear off. But I still do see my body as a mutilated body, it looks really weird.

Not all the women who had a mastectomy were prepared for what the impact on their body image would be:

Chantal (Pat3): You don't know what to expect. You don't know what it means when your breast is removed. Yes, you know that it will be gone, but you can't imagine what that does to your body. Or rather, what it does to you mentally. It is such a fundamental change.

In this study it was evident that the loss of a breast had a great impact, however, breast conservation therapy did not always result in a better body image than mastectomy (Zimmermann et al., 2010):

Grace (Pat4): After my first operation my breast looked strange, it was flat and the top of the nipple looked as if it had fallen off. After three years my cancer came back and I had a mastectomy. I felt much better after that, for me it looked much better.

Similarly, not for all women the loss of their second breast is a change for the worse:

Edith (C7pat): To be all flat, I don't think it's that ugly...when one breast was removed and the other one was dangling down there I thought, well guys this is something for an amusement park, a freak show, whereas now I tend to think okay, at least it is symmetrical so...

A woman's sense of femininity and sexual identity can be changed by changes in body image as Rose explains:

Rose (C4pat): Yeah, then I was confronted with the fact that I had undergone a major change; your body's not feminine, but half man and half woman. I am no longer complete. That troubles me a great deal. I was never really aware of other women's breasts until I had my mastectomy but now I am. And I can't get rid of that.

In contrast, Judith does not experience changes in her body image as impacting on her sense of femininity:

Judith (Pat1): The ovaries and the uterus had to be removed as a preventive measure, and instantly I felt something like 'away with them'. I didn't feel less feminine, which is what you hear so often. Not for me, not at all, to me my health was all that counted, always. Even if both of my breasts would have been removed, no, it was all about my health, I'd have done anything for that.

Apparently, Judith's sense of femininity does not (solely) depend on her body image. Maybe she has a stronger sense of self or other sources of internal worth that protect her from the impact of surgical alterations. Tan et al. (2002) point out that the impact of disfiguring surgery may be bigger for people whose self-esteem is mainly based on a sense of body integrity and physical attractiveness. Pek (2010) describes the work of Kiel, who is a psychologist and works as a 'body acceptance coach' with women who have a negative body image. She does not try to change these negative body images, because the bodily aspects these women are struggling with often indeed don't meet prevailing beauty standards. She does, however, try to make them aware of other sources that can boost their self-appreciation and self-esteem, because the more 'legs' these women have to stand on the more stable they will be, and the less their appearance will be determining how these women feel about themselves.

Body image is not only about how the body appears but also about how the body functions and feels (Zimmermann et al., 2010). Any operation, whether disfiguring or not, can result in an actual perceived change of body image.

Emma (C3pat): Your body is no longer your body; I no longer feel like a woman to be quite honest, even though I still happen to have my breasts, but down below feels differently and my stomach and everything has changed.

Chemotherapy is another form of treatment and it can be used at several points in the illness trajectory. Chemotherapy is a type of 'systemic' treatment that can impact on cancer cells anywhere in the body. Patients may have chemotherapy to shrink a cancer before surgery or radiotherapy, to try to stop cancer coming back after surgery or radiotherapy, as a treatment on its own in cancers that are

very sensitive to chemotherapy or to treat cancer that has spread from where it first started.

Vignette 8: Room 212 bed 4

Last Friday you got your cancer diagnosis and your oncologist suggested you start treatment straight after the weekend. It is now Monday evening and you are back home after your first chemotherapy. You are letting this experience sink in. You had no idea what to expect from this first day of treatment, although the procedure had been outlined to you. The oncologist had explained that the chemo cannot cure you, but it will help to improve your quality of life. He told you not to worry too much, as some patients just come in to have their chemo and then go back to work again. You were glad your partner came with you today as you still feel shocked, confused and muddled. Over the weekend you had to tell your parents and your children what is going on and the memories of their disbelief, anger and despair still stand out clearly in your chaotic mind.

You checked in to the hospital this morning and the nurse told you you were in bed 4 in room 212. So you and your partner looked for room 212 and went in, to find three other patients there. They looked rather skinny and a bit yellowish. You were terrified. Seeing these sick people brought back the shock element from the diagnosis. It was a reality check: is this going to be you in a few months? Nobody explained that to you; you feel ok and they all look sick. Your partner was aghast, and you didn't know how to help. You tried not to show how frightened you were. The nurse came in and explained to you what she was going to do. She did not acknowledge your partner, who, like you, was desperately in need of kind words and reassurance. The nurse was not unkind, but you felt like a number, another cancer patient to deal with. There was no recognition of what you and your partner were going through. You felt very lonely and even more afraid.

Although you assume your medical treatment was appropriate, you don't feel the nurse has shown much care or understanding of what all this means to you and your partner. And if they don't notice and care for you in this time of crisis, how could they ever care about the even more subtle and personal aspects of your life? One thing you know for sure now is that if these people ever would start to address intimate issues, you would definitely say you don't feel the need to discuss them.

This vignette reinforces the earlier point that the damage done here recurs later, and cannot be easily repaired, if at all. If no contact on a personal level is made in the initial stages it will be much harder to do later, and therefore communication has to be set from the very start. There is no second opportunity to make a first impression. As Brown et al. (2011) explain, the initial interaction between health care professional and patient is not just relevant for the actual situation, because “far more significantly, it is laying the groundwork for a whole legacy of expectations, assumptions, beliefs and hopes which will be drawn on at varying time-points well into the stages of treatment and beyond” (Brown et al., 2011 p. 285) .

It was evident from the participants that once they experienced the impact of chemotherapy on all aspects of life, including sexuality, the aftermath was worse than they expected based on the medical information given beforehand.

Bruno (Par2): I blame the doctor who told us the catastrophic news for talking so casually about the chemotherapy. He said it would improve quality of life, well that turned out to be a long way from the truth. He said "people react very differently, but I have a colleague who pops in for chemo treatment and goes back to work just like that". I believe that picture is wrong for 90% of the people and definitely my wife got so ill, as soon as her treatment started, that sexuality, well yes, for her that was completely beyond imagination, during those months of chemotherapy.

Sexuality was completely beyond the scope and possibilities of Bruno's partner. Heidi explains what the 'list of possible side effects' meant for her partner in real life and how this impacted on their sexuality:

Heidi (Par5): I do know that I personally was surprised at the poor condition of his hands. And the soles of his feet. His nose was affected, his ears were affected, his anus was affected, his penis was affected; the list was endless. The consequences are so far reaching. I think that at the moment we couldn't even have sex. And that is not just because XXX [partner] doesn't really feel like it, it's also because at the moment it is technically impossible. That chemotherapy ruined so much; he hurts everywhere. For instance his fingers hurt, so he wouldn't stroke me. He could only touch me with his hands stretched, which is, you know, really different. Well his stomach, of course you could avoid that if you wanted to, you could cuddle up differently or whatever, but for a year or more I couldn't even lay on top of him, you see. His penis is covered in blisters; the skin is so sore. So technically speaking there's nothing you can do with that. Imagine him having an erection, he'd be in agony, so you wouldn't want that, you see, you wouldn't try and arouse him or whatever.

It appeared from the interviews that clients did not understand from the information they were given what the impact of chemotherapy on their sexuality would be. Either it was not discussed at all or information was given in a way that did not give them a realistic picture of the meaning of the impact of the 'side effects' on their sexuality in real life.

As partners were not always offered appropriate information on adverse effects chemotherapy could have for them, some participants found their own somewhat drastic solutions, as was the case with Diana.

Diana (Par3): Whenever he was having chemotherapy, we had to be so careful with erm... if he perspired. I had to change the sheets, with gloves on, that is. Clean the toilet several times a day. And when that was finished there were only a few days

before the next chemotherapy would start. So there was fear... erm... big word, fear... But sex disappeared into the background, because you were afraid...particularly XXX [partner] was afraid to do me...to drag me into it. That I would be affected by the chemotherapy. I suppose we could have used condoms, but still.

Overall, based on the evidence available, risks from chemotherapy for partners seem to be minimal, so lack of clear instructions led Diana and her partner to such a far-reaching outcome. Sadly, at the time of the interview they were still struggling to pick up their sexual relationship again and were finding it so difficult they were unsure if they would succeed. Maybe that without the cessation things would have been different...

Vignette 9: Whose body is it anyway?

You are back in hospital for more surgery. You are, again, waiting to be seen. If you are honest, you have had more than enough of this. Everybody seems to have the 'right' to touch you wherever and whenever they want. They even take all sorts of 'samples' of you when they feel the need. You would really like to have your privacy back and you don't want to be touched or treated any more ... but here they come again.

Inevitably patients often experience a sense of loss of control over their body. In order to survive they have to hand over control to the health care professionals who then decide what is to be done, when it is to be done and why. Despite having good rapport with health care professionals, the handing over of the body still is an intense experience.

Anna (Pat2): I can't exactly remember which operation it was, but at some point I felt so...I was lying in that hospital bed, being wheeled along by the surgeon, such a wonderful man.... Very competent so I confided in him, I gave myself up and trusted him, but still, I was the one who had to do it, I had no choice, I had to sort of give myself away.... A kind of submission. Yes...yes for me that felt very lonely, it's a very lonely road.

Everybody considers the space surrounding their body as his or her 'personal space' (Altman, 1975). In normal life, other people respect this personal space. Not everybody is allowed to come very close to you or touch whenever they want. Physical intimacy and affectionate touching is reserved for the people you choose to share this with. Now all of a sudden these rules seem to have changed, and as a patient you have no choice but to accept this. For some

patients the experience feels so extreme that they see this having to 'hand over' their body as a violation of their bodily integrity.

Helen (Pat6): Well it already feels as if you have to hand yourself over to something you can hardly believe to be true; how dare you judge what's wrong with me, I don't feel anything ... nothing is wrong with me, I never had any sign that anything was wrong! And on top of all that they now even have the gall to cut into my body.

Helen is angry with her physicians for forcing her to realise she has got cancer, despite the fact she feels fine. This anger cannot be rationally justified. It is an example of 'shooting the messenger'; a phrase to describe the act of blaming the bearer of bad news. Although she knows her feelings are irrational, Helen experiences them all the same. On top of that, she has to accept that the physicians will 'knock her out' and while she is completely powerless, take out her womb that she so much wanted to use to foster a second child. For her, the surgical removal of her gynaecological tumour was as threatening as the cancer itself regarding body integrity and sense of femininity (Brown et al., 2011).

There is a very delicate balance between aggression and gratefulness here, and the attitude of the health care professional can tip the scale. Any superiority or arrogance from the side of the professional would be detrimental, whereas a modest, sensitive approach is very helpful. Afterwards, Helen was very grateful that the gynaecologist who did her hysterectomy was a kind man, who appreciated what this meant to her and her partner. She became able to see him as 'the man who saved my life', with gratefulness topping the pile of her emotions.

Helen made it clear that for her the impact of having to let physicians do internal examinations depended on how she was treated. She had no choice in this; she could only passively wait and see what they said and did. She did not feel she was in a position to ask them to be kind, she could only accept.

Helen (Pat 6): I had the feeling that I could discuss personal issues with the gynaecologist who did the surgery if I wanted to, but sometimes there were other doctors, one male and one female, who did the examinations and they were not as careful while ... erm doing the exam, they were not as nice, they were less friendly which annoyed me. And if I had a question regarding sexuality then I would think: I will discuss that next time with my own gynaecologist.

Not surprisingly, Helen chose not to discuss sexuality and intimacy with the gynaecologists that she described as 'rough' when doing an internal examination. For her the more rough, detached way of doing the examinations was already an indication of the lack of appreciation that she was a living, feeling human being. As a result, she felt dehumanized, and avoided discussing all issues, let alone intimate ones, with people who treated her in a mechanistic way. This supports Brown et al.'s (2011) study in a gynae-oncological setting which found that, whereas clear verbal communication is very important, it is body work including touch that is crucial in validating or undermining trust.

For some, the physical examinations proved to be so distressing, that they needed to find a way to dissociate themselves from the experience.

Alice (Pat 7): Internal examinations really trouble me. I hate them, they knock me off my feet completely and as a result I don't care whether there's one or five watching. My surgeon told me I tense up completely, and he questioned me about it and asked whether something happened in my childhood or in my sexual life. Then I said "well, I've gone through quite a lot down there". At first a large tube was protruding from my stomach and then there's this massive scar so you think the inside has also been cut up. And then having to undergo this examination, well the mere thought of it, really! But he mentions it every time and then he tells me I am doing slightly better, but I can't help it, I still tense up. I said "well I can't remember anything happened and, erm, you're a man so it may be a bit more difficult for you to imagine that that's got nothing to do with it". He said "no, but we do ask anyway when this happens".

Alice revealed that mentally she needed to make herself feel 'out of this world' in order to accept the physical contact when internal examinations were carried out. After dissociating, she did not mind whether several people were watching. But perhaps she would not have to mentally dissociate if the environment had felt safer for her. Her story was compounded because when her surgeon discussed her physical response to the examination his explanation was unacceptable to Alice. His only explanation for her 'locking' vagina was previous sexual abuse, despite the fact that Alice explained this had never happened to her. Yes, in her view there had been a violation of her body, but it was recent and by the medical practitioners. Health care professionals must learn to consider how every touch and encounter impacts on the individual on the receiving end of treatment. Having to deny what she perceived as an incorrect explanation for her contorted vagina caused additional mental distress for Alice.

Particularly as the surgeon kept returning to the same issue, never realising that perhaps he was in part causing the problem. As Brown et al. (2011) point out, Alice's reactions were not uncommon, as invasion of their intimate space by a strange man (the surgeon) makes gynaecological patients prone to dissociation. Therefore, "successful examination requires both the ability to inspire trust and facilitate relaxation as much as the dexterous expertise in accurately assessing cytology". (Brown et al., 2011 p. 284)

Grace had similar experiences and she too felt like an object rather than a person when she was in hospital, resulting in her blocking her emotions:

Grace (Pat14): When what was left of my breast shrivelled up some of the nursing staff came to have a look because they had heard what had happened, with the nipple going black and the whole thing was awful, and said "can we have a look". I sometimes felt well, like a guinea pig. The emotions of a patient are completely ruled out. And that's such a pity because of everything you're going through and everything that goes wrong and so on ... and you get so filled with emotions. And at some point it's like a brake is being put on and it just doesn't come out anymore and then I thought I shouldn't talk about it because it's too much and if I were to start talking about it I would spit out the whole lot and I didn't want that.

She felt like an object and she reacted like an object in order to mentally survive.

In addition to all the physical changes (whether external or internal), which result in a different body image, there are also the psychological changes in how individuals perceive their body. For some this leads to a loss of faith as Joyce explained:

Joyce (C5pat): Well for instance when I feel physical pains that are similar to the ones I felt before. Then I think: oh no! Not again... Last Saturday and Monday I drove my car myself again and yesterday my groin hurt. Well of course the driving could have caused that, a bit of a strain...But instantly you get worried, at moments like that you feel the fear again.

Similarly, Joan makes it very clear why her faith in her body will never be the same as before no matter how good she feels.

Joan (C6pat): February last year I had no pain and I felt nothing at all, I felt fine, I wasn't tired or feeling awful, no complaints, and then there turned out to be three

malignant tumours in my body. Well, what is there to rely on; should I say I feel okay so everything's okay?

Joan has learned the hard way that feeling good does not mean nothing is wrong (Kelly, 1992, Sewell, 2005), and she cannot forget it.

The following vignette illustrates how a combination of loss of control and loss of trust in one's body and health can be even further undermined by insensitive communication with health care professionals, resulting in a further loss of faith, this time in the health care professionals.

Vignette 10: Explosion

You are **furious**. Because some lumps had been detected in your breast you handed over your body to your doctors and nurses and it was their role to take care of it. After all, this is their area of expertise so you put your trust in them. They decided to take two small lumps out of your breast and you were told this was just a precaution and that there was nothing to worry about. These lumps turned out to be two small malignant tumours and you had to undergo surgery again and more breast tissue was removed. This time they and you were confident that the results would be ok. It was a complete shock that the oncologist told you that so many small cancer 'spots' had been found that they now need to remove your breast entirely. You asked if they would be removing some lymph nodes as well. The answer was: 'no, that will not be necessary'. You have now had your mastectomy and the surgeon has just been to see you (joined by four other people, two junior doctors and two nurses, and nobody asked if they could come in too). After he and what felt like the whole world looked at it, he said the wound looked fine. As he was about to leave the room he said: 'so now we will just have to wait for the results of the nodes we took out'. You replied: 'the nodes?' 'Yes' he said, 'we had to do a partial axillary clearance after all'. You were shocked and said 'but that was not the plan'. He said: 'oh, but there is no need for you to worry about it at all, I am sure they won't find anything'. At this point you exploded. Five weeks ago you were told not to worry and now you are lying here with your breast removed and the nodes gone, and once again you are told 'not to worry'. You angrily asked him to leave saying you don't ever want to see him again. You were determined, so after a bit of protest they all left. Just before leaving the room the junior doctor who was last to go turned around and gave you a thumbs up...

You are still furious, thinking it is easy for him to say there is no need to worry, but you don't believe him anymore. They've told you that so many times and it just wasn't true ... You don't feel taken seriously. But it was nice of the junior doctor to support you, even though he did it in a way only you could see. But at least there was somebody kind enough to show he understood...

Where is the partner in all this? During the period of treatment, most partners are trying their best to be supportive and yet maintain a 'normal' life. The focus of patients is often quite narrow at this time; they need all their energy to cope

with the side effects of treatment and to heal. For partners, this can result in psychological loneliness, as the next vignette illustrates.

Vignette 11: Multitasking

You are trying your very best to maintain a normal life. Of course, you are trying to support your partner (who is now in hospital) the best you can, but you also have to take care of the children and the pets, go to work and perform household duties like shopping and cooking, not to even mention the cleaning. The phone rings all the time because friends and relatives want to know how your partner is doing; very kind, but it takes a lot of your time and energy, especially when your partner's parents call. Your mother in law is so worried that she is crying on the phone, so you try to comfort her while the cat is chasing a fly into the net curtains. You look at the clock, you should be at the hospital, it's visiting time.

When you get to the hospital, a bit late, your partner is so sick she prefers to be left alone. So you leave, without even having had the chance to talk with her for a bit. You drive back home. Your house feels dark and cold, and your bed is empty.

Partners are on a parallel journey. They are doing all these extra tasks, and the person to whom they would normally turn for comfort and advice it is the one they are trying to support.

Walter (C6par): We had already planned to move home when Joan got her diagnosis. As it turned out we had to move just after we heard about her cancer. Our lives were completely upside down, with Joan having to have her surgery as soon as possible and me trying to deal with all the practical things having to do with moving home coming my way. They seemed completely irrelevant to me at the time, but needed to be done, as we couldn't stay in our former house. Thank God there were a lot of friends to help out, as I am not sure I could have handled everything myself, with Joan and our daughter needing my support, no to mention how shocked and upset I was myself.

Sometimes patients are literally fighting for their lives, like Joyce when having her autologous bone marrow transplant. Her focus was on survival and not on her partner, as she makes clear when reflecting on this period of her life:

Joyce (C5pat): I think that it must have been a very difficult period for him in particular, but I never realised it, not at that time ... I needed all my energy for myself just to survive. So I never saw it that way.

All this means that the nature of the relationship changes. In a time where you might need the support from your partner most and where the need to share is bigger than ever, your partner is not emotionally accessible. For most couples sexual contact, that used to provide a very pleasant and profound way of sharing intimacy, is beyond the horizon at this point in time. Partners are now

denied what would have been a comfort. They know it is unrealistic and might even feel ashamed that this is what they would like at this time: to have the sexual comfort again. There is a profound sense of loss; their soul mate and sexual mate is there but no longer in the same role. They are also mourning the loss of their partner as the person he or she used to be. Things will never be the same again, not even if the partner goes into remission or feels well again.

Dennis (C5par): But then you have these phases in which well, she was at home again but she was tired and then things didn't get better. And you listen, but you're not hearing anything so you try and sense whether things are going right or wrong. And whenever you pick up a sound you immediately think hey what's wrong. You're listening to something that's not there, and that's just... You must listen while nothing's being said that's a matter of learning.

In normal life Joyce and Dennis are used to supporting one another, they see each other as equals and they share and discuss things and speak plainly; they 'call a spade a spade' to use their own words. But at this time, Dennis receives no response or feedback from Joyce because she needed all her energy for herself, and he had to find his own way to take care of her without really knowing what to do for the best. Dennis had to continually adjust to a permanently changing situation, and that was difficult. While Joyce fought for her life, Dennis was the one outside watching. He describes how when it has gone well for a few days, there was always euphoria, and then the next day she was not so well, so he dropped further down (because he had gone up a bit). Metaphorically speaking, the partner is on an emotional see saw. In view of this it is not surprising that a review by Pitceathly & Maguire (2003), on the psychological impact of cancer on partners of the patient, showed that a substantial minority of these caregivers develop an affective disorder or become highly distressed, with other researchers reporting similar (Manne, 1998) or even higher (D'Ardenne, 2004) levels of distress in the partner compared to the patient.

Without ever having aspired such a role, or asking for or choosing such a role, Dennis became Joyce's carer, a transition known to potentially interfere with the role as a sexual partner (Palm and Friedrichsen, 2008, Hawkins et al., 2009, Gilbert et al., 2009).

Dennis (C5par): You're doing it because it is what you have to do, but I never wanted to be a nurse, that's not me, I just haven't got the patience. It means biting your tongue a hundred times before you say anything, well perhaps that's not the right way of putting it, but you really have to be listening all the time keeping an eye on what's happening... If she needed something, medication or whatever, you had to take care of it and put it there for her and, well ... how shall I put it, you get a list which tells you to do A and B and do them like so-and-so, and before it was never like that. It comes with the package.

The risk of finding themselves in the role of carer instead of partners seemed to be even greater where partners were health care professionals themselves. This was interesting as you would think for them caring might be easier as they are used to it, but this was not the case. Health care professionals are used to giving professional care, and that is not the same as supporting a seriously ill partner. James is a GP and his experience was as follows.

James (Par6): I would come home and then she would say to me that her bowels were troubling her, well and then I would more or less get stuck into my role as a GP and I would start giving her advice. That made her very angry because all she meant was that she was very worried.

James' wife was understandably cross with James; there are plenty of health care professionals who can give her advice, but she has only one partner, and that is what she needed James to be for her. She probably knew he was trying to help, but she wanted him to be her partner and not her doctor. These ambivalent feelings result in confusion for the patient as well as the partner, as Maureen, who is a nurse, explains.

Maureen (Par4): He felt I was too much on his back; I reminded him of his medication and his appointments and that annoyed him. So when he had to go for a blood sample I said: "why don't you go by yourself? Just go by yourself for the blood sample". And then he would say: "no no no you must come along". So I was on his back yet he couldn't do without me, and that's a very awkward position to be in. I reverted to a nursing role. In my role as a nurse I reminded him of the disease, the dark side. And being a nurse of course is what I was trained to do... and that's what he needed me for because he really couldn't do anything without me...but it also bothered him.

Professionals need to consider the background of the partner. If the partner is a health care professional, they should be very careful not to address this person as a fellow professional. As James and Maureen illustrate, this can be detrimental for both the patient and the partner. The patient needs emotional support and care from the partner, not professional advice. Health care

professionals need to encourage people like James and Maureen to accept their role as the partner, instead of encouraging them to move into in a professional role. For them staying or moving into their professional role can act as a coping mechanism: if one can rationalise personal distress into a situation one is familiar with, it is less stressful. The price is that people like James and Maureen and their partners are left lonely, because although rationalising puts their situation in a familiar setting, it does not actually address the issues. Fellow professionals who are now clients need and deserve the support other clients get. Health care professionals who are partner of a cancer patient (or get cancer themselves) need explanations that will guide them through their new role.

In general, professionals should look behind what seems obvious and not just accept what they see at face value. People who seem to be doing well because they are articulate and use the right words might still need emotional support. Then too, people coming from the older generation were often taught to be resilient and not to complain or cry, but they may need support all the same, as Maureen explains:

Maureen (Par4): Maybe you would get attention for the emotional side of it if you sort of broke down and cried. But that's not us. I mean, we're a generation which learned that crying.... Well, that's not done. You must be incredibly strong and 'there's always worse' and so on and on. So you don't do that, certainly not in front of your oncologist. You remain stoic but you are hoping that someone will pick it up.

Clearly, the different journeys patients and partners are on not only increase loneliness, but may result in drifting apart, a situation not helped by the different degrees of awareness of the life-threatening character from the illness:

Maureen (Par4): Then I would say to him "I'm so scared". And then he would say "you may be, but I'm not". A few months later I said "well I am really very worried"... "Well you may be", he said, "but I'm not", and for us that was just... We just couldn't get through to each other.

On a surface level, Maureen seemed to be the only one worrying about her partner's illness. Later on, it turned out that he was just as afraid:

Maureen (Par4): Once he approached me very carefully and then he said to me, just to illustrate his fear, he said "would you feel my stomach please?" And I felt and I said

"that's a very hard spot, that's not good". And he said: "no that's not good". I said "what a coincidence that you should just discover that now". And then he said "no it's not a coincidence; every week I check my stomach, my groin, my armpits".... so it really bothered him. But it was only a week before his death when he said: "now I'm going home to die"... Up to then he had really persisted: "I can't die of this; I'll live to be 94".

Both partners have to cope with the situation and they do this in their own way. To Maureen, her partner denies that he is afraid, probably because it was too much for him to take in or to openly acknowledge that he was actually dying. As he told Maureen much later, he did check his body for signs every week, so he must have been very worried about the way his illness might progress, but pretended not to be. As long as he denied to Maureen that he was afraid, they were both alone with their fear. This is in line with the study of Holmberg et al. (2001), who found that fear of dying was seldom shared in the partner relationship of women with cancer and their male partners whereas they do discuss these feelings in individual interviews. For a couple, this serves as a coping mechanism. As a system, they need a balance; they can't panic both at the same time or things will get out of hand (Hannum et al., 1991). There should always be one partner appearing to be the 'stronger' one. As a result, both partners stay alone with their fears. On the one hand it might be helpful and comforting if they would be able to find ways to share their fears. On the other hand, this can never completely erase their sense of existential loneliness. On an existential level no one can 'share' this burden: fear of dying, death anxiety is for the individual to deal with, just like the partner's fears are for the partner to deal with. Therefore, in a time when people have to handle maybe the most difficult issues in their lives, they may have to do this, at least partly, without the support of the person that is closest to them, and they may very well welcome alternative support coming from health care professionals.

Anna described the realisation that having to go through this alone and that nobody else could do that for her as very lonely and difficult.

Anna (Pat2): What I found out the hard way is that no matter how close you are to someone... in the end you have to do it by yourself. That was a rock-hard confrontation. Of course there are people who support you... but that's different. Surely that helps, but erm... others couldn't solve it for me, or do it for me, and in theory you know that's how it is, but in reality I had to find that out for myself. And it was very hard to take in.

This diverging road can in some instances raise the need for individual counselling. At any point in time the partner might feel a greater need for support and possibly counselling than the patient. For patients the road ahead is quite straightforward, and they focus on 'getting through the treatment', which is hard work, but does keep their mind from most other things for the time being. They 'undergo' the treatments as prescribed by their physician, whereas partners have to sit and watch from what often feels like an outsider's position as all the family, medical and nursing focus is on the patient. They know this is right, but still feel they now have to deal alone with all sorts of emotional and practical problems coming their way. When health care professionals ask how the partner is doing with the patient present, they might not get an answer truly reflecting the partner's feelings, as he or she may not want to reveal how hard it is, after all, they are not the one who is so ill.

Heidi (Par5): Of course I was asked how I am doing and of course I said that I could manage, with XXX [her partner] sitting there. I couldn't say that I had all sorts of doubts with him present.

Walter explained that at some point he felt the need for individual counselling:

Walter (C6par): At some point, when Joan had just fallen ill, I got quite confused in the sense that I needed a person to talk to ... to share my fears with. I could have said to Joan "Joan I am so scared that you are going to die", but that wouldn't have helped her nor would it have helped me. So at some point I contacted the hospital psychologist.

Such individual consulting could include queries and problems in the domain of sexuality and intimacy:

Heidi (Par5): I couldn't express my sexual frustration with my partner present. I would have liked to share it, but only when I was sure that he would not be confronted with it. I didn't want that, because first I had to find out for myself what I wanted to share with him about sexuality.

However, it is rarely that health care professionals focus on how partners are coping.

Ryan (C2par): You're just not part of it. On the other hand, what more could they do, well I don't know. But a little more support, that would be nice. That they acknowledge ... it's not easy for me either.

Just like the patient, the partner needs some personal attention. It is not just the patient facing the consequences of diagnosis and treatment. Especially in the

domain of sexuality and intimacy the couple is in this together, and an acknowledgment of this towards the partner is an empathic gesture that will be highly appreciated by most partners and patients.

Iris (Pat5): What I could point out to care givers is that they should not just focus on the patient but also on the partner; they should ask "how are you are you managing? How do you handle things?". I think they are a forgotten group. I don't remember them asking the partner, except for one nurse, a real star, we both got on with her very well and she did ask XXX [Iris' partner] "well how are you getting along?". That really impressed us.

However, even when partners themselves bring up their emotional problems not all health care professionals know how to respond. Maureen remembers seeing her partners' oncologist:

Maureen (Par4): It was after the third our fourth chemo treatment that we were with this oncologist and all sorts of physical matters were discussed, about blood and about..... and at some point the oncologist said "well anything else?" and XXX [Maureen's partner] had nothing left to discuss so I said "well I am having a hard time emotionally". And the oncologist replied "well I would have expected that even earlier". And that was it. And then later I thought: you should have pursued it, you should have responded to what I said!

Heidi had a similar experience with her oncology nurse:

Heidi (Par5): During the first stages of treatment I called this nurse a few times and asked if I could talk to her, because it was all so hard, I didn't know what to do, my husband being so sick and nothing seemed to help. Then she would say that I was rather negative, and they were trying so hard. I said "but you are the nurse, surely I can talk to you about how things are going, I just want to talk things over with you". She responded by suggesting that if I needed to talk to someone I should go and see a psychologist.

These examples illustrate the gap between the needs of clients and what some professionals have to offer, with clients feeling lost and unsupported.

Vignette 12: See me, feel me, touch me, heal me.....

You are feeling vulnerable. You were shocked to find out you had cancer to begin with, and the operation has left very concrete 'evidence' of the cancer. As a girl, you could not wait to have a cleavage, and it was only after your first pregnancy you finally got one. For you that was a source of pride. You never thought of yourself as a beautiful woman and your breasts were the only aspect of your body you were really pleased with. Now they are gone and you feel ashamed about this. Your partner does not really seem to understand what all this means to you. He simply says there is no need to be ashamed. You would like him to comfort you, but he doesn't really seem to see or feel the need. He was never much of a cuddler anyway. When you ask him to put his arm around you he does, but it doesn't feel the same as a spontaneous cuddle, which is

what you would really like. You can't make him understand what you have lost, he just keeps saying "at least you are still here". You feel the operation has taken your sexuality away and you can't see a way to get it back. There is no intimacy to replace it either, so all in all not much comfort is coming from your relationship at the moment. You are afraid the cancer will come back, but your partner does not want to hear this. He says "the surgeon said that the goal is to cure you, so you should focus on the positive, end of story". You feel so lost and alone ...

Accepting that sexuality is no longer on the agenda for many clients before and during the period of treatment, other forms of physical intimacy may still be pertinent. It seems that for most couples intimacy and especially physical intimacy is of major importance and a great source of consolation. Wilbert and Gemma had already stated that their sexual relationship had stopped before the cancer diagnoses. This was for them a natural process, but they value their physical intimacy very much, especially once cancer had come into their lives:

Wilbert (C1pat): Sexuality has been substituted by other things: we need each other's nearness, under these circumstances, first that cervical cancer [Gemma] and now what I've got.

Gemma (C1par): Yes to cuddle up, that's lovely isn't it? We still even have our first bed, after 50 years of marriage we still have that same bed and it's just four foot wide, we wouldn't want to change it, we want to lie cosily together in that old familiar bed.

Single people can also feel the need for physical intimacy; people who are not in a sexual relationship may succeed in 'parking' their sexual needs but not their need for physical intimacy:

Chantal (Pat3): When you're on your own the sexual thing disappears into the background. But touching and cuddling does not. That's still very important to me. But I do that with my male and female friends, I have a few friends, huge guys, oh so lovely and I say "just hold me for a while". But also my little cousin, she cuddles up to me with her little arms, it's great, I could eat her alive and sit there for hours, but of course that's too much for her. And of course I do the same with my doggies.

There is no standard response; in contrast to those seeking intimacy, some participants did not feel a great need for affectionate touching, sometimes even to the point where they experienced this as unpleasant or unwanted.

Alice (Pat7): During treatment I couldn't really stand people touching me or trying to comfort me. I tolerated it from my parents and my brothers, but to (female) friends it was easier to say "don't touch me", I got jumpy I couldn't stand it. It felt awkward. It's very difficult for me to comfort somebody by touching; I can use talking, but to hold someone who is crying or something, no.

According to Vargens and Bertero (2007) it must be acknowledged that the amount of emotional support needed varies from one person to another, with some people drawing upon their own emotional strength to handle their situation.

However, for some couples, physical intimacy became more important than it was before, especially when sexuality was (temporarily) no longer in the foreground. Unlike Gemma and Wilbert, Diana and her partner were still sexually active when Diana's partner got cancer. During treatment, Diana and her partner valued other forms of physical intimacy more than before:

Diana (Par3): Well... intimacy was very important then. More important than sex. There had always been intimacy, but now it was more intense. Every day.... Just the embraces, the cuddling, the stroking, you name it. It got more intense. Oh yes, absolutely. And erm ... the conversations went deeper. Normally you talk about lots of things and also about the things that really move you, but now, also because for XXX [Diana's partner] death was so always present, it became much more intense. Absolutely.

As Diana's quote shows, for her physical intimacy is related to psychological intimacy. In order to share intimacy, some patients need to feel understood by their partners, but this was not always the case.

Anna (Pat2): What made it difficult was that we looked at things differently. With my breast cancer I was stuck in the thought: shit, I've got breast cancer, shit, I've been hit again. We were with the surgeon and he said "it looks well encapsulated; I could do a breast conserving operation, it looks promising". And that is what he [Anna's partner] picked up. While I was thinking: I've got cancer goddamit, I am half dying. Or I am dying again. I was preoccupied with my death. And all he could think was, well, this might turn out to be all right. That's how it went. And yes theoretically, you are well aware of that. But at that moment it means nothing to you.

Similarly, Helen felt that her partner did not experience the impact of her cancer the way she did:

Helen (Pat6): The grief, not to be able to have another child, troubled me much more than it troubled XXX [Helen's partner]. I remember XXX saying to me: I wish I could pick a child from a tree for you; I would do it straight away, I would climb the highest tree for you. He experienced that differently, to me it was, well I can't say a physical absence, but something like that.

Psychological intimacy seemed to be a prerequisite for physical intimacy. If patients did not perceive their partners' response as empathetic, their willingness to share physical intimacy became blocked:

Iris (Pat5): Well, when those mastectomies were carried out I already felt ashamed about myself. But my then partner was absolutely not a feeling person. And communication wasn't exactly his strong point, so it just wasn't discussed. When I said that it really annoyed me, that I felt so ashamed about myself, he just said that there was no need for that. I needed some warmth so much, some kindness, but to me it felt that it was so being trivialized. And then I no longer felt the urge to give myself to him. It really was sheer aversion. Sexuality came to a standstill in the sense that I was completely finished with it.

Iris and her partner found themselves in a vicious circle: because her partner did not show any understanding for how she felt she did not want to have sex with him anymore. As a result, she declined all physical affection, because that used to be a precursor to sexual activity. Consequently, there were no more channels available for her partner to give any support in a tangible physical way, which made Iris feel even less understood by him. As a result of all this, Iris felt very lonely and her partner felt very rejected. Their relationship did not survive this crisis (Holmberg et al., 2001).

It can be concluded that not all couples have a form of physical intimacy to bridge the gap of existential loneliness and their diverging roads. This is especially challenging for those couples where physical intimacy was never really part of their repertoire, as was for example the case with Joan and Walter. They reported that when their sex life had gone, physical intimacy was gone.

For some couples where the patient did feel understood and supported by the partner and where (non-sexual) physical intimacy used to be on the agenda, this too was seen to disappear into the background.

Emma (C3pat): The other day I said to him: gee we don't even share one tiny kiss anymore when we go to bed, we always used to do that, and then I realised: hmm we do have to pay more attention to these things, yes I must pay attention to it, because it used to happen naturally.

Both Emma and her partner regret this, but Emma's sustained physical pains and also her special mattress (which is higher than his mattress) prevent them from sharing intimacy the way they used to.

In other couples, physical intimacy was a potential precursor to sexual intercourse, and with patients now trying to avoid that they might want to avoid all physical intimacy:

Edith (C7pat): Cuddling, that's what I do with my children, but as to him, well I don't know. Let me put it this way; children aren't sexually focussed when you touch them and then it's cuddling, but that's different with a man I think. And that's not a problem, I mean I do like sex, I'm not saying I am anti it or anything. But it's different. If you cuddle your partner, thoughts easily wander off to sex, or your partner starts thinking now I expect this or I want that.

Nevertheless, even when psychological and physical intimacy were shared, partners might still miss sexuality (Kind and Van Coevorden, 2002, Gilbert et al., 2010b):

Heidi (Par5): It's limited to just cuddling up nicely. That is erm ... you could say that's enjoyable too, yes it's enjoyable too [😊], but it wasn't our idea just to cuddle up for the rest of our lives, no. I do enjoy that, but I also do miss it [sex], definitely.

Ryan (C2par): Well, sex just isn't part of the deal for a while, and well, actually it is frustrating, because, well, you are still young you know [😊], and yes you do still feel the urge.

The diverging roads described by patients and their partners make it of major importance to find ways to 'stay in touch'. It appears from this study that, for some people, no consolation and sharing comes from sexuality during the treatment phase, making intimacy all the more important. Indeed, recognising this means that intimacy may be even more important where all hope that the sexual relationship can ever be restored is gone, as will be reported later by participants who were on the trajectory leading to the final goodbye: death.

End of treatment: remission

Vignette 13: Back to normal?

Treatment is over. After a final check-up by your surgeon you are leaving the hospital. You are told to come back in three months time: see you in September! For you this

feels like they said to you: "Goodbye and good luck with your life". All of a sudden you find the hospital door closed behind your back and you ask yourself: where do I go from here? Up to now there have been medical treatments to follow and you were busy fighting your way through them, but now suddenly you are supposed to be back in control and you find that rather difficult. Friends and relatives see you as 'cured' so everybody is happy for you and expects you to pick up your normal life again. But to you, it feels like you are at the very beginning of the journey towards 'a normal life'. What does 'back to normal' mean anyway? You know you will never be the same again, physically or mentally. You will have to live with the fact that somebody had to alter your body surgically in order for you to live. After the initial blow from being diagnosed with cancer, the treatment you needed has further deepened your awareness of your fragility and vulnerability. You have lost your faith in your body, it has let you down and the scars this has left are a constant reminder of changes that run much deeper and are there to stay. But now you have to 'pick up' your life again, but you have no idea how...

Alice explains it would be a big mistake to think that you are finished when treatment is over:

Alice (Pat7): When your treatment is finished you get a bit of a shock; all of a sudden it stops and you kind of experience an inner void which makes you... well I wasn't really depressed, but you shouldn't think: well that's done now. Because you ought to be very happy, but you're not, and it seems you belong to the normal people again with others thinking well, her treatment is over ... life goes on. And that's the moment you would like to talk about it rather than during treatment. But all contact with health care professionals more or less stops then, while you only just start to reflect ... start to ask questions because you no longer need treatment, but you're trying to get well again. So you rest a lot, you're at home most of the time, and things become quieter ... and then you start thinking. Then suddenly there's nothing ... I've heard from many others that, like me, they found themselves going through a bad patch then.

Having experienced that they had to hand over their body to health care professionals as an 'object' that needed treatment, patients now have 'to re-appropriate' their own body.

Anna (Pat2): At first I quite often felt inclined to show my scars to others. Then when getting ready to do it I thought, oh no, I shouldn't do that. You have to learn to ... to realize again: that's mine; that's private.

Patients first need to feel again that they 'own their body', including its personal space, before they are ready to 'share' it with someone else. In addition, first the patient and then the partner have to get used to the 'new' body:

Joan (C6pat): I had to learn to recognise my own body again. It not only looks different, but it feels completely different. Merely touching your own body feels very different; there are parts that feel completely numb or just feel different. And Walter, well has to rediscover my body too.

Getting used to a body that looks and / or feels different does not happen rapidly or in isolation. Patients described the impact of how the partner reacted. For Iris, the first time she undressed for her (new) partner, it was too much for her to see how he would respond:

Iris (Pat5): I clearly remember that, the first time that I was really naked, I deliberately closed my eyes. I thought: I need to give him the space as well as the opportunity to be shocked if he wants to, but without me watching. I really didn't want to see his reaction, because of running the risk of hurting myself so much.

Some partners are not bothered by the physical changes in their partner and respond in a positive, supporting way:

Gemma (C1par): The stoma never made any difference to me; perhaps at first I might have been afraid to hurt him, but for the rest not at all. It doesn't bother me at all, absolutely not.

Many patients will find consolation in such a supportive response from their partner.

Judith (Pat1): I had a lumpectomy and to my husband I am just as beautiful as I was before; he never made me feel any different.

Jacob did not have a problem accepting his partner's 'new' body. He never felt any different about Rose and therefore he never gave her the idea that anything had changed. But for him this is not necessarily unconditional. He explains that it might have been different if Rose's other breast had been removed:

Jacob (C4par): I have sometimes thought: what if the other breast had been removed instead of this one, well, that would have been much harder. Our way of making love, cuddling and caressing, it just so happens that I don't miss it. The thing is, Rose lies on the right side of the bed, and when she turns towards me the breast that is still there comes within my reach, and therefore I never really missed the breast that's gone now.

For Jacob it is a consolation that the breast that plays the major role in their love life is still there and as a result he is not really bothered with Rose's mastectomy. However, he is honest enough to say that he doesn't know how he would have responded if Rose had had a double mastectomy:

Jacob (C6par): I don't know how I would have responded had Rose lost both breasts instead of one. That would have been quite a loss, you know. And you might say: is that what makes the difference? No of course it isn't, but then again I can easily imagine

that people find it difficult. Losing two breasts, that's more than 50% more gone, as it were.

For Jacob, the impact of his partner losing both breasts would be more than double the impact of her losing one breast.

Some partners were found struggling with the patient's changed body, like Anna's partner, and Anna felt very hurt as a result of that:

Anna (Pat2): My husband has never actually touched my breast since the operation. Never wanted to touch it, even though it's not a nasty scar, my breast looks fine. But it's one of those things.... that hurts. As if that breast is no longer important.... well not so much the breast, but as if I'm not important. The breast and me. Anyway, I feel rejected. Not so much my breast but me entirely.

Because her partner does not want to touch her breast, Anna feels denied and rejected as a person, demonstrating the impact on Anna's sense of identity. A supporting partner can make all the difference. As described earlier, Iris did not feel her (former) partner was responding in an appropriate way to her changed body. She thought he was unfeeling and at some point she decided not wanting to be touched by him anymore, and eventually their relationship ended. Iris now has a new partner and with him the experience is very different:

Iris (Pat 5): I find the way he deals with it incredible, because he sometimes touches my breast and then I don't feel anything special, because the feeling's gone. But he also always touches, quite purposefully, or he may be doing it unconsciously, the other side, where there's nothing. And sometimes I withdraw, because the scar tissue, well, it just feels different. Then he asks "hey, do you mind?". Then I say "well, no I don't mind, but I don't feel much there, I don't feel anything". And then he says "well, but that side is also a part of you". Well the first few times he said that I burst into tears, I could even cry now [starts to cry]. It's just that it moves me that he treats me so sensitively.

Iris' partners responded very different to her body, and as a result completely different responses are elicited in her. This example shows how much the impact on sexuality and the (sexual) identity of the patient are based on how the couple deals with the situation as a couple. A couple acts as a system. Systems theory is based upon the principle that the whole is more than the sum of its parts, and a change in one part of the system changes the whole system (Watzlawick et al., 1967, Willemse, 2006). Therefore, the way a partner responds to the changed body of the patient after surgery will influence how the patient feels about it and what this change means for them as a couple.

Of course not everybody has a partner. Chantal for example was already divorced when she had a mastectomy. This does not mean that for Chantal the change in the way she looks is less relevant. Chantal would like to have a partner again and she feels very insecure about showing her body to a new partner:

Chantal (Pat3): What keeps me from starting a new relationship is my body; to show it with an imperfect breast. You see I am happy to have a new breast but it's not flawless; it's hard, it sits high up. Well and I think that if one has a long-term partner it is much easier. For me, my ex-husband was the first to see the operation area after my mastectomy. He sometimes asks "how it is going" and then I say "well feel it, or have a look". No problem at all, that feels so familiar. After all, I was with him for ten years. But just the thought of being with a strange man and then having to undress... Being a woman makes you vulnerable as it is and then on top of that an imperfect breast ...

She has tried to find a partner via Internet dating sites. It is not easy for her to decide when is the right moment to share with a potential partner that she has had a cancer operation. On one occasion, when she revealed she had a mastectomy and is now undergoing reconstruction the initial response was: "oh that is not a problem". After that she did not hear from this man again, and that hurt, especially because this happened to her more than once. Holmberg et al. (2001) found that single women with breast cancer were more vulnerable to problems in their adjustment process than partnered women, largely due to relationship issues. None of the women in Holmberg et al.'s (2001) study were able to suggest a satisfying solution for discussing their cancer with a potential partner.

Chantal's major reason for having for a breast reconstruction is her hope that this will make it easier to find a new partner. So far, she has undergone 10 reconstructive operations and she now has a 'very firm' breast without a nipple that looks rather different from her healthy breast. In a few weeks time she will have her next operation, this time to adjust the 'good breast' to the 'bad breast', as she puts it. Sacrifices have to be made in order to, hopefully, get what she feels is a 'presentable' body again, including operations on her normal, healthy breast.

It is not just single women who opt for reconstruction or implants; the same goes for women who do have a partner, even if these partners respond in a supportive way to the altered body. An accepting partner is very important, but this does not mean that the patient herself is happy with her body (Zimmermann et al., 2010). Rose, 20 years later, still isn't, and the only reason she never opted for reconstructive surgery is that she did not want to have any more operations. She suffers from quite a lot of side effects from her mastectomy and she did not want to run any more risks if this was not necessary in view of her health.

Edith's partner Mike is very supportive and says it does not make a difference for him at all that she no longer has breasts. After her first mastectomy, Edith had the option of a reconstruction. After her second mastectomy, she could opt to have implants. Even though the risk of inserting the implants seems minimal, especially compared to the reconstruction option, Mike is not in favour of it. For him, it would not add anything; on the contrary, for him the implants would be artificial 'extensions' of Edith's body.

Mike (C7par): I think it would be different, because I always cuddle right up against her, like two spoons, and quite often I used to hold her breast in one hand and now I hold that bare little chest and I don't care. But I could imagine that if there were silicones in there, that for me that would feel odd and whether I would like it ... It wouldn't add anything for me. I wouldn't think: oh, she's got breasts again. She doesn't have to do that for me. I am fine with that bare little chest.

Mike rather feels her flat chest as it is, because that is the real Edith for him. But as Edith comments, this is not about how it would be for him but how it is for her. Edith does not want to be reminded of her condition all the time by having to deal with her prostheses. It is important to her what she looks like when she sees herself in the mirror without any clothes on. She wants to restore her body image for herself.

However, the following quote from the interview with Joan and Walter shows that reconstruction is not by definition the perfect remedy. Joan had a double mastectomy with immediate reconstruction. From a medical point of view, immediate reconstruction could be viewed as the perfect solution for preventing

and overcoming difficulties with altered body image for women who need a mastectomy. In reality, it may work out different (Harcourt et al., 2003). As mentioned before, Joan had to get used to her new body because it looked but also felt very different. For her it was about learning to recognize her 'modified' body as her own body. The impact on her partner Walter was even more profound:

Walter (C6par): When Joan came home after surgery it was impossible for me to touch her. At first to me it felt like she was someone else. Then and even today I saw and see her in a different light. I was shocked. I never really meant it, but once I did say that actually it looked like a do-it-yourself kit. The doctor said well actually it is a kit, that entire section of her back has been moved to the front. A scar here, a scar there, a patch over there. Not that it's repulsive, but it's completely different. You see an entirely different body, and you know that it's the woman you love, but that woman has just changed except for her head. But then again, even when you look in her eyes, the look is different from before. I don't mean to judge, but it's just different. Touching was also entirely different and in the beginning that was rather difficult for me and it still is. Because of all the operations, barriers have arisen in our relationship, new barriers.

Walter knows Joan is still the same woman but knowing rationally is not the same as experiencing it. The change has been so abrupt and so drastic that he is struggling to feel Joan is still the same person. Even the look in her eyes has changed. As a result of all this, touching her is difficult for Walter. Even now, 16 months after Joan's surgery, this remains an issue:

Walter (C6par): Well it goes very gradually and there are some ... erm, I hardly ever touch her new breasts to be honest, and that is not because I don't want to touch them, but...well, I find that a little difficult, because there's ... I don't want to touch, I do want to touch.

Walter seems to have ambivalent feelings here, probably due to the fact that this woman is and at the same time is not his (trusted) partner. By touching her breasts, he could feel like he is betraying the 'old' Joan, as if he is adulterous by touching his own wife.

In view of the above, it might be wise to have in-depth discussions with women about whether to opt for reconstruction or implants or not. What are their motives, what are their expectations, and are these likely to be met? Should partners' preferences be taken into account? What 'normality' will be restored by the operations (Denford et al., 2011)? The only aspect most health care

professionals focus on is what the new breast(s) will look like, and even that outcome is not always a great success. Many women had complications and needed several operations without ever achieving a satisfactory outcome.

Iris (Pat5): Because you feel dissatisfied with your body you choose reconstruction. But that also failed in every respect. I ended up having one subcutaneous prosthesis and one unfinished breast, because the nipple was still missing. They said: we will take care of that during the same surgery in which we sort out the other breast. Well that was a complete and utter failure. During that operation they really got at me. They were supposed to move skin from my back to the front with that erm, dorsal muscle which I turned out not to have. So that backfired. And then there was no other possible way to do it. Well the only possibility left was to take tissue from my stomach and move that up. But I've had a Caesarian so I have a scar there, but for the rest it's one of the few places without scars. So I said: please let that alone, I am so fed up. I sometimes feel like I might still want to do it to relieve me of some of my limitations, but on the other hand nobody gives any guarantees, and I am not sure if I could cope with any more disappointments. Well, and now [Iris has metastases in her liver] the priority is zero.

Even if the reconstruction is a success technically, the reconstructed breast does not feel like a natural breast when it is touched. Women report changed sensations, with the most likely outcome being having no sensations at all. This means a complete erogenous zone is gone that has not been restored by reconstruction:

*Chantal (Pat3): The moment you decide to have reconstruction you don't realize what it means. Because you think, well I'm having a reconstruction and then it's [the breast] back on, but it's entirely different. It is **so** different, and I would never have expected myself to have problems with it, but the idea that he would be touching that breast...I think don't touch it because I don't feel a thing and **that thing** no longer serves a purpose. Leave it, they don't need to touch it anymore, because I don't feel it.*

This quotes reflects Sacks (1985) case histories in which stroke patients describe their own limbs as 'alien' to them because no sensations are coming from these limbs. To reconstruct something that (hopefully) looks like a breast does not mean that it will be experienced as a breast, either by the woman herself or by somebody else touching it. It compares with women with reconstructed vaginas who reported that internal stimulation of the vagina gave the sensation their thigh (where the skin used to do the reconstruction was taken from) was being stroked (Mercadante et al., 2010). The human body is not merely a 'technical construction' consisting of parts that can be replaced or substituted just like that. 'Body image' is related to sensory sensations and is

represented in the brain, and 'changing' the looks of the body does not mean that this representation is changed as well.

It is important that women are given realistic information on the costs and possible benefits of reconstructive surgery. Health care professionals should be aware that there is evidence to suggest that reconstruction does not give superior results to mastectomy without reconstruction in terms of emotional, psychological and sexual effects (Rowland et al., 2000, Harcourt et al., 2003). The decision to reconstruct or not should be made regarding whether it suits the woman in question (Denford et al., 2011). Only when the woman's motives fit what can be expected from reconstructive surgery, should she be encouraged to carry on. Otherwise a more supportive approach, helping her to deal with what it lost and gone forever, would be a better choice, as this will help to prevent her from having even more disappointments (Plette, 2011).

From a broader perspective, societal norms play a role here. It is not just the woman wanting to look normal 'for herself' or her partner, it is also wanting to look normal for the outside world. If this standard is not met, this can result in deep shame. In public, Iris wears a wig and breast prostheses and she is continually aware of this:

Iris (Pat5): That's what it feels like for me; to be constantly trying not to look different: is my wig in the right position, are my tits level, you know? And even then I sometimes realise, oh no, something is wrong and then, oh my God, I wish the ground would open and swallow me up. But that's how it is; it's too late because it's already happened. These really are awkward moments. They really emphasize so much that you are ill.

What is normal and desirable from a societal perspective, and is therefore constantly reflected in the media, is so internalized that we often fail to recognize that this is a construction from society itself. Health care professionals should be careful not to push patients towards 'normality' just because society has a problem with one-breasted or bald women (Kendrick, 2008). Edith does not always wear a wig or a head wrap when she leaves the house, and her partner Mike explains how this may contribute to societal realisation of people having cancer, instead of trying to hide this all the time:

Mike (C7par): Right from the start I said “don’t wear that stupid wig”, even if only to change the way society perceives it. Everywhere you read that women report baldness as the nastiest side effect. And that’s because of our society. If I shaved my skull and then walked out in the street nobody would say a word, whereas all these women determinedly wear their wigs. If they would stop doing that everybody would get used to it, and that would be it.

For Edith it is not so much about making a statement, although she does agree that it is ridiculous that bald men are considered ‘normal’ and bald women are not. Her main reason for not wearing a wig is a practical one.

Edith (C7pat): For me that’s not the point. I am just more comfortable without a wig. I wore it a few times because people wanted me to show it to them. But after a bit I thought: I am not going to bother. So then I would ask “have you seen it?” It itches and I think it’s brrrrr ... No, I prefer my baldness over artificial hair. But you never know, maybe one day I might want to wear it.

It should be the patients’ choice whether or not to wear wigs and prostheses or to have reconstructive surgery, without too much pressure coming from societal norms. This is not to deny that programmes designed to make cancer patients look good and as a result feel better are a great achievement. It is very understandable that cancer patients don’t want to be ‘the odd one out’ every time they appear in public. The downside is that hiding visible signs of cancer and cancer treatment helps to sustain the ‘conspiracy of silence’ as described by Rasmussen et al. (2010), because by hiding these traces the cancer patient secures that it will not be talked about. Other people complement this by ignoring the altered appearance and by not mentioning the cancer. The message from society is: ‘you are supposed to disguise your physical signs of cancer, because we don’t want to see them’. This is another example of secondary victimization as this message conveys that the stigma rests with the cancer patient rather than with society (Kendrick, 2008). However, the way cancer patients themselves experience their altered body is a mirror of how the body is perceived socio-culturally, so patients are part of this conspiracy of silence. This once again proves the point raised by Heidegger (1953/2010) that ‘being’ is always ‘being-with’. As a result of the cultural taboo, there is no outlet for patients’ need to discuss their cancer experience with other people in society, because “they meet a silence (in themselves and in others) that they feel unable to break” (Rasmussen et al., 2010 p. 158).

One way or the other, it is important that patients do gain ownership of their bodies again and, where possible, also reconnect with their partner on all levels to synchronize the very different experiences they have gone through. Joyce compares the way she felt after she came out of hospital with the way she feels now, nearly one year later:

*Joyce (C5pat): At first I could do absolutely nothing, I could barely take a shower, even that completely wore me out and it was all I could do, so I would just sit in a chair for the rest of the day. I just couldn't do anything, I had no energy at all. That lasted for months. And now, not even a year later, I am sitting here like this; so what's the problem? I work out twice a week for an hour and a half. The recuperative power of the body, if you bear in mind where I came from, it's unbelievable. Well, I mean, before long I'll be back to work full time, it may take me another year. But just look at what I already **can** do again, hey?*

However, when Joyce leaves the room to go to the bathroom Dennis openly mentions his concerns:

Dennis (C5par): Well I am afraid it will take rather more time. Joyce still needs to catch up with a lot of things such as remembering what she is supposed to do; I need to be constantly alert. Like yesterday morning, she had to leave at nine. And half past eight she was still sitting there wearing her pyjamas and then I don't always want to say to her "Joyce it is eight thirty already". So I didn't say it and then she was still sitting there at nine. And that is very hard.

Joyce's point of reference is the time she was having her autologous stem cell transplantation and felt extremely weak: from an emic perspective she has felt in her body what that was like and she is amazed at how much she can do again already. Dennis' point of reference is the way Joyce was before her illness, and from that etic perspective he feels she still has a long way to go.

'Back to normal' also includes returning to previous roles. Instead of being a patient, the individual has to pick up activities related to being a partner, a parent, an employee again. Coming back into the relationship as a partner is a process by itself:

Dennis (C5par): Like now, you have to try and resume all kinds of activities related to your personal life.

Joyce (C5pat): Yes and that can be difficult sometimes. He is a very caring person and I need to do more, I need to claim that back, and I have to find out how to do that.

Dennis: Well, it has to wear off gradually, that nursing attitude. I mustn't see her as a patient anymore.

Joyce: Well, speaking for myself, I was a patient but I always considered myself to be his wife and although I have been ill I never called myself his patient. I was just ill. There were things I could no longer do but now he has to let go of things and I have to pick them up again, to get back to normal. Sometimes it goes smoothly, and sometimes you get to each other's nerves.

Roles changed when Joyce became ill and now roles have to change again as she moves on. The fact that there is no consensus on **how** the roles had changed does not make things any easier. Joyce felt she was Dennis' wife all along and never thought of herself as his patient but that is what she was to Dennis. Joyce and Dennis will have to go through a process of converging and merging to restore the balance. Their habit of discussing any issue that might turn up along the way will no doubt help them to achieve this.

Vignette 14: Fog is lifting

Now that you are coming back into 'yourself' it is more and more like fog is lifting. Your scope becomes broader than 'survival' and 'treatment' again and you are becoming more aware of what has been and is going on around you. You start realising that your partner has needs for sexuality and intimacy, and that especially in the domain of sex your partner has been neglected for some time. And although this is not your fault, you feel guilty and uneasy about it. Fear that your partner may be finding someone else is creeping in and you don't like that idea at all. But you don't feel like having sex yet, your body feels different and vulnerable and you are afraid sex might hurt or might damage things. So you postpone it a little longer, although you are well aware that you can't postpone it forever ...

Patients may feel it is because of their illness that so many things have changed in the relationship, including changes in the domain of sexuality and intimacy.

Joan (C6pat): I know that I didn't ask for it, I can't help it, but because what happened to me threw a spanner in the works. After all, Walter is a man, and I don't mean to say that men should always have it their own way, but I do know it works differently for men and women. And well, he's had to do without [sex] for so long, I realise that something needs to be done.

Joan feels conscience-stricken despite the fact that she knows she can't help her cancer. The same goes for Emma:

Emma (C3pat): It sometimes feels as if it's my fault. Rationally I know I can't help it, but intuitively I know that he misses it [sex] very badly. For myself I've grown used to it; just for myself it's ok to do without.

The difference between Joan and Emma's situation is that Joan's partner Walter is not ready yet to have sex with Joan whereas Emma can sense the desire in her partner Richard. What they have in common is the fear that the disruption in their sexual relationship might lead to a further drifting apart. Joan picked up that her partner Walter said: "*at the moment I can live with the situation but I don't know for how long*" with Joan responding: "*that is exactly what I mean*". She senses a danger in this sexless state of their relationship, and absolutely does not want their relation to stay like this:

Joan (C6pat): Recently you told me you had already accepted that it might never change and that really shocked me, and I said "well, that's not the way I want to grow old with you at all". I cannot, I will not go on like this, you know that. For a while, okay, that's all very well, and there all sorts of reasons, but I don't want a sexless relationship.

Talking about what seems to be the problem revealed an interesting but not very clarifying way of communication:

Walter (C6par): Maybe I don't touch her because I am afraid I might hurt her, and then she says that that isn't the case, but I don't want her to feel guilty because of me, and therefore not to say when it hurts.

Joan (C6pat): Maybe we are not good at in expressing things to each other.

Walter: No.

Joan: Maybe it's to protect each other. But it doesn't really, not genuinely protect. It's better to be honest, and although that might be tough at the time, at least it's clear.

Walter: Yes, because now we sometimes assume what the other person might be thinking and that makes it all very muddled.

This is an interesting shadows in the dark play that Joan and Walter describe here. Instead of speaking freely they try to fill in what the other person is thinking and then behave accordingly. This in turn can lead to the other person questioning: "why do you behave like that?" If the first person then says: "because I thought ..." the other person can think: 'how can you assume that that is what I am thinking; what are your ideas about me? I am thinking something completely different'. This could even result in mistrusting the other person. Trying to protect each other can lead to a very misty and messy situation, especially when it is not just about protecting the other but oneself as well (Kind and Van Coevorden, 2002). Protecting one another and repressing feelings can be a hindrance to intimacy (Palm and Friedrichsen, 2008).

For Emma it is clear that her partner Richard would not hesitate to have sex with her again if only she was ready for it. She explicitly, although jokingly, brings up the point of Richard having sex with someone else:

Emma (C3pat): Just for fun I once said to him that I could imagine him having it...with someone else, you know? And then he said, well as long as you're here beside me in our bed ... now he may have just have said that for form's sake [☺], but I thought I'd just bring it up. And yes, that's how we go about it jokingly, but at some point I thought, it has been like this for one and a half years now, and you never know what might happen...

The same thought has crossed Joyce's mind:

Joyce (C5pat): I will have to wait and see when I will feel like making love again. But the question is: does he have to wait that long? It just isn't easy, and I do feel some kind of obligation, well that's maybe a bit too strong, but I wouldn't like it if he had sex with someone else, I mean there's so much going on these days, ...how long can a man not have sex? He might just encounter someone whom he really fancies and then what? Then the fat's really in the fire, you see? But then again I don't expect him to be unfaithful, that's not what I mean.

This realisation that there is an existing possibility that Dennis might resort to another woman puts pressure on Joyce. But there is a discrepancy between what Joyce feels she can offer Dennis at the moment and his needs, resulting in ambivalent feelings:

Joyce (C5pat): You know, my body has gone through so much pain and everything, and then to consider sex, well I don't really fancy that right now. But I recognise he's a healthy man so ... on the one hand I feel I should do something about it, but on the other hand I think pff, let it rest a little longer. My feelings go up and down and erm, every now and then he indicates that he does need it, but then he says "well let's see how things are by Christmas" and that makes me conscious-stricken. I also realise that the longer I wait, the more difficult it gets to take that first step. So I don't find it easy at all.

For now, Joyce resolves her ambivalent feelings in the following way:

Joyce (C5pat): But it's not like I think that this could ruin our relationship. Our relationship doesn't depend just on that. We've been together for too long and we've been through a lot together, so erm ... Wouldn't you agree?

Unfortunately, Dennis is not very convincing when responding to Joyce's question:

Dennis (C5par): Well sure.

Joyce (C5pat): Really? You can just say it.

Dennis (C5par): No thank you, I have said enough for today [☺]

For now, they can both live with the situation. But they also both know that the situation as it is now is not satisfying for Dennis in every respect:

Dennis (C5par): But of course I would like to make love to Joyce again. I mean we've had that for so long and it's just great and yes, that's gone now. So it's just a matter of waiting and seeing how it develops.

For patients who consider resuming sexual activity there often is an important hurdle to take: the physical changes or problems related to sexual function due to cancer and cancer treatment. Patients reported physical problems that directly or indirectly hindered them resuming their sexual life.

Patients described side effects of chemotherapy, radiotherapy, hormone therapy or lingering symptoms from surgery. These included fatigue, painful muscles and joints, a change of their sense of taste, painful and dry mucous membranes, erectile dysfunction, loss of libido, painful hands and feet with the nails coming off, oedema, cardiac arrhythmia, increase in weight and so on. Some patients now have a stoma or need to catheterise themselves. Physical symptoms vary according to the type of cancer and the type and phase of treatment but all of them will have an impact on their experience of sexuality and intimacy (Hughes, 2009).

To avoid unnecessary complications it is important to take patients' complaints regarding physical problems seriously.

Vignette 15: Little pains ...

Two months after your operation (in your genital area) you still experienced a lot of pain. You couldn't even sit down properly. This had a great impact on you and your daily life. You couldn't lead a normal life with your family due to the pain and the difficulty of movement. Sexual intercourse was out of the question. You discussed your pain with your surgeon when she saw you for a post-operative check. She replied that this is a matter of scar tissue (without examining the painful area). When you saw her for your next appointment, you again complained about the pain that was still there, disrupting your life. This time the surgeon told you not to think of your 'little pains'. Finally, half a year after the operation, they found that you still have a metal stitch in place that should have been removed. Even now, after the stitch has been removed, the after effects are still there because the area was so inflamed it is taking ages to heal.

Being absorbed in pain will keep the thought of returning to an intimate relationship out of mind because the physical problems override. Not being

taken seriously by health care professionals when bringing up very tangible, physical symptoms is not very helpful. Not only does this prevent optimal treatment at this point in time, but it will also discourage patients from discussing less tangible and more personal topics like intimacy and sexuality with this health care professional later on.

Providing information preceding treatment does not mean that health care professionals will check how things are going later on. Emma said about her surgeon:

Emma (C3pat): She [the surgeon] said to me before the operation "well it could be that you will have no more [sexual] sensations because we might hit that particular nerve". Then I thought she would come back to that afterwards and ask how it turned out for me, and discuss the possibilities or the impossibilities so that you know ... It wouldn't change the situation, but there are things you need to know so you can try to live with them ...

In this study, most clients were treated in regional (non-academic) hospitals. Two participants were referred to a big academic hospital for part of their treatment. They reported that in this hospital their experience was different, illustrating that there seem to be differences between health care settings regarding the attention given to aspects of sexuality.

Alice (Pat7): In the preparation for surgery they were very clear about the consequences regarding sexuality. And at every consultation afterwards sexuality was brought up. They left it entirely up to me to expand on that or not. The nursing staff always indicated "if you want to discuss it you just mention it. You may now be finding what the consequences are for you and what they aren't, and if something is bothering you, just ask us".

In contrast, in the regional hospital where Alice underwent the rest of her treatment sexuality was not discussed.

Alice (Pat7): During chemo and other treatments in this hospital, and where I also once visited an urologist, that sort of things was not discussed at all, no.

Despite the fact that clients not always experience their contact with health care professionals as very personal, they sometimes do bring up problems in the sexual domain. They report that this is not an easy thing to do, requiring the crossing of a threshold.

Emma (C3pat): Because before even daring to ask whether you can have sex again you are so worked up and when I finally asked she said “yes, with condoms” and that was all. Nothing else, like “you might try this or that”. It felt a bit crude.

Emma asked her surgeon whether it was safe for her to have sexual intercourse. It was not easy for her to do this and all she got was a three word ‘technical’ answer, which she found very disappointing.

Mia had a similar experience with her doctor. Mia was not given much information beforehand about the side effects of her hormone therapy. When Mia and Ryan were experiencing sexual problems due to vaginal dryness they took the initiative to discuss this with Mia’s doctor.

Mia (C2pat): “Well” she said “we’ve got Replens” [a lubricant]. I used that for a while. But well, that wasn’t really the solution. It helps a little, but because the skin in my vagina was ruined it also caused more irritation so it did more harm than good. Perhaps I should have started using it earlier and then the skin might not have torn. That would have saved me the negative experience.

In Mia’s case it is a shame that the use of a suitable lubricant was not pro-actively recommended, as this could have resulted in a better condition of her mucosa. Moreover, the association between intercourse and pain might not have become so strong, which would have made it easier to return to having intercourse again after hormone therapy was finished. Ryan explains:

Ryan (C2par): At one point it probably was more the idea than actually the inconvenience, because even some time after the hormone therapy you were still afraid
Mia (C2pat): Yes, that didn’t make it any easier.
Ryan: That made it so much more difficult for you, I’m a 100% sure of that.
Mia: Yes of course, but well yes, I’m still afraid the pain might return
Ryan: Yes that’s an extra hurdle you need to take.

For Mia, a process of classical conditioning has established the link between intercourse and pain and it takes time to ‘disconnect’ these two again. Unfortunately, the fear of pain will cause stress and tension on Mia’s side when engaging in sexual activity, which will make it harder to extinguish her fear of pain. So the fear of pain sustains the tension that consequently might result in pain, leading to a vicious circle. Therefore, it is of paramount importance that health care professionals pro-actively give all the tips they can to prevent unnecessary problems and damage.

James and his partner had a similar problem and decided to discuss this with the gynaecologist:

James (Par6): Because of all the chemo treatments all the mucosa had become so terribly dry, that intercourse only hurt. We talked to the gynaecologist and all he said was that there was a good sexologist available. We then said that that wasn't actually the problem. It was more of a mechanical, well medical, technical problem or whatever you call it, but he just ignored that "no no, but in that case I will refer you to the sexologist", but we never followed it up. You know...they are really specialists, oncologists too, it's all about medicine, side effects and the like. They don't show interest in real life; you're one of many when you're with an oncologist. They just don't get it, they've got a wall around them. Don't you come near, whooo, please stop it!

Obviously, this gynaecologist did not feel very comfortable responding to these questions and as a result was not able to help James and his partner. Health care professionals should feel enough at ease to discuss sexual issues so that a conducive situation is created for providing realistic information about what interventions for sexual dysfunctions after treatment for cancer are available (Miles et al., 2007). When a health care professional does not seem to be at ease addressing intimate topics or responding to sexual issues brought up by the patient, this will not encourage or invite clients to talk about these issues.

Some professionals admitted not feeling comfortable discussing sexual issues with seriously ill patients, resulting in not bringing the topic up and trying to steer away from it when the patient brought it up:

GP (Prof1): When patients brought up a sexual issue it was briefly discussed, but not as in-depth as it should have been. Next time you just waited to see whether or not the subject was raised again, and you would be really glad if it wasn't. Although overall you have an open attitude, you can still try to avoid that area. In the back of your mind you think: I hope he doesn't bring that up. You are not constantly thinking that of course, but you can encourage people more or less to go in certain directions. Yes. But when it was mentioned two or three times I would discuss it. I don't think I still ignored it then.

Patients had to be very determined and bring up their sexual issues two or three times before this GP picked them up as a point that needs attention. Not all patients were brave enough to bring up their sexual problems even once, let alone two or three times....

Patients reported that only very rarely sexuality was raised by a health care professional during or after treatment. Unfortunately, when this was the case it

was not always done in the most appropriate way. Joan and Walter remember how their gynaecologist once asked about their sex life:

Walter (C6par): I do remember one question from the gynaecologist. He asked "how's your sex life?" and we answered "it isn't". That is the only time it was mentioned that I can remember.

Joan (C6pat): Yes, but we didn't really discuss it then.

Walter: No, well, you said something like "it may come back again". And I remember him saying "we've got medication for that".

Joan: Then he suggested Prozac for me. And I said "no I don't want that" and then he said "well perhaps you should consider it". And that was that.

Without exploring what the experience of this couple was like, or what the nature of their problem seemed to be, this gynaecologist recommended Prozac as a way to solve the problem. Moreover, there was no build-up towards his question and it never had any follow up:

Walter (C6par): I remember that for me the question from the gynaecologist about our sex life was rather shocking, because it came right out of the blue, and it was the only time he ever mentioned it. He never came back to it to ask whether anything had changed.

Joan (C6pat): Or to ask have you thought about Prozac yet.

Walter: No, nothing at all.

It is a shame that the way this gynaecologist brought up the subject did not give any help or result in any improvement for this couple, neither on an emotional level nor on a practical level.

Vignette 16: Bring it up

You and your husband have not made love for quite some time. You are wondering whether your nurse will ask you about the intimate side of your life, but she doesn't. You think: 'If she doesn't mention it, I don't know how to say anything either'. You are worried though. Sexuality was part of the whole of your relationship, and you feel you have lost it. How are you going to deal with that? How can you still experience intimacy with your partner, especially now that you know that in the end his cancer will kill him? How to share the grief and distress and how to shape the final goodbye? Just words are not enough to express how you feel ...

You cannot discuss these things with your children or family. You feel the need to share your worries with somebody professional, who knows about these things and who might be able to offer some help and support. But maybe you are the only one struggling with these issues.... If you would bring them up they might think: 'she is oversexed', so you decide not to talk about it ...

Participants in this study agreed that health care professionals should take the initiative to offer the possibility to discuss sexuality and intimacy during and after treatment.

Emma (C3pat): I think a doctor should sense things or the oncology nurse or whoever. I would have liked her to bring it up, I mean that seriously. You see, it comes with the job, at least I think it does, it is a fundamental aspect of quality of life.

Joan subscribes to this viewpoint by stressing the importance of sexuality in a relationship:

Joan (C6pat): You see, you're together, or married because you love each other, but sexuality is an essential part of that. If that disappears completely, then a major component gets lost. So once that is really gone, there's not so much left, and thing get a bit dreary.

The fact that many people see sexuality and intimacy as important components of quality of life does not mean that everybody would accept the invitation to discuss these personal topics with health care professionals, as one participant made clear:

Richard (C3par): I wouldn't ask them that question, because I think it doesn't belong there. I don't need to discuss that with them, I discuss that with Emma.

His partner Emma, as the patient, still feels that health care professionals should bring the topic up and that they should at least leave the choice with the patient and partner:

Emma (C3pat): Well at least they should say "do you feel the need to talk about this or do you think you can manage" ... Then you leave it up to the people concerned, but at least you mentioned it. I would have liked that, I would have...I missed that, but perhaps that's because I am a woman, of course that might make a difference. And the fact that it was about me.

Ryan makes it even clearer that it should be for the patient and partner to decide:

Ryan (C2par): Yes they should bring it up, because if a patient doesn't want to talk about it, well he or she could say so. It should not be the caregiver who decides well, erm, are we going to discuss it or not.

As Taylor and Davis (2006) point out, by giving patients permission to discuss sexual issues, professionals should at the same time give them permission to decline.

The specialist oncology nurse who participated in this study always brought up the topic of sexuality when providing aftercare for cancer patients. Most of his clients respond to his initiative gratefully. When asked if people sometimes do decline discussing this topic he gave some examples.

Specialist oncology nurse (Prof12): Yes, some people say "oh we don't need to go into that". Or people say that it no longer applies to them. One woman with a history of incest, who had come to us with a gynaecological tumour said "that's been over for us for a long time. Intimacy yes, but sex no, so we really don't need to talk about it". So some people explain why there is no need. But people actually refusing to talk about it, that happened to me only twice... and by chance, well not by chance, on both occasions they were from a strict Christian background and they just didn't want to discuss it. Okay, that's fine if they don't want to talk about it. I mean, we have the information on paper too: "Fine, we won't talk about it, should you want to read about it, you know it's there". And that's fine too.

From the feedback in this study it seemed that it was all the more essential for health care professionals to take the initiative putting sexuality and intimacy on the agenda, because clients themselves were not always aware at the time of their need for (emotional) support regarding these intimate issues.

Anna (Pat2): If anyone had asked me then, I might have denied it. You see, I never missed sexuality as such, but I did miss him putting his arms around me, but I coped with that by thinking: this is it, I'll have to make do with this. And I would never have considered to erm, ask for help. Had somebody asked me "do you want any help with that or do you want to discuss it" I probably would have said no. But that doesn't mean they shouldn't have brought it up. Those are two different things. But then it does matter to me who's asking it and in what way. It has to be someone who can actually handle it as a person. When it's done merely professionally you immediately think "there's something wrong with me". But I think they could make a big difference in a normal conversation.

It is only when patients and partners look back that they realise fully that it would have been helpful to get some support in an earlier stage, as this might have helped to prevent problems at a later point in time.

Walter (C6par): Looking back on the whole thing I think that the hospital should have paid attention to it. Suppose sexuality means so much to you that your entire relationship is put under serious pressure, and then some professional guidance would

have been very welcome. Fear is a bad counsellor in this case, because you try to run away from it, but sexuality is a part of your human existence, your identity, and you have to handle it carefully. If you can't cope yourself it isn't wrong to turn to a professional. It might even prevent the relationship from faltering, and even very simple words may help.

Maureen makes an important statement, pointing out that what is routine for health care professionals is the first time for clients.

Maureen (Par4): Well it's your first time, what do we know. It is only with hindsight that I began to see and understand things.

The clients explained that it would be too much to expect for them to take the initiative to broach the subject of sexuality once treatment had started.

Heidi (Par5): They never came back to sexuality of their own accord and I am convinced that it's expecting too much from people in our situation when they say: if you have any queries you should let us know. Am I the one who should take the initiative; I am in shock! I shouldn't have to do that; they should! They should do just one thing and that is to take the initiative, that's my firm belief.

So at the least health care professionals should bring the relevance of discussing sexuality and intimacy issues within the scope of their clients.

Dennis (C5par): You see, when you come to the hospital to have a blood sample taken, there's only one thing that really counts: are my blood values okay? I think up until now Joyce has mainly focussed on her recovery. It might have been helpful if a nurse or a haematologist had said "if you do have any questions about sexuality don't hesitate to ask". Then, if you have any questions, you could bring them up.

At some point it can be helpful to bring sexuality to the attention of the people involved, even when the patient is not yet actively asking for advice. This might also do justice to the partner or even help to bridge the gap between partners, as the partner might be ready to discuss these issues before the patient is. It is not possible to pinpoint what is exactly the right moment to bring the topic of sexuality up (Bruner and Boyd, 1999, Rasmussen and Thome, 2008). Patients and partners did agree that they don't feel the need to discuss sexuality and intimacy in the acute phase of diagnosis and initial treatment, as survival is their main focus at that time. Joan said that while she was fighting for her life it would even have been offensive for her if people had brought the topic of sexuality up:

Joan (C6pat): Well, I think had it been offered at that moment, I would have said, what are you talking about? I am trying to survive here!

So good timing is crucial and fully discussing the impact diagnosis and treatment turn out to have on sexuality and intimacy has to wait until people are ready to pick up their lives with sexuality as one of the aspects of 'new normal' life (Katz, 2011). Some people said they would have welcomed help in this domain a few days after surgery; others said a few months after their treatment phase started would have been the right time; still others say they would not have been ready for this until well after their treatment phase was over. It is clear that the time people need before they are ready to discuss the impact of cancer and cancer treatment on their intimate lives may vary. However, one way or the other, the topic of sexuality and intimacy should be brought up by health care professionals before clients find themselves struggling with these issues, so that clients know that these professionals are available to support them when needed and that it is not at all exceptional if these issues require attention.

Participants made clear that it makes all the difference **how** the topic of sexuality is brought up. Emma makes it clear that the topic should not come out of the blue:

Emma (C3pat): You don't visit a doctor and he simply asks "well Mrs XXX, how's your sex life", that's just not how it works.

Mike appreciated that the health care professional he met started by finding out if there was a need to go into the topic any further.

Mike (C7par): They don't so much ask: "how's your sex life", but they ask if everything is fine with the two of you and if you say "we're fine" then there is no need for them to start digging.

According to the participants, just to give folders including information on the impact of treatment on sexuality is not enough.

Judith (Pat1): It was never discussed with me, but I did get some leaflets. You get these leaflets pushed into you hands, and the gynaecologist said "so much will change in your body and erm, I am giving you these leaflets so you can prepare yourself", and that was all.

The use of self-assessment questionnaires does not seem to be the perfect solution either.

Diana (Par3): But what we did notice, was that in the hospital you were asked about sexuality for the records ...he could fill out 1, 2 or 3. But they never came back to it. Although I should mention that he filled out that everything was fine, to prevent any questions. He didn't feel the need be questioned on that.

The rest of Diana's story revealed that a few problems in the domain of sexuality and intimacy were existent at the time. Maybe a different way of trying to make Diana's partner disclose them would have worked better. But even if her partner still had opted not to discuss these issues with his health care professionals, Diana would have wanted to do so. The self-assessment questionnaire approach does not provide for that.

When bringing the topic of sexuality and intimacy up this should be done in a way that shows interest in the personal well being of the patient and partner.

Judith (Pat1): It should have been asked, just out of interest, absolutely. It is part of the larger whole. Even though to him [the doctor] it may be just a tiny fraction and although he might refer you, for us it is part of our life. To us it's even a very important part, but it was covered up.

Anna makes clear that for her the key thing is to have the opportunity to tell her story to somebody willing to listen, instead of just checking for physical problems.

Anna (Pat2): During treatment the main focus is on symptoms, which in fact is a missed opportunity to ask "and how are thing with you?", and to ask the partner the same. "How are the two of you doing? Can you manage?" but we never had these kinds of chats. It was more like lists with questions, that sort of thing. You should just get the opportunity to tell your story.

If the prerequisite of a person-based approach is not met, clients will not respond to the initiative of the health care professional to discuss intimate issues.

Heidi (Par5): All we got every now and then was a letter from the oncology nurse with an invitation to discuss things. The letter mentioned all sorts of subjects you could discuss, amongst which was sexuality. But with these people I didn't feel any urge at all to share any private matter whatsoever. Because I need a sense of trust with people before I feel able to share such things.

Patients would also have liked to hear about possibilities instead of just side effects, problems and limitations. They reported lacking the creativity or energy to think of alternatives and would have welcomed suggestions and practical tips from health care professionals with experience in guiding and supporting clients in this personal domain (Gianotten, 2007) :

Emma (C3pat): You can keep focusing on the impossibilities, but I prefer to focus on possibilities. Sometimes you're just not able to think of them yourself. And if someone could help you with that with a little humour or by suggesting "well what if you look at it his way", I would really appreciate that. Particularly when there's so much on your mind and you just can't think properly.

Judith gave a similar response and gives some examples of tips that might have been helpful.

Judith (Pat1): I think these are very important things to point out, because that may just help you to cross that barrier: "start doing fun things, go out for a weekend, find yourself a nice hotel even if it's for just the one night, then you create an atmosphere; there is no need to be afraid, and these are all possibilities you could try".

Toombs (2004) argues that even simple strategies can significantly improve a patients' quality of life. She therefore advocates that health care professionals ask questions such as: "What is the most difficult thing for you to deal with in your daily life?" (Toombs, 2004 p. 646) as this would be helpful in exploring the manner in which the illness disrupts the patient's life, which includes sexual aspects.

Apart from when and how these personal topics should be brought up, another relevant question is with whom clients would like to discuss them. Their preference was not based on the disciplinary background of professionals, but on their impression of the professional as a person. Asked whether she would have preferred for her specialist to bring up the topic of sexuality, or maybe her GP, Rose replied:

Rose (C4pat): I wouldn't really care, as long as there is basis for trust.

Most participants reported that the gender and age of the health care professional discussing sexuality and intimacy with them would have been irrelevant, although for a few these aspects would have affected their expectations regarding the professionals' capabilities and willingness to discuss

sexuality and intimacy. However, in this study not one participant reported that age or gender of the professional was a decisive factor. Ultimately, for both patients and partners, it is all about the person.

Emma (C3pat): It's the person that matters

Ryan (C2par): For me it's the personality that counts

Edith and Mike explain:

Mike (C7par): Doesn't matter if it's a man or a woman; it's the type of person that counts.

*Edith (C7pat): A younger person would have been fine as long as he or she would have given me the same feeling I experienced from the person I actually met. It could have been an older person as long as I got the feeling that it's **me** that mattered.*

The good news was that it appeared from the discussion that preconceptions regarding the age and gender of the health care professional could be quickly removed by the right professional attitude. As stated above, from the very start, this attitude's main characteristic should be a person-oriented approach.

Iris (Pat5): No high-handed manners, you should really be listened to, so they actually hear what you are saying. Empathy, a sense of security and erm, no professionalism per se. However, I do expect that what's being said is treated with confidentiality, as you are in a vulnerable position.

The clients did appreciate that not every health care professional had enough time or felt capable enough to deal with sexual issues. What they would have liked, though, was to be taken seriously. Both patients and their partners would have liked health care professionals to confirm that their worries were legitimate and that it was important they were dealt with.

Judith (Pat1): The recognition of the importance of sexuality is important to begin with, and if you indicate that you need special attention for that aspect, then that should be dealt with.

Where necessary, the health care professional should refer clients in a caring way to a colleague, preferably someone who can respond quickly and is easy to access.

James (Par6): They should acknowledge that it must have been difficult for you to bring it up, and once you have, you should not be referred to someone who has a long waiting list; if they cannot deal with it themselves the waiting time to see somebody else should be very short.

Many participants don't like the idea of being referred to a sexologist.

Emma (C3pat): To have to go to a sexologist for that, I wouldn't like that, because that would yet be another person to add to my list.

Emma reported she was already seeing ten different health care professionals and the thought of another one to add to the list was not very appealing to her. Her partner Richard explained that this was not the only barrier to go and see a sexologist:

Richard (C3par): Well I think that most people wouldn't like to be referred to a sexologist, because it would make them think: oh my, what's wrong with me then? It's not that bad!

An adequate response from health care professionals to sexual issues was all the more important because in this study it appeared that the sexual life a couple once had was often not being picked up again easily. Consider sexual intercourse: in what was stopping women from having intercourse again with their partners physical factors obviously played an important role. But in the 4 couples who had not yet picked up the 'habit' of sexual intercourse (Mia and Ryan, Emma and Richard, Joyce and Dennis, Joan and Walter), technically / medically speaking intercourse was a possibility, albeit that in two cases the use of a condom has been recommended (which of course would have meant another change to deal with). Some woman reported that they were afraid of the pain intercourse might cause or they feared the damage to their bodies that could be a result of it.

Joyce (C5pat): In the back of your mind you are afraid it might hurt; the operation may have made you tighter down there. And because I am now all of a sudden menopausal things are dry. The idea that making love results in an infection or something else really scares me, it is the last thing I need. We did buy condoms last week [☺] but we haven't used them yet...

Emma gives perhaps the clearest explanation of this for fear of pain and damage played an important role:

Emma (C3pat): Sexuality is an enrichment of your relationship, I really mean that, but I am afraid, really very afraid, that something will be damaged or that it will be very painful and that doesn't really help. And I still have this vaginal leaking, and that stops me from making love to Richard; I am so scared that I will have an infection again. That the abscess will play up again and that I will end up in hospital. And we were told we could do it using a condom, but I am afraid it might burst, so you see, it is on my mind, but for me it is still too early.

As these examples show, 'medical permission' to have intercourse again does not mean patients are 'ready' for it. The lost faith in the health and functioning of their bodies resulted in fear of pain and (further) damage. Patients reported how vulnerable they believed their body was, and they didn't automatically assume it would function properly.

In this study there were major differences between couples regarding how easy or how hard it was for them to pick up their sexual relationship again. For Edith and Mike, this turned out not to be a big hurdle. According to Edith, this was to do with her not really feeling very different, despite her mastectomy, and Mike agreed.

Edith (C7pat): Not much has changed in our sexual relationship. And I think this partly has to do with me, because I did not change a bit, apart from my physical appearance and some physical ailments, but then again, I don't see that as....

Mike (C7par): Yes I agree; without wanting to trivialise it, what has actually changed?

Edith: Well, it's two slices of meat that have been removed.

Mike: Yeah, and that doesn't make you another person.

Despite several physical changes and barriers, for Edith and Mike, picking up their 'normal routine' was a quick and 'natural' process. In contrast, Joan and Walter, nearly one and a half year after Joan's double mastectomy with immediate reconstruction, were still struggling. Intimate touching was a problem for Walter, and sexuality was not on the agenda yet. Joan's body image and sexual identity had changed for her and for her partner:

Joan (C6pat): Well, everything has changed. It is only in the last few weeks that we've been talking about not having sex and that there's very little intimacy. I really want us to have an intimate relationship again, but I first need to recognise my own body again, as everything feels different.

Walter (C6par): To me Joan looks like a completely different person.

For them everything changed, and returning to their 'normal routine' is not a natural process at all. They feel they need to talk about it and make agreements in order to 'force' themselves to overcome a huge barrier.

It has to be accepted that the cancer diagnosis may just have been a catalyst with some relationships. As Iris made clear, problems caused by her cancer and cancer treatment and her partners' response to these problems clarified what

she already knew: that she did not want to share the rest of her life with this man.

Apart from the points made above, it is important to take into account what is the 'baseline' for those facing a cancer diagnosis. The study of Ananth et al. (2003) demonstrated that the impact of cancer on sexual function is significant, compared to a control group of the same age. However, a considerable amount of women (43,1%, N=31,581) without cancer reported some type of sexual problem (Shifren et al., 2008), therefore it can not be concluded that all sexual dysfunction or changes in sexuality in cancer patients are a result of cancer and cancer treatment. Based on her own experience, Helen highlighted this point:

Helen (Pat6): We are intimate, we do have sex every now and then, but not very often though and I am not sure whether that would have been different if I hadn't been ill. We're talking about a long relationship here and there is a certain routine, and let's be honest, we're incredibly busy and at night we're completely exhausted [☺] ... having a child that could walk in any time doesn't help.

End of treatment: death

Nearly all diagnosed with cancer will get some sort of treatment, resulting in a five-year survival rate of 59% in the Netherlands over the years 2004-2008 (IKC, 2011). For some patients, the cancer turns out to be incurable. Many of these incurably ill patients will have gone through a similar 'cancer story' as the ones described so far, as they went through treatments (curative and / or palliative) and longer or shorter periods of remission. But for them, the story does not end with trying to find a new balance after their cancer episode. For them, and for their partners, there is a final cancer chapter: the trajectory towards death.

Vignette 17: To know or not to know

Today you took part in a research interview. The researcher asked whether you think of your illness as life threatening. You replied that you should see it that way, as your cancer has now spread to your liver, but that you are burying your head in the sand. Of course, every now and then you are confronted with the facts, but you find it a waste of your time to allow them to influence your whole life. You don't know whether that is realistic or not, but it is your survival strategy. You are trying not to be occupied with it all the time. Of course you do have physical limitations but you are just not going too deep into acknowledging that, because it might be too confronting to face that before too long you will not be there anymore. The thought that you will no longer be able to be a mother to your 14-year-old son is just too painful.

On a rational level, most seriously ill participants were aware of the life-threatening character of their illness, but in order to enhance their quality of life, most of the time they kept this awareness in the back of their mind. There is a “slumbering awareness” (The, 1999 p. 259) and this has implications for the experience of intimacy and sexuality. If patients are focusing on death and dying all the time, sexuality might disappear into the background.

It is important for professionals to realise that in this study there was no clear boundary between the experience of patients with curative options and the incurably ill regarding the awareness of impending death, as the next two quotes illustrate:

Helen (Pat6): From the start I was told I had a good prognosis, but it took me a long time to believe that the threat wasn't there anymore. I remember just before having surgery I felt a huge pressure on my temples, and when I had been watching a film and had been completely absorbed in it, then afterwards this pressure would come back again full force. After surgery, I remember staring at my hands thinking well, now I see these two hands; will they still be here next year? Or will I be pushing up daisies?

Helen had a good prognosis from the start but experienced very tangible death anxiety. For Judith it seems to be the other way round:

Judith (Pat1): Two years later I got metastases in my bones, which for years didn't cause problems. I worked out every Saturday until it grew worse ... more and more is taken away from you because there's increasingly less you're allowed to do. My entire spine is affected and my pelvis and then you can't cycle or do anything. Last year I got metastases in the liver which is life threatening and then you get chemo treatment. So that's my history. Actually I think I'm doing well and have been doing so for a very long time.

The level of awareness of impending death does not seem to positively correlate with medical prognosis. In these examples, there even seemed to be a negative correlation. Helen was told her chances of survival were high, but was very aware that she might die as a result of this cancer, whereas Judith surprisingly thought she was doing well where in fact she was approaching death. Often even within one interview fluctuating levels of awareness (Kellehear, 1992) were evident. Although Judith felt she was doing well, she did mention later on in the interview having arranged for her funeral in every detail. However, she felt it was still too early to order the special type of coffin she

would like, although her partner suggested it might be timely to do that now. For her, ordering her coffin would have been the final step, and that was a step too far.

Similarly, Wilbert (C1pat) seems to be very aware of the fatal character of his condition; at some point he literally says *'because in the end, this is going to kill you'*. Nevertheless, later on he declares: *'a lot of things aren't important anymore, while other things are much more important now; that I will be cured'*.

Such fluctuating levels of awareness serve as a defence mechanism, especially for those who know they are dying, and seem to match how much a person can or is willing to take in at a certain point in time. These subconscious psychological defence mechanisms protect individuals from experiencing more distress than they can cope with at a given point in time.

In addition, participants in this study coped by making a deliberate choice of not putting the awareness of their impending death in the foreground of their lives all the time.

Tristan explained how this worked for him:

Tristan (Pat8): I prefer discussing things that don't relate to my illness; I am through with all that now. Not that I want to cover it up, but you can't just occupy yourself with that all day long. You get depressed, so stimuli from outside, talking about live topics, politics, I like to do that too. So I prefer to engage in living things rather than talking about death all the time.

The example of such defence and coping mechanisms at work can result in seemingly contradictory health beliefs, with for example Judith accepting her death and preparing her funeral but not wanting to buy her coffin because that would mean she is dying. Or Joyce suggesting that her cancer will not come back because she already had a relapse:

Joyce (C5pat): And well, I mean I've had a relapse so yes, so I reckon it won't come back.

Rationally, having had a relapse does not guarantee this will not happen again (maybe risks are even greater), but for Joyce this thought helped to keep panic at bay.

Vignette 18: Never again

You used to have an enjoyable sex life with your long-term partner. It was not very spectacular and the frequency of intercourse wasn't very high, but for you and your partner it was fine as it was. Overall your partner's need for sexual contact was greater than yours. This never caused any problems; you could always find a 'middle ground'. Now things have changed drastically. Your partner is incurably ill and your sex life has come to a stop, because your partner doesn't have any sex drive at all. As a result you are very confused and restless. The idea that you will never have sex again with him is becoming an obsession. You keep trying to bring back to your memory when was the last time you made love, and how that was for you and your partner. You find it very hard to accept the finality of this 'last time' and you are craving for sexual contact with your partner now that you know you will never have it again. At night, you leave the bed you share with your partner to sleep in the spare room. Although you never used to do this, you masturbate every night to bring some peace to your restless body. It is the only way you can get some sleep ...

Sooner or later, for all couples facing a life-limiting illness, sexuality comes to a stand still. For those dying, this can feel like a natural process in the sense that they are no longer capable of being sexually active, even if they wanted to. Their body tells them that sexual activity is out of the question, and although remembering the good old days they might regret, it is simply beyond possibilities and therefore beyond their scope.

Tristian (Pat8): My sexual desires have waned somewhat; well actually they've disappeared altogether. It's odd to feel no sexual impulse, that's not like me, but sex isn't on my mind at all. A lot of intimacy all right, but that's a different chapter, I mean sexuality as such plays no role whatsoever.

The patients described this as a different experience from stopping having sex due to external circumstances. They felt on a bodily level they had no choice; this was how it was. For both partners there is the realisation that this will not be a temporary interruption; it means a goodbye forever to the sexual relationship with this partner.

The way sexuality disappeared out of couples' lives varied. For some couples, sexual life stopped at the time of diagnosis, or even before that, and was never resumed. For others, there was a period of remission in which sexual activity was back on the agenda again, albeit sometimes in a somewhat different way, as a consequence of physical changes.

Some couples in this study continued having intercourse until physical deterioration made this impossible:

Nancy (Par1): We were always touching and feeling, we always longed for each other, even during his illness, and we did have sex then. And I think that it more or less stopped only the last two months. Because the chemotherapy and the radiotherapy really began to take its toll. His fatigue, his breathlessness, he just wasn't up to it anymore.

Sometimes the patients tried to keep the sexual relationship going for the partner's benefit:

James (Par6): She really fought for it and then she would say "try it anyway", but at some point her mucosa were so dried out and atrophic that it always hurt and then it became such an artificial act. We tried some aids, but it kept hurting so we just stopped.

This might be challenging for partners, as they still are healthy sexual beings with sexual needs. Although this may be true, partners are also part of a 'coupled system', and changes in the patient brought about changes in partners as well.

James (Par6): I never thought of her body as awful or repulsive, but it was no longer a beautiful female body. The look of a female body without breasts tends to be dominated by the stomach. It loses its proportions, so for me the sexual attraction was gone.

Bruno very aptly described how changes in his partner resulted in a different response from his side and in a change in their (sexual) interaction:

Bruno (Par2): I must say that even though I usually enjoyed sexual contact, her illness stopped me. I had a physiological reluctance to feel the gaunt body of my beloved partner. For me that mainly has to do with how I perceive sex; it's an act you perform together and that was no longer possible. I mean the players had changed, including me; I respond to my partner and if my partner can no longer respond to me then I can no longer respond appropriately, so that play was over. It wasn't just the way she looked, I mean she was bald and gaunt and felt very bony, and that didn't arouse me, despite everything I feel for her, but it wasn't just the sight, it's also ideas, fantasies about what happens in the act. So I didn't feel the urge, no.

Nancy's partner encouraged her to masturbate when he could no longer satisfy her sexually, but for Nancy that was not an option:

*Nancy (Par1): He was so worried that he couldn't meet my needs. He said "if you want it [sex] can you do it yourself" and then I would say "no, that's not what I want". I had no sexual desire as such, my desire was towards **him**.*

It was the sexual intimacy with her beloved partner Nancy was missing; not sexual satisfaction per se.

James' partner was worried about not having much to offer anymore as a sexual partner and she sometimes helped him to get sexual satisfaction:

James (Par6): She sometimes said "as a woman there's nothing I can offer you anymore" and the I would say "come on, you have a lovely face and you still are very sweet and we still share our deepest thoughts". And sometimes she lent me a helping hand [☺], which was very pleasant, and also part of our intimacy. And to her it felt like an acknowledgement that she still had something to offer.

To leave your sexual relationship behind is a sad thing, but sooner or later unavoidable in the given circumstances, and this was clear both to the patients and their partners. Saying goodbye to physical intimacy altogether is a different matter.

Bruno (Par2): It's understandable that you no longer think of sex at that stage or that you consider it unimportant or that it's evident that it's no longer there, but you do think: that sex is disappearing is quite understandable, you shouldn't fuss about that too much; physical intimacy however is quite another thing.

Nancy (Par1): I didn't miss sexual contact then. Touching was much more important. If I imagine him no longer touching me that really would have affected my emotions very deeply. At that stage touching was much more important.

It can be a challenge to sustain physical intimacy when the patient is seriously ill. Bruno has lost two wives; both of them died from cancer. His first wife had been in hospital for some time when this happened:

Bruno (Par2): Her surgery took 12 hours. And it took her a long long time to recover. She was in hospital and when she was a little better and she could walk a few steps I remember her saying, while she pulled up her skirt, "I still do have a beautiful leg, don't you think?" and at that moment I didn't respond to that, blimey. I still blame myself for that. I mean I allow myself to feel some reticence when you feel different because of her physical deterioration. But I really regret the fact that at that time I couldn't find a way to establish any other form of intimacy, because this lasted from August till December. Looking back I don't feel good about that. Of course I can't tell what she was thinking, but she asked for a response, and it was still a beautiful leg. I didn't say anything and ... it keeps coming back to me.

Bruno still feels bad about not having been able to respond to his first wife's need of being acknowledged as a sexual, attractive being, instead of 'just' being a patient. He does not blame himself for the fact that her sexual attractiveness had changed for him, but he does feel that he did not do justice to her. He was confused and did not know how to respond when she showed him her leg, and

he could not think of a way to re-establish physical intimacy once that their 'normal' way of doing so had been cut off.

He then went on to compare this experience with the illness trajectory of his second wife. She took the initiative for physical intimacy by asking Bruno to massage her when it was no longer possible to be sexually active, and to Bruno that made a major difference. From the very start of the research interview, he stressed the importance of conveying to other people that this can be a good way to sustain physical intimacy with your partner:

Bruno (Par2): What I considered pleasurable as well as easy was that she wanted to be massaged continuously. If there's anything you should convey to other people it's that that's a good way too. Physical intimacy can be shared in many different ways.

Bruno knew from experience what a major difference it made for both of them when there was a way of sharing physical intimacy, even in the face of terminal illness. This is a major change and some partners could benefit from professional help in facilitating this experience (Palm and Friedrichsen, 2008).

As these examples show, seriously ill patients still value to be seen and treated as sexual beings (Flynn et al., 2011b), albeit in a different way. They value being touched in an affectionate way and expressing feminine and male traits.

Judith (Pat3): Fortunately my wig looks quite real. I consider the way I look like absolutely important. Although I may have a bad day, I take a shower every morning, put on make-up and then I feel a little better than when I'm hanging on the sofa in my jogging suit. Most people don't even know how ill I am. I radiate health and that's my own doing, and for me that's important.

Every person is a living and sexual being until death, and it is important to find ways of nurturing patients' sexual identity.

The participants, both patients and partners, testified how physical intimacy was a major source of consolation during the trajectory towards death:

Tristan (Pat 8): The physical aspect is important, cuddling up, holding each other, saying nice things to each other. I don't know if I could say that it's more intense now; our contact has always been very intense, but its shape has changed, it's like there's a film covering it giving you the feeling: how long will you still be doing this? Now that death draws so close, there is a different quality to our intimacy, I couldn't say of sadness, but there is a sense of finality.

During his final illness trajectory, Maureen's partner perceived her mainly as his private nurse, who was there to help him 'sort' his life-threatening illness. Only when it became clear to him that nothing could avert his approaching death, did he revert to seeing her as his partner.

Maureen (Par4): I only reverted to being a partner at the end. When we knew there was nothing anymore that could be done. The last week before he died he pulled me towards him and started stroking me and then he started to undress me. He did that just once and he was signalling: I need this. And I think it must have been some sort of goodbye to the physical...or some sort of goodbye to me. And he then cried and cried. And he never used to cry.

Partners don't want to lose all physical intimacy with their loved ones, and they report that for these loved ones this is very important as well:

*James (Par6): I always knew that I still loved her body the way it was, because it was **her** body. I told her so, and that meant a lot to her, she told me so later on.*

As the disease progresses, patients get weaker and weaker. At some point, they are bedridden and death only seems days away. It is important for professionals to explore with the patient what makes them experience quality of life, and not just focus on the disease and options to (palliatively) 'treat' the disease.

Vignette 19: There is still something we can do to.....

Your doctor has been clear: you are terminally ill and there is nothing he can do to cure you. You are feeling weaker and weaker, spending most of your time on the settee during the day and dragging yourself upstairs to bed for the night. A special bed has been put in your front room, but you are dreading the moment you will have to lie on that bed, as you are afraid you might never come out of it again. Until recently, you were undergoing chemotherapy, but as this no longer had a beneficial effect on your cancer, treatment has now stopped. However, the doctor has suggested another way to prolong your life: you can come to hospital to have blood platelets infused into your bloodstream. You went for this, but you are now beginning to find it a burden. Every day you need to have the level of platelets in your blood checked and based on the results you will be told whether or not to come into hospital for another transfusion. Although the hospital is not very far from your house, you find it very tiring to go there and back. Weak as you are, you still want to prepare for this hospital visit by dressing up and putting on some make-up. Your partner tells you not to bother, but for you it is very important. You were always proud of people estimating you much younger than you are, and you still want to be presentable. You told your doctor that you are now finding the transfusions quite difficult, but he persuaded you to carry on, as this will prolong your life. "There are still things we can do" he said, so you went again. You have now come to the point that you really don't want to go anymore. You are now lying in the special bed in the front room. Last night there was a real panic because you had a serious nosebleed that did not stop. You had to be taken to hospital in the middle

of the night. You were afraid you were going to die but once in hospital they managed to stop the bleeding. You don't want to have to go through this extremely frightening experience again. Also, you don't want to have another complication, in case this results in you dying in hospital. You want to die at home. You ask your husband to cancel your appointments. Your doctor rings you to let you know he was expecting to see you again as you might benefit from another transfusion. This upsets your husband because he wonders whether he was not clear when cancelling the appointments, did he do something wrong? So you speak with your doctor and you find it difficult to say no to him, but you feel ill and you stick with your decision.

Participants in this study made clear that for them the focus in the terminal phase was on bidding loved ones farewell and on concluding their lives. Optimal symptom control is paramount in order to enable people to focus on these key aspects. As part of this process, touch and holding one's partner can be important right up to the very last second:

Nancy (Par1): At one point he sat up and he said "Nancy I'm so short of breath" and I said "just take it easy, try to synchronise with my breathing, in and out, in and out" and he was lying in my arms and he looked at me and said "it's okay, I love you, it's been good" pffffff, and then he was gone. That's how it went. It's a pity that it went so rapidly because I couldn't answer anymore, but it was a very beautiful death.

Sometimes it can be necessary to literally let go to let die and Maureen tells about how hard this is:

Maureen (Par4): We were holding his hands. Then the nurse came in and she said "maybe you'd better let go of his hands, because it will be easier for him to go"... and of course I knew all this, but you can't, can you? You can't...you feel like...well we let go of him we put his hands by his body and then very soon he passed away. That happened in a flash. And yes, I think we had been holding him back.

Vignette 20: The consolation of intimacy

For the first time since your partner died a few weeks ago, you have the space to reflect on the hectic period you have gone through.

When your partner was terminally ill and the devastating impact of the illness was beginning to show, you no longer felt like having sexual contact. Looking back, you think you suppressed your own need for that ... because your partner needed his energy differently. Toward the end you preferred intimacy, mainly just holding your partner's hand. That was very important to you. That's what you did at night, you felt for his hand and that was good, so you could both sleep. That was all, no need to make love, but just to touch ... to feel. Hands were very important then. And that's in fact all you need ... gestures and touches do say more than a thousand words. It made you and your partner feel so deeply connected ...

That's what you miss most now that your partner has died. Just to be able to hold his hands ... On the other hand you derive much comfort from the intimacy you shared, in particular from the physical intimacy you had, cuddling, touching. It was good, it was beautiful, and to be able to look back at it this way is a great help in your grieving process.

For partners, the consolation of having shared a physically intimate relationship until the end extends beyond the death of their loved ones and can help them through grieving.

James (Par6): At some point we both became reconciled to the idea that sexuality was no longer present, but intimacy stayed till the end and even got deeper and I can look back on that with satisfaction. Just cuddling up, hugging, kissing or when she said "I want you to be the one taking care of me till the end, when I can no longer do it for myself". I managed to do that for her, and I even washed her after she died. In coming to terms with my loss that was the crux. My grief wore off very quickly, well sure I miss her every day, but the real mourning was over within a year and that's because we had such a good life together, so close, so intimate. I think that that's very helpful for coping with bereavement. She said to me: "thank you, you've been good to me", well that really helped me to carry on.

For James, the intimacy with his former wife helped enormously as he had good memories of her and of what they shared. This paved the way for him to pick up his life, and find the emotional space to love again, although he will always cherish the memory of his former partner.

To conclude, Maureen admitted us to her experience of how she and her partner connected the night before he died in order to share a final goodbye.

Maureen (Par4): The evening before he passed away...he was very short of breath and I sat beside him. He lay on his side, so I put my hand on the hand that was lying there, and his other hand covered mine... My other hand was on his forehead. In fact it was a circle...very special...and everything turned very quiet. He didn't cough, he just breathed...we just looked in each others eyes, just like...you can't go any deeper than that...saying goodbye with our eyes...it was just perfect. In fact that was our farewell. Actually having the feeling that you are one...you know, it was such a...well, yes a sacred moment. That you really feel...well, it can't...it couldn't be more beautiful, and I can take that with me. It's something I cherish very much and which was very important in coming to terms with my grief.

No words can add to the beauty of this 'sacred' moment. The way they touched and merged said it all. What a way to say goodbye....

Reflections of the lived experience: on worlds apart

The chronological story demonstrated the role of sexuality and intimacy for all participants, but to develop ways to use these findings to inform practice, each of the concentric circles from which the story grew needs to be considered in the light of the others.

Worlds apart: the professionals' world versus the patients' and partners' world

The professionals' world is based on rationality, evidence, facts, and logic. It is a world where professionals work in cooperation with other professionals, earn money, and although this is health care, have to meet production and quality standards. In today's world within health care settings reorganisations repeatedly occur, threatening conditions of employment and job security. Support staff may be ill and colleagues can disagree about the best way forward in these turbulent times, all of which impact on service provision. As Toombs' seminal work (1992) illuminates, the professional, especially the physician, is trained to see the body of the patient as a scientific object. Symptoms are interpreted as physical signs and physiological processes are translated into objective, quantified data. For the physician, disease mechanisms should be wholly explicable (at least in principle) in terms of natural science. The patient's body is an exemplar of 'the' human body, and can be studied independently from the patient who is presenting 'the body'. Taken to its extreme, this means that "the anatomical body represents not the lived body (one's intentional being and mode of access to the world) but rather the cadaver which may be dissected at autopsy" (Toombs, 1992 p. 79). Thus professionals focus on linear models, based on the medical / physical aspects of their patients. They are trained to think in terms of cancer trajectories based on functional status of patients and providing palliative care tuned to this functional status.

When clients come to visit the professional world they do so because of a problem. Something is wrong with their health, and they are worried about it. When they experience their diagnosis as life-threatening this has a major impact on all aspects of life. They are confused, shocked, in a state of chaos

and may be angry or become depressed. Their state of mind is determined by emotions that are not linear or rational but associative, wavy and circular. Most patients and partners try to behave as they think they are expected to, when they enter the professional's world, but, the emotional turmoil lurks below the surface. There is so much at stake: their happiness, the well being of their loved ones, the fulfilment of their roles in life, their future. Everything that has meaning for them as a person is affected by the cancer diagnosis. This 'lived experience' from the patient then meets the 'scientific attitude' of the professional, with the professional reclassifying the lived experience in terms of natural science. This tells the physician 'what really is the case', as science is understood as 'revealing the real truth' (Toombs, 1992), but for the patient there may be negative connotations from this attitude. Sometimes health care professionals are able to engage with the 'lived experience' of their patients, but sometimes, as this study reveals, the gap remains immense. The pain Emma (C3pat) reported was dismissed as something 'she should not think about for a while' until the 'objective' truth of the metal stitch that was left behind explained it. Such striking examples as this, of the different worlds patients live in and professionals work in, are not unusual and can be found in accounts of professionals who themselves become patients (Sacks, 1984, Rosenbaum, 1988, Ten Haaf, 2010).

Worlds apart: the patients' world versus the partners' world

There is a difference between being given a cancer diagnosis and being the partner of someone receiving the cancer diagnosis. The patient is threatened on the most basic existential level: the bodily level of life and death. And although turmoil and chaos is omnipresent on all levels of the patient's existence, the initial focus is on the fight for survival. The epicentre of the 'earthquake' that hits the patient is on this level. Following the intense experience of facing a life-threatening illness, patients cannot be as they were. They have had to face their mortality, instead of 'just knowing' that they are a mortal being. Little et al. (1998) describe the initial phase of this process as looking like a 'black box' to the outsider. The diagnosis of a life threatening illness sets the patient apart from others; they enter the black box and emerge much changed by the time they reach the convalescent or terminal phase.

Partners are on a different journey; they have to cope with the emotional and practical problems coming their way, without having the person they would normally turn to for support fully available. They carry on with life, albeit in a different and often more difficult way, while the patient is firstly immersed in the treatment trajectory and then trying to return to a normal life again. Although for partners lightning has struck very nearby, which is frightening enough by itself, they were not the prime target. They may be deeply affected and distraught by the idea that they might lose their loved one, however, intense as this experience may be, it is different from the one the patient is going through. According to Lindop and Cannon (2001), who considered women with breast cancer, the main source of emotional support for the women appeared to be the partner. However, this was problematic when the women perceived their partners to be coping badly themselves or when they were showing too much sympathy, emphasising the helplessness of being a patient. The relatives of these women were on a difficult journey of their own, and even if the women were aware of this, it still often resulted in conflicts with the ones with whom they had close relationships. Although none of the women in the current study had, as Vargens and Bertero (2007) found, chosen to hide their disease to protect their close relationships, some did experience communication problems. These findings reflect those of Little et al. (1998) that patients feel that they cannot communicate and share the nature of the experience of their life threatening illness, not even with their partners. The experience cannot be fully explained to persons who have not had the experience themselves, as Anna (Pat2) and Iris (Pat5) have highlighted in this study. Toombs (1992) describes this as the 'unshareability' of the experience. It is on the intra-psychic 'world' of the patient the third level of 'worlds apart' focuses, in an attempt to grasp a fraction of understanding of this unshareable experience.

Worlds apart: the patients' authentic world versus the patients' inauthentic world

In everyday life we tend to live in our 'inauthentic mode' (Heidegger, 1953/2010). We live our lives the way we do as part of the society we live in. We don't think about our 'condition humaine' too much, we simply 'are' alive. A cancer diagnosis increases mortality salience, can generate death anxiety, and serve as a 'call of conscience' (Ruf des Gewissens) as Heidegger (1953/2010)

calls it. This call of conscience can cause a shift to the 'authentic mode', a mode in which individuals are aware of 'being-towards-death' (Sein zum Tode) and the inescapable existential loneliness. The 'condition humaine' means that lives are finite. The death sentence is signed the moment a person is conceived. It is the only certainty; yet few are fully aware of this. For many people, being diagnosed with cancer results in experiencing their mortality in a tangible way. This concrete awareness of being mortal is at the heart of the 'unshareable experience' they go through while they are in the 'black box' as described by Little (1998). However, this does not mean that this awareness will be at the forefront of their minds for the rest of their lives.

Just as healthy people tend to live in their 'inauthentic mode' so most patients tend to return to this mode, whilst still facing a life-threatening illness, even when they know their cancer cannot be cured. In the interviews it became evident that patients 'drift' in and out of authentic and inauthentic modes. They cannot deny they are dying, and when asked, they will confirm they are. But most of the time they push this knowledge to the back of their mind. They want to live their lives and be seen by others in the same way as they were before their cancer diagnosis, although they know they are not the same anymore. This helps to explain the seemingly paradoxical description that Vargens and Bertero (2007) provide of the lived experience of women with breast cancer: "These women think that they are the same as before, but they know they are not the same anymore. At the same time, they want others to see them as the same they were before, even when they know that it is impossible because they have changed" (Vargens and Bertero, 2007 p. 476). Rasmussen et al (2010) argue that cancer patients not only meet silence in others, but also in themselves, possibly as a coping mechanism. As Vargens and Bertero (2007) point out, hiding the truth about their disease is sometimes done by patients not (just) to protect others but also in order to protect themselves.

Fusing horizons: lifting the veil

In this study the findings suggest that patients have intra-psychic 'worlds apart'. This became apparent when the patients were asked about their awareness of the life-threatening character of their illness. Patients proved to be the ideal people to learn from regarding what it is like to have a life threatening condition, albeit in a surprising way. When exploring the character of their illness, none of the patients stated unequivocally that they saw their condition as life threatening, not even those who were terminally ill. This does not mean they denied their diagnosis, it means that they didn't subjectively **experience** their condition as life threatening, although they knew that (objectively) it was. This perception became gradually clearer, as patients willingly helped the researcher to gaze below the surface of their experiences. Trying to find the answer to the question 'Do you see your condition as life-threatening' was like staring at the bottom of a pond, expecting to find the answer there, only to gradually come to the realisation that the answer was to be found by focusing on the reflecting surface of the water, seeing one's own face. Regarding the experience of the life-threatening character of their condition there was no clear boundary between the terminally ill and the incurably ill. Similarly, there was no clear boundary between those who were incurably ill and those who might be cured. Nor was there a clear boundary between those that might be cured and those who were told they would be cured. From there on, it was only one step further to realise there is no clear demarcation between those cured, and 'healthy' people, as their chances of getting cancer in the future are in many instances the same. Metaphorically, the reflecting surface of the pond was like a mirror showing the final truth. To take the metaphor to its logical conclusion, looking in a mirror is like looking at a dying person. Instead of asking 'them', all we have to do is ask ourselves exactly the same question: 'Do I experience my condition as life threatening?'. Most healthy people would answer this question by saying 'no', and so would most cancer patients, even, or maybe most of all, incurably ill persons. They are ordinary people, just like us, for whom life itself is a life threatening condition, as illustrated in figure 2.

Figure 2: Looking in the mirror to see a dying person



All people share the 'condition humaine': patients, partners, health care professionals and researchers. People in these groups are both the same and different. We all share our powerlessness, fragility and mortality; it is just that some of us are nearer death than others. True as this may be, in their 'everydayness' people are not aware of this. It is the 'healthy ones', who alienate the seriously ill and dying people by putting them in a different category. In 'everydayness', we tend to stare at the bottom of the pond, and not at the reflecting surface, feeling sorry for the struggling creatures crawling around down there at the bottom. This could be seen as an unconscious form of self-deception, because we are in exactly the same predicament. "In the long run we are all dead" (Keynes, 1924 p. 65), and in that sense we are all dying. We could be hit by a bus on our way home or have a massive heart attack and die before the cancer patient does. But we don't like to be reminded of our mortality; we don't like to see people dying; we don't like to be confronted with mutilating surgery or other reminders of our vulnerability.

Interestingly, for most of the time, patients feel just the same. They spend much of the time in their inauthentic mode, sometimes knowingly and willingly, because like us, they want their quality of life and therefore push the thought of death away. Dying patients feel "I am still me" (Kagawa-Singer, 1993) and never really get over the astonishment of the diagnosis of their illness. They are just like us; they want to belong to the living, but the tragic thing is that we push them away, because we feel they are different as they are dying, and that scares us. As Van den Berg (1987) points out, visitors accept the patient's

illness as a *fait accompli* and remove him from the world of their daily existence, with everywhere in the outside world his or her place taken by others. Negative stereotypes associated with diseases such as cancer and physical disability set patients apart from others, adding to a sense of loneliness, and resulting in being treated differently by others once they know the diagnosis, even when there are no visible signs of the disease (Vargens and Bertero, 2007, Toombs, 2008, Rasmussen et al., 2010). The tragedy here is that, as an individual, one cannot force others to perceive you as the same person, because being-in-the-world is always 'being-with'. If others see and treat you as different you **are** different. If a teacher, at the age of 50, feels he is still the same person as he was at the age of 25, his students will show him he is not. They see and respond to him in a different way now and therefore he **is** different. Being is not an isolated intra-psychic state; being is being-in-the world and being-with. That is where and how each individual is 'defined' and shaped. It is not possible to escape interactions with others or the way these interactions influence and shape one's sense of 'being'. To be is to interpret, to give meaning; something that happens all the time. So even where there is no (external) perceivable change in the patient as a result of the cancer diagnosis and treatment, others who know about it will perceive and treat this person differently, which in turn will change him/her. This Rosenthal effect is well accepted and it is recognised that changed perceptions will change interactions between and opportunities for individuals, which in turn impact on the person (Rosenthal and Jacobson, 1968).

This study raises the question of how death and dying have become something that we set apart from our daily lives. In past times, death was part of 'normal' life, with everyone witnessing the journey from birth to death, throughout his or her own life span. This included epidemics, sickness, war with all its atrocities, deformities and suffering (Little et al., 1998). However, being more familiar with death does not mean that people did not experience death anxiety. From the earliest days, philosophers have written about the omnipresent fear of death, and how to handle this best. Epicurus (who lived around 2300 years ago) constructed perhaps the first recorded series of arguments on how to relieve death anxiety, stating that "Where I am, death is not; where death is, I am not"

(Yalom, 2008 p. 81). In those earlier times, people had different means of dealing with death anxiety: grounding their lives in tradition; keeping very close bonds with family; adopting a religious worldview that would give them a blueprint of how to live a meaningful life and the promise of transcending death in the afterlife (Giddens, 1990).

In modern society, life has been sanitized, with death removed from everyday life. Illness has now become an aberration of normal life, to be dealt with by the omnipotent health care system, out of sight of the average citizen. It has been possible to push death out of 'normal' society¹¹, because medicine can do so much more, and as a result people are less familiar with it. This makes the shock even bigger when they are confronted with dying and death and have to accede to the powerlessness of modern medicine to 'fix' mortality. However, pushing death out of sight does not take death anxiety away, it may just result in different strategies for handling it, as the Terror Management Theory demonstrates (Greenberg et al., 2004, Pyszczynski et al., 2010).

Health care professionals working in cancer and palliative care have a different viewpoint than that of the average person. Just as their terminal patients are bombarded with potential 'calls of conscience' day in day out, so are they (although in a different way). All day, every day they are confronted with deterioration, imperfection, decay, mortality and their inability to restore health, whereas society expects them to 'fix' all problems and is willing to spend enormous amounts of money enabling them to do so. The question remains as to what health professionals do with these calls of conscience, these reminders of their own ephemeral being, and their powerlessness to take death away from their patients or themselves. Evidence suggests that they flee into their inauthentic mode, just as the patients do (Horder and Street, 2007d). There appears to be a parallel process such that, when there is a threat of death, individuals resort to their inauthentic state to survive, to live and experience quality of life in and outside their work.

¹¹ Although we are confronted with many images of death (in films, novels, expositions) these are examples of socialised, sanitized, dehumanized death that not necessarily make us dwell on the reality of our own death (Little et al., 1998, Desmond, 2008).

The regrettable outcome of this is that, in their inauthentic mode, professionals are not able to recognize patients as fellow passengers who are 'in the same boat' or on the same journey as they are themselves. They create a 'world apart', where they, the professionals, are 'us' and the patients are 'them', thus unconsciously alienating patients. Perhaps the clearest example of this is the research of Kuhl (2002), a physician himself. He used in-depth conversations with dying patients which revealed how a doctor, unintentionally, can add to patients' suffering. The detailed reflection on the findings from his study poignantly express the multi-faceted dilemmas and concerns experienced by professionals:

In my experience, iatrogenic suffering occurs when patients bear the burden of a doctor's own unresolved psychological and emotional issues about death, suffering, pain and relationship. Whatever the personal issues may be for the doctor, if not addressed or unresolved these will likely affect the patient. My tone and manner might convey disregard for their very humanity – for their grief, fear and anxiety. I might be keeping a physical and emotional distance because I resist the grief, fear and anxiety of my own feelings. I'm afraid that if I get too close, then I might have to experience aspects of *his* life that are very sad, unjust, complicated and unfixable. I'll be helpless in the face of tragedy, far too aware of the limitations of the science of medicine and my personal inability to cure, fix or repair his suffering and death. I'll feel like a failure. (Kuhl, 2002 p. 55-56)

Not all professionals in this study were able to analyse their behaviour so fully, but the unrehearsed dilemmas can make it difficult for them to cope with a patient who does not conform to their expectations. Kendrick (2008) gives the example of a woman not wearing a breast prosthesis being sent out of the waiting room because "it would be too painful for other patients to see" (Kendrick, 2008). While in this study such extreme examples were not given, nevertheless there were examples of professionals trying to over-rule decisions or, as with Edith (C7pat) and Emma (C3pat), ignore what they saw as irrelevant, illustrating Kuhl's (2002) findings.

Lifting another veil: sexuality and intimacy

Searching for a theoretical context for the findings from the study, it became apparent that much of the data from this study could be explained within Terror Management Theory (TMT)¹². This makes it possible to illuminate the existence of a more general culture (Rasmussen et al., 2010) of 'worlds apart' isolating cancer patients from their health care professionals, their partners and in some way themselves. TMT emphasises man's attempts at hiding and disguising the creatureliness of the human body. Health care professionals, like everybody else, share the cultural taboos on death and sexuality. In their work, they are repeatedly confronted with the reality of death (which as previously stated results in fleeing in an inauthentic state), but at the same time they are facing a second cultural taboo: sexuality. Thus, for this group of patients they have to overcome one taboo (death and dying) and then introduce a discussion of the second one (sexuality). On top of that, health care professionals might have their own personal sexual issues or problems, resulting in an even stronger taboo. They may not feel at ease with sexuality in their personal lives, they may have no or very limited sexual experience, they may very well have negative experiences with sexuality, as this regrettably is a very wide spread problem from which health care professionals are not excluded. Existential experimental psychologists have for many years found evidence for the supposition that people are ambivalent about sex, because it reminds us of our creatureliness, which in turn reminds us of our mortality (Goldenberg et al., 1999). In the light of all of this, is it any wonder that professionals without additional education and training find it difficult to raise such a contentious issue. As Rothenberg and Dupras (2010) state "for many individuals, death is a difficult topic to address. The challenge is intensified when addressing sexuality as well" (Rothenberg and Dupras, 2010 p. 151).

¹² Other theoretical frameworks could be used to interpret the findings, but the best way to encapsulate the study findings was to look at TMT, as TMT links death and sexuality on an existential level. Therefore, in view of the scope of the study, the best analogy was to be found in TMT. Earlier on in the discussion, Heidegger's ideas regarding (in)authenticity were revisited, as these provide a complementing way of interpreting the dynamics at the intra-psychic level of the patient.

When considering the TMT experimental approach in relation to the current study, it could be argued that being diagnosed with cancer is a strong, real life way of increasing mortality salience. The illusion of being an immortal entity is rudely interrupted; suddenly the awareness of being a mortal creature 'hits home'. Deducing from TMT, it would seem that this does not combine well with the awareness of being a sexual creature (as this puts more 'creatureliness' on the scale, raising death anxiety to even higher levels). Therefore, dying and death should be dignified; after all, these things are bad enough as they are. Nasty smells should be avoided before and after dying, bodies should be groomed, make up used to camouflage post mortem lividity, the mouth must be closed and we break fingers to create a peaceful and transcending image of folded hands. Even (or maybe most of all) the dead body has to be decreaturealized.

However, there is a paradox here, as for the professionals this split between a life threatening illness and sexuality remains the case, but for those living the journey, adaptation to their changed situation (with its drifting in and out of authentic mode) means that their previous sexual identity begins to creep out again. For men (but not for women), exposure to low survivability cues might even result in increased sexual preparedness (Gillath et al., 2011). The current study illustrates returning sexuality and the need for physical intimacy, with, for most couples, the problem being an inability to engage in sexual activities rather than rejection of it. So, there is a problem: for the professionals in the context of dying, sexuality does not seem to be an 'appropriate' theme; why would couples want to focus on this rather than the (in their eyes) much more important topic of treatment and survival. For some, just the thought of raising the subject would be disrespectful to the dying person. This caring but unfortunately restricted approach leaves the patient and their partner in limbo, often not knowing how or whom to ask for advice without seeming 'beyond the pale'.

The explanation of the underlying conflicting perspectives between professionals and patients could very well be that for the professional to face the fact that this dying person is still a sexual creature is too much to take in. If dying is accompanied by such a physical attribute (as sex), it is difficult to follow what are seen as the dignified practices and procedures that objectify death.

The person remains a living, breathing, sexual individual with wants and needs that once recognised cannot be neatly parcelled, or ignored. The fear is that to address these needs, the professional would have to cross what they unconsciously perceive to be a threshold designed to protect the patient/professional relationship. Yet ironically by not acknowledging these needs the very relationship they are trying to protect is damaged. In this study the participants made it plain that on the whole they believed they were not seen as sexual beings, they were just patients or partners who only had treatment needs.

In addition, it has to be recognised that, in order to cope, professionals can use strategies that include distancing themselves, or objectifying the patient rather than the disease (Toombs, 1992, Kuhl, 1999). They do not want to accept that something seen as a vital part of 'normal' life is present in the dying, as they might then have to see elements of themselves reflected in the patient. Thus even the professionals reflexive enough to acknowledge that they themselves are sexual creatures (despite the cultural taboo on sexuality), may then find themselves making neat categories that patients can be fitted into. Either the individual is dying and therefore cannot be a sexual creature, or they are a sexual creature but are not dying. To cope (and keep death anxiety manageable), seriously ill patients are put in the first category and professionals in the second. Case solved.

TMT offers a way to explain some of the underlying reasons why health care professionals are unable to discuss sexuality with their patients which can result in patients and partners not feeling acknowledged as a person by these professionals. Person to person contact requires recognizing the other person as a human being. It is made on an existential level where the sameness of the other person is recognized and acknowledged. Making person-to-person contact with a vibrant, witty, successful and attractive person is very rewarding, because the 'sameness' in this case is one happily acknowledged and identified with. In this case we don't mind belonging to the same species. Making person-to-person contact with a dying person is more challenging because the sameness in this case is much more confronting, exposing a side of human life

that is not willingly embraced. As a result identifying with them is avoided, as is acknowledging the 'sameness' in this case, because we (professionals and everyone else) don't want to experience that we are mortal and dying creatures as well. It is easier not to have these emotions so they are sanitized out. Consequently, person-to-person contact between professionals and patients/partners is limited, and the dying person and his or her partner sense this. They know when health care professionals are avoiding the issues they really want to raise, as Mia and Ryan (C2) and James (Par6) made plain. Discussing the patient's sexuality could interfere with professionals' defence mechanism, forcing them to realise that this person **is** (at least in that respect) 'alive' just like them, somewhere that they don't want to go. If they do manage to cross their own barriers and raise the subject, they tend to do this in mechanistic way, focusing on 'physical' activity rather than the underlying emotions and intimacy issues, so distancing themselves from the lived experience.

This can be compared to groups not wanting to share their status symbols with those they see as outside the group (Greenberg et al., 2004). Status symbols by no means have to represent a material value; it could be the way you wear your trousers way below your waist, and not wanting your middle-aged dad to do the same. People don't want out-group people to erode their in-group boundaries by interfering with their symbols. Research showed that unattractive people using sophisticated gadgets (for example the latest iPod) resulted in making them even more unattractive, especially in the eyes of the 'in-group' of materialists who highly value such gadgets (Das et al., 2010). The 'in-group' wants outsiders to stay out, and identification and acceptance of outsiders is avoided. Realistically, if professionals identify too closely with patients and their partners, this would trigger issues they would rather not face, and consequently they would find it difficult to face day in and day out the experiences of death and dying. A way has to be found to enable professionals to cross these barriers whilst maintaining their professional roles.

TMT and sexuality for patients and partners

TMT can also (partly) explain why patients themselves might not raise sexuality in the first period after their cancer diagnosis. The existential emotions that arise “because the transparencies of bodily function, of mortality and of the strategies around which we have constructed our lives are suddenly made visible” (Little et al., 1998 p. 1491) need to be accepted before the individual can move on. Like for other people, this most feared manifestation of creatureliness, mortality, leaves no space for other reminders of creatureliness like sexuality. Their capacity for handling ‘creatureliness awareness’ is already overloaded by the ‘death sentence’ experience (which is how most people perceive a cancer diagnosis). Trying to return to a normal life (including its mode of inauthentic everydayness) was described as a ‘turning the switch’ experience (C3pat, C6pat, Pat7), no longer letting fear of death and the focus on survival dominate every aspect of life, even whilst accepting life will never be exactly the same again. Little et al. (1998) have described that, after a diagnosis of cancer, people’s state of mind is often one of liminality, a process involving a permanent identity change to being a cancer patient, regardless of how long ago the diagnosis was made or how successful the treatment was. But even this liminal state moved from acute liminality, where the patient experiences an existential threat, to sustained liminality. So one way or the other, after a variable time, death anxiety is no longer centre stage, making room for the resurgence of a sexual life. With the existential threat no longer in the foreground, other aspects of ‘creatureliness’, like sexuality, can be admitted again.

However, partners don’t experience the existential threat the way patients do. As argued before, there is a fundamental difference between being the one diagnosed with cancer and being the partner. For most partners, at this stage, sexual awareness and desire are not banished altogether. Partners would like to have sexual contact with their loved one, and they patiently wait for the patient to ‘be ready’ for sexual contact again, as Ryan (C2par), Richard (C3par) and Dennis (C5par) made clear. Sexuality remains on their mind and for some masturbation is a way to relieve sexual tension.

Things change yet again when cancer turns out to be incurable and patients know they will die. Those who are told that they are terminally ill are in ‘the eye

of the storm' and as Tristan (Pat8) pointed out he coped by deliberately avoiding the thought of death. In the title of his book Yalom (2008) used the metaphor of 'staring at the sun' (from Francois de La Rochefoucauld: "Le soleil ni la mort ne se peuvent regarder en face" [One cannot stare straight into the face of the sun, or death]). Unconsciously people know it is impossible to stare straight into the face of death, so don't, especially not when dying has become a tangible reality. Dying patients oscillate (Weijmar Schultz and Van de Wiel, 1991) between awareness of their impending death on a rational level and (most of the time) an inauthentic way of being regarding their awareness of dying. They are in state of slumbering awareness (The, 1999). They know and they don't know. Using yet another metaphor they know that their house has a basement but they only go there if they really have to and they'd rather not go there at all. This 'not knowing' enables still feeling and wanting to be seen as a sexual being, although cancer, cancer treatment and the enfeeblement that arises as part of the terminal illness makes sexual activity at some point impossible for most patients.

At this stage of terminal illness, the partner now has to face the fact that their loved one is dying. For him or her, this can influence the sexual attractiveness of the partner, and the desire for physical relationships may diminish. The partner is only human, and the combination of impending death and sexuality can generate more awareness of creatureliness than would be still appealing. Bruno (Par2) explained how the 'act' of sexuality had changed (and therefore for him it had become impossible to 'perform') because the other 'player' had physically changed as a result of the dying process.

One of the advantages of using TMT is that it gives an explanation as to why nonsexual physical intimacy is such a highly valued form of physical contact when people are confronted with life threatening or even terminal illness. Unlike sexuality, affectionate touching can and often does remain a source of consolation until the very end of life. TMT illuminates how affectionate touching, unlike sexual contact, is not associated with creatureliness. It is not seen as animal like behaviour, but as a transcended, human form of showing love and affection (Goldenberg et al., 1999). It is the romantic counterpart of copulating,

and therefore acceptable even in the face of death. This can leave the partner with a lasting impression of closeness, something that can help with the grieving process.

5. CONTINUING THE DIALOGUE: IMPLICATIONS FOR PRACTICE

The starting point of thinking and writing about implications for practice was to reflect on the theoretical aspects directly related to the core theme and the existential and phenomenological literature underpinning the current study. This further interpretation of the study findings is presented below in 'bridging the gap on all levels of 'worlds apart''. However, the aim was not just to have a theoretical dialogue with theoretical implications, as for many students and professionals the real problem is moving from theory into practice. Therefore, a linking pin to more practical implications for health care practice and education was essential. The true essence of hermeneutics is to generate study findings that are useful for practice and, based on that, create a dialogue that stimulates to action (Guba and Lincoln, 1989, Witt and Ploeg, 2006).

Using the study findings (including the expert opinions from the participating professionals) in combination with the literature, practical support for health care practice and education had to be devised. Immersion in the findings lead to a gradual emergence of tools and models that could be of help to busy professionals. As the models began to crystallize, they were presented and discussed at national and international conferences, both formally and informally (see appendix 5 for a list of relevant conferences and workshops), while the educational tools were piloted with students and tested with health care professionals working in cancer and palliative care. These practical outcomes are a crucial element of the study and are therefore discussed in some detail (in 'bridging the theory – practice gap').

Bridging the gap on all levels of 'worlds apart'

It should be clear from the start that 'the gaps' between the worlds apart cannot and should not be taken away. The experience of a patient is different from the experience of a health care professional or a partner, and as no experience can be fully shared (Toombs, 1992) the gap will always be there. In a way this is positive, as professionals and partners have different roles to fulfil, and complete merging with the experience of the patient may hinder them in fulfilling

their own roles, including supporting the ill person. Similarly, the gap ‘within’ the seriously ill person serves a useful purpose, as it enables the patient to be aware of (potentially) impending death without the need to stare death in the face all the time.

However, it is desirable to make sure there are bridges connecting the ‘worlds apart’ in order to strive for healing, mutual consolation and wholeness. In each of the next three sections the relevance of this for the experience of, and communication about, sexuality and intimacy is highlighted, with an overview presented in table 8.

Table 8: Overview of gaps, aims of bridging the gaps and relevance for sexuality and intimacy on the three levels of ‘worlds apart’

Level of ‘worlds apart’	Gap	Aim of bridging the gap	Relevance for sexuality and intimacy
Patients and partners communicating with health care professionals	Lived experience vs. scientific attitude	Healing	The context of a person oriented approach is needed to discuss sexuality and intimacy, the focus should not be just on sexual functioning but also on the meaning of the sexual relationship and sexual identity, to contribute to achieving mutual consolation and wholeness respectively
Patients and partners interacting	Unshareability of experience with others	Mutual consolation	Sexuality and intimacy can provide consolation for both partners beyond words, can embody a meaningful exchange which includes a meaningful contribution of the patient; this can soften the experience of existential loneliness and make it more bearable
Intra-psychic level of the patient	Inauthentic vs authentic intrapsychic state	Wholeness	Sexuality and intimacy can contribute to a feeling of wholeness, because they are aimed at the person (who still <u>is</u> a sexual being, still <u>is</u> a man or a woman, still <u>is</u> a partner, worth loving and touching)

Level of patients and partners communicating with health care professionals: healing

As has been illuminated by Cassel (1982) in his classic paper, suffering is experienced by whole persons, not just by their bodies. Suffering originates from threats to the intactness of a person as a psychological and social entity. Participants in this study illuminated how a life threatening illness affects every

aspect of their existence and threatens their sense of personal wholeness (Toombs, 2008) through the loss of many things that were taken for granted until the point of diagnosis and that now have become uncertain, e.g. the transparency of their functioning bodies becoming 'opaque' (Little et al., 1998). The threatening character of the potentially fatal illness disappears when either the threat is gone or when a sense of integrity and wholeness is restored in another way (Cassel, 1982). The restoration of a sense of integrity and well-being is related to the concept of healing (Mount et al., 2007, Toombs, 2008), which involves whole-person care. It is important to realise that 'healing' is not the same as curing disease, as someone can be cured and not healed. For example Rose (C4pat) was 'cured' but her sense of wholeness has not been fully restored; she perceives her body as 'half man half woman' even 20 years after her mastectomy. Conversely, someone can be healed and not cured, as is the case with terminally ill patients preserving a sense of wholeness and living well in the face of terminal cancer (Kagawa-Singer, 1993, Toombs, 2008), as for example Tristan (Pat8) in this study demonstrated.

The thinking in terms of linear models interferes with a truly person-oriented approach. As the vignettes so eloquently demonstrate, patients trajectories are not linear, as their well being is not determined solely or even mainly by their level of physical functioning (Kagawa-Singer, 1993, Toombs, 2008). Some of the participants in this study needed support most when their (successful) treatment phase was over. From the perspective of how patients experience their 'real life' as human beings, it is mainly their psychological status that will determine their need for person-oriented support. Their psychological status requires support from the point of diagnosis through readjustment to a life as a cancer survivor or to a life as a cancer patient dying from cancer. Suppression of physical symptoms at a later stage of their illness is of paramount importance and a prerequisite for psychosocial support, but not the key aspect determining how much palliative care is needed.

In order to arrive at a person oriented approach, health care professionals should, just like members of society in general, be brave enough to realise that what happens to patients today **will** happen to them tomorrow. Based on statistics, there is no risk whatsoever in identifying with patients: their fate will be ours. We all will die. This does not mean that professionals should be

'towards death' all the time; there is no need to jump into the pit to join the dying patient. However, they should leave the door to their authentic mode ajar, instead of shutting it completely. Just a hint of authenticity (in the sense of 'being towards death') would be enough for them to recognize patients as fellow human beings, travelling the same route as we all are. This would evoke enough proximity, without losing themselves, to reach out in a human-to-human way, instead of undeservedly stigmatizing and emotionally shutting out cancer patients as reminders of their finitude, merely tolerating them instead of accepting them. It would help them to focus on supporting suffering people, instead of solely focusing on taking the suffering away from them.

With this realisation at the back of their minds, professionals should, as long as they are the lucky ones still healthy and working, be able to support the ones who are nearing the end, and be grateful that they can mean something to them. As a reward, their work and lives should be more fulfilling and rewarding. There is no such thing as one-way authentic contact. By definition, authentic contact involves more than one person. Human to human contact gives meaning to us and to our lives, because it bridges the gap of existential loneliness that is inherent to the 'condition humaine'. In bridging this gap, however briefly, consolation is to be found for both parties. Beyond providing this consolation, we can only humbly hope that, when our own time has come to die, somebody will be there to do the same for us.

Health care professionals need to focus on improving quality of life by adopting a 'healing' approach that can help patients move from an experience of suffering and anguish to an experience of wholeness, integrity and well-being, even in the face of life threatening or fatal illness (Kuhl, 1999, Mount et al., 2007). In order to do this, they should not focus exclusively on the illness, but on the whole of the patient. To quote Hunter Adams as personified in the movie 'Patch Adams': "You treat a disease, you win or lose. You treat a person, and you always win." Gadamer (1996) pointed out that in all medical treatment the patient needs to receive assistance and guidance in the process of adaptation and re-entry into the cycle of human life, and that this should transpire in the shared dialogue between physician and patient. A recent review by Hillen et al. (2011) showed that one of the factors enhancing patients' trust in their physician

is the display of patient-centred behaviour, and that the effects of a trusting relationship between patient and physician are not to be underestimated, as it leads to better treatment compliance, decreased patient fear and facilitated communication and decision making. Brown et al. (2011) showed that in building trust, nonverbal communication is the decisive factor, so the 'shared dialogue' encompasses not just words, but also, and even more importantly, the nonverbal self-presentation of the professional.

In order to build trust, the professional is required to make contact with the patient on a person-to-person basis. For every patient there are personal meanings associated with their illness, as for example for Grace (Pat4) who thought of her breasts as the only part of her body she was really pleased with and then had a mastectomy, or for Helen (Pat6) who so much wanted another child and then had a hysterectomy as a result of her cancer. In order to 'guide and assist' a patient a professional will have to explore what the illness means. He or she will have to do this with a 'human face' and not hide behind the façade of the medical profession, as this does not invite individuals to disclose aspects of their personal lives. This does not mean that health care professionals need to disclose personal information to their patients, but approaching their patients in a compassionate way, as fellow human beings, travelling in the 'same boat' (albeit in a different 'role' for the time being), they recognize that "the existential nature of human reality makes brothers and sisters of us all" (Yalom, 1980 p. 148). Participants in this study highly valued encounters with professionals who were offering a 'healing' approach, and described the soothing effect of an empathic professional attitude in times of great vulnerability. As Kuhl (2002) argued, this means that health care professionals must deal with their own emotions:

But if I want to be a compassionate physician and not cause harm, then I must address my feelings. Any emotion that I have not recognized or expressed is likely to be projected onto my patient, potentially adding to his suffering. The patient will experience my avoidance, fear, guilt, sense of failure, and other denied emotions as a deliberate failure to engage them as a human being, a deliberate decision to disregard the meaning and importance of their life. They will feel that I abandoned them at the very moment they needed me most. (Kuhl, 2002 p. 56)

It is of paramount importance to adopt a 'healing' person-to-person approach when it comes to discussing sexuality and intimacy. Participants in this study were unanimous about the necessity of the health care professional connecting with them 'as a person' in order to discuss intimate issues. Sexuality and intimacy for many people are the most personal aspects of their life, so discussing and receiving guidance concerning these issues requires a 'healing' approach more than ever. According to Toombs (2004), a shift in focus from bodily to personal well being, including exploring the ways a serious illness interferes with daily life, including intimate domains, creates the possibility to engage in close and rewarding relationships with patients. This does not require professionals to disclose their own sexlives, but to show they are human, just as their clients are.

Level of patient and partner interacting: mutual consolation

The experience of existential loneliness and the unshareability of the cancer journey does not exclude the possibility of an intense, supporting, loving and consoling relationship with a partner. And although even the most devoted partner cannot take death away from the patient, the support and consolation from sharing the loneliness with a partner can make all the difference.

Professionals need to be aware of the different journeys patients and their partners are on, and how they can show understanding for the experience of both parties. This may mean that patients and partners are seen separately at those points in time when it is difficult for them to speak freely with the partner present. But most of all, the aim should be to create a dialogue between partners to make them aware of and understand as much as possible the experience of the other person.

The breast care nurse (Prof13) made it a rule for the partner to see the wound of the woman after her mastectomy before discharging her from hospital, to avoid them playing 'hide-and-seek' back home. Though it can be argued that it may be a bit strict to make this a general rule, the idea behind this is clear: make sure that partners are in touch instead of drifting further and further apart on their diverging roads. Often partners try and protect one another by not speaking freely, but this can result in a 'play in the dark' (Rolland, 1994) as described by Joan (C6pat) and Walter (C6par), with Joan concluding that this

resulted in a state of 'false protection' that only made their situation worse. Some of the health care professionals who participated in this study explained that they deliberately bring up the topic of intimacy and sexuality with both partners present in order to catalyse discussion of the topic between partners back home. It can be very helpful to point out that most couples experience changes in the domains of sexuality and intimacy along the cancer trajectory, and that it might be helpful to discuss these changes. This may lower the threshold for discussing of any intimate issues that could arise, with or without the professional present.

It is worth the effort to keep communication between partners open, so they can discuss intimate issues, and hopefully find (new) ways to experience physical intimacy and, if desired, sexuality. For the couples in this study who did find ways to 'stay in touch' despite cancer and cancer treatment this was an enormous source of consolation. Affectionate touching for many couples gave a sense of deep connectedness, cushioning the fear and pain and making the journey less of a lonely one. There was a major difference between the experience of Bruno (Par2) not knowing how to respond to his first wife's need to be seen as a sexual being and the massage that made him stay physically close to his second wife when she was dying from cancer. For both the ill and the healthy partner the difference is significant, and for surviving partners the difference is perceptible when mourning the death of their beloved ones. Memories of affectionate touching were often deeply engraved in their memory.

Intra-psychic level of the patients: wholeness

Kagawa-Singer's (1993) seminal study showed that 'feeling healthy' cannot be equated to 'absence of physical illness'. None of the 50 cancer patients that participated in her study described themselves as sick. A surprising number (33) of cancer patients considered themselves very healthy, and this included 12 patients who died during the period in which the study was carried out. The 17 remaining patients described themselves as fairly healthy. As long as these people were able to fulfil their social roles they saw themselves as healthy, albeit with cancer. Even when patients come to a stage where they cannot 'do' a lot of activities anymore, they can still 'be' the person they are and have meaningful exchanges with other people (Toombs, 2008). An important step

towards 'wholeness' is to acknowledge that personal worth is as much about 'being' as it is about 'doing'. Cancer patients want others to acknowledge that the fact that they can no longer do everything they used to do does not mean that they stopped **being** the parent, lover, social person and professional they used to be (Vargens and Bertero, 2007). Affectionate touching can be a way of demonstrating that the ill person still **is** the beloved partner, and withdrawing affectionate touching can be experienced as no longer **being** lovable, resulting in a feeling of shattered 'wholeness' in the patient, as Toombs' (2008) example from a hospice patient illustrates:

"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." Although his wife was probably unaware of her behaviour, she was slowly but steadily withdrawing from her husband. When others withdraw in the face of illness, the sick person experiences a social death prior to physical death. (Toombs, 2008 p. 6)

Partners should realise that caregiving is a two-way process; it is not just 'giving' care, it is a way of communicating that offers the possibility of maintaining or developing deep relationships, with input coming from the patient's side as well. This will contribute to the patient's experience of 'health' and 'wholeness'.

Professionals can help patients to strive for wholeness and self-integrity, recognizing that this does not mean that patients have to 'accept' their fate and be constantly aware that their days are numbered. On the contrary, the experience of wholeness and well being seems to come from being able to fulfil social roles (Kagawa-Singer, 1993) and a sense of healing connectedness (Mount et al., 2007). The paralyzing effect of 'staring death in the face' would only interfere with this. As in Kagawa-Singer's study (1993), none of the participants in this current study denied their diagnosis, as indicated previously, but the awareness of the diagnosis did alternate with suppression strategies. Tristan (Pat 8) pointed out that, as long as they are '*here*', these patients want to live, not just exist. They don't want to focus exclusively on dying. As Tristan (Pat8) went on to say: '*I don't want to hide the fact that I am dying, but I prefer to talk and think about other things*'.

Of course it is important not to act as if everything is still the same, closing down possibilities to discuss impending death and the practical issues that come with terminal illness (Haraldsdottir, 2011), but there is no need to relentlessly pursue the topic of the patient's mortality if he or she does not feel like talking about it. According to Mount et al. (2007), dying people experiencing the highest quality of life were characterized by their success in accepting their present reality and letting go of the need for control, which included stopping worrying about the past and the future. This created the space to focus on the present and on what was still possible in the given circumstances, an attitude succinctly captured in "so that is the way my cookie crumbled, now what am I going to do with it" (Mount et al., 2007 p. 385). It's a way of spending energy on options that are still open, instead of wasting it on things that cannot be changed. This attitude can be contrasted with full-blown denial or passive 'giving up' and is aimed at finding meaning. In the study by Mount et al. (2007) a sense of meaninglessness was common to participants with a life-threatening illness experiencing low quality of life.

Kuhl (2002) stresses the importance of speaking the truth, of life-review and self-realization when death is approaching, and of organizing meetings with everyone involved to create a good pathway to death (Kuhl and Wilensky, 1999). Although this may suit some people, this should not be held up as the ideal for all. People die the way they have lived, and they will use coping mechanisms and problem solving strategies they have used all their lives, and trying to change these in the last phase of patient's lives is both difficult and distressing. Having said that, professionals should try to do everything they can to achieve well being and wholeness for their patients, treating them as individuals that matter, and whose opinions and preferences are important. They need to try and lift the life of the ill person above the disease (Grypdonck, 2007). They can show patients how to live in the present moment using mindfulness strategies or music or other interests they may have. More specifically when it comes to physical intimacy and sexuality, professionals should offer emotional support and practical guidance, accepting that every person is a sexual being (including their patients). They should listen to the fears and pains of people trying to get to grips with their altered body image and sexual relationships. They should offer emotional and practical

support. They should help people to find a new 'wholeness', whether this is through helping them find a prosthesis that suits them, sexy lingerie that will make them feel attractive, a scarf to hide their stoma, considering reconstructive surgery, or by helping them to find the courage to face the world without hiding the traces their cancer treatment has left. There is no one recipe that will fit all. Judith (Pat1), who was dying of breast cancer, spent her sparse amount of energy on putting on her make-up, her wig and nice clothes and jewellery, as that made her feel 'whole'. Edith (C7pat) found strength in leaving her house without a wig, exposing her bald head and showing the world 'this is me'. One way or the other, professionals have to try and help people to feel lovable again. This can also include tactfully encouraging partners or other relatives to touch patients by holding their hands, and if they checked whether the patient would appreciate this, making sure they are not disturbed. In those circumstances patients may then feel able to extend physical intimacy by lying on the bed with their loved ones. Alternatively, professionals could encourage partners to massage the patient, as massage can promote a sense of closeness and support between patients and their significant other (Forchuk et al., 2004). This could also include professionals themselves touching patients in a way that makes them literally feel that they matter. Even when touching is 'functional' as in bathing or escorting someone to radiotherapy, it makes all the difference whether someone feels touched like an 'object' or a 'subject'. Several of the participants in this study described the dehumanizing and 'fragmenting' effect of being touched as if they were an object, up to the point of dissociating, as happened to Alice (Pat7) when she had her internal examination. This fits with a recent study by Brown (2011), which revealed that a gynaecologist's non-verbal self-presentation (including touching, for example when performing an examination) is the decisive factor in determining the amount of trust of the patient. Research has demonstrated that professionals touching patients in a 'comforting way' (for example by offering hand and or foot massages) often results in relaxation, a sense of well being, improved sleep and less pain (Grealish et al., 2000, Smith et al., 2002, Listing et al., 2009). Although it should be noted that a systematic review by Wilkinson et al. (2008) showed that a lack of rigorous research evidence precludes drawing final conclusions regarding these effects, in the same year Kutner et al. (2008) published a rigorous study

using a randomized trial design, including patients with advanced cancer, and found that massage can have immediately beneficial effects on mood and pain. Interestingly, they also observed improvements in patients who were in the control group that only received 'simple touch sessions'; therefore they recommend also considering the potential benefits of attention and simple touch. This recommendation fits seamlessly in the plea for a person-oriented approach arising from the findings of this study.

Bridging the theory – practice gap: implications for health care practice and education

The next step in the cycle was that insights from the current study were interpreted further and translated into practical implications and recommendations for health care practice, education and training. Munhall (2007 p. 169) argued that "the addition of critique would certainly have the benefit of increasing the significance of phenomenological work and, in a pragmatic way, provide direction to practice or to theory". By deducing implications from the findings of the current study, the aim was to make a contribution to providing guidance for cancer and palliative care practice, fully realising that findings from this study are not generalizable in a statistical way. The point is that, every time they engage in patient contact, professionals working in cancer and palliative care meet unique individuals with a unique history and context. For professionals, statistically generalizable information is relevant when it comes to deciding what in a given situation might be the best evidence based treatment option or intervention. When it comes to supplying personalised support, as is or should be the case when dealing with sexuality and intimacy, different rules apply. Statistical probability and average scores might not be relevant to the individual involved, nor are they very helpful to professionals trying to support unique individuals in a unique situation. For these professionals, it would be more helpful to have knowledge of the issues, themes and contexts that **might** play a role for a particular individual or couple. Thus knowledge, coming from phenomenological studies, can be helpful in

sensitizing professionals to the issues at stake, helping them to empathise with a specific person or couple.

No protocol can ever prescribe exactly how to do this with a particular client in a given situation. There will always be a unique expression of more general themes and issues. This will always require a certain amount of professional and personal expertise. Therefore, professionals might benefit from models for care that do justice to the variation between clients while at the same time providing some guidelines. It is this type of model, based on clients' preferences as explored in the current study, which was developed as a possible way forward for professionals.

Competence description and contextual prerequisites

Clients participating in this study offered invaluable insights into their preferences regarding discussing intimacy and sexuality with health care professionals. Expert health care professionals working in cancer and palliative care interviewed added to these insights by sharing their experiences. Findings from the extant literature supported the validity and further supplemented these insights, resulting in a comprehensive view of attitude, knowledge and skills required to deal with the issues of sexuality and intimacy in cancer and palliative care. These are summarized in box 3.

Box 3: Competence: Addressing sexuality and intimacy in cancer and palliative care

Attitude:

- At ease with discussing sexuality and intimacy
- Non-judgemental (be aware of personal values)
- Person-oriented approach

Knowledge:

- Regarding impact on sexual function
- Regarding impact on sexual identity
- Regarding impact on sexual relationship

Skills:

- Build rapport
- Active listening (the client = the expert)
- Focus on patient, partner and the relationship
- Offer emotional support instead of (just) solutions
- Find additional information when needed or refer
- Make use of affective touching

Professionals need a conducive environment in order to develop and demonstrate their competence. Management needs to support the placing of sexuality and intimacy explicitly on the agenda, and different roles for different team members should be clear. Team members need to value one another's complementing qualities, as is discussed later in the section on stepped skills. Key aspects of competence regarding sexuality and intimacy in cancer and palliative care are discussed in the following sections and have been supplemented with practical tools and models.

Sexual identity, sexual relationship and sexual functioning

It was not the aim of the current study to establish causal relationships. The findings from this study are, however, in line with findings from other studies in which it was demonstrated that "after a diagnosis of cancer, there is great diversity in potential (physical and psychological) hindrances regarding sexual functioning. Consequently, there is no uniform, causal model to explain for a certain patient having certain problems regarding sexual functioning" (Pool et al., 2008 p. 327). However, based on the findings of this study and supported by the literature as presented in the literature review, it seems that for a successful restart of a sexual life at least the next three aspects and prerequisites are relevant:

1. Sexual identity

Prerequisite: a restored sense of sexual identity (with appropriation of the changed body image as an important component)

2. Sexual relationship

Prerequisite: rapport with the partner (feeling understood and accepted by the partner)

3. Sexual functioning

Prerequisite: an absence of major physical hindrances regarding sexual functioning and of fear for physical damage as a result of sexual activity

The current study shows that, important as it may be to pay attention to physical problems related to sexual functioning, it is no use focusing merely on sexual functioning without paying attention to problems in the domain of sexual identity

and the sexual relationship. To pay attention to issues regarding sexual identity and sexual relationship is and remains relevant in every stage of the illness trajectory and is important regardless whether people are sexually active or not. For those who choose not to be sexually active or for whom sexual activity is no longer attainable, attention for sexual identity and relationship is crucial in finding alternative ways of achieving physical intimacy. Problems in any of the three domains might result in sexual or intimate life not being picked up, and sometimes in a break up or divorce. Therefore, if health care professionals are to support clients with issues concerning sexuality and intimacy, they should consider all three aspects.

Person-oriented approach

For clients, a person-oriented approach is key from the very first time they meet their health care professionals. If clients don't sense that the professional 'sees' the person that they are, including their emotional layer and a real life in the world 'out there' with everything that comes with it, they will be very hesitant to disclose personal issues. A professional driven, questionnaire-based approach is not conducive for discussing sexuality or intimacy. For the professional it might be a box to tick, for clients it represents the most intimate and emotionally charged information they could think of, and they are not going to reveal information just like that, not even when they are facing serious problems in the domains of sexuality and intimacy.

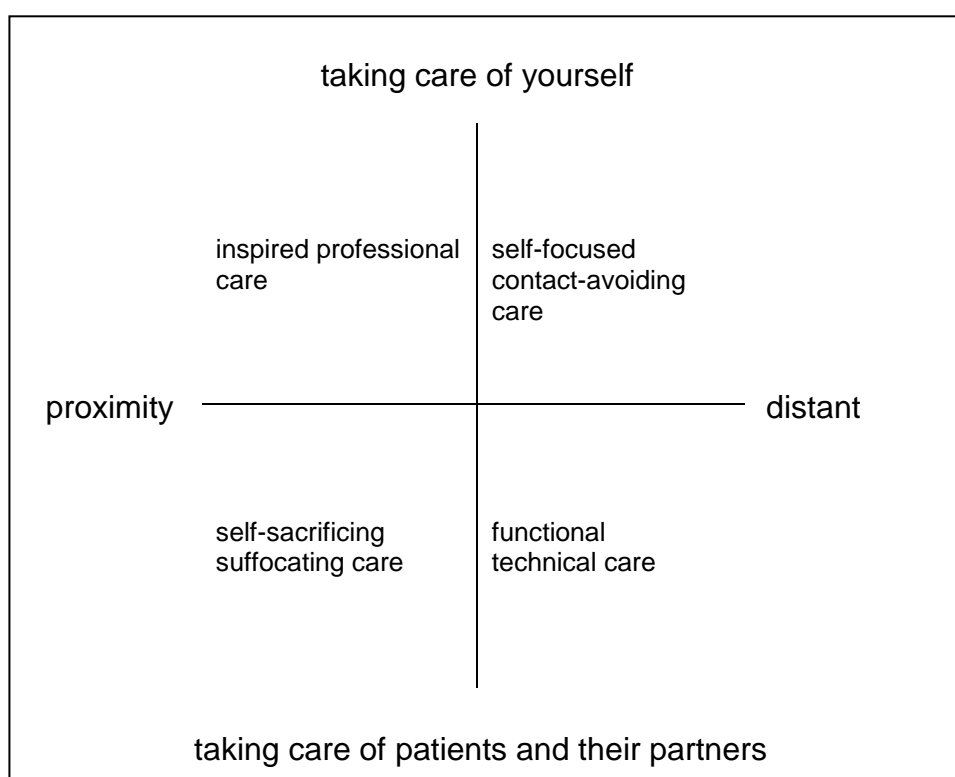
A person-oriented approach does not mean professionals need to have long and deep conversations with their clients. As Emma (C3pat), Ryan (C2par), Anna (Pat2) and Tristan (Pat8) in this study pointed out, it is more about the basic attitude of the professionals and the quality of the interaction with clients within the time available. It is about shaking hands, looking people in the eye, knowing their name, appreciate that things must be tough for them and their families and feeling sorry for someone who gets bad news. Paying attention to these aspects does not have to take much time, but can make a world of difference¹³. Of course there is a challenge for professionals here, because they don't meet with patients on a personal basis. Patients are not friends they have

¹³ These suggestions need to be tailored to the cultural background of clients.

chosen to meet, they are clients and they come with the profession. Nevertheless, it should be possible to adopt a person-oriented approach within a professional context.

Two dimensions seem to be relevant here: how to balance distance and proximity within a professional relationship and how to balance taking care of your clients and taking care of yourself. Combining these two dimensions results in four 'types' of care (De Vocht et al., 2010b) (figure 3).

Figure 3: Four types of care



Self-focused, contact-avoiding care is about getting through the working day as easy as possible, spending no more energy than is strictly necessary. The reason to go to work is to generate income, and the 'person behind the patient' leaves these professionals completely indifferent. A sad example of this is that some patients offer money to professionals in order to get good care, and that apparently there are professionals who accept this money (Anonymous, 2010).

In functional technical care the technical quality of care is up to standards, but this type of care is delivered in a distant, impersonal way. It is protocolised care that makes both professionals and patients exchangeable. For example, the nurse could be any nurse, just as the patient could be any patient.

Professionals providing self-sacrificing, suffocating care tend to 'jump into the pit' with the people who need their help. These professionals make patients' problems their own problems and they 'suffocate' patients with their overwhelming, indispensable care. This does not empower patients or stimulate them to tap from their own resources. Furthermore, in the long run this type of professional is prone to burnout as they devote all their care to their patients and not to themselves.

In inspired professional care there is a balance between proximity to patients and taking care of one's own needs. Professionals characterised by this style offer authentic contact on a person-to-person level (which is highly appreciated by their patients), but they restrict their involvement with these patients to working hours. They realise that the problems of their patients are not their problems (at least not at this point in time). By keeping this in mind, these professionals make sure they recharge their batteries during their time off. They value their blessings, and enjoy them even more knowing that none of them will last forever. This helps them to support patients by maintaining an authentic person-to-person approach throughout their entire career.

These four types of care are extremes and all sorts of intermediate forms are conceivable. However, they provide a means to reflect on the way health care professionals give shape to their roles in daily practice.

In patient contact, professionals should aim for 'inspired professional care'. This will yield the person-oriented approach that is conducive to discussing personal topics like intimacy and sexuality. It will also result in job satisfaction for professionals, because they will be greatly appreciated by their clients and they will experience, within the context of their professional role, authentic contact with other people, which can be very rewarding, making a difference for people who are facing tremendous challenges can give great meaning to a career in health care. After 9 years Grace (Pat4) is still grateful for the one nurse who

said to her *“it’s easy for us to say that it’s not that severe, but you are the one who has to endure it”*.

It is however very understandable that it is not that easy for professionals to continually make authentic contact with their patients. Just as patients have a ‘slumbering awareness’ in order to cope with their life-threatening illness, professionals cannot face the full impact of what they see every single working day. It is hard to realise that all of the time the people you are treating are people just like you, and that the cancer that they now have you could have in the future, or it could be your partner, parent or child. Or maybe they have already witnessed similar illness trajectories in their personal lives, and they don’t want to be reminded of them. Recent case histories indicate that many professionals tend to think in terms of two categories: the (healthy) professionals (us) and the (sick) patients (them), instead of one group of human beings that we all are part of (Ten Haaf, 2010). This will hinder them in adopting a truly person-oriented approach, because that would require recognizing and acknowledging the human being that you are yourself in the other person. How to deal with this when it comes to communication about sexuality and intimacy will be discussed in the section on ‘stepped skills’.

Before treatment: professional driven communication

The participants in this study made it plain that they would like health care professionals to take the initiative to discuss sexuality and intimacy, before treatment and during / after treatment.

Before treatment, information should be given on the possible side effects treatment could have on sexuality and intimacy. This is a professionally driven activity, as this is the area of expertise of the professional. They should be careful not to ‘overload’ clients with information at this stage. However, impact on sexuality should be addressed, if only briefly. At least one professional seeing the patient and partner should ‘translate’ medical side effects in a caring way to what they might mean in real life, in line with a person-oriented approach. This would also include avoiding heterosexism by not assuming that everybody has one partner of the opposite sex. Many people are single (which does not make them asexual); many people are homosexual or bisexual or have more than one sexual partner, for example those who are having extra-

marital affairs. In view of this, as a starting point, it would be better to talk about 'your partner(s)' than to talk about 'your wife' or 'your husband'. Any queries that might come up during this pre-treatment conversation should be addressed. In addition, this professional should point out that (s)he will revisit this topic later on.

A professionally driven communication model like PLISSIT (Annon, 1976) would be useful at this stage. As discussed in the literature review, the PLISSIT model consists of the following steps: give permission; provide limited information; provide specific suggestions; give intensive therapy. At this stage, 'permission giving' and 'providing limited information' would be the suitable steps to take. Permission giving would entail 'normalizing' sexuality and intimacy in the context of cancer and palliative care. The provision of limited information would entail supplying information on the potential side effects of treatment on the experience of sexuality and intimacy.

During/after treatment: client centred communication: BLISS model

Because we know there is no uniform causal model that will predict what the impact of cancer and cancer treatment for a specific person or couple will be, and because we know this impact will involve highly personalized issues like sexual identity and sexual relationship, we should acknowledge that our clients are the experts regarding their unique experience. This means that during and after treatment, professionals should adopt a truly client centred attitude. This would require expanding their medically oriented role in order to communicate about patient sexuality and intimacy beyond the domain of medical expertise. This in turn would require letting go of a professional driven style of communication. In the absence of finding such a model in the literature, the findings of this study have been used to develop a new model: the BLISS communication model (box 4). During the years of working as a nurse educator, it has become evident that students find acronyms helpful, therefore this approach has been used with the new model.

Box 4: BLISSS communication model

B: Bring up the topic in an appropriate way
LI: Listen actively to the Individual experience
S: Support the individual
S: Stimulate communication between partners
S: Supply personalized advice and information; where necessary, refer to a specialized professional

B: Bring up the topic in an appropriate way

This study showed that it is too much to expect for many clients to disclose their sexual issues spontaneously, as they feel they have a high threshold to do so. Some of them may not even be aware yet that they might need some help and guidance in order to restore an enjoyable intimate life. So it is for the professional to bring up the topic of sexuality and intimacy in an appropriate way. Appropriate means being sensitive to what would be the best timing, but most of all the initiative should be embedded in an atmosphere of trust that has been established from the very first meeting onwards. Appropriate also means that there should be a gradual transition towards this personal topic; the topic should not come out of the blue. Many clients don't like to be questioned directly about their intimate life. They would prefer an approach where the professional brings the topic within the scope of the conversation in a way that would give them the option to respond or not. Others would not mind being probed more directly, as long as there is a gradual build up from less towards more sensitive aspects. This would imply that the probing stops at the point where it becomes clear that further probing would be unwanted or irrelevant. Using self-assessment questionnaires to check whether there are any problems or queries in the sexual domain does not seem to be very effective, as clients perceive this as a too impersonal way of approaching a very personal topic. As a result, they are not likely to disclose any intimate information. Many clients would be unfavourably disposed towards a formal assessment based on a sexual history questionnaire, especially if this questionnaire is as detailed and comprehensive

as for example the questionnaire presented by Katz (2007) (based on information from (Kaschuk and Tiefer, 2001)).

Bringing up the topic, even in the most sensitive and appropriate way, does not mean that clients will accept the invitation to discuss their sexuality and intimacy with this health care professional at this moment. They might decline it altogether, or decline it for now and come back to it later. Many clients said that, even though they declined the invitation, they still appreciated the gesture, because it made them feel acknowledged as a sexual being by the health care professional. None of the professionals who participated in the current study reported that clients were offended by an appropriate initiative to discuss sexuality, although some clients made it very clear that this is a no-go area, for example clients with a very strict religious background. Professionals also warned not to make assumptions, e.g. based on clients' age, religion or culture, whether or not it would be relevant to discuss sexuality. Many professionals reported surprising responses, contradicting their own expectations. Professionals should gracefully respect clients' wishes not to discuss sexuality and intimacy with them, and might close the topic by saying that clients should feel free to bring the topic up any time they might feel the need in future.

LI: Listen actively to the Individual experience

If clients do wish to respond to the initiative to discuss their sexuality and intimacy, the professional should first of all listen attentively and actively to their personal account. Clients are the experts here, and the professional should adopt a not knowing stance in order to fully explore the experience from a clients' perspective. The professional can use paraphrasing, reflecting and probing skills to get the full picture of the story as presented by clients. This active listening serves several purposes: clients can give vent to their emotions, the professional acting as a sounding board can help clients to diminish chaos by bringing order to thoughts and emotions, and last but not least, the professional gets a clear picture of the sexuality and intimacy related issues at play. If necessary, professionals can ask specific questions but these should be tailored to the need to broaden their understanding of the issues at stake.

S: Support the individual

S: Stimulate communication between partners

Active listening would include responding in an empathic way, which will support clients emotionally. This will contribute to boosting clients' sense of (sexual) identity. In addition, if the conversation takes place with both partners present, the professional has the opportunity to make partners listen to each other's account, which might be very helpful in 'bridging the gap' that might well exist between partners at this stage.

The main idea behind responding in the way described is to empower patients and partners to deal with issues in the domain of sexuality and intimacy. Many clients and expert professionals participating in this current study made clear that what clients need most is somebody to attentively and empathically listen to their story, to 'normalize' their queries, to support emotionally and to catalyse communication between partners. Listening actively, employing basic communicative skills, and most of all be human and appreciate the humanness of others, can meet all these needs.

S: Supply personalized advice and information; where necessary, refer to a specialized professional

At some point, but only after the professional has a clear picture of what might be helpful in the given situation, tailor-made advice and tips can be given. This could be very helpful, as clients indicate that they are not always capable of thinking of creative solutions in view of the taxing situation they find themselves in. But it should be kept in mind that the basic attitude of the professional should be support-focused instead of solution-focused.

When clients and the professional agree that clients might benefit from more specialized care, referral to a specialist should be made. Depending on the issues discussed, this could be a sexologist, a relational therapist, a gynaecologist or an urologist, to mention a few. Based on the literature and on the opinion of experts consulted in this study, only a minority of clients would need a referral to a more specialized professional, but those who do, should get the best care available.

The client centred communication regarding sexuality and intimacy, that would meet clients' preferences during and after treatment, is captured in the BLISS communication model. In an ideal world, every health care professional would be capable of adopting such a client centred approach. However, informing health care professionals that they should communicate with clients about intimacy and sexuality does not mean that these professionals will be able and willing to do so (Gamlin, 2005, Hordern and Street, 2007b). Both by professionals who participated in this study and in the literature (Cort et al., 2004, Hordern and Street, 2007c), barriers have been described that might stop professionals from providing clients the opportunity to explore sexuality and intimacy issues, e.g. their own upbringing and socialization processes (Gamlin, 2005) or negative sexual experiences. Many of these barriers are not likely to be removed easily, as they are deeply rooted in the persons involved. Adopting the BLISS communication model means that professionals should go "beyond the safety of 'medicalised' concepts, which could be communicated in a traditional expert manner" (Hordern and Street, 2007b p. 57) and for many professionals this is not an easy step. Not all professionals are capable of or have affinity with making authentic, human-to-human contact within their professional role in order to discuss intimacy and sexuality. Some professional participants in the current study made clear that they themselves don't feel qualified or attracted to doing so. Other professionals pointed out that some of their colleagues definitely don't have what it takes to discuss private issues, no matter how much education and training would be given. In light of the above, a 'stepped skills' approach needed to be developed as a possible way forward.

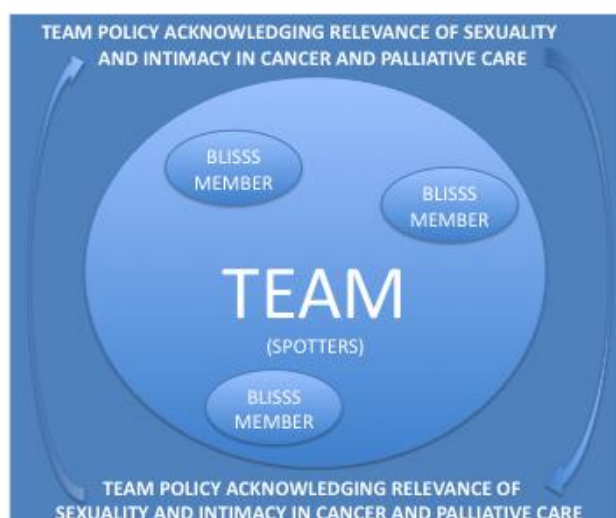
Stepped skills

A more sensible approach might be to think in terms of stepped skills. This means that, as a team, health care professionals should discuss what their team policy regarding sexual and intimate issues is or should be. In order to take these issues seriously, as a team, a 'sexuality and intimacy including approach' should be adopted. The team should acknowledge that sexuality and intimacy are basic and enduring aspects of life, which can contribute to quality of life and are relevant to discuss in the context of cancer and palliative care. This does not mean that every member of the team has to discuss these private

topics profoundly with clients. Part of the 'stepped skills' policy is to work out which team members will 'specialize' in exploring the impact of cancer and cancer treatment on sexuality and intimacy, including aspects of sexual identity and sexual relationship. These team members should have the competence (box 3) to discuss intimate topics using language that makes sense to clients and they should have enough time to do so. They should be capable of providing 'inspired professional care': offering an authentic person-oriented approach that is so much valued by clients while at the same time taking good care of their own psychological needs. This will clear the way to offer emotional support and practical advice about issues of sexuality and intimacy to patients and partners, be it jointly or separately.

These 'specialists' are not specialised in the domain of sexuality and intimacy in the way a sexologist is; their strength is their personal quality of relating to other people in a way that will establish sufficient trust to discuss very private issues. It could be argued that in an ideal world, every health care professional would possess this quality, but it is not realistic to strive for an ideal world. Every team member has stronger and weaker points, and the art is to think in terms of complementing competencies in order to provide optimal care. A way had to be found to visualise this complementing team approach (see figure 4).

Figure 4: Stepped skills model: Team approach for cancer and palliative care teams using complementing skills in acknowledging the importance of sexuality and intimacy



The team members best equipped to apply the BLISS model are the ones who should be doing so. Therefore, in figure 4, they are called 'BLISS members'. Other team members have the responsibility to 'spot' issues related to sexuality and intimacy and, when necessary, can kindly refer clients to these BLISS members. Therefore, these other team members are called 'spotters'. These spotters might be relieved to know that their task is a very important but well-delineated one. This might give them the confidence to carry out this task, instead of avoiding sexual issues altogether.

From the above, it should be clear that being a BLISS member is not by definition linked to a particular disciplinary background. The deciding factor is being able to connect with clients on a personal level within a professional role and to feel confident and comfortable discussing sexual issues. However, based on job roles and descriptions, nurses would be likely candidates. A nursing role includes being a skilled companion, and it is companionship that is at the core of the competency sought for in this case. Companionship is about accompanying patients during their journey (Titchen, 2000) and that is what clients would value when trying to find a balance in their intimate lives after a cancer diagnosis and treatment. This would require nurses to reflect on what is the core of nursing, as there seems to be a tendency to medicalise their roles, meeting requirements of evidence-based practice and resulting in protocolised care (Burger, 2009).

Age and gender are not decisive factors when it comes to deciding who might be best qualified to be a BLISS member. However, professionals aspiring to be BLISS members might need education to update their knowledge on sexuality and cancer and some training to optimise their counselling competencies. Nevertheless, the talent and drive to be a skilled companion should be the foundation of being a BLISS member.

Make a difference in 10 minutes

Team members who are not BLISS members have the responsibility to 'spot' sexual issues when they surface and to refer clients to a BLISS member who can then explore these issues. Spotters are not required to apply the BLISS model, however, they should realise that in order for clients to be willing to disclose sexual and intimate issues a conducive communication context is

required. Clients need to feel acknowledged not just as a patient but also as a person. For them, sexuality and intimacy are very private topics that are not so much related to being a patient but are aspects of their personal lives. Spotters should therefore ideally meet the ‘minimal requirements’ (see box 5) regarding communication about sexuality and intimacy.

Box 5: Minimal requirements for ‘spotters’¹⁴

Minimal requirements concerning a ‘personal’ approach:

- shake hands and make eye contact while mentioning the patient’s name
- ask how he or she or they (the couple) are doing
- listen to a (brief) response to this question
- provide an adequate (authentic) response (I am pleased to hear that / I am sorry to hear that) and make a smooth transition to consultation

Minimal requirements concerning sexuality and intimacy:

- before treatment: name potential side effects of treatment (prescribed by the ‘spotter’) on sexual functioning
- during treatment: check for side effects on sexual functioning and prescribe a ‘remedy’ if possible
- be open to questions about private issues and acknowledge the importance of sexuality and intimacy for patient and partner
- where necessary, refer to a BLISS member in a smooth and adequate way, making clear that the referral is based on wanting to ensure optimal care regarding these important aspects

Dialogue about the implications for practice with health care professionals

Validating and testing out the implications with different target audiences

A portion of the last 18 months of the study was spent discussing the findings, ideas, and practical implications coming from the current study with different national and international target audiences from the professional groups in different arenas (for an overview see appendix 5). Many people in the audiences responded very positively to these presentations of the outcomes of the study, both formally during the sessions and informally, on an individual basis, afterwards. Many appeared touched by the experiences of patients and partners presented. This was ‘tangible’ during the presentations and acknowledged by many members of the audience who came up to discuss their

¹⁴ These requirements need to be tailored to the cultural background of clients.

feelings and reactions afterwards. Some professionals reported that the findings of the study offered them new insights, and shared in return their experiences and ideas, and as such validated and contributed to the outcomes of the study. Other professionals were interested in the practical tools and models, and were quite keen to have them and to have more information. Tools and models were piloted with different groups, initially with groups of Dutch nursing students and later in several national and international workshops. Several of these presentations and workshops were formally evaluated with excellent results.

Developing a one-day training programme

The feedback from the professional audiences contributed to the refining of the tools and models and resulted in the development of a one-day training programme (based on the competence presented in box 3) for health care professionals working in cancer and palliative care (see appendix 6 for an overview of this training programme). When preparing the one-day training programme two more practical tools were created to address all aspects of the competence: happy families and the use of the vignettes.

- Happy families

Hordern and Street (2007b) have noted that the use of medical jargon can be a way of avoiding the topic of sexuality. The use of jargon medicalises client's sexuality and intimacy and will result in confining the conversation to the area of medical expertise. A client-centred approach requires the use of language that makes sense to clients from a 'real life' perspective. Different clients will use different terms to express their sexual and intimate concerns. BLISS members should feel comfortable using similar terms as their clients do, or at least use language stemming from the same 'vein'. In order to train professionals to do this, a new version of the card game 'happy families' has been developed (see figure 5 for an example).

In a light-hearted way, this helps professionals to overcome their embarrassment to use words relevant for sexual counselling that they might normally not feel confident to employ. The 'sexual counselling' version of happy families can serve as an icebreaker. It helps to expand comfort zones in a light-hearted way and it results in picking up and discussing information on relevant topics. After successfully piloting 'happy families' with several groups of Dutch

nursing students, it has been presented at a conference for Cancer Education (EACE 2010), where it was very well received, and has been used in four workshops as part of two national conferences on palliative care, resulting in many educators and professionals wanting to order a copy of this special version of 'happy families'.

Figure 5: Example taken from the card game 'happy families'



- Use of the vignettes

The vignettes presented in the findings chapter were used as part of the one-day training programme. By putting the vignettes together they can be read in their entirety and actually tell a story themselves (see appendix 7). The reality is that, when teaching on sexuality and intimacy in cancer and palliative care, the audience is not going to read the complete findings of this study. But the vignettes capture the essence of the findings, and are in a format that aims to create resonance. As part of the one-day training programme, participants can read a selection of the vignettes in silence and discuss them afterwards. Findings from this study can be used to create a dialogue on different levels, and the amount of vignettes and further information from the findings can be tailored to the time available and the level and background of the participants.

Piloting the one-day training programme

The researcher was invited to train a Belgium Palliative Care Team (consisting of mainly nurses) which provided the opportunity to pilot it in another country. The training programme definitely created resonance and a dialogue. In the formal evaluation these professionals unanimously declared that the programme was highly relevant for their daily practice. The overall score for this training was 9,3 points (out of 10).

6. COMPLETING THE CYCLE: CRITIQUE AND HERMENEUTIC REFLECTIONS

In this chapter the critique and reflections are presented in two separate sections because in hermeneutics reflections (including reflexivity) are a key part of the hermeneutic circle and therefore should be open for inspection separately.

Critique

The first point to address in this critique is whether the study achieved the aims that were set at the start.

- Aim 1: To increase understanding of how cancer and cancer treatment impact upon the experience of sexuality and intimacy of patients and their partners

For the researcher the willingness of participating clients to share details of their private lives has tremendously contributed to understanding the varied impact cancer and cancer treatment had upon their experience of sexuality and intimacy, although it should be acknowledged that there will always be an amount of 'unshareability' regarding these experiences.

- Aim 2: To increase understanding of how cancer patients and their partners experience the way health care professionals address sexuality and intimacy

Participating patients and partners painted a very clear picture of how they experienced the way health care professionals addressed sexuality and intimacy and they were quite unanimous in expressing their preferences regarding this communication.

- Aim 3: To gain insight into health care professional's perceptions of their role regarding sexuality and intimacy for cancer patients and their partners

The interviews gave a good insight into health care professionals' perceptions of their role regarding sexuality and intimacy for cancer patients and their partners, and that included insights coming from health care professionals sharing their expertise in addressing these issues.

- Aim 4: To develop patient driven models, tools and recommendations to acknowledge sexuality and intimacy in cancer and palliative care

All the combined input, generated as a result of undertaking the current study, resulted in the development of patient driven models, tools and recommendations to acknowledge sexuality and intimacy in cancer and palliative care that proved to be very useful in education and training. They were so well received by the professionals involved that this exceeded expectations, with professionals spreading by word of mouth and requests for more presentations and training coming in.

The second point to address in the critique is whether the study meets the quality criteria suitable for a hermeneutic approach. The rigour of the current study is assessed using the criteria as described and justified in the methods section.

- Balanced integration

Balanced integration refers first of all to the in-depth intertwining of philosophical concepts within the study methods. The philosophy behind the method has been intertwined with the study in all stages, informing the aims, sampling, interviewing, analysis and presentation and dissemination of the findings. In all stages the study has been informed by the principles of 'being-in-the-world', of systems theory and of the creation of a dialogue by going through the hermeneutic circle in order to arrive at a fusion of horizons.

Balanced integration also refers to finding a balance between the voice of study participants and the philosophical explanation, relating to the concept of

convergence, meaning the extent to which the perspectives of the participants, the researcher and other data sources are merged in the interpretation. This would require reflexivity from the side of the researcher. As it is impossible to become fully aware of the researcher's preconceptions and how they influence the interpretation, reflexivity of the researcher has been complemented by peer debriefing and expert consultation. Reflexivity was enhanced by developing a transcultural approach before the onset of the study, resulting in increased awareness of the frame of reference of the researcher. During the study a journal was kept, enhancing awareness of how the researcher was involved in the study and how this shaped the way the researcher perceived participants and their accounts. Throughout the study supervisory meetings were frequently held, including joint meetings as well as separate meetings with the Director of Studies and the Dutch supervisor. Both supervisors read the data and the analysis and this resulted in fascinating dialogues, which not necessarily resulted in a unanimous interpretation but made the researcher aware of how the researcher's pre-understandings influenced the interpretation. Combining three interpretations of the same data enforced the 'voice' coming from these data compared to an interpretation based on the pre-understandings of only one researcher. Peer debriefing with highly qualified supervisors generated many additional insights and resulted in increased intersubjectivity regarding the final interpretation. Outside supervisory meetings expert consultation took place, involving two national experts in the field who did not participate in the study. Credibility of the study findings was maximised by offering many quotes from the interviews to enable the reader to judge whether participants' experiences were represented in a fair way.

Participant validation was not used as a way to verify the findings of the study, as it would not fit the hermeneutic premise that there is no context-free absolute truth. Participants will not be the same anymore when revisited, or they might want to present themselves in a more desirable way, or they might not recognize (all of the) vignettes or the core theme, as every participant will have contributed only a fraction of the data (Burnard et al., 2008).

- Openness

Openness is related to the open orientation of hermeneutic researchers, willing to put their own pre-understandings at risk when exploring the issues at hand. In this study, the philosophy of Heidegger and Gadamer regarding the hermeneutic circle was adhered to. The researcher was willing to put pre-understandings at risk in order to learn from participants by keeping the dialogue open. Participants reported that they appreciated the way interviews were held, as it gave them the opportunity to express their experiences with the researcher engaging in the dialogue in a non-judgmental way.

Openness also related to opening up the study to scrutiny through a systematic and explicit accounting for decisions made throughout the study process. The current study is open to scrutiny by making explicit as clearly as possible how data were collected and analysed, demonstrating a systematic approach by making use of a voice recorder, maximising the quality of the transcripts, performing rigorous data analysis using ATLAS.ti. The use of ATLAS.ti proved very helpful in forcing the researcher to consider all fragments, and not just the ones that appeared most meaningful at first sight. As argued in the section on reflexivity, the true learning of the researcher took place in the blank spots in the researcher's pre-understandings, and because blank spots were by definition outside the researcher's frame of reference they could easily have been missed if no rigorous way of analysing the data had been employed.

- Concreteness and catalytic authenticity

Concreteness relates to the usefulness of study findings for practice. Study findings and recommendations are relevant and useful for both educational and health care practice. Great care has been taken to give the presentation of the findings the potential of creating resonance and many practical tools and models were developed as outcomes of this study. In order to achieve catalytic authenticity it was not deemed sufficient to hand these outcomes in as the final results of this study, and in line with a hermeneutic approach the dialogue with a range of professional audiences was sought, by publishing and by presenting the findings to and providing workshops for a range of national and international audiences (for an overview see appendix 5). Engaging in a dialogue with these professionals gave evidence for the catalytic authenticity of the study, with

many professionals wanting to know more and wanting to act on the outcomes of the study. Piloting the model and tools reinforced the usefulness of the outcomes of the study in both educational and health care practice.

- Resonance and educative authenticity

Resonance encompasses the experiential or felt effect of reading study findings upon the reader and is related to educative authenticity that refers to the ability to help people appreciate the experiences and viewpoints of others. Many professionals who were invited by the researcher to read the clients' 'story', that was composed to capture the findings of this study, reported great amounts of resonance and willingness to act upon the insight the story gave them, and this even included people who proof read the story or translated the quotes. In both conferences and workshops professionals reported that presentation of the findings from the current study did create resonance and gave them a better understanding of the phenomenon, resulting in a different appreciation of the situation patients and partners are in which in turn will affect their practice.

- Actualisation

Actualization refers to the impact of the resonance of the study in the future and can therefore not be assessed at the present time. However, the study has already shown to have the potential for actualisation and very concrete plans are made to take this study and its outcomes further, as will be briefly described at the end of the final chapter.

The third point to address in the critique is whether findings from this study can be transferred to other settings. The generalizability of the study findings was assessed using the criteria presented in the methods section as provided by Smaling (2003). There is a basis for variation based inductive generalisation, as the sample was varied. All in all, the mixed groups of patients, partners and couples provided a satisfying variety of views on the impact of a life threatening illness on their experience of sexuality and intimacy. This was further enhanced by the fact that their distances to the phenomenon (in terms of time) were varied as well. Some of them were in the midst of the turmoil of potentially curative treatment whereas others were close to death. Some patients survived their life

threatening illness and could reflect on the experience from yet another stance. Others were reflecting from a point in time where their partner died years ago. All these perspectives proved valuable and contributed to coming to an understanding of the impact of a life threatening illness on the experience of sexuality and intimacy. However, maximum variation was restricted by the voluntary character of the sample and maximum size of the sample in view of the hermeneutic approach that was adopted. Not all 'voices' were represented as not all cancer types were covered and there were no same-sex couples or representatives of non-Dutch cultural groups included. Therefore, variation based generalization is limited.

There is also a basis for theory-carried inductive generalization, as TMT has a firm evidence base and, in view of its existential line of approach and the universality of the evidence, the researcher has good reasons to believe that the theory will hold in all 'cases' that health care professionals may encounter (Smaling, 2003). Using the theoretical perspectives of TMT and Heidegger moves empirical data conceptually to a more abstract and general level, thus moving towards generalisation (Coffey and Atkinson, 1996). System Theory is a meta-theory and as such is 'empty', but offers a view on human relations that has the potential to offer valuable insights in any setting.

Additionally, based on analogical (case-to-case) generalization, professionals can deduce for themselves whether study findings and recommendations plausibly hold for the patients and partners they meet in their daily practice by assessing whether their situation compares sufficiently to situations as described in this study.

Both forms of communicative generalisation, responsive and receptive generalisation, proved to be applicable to the current study. Responsive generalisation is based on interactive communication of the study findings before the publication of the final research report, whereas receptive generalization is related to analogous transferability of the study findings and usefulness for practice, the relevance of which for the current study were previously discussed.

Although findings of the study may be transferable to and useful in other (similar) settings, it should be stressed that (statistical) generalisation is not possible nor the aim. Professionals will always have to fine-tune the findings of this study to the situation they find themselves in with a particular patient or couple. The study offers insights and 'themes' that might be relevant in other situations but it will always require a sensible professional to apply these insights. However, care has been taken to develop models and tools and formulate recommendations that do justice to the variety within the sample and the cancer and palliative care population, making them widely applicable without risks related to illegitimate generalization.

As the final part of the critique, limitations of the study are discussed. Possible limitations were identified at the start of the study. One possible limitation was that this was the researcher's first hermeneutic study. It was anticipated that it would be challenging for the researcher to embrace the philosophy of hermeneutics, as she came from a positivist background. In preparation for the PhD, the researcher undertook several qualitative studies under the supervision of the PhD Director of Studies, adapting to employ qualitative methods. She read extensively on the topic, and attended several courses on qualitative methods and qualitative analysis at the Dutch Humanistic University, which specialises in qualitative approaches. A seminar on Interpretative Phenomenological Analysis was attended at Aston University in Birmingham (2009). Many exchanges with other doctoral students took place, for example at the European Doctoral Conferences Nursing Science (2005, 2006, 2007, 2009), the Birmingham City University Student Presentation days (2008, 2010) and informally through professional networks, focusing mainly on the UK in view of the expertise in qualitative methodology. The Director of Studies offered specific guidance and inspiring discussions. All this helped to expand the researcher's horizon to include the philosophy of hermeneutics.

Another potential limitation was the use of different groups. This could have resulted in different perspectives leading to a fragmented view on the phenomenon. A solution was found in doing the thematic analysis for the different groups separately, and then drawing the different perspectives together in the higher order analysis, in which conceptual threads and a core

theme were sought and found. The different perspectives complemented each other, resulting in a broad view of the phenomenon under study.

The use of ATLAS.ti was also seen as a potential limitation of the study, as a 'mechanistic' way of analysing would not be compatible with the idea of the hermeneutic circle. However, in this study ATLAS.ti was only used to do a part of the analysis (the thematic analysis) and even in the thematic analysis ATLAS.ti was used to support the analysis by making it systematic and easy to handle the large amount of data. The actual 'analysing' takes place in the minds of the people involved in doing the analysis (mainly the researcher and supervisors).

The key limitation of the study is the voluntary sample. As explained in the methods section, this is inherent to studies exploring sensitive topics, regardless of the method employed. This study was designed to supply one type of view on the topic of study, and combining studies based on different approaches will no doubt result in a more complete picture. It can only be hoped that the participants in this study acted as the spokespersons for the clients who did not come forward to participate, contributing to giving them a voice as well. It can be argued that for the group of clients that might experience a higher threshold to talk about sexuality and intimacy, the recommendations coming from this study are at least as relevant as for the people who were willing and capable to discuss their private lives. Using the stepped skills and BLISS model should do 'no harm' to this more reluctant group and would maximise chances for them to talk about sexual problems or queries if there are any. Nevertheless, it was a limitation of this study that not all cancer types were represented and that no participants with same-sex relationships and non-Western cultural backgrounds were included.

Reflections

Reflexivity

In a hermeneutic study it is relevant to be cognisant of the horizon of the researcher, as this horizon is indispensable in coconstructing meaning with participants. However, it is impossible to describe the researcher's pre-understandings exhaustively, as many of these pre-understandings are not accessible to the conscious awareness of the researcher. To give the reader an idea of influences that have shaped the researcher's worldview some researcher characteristics were provided in the introduction.

Drauckner (1999) stated that in research reports, the narratives of the participants, the presuppositions of the researcher, and the processes by which these viewpoints are merged should be described in enough detail for the reader to evaluate the quality of the analysis. However, similar to the pre-understandings of the researcher, most of the processes involved in the merging of horizons work outside the sphere of awareness of the researcher. Long before a person becomes aware of or 'discovers' a pattern, pattern recognition takes place on an unconscious level (Nyatanga and De Vocht, 2008). Heidegger also did not believe that one's background can be made completely explicit (Laverty, 2003). The ontological way of understanding is prior to any specific understanding, so it must always be presupposed even in the attempt at its own explication (Malpas, 2009). Presuming that it is possible to map out one's preconceptions would imply a type of 'reversed bracketing' that would not be compatible with a hermeneutic approach. Gadamer (1960/1982) does acknowledge that there are pre-understandings helping and hindering the interpretation, but also states that it is impossible to distinguish between them beforehand. The idea is that by repeated questioning it is possible to come to an understanding in the dialogue.

Therefore, from the researcher's perspective it is impossible to meet Drauckner's requirement fully. One often becomes only aware of preconceptions when these are challenged (Fay, 1996). The fish is not aware of the water until it is taken out; it is only against a moving background that the foreground becomes visible. However, it is accepted that engagement of the researcher entails more than a confession of positionality or simply inventorying

‘where one stands’ relative to that that is being interpreted. Engagement means risking one’s stance and acknowledging the on-going liminal experience of living between familiarity and strangeness (Schwandt, 2000). Therefore, three examples will be given of how the researcher’s pre-understanding was challenged by the account of the participants, resulting in an extended range of vision.

The first example has to do with the inclusion criterion for patients. The idea was to include patients in the domain of palliative care, and according to the WHO (2002a) these are people facing a life-threatening illness. Initially, attempts were made to ‘objectify’ which illnesses are life threatening, but as was discussed in the section on defining the literature search, it proved problematic to objectify whether an illness will result in death or not as answers are based on probabilities (based on the stage the illness is in) and on averages for groups of patients. In order to have a clear inclusion criterion, despite these ‘fuzzy’ boundaries, the choice was then made to include patients who were told that their illness was incurable and who therefore had a life-limiting illness. However, engaging with these patients revealed that, although from an etic perspective this may seem a clear demarcation, from an emic perspective it was not. Even terminally ill patients did not always acknowledge that their illness would cause them to die, or, even more fascinating, at some point in the interview they did and at other points they did not, demonstrating an oscillating awareness. As discussed previously, this eventually resulted in including patients with a cancer diagnosis, regardless of their prognosis, because these participants could share the experience of having what they perceived as a life-threatening illness. The researcher did not exclude patients with other life-threatening illnesses, but these patients seemed to be less inclined to perceive themselves as having a life-threatening illness, as an interview with a patient with heart failure made clear. She participated in the study from a partner’s perspective (her partner having non Hodgkin’s disease), whereas the researcher had planned to interview her as a patient.

The second example of challenged pre-understandings of the researcher is about with whom patients and partners would prefer to discuss sexual and intimate issues. The researcher was expecting answers that could be fitted into disciplinary categories. So while politely listening to clients explaining that it had

to be a nice person who would acknowledge them as a person, waiting for them to come to the point of whether they would prefer their GP, oncologist, oncology nurse or medical social worker, it gradually dawned on the researcher that clients were not thinking in terms of disciplines. They sometimes hardly knew what was the exact disciplinary background of the professionals they met, and it was definitely not the way they 'structured' health care. The strategy employed by clients was to search for a nice person from a range of health care professionals that they could talk to, regardless the professional background of this nice person.

The third example stems from doing interviews with health care professionals. Professionals knew beforehand that the interviews would be about sexuality and intimacy in oncology and palliative care and were asked an open question about how they perceived their role regarding these issues. Several times professionals responded in a completely different way than was anticipated by the researcher, talking about sexual abuse of patients or about staff being sexually intimidated by patients or partners. After realising that these professionals came from a different horizon than was intended by the researcher, the discussion was politely refocused in order to also get some information on the intended topic of the study.

These examples were chosen because they surfaced in more than one interview, but there were numerous more incidental occasions of similar experiences on the researcher's side where the researcher's horizon was expanded to incorporate the participant's point of view. An important point to make is that these are the moments where true learning took place, because participants turned out to respond differently from what was anticipated by the researcher. The researcher has learned to be extremely alert whenever responses were given which at first sight appeared strange, unexpected or irrelevant. If a response did not immediately make sense from the researcher's perspective, it was important to explore how and why this response arose from the participant's horizon. The unexpectedness of the response of the participant has to do with the participant's horizon being different from the researcher's horizon, and the whole idea is to come to an understanding of the horizon of participants. Therefore, key to coming to an understanding was paying attention to participant responses that were not in line with or added to the pre-

understanding of the researcher, enabling the researcher to adapt and expand her horizon. This is truly adopting a 'not knowing stance' in order to learn inductively from people who were willing to share their experiences. Key findings in this study can be traced back to these unanticipated responses from participants, for example the existence of a 'worlds apart' between professionals and clients, created by the healthy people (professionals and researchers) who define patients as belonging to another category. The awareness of clients not thinking in terms of professional disciplines resulted in defining a personal approach as a prerequisite to discuss intimate issues. The initial (unexpected) responses from some of the professionals demonstrated the need to present patient sexuality and intimacy as important cornerstones of quality of life and connectedness with others.

There is a parallel to the research process in professionals who were often not aware of their top down approach. They often demonstrated that they had very strong (professional) frameworks that they projected on patients' realities, for example when offering patient education without much space for bottom up communication. The downside of such an approach was that it is not very helpful in giving patients and partners the feel of a personal approach, with the resulting education not being tailored to the needs of the clients.

Despite the fact that the researcher was willing to put her pre-conceptions at risk, it was inevitable that the researcher's horizon would 'colour' the analysis and interpretation, as there is no such thing as 'objective subjectivity'. Similarly, the translation of the interpretation into further implications was coloured by the researcher's background. The fact that part of the researcher's job is to train and educate health care professionals has no doubt contributed to an emphasis on implications for educative and health care practice in the outcomes of this study.

Personal reflections

- Intellectual development

As a psychologist educated within a positivist paradigm I was, at the start of my PhD trajectory, only vaguely aware of different ontological and epistemological perspectives and I was not at all aware of different scholars conceptualising these perspectives differently. As a result, reading an ever-expanding range of different books and articles on the topic made me more and more confused. Just when I thought I more or less understood what this was all about, another reading did not seem to match with this initial understanding. There turned out to be a sea of information to drown in. How to swim? First of all, I learned that one label (e.g. grounded theory, phenomenology) covered different strands, with sometimes rather varied ontological and epistemological positions (e.g. classic grounded theory (which is quite positivist) versus constructivist grounded theory; descriptive phenomenology versus interpretive phenomenology). Therefore it was helpful to pay attention to underlying paradigmatic positions. Unfortunately, not all authors clearly express their position or their studies are not in line with these positions, which adds to the confusion, with some studies claiming to be grounded theory or phenomenological where they do not demonstrate the epistemological goals and (all) the characteristics of these approaches. Secondly, I learned that there indeed are different conceptualisations of ontological and epistemological positions (see the methods section for several examples). For a long time I tried to find the 'right' conceptualisation, one that would map all possible perspectives in a clear and comprehensive way, corresponding to the way 'it is'. This is maybe the best (but a hard and frustrating) way of learning that no such 'map' exists or alternatively, that more than one exists: there is not one absolute truth; there are many perspectives. (This is not to imply that any map is as good as another. Some maps are not internally consistent; others are so 'unconnected' to most other maps that they seemingly lack an intersubjective basis.) The art was to construct, based on all the information available, a map (frame of reference) that gave an overview, and in which other possible conceptualisations could be positioned without getting (too) confused. It is the art of developing a helicopter view of the ontological and epistemological domain and this was not easy. Far from being an expert, I do now feel that my swimming is good enough to keep

my head above the water and for me that was a great step forward. It has to be acknowledged though that there is no end to reading and thinking about the philosophy of science, and doing a PhD was a great start but definitely not an end point.

For now, I position myself as a pluralistic and paradigmatically pragmatic researcher, inclined to adopt the research approach that is most suited to address the aims of a particular study (Patton, 2002), instead of identifying myself as a researcher with one particular worldview. Paradigmatically and metaphorically speaking, I see myself as a chameleon flying a helicopter over the ever-changing scientific landscape, enjoying the view of the positivist metropolis with its skyscrapers and rectangular lay-out, the phenomenological town with its transcendental, hermeneutic and existential quarters, the postmodern mountain village with its winding alleys, artistic cafes and central forum and ethnographers crossing transcultural bridges. Over the years, the landscape has changed, with paradigms shifting from more objectivist to more constructivist orientations, for example ethnography evolving from neo-colonial to indigenous, grounded theory moving from classic to constructivist and phenomenology from purely descriptive to more hermeneutic. The wind has blown the chameleon, originally trained in a positivist tradition as psychologist MSc, in the direction of now concluding a hermeneutic PhD. Maybe these are all indications of the vision of the future as sketched by Guba and Lincoln (2005), in which the 'postmodern turn' will overtake modernist assumptions of an objective reality, as it has already done, to some extent, in the physical sciences. If Guba and Lincoln are right, this would mean that another Kuhnian revolution is at hand, as they suggest a 'taking-over' and not a resolution through dialogue. They predict that "if not in our lifetimes, at some later time the dualist idea of an objective reality suborned by limited human subjectivities will seem as quaint as flat-earth theories do to us today" (Guba and Lincoln, 2005 p. 205).

However, no matter what the scientific landscape will look like in the future, it is important to realise that the chameleon's helicopter can never leave the atmosphere with its boundaries defined by the limits of human perception and experience, and therefore can never aspire to the 'God's eye view' overseeing the ultimate 'whole'. A researcher has a personal biography and speaks from a

particular perspective, influenced by gender, class, race and culture (Denzin and Lincoln, 2005 p. 21). No matter how versatile the chameleon's helicopter is, it will never find the all-encompassing 'theory of everything'. Interestingly, some, for example Green (1969), challenge this perspective, stating that we should not be guided by the 'Uncertainty Principle' that dictates that there is a limitation to the human knowledge that can never be surmounted, but that we should be inspired by the idea that there is infinitely more to discover. Green (1969) claims that no future event can be demonstrated to be impossible (which is logically 100% correct), implying that it is impossible to prove that we will never arrive at the 'Theory of Everything'. It would be extremely exciting if she proved to be right, but based on my current stance I find it highly unlikely that the 'Uncertainty Principle' will turn out to be a mistaken notion.

I do hope my testimony inherently makes clear that I do not take my point of view as an absolute truth, as for me there is no such thing. It is, instead, my attempt at 'scratching around in order to make my experience and world view as comprehensible as possible' (which is, according to Fay (1996) all we can do), in order to fulfil the rightful demand of identifying one's paradigmatic position as a researcher in order to provide an epistemological framework for positioning the researcher's academic work. Understandably, not everybody likes to be pictured as a creature that is scratching around, and most people hang on to a more robust idea of science in order to cope with the 'condition scientifique'. However, letting go of the idea of 'one big truth' for me creates the space to respect and use different research paradigms in order to get as many complementing glances of our world as possible.

- Rough spots

At the onset of the study, there were many questions asked about this method and how it was to deliver useful outcomes. This was especially the case in the Netherlands, where hermeneutics turned out to be an approach that many people were not familiar with and did not understand, with responses varying from people being very interested and curious to people being very critical and sceptical. It would therefore be gratifying if the current study would help to legitimize the approach, as creating the dialogue has proven to be effective in

generating knowledge that contributed to raising awareness in professionals and motivating them to take outcomes of the study on board in their daily practice, as the overwhelming feedback from a range of professional audiences has shown.

- Interviewing, analysing and writing the findings

Doing the interviews was an intense and fascinating experience. One of the hermeneutic circles in this study was on the level of doing the interviews in relation to the findings, and the interviews themselves demonstrated the importance of a 'personal' approach, of building rapport, of gradually moving to the most sensitive topics, of being truly interested and non-judgmental, and of wrapping things up in a caring way at the end of the encounter. The interviews also 'proved' that participants are willing to share extremely personal details if these prerequisites are met, and they reported that the interviews were a positive experience for them. Interviewing is a personal activity from the side of the researcher as well. As a researcher you lend yourself for the emotions of participants; they open up to share their experiences with the researcher; the researchers plays it back to them, they hear their music played on the instrument the researcher is, so they engage with the researcher as a person. The interviews also 'proved' that this person-to-person contact is rewarding for both parties. The researcher can testify that the authentic contact during the interviews was intense and therefore challenging but also extremely rewarding, as 'a gift' to be cherished; with participants reporting similar experiences. The writing of the memo's following the interviews was both helpful in mapping relevant contextual information and as a form of emotional reflection of the researcher. Debriefing was crucial, both in the researcher's personal life as well as with supervisors, who always offered the space to hand off and to discuss freely what the impact of doing the study on the researcher was.

Transcribing and analysing involved total immersion in the data and was intellectually and emotionally intense. While doing the interviews the emotional impact could not fully sink in, because that would have hindered conducting the interviews. Especially when transcribing (hearing the non-verbal aspects of speech) and while reading the transcripts the researcher was and should be

open to experiencing the emotional layers in the data. As a researcher one has to immerse in the data, with the researcher being the instrument. The words and non-verbal behaviour of the participants play the strings of this instrument, with the researcher acting as the sounding board. Immersion in the data sometimes resulted in a trance-like state, losing the sense of time. This turned out to be an exhausting process, as experiencing one's own emotions often is. Immersion in the data was a crucial part of the analytic process, which had to be counterbalanced with an amount of distancing in order to arrive at an analytic framework. Data reduction was inevitable but painful, as it felt like leaving (parts of) stories out that people shared in such a personal way; as if a precious gift was declined. However, in order to analyse the data the researcher had to learn to zoom in and to zoom out, in an on-going process of immersion versus distancing. For researchers, therefore, the focus becomes appropriation of a texts' meaning rather than a search for research participants' unique meanings (Geanellos, 2000). Appropriation is not an act of possession of the text but rather a moment of dispossession of narcissistic ego (Ricoeur, 1981). Or as Gadamer would say: the researcher needs to expand his or her horizon in order to 'assimilate' the horizon of the other person.

This type of inductive analysing was challenging, as it is completely different to deductive analysing. The challenge was to create the structure (or framework) from the data that were to be structured, with the relationship between the structure and the data to be structured being completely open at the start of the analysis. It is a form of pattern recognition that cannot be forced; it takes time and repeated immersion in the data, and as pointed out before this involves many unconscious processing (Nyatanga and De Vocht, 2008), with flashes of insight arriving sometimes unexpectedly; at moments where there was no conscious 'thinking about the data'.

Reading the ATLAS.ti output listing 'isolated' quotes that were grouped under the same theme the researcher experienced that these quotes 'meant' nothing to her until the Gestalt they were coming from was (mentally) found. This Gestalt was made up from the entire content and context of the interview the quotes were taken from. As soon as the right Gestalt was found (they were all on the researcher's mind) the quote would 'spring' to life, like a picture in black

and white all of a sudden showing all its colours and nuances. To the researcher this illustrated that quotes taken out of context lost their meaning, or to put it differently, the very fact that these quotes had meaning was a function of their context.

Presenting a list of themes would have been similar to health care professionals giving a list of side effects without translating them to 'real life'. For the researcher this felt as if another 'world apart' would have been created, this time between the participants and the researcher (and as a result between the participants and the reader). Writing the vignettes was a way to do justice to what participants shared, by making the themes come to life by providing them with a real life context. The vignettes enabled the researcher and enable the reader to stay close to the lived experience of the participants.

- Personal development

Undertaking this study was an enriching experience and not just intellectually. It has changed me as a person. In a way I have become less naive, because of having had to deal with negative and sceptical responses at the start, teaching me that not everybody will automatically support me in fighting for what I saw as a good cause. I have become more assertive, as I needed help and cooperation from a lot of people to meet the aims of this study, and it was me who had to go out there and get their support. Initially I was inclined to shy away from this, but during the process I learned to ask for help when needed, and was often warmly welcomed by people willing to offer their support, which was very stimulating and encouraging. I now feel different about networking; it is nice to help and be helped and to experience that the whole **is** more than the sum of the parts, so I learned that networks are not by definition 'old boys networks' designed to keep outsiders out. I have become more versatile when it comes to opinions and I am less affected by people offering critique or different points of view, realising that there is not one absolute truth but many different perspectives. There is more space for humour; the relativity of it all makes life lighter.

I have a more phenomenological approach to life, more tuned to the perspectives of others and more aware of my own preconceptions. An important learning point in all this was to let go of the question: 'is it this **or** that' and

instead learn to appreciate that very often the answer is to be found in: 'there is a bit of both, it is this **and** this'. In other words, I changed from being an exclusive thinker into a (more) inclusive thinker. A very interesting (and rewarding) side effect of this it that this 'change' extends beyond intellectual development but has now seeped into my personal life as well. I have learned to be more flexible when it comes to, for example, problem solution. This resulted in a more 'relaxed' attitude and feels like a great improvement in terms of quality of life, even when it is only small problems I have to deal with.

Undertaking a PhD has brought me a lot of wisdom, most importantly the realisation that there is so much to know and of all that I know so little, and that there is no absolute certainty in knowledge to begin with. So as an academic, doing my PhD taught me to be humble and modest, but at the same time made me more assertive and self-confident, and I like the combination of these aspects.

Exploring existential layers and being confronted with death and suffering did not leave me unmoved. As a researcher, I was confronted with my own 'condition humaine'. Reflecting on clients' experiences and analysing them while taking my own horizon into account left me no escape. This was inherent to the hermeneutic approach and the topic of my study, so it had to happen in order to do this hermeneutic study the way it is supposed to be done. It resulted in a form of 'bittersweet' suffering. It hurt, but it gave as well, it created suffering but also made me appreciate even more what life has to offer, and it created wholeness through embracing both pain and happiness. This is in line with Heidegger's thoughts on being and time. 'To be' can only be fully experienced by fully realising that one day one will 'be not', resulting in the insight that 'I will be not, therefore I am'.

Now that I am nearing the end of my PhD journey I can fully appreciate the comment from my Director of Studies that not anybody can do this type study. Of course, a perseverant researcher and support coming from the researcher's inner circle and supervisors proved to be crucial aspects, and without these it must be very hard to successfully complete a PhD. But my Director of Studies

meant more than that: because I am a mature person and a psychologist she could tell that I had the skills to undertake this hermeneutic journey. It took both the psychological theoretical underpinning and the communicative and counselling skills to maintain the ethical principle of doing no harm. I can now tell from experience that a study of this type should not be undertaken lightly, but I can also testify that successfully completing the journey is a most rewarding experience.

7. CONCLUSIONS AND RECOMMENDATIONS

It is important here to reiterate that most of the research reviewed for this study focused solely on the impact of cancer treatment on sexual function and therefore mostly on the acute treatment phase of cancer. However, cancer and cancer treatment may and often do have a major impact on sexual function, sexual sense of self and sexual relationship at all stages of the illness. A minority of the literature was aimed at exploring the impact on sexual identity and sexual relationship by focusing on the clients' perspective. However, when studying the clients' perspective, more researchers focused on patients than on their partners, and most studies were limited to one type of cancer. These studies revealed that all types of cancer (be it sexual or non-sexual) could have a major impact on sexual identity and sexual relationships, both for the patient and the partner. In the literature review, no phenomenological studies were found that studied the impact of cancer in general on the experience of sexuality and intimacy of both patients and their partners and in which joint interviews with couples were included. It was clear that the lived experience of patients and their partners needed further exploration as there was a gap in the literature. The only studies that were identified exploring communication about sexuality, including both sexes across a variety of cancer types, were a USA-based study (Flynn et al., 2011a), and an Australian study by Hordern and Street (2007c). None of these studies included partners of cancer patients or couples affected by cancer, hence the need for this study.

It was evident in this study that most health care professionals were not sure how and when best to address sexual issues, and therefore, did not do it at all or, as some of the participants pointed out, rushed through the subject in a manner that left no room for questions. Technically, they have acknowledged the relevance of sexuality for the patient (Redelman, 2008) but as Hordern and Street (2007c) found, there was clearly a gap between the professional's approach and the clients' needs and expectations. There appeared to be little evidence of pro-active information sharing, despite the fact that most professionals acknowledged the profound and enduring impact of a cancer diagnosis and treatment on all aspects of life.

This study was unique in that it included three perspectives: patients, partners and couples, thus it gave increased insights into the differing journeys of patients and partners and how using a one-size-fits-all approach fails to help patients and partners maintain the key elements of sexuality and intimacy in their changing relationships.

The willingness of patients and partners to share such intimate and sensitive aspects of their lives is an indication of the strength of their wish to provide the information that could be used to help other cancer patients and their partners. The lack of acknowledgement of such key issues of their lives has to be a cause for concern. For these patients and partners there is limited opportunity to redress the problem. Those in remission were no longer in contact with professionals who could raise the subject and were themselves unsure whom to contact. In contrast to those that had struggled to cope with their illness and in some cases were still struggling to cope with their changed sexuality and intimacy, were those who had found their own way forward. Examples from these participants were important as they informed the development of the practical tools and models.

This study has met all of the aims, indeed it has exceeded in some instances. For clarity, evaluation of the aims is presented using the same format as in the critique.

- Aim 1: To increase understanding of how cancer and cancer treatment impact upon the experience of sexuality and intimacy of patients and their partners.

The willingness of patients and partners to share their experiences increased understanding of how cancer and cancer treatment impacts on sexuality and intimacy and demonstrated how immense and varied the impact on these profound and enduring aspects of quality of life was, illuminating that there is no uniform causal way to predict this impact and how essential it is that this impact is carefully addressed.

- Aim 2: To increase understanding of how cancer patients and their partners experience the way health care professionals address sexuality and intimacy.

Patients and partners gave a very clear picture of how they experience the way health care professionals do (or more often don't) address these issues. There appeared to be an enormous gap between the needs of patients and partners and the guidance offered by professionals.

- Aim 3: To gain insight into health care professional's perceptions of their role regarding sexuality and intimacy for cancer patients and their partners.

Professionals indeed declared that they tended to shy away from these topics, with the main reasons given for this not realising how crucial these topics are and not knowing how to address these issues. Other professionals reported that they do address sexuality and intimacy and were willing to share their expertise.

- Aim 4: To develop patient driven models, tools and recommendations to acknowledge sexuality and intimacy in cancer and palliative care.

Supported by expert professionals (purposefully sampled participants in the current study; professionals consulted as part of the expert validation; professionals offering feedback on (inter)national presentations and workshops based on the study findings; professional authors in the literature) it proved to be possible to build bridges between clients and professionals by offering clear guidance based on practical models and tools that were outcomes of this study.

It cannot be stressed enough that the aims could only be reached through the support of the people who so willingly gave their time. The fact that the resonance coming from the study is so strong is only because the participants really gave of themselves. Hermeneutics is about partnership and dialogue. Participants had to be willing to create resonance in the researcher in order to enable the researcher to create resonance in others. In hermeneutics the researcher is the Hermes, translating the message from one group to another, using him or herself as 'the medium' that passes the resonance on. Participants from the client group were so determined to help other patients and partners that they were willing to share their time and their most intimate life to create the

dialogue that is at the heart of this study. Professionals gave valuable time and had the courage to step outside the trodden paths of medical routine and jargon to engage in a dialogue about how the highly personal topics of sexuality and intimacy are or could be an aspect of their professional care. They gave their trust by sharing how they are currently dealing with these issues, allowing the researcher to use that information to propose an overall strategy.

This study has contributed to the existing body of knowledge in several ways. Firstly, going through the hermeneutic circle by combining the findings from the study with Terror Management Theory and Heidegger's philosophical ideas, informed by a systemic view, resulted in new knowledge. The label of this new knowledge is 'worlds apart', the core theme of this study. 'Worlds apart' is a relevant theme on three levels: the level of patients and partners interacting with health care professionals, the level of patients interacting with partners and on the intra-psychic level of the patient. On all three levels bridges can and should be created in order to arrive at healing, mutual consolation and wholeness respectively.

Secondly, the study has produced a wealth of models and tools that can be used in health care education and practice. The competence required to address sexuality and intimacy in cancer and palliative care has been described, encompassing attitudinal, knowledgeable and skills-related aspects (box 3). A model combining the dimension of 'distant' versus 'proximity' with the dimension of 'taking care of yourself' versus 'taking care of patients and their partners' (figure 3) can help educators and professionals to become more aware of the balance required for professionals to offer good care while retaining their physical and mental health. A special version of the card game happy families was created to serve as an icebreaker when training professionals to expand their comfort zone regarding the use of sexual language (figure 5). Vignettes were created to capture the lived experience of cancer patients and their partners (appendix 7). They can be used as a tool to create resonance in professionals as a component of education and training and to motivate professionals to action. The stepped skills model (figure 4) was designed to demonstrate how health care teams could put sexuality and intimacy on their agenda while using complementing skills to acknowledge

these issues. The stepped skills model is an inclusive model which enables people either not confident or unwilling to discuss such sensitive issues to recognize the need and to refer on appropriately, thus they no longer have to ignore or avoid these important issues. These team members would be 'spotters' and the requirements to fulfil this role were presented in box 5. Other team members would have to be 'BLISSS-members' and they were offered the BLISSS communication model (box 4) to promote client driven communication about sexuality and intimacy in cancer and palliative care.

Thirdly, the study elucidated the value of adopting a hermeneutic approach when researching emotive contentious issues and demonstrated how a hermeneutic approach can be a means with a practical end. The hermeneutic approach gave understandings that for example content analysis or descriptive phenomenology could not have given, because the interpretation of the experiences gave way to focus on the dialogue and the interaction and the circular, systemic processes involved. The story that was created, based on the dialogue with participants, is appreciated and accepted by professionals who otherwise would not have gone down that path. It facilitates walking in the shoes of patients and partners; therefore, by creating the storyline professionals are offered a path into these issues. For busy professionals who don't have the academic background it is crucial they have an easy path in, because this will lower the threshold to follow it. It recognizes that too much too soon is overwhelming. It is a way of drip-feeding them emotionally charged information; they are given small amounts of knowledge that are easy to swallow so they can cope with it. The non-standard way of presenting the findings contributes to creating resonance in the reader, and by using the vignettes on their own accord a succinct way of capturing the findings was achieved, making it feasible to present them as part of training and education. By using the hermeneutic circle on all levels, going from the parts to the whole and back, from words to sentences; sentences to transcripts; transcripts to relevant literature, it was possible to find a conceptual thread expressed in the core theme and to develop many useful models and tools. Yet another hermeneutic circle was entered by presenting these outcomes to different national and international professional audiences, with overwhelming responses. Presenting the findings of the study proved to create resonance, with many professionals in the

audience acknowledging that the presentation of the findings moved them, resulting in professionals wanting to know more. They were disappointed to learn that not all outcomes of the study were published yet, and asked for copies of 'happy families' and the other tools and models. Presentations and workshops were evaluated very positively, resulting in more invitations to present, to do workshops and trainings, to publish and to give interviews. Presenting the findings resulted in two things: they made professionals aware of what the problems are, and they also motivated them to find out more and to do something with the insights the findings gave them. And that is what hermeneutics is all about, creating the dialogue and inspiring to action; the whole point about dialogue is it is exchange so by creating a dialogue professionals will look for the next thing, it makes them want more, so it moves them on themselves. An important criterion of the impact of a study is its authenticity: does it motivate to action, does it bring about change. In this emerging world as qualitative research develops more this is a crucial way to assess the effectiveness of what a study has produced, what the impact of the study is. Feedback to international presentations showed the universality of the problems addressed and the solutions offered, although in the solutions different nuances may need to be taken on board to do justice to cultural variation.

From the reception of the findings by professionals it would seem that hermeneutics was the right approach for this study. What this hermeneutic study did was

- allow health care professionals to relate to the patients, partners and couples. The vignettes and the quotes proved helpful in initiating a dialogue aimed at creating resonance
- raise awareness among professionals that patients and partners need and value their support to deal with sexual and intimate issues
- give professionals concrete models and tools to offer this support

Although this is a qualitative study, the nature of the hermeneutic cycle and the resonance it created was so strong that the following conclusions and tentative recommendations have been made, based on all aspects of this study,

including expert opinions and feedback from many different professional audiences, and on relevant literature. Recommendations are formulated in a non-descriptive way that does justice to the variation found in the sample of this study (and therefore in the population), and are based on analogous generalization (as opposed to statistical generalisation).

Conclusion

- The hermeneutic approach was a valuable approach to use in the context of this study, providing an in-depth exploration of the lived experience of participants.

Recommendation

- More recognition should be given to the benefit of a hermeneutic approach with sensitive and emotive issues. Cautionary note: it is not recommended for junior researchers and there is a cost to the researcher with this approach. Therefore, for the researchers adopting this approach there should be adequate backup and safeguards, as these are essential for this, also in order to protect participants.

Conclusion

- 'Worlds apart' is relevant theme on the level of patients and partners interacting with health care professionals, on the level of patients and partners interacting, and on the intra-psychic level of the patient.

Recommendation

- Efforts should be made to bridge the gaps on all levels, although at the same time it has to be acknowledged that gaps cannot be taken away.

Conclusion

- All types of cancer and cancer treatment can have an enormous adverse and enduring impact on the experience of sexuality and intimacy. Sexuality and intimacy are important components of quality of life until death.

Recommendation

- Sexuality and intimacy should be put on the agenda of every cancer and palliative care team and addressing these topics should be part of education and training for health care professionals.

Conclusion

- Cancer and cancer treatment impact on sexual function, sexual identity and sexual relationship, resulting in a unique outcome for every client or couple.

Recommendation

- A systemic client driven communication model, for example the BLISS model, should be adopted to discuss sexuality and intimacy in cancer and palliative care. Knowledge coming from studies exploring and interpreting the lived experience of clients should be disseminated to health care professionals, and should be part of their education and training.

Conclusion

- Health care professionals are struggling with discussing sexuality and intimacy with clients, due to both personal factors and lack of guidance.

Recommendation

- Using the model of stepped skills, team members can develop clear and complementing roles in order to properly address sexuality and intimacy issues. Team members should be trained to develop the competencies matching their role.

The way forward

Both national and international journals have asked for a contribution based on the findings of this study, and a UK Publisher has shown interest in publishing a user-friendly version of this thesis, resulting in more requests than could be handled within the time constraints of this PhD. Therefore some journals opted for interviewing the researcher. However, some publications are out (appendix 8), and more will follow. The next planned publication is the outcome of an invitation from an eminent researcher (who is one of the most frequently cited authors in this thesis) to co-author a paper with her, an offer that could not be refused¹⁵

The next step will be to implement and evaluate the effects of the stepped skills model and the BLISS communication model in cancer and palliative care practice. Relevant stakeholders are interested in participating in such a project and funding will be sought. The author of this thesis has now been invited to carry on with her line of study by doing a Dutch PhD (by publication) at the University Medical Centre Groningen, an opportunity that has been gratefully accepted. This will no doubt be very stimulating and further disseminate the findings of this study, so keeping the momentum and hence the dialogue going.

There is no end to a circle.....

¹⁵ This has now resulted in the publication of 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, 610-619.

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Sexuality and intimacy in cancer and palliative care

in The Netherlands: A hermeneutic study

Hilde de Vocht

Birmingham City University, July 2011

APPENDICES

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| Appendix 1: | The detailed debate that underpins the adoption of terms for use in this study |
| Appendix 2: | Written information sent to potential participants |
| Appendix 3: | Informed consent form |
| Appendix 4: | Overview of the final 22 codes of the PD-family 'couples' and the grouping of these codes into 'code families' |
| Appendix 5: | List of conferences and workshops where findings from the study were presented, discussed and piloted with health care professionals by the researcher Hilde de Vocht |
| Appendix 6: | Overview of the one-day training programme |
| Appendix 7: | Vignettes |
| Appendix 8: | Publications based on the study |

Appendix 1: The detailed debate that underpins the adoption of terms for use in this study

Many authors refer to a hermeneutic approach as 'interpretive phenomenology', but the terms 'interpretive', 'interpretative' and 'interpretivist' are conceptualised differently by different scholars and use of these terms might therefore be confusing. For example, Denzin and Lincoln (2005a p. 22) state that 'all research is interpretive; it is guided by the researcher's set of beliefs and feelings about the world and how it should be understood and studied'. Later on, the same authors use the word 'interpretive' to mark out 'interpretive epistemologies' (meaning that the knower and known interact and shape one another) (Denzin and Lincoln, 2005a p. 22)) and use 'interpretive' as an equivalent of 'qualitative' (Denzin and Lincoln, 2005b p. xv). Others delimit an interpretive paradigm as one of the prevailing qualitative paradigms besides other qualitative paradigms or philosophies (Leiba and Notter, 1996, Schwandt, 2000). Interestingly, according to Schwandt (2000), interpretivist epistemologies aim to reconstruct the self-understandings of people engaged in actions, and interpretevists claim that it is possible to do this in an objective manner. As Kerdeman (1998 p. 251) puts it: 'an interpreter's self-understanding neither affects nor is affected by the negation of understanding', and this Cartesian view is the main point that is challenged by philosophical hermeneutics.

What this demonstrates, is that the use of the label 'interpretevist' is very confusing, as many scholars make a distinction between (Husserlian) descriptive phenomenology and (Heideggerian / Gadamerian) interpretive phenomenology, using 'descriptive' where Schwandt would use 'interpretive' and 'interpretive' for what Schwandt would call 'hermeneutic'.

Trying to avoid the use of the word 'interpretive' one could consider using 'Heideggerian phenomenology' but some claim that this is an oxymoron, based on the claim that Heidegger never developed a 'phenomenology' in the sense of a research method, and consequently they reserve the term phenomenology to refer to Husserlian phenomenology. Therefore it would be more correct to speak of 'Heideggerian hermeneutics' (although it is based on Gadamer's ideas as well) or 'hermeneutic phenomenology'. This might again be confusing, as others have adopted the label 'hermeneutic phenomenological research' (Cohen et al., 2000), to indicate that they combine the features of descriptive and interpretive phenomenology, in a very similar way van Manen (Van Manen, 1990) and the Dutch Utrecht school of phenomenology do.

In order to make clear that in this study a methodology is adopted that is inspired by the philosophies of Heidegger and Gadamer the use of the word 'interpretive' is avoided and it is referred to as 'a hermeneutic approach'. A hermeneutic approach can be seen as an inquiry arm of philosophical hermeneutics. For many authors, this would be equivalent to the label: 'interpretive phenomenology' or 'Heideggerian hermeneutics' (Cohen et al., 2000).

The word 'interpret' is used in this thesis, meaning 'coming to an understanding of', as highlighted by Gadamer (1960/1982) by stating that to understand is to interpret.

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This reference list is presented in accordance with Endnote for Mac version 4 of the Harvard author-date system

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Appendix 2: Written information sent to potential participants

(The first form was sent to patients and partners; the second form to professionals. Forms are in Dutch, are in accordance with Dutch guidelines, and have been approved by the UK Director of Studies and the Dutch second supervisor.)

Informatie voor patiënten en partners:

‘Seksualiteit en intimiteit bij mensen met een levensbedreigende aandoening ’



umcg



Geachte mevrouw / meneer,

Hierbij willen wij vragen om uw medewerking aan een onderzoek naar het thema **‘Seksualiteit en intimiteit bij mensen met een levensbedreigende aandoening ’**.

Hoewel algemeen bekend is dat het hebben van een levensbedreigende aandoening verstrekkende gevolgen heeft, ook op het gebied van intimiteit en seksualiteit, is over de aard en omvang van deze gevolgen weinig bekend. Dat heeft onder andere tot gevolg dat handvatten voor begeleiding ontbreken. Behalve met patiënten zal daarom ook met professionals over dit onderwerp worden gesproken. Het uiteindelijke doel van het onderzoek is om de voorlichting en begeleiding over intimiteit en seksualiteit aan patiënten en, indien aanwezig en gewenst, hun partners te verbeteren.

Wat kunt u verwachten als u besluit mee te doen aan het onderzoek?

Als u en/of uw partner bereid zijn mee te werken aan het onderzoek dan zal ondergetekende namens de onderzoeksgroep¹⁶ eenmalig een gesprek met u voeren. In dit gesprek bespreekt u wat de invloed is van de levensbedreigende aandoening op uw beleving van seksualiteit en intimiteit. Wat u hierin verwacht van de mensen waar u binnen de gezondheidszorg mee te maken krijgt zal ook onderwerp van gesprek zijn.

¹⁶ Het onderzoek wordt uitgevoerd onder begeleiding van professor H.B.M. van de Wiel van het Universitair Medisch Centrum Groningen en professor J. Notter van de Birmingham City University.

Het is een open gesprek dat maximaal een uur duurt. Dit gesprek wordt met een voice recorder opgenomen.

Waar vindt het gesprek plaats?

Het gesprek wordt gevoerd op de plek van uw keuze. Desgewenst bent u ook van harte welkom op de Saxion Hogeschool. In dat geval ontvangt u uiteraard een vergoeding voor de gemaakte reiskosten.

Wat gebeurt er met uw gegevens?

Al uw informatie wordt vertrouwelijk behandeld en onder een codenummer bewaard. De enige die dus weet welke deelnemer aan het onderzoek bepaalde informatie heeft verstrekt, is de onderzoeker en haar begeleider. Gegevens worden uitsluitend op anonieme wijze verwerkt in de onderzoeksrapportage. Na afloop van het onderzoek worden al uw persoonsgegevens vernietigd.

Wat zijn mogelijke voor- en nadelen van deelname aan dit onderzoek?

U heeft zelf geen direct voordeel van deelname aan dit onderzoek. De bedoeling van het onderzoek is om nuttige informatie voor de toekomst te leveren. Hierdoor kan mogelijk de begeleiding aan andere mensen met een levensbedreigende aandoening en hun partners worden verbeterd.

Hoe nu verder als u wel of juist niet mee wil doen of nadere informatie wil?

Als u besluit niet mee te doen dan hoeft u verder niets te doen. U hoeft ook geen reden op te geven waarom u niet wilt meedoen. Niet meedoen heeft uiteraard geen gevolgen voor uw behandeling.

Als u in principe wel mee wil doen, dan kunt u contact met ondergetekende opnemen op de wijze die u het prettigst vindt (bellen, mailen of schrijven). De bedenktijd om al dan niet mee te doen aan het onderzoek bedraagt twee weken.

Ga ik door toestemming te geven een verplichting aan?

Als u definitief besluit mee te doen, dient u dit kenbaar te maken door een toestemmingsformulier te ondertekenen. Hiermee geeft u aan dat u vrijwillig besloten heeft aan het onderzoek mee te doen. Dit betekent overigens NIET dat u dan aan het onderzoek vastzit. U heeft altijd het recht om van gedachten te veranderen en zonder opgaaf van reden alsnog niet mee te doen.

Wilt u verder nog iets weten?

Met vragen over het onderzoek kunt u terecht bij de onderzoekster, mevrouw de Vocht (zie de contactinformatie onderaan deze pagina).

Met vriendelijke groet,

Drs. Hilde de Vocht / docent en onderzoeker Saxion Hogescholen

Academie Gezondheidszorg

Handelskade 75 7417 DH Deventer

[**h.m.devocht@saxion.nl**](mailto:h.m.devocht@saxion.nl)

Telefoon 06 1275 1295

Informatie voor gezondheidszorgprofessionals: 'Seksualiteit en intimiteit bij mensen met een levensbedreigende aandoening'



umcg



Geachte mevrouw / meneer,

Hierbij willen wij vragen om uw medewerking aan een onderzoek naar het thema **'Seksualiteit en intimiteit bij mensen met een levensbedreigende aandoening'**. Hoewel algemeen bekend is dat het hebben van een levensbedreigende aandoening verstrekkende gevolgen heeft, ook op het gebied van intimiteit en seksualiteit, is weinig bekend over de aard en omvang van deze gevolgen. Ook is weinig bekend over wat mensen met een levensbedreigende aandoening op dit gebied verwachten van de professionals waar zij binnen de gezondheidszorg mee te maken krijgen. In het kader van dit onderzoek zal hierover met patiënten en partners gesproken worden. Het uiteindelijke doel van het onderzoek is om de voorlichting en begeleiding over intimiteit en seksualiteit aan patiënten en, indien aanwezig en gewenst, hun partners te verbeteren. Hiertoe is het ook relevant om in kaart te brengen hoe gezondheidszorgprofessionals hun rol ten aanzien van deze aspecten zien.

Wat kunt u verwachten als u besluit mee te doen aan het onderzoek?

Als u bereid bent mee te werken aan het onderzoek dan zal ondergetekende namens de onderzoeksgroep¹⁷ eenmalig een gesprek met u voeren. In dit gesprek bespreekt u hoe u uw rol ziet ten aanzien van de aspecten seksualiteit en intimiteit bij patiënten met een levensbedreigende aandoening en hun partners. Het is een open gesprek dat maximaal een uur duurt. Dit gesprek wordt met een voice recorder opgenomen.

¹⁷ Het onderzoek wordt uitgevoerd onder begeleiding van professor H.B.M. van de Wiel van het Universitair Medisch Centrum Groningen en professor J. Notter van de Birmingham City University.

Waar vindt het gesprek plaats?

Het gesprek wordt gevoerd op de plek van uw keuze. Desgewenst bent u ook van harte welkom op de Saxion Hogeschool. In dat geval ontvangt u uiteraard een vergoeding voor de gemaakte reiskosten.

Wat gebeurt er met uw gegevens?

Al uw informatie wordt vertrouwelijk behandeld en onder een codenummer bewaard. De enige die dus weet welke deelnemer aan het onderzoek bepaalde informatie heeft verstrekt, is de onderzoeker en haar begeleider. Gegevens worden uitsluitend op anonieme wijze verwerkt in de onderzoeksrapportage. Na afloop van het onderzoek worden al uw persoonsgegevens vernietigd.

Wat zijn mogelijke voor- en nadelen van deelname aan dit onderzoek?

U heeft zelf geen direct voordeel van deelname aan dit onderzoek. De bedoeling van het onderzoek is om nuttige informatie voor de toekomst te leveren. Hierdoor kan mogelijk de begeleiding aan patiënten met een levensbedreigende aandoening en hun partners worden verbeterd.

Hoe nu verder als u wel of juist niet mee wil doen of nadere informatie wil?

Als u besluit niet mee te doen dan hoeft u verder niets te doen. U hoeft ook geen reden op te geven waarom u niet wilt meedoen.

Als u in principe wel mee wil doen, dan kunt u contact met ondergetekende opnemen op de wijze die u het prettigst vindt (bellen, mailen of schrijven). De bedenktijd om al dan niet mee te doen aan het onderzoek bedraagt twee weken.

Ga ik door toestemming te geven een verplichting aan?

Als u definitief besluit mee te doen, dient u dit kenbaar te maken door een toestemmingsformulier te ondertekenen. Hiermee geeft u aan dat u vrijwillig besloten heeft aan het onderzoek mee te doen. Dit betekent overigens NIET dat u dan aan het onderzoek vastzit. U heeft altijd het recht om van gedachten te veranderen en zonder opgaaf van reden alsnog niet mee te doen.

Wilt u verder nog iets weten?

Met vragen over het onderzoek kunt u terecht bij de onderzoekster, mevrouw de Vocht (zie de contactinformatie onderaan deze pagina).

Met vriendelijke groet,

Drs. Hilde de Vocht / docent en onderzoeker Saxion Hogescholen

Academie Gezondheidszorg

Handelskade 75 7417 DH Deventer

h.m.devocht@saxion.nl

Telefoon 06 1275 1295

Appendix 3: Informed consent form

(This form was used for patients, partners and professionals. The form is in Dutch, is in accordance with Dutch guidelines and has been approved by the UK Director of Studies and the Dutch second supervisor.)

Toestemmingsformulier onderzoek ‘Seksualiteit en intimiteit bij mensen met een levensbedreigende aandoening’

Ik bevestig dat ik de informatie voor deelnemers aan het onderzoek ‘Seksualiteit en intimiteit bij mensen met een levensbedreigende aandoening’ heb gelezen. Ik heb de gelegenheid gehad om aanvullende vragen te stellen. Deze vragen zijn in voldoende mate beantwoord. Ik heb voldoende tijd gehad om over deelname na te denken.

Ik weet dat mijn deelname geheel vrijwillig is en dat ik mijn toestemming op ieder moment kan intrekken zonder dat ik daarvoor een reden hoeft te geven.

Ik geef toestemming om de gegevens te verwerken voor de doeleinden zoals beschreven in de informatiebrief.

Ik stem in met mijn deelname aan bovengenoemd onderzoek.

Naam proefpersoon :

Handtekening :

Datum : __ / __ / __

Ik verklaar hierbij bovengenoemde proefpersoon volledig geïnformeerd te hebben over het genoemde onderzoek.

Naam onderzoeker:

Appendix 4: Overview of the final 22 codes of the PD-family ‘couples’ and the grouping of these codes into ‘code families’

CODING SCHEME COUPLES

Code family IG: IMPACT (of cancer and treatment) IN GENERAL

1. IG awareness
2. IG survival/coping
3. IG physical + other psychological (not 1 or 2)
4. IG pick up the pieces

Code family ISI: IMPACT (of cancer and treatment) ON SEXUALITY AND INTIMACY

5. ISI (no) changes
6. ISI physical
7. ISI psychological
8. ISI pick up the pieces

Code family COM : COMMUNICATION WITH HCP'S

9. COM (no) initiative /they should do it
- 10.COM who
- 11.COM timing
- 12.COM age
- 13.COM sex
- 14.COM hindering
- 15.COM helping
- 16.COM tips
- 17.COM NOS

Code family REPRO: RESEARCH PROCESS

- 18.REPRO systemic effect / intervention
- 19.REPRO horizon researcher
- 20.REPRO feedback interview

Code family CONTEXT

- 21.CONTEXT immaterial
- 22.CONTEXT material

Appendix 5: List of conferences and workshops where findings from the study were presented, discussed and piloted with health care professionals by the researcher Hilde de Vocht

19-9-2009: Graz (Austria), European Doctoral Conference Nursing Science: 'Sexuality and intimacy in palliative care'

12-3-2010: Bournemouth (UK), The 8th Palliative Care Congress: 'Sexuality and intimacy in palliative care in the Netherlands'

4-6-2010: Rotterdam (the Netherlands), the 2nd Rotterdam Symposium on Cancer and Sexuality: 'Sexuality and intimacy: impact of cancer & discussion with health care professionals from a clients' perspective'

16-6-2010: Birmingham (UK), Research Students' Presentation Day: 'Sexuality and intimacy in cancer and palliative care in the Netherlands'

17-6-2010: Ede (the Netherlands), National Congress Palliative Care: 'Intimacy and sexuality in palliative care' (key note) + workshop sessions

24-6-2010: Enschede (the Netherlands), 23rd Annual Scientific Meeting European Association Cancer Education: 'Sexuality and intimacy: input for cancer and palliative care education from the client's perspective'

25-3-2011: Antwerpen (Belgium), training 'Sexuality and intimacy in palliative care' for community palliative care team

19-5-2011: Lisbon (Portugal), European Association for Palliative Care Congress: 'Sexuality and intimacy from the clients' perspective: How are health care professionals to discuss the impact of cancer?'

14-6-2011: Ede (the Netherlands), National Congress Palliative Care: 'Intimacy in palliative care' (key-note) + workshop sessions

17-6-2011: Washington (USA), Cancer Survivorship and Sexual Health Symposium: 'Sexual intimacy in couples coping with cancer: How are health care providers to discuss the impact of treatment?'

16-9-2011: Maastricht (the Netherlands), European Doctoral Conference Nursing Science: 'Sexuality and intimacy in cancer and palliative care: a hermeneutic study' (Award for Best Oral Presentation)

Appendix 6: Overview of the one-day training programme

Opening

Introduction intimacy and sexuality (power point 1)

Card game 'Happy families'

Impact of cancer and cancer treatment on sexual function (power point 2)

Team exercise: opinions

Introduction verbal communication (power point 3)

Mini-survey

LUNCH

Read vignettes: impact on sexual identity and sexual relationship (power point 4)

Exercise verbal communication

Results mini-survey: team policy (power point 5)

Introduction non-verbal communication (power point 6)

Exercise non-verbal communication

Write yourself a post card

Evaluation

Appendix 7: Vignettes

Vignette 1: Moment of truth

You have an appointment with your oncologist today. You have some symptoms that have caused you concern and you have had some tests. Today your oncologist is to tell you the results. The days between the tests and today were the longest and most difficult of your life. Last night you did not sleep at all. You are now sitting in the waiting room and you are very nervous. The nurse comes to call you in. You scan her face to see what it tells you but it is neutral. You feel lost and afraid. Then you meet your oncologist. The appointment lasts for 10 minutes but your whole world revolves around those 10 minutes. This is what happens.....

Vignette 2: No longer taking for granted

The cancer diagnosis felt like a real blow. From that moment on, the way you experience your body has changed. Before your diagnosis, you never really thought about your body as a 'functioning body', it simply **was**. The diagnosis of cancer has disrupted the self-evident character of this 'perfectly functioning body'. You now feel like you **have** a body and you feel betrayed by it, because it is now problematic and defective. Nevertheless, this is the one body you have, and this is the body you will have to 'deal' with; there is no alternative. All you want now is to restore the healthy body again. Your focus is on getting rid of the cancer, on treatment, on survival.

Vignette 3: Unshareable

It is now one week since you got your cancer diagnosis and you have told your relatives and closest friends about it. Some of them say to you: 'I can imagine what you must be going through' but you don't think they can. You remember saying this yourself to other people who got cancer before you, and you now realise you had no idea what you were talking about. Now you know from your own experience what it is like to be diagnosed with cancer, but you cannot really explain this to other people. When you try to communicate how you are feeling, you hear yourself say 'it is **as if** my world is upside down' or 'it is **as if** everything is out of perspective' so you can tell what it is like but not how it **is**. It is like your whole existence is completely lacerated, whereas in the rest of the world, somewhat to your surprise, it is business as usual. Your closest friends, although very sympathetic, rush back to their own lives, leaving you behind with this feeling of being on your own. It's you and nobody else who experiences what this cancer diagnosis means to you. Even to your partner, who is trying to support you the best he can, you cannot convey the enormous impact of knowing you have cancer has for you. He is trying to stay calm and reassuring and although you know this is what you need, you would sometimes like to hit him really hard and shout '**I have got cancer for godsake**' to disrupt his calm and make him feel the intensity of your emotions.

Vignette 4: What to expect.....

You are anxious; this is a very important day for you, you are about to find out what is going to happen now the oncologist has decided on your treatment. He is discussing it with you, so you will know what to expect. He has a long list of possible side effects to go through, and briefly mentions 'dryness of the mucosa'. You have no idea what this means, but you don't really pay much attention to this one point; there is so much information to take in, you need to remember it all but are finding it hard to concentrate, there is so much going on inside your head. You want him to stop, but at the same time you think you should know everything.

After this appointment with the oncologist you see the nurse. She seems a nice person so you are hoping for a 'human touch' and some consolation, as you feel very confused and slightly panicky about everything that is happening to you; it feels like a bad dream that you can't get out of. This is what happened next.....

Vignette 5: Changes in the bedroom

In the privacy of your home, you are still locked in your nightmare, so in the bedroom things have changed as well. The thought of sex has not once crossed your mind since you got your diagnosis. Sexuality is just not in your mind, despite the fact that you and your partner used to have a pleasant and satisfying sexual relationship. You are focused on survival, you are mentally trying to prepare for the treatments you are facing and this requires all the energy you've got. Thinking about what the loss of sexuality means to your partner is even further out of mind and you simply assume (s)he is thinking the same way you are.

Vignette 6: Goodbye to your sex life (for now)

Your partner has been diagnosed with cancer and is waiting for her treatment to start. Like her, you were shocked to find out that she is seriously ill. Of course, her health and well being is your first concern, but on the other hand you are still a healthy person with a 'healthy' sexual interest. You miss the warmth and the feeling of 'merging' with her, and you feel that making love would help you to cope better. You're in a bit of a dilemma and you feel guilty and ashamed about this, here is your partner seriously ill and you are thinking about sex; why can't you get rid of these thoughts? And of course you don't want to ask anything from your partner that he or she feels not ready for, but for you it feels as if a pleasant, comforting and exciting sex life has very abruptly been cut off, at least for now. It might take some time before she is ready for it again and you will wait patiently for that moment to arrive, but you are looking forward to it already...

Vignette 7: Unwanted friend

You have woken up from your surgery with a stoma. The nurse said you have to 'make friends' with it, but even now that you are back home you still don't feel like 'making friends'. For you the stoma is an unwanted friend and you find living with it neither easy nor pleasant. At first you avoided going out altogether, as you were afraid other people might perceive noises or smells coming from your stoma. Just the thought of that made you very anxious and insecure. For you, this stoma is an obstacle that is always in the way, especially when you want to be intimate with your partner. You don't like this new 'friend' at all; it's like an intrusive and uninvited visitor who is always on your tail and that you can't shake off. Your GP tries to put things in perspective by reminding you that if you had not had the operation including the stoma, you would have been dead by now.... You know this is the case, and you **are** grateful to be alive, but that doesn't make living with a stoma any better...

Vignette 8: Room 212 bed 4

Last Friday you got your cancer diagnosis and your oncologist suggested you start treatment straight after the weekend. It is now Monday evening and you are back home after your first chemotherapy. You are letting this experience sink in. You had no idea what to expect from this first day of treatment, although the procedure had been outlined to you. The oncologist had explained that the chemo cannot cure you, but it will help to improve your quality of life. He told you not to worry too much, as some patients just come in to have their chemo and then go back to work again. You were glad your partner came with you today as you still feel shocked, confused and muddled. Over the weekend you had to tell your parents and your children what is going on and the memories of their disbelief, anger and despair still stand out clearly in your chaotic mind.

You checked in to the hospital this morning and the nurse told you you were in bed 4 in room 212. So you and your partner looked for room 212 and went in, to find three other patients there. They looked rather skinny and a bit yellowish. You were terrified. Seeing these sick people brought back the shock element from the diagnosis. It was a reality check: is this going to be you in a few months? Nobody explained that to you; you feel ok and they all look sick. Your partner was aghast, and you didn't know how to help. You tried not to show how frightened you were. The nurse came in and explained to you what she was going to do. She did not acknowledge your partner, who, like you, was desperately in need of kind words and reassurance. The nurse was not unkind, but you felt like a number, another cancer patient to deal with. There was no recognition of what you and your partner were going through. You felt very lonely and even more afraid.

Although you assume your medical treatment was appropriate, you don't feel the nurse has shown much care or understanding of what all this means to you and your partner. And if they don't notice and care for you in this time of crisis, how could they ever care about the even more subtle and personal aspects of your life? One thing you know for sure now is that if these people ever would start to address intimate issues, you would definitely say you don't feel the need to discuss them.

Vignette 9: Whose body is it anyway?

You are back in hospital for more surgery. You are, again, waiting to be seen. If you are honest, you have had more than enough of this. Everybody seems to have the 'right' to touch you wherever and whenever they want. They even take all sorts of 'samples' of you when they feel the need. You would really like to have your privacy back and you don't want to be touched or treated any more ... but here they come again.

Vignette 10: Explosion

You are **furious**. Because some lumps had been detected in your breast you handed over your body to your doctors and nurses and it was their role to take care of it. After all, this is their area of expertise so you put your trust in them. They decided to take two small lumps out of your breast and you were told this was just a precaution and that there was nothing to worry about. These lumps turned out to be two small malignant tumours and you had to undergo surgery again and more breast tissue was removed. This time they and you were confident that the results would be ok. It was a complete shock that the oncologist told you that so many small cancer 'spots' had been found that they now need to remove your breast entirely. You asked if they would be removing some lymph nodes as well. The answer was: 'no, that will not be necessary'. You have now had your mastectomy and the surgeon has just been to see you (joined by four other people, two junior doctors and two nurses, and nobody asked if they could come in too). After he and what felt like the whole world looked at it, he said the wound looked fine. As he was about to leave the room he said: 'so now we will just have to wait for the results of the nodes we took out'. You replied: 'the nodes?' 'Yes' he said, 'we had to do a partial axillary clearance after all'. You were shocked and said 'but that was not the plan'. He said: 'oh, but there is no need for you to worry about it at all, I am sure they won't find anything'. At this point you exploded. Five weeks ago you were told not to worry and now you are lying here with your breast removed and the nodes gone, and once again you are told 'not to worry'. You angrily asked him to leave saying you don't ever want to see him again. You were determined, so after a bit of protest they all left. Just before leaving the room the junior doctor who was last to go turned around and gave you a thumbs up...

You are still furious, thinking it is easy for him to say there is no need to worry, but you don't believe him anymore. They've told you that so many times and it just wasn't true ... You don't feel taken seriously. But it was nice of the junior doctor to support you, even though he did it in a way only you could see. But at least there was somebody kind enough to show he understood...

Vignette 11: Multitasking

You are trying your very best to maintain a normal life. Of course, you are trying to support your partner (who is now in hospital) the best you can, but you also have to take care of the children and the pets, go to work and perform household duties like shopping and cooking, not to even mention the cleaning. The phone rings all the time because friends and relatives want to know how your partner is doing; very kind, but it takes a lot of your time and energy, especially when your partner's parents call. Your mother in law is so worried that she is crying on the phone, so you try to comfort her while the cat is chasing a fly into the net curtains. You look at the clock, you should be at the hospital, it's visiting time.

When you get to the hospital, a bit late, your partner is so sick she prefers to be left alone. So you leave, without even having had the chance to talk with her for a bit. You drive back home. Your house feels dark and cold, and your bed is empty.

Vignette 12: See me, feel me, touch me, heal me.....

You are feeling vulnerable. You were shocked to find out you had cancer to begin with, and the operation has left very concrete 'evidence' of the cancer. As a girl, you could not wait to have a cleavage, and it was only after your first pregnancy you finally got one. For you that was a source of pride. You never thought of yourself as a beautiful woman and your breasts were the only aspect of your body you were really pleased with. Now they are gone and you feel ashamed about this. Your partner does not really seem to understand what all this means to you. He simply says there is no need to be ashamed. You would like him to comfort you, but he doesn't really seem to see or feel the need. He was never much of a cuddler anyway. When you ask him to put his arm around you he does, but it doesn't feel the same as a spontaneous cuddle, which is what you would really like. You can't make him understand what you have lost, he just keeps saying 'at least you are still here'. You feel the operation has taken your sexuality away and you can't see a way to get it back. There is no intimacy to replace it either, so all in all not much comfort is coming from your relationship at the moment. You are afraid the cancer will come back, but your partner does not want to hear this. He says: 'the surgeon said that the goal is to cure you, so you should focus on the positive, end of story'. You feel so lost and alone ...

Vignette 13: Back to normal?

Treatment is over. After a final check-up by your surgeon you are leaving the hospital. You are told to come back in three months time: see you in September! For you this feels like they said to you: "Goodbye and good luck with your life". All of a sudden you find the hospital door closed behind your back and you ask yourself: where do I go from here? Up to now there have been medical treatments to follow and you were busy fighting your way through them, but now suddenly you are supposed to be back in control and you find that rather difficult. Friends and relatives see you as 'cured' so everybody is happy for you and expects you to pick up your normal life again. But to you, it feels like you are at the very beginning of the journey towards 'a normal life'. What does 'back to normal' mean anyway? You know you will never be the same again, physically or mentally. You will have to live with the fact that somebody had to alter your body surgically in order for you to live. After the initial blow from being diagnosed with cancer, the treatment you needed has further deepened your awareness of your fragility and vulnerability. You have lost your faith in your body, it has let you down and the scars this has left are a constant reminder of changes that run much deeper and are there to stay. But now you have to 'pick up' your life again, but you have no idea how...

Vignette 14: Fog is lifting

Now that you are coming back into 'yourself' it is more and more like fog is lifting. Your scope becomes broader than 'survival' and 'treatment' again and you are becoming more aware of what has been and is going on around you. You start realising that your partner has needs for sexuality and intimacy, and that especially in the domain of sex your partner has been neglected for some time. And although this is not your fault, you feel guilty and uneasy about it. Fear that your partner may be finding someone else is creeping in and you don't like that idea at all. But you don't feel like having sex yet, your body feels different and vulnerable and you are afraid sex might hurt or might damage things. So you postpone it a little longer, although you are well aware that you can't postpone it forever ...

Vignette 15: Little pains ...

Two months after your operation (in your genital area) you still experienced a lot of pain. You couldn't even sit down properly. This had a great impact on you and your daily life. You couldn't lead a normal life with your family due to the pain and the difficulty of movement. Sexual intercourse was out of the question. You discussed your pain with your surgeon when she saw you for a post-operative check. She replied that this is a matter of scar tissue (without examining the painful area). When you saw her for your next appointment, you again complained about the pain that was still there, disrupting your life. This time the surgeon told you not to think of your 'little pains'. Finally, half a year after the operation, they found that you still have a metal stitch in place that should have been removed.

Even now, after the stitch has been removed, the after effects are still there because the area was so inflamed it is taking ages to heal.

Vignette 16: Bring it up

You and your husband have not made love for quite some time. You are wondering whether your nurse will ask you about the intimate side of your life, but she doesn't. You think: 'If she doesn't mention it, I don't know how to say anything either'. You are worried though. Sexuality was part of the whole of your relationship, and you feel you have lost it. How are you going to deal with that? How can you still experience intimacy with your partner, especially now that you know that in the end his cancer will kill him? How to share the grief and distress and how to shape the final goodbye? Just words are not enough to express how you feel ...

You cannot discuss these things with your children or family. You feel the need to share your worries with somebody professional, who knows about these things and who might be able to offer some help and support. But maybe you are the only one struggling with these issues.... If you would bring them up they might think: 'she is oversexed', so you decide not to talk about it ...

Vignette 17: To know or not to know

Today you took part in a research interview. The researcher asked whether you think of your illness as life threatening. You replied that you should see it that way, as your cancer has now spread to your liver, but that you are burying your head in the sand. Of course, every now and then you are confronted with the facts, but you find it a waste of your time to allow them to influence your whole life. You don't know whether that is realistic or not, but it is your survival strategy. You are trying not to be occupied with it all the time. Of course you do have physical limitations but you are just not going too deep into acknowledging that, because it might be too painful to confronting that before too long you will not be there anymore. The thought that you will no longer be able to be a mother to your 14-year-old son is just too painful.

Vignette 18: Never again

You used to have an enjoyable sex life with your long-term partner. It was not very spectacular and the frequency of intercourse wasn't very high, but for you and your partner it was fine as it was. Overall your partner's need for sexual contact was greater than yours. This never caused any problems; you could always find a 'middle ground'. Now things have changed drastically. Your partner is incurably ill and your sex life has come to a stop, because your partner doesn't have any sex drive at all. As a result you are very confused and restless. The idea that you will never have sex again with him is becoming an obsession. You keep trying to bring back to your memory when was the last time you made love, and how that was for you and your partner. You find it very hard to accept the finality of this 'last time' and you are craving for sexual contact with your partner now that you know you will never have it again. At night, you leave the bed you share with your partner to sleep in the spare room. Although you never used to do this, you masturbate every night to bring some peace to your restless body. It is the only way you can get some sleep ...

Vignette 19: There is still something we can do to.....

Your doctor has been clear: you are terminally ill and there is nothing he can do to cure you. You are feeling weaker and weaker, spending most of your time on the settee during the day and dragging yourself upstairs to bed for the night. A special bed has been put in your front room, but you are dreading the moment you will have to lie on that bed, as you are afraid you might never come out of it again. Until recently, you were undergoing chemotherapy, but as this no longer had a beneficial effect on your cancer, treatment has now stopped. However, the doctor has suggested another way to prolong your life: you can come to hospital to have blood platelets infused into your bloodstream. You went for this, but you are now beginning to find it a burden. Every day you need to have the level of platelets in your blood checked and based on the results you will be told whether or not to come into hospital for another transfusion. Although the hospital is not very far from your house, you find it very tiring to go there and back. Weak as you are, you still want to prepare for this hospital visit by dressing up and putting on some make-up. Your partner tells you not to bother, but for you it is very important. You were always proud of people estimating you much younger than you are, and you still want to be presentable. You told your doctor that you are now finding the transfusions quite difficult, but he persuaded you to carry on, as this will prolong your life. "There are still things we can do" he said, so you went again. You have now come to the point that you really don't want to go anymore. You are now lying in the special bed in the front room. Last night there was a real panic because you had a serious nosebleed that did not stop. You had to be taken to hospital in the middle of the night. You were afraid you were going to die but once in hospital they managed to stop the bleeding. You don't want to have to go through this extremely frightening experience again. Also, you don't want to have another complication, in case this results in you dying in hospital. You want to die at home. You ask your husband to cancel your appointments. Your doctor rings you to let you know he was expecting to see you again as you might benefit from another transfusion. This upsets your husband because he wonders whether he was not clear when cancelling the appointments, did he do something wrong? So you speak with your doctor and you find it difficult to say no to him, but you feel ill and you stick with your decision.

Vignette 20: The consolation of intimacy

For the first time since your partner died a few weeks ago, you have the space to reflect on the hectic period you have gone through.

When your partner was terminally ill and the devastating impact of the illness was beginning to show, you no longer felt like having sexual contact. Looking back, you think you suppressed your own need for that ... because your partner needed his energy differently. Toward the end you preferred intimacy, mainly just holding your partner's hand. That was very important to you. That's what you did at night, you felt for his hand and that was good, so you could both sleep. That was all, no need to make love, but just to touch ... to feel. Hands were very important then. And that's in fact all you need ... gestures and touches do say more than a thousand words. It made you and your partner feel so deeply connected ... That's what you miss most now that your partner has died. Just to be able to hold his hands ... On the other hand you derive much comfort from the intimacy you shared, in particular from the physical intimacy you had, cuddling, touching. It was good, it was beautiful, and to be able to look back at it this way is a great help in your grieving process.

Appendix 8: Publications based on the study

For copyright reasons the full-text versions of the publications have been left out of this appendix. They were open for inspection by the examiners and can be accessed through the journals they were published in:

- ANONYMOUS 2011. Hilde de Vocht onderzoekt seksualiteit en intimiteit bij kankerpatienten: Minder lust, meer liefde? [Hilde de Vocht studies sexuality and intimacy in cancer patients: Less lust, more love?]. *Pal voor U*, 1, 30-31.
- BRUNTINK, R. 2011. Meer praten over seksualiteit en intimiteit in de palliatieve fase [More communication about sexuality and intimacy in palliative care: interview with Hilde de Vocht]. *Bijzijn*, 7-8, 24-25.
- 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, 610-619.
- DE VOCHT, H., NOTTER, J. & VAN DE WIEL, H. 2009. Sexuality and intimacy in palliative care. *Verpleegkunde*, 4, 33.
- DE VOCHT, H., NOTTER, J. & VAN DE WIEL, H. 2010a. Communicatie over seksualiteit en intimiteit in de oncologische en palliatieve zorg [Communication about sexuality and intimacy in cancer and palliative care]. *TvZ*, 9, 32-37.
- DE VOCHT, H., NOTTER, J. & VAN DE WIEL, H. 2010b. Seksualiteit en intimiteit in de zorg, wat doen we ermee? [Sexuality and intimacy in professional care, what are we going to do with it?]. *Tijdschrift Geestelijke Verzorging*, 13, 30-44.
- DE VOCHT, H., NOTTER, J. & VAN DE WIEL, H. 2010c. Sexuality and intimacy in palliative care in the Netherlands. *Palliative Medicine*, 24, 215.
- TAYLOR, B. & DE VOCHT, H. M. 2011. Interviewing separately or as couples? Considerations of authenticity of method. *Qualitative Health Research*, 21 1576-1587.