Sexuality and intimacy during terminal illness: a qualitative multi-method study about the experiences of patients and partners, and the role of palliative care nurses

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Doctoral dissertation

Dissertation submitted in the fulfilment of the requirements to obtain the PhD-degree in:

Social Health Sciences
Faculty of Medicine and Pharmacy
Vrije Universiteit Brussel

Mental Health and Wellbeing Research Group (MENT)
Vrije Universiteit Brussel

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CONTENT

Chapters 2-7 are based on the following publications

Chapter 2

Benoot, C., Saelaert, M., Hannes, K., & Bilsen, J. The sexual adjustment process of cancer patients and their partners: a qualitative evidence synthesis. *Archives of sexual behavior*, 2016 *46*(7), 2059-2083. IF_{2016} 2,720 Q1

Chapter 3

Benoot, C., Hannes, K., & Bilsen, J. The use of purposeful sampling in a qualitative evidence synthesis: A worked example on sexual adjustment to a cancer trajectory. *BMC medical research methodology*, 2016, *16*(1), 21.IF_{2016} 3, 295 Q1

Chapter 4

Benoot, C., Enzlin, P., Peremans, L., & Bilsen, J. The meaning and expression of sexuality in terminal cancer: experiences of patients, partners, and bereaved partners. *(submitted)*

Chapter 5

Benoot, C., Enzlin, P., Peremans, L., & Bilsen, J. Intimacy during terminal illness: Dynamic meaning making of lived and anticipated relationship losses. *(submitted)*

Chapter 6

Benoot, C., Enzlin, P., Peremans, L., & Bilsen, J. Addressing sexual issues in palliative care: A qualitative study on nurses' attitudes, roles and experiences. *Journal of Advanced Nursing* (In press) IF_{2016} 1,998 Q1

Chapter 7

Benoot, C., Enzlin, P., Peremans, L., & Bilsen, J. " It's in the little things": how nurses offer relationship support to couples in palliative care. *(Submitted)*

PART I

GENERAL INTRODUCTION

CHAPTER 1

GENERAL INTRODUCTION

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1.1. Introduction

Living with terminal illness is probably a stressful and upsetting experience for most people. Patients living with the awareness that the end of life is approaching experience their life as increasingly unpredictable, are in an unconquerable struggle to maintain control (Rydahl-Hansen, 2005), commonly experience substantial pain (Weiss, Emanuel, Fairclough, & Emanuel, 2001), and suffer from clinical depression (Breitbart et al., 2000). Partners, in turn, often suffer by worrying about the imminent loss of their partner and about their ability or inability to continue their role as caregiver (Manne & Badr, 2008; McLean, Walton, Rodin, Esplen, & Jones, 2013). A terminal illness also affects a couple as a unit, rather than only the isolated individuals. The couple must cope together with additional challenges such as anticipatory grief, role and lifestyle changes and changes in responsibilities. Furthermore, they need to negotiate difficult choices regarding end-of-life care, and have to talk about the ill partner's legacy(Manne & Badr, 2008; McLean & Jones, 2007; McLean et al., 2013; Tie & Poulsen, 2013). When the end is nearing, patients and their partners also wish to say goodbye, to spend time with each other, and sometimes to resolve longstanding conflicts (Sherman, 1998; Zaider & Kissane, 2009).

It has been shown that quite a lot of couples are particularly vulnerable to relational difficulties as the patient's health starts to deteriorate during terminal illness (Persson & Sundin, 2008). More specifically, in one study, 33 to 50% of patients and their partners reported experiencing relational distress during the terminal illness of one of the partners (McLean & Hales, 2010). From a couples' perspective, successful adaptation may not be dependent on the physical circumstances of the terminal illness, but rather on how well the couple integrates illness, and relational challenges in this stage of life (Manne & Badr, 2008). One of the relational challenges patients and partners have to face together and integrate into their lives are changes in their intimate and sexual relationship. This implies that healthcare providers working in palliative care should be able to support couples who have difficulties with their intimate and sexual relationship. Although the holistic philosophy of palliative care – which considers both patients and close relatives as the unit of care – encourages healthcare providers to address intimacy - and sexuality-related issues, healthcare providers indicate difficulties doing so, due to their lack of knowledge and skills (Higgins, Barker, & Begley, 2006).

In this introduction, we first want to present a general understanding of a couple's relationship when one of the partners has a serious illness such as cancer, by describing different frameworks depicting the role of relationship processes in couples dealing with serious illness as cancer (1.1.). In that context, we will also describe our own framework. Next, we will focus particularly on intimacy and sexuality in couples dealing with terminal illness, by explaining in detail the difference between the two concepts (1.2). Also, we will discuss the importance of both intimacy and sexuality in the context of terminal illness, as well what is known and still lacking in the literature (1.3.).

Next, we will focus on palliative care nurses and what is known about how they address sexual and intimate relationship issues (1.4). To do so, we will first describe the palliative context, and the reason for focussing on the palliative care nurses. We will describe the relevance of addressing these issues in palliative care, as well what is already known and still lacking in the research literature about the way they address issues related to intimacy and sexuality.

In what follows, we will describe the study objectives and research questions (1.5), the methods being used in this dissertation, (1.6), the theoretical considerations (1.7) , and the outline of the dissertation (1.8.).

1.1.1. Couple relationships in the context of terminal illness

We will give a short overview of possible approaches to research into couples' relationships in the context of terminal illness or cancer, to arrive finally to our own argumentation for our particular conceptualization of intimacy and sexuality as specific couple relationship processes.

Approaches focussing on the impact of a serious illness on marital quality

The first approach derives from the view that common factors – such as terminal illness – impact on both the patient and partner and affect an entire family system (Baider & De-Nour, 2000; Kissane, 2000) Most of this research focuses on the quantification of the psychosocial impact of the illness on both partners. These studies mostly indicated that, although patients usually have a higher distress levels than partners(e.g. Verdonck-de Leeuw et al., 2007), the levels of distress of seriously ill patients and that of their partners are inextricably linked (Manne & Badr, 2008) (McLean & Jones, 2007; L Northouse, 1989) (Hodges, Humphris, & Macfarlane, 2005; Loaring, Larkin, Shaw, & Flowers, 2015; Murray et al., 2010). In this context, there has been also some research on the impact of the illness on marital satisfaction (e.g. Giese-Davis, Hermanson, Koopman, Weibel, & Spiegel, 2000). Northouse et al. (1989) reported that couples facing advanced disease reported significantly less marital satisfaction than couples with early stage disease, and that these decreases persisted over time.

Approaches focussing on couple relationships as a resource for adjusting to serious illness

Some approaches view couple relationships primarily as a resource for the patient to draw on during serious illness (Manne & Badr, 2008). There are studies that investigate how talking with a partner help emotional processing (Badr & Taylor, 2006; Pistrang & Barker, 1992), studies that show how a spouse can provide practical and emotional assistance that protects against the negative effects of illness (Manne, Taylor, Dougherty, & Kemeny, 1997), and studies that place emphasis on the exchange of support between partners and the value that partners place on the level of equity in their support related exchanges (Kuijer, Buunk, & Ybema, 2001).

Towards a relationship-centred approach

The aforementioned studies on couples confronted with serious illness focused mainly on outcomes – for example the influence of the illness on the quality of the relationship or vice versa – and did not offer a detailed insight in the processes and interactions that led to these outcomes. Moreover, most resource theories focused on the individual as the unit of study and saw the relationship as a source of support to draw on (Manne & Badr, 2008; Park, 2010). It has been suggested that there is a need to focus more on a couple as a unit, and more narrowly on the specific interactions between partners (Weingarten, 2013), in our case intimate and sexual interactions.

This approach is in line within a new trend, which is however still in its infancy, that proposes a discourse of dyadic level theory (Manne & Badr, 2008) or relationship-centred research (Li & Loke, 2014; Lo et al., 2013; Lyons, Miller, & McCarthy, 2016). It puts more emphasis on the patient-partner dyad, i.e. it investigates the interactions between patients and partners. It encompasses approaches that propose investigating the strategies that partners use to strengthen their relationship, which might eventually help to adapt to serious illness (Badr & Taylor, 2008). It also encompasses those approaches that specifically investigate communication patterns, conflict resolution strategies and problem-solving skills in the context of serious illness (Manne & Badr, 2008; Manne et al., 2006).

The approach used in this dissertation is inscribed in the aforementioned relationship-centred discourse by conceptualizing patients and partners as an interdependent emotional unit (Broom & Kirby, 2013; Nebel, 2011). This is reflected in the chapters that will focus on how patients and partners reframe their sexual and intimate relationship, and on how their meaning-making of the illness and the losses/changes in sexuality can be seen as *a shared* process. We thereby adhere to the belief that the discovery of important and helpful interactions can be a step forward in the development of guidelines for practice and policy (Morhardt & Spira, 2013). This relationship-centred approach is also visible in our conceptualization of intimacy and sexuality that is described below, and that also focuses on the interactions and negotiations between patient and partner.

1.2. Conceptualization of intimacy and sexuality

1.2.1. Difference between intimacy and sexuality

Very often, intimacy and sexuality are not defined at all in empirical, qualitative articles that investigate these concepts it in the context of (terminal) illness (e.g. Taylor, 2014). Moreover, the concepts of intimacy and sexuality are often confused and are used interchangeably (DeFord & Gilbert, 2016) or intimacy is – perhaps deliberately - used as a euphemism for sexuality (Couper et al., 2006).

In this dissertation, we have chosen to separate the concepts of sexuality and intimacy. Intimacy is used when we want to refer to emotional and psychological aspects in a relationship, and sexuality is used – although not uniquely – to refer to relational aspects related to the body and senses. Although it is acknowledged that sexuality cannot be regarded in isolated from emotional and psychological intimacy, we have deliberately chosen to not include the term "intimacy" in our definition, as we wanted to avoid the risk of using this as a "euphemism" for sexuality, thereby implicitly agreeing with the general assumption that sexuality is not a suitable topic for the final stage of life, in the context of terminal illness. In what follows, we will further introduce both concepts so that it becomes clearer what the differences and similarities between the concepts are.

1.2.2. Intimacy as a relationship process

Prager (1997) was the first to split the concept of intimacy into an outcome aspect – i.e. an intimate experience or the quality of an intimate relationship – and an interactional aspect – i.e. a set of interactions and communication processes that partners typically use to regulate relational intimacy. In line with the relationship centred-approach that focuses on interactions, we have chosen to conceptualize intimacy as a relational *act,* as something people *do*, *how* partners intimately interact with each other during illness, specifically terminal illness (McLean & Jones, 2007; Shields, Finley, Chawla, & Meadors, 2012). A popular conceptual model based on this relationship-centred approach that investigates intimate interactions is the interpersonal process model of intimacy (Manne & Badr, 2008). This model has been described in detail in the context of cancer by Manne et al. (2004) and has been used in several empirical articles (Manne et al., 2010; 2014), and intervention studies (Manne et al., 2011; Rowland et al., 2009). This model describes intimacy as a process in which one person is able to express important, self-revealing feelings and information to another person (often formulated as "self-disclosure), and as a result of the other's response (often formulated as 'other disclosure', feels understood and cared for (often formulated as 'perceived partner responsiveness') (Manne et al., 2004). This conceptualization of intimacy implies that it requires the personal ability to be vulnerable and emotionally open (DeFord & Gilbert, 2016). It further holds the notion that someone's capacity for intimacy with others is based on one's capacity for intimacy with them self. It means that – in order to be intimate – each partner in the relationship must have developed a sense of "self" that they are willing to put forward and "risk" being vulnerable to another (DeFord & Gilbert, 2016; Weingarten, 1991). However, one of the criticisms of this discourse is that it frequently polarizes interactions/behaviour as either likely to produce intimacy or not (Weingarten, 1991). More specifically, self-disclosure is seen as intimacy-enhancing communication, holding back/avoiding is seen as intimacy-compromising communication (Zhang & Siminoff, 2003). In this dissertation, we wish to prevent, overcome or go beyond this polarization and start from the premise that intimacy cannot be judged by the behaviour (in the latter example, disclosure or non-disclosure) *per se*, but rather by the extent to which the interaction carries a meaning that is shared, understood and constructed by both partners (Weingarten, 1991). A definition of intimacy that attempts to overcome this duality is formulated by Weingarten (1991, p. 287), who conceptualizes intimate interactions as follows: “Intimate interaction occurs when people *co-create meaning* and are able to *coordinate their actions* to reflect their mutual meaning-making. Meaning can be shared through writing, speech, gesture or symbol. Refraining from meaning-making and providing, imposing, rejecting and misunderstanding meaning are associated with non-intimate interaction”. We chose to use this conceptualization of (non-)intimate interaction because it integrates symbols and gestures, which is especially useful in the terminal phase, when patients are often unable to communicate verbally but often do communicate poignantly without words.

1.2.3. Sexuality as a relational process

As explained above (1.2.1), sexuality refers to different aspects of a relationship than intimacy and thus requires its own conceptualization. Sexuality is a complex concept that encompasses several layers – i.e. feelings, values, beliefs, physical, and cultural components – and this implies that each attempt to define sexuality is always somehow restrictive and reductive.

Therefore, our concept of sexuality aligns with the principles of a material-discursive-intrapsychic approach (Kadwell, 2016; Ussher, 2012) which guided dissertation. Concerning the “materiality” factor in this approach, we will argue - in line with Cromby & Nightingale, (1999, p. 11), that sexuality (its embodiment and its materiality) is not entirely reducible to discourse and that any material changes to the body, in our case due to terminal illness, can impact on a person’s - and thus a couple’s - wellbeing and sexual relationship (Cromby & Nightingale, 1999). At the same time, with respect to the discursive part, the approach of this dissertation also acknowledges that this material body stands in relation to cultural discourses (Kadwell, 2016; Ussher, 2012). Applying this to the dissertation’s theme, it is for example through sexual expression that women and men perform their gendered identities, and thereby reproduce the dominant discourses that establish the dichotomised sexual differences between men and women. Lastly, concerning the “intrapsychic part”, this approach considers how a person’s behaviour and subjectivity are also shaped by their psychological interpretations of previous experiences (Kadwell, 2016; Ussher, 2012). Applying this to the dissertation’s theme, it is through previous sexual experiences and preferences that patients and partners can evaluate their sexuality during terminal illness, or engage (or not) in sexual interactions. Any material changes to the body because of the illness can thus impact the way a person presents their gendered identity and their positioning within dominant discourses about gender/sexuality. This in turn will affect wellbeing and sexual relationship.

This material discursive approach can also be applied to our research on palliative care nurses' roles in addressing sexuality. The inclusion of "materiality" here is for example the influence of the particular health care settings (e.g. ambulant care vs. hospital care) on the way palliative care nurses address sexual issues. The inclusion of discursive factors might be to look at how the discourse of palliative care, as well as their own scripts regarding sexuality, may influence their practice of addressing it. The inclusion of intrapsychic factors might involve looking at the nurses' individual preferences, experiences and feelings about addressing sexuality or intimate issues, for example by exploring feelings of embarrassment and powerlessness.

However, we will not approach the material, discursive and intrapsychic aspects as different entities: rather, we will examine the interaction between the material, subjective and discursive worlds, which shapes an individual's experience of sexuality (Ussher, 2012).

We have also chosen to emphasize the relational dimension of sexuality, i.e. how these emotional, social, and physical dimensions are expressed in the interactions between patients and partner. This is in line with the relationship-centred approach of our dissertation (see above). More specifically, we are emphasizing the way sexuality is expressed between patient and partner, and how they negotiate/interact about it. This way, sexual interactions can also be a way of co-creating meaning, which overlaps with our conceptualization of intimacy (see above).

1.3. Sexual interactions and intimate interactions during terminal illness

1.3.1. Concept of terminal illness

As stated above, the population that is completely underrepresented in studies concerning intimacy and sexuality in advanced illness are the partners of patients who are terminally ill (Taylor, 2014). Therefore, our study takes place in the context of terminal illness. One way to conceptualize terminal illness is in terms of "stage", reflecting the biological status. Terminal illness is then the stage in which therapy cannot significantly prolong survival due to the progressive nature of the disease. Advanced illness is the stage where an illness is not curable but still responds to treatment, and where disease-directed therapy is still very important because it prolongs life (Kim et al., 2016; Llobera et al., 2000). Lee et al. (2014) operationalize it as "6-months life expectancy" and "treatment refractoriness".

Another way to conceptualize an illness trajectory is in terms that reflect the experiences of patients and partners, rather than the biological status. The illness trajectories then consist of "phases" referred to as "critical moments" or "transitions" in the illness experience (Fletcher, Miaskowski, Given, & Schumacher, 2012; Soothill et al., 2001; Thomas, Morris, & Harman, 2002). These critical moments or transitions are characterized by uncertainty about what comes next, and a sense of disconnection from the familiar, and specifically for our study, a stage in which relationships take on new meaning and functions (Fletcher et al., 2012). The phases from advanced to terminal illness and from terminal illness to bereavement are described as important transitions in the illness experience. Therefore, our research will take place in the context of terminal illness.

Although the general aim of this dissertation is to investigate sexuality and intimacy during terminal illness, we will focus on terminal cancer in some of the following chapters. This is mostly to ensure a degree of homogeneity in our data collection.

1.3.2. Sexual interactions during terminal illness

The little research available suggests that the sexual experiences of advanced or terminally ill patients change considerably (Ananth, Jones, King, & Tookman, 2003; Lemieux, Kaiser, Pereira, & Meadows, 2004; Leung, Goldfarb, & Dizon, 2016b; Taylor, 2014; Vitrano, Catania, & Mercadante, 2011) and is more compromised than in the case of curable diseases (Ananth et al., 2003; Badr, Carmack, Kashy, Cristofanilli, & Revenson, 2010). For instance, the intense emotional reactions provoked by the experience of proximity to death may have an influence on the sexual experience of both patients and partners: some couples have sexual interactions to reinforce their emotional connectedness or to console each other, while others restrain from sexuality due to altered feelings or miscommunication (Taylor, 2014). Physical factors related to the palliative stage, such as immobility, general malaise and the physical weakness related to advanced illness may decrease sexual desire, decrease the spontaneity of sexuality, and negatively affect body image (Leung et al., 2016b). Environmental conditions (e.g., a single hospital bed, a lack of privacy in in-patient settings) may also be barriers to the expression of sexuality between partners (Lemieux et al., 2004; S. Manne & Badr, 2008a; Shell, 2008).

Sexuality has been recognized as an important component that needs to be addressed in care settings working with people with terminal illness (Gamlin, 2005; Watson et al., 2005, p. 333)(De Vocht, 2017). A few studies have shown that although the content and meaning of sexuality might change, it remains important until the end of life (Ananth et al., 2003; Lemieux et al., 2004; Taylor, 2014). Moreover, a perceived increase in the quality of life through sexual expression has been found (Matzo, Ehiemua Pope, & Whalen, 2013). Besides for its importance for couples' quality of life, experiences with sexuality towards the end of life might also have an impact on the experiences of the bereaved partner following the patient's death (DeFord & Gilbert, 2016; Kadwell, 2016; Taylor, 2014).

Moreover, it has been shown that patients and partners want their sexual issues to be addressed and generally prefer their healthcare providers to take the initiative in addressing sexual issues, even in an advanced stage of disease (Ananth et al., 2003; Cagle & Bolte, 2009; Lindau, Surawska, Paice, & Baron, 2011b).

Despite this recognition that sexuality is important, there is very little empirical qualitative evidence that focused on the experience of sexuality when faced with terminal illness: we found only 3 qualitative studies focussing on patients' and partners' sexual experiences at the end of life (De Vocht, 2011; Lemieux et al., 2004; Taylor, 2014). To the best of our knowledge, there has not been any research on the experiences of sexuality of bereaved partners, and other studies concerning sexuality at the end of life recommend investigating this topic to further inform professional practice (Taylor, 2014; Kadwell, 2016). The reason for not addressing this topic is probably that both sexuality and death are sensitive and value-laden subjects in contemporary society. This has been called the 'double barrelled taboo' (Cagle & Bolte, 2009; Jaffe, 1977), which makes it very difficult to recruit participants for such studies (De Vocht, 2011; Taylor, 2014).

1.3.3. Intimate interactions during terminal illness

In general, satisfying intimate relationships are crucial for a couple's wellbeing (Prager, 1997). Especially in Western cultures, intimacy is considered a primary psychological need (Zalenski & Raspa, 2006) and a vitally important component of a couple relationship (Manne & Badr, 2008). In the context of a serious illness, intimate relationships seem to buffer people from the pathogenic effects of stress because of illness (Manne et al., 1997). A satisfying intimate relationship can draw on a stable foundation of mutual trust, affection, and respect, and tends to result in lower levels of distress, depression, anxiety and psychological morbidity (Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008; Manne & Badr, 2008; Manne, Badr, & Kashy, 2012; Manne et al., 1997) when being confronted with the distressing event of a diagnosis of a serious illness. Furthermore, it has been shown that the most important source of intimacy is the partner (Hunter, Davis, & Tunstall, 2006; Porter et al., 2009). Intimacy is also associated with higher posttraumatic growth and less anxiety during a cancer trajectory (Canavarro, Silva, & Moreira, 2015) and also reduces the burden related to caregiving (Braun, Mikulincer, Rydall, Walsh, & Rodin, 2007; McLean et al., 2013). In the context of advanced illness, having meaningful intimate relationships and privacy are two important characteristics of dying with dignity (Guo & Jacelon, 2014). Moreover, a satisfying intimate relationship may protect the bereaved partner from dysfunctional/problematic grieving (Dumont, Dumont, & Mongeau, 2008; Holdsworth, 2015; Kissane et al., 2003). Inversely, the absence of intimate interactions (e.g., negative, avoidant, hostile interactions) between the patient and partner can compromise the relational experience of both partners at the end of life and can impact the mourning process of the bereaved caregiver following the patient's death (Kissane, Bloch, Burns, McKenzie, & Posterino, 1994; MacCormack et al., 2001; McLean et al., 2013). As a consequence, researchers suggest that intimacy might be a better concept than quality of life (QOL), to use as an outcome for studies of well-being in the context of the end of life (Mohr et al., 2003).

1.4. Palliative care nurses addressing sexual and intimate relationship issues

1.4.1. Palliative care in Belgium

Belgium has well-developed and varied palliative care services, providing palliative care in hospitals, palliative care units, palliative care at home, in long-term care settings and day care settings (Federal Evaluation Commission Palliative care, 2014). In Belgium, these services are formally coordinated by 25 regional palliative care networks. First, palliative care is offered at home, generally coordinated by a family physician, but also involving home care nurses, informal caregivers, volunteers, etc. They can be supported by a palliative ambulant care team. Second, patients residing in a nursing home can also receive palliative care, coordinated by an advising physician involving also nursing home caregivers that can be supported by an ambulant palliative care team. Third, in a hospital setting, two structures are set up for the provision of palliative care. In general hospitals, regular caregivers (i.e. nurses, physicians, and other paramedics) are considered to be the main providers of generalist palliative care, supported by a mobile palliative support team that is specialized in providing palliative care. There are also residential palliative care units for those patients who cannot be cared for at home and for whom an admission to a hospital might be considered unnecessary. Such a unit usually has six to 12 beds, and has a multidisciplinary team that provides specialized palliative care, coordinated by a palliative care physician. Lastly, there are palliative day care centres that have been created as a complementary service to home care. These were set up in order to prevent unnecessary hospital admissions.

1.4.2. The role of palliative care nurses

Although a palliative care team is multidisciplinary, consisting of nurses, physicians, psychologists, social workers, and volunteers, our study focuses on palliative care nurses, as they play a pivotal key role in the provision of emotional care and support for emotional difficulties that both patients and close relatives experience (Skilbeck & Payne, 2003). Indeed, the World Health Organisation (WHO, 2010) also positions nurses at the forefront to deliver “sexual health care”.

Moreover, although nurses working in palliative care in Belgium all have the same education, the function they have in ambulant palliative care teams is somewhat different to that of those working in the palliative care unit or general home care. They provide a rather advisory role and are thus not directly involved in the physical care of the patients, this in contrast with the other nurses. However, as one of their core tasks is to provide psychological and moral support to patients and partners, they are also included in the present study.

1.4.3. Why addressing intimacy and sexuality in palliative care is important

A unique characteristic of the palliative care philosophy is that it considers both patient and close relatives as a unit of care, which implies that palliative care can offer couples an opportunity to reconcile conflicts or even heal their intimate relationship (Altschuler, 2015; Broom & Kirby, 2013; King & Quill, 2006). This is especially salient in palliative care, as healthcare providers working in this setting are often confronted with couples experiencing relational intimacy issues, which is probably due to the fact that invoking palliative care may follow exhaustion related to the high demands placed on couples and their capacity to cope at home (Broom & Kirby, 2013; Harding & Higginson, 2003; Hjermstad et al., 2013; von Heymann-Horan et al., 2017). It is also shown that providing relationship support at the end of life can result in a reduction of psychosocial distress for the patient and partner, and may even provide an opportunity for relational growth during the last stage of life (Hodges et al., 2005; McWilliams, 2004; Murillo &Holland, 2004). Additionally, it may ease the bereavement process and reduce the potential of future complicated grief and mental health difficulties (MacCormack et al., 2001; McWilliams, 2004).

Moreover, as the underpinning philosophy of palliative care emphasizes holistic care – encompassing all domains affecting the person – then issues related to intimacy and sexuality must also be addressed (Pastrana, Junger, Ostgathe, Elsner, & Radbruch, 2008). This is also in line with recommendations formulated in the National Consensus for Quality Palliative Care in the United States, where sexuality is recognized as an important component that needs to be addressed in palliative care (National consensus project for Quality palliative care, 2012).

This all implies that palliative care staff should be educated to use basic counselling skills in their everyday practice to deal with these intimate and sexual issues during daily care (Bowden & Bliss, 2009; Lemieux et al., 2004; Leung et al., 2016).

1.4.4. Palliative care nurses addressing intimate and sexual issues

Even though there is the expectation for palliative care nurses to address sexual and intimate relationship issues, the reality is that in many services this support is suboptimal (Hudson & Payne, 2011). The existing literature on the healthcare providers' roles in addressing sexuality mainly consists of a description of the barriers and challenges for healthcare providers to address sexuality related issues (Dyer & das Nair, 2013; Hordern & Street, 2007; Lindau, Surawska, Paice, & Baron, 2011; Stead, 2003). First, they mention a lack of knowledge about how serious illness affects patients' and partners' experiences of sexuality (Canzona et al., 2016; Reese et al., 2017). This is even more the case when it comes to terminal illness compared to early stage illness/cancer that has been better studied until now (Gleeson & Hazell, 2017; Hordern & Street, 2007). Moreover, no research has specifically investigated *how* nurses working in palliative care do actually address these sexual issues. They also frequently claim that apart from knowledge, they lack the skills to initiate a conversation about sexuality (Higgins, Barker, & Begley, 2008). The topic often provokes conflicting feelings such as fear and embarrassment (Saunamäki & Engström, 2014). Moreover, healthcare providers are more inclined to address ‘medicalised’ aspects related to sexual functioning (e.g., erectile dysfunction or vaginal dryness) than emotional and relational aspects related to sexuality, while the latter are the aspects that couples themselves would prefer to be addressed by health care providers (Hordern & Street, 2007). This lack of knowledge, skills and feelings of fear and embarrassment result in healthcare providers’ ignorance of the topic, denial of its importance and avoidance of conversations about this sensitive topic (Hordern & Street, 2007). Palliative healthcare providers also mention not being sufficiently trained to address intimate issues during terminal illness care (Sinclair et al., 2016; von Heymann-Horan et al., 2017). This may be partly due to the lack of empirical information on how to deal with these intimate relationship issues (King & Quill, 2006). Despite advocacy for couples’ interventions on enhancing the quality of relationship and intimacy during terminal illness (Harding & Higginson, 2003; Hodges et al., 2005; Manne, Badr, Zaider, Nelson, & Kissane, 2010; McLean et al., 2013; Murillo & Holland, 2004), very few studies have done so. So far, we have found four randomized control trials (RCT’s) – (McLean et al., 2013; Laurel Northouse, Kershaw, Mood, & Schafenacker, 2005; Porter et al., 2009, Kuijer et al., 2004) that aimed at enhancing the quality and intimacy of a couple’s relationship during advanced illness. All these studies proved to be more or less effective. This lack of empirical evidence is in contrast to the abundance of intervention studies for couples coping with early stage cancer (Badr & Krebs, 2013; Ferrell & Wittenberg, 2017; Regan et al., 2012). To the best of our knowledge, there have been no intervention studies on addressing sexuality in the context of terminal illness.

Moreover, the few existing interventions were all aimed at psychotherapists working in palliative care, thereby overlooking palliative care nurses’ pivotal role in providing relationship support to couples. In palliative care is including nurses especially relevant as most members of the palliative care team (i.e. psychologists, physicians, nurses) do not usually work with distinctly defined roles (O’Connor & Fisher, 2011). Unless there is more empirical information about which ways nurses provide support, there will be a disconnection between the policy of palliative care and actual clinical practice, where palliative care nurses continue to operate in the absence of evidence-base recommendations (Hudson & Payne, 2011).

Therefore, there is a need for research exploring how palliative care nurses address intimate and sexual relationship issues in their daily practice.

1.5.Study objectives and research questions

This dissertation is guided by three main aims, each related to specific research questions:

The **first aim** is to systematically synthesize the available evidence from qualitative research on sexual interactions during cancer to inform a theoretical model about how patients and partners adjust to the sexual changes during a cancer trajectory, which might further guide an empirical interview study. The following research question is answered:

- What does qualitative research tells us about the sexual adjustment process in cancer patients and their partners?

The **second aim** is to explore how patients with terminal cancer and their partners experience sexuality and intimacy. More specifically, the following research questions have been answered:

- How do patients and partners experience and express their sexuality when dealing with terminal cancer?
- What are the (non-)intimate interactions between a patient and partner when dealing with terminal cancer?

The **third aim** is explore how palliative care nurses address sexual and relationship issues between patients and their partners in their daily practice. The outcome of that evaluation can eventually function as a basis for evaluation and education of, and intervention in daily palliative practice. More specifically, the following research questions have been answered:

- What are palliative care nurses' attitudes towards sexuality in palliative care, what are their assumed roles towards addressing sexuality, and what are their specific experiences with addressing sexual issues in palliative care?
- How do palliative care nurses address relationship issues between patients and their partners in their daily practice?

1.6. Methods

To answer the research questions in this dissertation, we conducted three different qualitative methods and five types of data collections. We fulfilled a qualitative evidence synthesis of a purposeful sample of qualitative papers, using principles of meta-ethnography (Chapter 2 and 3). We performed an Interpretative Phenomenological Analysis (IPA study) with a multi-perspective design, in which we conducted in-depth interviews with terminally ill patients and their partners (Chapter 4 and 5). We also performed a generic qualitative study, in which we conducted in-depth interviews with palliative care nurses (Chapter 6 and 7); an observation study of palliative care nurses in a palliative care unit and an ambulant care team (Chapter 7) and peer debriefing groups with palliative care teams from palliative care units and ambulant care teams (Chapter 7).

1.6.1. Qualitative evidence synthesis

Our first aim was to develop a theoretical model about how patients and partners are adjusting towards the sexual changes during a cancer trajectory, which might further guide our empirical interview study. Therefore, we conducted a qualitative evidence synthesis with a meta-ethnography method based on the work of Noblit & Hare (1988), which is a particular form of synthesizing qualitative research designed to construct theories (Campbell et al., 2003; Noblit & Hare, 1988).

Moreover, it is one of the most frequently-used qualitative methods in systematic reviews of health care literature (Hannes & Macaitis, 2012). First of all, we performed a scoping review of the literature available on the topic (Levac, Colquhoun, & O'Brien, 2010) that delivered 58 primary research reports. Next, we performed a purposeful sampling and analysing of these papers. This process was necessary to go beyond a simple, descriptive aggregation of the findings and to achieve theoretical development, to put the emphasis on conceptual robustness rather than on completeness of the data (Campbell et al., 2003; Dixon-Woods, Agarwal, Jones, Young, & Sutton, 2005). As performing a purposeful sampling in a qualitative evidence synthesis has been rarely performed, we wrote a worked example explaining in detail how we performed this purposeful sampling (see chapter 3). The analysing process and the purposeful sampling went hand-in-hand. In total, because of the purposeful way of sampling and analysing, 16 of the 58 initial articles were included in this synthesis. The analysis was completed when the resulting conceptual model was sufficient rich and dense, and comparison to findings of other articles did not yield any important new information.

1.6.2. An Interpretative Phenomenological Analysis (IPA study)

The second aim of the dissertation was to explore how patients with terminal cancer and their partners experience sexuality and intimacy.

Therefore, we performed an Interpretative Phenomenological Analysis (IPA study) (Smith & Osborne, 2015) with a multi-perspective design, in which we conducted in-depth interviews with terminally ill patients and their partners. This qualitative research approach has been widely used in health psychology (Loaring et al., 2015). IPA is one of the several approaches described as phenomenological psychology, whose central concern is to give a rich description of people's world of experience. IPA is intellectually connected to hermeneutics and theories of interpretation (Packer & Addison, 1989, Smith & Osborn, 2015) rather than to the descriptive approaches, as it postulates that the participant always interprets his/her own experience, and that the researcher always interprets the participants' interpretation. This is called a "double hermeneutic" (Smith & Osborn, 2015). IPA is also committed to an idiographic analysis of cases rather than jumping to generalizations. Therefore, IPA studies often involve semi-structured interviews with a small, homogeneous sample (Smith & Osborn, 2015), where the participants share a mutual perspective on a specific experience. More recently, IPA researchers have begun using more complex designs to explore an experience from more than one perspective, i.e. a multi-perspective design (Borg Xuereb, Shaw, & Lane, 2016; Loaring et al., 2015). We used this multi-perspective design in our dissertation, which means we explored the experiences of sexuality/intimacy from three different perspectives, namely patients', partners', and bereaved partners' perspectives. Combining different perspectives can give us a fuller understanding of the phenomenon, as our understanding of phenomena in the world is always partial (Moran, 2000). More specifically, patients can inform us about the perspective of the sick person, partners about their perspective in a relationship with the sick person, and bereaved partners about their experiences in the relationship with the sick person until the very last moments of life, as well as how experiences of sexuality/intimacy in the terminal phase colour their current experiences of sexuality/intimacy.

Data collection started in November 2014 and lasted until March 2016. Participants were sampled from palliative and oncology units in university and regional hospitals, from ambulant palliative home care, and from support groups for couples with cancer/bereaved partners to ensure sufficient diversity in the selected population. Nurses or physicians working in the aforementioned settings were asked to recruit patients or partners of patients diagnosed with incurable cancer and with an estimated "life expectancy" of 6 months, according to the current definition of terminal cancer (Llobera et al., 2000). Bereaved partners, also recruited by nurses or physicians, had had an ill partner, who died between 3 months and 2 years ago. Although recent grief theories tend to deemphasize the importance of time since loss, this 2 year time-frame has been often used in research (Holland, Currier, & Neimeyer, 2006). 18 participants (six patients, seven partners and five bereaved partners) were included in the study. The participants' ages varied from 31 to 71 years old and most of them (n=16) were heterosexual, while two male participants were homosexual. The relationship duration varied from 2 to 40 years before diagnosis. The majority of the interviews took place between two weeks and nine months before the patient's death. Two patients were still alive at the time of finishing the analysis. The sample size of this study exceeds the average range for an IPA study (Smith & Osborne, 2015). However, we believed that – as intimacy and sexuality appear to be a difficult subject to put into words – it was necessary to include more respondents to acquire a sufficiently detailed interpretative account of the topic and to reach data saturation on the subject. Patients and partners were recruited individually, and where couples wanted to participate, interviews were conducted separately. We chose this option because we considered that participants might be willing to disclose things to the researcher that they would not disclose in presence of their partner, especially concerning sensitive issues such as intimacy, sexuality and death. Separate interviews have proven to work well for exploring sensitive experiences (Taylor & de Vocht, 2011). We also learned during recruitment that several participants only agreed to participate in the study on the condition that their healthy or ill partner did not participate and sometimes even that their partner was not aware of them participating in the study.

The interviews were done by the author of this dissertation, who had no personal connection with the participants. The interview started with broad questions on experiences with diagnosis and treatment in order to help participants to feel at ease and enable them to tell their story. Gradually, the questions began to focus on sensitive topics such as their experiences about changes in their intimate relationships or their experiences about changes in their sexuality and the difficulties they encountered in both.

The interviewer used prompting and probing. Interviews took between 1.5 and 3 hours, and were audio-taped and transcribed verbatim.

In accordance with the IPA approach and its double hermeneutics, we used multiple levels of interpretation throughout our analysis: we did not only look at the content of the participants' meaning making, but also at the words they chose to communicate this meaning making (e.g. what words or metaphors they used to describe sexuality, where they had difficulties in describing their experience). This is because IPA researchers realize that the connection between people's talk and their thinking and emotional state is complicated, that people struggle to express what they are thinking and feeling, and that the researcher has to interpret people's mental and emotional state from what they say (Smith & Osborn, 2015). We believe this is particularly important in research about sexuality (Wiederman & Whitley, 2002, P. 532). Moreover, IPA follows the interpretative phenomenological approaches that one cannot and should not bracket the researchers' experience and understandings, which means setting aside one's assumptions about the phenomenon, thereby trying to be as non-influential and neutral as possible (Finlay, 2009).

The analysis process was a cyclical process. When we constructed higher order themes across the groups, we consistently went back to the individual transcripts to check whether these themes could be found there as well.

More details on this method are described in Chapter 4 and 5 of Part III.

1.6.3. A generic qualitative study

The third aim of this dissertation is to explore how palliative care nurses address sexual and relationship issues between patients and their partners within daily practice. Therefore, we performed a 'generic qualitative study' (Kahlke, 2014), with data triangulation, consisting of an in-depth interview study, an observational study, and then peer debriefing groups. Generic qualitative studies are those that exhibit some or all of the characteristics of qualitative endeavour but rather than focusing the study through the lens of a known methodology, they combine several methodologies or approaches (Caelli, Ray, & Mill, 2003).

a. In-depth interviews with nurses

For this part of the study, we recruited nurses working in the different palliative care services throughout Flanders. Recruitment was done through the directors of these Services. In total, 21 nurses were interviewed, based on willingness and availability at the time: two from palliative support teams in hospitals, six from residential palliative care units, 11 from palliative home care teams, and two from palliative day care facilities.

At the start of the in-depth interviews, we told the participants we were interested in how they addressed their patients' and partners' intimate relationship and sexual issues in everyday work. We asked nurses about their experiences with addressing relationship and sexual issues, what they find difficult about it, what they find easy, etc.

In chapter 6, we shared our broad conceptualization of sexuality with the nurses we investigated. This was because we wanted to avoid the common reflex of healthcare providers of adhering to a biomedical model of sexuality, which reduces sexuality to sexual intercourse.

Although the nurses' interpretation of sexuality might also be an interesting perspective, we chose to describe their attitudes and roles towards the different dimensions sexuality entails. Therefore, we chose to share with them the definition of Gilley (2000, p. 121) who translated the concept of sexuality to the context of palliative care, by including the term "physical intimacy": "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"

All interviews took place between September 2014 and September 2016, and were done by the author of this dissertation, who had no personal connection with the nurses. Interviews took between one and two hours, were audio-taped and transcribed verbatim.

We performed our analysis according to the six phases of thematic analysis offered by Braun & Clarcke (Braun & Clarke, 2006). We identified themes at a latent level, which means that we interpreted the nurses' accounts, examining underlying ideas, assumptions, and conceptualisations/ideologies. In our case, we interpreted the nurses' accounts in relationship with the philosophical principles of palliative care (Pastrana et al., 2008).

More details on this method are described in Chapter 6 and 7 of Part IV.

b. Observation study of palliative care nurses

We also performed an observation study. The observation study was done after the interviews – as a form of triangulation - in one palliative care unit and one palliative ambulant care team. This was because we expected to see skills and actions during our observations that were not revealed by the nurses during the interviews (Walshe, Ewing, & Griffiths, 2012). Additionally, observational research can facilitate understanding of what people do and how their actions can alter in response to situations, especially where people find their own practice difficult to articulate. We found this was the case during the interviews, as the nurses saw their actions and skills for supporting relationships as taken for granted, and thus difficult to explain.

The team in the palliative care unit consisted of 16 nurses (2 m, 14f). 2 of these nurses had participated in the previous interview study. The ambulant care team consisted of 11 palliative care nurses (2m, 9f), of whom one had participated in the previous interview study.

All nurses working in the palliative care unit and home care team were informed about the study, and advance written consent was obtained. No nurses refused to participate in the study. Although the focus of the study was on the nurses and not the patients and partners, they were indirectly observed as well, and we also informed them about the study and asked – orally – for permission to observe the nurses in their presence/ in interactions with them. No patients/partners refused this.

Data were collected through “negotiated interactive observation” (Wind, 2008): Observations were specifically focused on the nurses’ interactions with patients and their partners, aiming at addressing relationship issues; on the way nurses talked about relationship issues during team meetings, patient debriefings, and informal moments (e.g. lunch) . The researcher also used the written notes that nurses use as communication tools, screening them for parts where they took notes about relationship issues. The observations in the palliative care unit and ambulant care setting were conducted over a period of 3 months, consisting of 75 effective observation hours in the palliative care unit and 25 in the ambulant care team (i.e. hours that we were effectively observing and taking notes). Observation notes were written out in detail immediately after the observation period.

We performed our analysis according to the six phases of thematic analysis offered by Braun and Clarke (2006).

More details on this method are described in Chapter 7 of Part IV.

c. Peer debriefing groups with palliative care nurses

The results of the above interview and observation study - after preliminary analysis - were also presented and discussed in 3 palliative care teams: 2 palliative care units and 1 ambulant care setting. One of the palliative care units was the unit where we did the observation study (16 nurses, 2m, 14f). The second palliative care unit consisted of 11 nurses (3m, 8f), and the palliative ambulant care team consisted of 11 nurses (3m, 8f). The nurses in these two teams did not actively participate in the study. The nurses critically reviewed the results and thereby their own nursing practice in terms of relationship support: what they do, how they do it, and why -. This type of research is similar to peer debriefing, which is, according to Guba & Lincoln (1994, p. 308), "the process of exposing oneself to a peer in a manner paralleling an analytic session and for the purpose of exploring aspects of the inquiry that might otherwise remain only implicit within the inquirer's mind." However, what is different in our approach is that we held these peer debriefings at the end of our study and not during the data collection process, as Guba & Lincoln (1994) prescribe.

The nurses gave feedback by either affirming or challenging the results and assumptions of the researcher. This way, we could refine and deepen our analysis. These presentations and discussions lasted between 2 and 2 ½ hours each time. We performed our analysis according to the six phases of thematic analysis offered by Braun and Clarke (2006). More details on this method are described in

Chapter 7 of Part IV.

1.6.3. Team approach to this dissertation

The author of this dissertation did the whole research process – from pre-data collection to analysis – under the supervision of a research team, which met regularly over the course of the research process. During these meetings, the first author presented her rationale for data collection, analysis and her interpretation of the data, in order to enhance reflexivity and to check plausibility and coherence in her interpretation. The members of the research team – that varied according to the specific methodology applied – looked at the data from their particular research and health work perspective. We used NVIVO 10 to facilitate the analysis process.

1.6.4. Ethics

This study was approved by the ethical committee of the Academic Hospital of the Vrije Universiteit Brussel (B.U.N. 143201420594). Data collection was carried out after participants gave informed consent and data analysis was done with care and concern while strictly guaranteeing the privacy and confidentiality of the participants. A more detailed discussion of the ethics can be found in the discussion.

1.7. Theoretical considerations

Being transparent about the research design and methods used is inherent to reporting on research, but it is also vital to reflect on the assumptions about reality that can and do underpin these methods (Clark, Lissel, & Davis, 2008). This set of assumptions we call “paradigms”. A paradigm represents a worldview that defines, for its holder, the nature of the “world”, the individual’s place in it, and the range of possible relationships to that world and its parts (Guba, 1994). Especially in qualitative research, it is becoming more and more the norm to mention the underlying paradigm explicitly. Explaining and justifying the paradigm, and its particular ontological and epistemological positions give credibility and transparency to research.

Moving between a constructivist and critical realist paradigm

As this dissertation consists of different chapters with distinct research questions and different methodological approaches, we consequently combine two different paradigms for this dissertation. Depending on the chapter, we move between a constructivist and critical realist tradition. In doing so, we adhere to the critique of claims that different research paradigms are incompatible, and the idea that these are fixed and timeless entities with clear-cut boundaries (Morgan, 2007).

In Chapter 2, 4 and 5, which consist of the meta-ethnographic qualitative evidence synthesis and the interpretative phenomenological analysis to explore how patients with terminal cancer and their partners experience sexuality and intimacy, we tend to approach this part of research from a more interpretive/constructivist paradigm (Haverkamp & Young, 2007). This paradigm posits multiple equally valid social realities. Knowledge or meaning is described as constructed; it cannot be observed directly but must be interpreted. Furthermore, the researcher's values are assumed to influence the research process, and the researcher is expected to examine and understand how their values, personal beliefs, and characteristics have influenced this construction of meaning. However, because we adhere to a rather flexible and porous interpretation of paradigms (as stated above), we take a light constructionist stance rather than the strong constructionism, suggesting that the lived life with its vicissitudes is much more than historically situated linguistic interactions between people, which is exactly also the position of IPA (Eatough, 2006). In Chapter 6 and 7, in which we use a generic qualitative approach to explore how palliative care nurses address sexual and relationship issues between patients and their partners in their daily practice, we tend to approach this part of research more from a critical realist paradigm, which holds a pragmatic position between the two poles of realism and relativism (Denzin & Lincoln, 2011, p. 11), synthesizing aspects of both. This tradition accepts the that a real world exists objectively outside human perception, but that it is socially constructed (Benton & Craib, 2001). It is also important that the person is not a mere automaton who is at the mercy of these mechanisms; rather, the person can actively transform his or her social world and is, in turn , transformed by it (Danermark, Ekstrom, & Jakobsen, 2005). There is an acknowledgement of the constructivists/relativists' insight that people can transform their everyday worlds and yet, the theory provides a more adequate account to social life by also acknowledging the role of structural factors.

We adhere to this critical realist paradigm as it is empowering, focusing on human agency (Haverkamp & Young, 2007). This is especially important in nursing/ health science research, as critical realism states that the structure and discourses do not fully determine the health and wellbeing of persons, but only provide the conditions in which an individual has to act, so there has to be an emphasize on how individuals (in our case patients and partners) deal with the structure (illness , bodily restrictions) and discourses (e.g. gendered discourses) (Angus & Clark, 2012).

Moreover, a critical realist paradigm promotes the raising of awareness as a key strategy for change (Houston, 2001). It is only when people become aware that meaningful change can take place. In effect the role of critical realism is not only to uncover psychological, discursive and material mechanisms, but to challenge their existence, which stands in contrast to the inherent relativism of constructivist approaches. This approach is visible in the practically oriented approach of these chapters, where the focus is consistently on changing and challenging the status-quo in the field.

1.8. Dissertation outline

Following this introduction, Chapters 2-7 of the dissertation are based on articles that have been published or accepted, or manuscripts that have been submitted for publication. Each chapter can be read independently. The three main aims of this dissertation (see point 1.5) are addressed in three separate parts. Each part consists of different chapters in which the specific research questions related to each aim are addressed.

Part II of the dissertation addresses the first aim of the study and consists of a synthesis of qualitative evidence or qualitative research on sexual interactions during cancer, in order to arrive at a theoretical model of how patients and partners adjust to the sexual changes during a cancer trajectory (Chapter 2). As we are using a new methodology, i.e. “mixed purposeful sampling”, in this qualitative evidence synthesis, we have inserted an extra chapter that consists of a worked example discussing this method in detail to enable other researchers to adapt this methodology (Chapter 3).

Part III of this dissertation addresses the second aim of the study and consists of an exploration of how patients, their partners, and bereaved partners experience sexuality (Chapter 4) and intimacy (Chapter 5) during terminal cancer.

Part IV of this dissertation addresses the third aim of the study by exploring how palliative care nurses address sexual (Chapter 6) and relationship issues (Chapter 7) in their daily practice with patients and their partners, and by discussing how the results can create a basis for evaluation and education of, and intervention in, daily palliative nursing practice.

The final chapter of the dissertation, Part V and Chapter 8, consists of a general discussion of the main findings of our study, including a reflection on ethical issues related to the current study, a reflection on the methodological approach, the limitations and strengths of the study and what the dissertation might add to clinical practice, policy and future research.

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PART II

A SYNTHESIS OF THE AVAILABLE EVIDENCE FROM QUALITATIVE RESEARCH ON SEXUAL INTERACTIONS DURING CANCER

CHAPTER 2

THE SEXUAL ADJUSTMENT PROCESS OF CANCER PATIENTS AND THEIR PARTNERS: A QUALITATIVE EVIDENCE SYNTHESIS

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Published in Archives of Sexual Behaviour, 2017, 46(7): 2059-2083

ABSTRACT

When confronted with cancer, a prominent challenge for patients and their partners is their changed sexual relationship. An empirically based theoretical model of the sexual adaptation process during cancer might be helpful in guiding the development of adequate interventions for couples who struggle with their sexual relationship. Therefore the purpose of this study is to synthesize evidence from primary qualitative research studies and to arrive at a detailed description of the process of sexual adjustment during cancer. We conducted a qualitative evidence synthesis of a purposeful sample of 16 qualitative papers, using the meta-ethnography approach to synthesis. We found that the subsequent studies used different theoretical approaches to describe the sexual adaptation process. This led to three divergent sexual adaptation processes: 1. the pathway of grief and mourning, depicting sexual changes as a loss, 2. the pathway of restructuring, depicting the adjustment process towards sexual changes as a cognitive process with a strong focus on the social and cultural forces that shape the values and experiences of sexuality and, 3. the pathway of sexual rehabilitation, depicting sexual changes as a bodily dysfunction that needs treatment and specific behavioural strategies. All three pathways have their own opportunities and challenges. A greater awareness of these different pathways could help healthcare providers to better understand the ways a particular couple might cope with changed sexuality, offering them opportunities to discover alternative pathways for sexual adjustment.

INTRODUCTION

"To have and to hold … in sickness and in health…" reads one of the most famous wedding vows. However, when a person becomes seriously ill with cancer, difficult times arise for the couple. One of the most significant challenges for the couple is their changed sexuality. Sexual dysfunction has been cited as one of the top adverse effects of cancer treatment on survivors (Hampton, 2005). Studies found that between 67% and 85% of the patients felt that cancer had had an impact on their sexuality (Corney, Crowther, Everett, Howells, & Shepherd, 1993; Hawkins et al., 2009; Ussher, Perz, Gilbert, Wong, & Hobbs, 2013).

Healthcare providers often fail to address couples' sexual issues appropriately (Kotronoulas, Papadopoulou, & Patiraki, 2009; Lavin, Hyde, & White, 2006; Gilbert, Perz, & Ussher, 2014), partly because they hold a less reflexive, more medicalised approach about patients' sexuality after cancer, which is in stark contrast to the expectations of patients (Hordern & Street, 2007). This is due to a dominant definition of sexuality throughout the literature which reduces it to fertility, menopausal, erectile dysfunction, or capacity for intercourse (Hordern, 2008).

Qualitative research -in contrast- has recently contributed remarkable insights to cancer patients' experiences with sexuality due to cancer, using a broader, holistic approach to describe sexual challenges. Examples of these changes and challenges of sexuality between a patient and the partner are described in the literature: a fear of initiating sexuality , a fear of being rejected by the partner or a fear of hurting the patient (Couper et al., 2006; Juraskova et al., 2003); decrease of spontaneity during sexual activities because of the use of assistive mechanical devices (Beck, Robinson, & Carlson, 2013; Taylor, 2011); different expectations regarding sexuality between the patient and partner; role strain, where the partner becomes the caregiver and sees the patient as needy and asexual (Cort, Monroe, & Oliviere, 2004; Gilbert, Ussher, & Perz, 2010; Hawkins et al., 2009). These sexual changes do impact the quality of the relationship in different ways. Some studies suggest that sexual problems may be persistent and lead to conflict within the relationship, while other couples strive and succeed to restore a satisfactory sexual relationship (Burns, Costello, Ryan-Woolley, & Davidson, 2007; Walker & Robinson, 2012).

Although these sexual challenges and changes recently have been well-described on a more descriptive, a-theoretical level, this information has not yet been brought together in a systematic way, leading to a theoretical model about how couples are adjusting towards these sexual changes and challenges. Furthermore, most intervention studies addressing sexual adjustment in couples are a-theoretical in nature (Canada, Neese, Sui, & Schover, 2005; Kalaitzi et al., 2007; McCorkle, Siefert, Dowd, Robinson, & Pickett, 2007; Badr & Krebs, 2013). Consequently, there is a need for a theoretical framework to inform programmatic research and to facilitate the design of interventions.

Therefore, the purpose of this study is to synthesize evidence from primary qualitative research studies, in order to arrive at a theoretical model of the process of sexual adjustment during cancer.

METHOD

We chose to use a meta-ethnography method based on the work of Noblit & Hare (1988), a particular form of synthesizing qualitative research that offers a clear set of procedures by which data can be analyzed (see fig. 1). We chose this meta-ethnography method as it is an approach designed with the purpose of constructing theory (Campbell et al., 2003). Moreover, it is one of the most frequently-used methods in systematic reviews of health care literature (Hannes & Macaitis, 2012).

Data Collection and Analysis

The process of data collection and analysis was done by a research team which included 4 researchers from different disciplines (sexology, social-cultural sciences, philosophy and social health sciences). CB and MS performed the scoping review and the purposeful sampling and analyses, KH and JB supervised the process. The research team began with a scoping review of the literature, in order to create a pool/archive of primary research reports that are easily accessible and can be used to purposefully sample from (see also figure 1 for an overview of our methodology).

Scoping Review

Scoping is an exploratory and systematic way of mapping the literature available on a topic (Levac, Colquhoun, & O’Brien, 2010). A methodological filter for extracting qualitative research in databases (validated in different electronic databases by McKibbon, Wilczynski, & Haynes, 2006; Wilczynski, Marks, & Haynes, 2007)-was used to extract qualitative papers. The research string we used in Medline was (interview* or qualitative or experience*) and (cancer and sexual*). It was adapted for re-use in other search engines.

One researcher (CB) applied general inclusion and exclusion criteria to the abstracts retrieved: the studies included should be qualitative in nature, written in English and carried out between 1994 and 2015, for pragmatic reasons. They should focus on the sexuality of the patient and partner in the context of a cancer diagnosis. Participants could be the couple as the unit of focus, but we also included articles where the cancer patient or partner of the cancer patient is the unit of study, as long as the content of the study implies the sexual relationship.

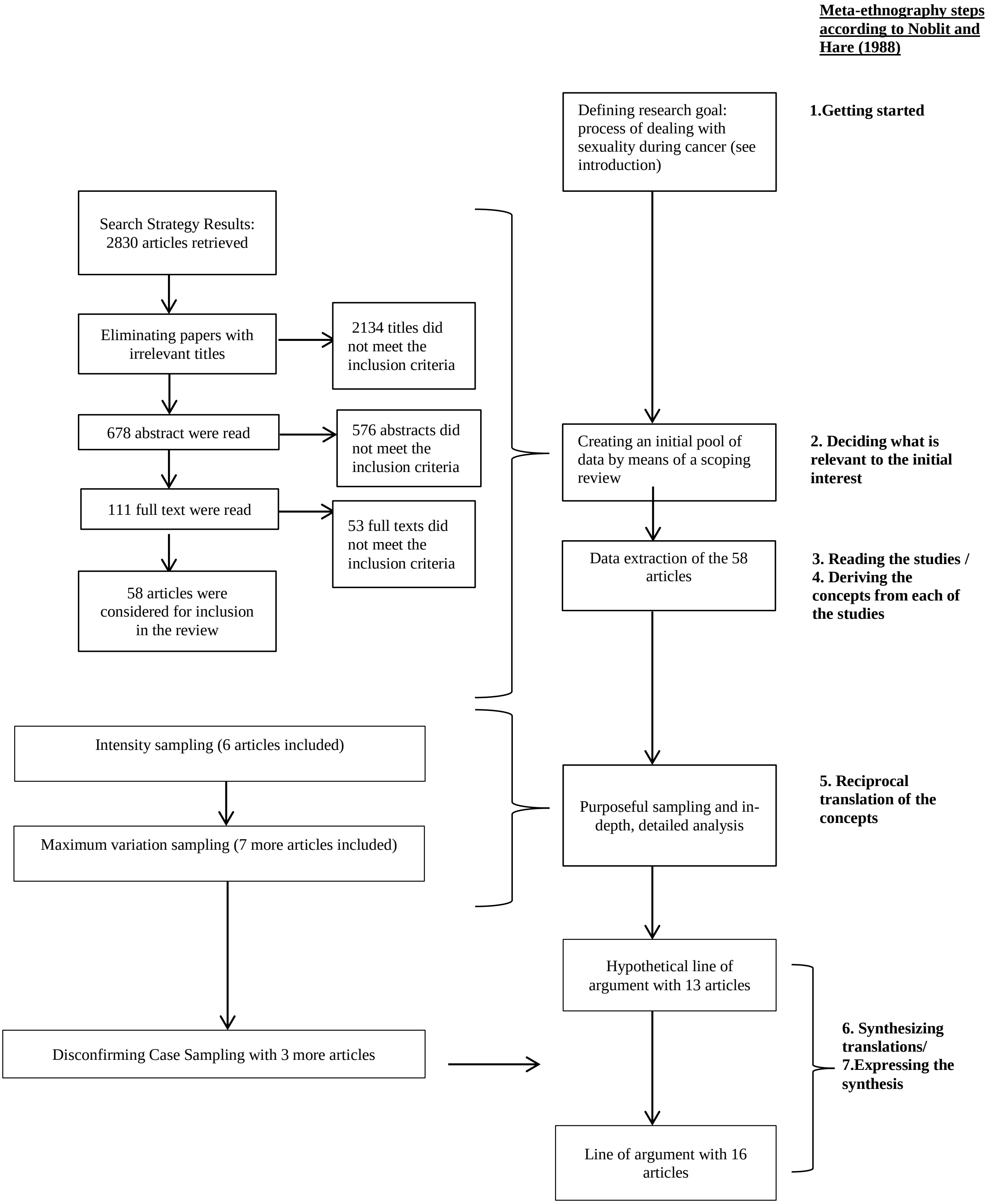

Fig. 1 Schematic overview of the methodology

As can be seen in figure 1, a total of 58 articles were included in our archive of data. This is the pool of data we used to start purposeful sampling. In order to prepare for the purposeful sampling phase (see below), we constructed a standardized data extraction sheet of each of the 58 articles to highlight the specific characteristics identified in each of the studies, i.e. data collection, method, research question/goal, sampling characteristics and main theoretical arguments and concepts. This way we could easily compare different articles (see fig. 1 and an example of a data extraction sheet in table 1). The concepts for analysis were extracted from an in-depth reading of the findings and discussion sections of each selected article.

Table 1: Example of Descriptive Data Extraction Sheet

	Walker and Robinson (2012)
Data collection	Interviews together as a couple, unstructured interviews
Method	Grounded theory methodology
Research question/ goal	To present the struggles that these couples faced when trying to adapt sexually to the side effects of prostate cancer treatment
Sample characteristics (Age, sex)	18 heterosexual couples (m 47-83 years) (f 32 -82 years) Average age of patients: 65.4 y Average age of partners: 61 y Ethnicity: Euro-Canadian or American heritage, 1 who was Afro-American Type of cancer and treatment: Prostate cancer, all undergoing Androgen Deprivation Therapy
Concepts	*Discomfort about sexuality* *Avoidance of sexuality* *"The more romantic husband"*
Main theoretical arguments	*Whether couples choose to maintain sexual activity or cease engaging in sexual activity, they BOTH encounter a variety of struggles and for both choices, these struggles can be successfully overcome.*

Purposeful Sampling and Analysing

Purposeful sampling is not meant to be comprehensive in terms of screening all potentially relevant papers (Hannes, Booth, Harris, & Noyes, 2013). The emphasis is on conceptual robustness rather than on completeness of the data (Dixon-Woods, Agarwal, Jones, Young, & Sutton, 2005). Because of this emphasis on conceptual robustness, this purposeful sampling fits our goal to go beyond a simple, descriptive aggregation of the findings and to achieve theoretical development (De Casterlé, Gastmans, Bryon, & Denier, 2012; Campbell et al., 2003). Also, because of this purposeful sampling, research directions may be divergent and iterative, rather than linear (Walsh & Downe, 2005) which aligns better with the philosophy of qualitative research (Hannes et al., 2013). The search strategy we developed is based on a full screening of potential purposeful sampling techniques developed for qualitative meta-synthesis as described by Suri (2011).

As iterativity -a basic principle in qualitative research (Noblit & Hare, 1988)- implies that purposeful sampling and analysing run simultaneously, we will present them both together in this methodology section. Table 2 represents visually the whole process of sampling and analysing.

First we did an intensity sampling, which means that we did a close examination of papers that generated an in-depth understanding of our phenomenon of interest, providing rich descriptions of the sexual adjustment of couples during the cancer trajectory (Patton, 1990, see fig. 1). The reason we chose this sampling technique is because we believe that the starting point of the literature synthesis will influence further analysis, so it is important to choose rich examples of the phenomenon of interest, but not highly unusual cases. The factors for the inclusion through intensity sampling where threefold: first, a high degree of overlap between the research question of the article and those of the qualitative evidence synthesis; second, a high methodological quality of the paper, evaluated by means of the CASP; third, a high conceptual clarity within the article (Benoot, Hannes, & Bilsen, 2016).

On articles that were included through intensity sampling, we started performing our analysis. As described before, we used the data-extraction sheets of the included articles (see also table 1) for the analysis, in which we compared the concepts of each of these articles, and with which we performed a "reciprocal translation" of these concepts, which is the translation of one study's concepts into another, using a new overarching concept as an outcome for this translation (Noblit & Hare, 1988; Britten et. al., 2002). For example, an overarching concept that we retrieved was "exacerbation of struggling", encompassing strategies, situations, characteristics that were leading to an increased struggling with the sexual changes. In Gilbert's study (Gilbert, Ussher, & Perz, 2013), this is formulated as "sticking to the coital imperative", a concept which means that intercourse is the most normal and natural form of heterosexuality, and condemns those who cannot live up to these expectations as dysfunctional. In Walker & Robinsons' study (2012), this is formulated as avoidance of communication about the sexual changes. In Juraskovas' study (2003), exacerbation of struggling is the case when the patients are "receiving radiotherapy combined with external radiation and brachytherapy". See also table 2.

We continued intensity sampling until saturation was reached, i.e. where no new concepts were derived from reading further articles (Thompson, 1999). At that point, we analysed 6 papers (see table 3 for characteristics of these papers). The different concepts derived from the intensity sampling, defined the key dimensions that served as a basis for selecting additional papers.

Initial stages of the adaptation process	Avoidance of sexuality (Walker & Robinson, 2012) + *Minimization (Boehmer & Babayan, 2004)* **Denial**	Sticking to a coital imperative (Ussher et al., 2013) + *No change of sexual roles in the relationship (Wilmoth, 2001)* **Dominant discourses of sexuality**	Reduced vaginal lubrication (Juraskova et al., 2003) + *Loss of libido (Hartman, 2014)* **Initial sexual dysfunctions**
Sexual struggling	Having a sense of loss (Walker, 2011) + *Anger, depression (Hanly, 2014)* **Grieving about sexual changes**	Altered body image (Gilbert, 2010) + *Identity struggle (Fergus, 2002)* **Identity crisis and stigmatization**	Trying out novel sexual techniques (Walker, 2011) + *Struggling with urinary incontinence (Wittmann,2014)* **Struggling with Sexual dysfunction**
Sexual adaptation	Accepting each other's feelings (Beck et al., 2013) + *Incorporating sexual changes into a new, expanded sense of self (Gilbert et al., 2013)* **Sexual acceptance**	Renegotiating sexual intimacy (Beck et al., 2013) + *Redefinition of what sexuality means (Gilbert et.al, 2013)* **Sexual rediscovery**	Sexual adjustment and quality of life (Juraskova et al., 2003) + *Using Viagra leads to sex similar to before cancer (Hartman et al., 2014)* **Sexual recovery**
Pathways of sexual adjustment	**= Sexual adjustment as a grieving process** **Navon et al. (2003)**	**= Sexual adjustment as a cognitive restructuring process** **Oliffe (2005)**	**= Sexual adjustment as a rehabilitation process** **Ramirez et al. (2010)**

Table 2: Example of the Purposeful Sampling Process of the 16 Articles

Note 1: The concepts in the left column are the overarching concepts that are derived from the reciprocal translation of the concepts of articles included by intensity sampling
Note 2: The non- discursive parts are the articles and concepts coming from the included papers as a result of intensity sampling
Note 3: The discursive parts are the articles and concepts coming from the included papers as a result of maximum variation sampling
Note 4: The bold parts are new findings resulting from reciprocal translation of the concepts of articles included by maximum variation sampling
Note 5: The last row shows the line of argument, which are the three overarching pathways of sexual adjustment. The articles in this row are a result of disconfirming case sampling, each of them refining the subsequent sexual adjustment process

These papers were included through a maximum variation sampling, aiming to deepen our understanding of the core concepts by exploring different dimensions of them, in order to develop relationships between different categories (Patton, 1990). The articles needed to vary from each other in these particular dimensions. During this sampling phase, we chose to deepen our analysis towards the different theoretical underpinnings of the articles, and how these different underpinnings described different processes of sexual adjustment. As such, we chose articles who varied in their theoretical underpinnings (articles who are using different perspectives or coming from different disciplines, e.g. Hanly, Mireskandari, & Juraskova, 2014, published in a more medical journal, vs. Fergus, Gray, & Fitch (2002), published in a more psychology- oriented journal) or in the way the process was described (e.g. Boehmer & Babayan, 2004, who described mainly the beginning of the adjustment process). This resulted in the inclusion of 7 more papers (see table 2 and table 3 for characteristics of these papers).

This is how we arrived at a preliminary line of argument. The concepts were linked to three overarching pathways of sexual adjustment, each of these pathways representing a different theoretical underpinning of sexual adjustment: a grieving pathway, a restructuring pathway and a rehabilitation pathway (see table 2). During this last phase of building our theory, we used a disconfirming sampling strategy (Patton, 1990) as this strategy implies a selection of papers with a disconfirming main theory (e.g. Navon & Morag, 2003, who had a different interpretation of the grieving pathway) to determine whether the theory holds up under a variety of circumstances (disconfirming case sampling). This led us to an inclusion of 3 more articles (see table 2 and table 3). The analysis was completed when the resulting line of argument was sufficiently rich and dense, and when comparison to subsequent data sources did not yield any important new information or theoretical alternatives to explore. In total - because the purposeful way of sampling and analysing- 16 of the initial 58 articles were included in this synthesis.

Source	**Included through**	**Objective**	**Method**	**Epistemological background**	**Participant characteristics**	**Type of cancer/treatment**
Beck et al. (2013)	Intensity sampling	Understanding strategies that lead to successful adaptation and maintenance of sexual intimacy after prostate cancer treatment	Individual and conjointly interviews Grounded theory	/	17 heterosexual couples f= 57 y m= 64 y Primarily Caucasian and Asian 2 Latina	Prostate cancer Time since diagnosis 1 -8 years
Boehmer & Babayan (2004)	Maximum variation sampling	understanding couples' reaction to potentially losing sexual capacity because of prostate cancer	Separate semi-structured interviews Grounded theory	/	21 patients 13 partners Age= 37 y -70 y 14 white 6 african american 1 hispanic	Diagnosed with early prostate cancer, but not yet treated

Source	**Included through**	***Objective***	**Method**	**Epistemological background**	**Participant characteristics**	**Type of cancer/treatment**
Fergus et al. (2002)	Maximum variation sampling	*Exploring prostate cancer patients' beliefs, values and sexual performances regarding masculinity vis-à-vis prostate cancer treatment*	Series of 4 to 5 in-depth interviews Grounded theory	Social constructionist	18 men diversification in sexual orientation average age= 65 y 4 Afro-American 14 Caucasian	Prostate cancer Radical prostatectomy = 11 Radiotherapy= 6 Hormonal therapy= 4 3,7 y since diagnosis (1 -8,5 y)
Gilbert et al. (2010)	Intensity sampling	*Investigating the ways intimacy and sexuality are renegotiated during cancer, and what factors are associated with successful or unsuccessful renegotiation, from the perspectives of partners*	Semi-structured interviews Grounded theory	Material discursive framework	20 partners 14 female 7 male Average age: 53 y 18 Anglo-Australian 1 Filipina 1 Italian	3 brain tumor 4 prostate cancer 2 lung cancer 7 breast cancer 1 mesothelioma 2 metastasis
Gilbert et al. (2013)	Maximum variation sampling	*Exploring the post-cancer experiences of embodied sexual subjectivity of cancer patients and partners*	Semi-structured interviews Theoretical thematic analysis	Poststructuralist approach	44 patients 23f 21m 35 partners 18 f 17 m Average age: 54, 6 y Anglo-Australian (91%)	A range of cancer types and stages 5y post-diagnosis
Hanly et al. (2014)	Maximum variation sampling	*Exploring factors influencing sexual adjustment of prostate cancer patients and partners.*	semi-structured interviews Thematic analysis	/	21 men Age: 50y-59y= 8 60y-69y= 13	Localized prostate cancer = 19 Radical prostatectomy = 2 Initial treatment: 12 months ago= 6 less than 3 years ago= 13 less than 5 years ago= 2

Source	**Included through**	***Objective***	**Method**	**Epistemological background**	**Participant characteristics**	**Type of cancer/treatment**
Hartman et al (2014)	Maximum variation sampling	*Exploring the experience of gay couples managing sexual dysfunction because of radical prostatectomy*	Semi-structured interviews Interpretive phenomenological analysis	/	3 gay couples Age= 40y-62y	3 to 6 months after radical prostatectomy
Juraskova et al. (2003)	Intensity sampling	*Exploring dynamics and components of post-treatment sexual adjustment of patients following cervical and endometrial cancer*	Semi- structured interviews Qualitative phenomenological approach based on grounded theory	/	20 patients Age= 19y-64y	Cervical and endometrial cancer (stage I , II) Treatment: Surgery alone Surgery + external beam and brachytherapy Posttreatment (immediately to 2 years after)
Navon et al. (2003)	Disconfirming case sampling	*Examining coping strategies employed by advanced prostate cancer patients receiving hormonal therapy to learn from their experience about solutions to sexual needs*	In-depth interviews Constant comparative method	/	25 patients Age= 57y-85y	Advanced prostate cancer hormonal therapy 6 months to 3 years
Oliffe (2005)	Disconfirming case sampling	*Exploring men with localized prostate cancer experiences of impotence following prostatectomy*	in-depth semi-structured interviews Ethnography	Social constructionist	15 men with a current female partner Age= 57,6 y Anglo-Australian	Prostate cancer patients with prostatectomy Months since prostatectomy: 3 -72

Source	**Included through**	***Objective***	**Method**	**Epistemological background**	**Participant characteristics**	**Type of cancer/treatment**
Ramirez et al. (2010)	Disconfirming case sampling	*Examining the sexual challenges and adaptations made by female colorectal cancer survivors with ostomies*	Interview study Grounded theory	/	30 females Average age= 74 y White Non-Hispanic(N=22) Asian (N=3) Pacific Islander (N=2) African American (N= 2) Hispanic (N=1)	Colorectal cancer survivors with ostomies At least 5 y post-diagnosis
Ussher et al. (2013)	Intensity sampling	*Exploring renegotiation of sex in couples with cancer*	Semi-structured interviews Theoretical thematic analysis	Material-discursive	44 patients 23f /21 m 35 partners 18 f/17 m Age= 54, 6 y Anglo-Australian (91%)	All types and stages of cancer
Walker & Robinson (2011)	Intensity sampling	*exploring how prostate cancer patients and their partners adjust to changes associated with androgen deprivation therapy*	Unstructured interviews Grounded theory	/	18 heterosexual couples m= 47-83 y f= 32- 82y Average age patients= 65,4 y Average age partners= 61 y Euro-Canadian or American 1 Afro-American	Prostate cancer, undergoing Androgen Deprivation Therapy Time since diagnosis: 8 months to 15 years Duration of ADT: from 4 months to 13 years
Walker & Robinson (2012)	Intensity sampling	*Exploring struggles couples with prostate cancer faced when adapting sexually to side effects of Androgen Deprivation treatment.*	unstructured interviews Grounded theory	/	18 heterosexual couples m= 47-83 y f= 32 -82 y Average age patients= 65,4 y Average age partners= 61 y Euro-Canadian or American heritage, 1 who was Afro-American	Prostate cancer, all undergoing Androgen Deprivation Therapy Time since diagnosis: 8 months to 15 years Duration of ADT: from 4 months to 13 years

Source	Included through	*Objective*	Method	Epistemological background	Participant characteristics	Type of cancer/treatment
Wittmann et al. (2014)	Maximum variation sampling	*Examining a proposed conceptual model of couples' sexual recovery of prostate cancer*	Interviews preoperatively and 3 months postoperatively Analytic induction	/	20 couples m= 60,2 y f= 57,6 y White	Prostate cancer pre-surgery and post-surgery 30% had erectile dysfunction pre-operatively Most men had erectile dysfunction post operatively
Wilmoth (2001)	Maximum variation sampling	*Describing aspects of sexuality that were important to women after breast cancer treatment*	Qualitative descriptive study , interviews Grounded theory	/	18 white women Age= 35y-69 y	Breast cancer Time since diagnosis= 5 months - > 10 years 39% lumpectomy 61% Mastectomy

Table 3: Characteristics of the Included Studies

RESULTS

First, we will describe certain characteristics of the articles included. Second, we will explain the different theoretical pathways for sexual adjustment during cancer that we generated by synthesizing evidence from the primary research articles. These can be summarized as 1) the pathway of grief and mourning, 2) the pathway of restructuring, and 3), the pathway of rehabilitation.Third, we will explain the different concepts that are inherent to the tree different theoretical pathways: those describing the initial stages, those describing sexual struggling and those describing the sexual adjustment within each pathway. Lastly, we will integrate the concepts and describe the process of sexual adjustment, by linking the different concepts (i.e. initial stages, struggling and adjustment) to each other (see also Table 2 and 4).

Characteristics of the Articles

16 articles were included in this qualitative evidence synthesis. Articles were published between 2001 and 2015. The age of the participants ranged from 19 to 85 years. The population described in the articles was mainly Caucasian/white. The samples of the articles were mainly composed of prostate cancer patients (n=9). Only three articles discussed uniquely female patients (breast cancer, gynaecological cancer and colon cancer). The other articles had a mixture of gender and cancer types. 7 articles covered only heterosexual couples. 6 articles covered a mix of sexual orientations. 1 article covered only homosexual couples. 2 articles did not explicitly mention the sexual orientation of the participants.

Patients included in the sample of the articles were between 3 months and 15 years after diagnosis. Most of them were in remission, with the exception of 3 articles with advanced cancer patients. 2 articles interviewed patients before treatment.

Most of the primary studies used a methodology with the aim of building theory (grounded theory, ethnography, theoretical thematic analysis, analytical induction); 1 article worked with interpretive phenomenology and 2 with thematic analysis. Only 6 articles revealed their epistemological background. All studies were cross-sectional with the exception of 1 article.

All articles used interviews. In 8 articles, the patient and partner were both interviewed, in 7 articles, only the patient was interviewed, and in 1 article, only the partner was interviewed. More characteristics of the included studies are detailed in Table 3.

Three Different Pathways for Sexual Adjustment during Cancer

We found that the included articles work along three different pathways for sexual adjustment during cancer.

The pathway of grief and mourning First, there are articles following a grief theory to describe the adjustment process (Beck et al., 2013; Fergus et al., 2002; Hanly et al., 2014, Hartman et al., 2014, Juraskova et al., 2003; Navon & Morag, 2003; Walker & Robinson, 2011; Walker & Robinson, 2012; Wittmann et al., 2014; Wilmoth, 2001). In this case, sexual changes are depicted in terms of a loss, and the adjustment occurs through the pathway of grief and mourning. Different stages of sexual adjustment are described in these articles, parallel with stages in the grief work theory, such as denial, anger and acceptance. Articles inscribing themselves in this pathway use a more psychological explanation (theory).

The pathway of restructuring Second, there are articles following a “restructuring theory” during cancer (Beck et al., 2013; Boehmer & Babayan, 2004; Fergus et al., 2002; Gilbert et al., 2010; Gilbert et al., 2013, Hartman et al., 2014, Juraskova et al., 2003; Oliffe, 2005; Ramirez et al., 2009; Ussher et al., 2013, Walker & Robinson, 2011; Walker & Robinson, 2012). Unlike the grief theory, where the patient and partner work through different emotional stages, in the restructuring pathway the patient and partner sexually adjust to cancer more cognitively, by developing a new sexual paradigm. Flexibility is the central concept of this adjustment. This pathway is embedded in a social constructionist paradigm, which means there is a strong focus on the social and cultural forces -inherent to the social environment of a person- that shapes his or her experiences of sexuality. These constructions create some dominant discourses about sexuality that couples adhere to.

The pathway of sexual rehabilitation Third, there are articles following the pathway of sexual rehabilitation (Hanly et al., 2014, Hartman et al., 2014; Juraskova et al., 2003; Ramirez et. al, 2009; Walker & Robinson, 2011; Wittmann et al., 2014). This pathway is embedded in a more positivistic approach where the adaptation process does not emphasize psychological changes or cognitive restructuring, but emphasizes sexual changes as a bodily dysfunction that needs treatment and specific behavioural strategies.

Many of the articles address more than one pathway. However, there is often an explicit emphasis on one of the pathways in each article. We noticed that the majority of the articles mainly worked around the pathway of restructuring. A few articles mainly worked around the pathway of grief, and no articles worked exclusively around the pathway of sexual rehabilitation (see also addendum data extraction sheet for more detailed information).

Translation of the Concepts

Depending on which pathway the authors take, the concepts of the initial stages of the adaptation process, of struggling and of sexual adaptation are interpreted differently.

Concept of the initial stages of the adaptation process When the articles followed the pathway of grief, the initial stages of the sexual adjustment process were equated with the initial phase in the grief work theory, which is denial. On an individual level, initial reactions to the sexual changes are formulated through concepts such as “minimization”. For example, several authors talk about the minimization of the impact of possible side-effects of the cancer treatment on their sexuality (Boehmer & Babayan, 2004; Hanly et al., 2014). They also address the minimization of the importance of sexuality compared to surviving cancer (Hartman et al., 2014; Navon & Morag, 2003; Walker & Robinson, 2011). Some report on unrealistic expectations of adjustment within couples who are expecting full sexual recovery (Wittmann et al., 2014). On a more interactionist level, articles that followed the pathway of grief used two concepts to describe communication patterns, which are avoiding and suppressing sexuality. Articles described the avoidance of sexuality as a topic and as an act (Hartman et al., 2014; Juraskova et al., 2003; Walker & Robinson, 2011, 2012). For example, some articles report that couples do not initiate intimacy or any emotional or romantic entanglement (Hanly et al., 2014; Ramirez et al., 2009; Walker & Robinson, 2012). The suppressing of sexual needs by patients has been described by Walker & Robinson (2012): they distract themselves from sexual thoughts and fantasies. Juraskova et al. (2003) describe an emotional detachment of the patients during sexual experiences. Concerning the process of denial in the initial stages, we discovered a trend where the psychology of female patients/partners is tended to be described in more relational terms, while the initial stages of denial in male patients are described on an individual level. When the articles follow the pathway of restructuring, the concepts inherent to the initial point of the sexual adaptation process during cancer were usually embedded in the dominant discourses of sexuality (Gilbert et al., 2013; Oliffe, 2005; Ussher et al., 2013). These articles describe how partners and patients initially follow several dominant discourses about sexuality. An example of these dominant discourses is the “coital imperative”, in which sexual interaction is equated with penetrative intercourse, which means that coital sex is seen as the real way of having sex (Hanly et al., 2014; Ussher et al., 2013). Another example is “the companionate model of marriage”, where regular intercourse is seen as the core affective bond and where there is cultural pressure to stay sexually active (Ramirez et al., 2009). There is also the discourse of “ageism”, where sexuality is restricted to young adults (Oliffe, 2005). A last dominant discourse often described is that of masculinity or femininity, which reduces a woman’s sexuality with her need to be romantically attached to a man, and positions the man as having a driving need for sexuality (Fergus et al., 2002; Oliffe, 2005; Ussher et al., 2013). The extent to which patients and partners initially follow these dominant discourses varied. When they followed these discourses, the following patterns could be observed: patients and partners had the idea that their sexuality could be normalised through techno-medicines such as operation techniques or assistive aids (e.g. Viagra, lubricants) (Boehmer & Babayan, 2004; Fergus et al., 2002; Oliffe, 2005; Ramirez et al., 2009; Ussher et al., 2013). Moreover, patients and partners did not discuss their sexuality with each other, as they had the idea that sex is something you do, not something you talk about (Gilbert et al., 2010). Neither did they want to expand their sexual repertoire, nor to change their sexual roles in the relationship (Wilmoth, 2001; Wittmann et al., 2014). Furthermore, male patients demonstrated sexual prowess despite sexual dysfunction, while female patients demonstrated an other-orientedness, by providing their partner with sexual intercourse despite their own difficulties (Hanly et al., 2014; Juraskova et al., 2003).

Patients and partners who were less sensitive to this discourse were mainly the ones that already had a broad sexual repertoire. Moreover, these couples had already questioned the central position of sexuality in a relationship before the onset of cancer, e.g. due to other sexual dysfunctions, or they had already an alternative sexual discourse because of their sexual orientation (Hartman et al., 2014). When the articles worked around the pathway of sexual rehabilitation, the initial stage of the sexual adaptation process was equated with the physical body experiences of dysfunction (Hartman et al., 2014; Juraskova et al., 2003) and not solely by the emotions or thoughts about these experiences (Wittmann et al., 2014, Hartman et al., 2014). Gender differences in these experiences of dysfunctions observed in our sample of papers were related to anatomic sex differences, such as erectile dysfunction, or vaginal dryness.

Concept of sexual struggling In the articles following the pathway of grief theory, the concept of sexual struggling aligns well with an acknowledgment of sexual dysfunctions and is equated with the traditional grief stages of depression and anger. At an individual level, these stages of struggling have been described mostly as emotions, such as disappointment, frustration, fear, and a sense of loss and grief (Hanly et al., 2014; Juraskova et al., 2003; Walker & Robinson, 2011; Wittmann et al., 2014). At the interactionist level, struggling is described as based on incongruence in the concerns about sexuality between the partners (Hanly et al., 2014).

In the articles following the pathway towards restructuring, sexual struggling is mainly described in forms of crisis of identity (Boehmer & Babayan, 2004). At an individual level, this is formulated, for example, as a feeling of inferiority (Fergus et al., 2002), an altered body-image (Gilbert et al., 2010), a sense of disembodiment (Ussher et al., 2013), or a loss of masculinity or femininity (Fergus et al., 2002; Oliffe, 2005; Ussher et al., 2013). At an interactionist level, struggling is described as stigmatization because of sexual dysfunction (Fergus et al., 2002).

In the articles following the pathway of sexual rehabilitation, sexual struggling is described as a physical state , e.g. struggling with urinary incontinence that is seen as an interference with sexual adjustment (Wittmann et al., 2014), with the side effects of treatment, with the unpredictability of these side effects and as a process of trial and error with assistive aids (Hartman et al., 2014).

Concept of sexual adaptation

The stage of adaptation in the pathway according to the grief theory is the “acceptance” of changed sexuality, which can be described as “getting on with life” (Hanly et al., 2014),“acceptance of the use of assistive aids” (Wittmann et al., 2014), “acceptance of the sexual status as the new normal” (Hartman et.al., 2014), “ the development of realistic expectations” and “the acknowledgement that railing against the current situation was a waste of energy”(Beck et al., 2013). Accepting the changed sexuality is not only individual, but also occurs on an interactionist level, i.e. when the partners accept each other’s feelings (Beck et al., 2013). Accepting the changes is also formulated as a sign of resilience (Wittmann et al., 2014).

Adaptation in the pathway of restructuring means that the patient and partner restructure, abandon and challenge the dominant discourses of sexuality mentioned above. We have called this adaptation “sexual rediscovery” rather than “sexual acceptance”. This is because this form of adaptation does not only accept the changes, but incorporates them into a new, expanded sense of the self (Gilbert et al., 2013). A first example of this rediscovery is the questioning of the importance of sexuality: couples no longer see sexuality as a centrifugal force around which a relationship revolves (Gilbert et al., 2013).

Another example is the rediscovery of the meaning of sexuality. Some authors describe this as the conceptualization of sexual alternatives as the norm (Oliffe, 2005; Walker & Robinson, 2011). Oliffe

(2005) describes this as a disruption of "essentialist constructions" of male sexuality, which means they challenge the idea that male sexuality is biologically determined. Hartman et al. (2014) describe a change of language about sexuality: from having sex to "love-making".

A third example is the rediscovery of the way of expressing sexuality. Authors describe how couples include sexual practices that previously have been marginalized, such as touching and hugging (Beck et al., 2013; Gilbert et al., 2010; Oliffe, 2005). Rediscovery could be an individual process but also an interactionist process (Fergus et al., 2002). In this case, we use the concept of renegotiation instead of rediscovery. Renegotiation happens through open and flexible communication (Beck et al., 2013; Ussher et al., 2013), and through challenging the social discourse of shame about talking about sex (Fergus et al., 2002). Often, this renegotiation is described as an amelioration of sexuality and intimacy (Gilbert et al., 2010; Fergus et al., 2002). The onset of cancer is then conceptualized as a site of possible personal growth (Gilbert et al., 2013)Adaptation according to the pathway of sexual rehabilitation means that patients and partners are able to resume intercourse (Ramirez et al., 2009). Therefore we have named this endpoint sexual recovery rather than sexual rediscovery. In these cases, articles write about resuming a sexual relationship due to modifications to their sexual repertoire, e.g. novel sexual tools and techniques, but without including a reconstruction of what sexuality is (Walker & Robinson, 2011).

The Sexual Adaptation Process: Integrating the Concepts

As stated above and shown with examples in Table 4 and figure 2, the different pathways each have a different and often contradictory processes of sexual adjustment. For example, some strategies -following the restructuring pathway- can be seen as inhibiting sexual adjustment, while the same strategies -following the rehabilitation pathway- can be seen as facilitating sexual adjustment.

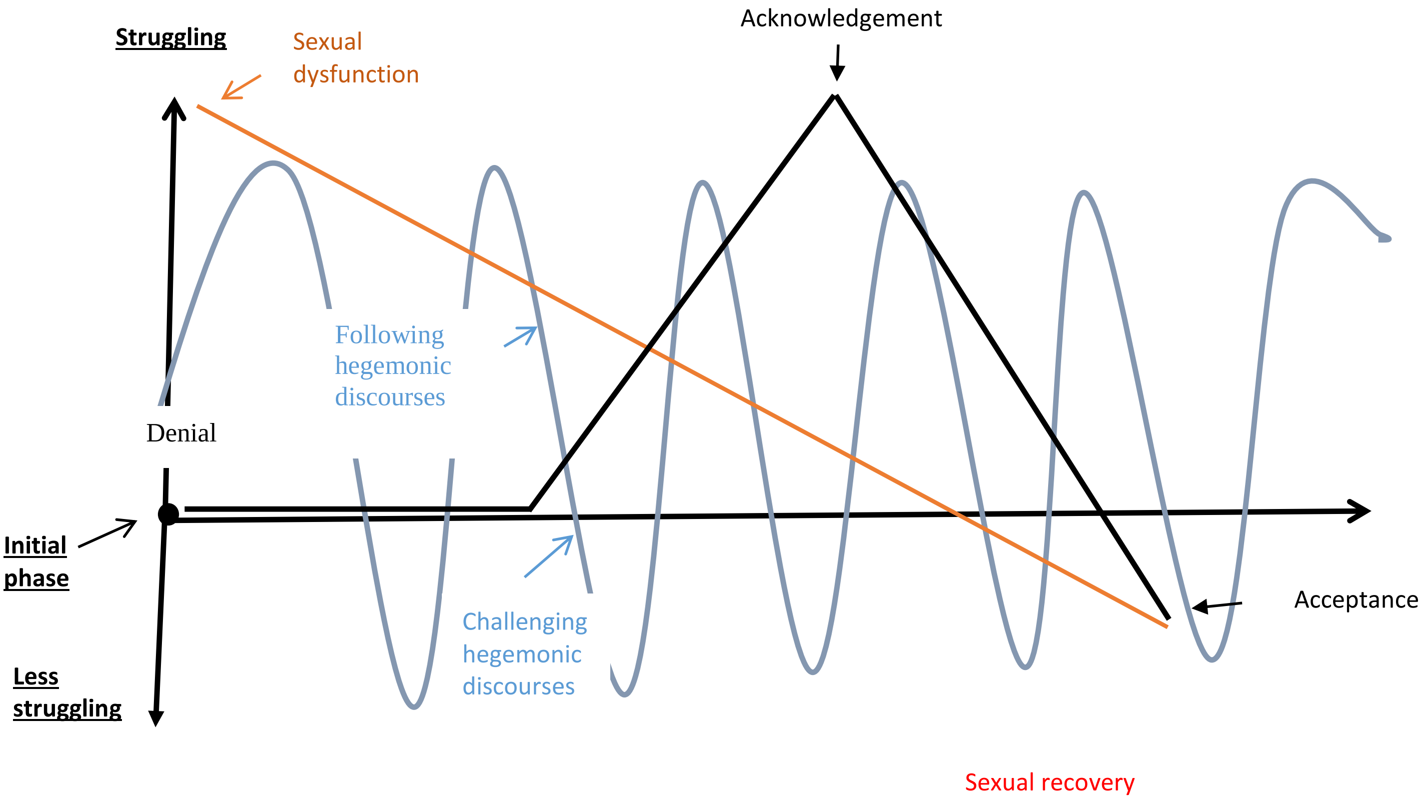

Fig. 2 Relationships between the concepts, according to the different pathways. The *black line* describes the pathway of grief and mourning, the *blue line* the pathway of restructuring, and the *red line* the pathway of rehabilitation.

Relationship between initial states of the sexual adaptation process and struggling In the case of pathways of grief, the initial state of denial is depicted as a productive state in the sexual adaptation process because at that moment the strategies used to adjust to sexual changes do not interfere with the strategies used to cope with the disease (Wittmann et al, 2014). Wilmoth (2001) calls this the "taking in" phase. E.g. "minimization of sexuality" , as a sexual strategy, is also a helpful coping strategy, for example because it facilitates treatment decisions (Navon & Morag, 2003). In the initial state of denial, the couple is not struggling. These strategies are thus effective, but according to most articles, not sustainable: the effectiveness of this strategy diminishes due to increasing acknowledgement of its self-deceptive nature (Hartman et al., 2014; Navon & Morag, 2003). Wilmoth (2001) formulates this acknowledgement as the "taking hold" phase.

Some authors therefore interpret an immediate acceptance of sexual changes as provisional (e.g. Walker & Robinson, 2011). These authors acknowledge that this immediate acceptance is based on assumptions and avoidance -concepts that could be linked with denial - but due to the cross-sectional nature of the study, they only could suggest that this state was temporary. According to this grieving pathway, knowledge about the possibility of sexual side effects prior to cancer treatment is an important facilitator to go from the initial state of denial to struggling, because knowledge lessens the risk of patients and partners getting stuck in the denial process, which inhibits the adjustment process (Hanly et al., 2014; Juraskova et al., 2003; Ramirez et al., 2009).

	Grieving pathway	**Restructuring pathway**	**Rehabilitation pathway**
Sexual changes after cancer	Sexual loss	Disruptions in identity	Sexual dysfunction
Questioning the importance of sexuality	Minimization – Denial	Challenging a hegemonic construction of sexuality	/
Not communicating about sexuality	Avoiding and Suppressing - Denial	No renegotiation - Following a hegemonic construction	/
Using assistive aids	/	Following hegemonic constructions- leading towards struggling	Strategy leading towards adaptation
Sexual adaptation	Acceptance of sexual losses	Sexual rediscovery	Sexual recovery
No struggling (in the initial state)	Immediate acceptance – Denial	Less struggling because of already challenging the hegemonic discourses before onset of cancer	No severe sexual dysfunction
Communicating about sexuality	Acknowledgment and disclosure of emotions	Renegotiating sexuality - Challenging hegemonic discourses	/

Table 4 Examples of how the same concepts are interpreted differently according to the pathway being used

In the pathway of restructuring, however, struggling has been mostly described simultaneously with the initial state of alignment with dominant discourses. The initial state in these cases is often depicted as a state of struggling. For example, Boehmer & Babayan (2004) describe how patients and partners even start to worry before the onset of treatment. The less the initial adherence to dominant discourses, the less the struggling (Juraskova et al., 2003; Wittmann et al., 2014). For example, when intimacy and not sexual pleasure is the motivation for having sex, patients and partners will struggle less because there is less need for restructuring (Beck et al., 2013). Moreover, when couples already downplayed the centrality of sexuality in their relationship before the onset of cancer, there will be less struggling than in those relationships where sexuality played an important part (Ussher et al., 2013, Beck et al., 2013; Walker & Robinson, 2011).

In articles working with the pathway of sexual rehabilitation, the degree of sexual dysfunction is the determining factor in the possible onset of struggling. A significant loss of sexual function led to a higher probability of profound sexual struggling, as it makes it more difficult to adjust to sexual changes.

Relationship between struggling and adaptation In articles working with the grieving process, struggling is a necessary phase when acceptance of sexual loss is to be reached. Because both are emotional states, the evolution from struggling to acceptance needs no specific behavioural or cognitive restructuring, but rather requires emotional adjustment. No active coping mechanisms were described in these articles; most authors formulated the development in similar terms to Walker & Robinson (2012), i.e. "allow time to pass and have patience" (Wittmann et al., 2014). One exception was the explicit acknowledgement and disclosure of these emotions and open and honest communication, in contrast to the denial of these emotions (Walker & Robinson, 2011, 2012; Wittmann et al., 2014). According to this pathway, the acceptance of sexual losses is described as a final end point.

However, in the articles working around restructuring, there is a need for individual, active restructuring and interactive renegotiation, starting on a cognitive level but with consequences on the behavioural level. In these cases, challenging the discourses is a prerequisite to overcome the struggling and achieve good sexual adjustment (Fergus et al., 2002; Walker & Robinson, 2012; Hartman et al., 2014). For example, Ussher et al. (2013) says that non-coital intimacy led to increased relational closeness. When patients and partners are following dominant discourses however, this will exacerbate the struggling and can lead to "tremendous" sadness and frustration in the couple (Ramirez et al., 2009; Ussher et al., 2013; Walker & Robinson, 2012; Oliffe, 2005). This restructuring and renegotiation is depicted as a process that takes time and patience, which needs to be developed slowly and with good communication before it can be integrated and incorporated into the self and the relationship (Walker & Robinson, 2011). In contrast with the articles using the grief process, there is no real endpoint in this adjusting process. Instead it is seen as a process of oscillation between struggling and adaptation, between sticking to and challenging the dominant discourses of sexuality (Hanly et al., 2014, Gilbert et al., 2011, 2013; Ramirez et al., 2009).

In articles working around sexual rehabilitation, strategies that would be interpreted as exacerbating the struggling -in the pathway of restructuring-, are here, in contrast, depicted as leading towards adjustment. For example, Wittmann et al.(2014) pointed to the effective use of assistive aids and regular sexual activity as a facilitator of sexual adjustment.

DISCUSSION

This qualitative evidence synthesis revealed how the theoretical approaches of the subsequent studies influenced understanding of the sexual adaptation process during cancer: the three different pathways (grief, restructuring, rehabilitation), led to three divergent adaptation processes. All three pathways have their own opportunities and challenges.

First, the grief process offers an explanation for the common finding in quantitative research that there is less sexual dysfunction right after diagnosis than a couple of months afterwards (O'Brien et al., 2011; Ramsey et al., 2013). Furthermore, the grief process clearly makes a link between the different stages of cancer treatment (e.g. diagnosis, remission) and the stage of sexual adaptation, and consequently shows us the necessity of performing longitudinal research in order to see different stages of sexual difficulties according to the stage in the cancer trajectory.

Working according to the grief process, however, risks to be judgmental and based on the assumption that the loss of sexuality is a stressful event in all cases. Patients and partners who are not struggling with sexual side effects are then considered to be in denial. Morse (2000) and Zimmermann (2004) also pointed out the problems of using the term "denial" in qualitative research, as it places the researchers' values above the patients' and partners' behaviour.

The advantage of the restructuring process is that it does take into account people who do not suffer from sexual dysfunction, by claiming that these people are not following dominant discourses of sexuality, i.e. regular, active sex life in a couple. Another advantage is that the pathway towards restructuring moves clearly away from an image of sexual dysfunction - often used in biomedical science - towards an image of sexual transition, with rediscovery and even transcendence as possible "outcomes". Consequently, this process is empowering as it emphasizes the patients' and partners' strengths instead of emphasizing illness and dysfunction. It also implies that dysfunction is not only a definition describing what is "not normal", but that it also describes cultural factors, i.e. what is expected to be normal. A last opportunity is that the restructuring theory challenges the overly linear approach of the other approaches (grief and rehabilitation), stating that an adaptation process is an ongoing and continually shifting process between challenging and following discourses of sexuality.

A disadvantage of the restructuring pathway is the absence of the influence of material factors, such as the physical influence of cancer or cancer treatment. For example, in contrast with the grief theory, there is no attention for the specific stages of the cancer treatment and their effect on experiences of sexuality. Moreover, hardly any article that is based exclusively on the restructuring process mentions stories of participants who have positive experiences with assistive aids (e.g. Viagra, erectile aids etc.), although other clinical research reports some success with these aids (e.g. Titta et al, 2006). This could be a selection bias, because the strategy of using assistive aids follows a more essentialist discourse, going against a constructivist perspective. The material aspects of sexual dysfunction are thus ignored, downplaying the significance of its functional, physiological and hormonal aspects. It shows us that refutations of the essentialist dogma may be dogmatic in themselves.

Articles based on the process of sexual rehabilitation, however, in contrast with the processes above, incorporate these biological, material aspects into the qualitative research.

A disadvantage of the sexual rehabilitation process is the relative neglect of psychological or social components of sexual difficulties. However, none of the included articles works exclusively around the process of sexual rehabilitation. This could be explained by the general tendency of qualitative research to challenge the biomedical perspective of sexuality that is still dominant in sexology and oncology (White, Faithfull, & Allan, 2013).

Towards a "Re-integration" of the three Pathways, with Implications for Practice

As stated above, many of the included articles address more than one pathway. It was an analytical choice to separate these contrasting pathways in order to bring them back together, as this re-integration would lead to more awareness of the different pathways that could be used to interpret sexual adjustment during cancer.

This higher awareness of the different pathways could help healthcare providers to better assess and understand the ways a particular patient is behaving. What is more, it could help them to give their patients insight into their own coping behaviour, offering them opportunities to discover alternative pathways for adjusting to sexual changes after cancer. Additionally, interventions based on sexual adjustment after cancer could acknowledge that sexuality is malleable and can take on new meanings, and that modifying sexual behaviour should be accompanied with a change of mentality (according to the restructuring process). However, this should not be taken to the extreme where sexual dysfunctions are overly relativized (according to the rehabilitation process).

Furthermore, when combining the findings of the grief process with the restructuring process, interventions could incorporate the idea tohat there is not so much of a polarisation between good and bad with strategies of sexual adjustment: healthcare providers do not have to ask themselves the question of which strategies are effective and which are not, but when these strategies are effective. Strategies following dominant discourses about sexuality (according to the restructuring process) could be helpful during a "taking-in phase" (according to the grief process), as Wilmoth (2001) formulates it. Inversely, strategies challenging dominant discourses about sexuality (according to the restructuring process) could only be effective after a certain time, as it needs a struggling phase (according to the grief process).

Moreover, interventions could not only be used to accept the limitations of a couple's sex life (according to the grief process), but - if possible - also to work towards a rediscovery or even a transcendence of sexuality during cancer (according to the restructuring process). Interventions could thus follow a “strengths-based” approach (Thorne & Paterson, 1998), which means they choose to work with those aspects of illness that are healthy, transformative and positive instead of focussing on loss and suffering, without being blind to the vulnerability of patients and partners. Another important implication for practice is that resuming intercourse may not be a primary therapeutic goal for all cancer patients, as some do experience sexual continuity rather than disruption (according to the restructuring process). However, patients and partners can also use the concealment and avoidance of sexual problems (according to the grief process). Consequently, it is the task of the healthcare provider to follow the couple longitudinally to distinguish patients and partners who really do not prioritise sexual aspects of their lives and those who are hesitant to raise the topic. What is more, the restructuring process could offer an explanation of why interventions aimed at sexual adaptation during cancer are unsure to work in the long term (Canada et al., 2005; Badr & Krebs, 2013), as it shows us that patients and partners are continually shifting between challenging and following dominant discourses. Indeed, Ramirez et al. (2009) point out in their conclusion that resisting the norm is hard, and that patients often return to it. A more continuous training could prevent patients and partners from going back to initial states of struggling.

The results of this qualitative evidence synthesis also challenge the dominant emphasis in qualitative research on the emotional, cultural and social aspects of sexuality, (i.e. on the grief process and on the restructuring process) thereby neglecting the bodily aspects of sexuality (i.e. the sexual rehabilitation process). Future qualitative research should move away from a unilateral opposition against a medical approach of sexuality. Only then we can come to a holistic, biopsychosocial interpretation of sexuality. Research – qualitative or quantitative - should incorporate an investigation of all three pathways in order to be more complete.

Limitations

We did not examine in depth the role of several possible influencing factors (e.g. stage or type of cancer, race, gender, class status) towards the sexual adaptation process. This because the included papers were either too diverse in their sample or did not provide sufficient detail in order to analyse these dimensions. As explained above, a lot of articles are not taking the physical conditions as influencing factors into their analysis. Also, it was an analytical choice to focus on the link between the theoretical approaches of the studies and the interpretation of the sexual adaptation process, thereby purposefully sampling on these concepts, letting go potentially other interesting angles of investigation, for example, analysing the articles from a feminist perspective, which can focus on the gendered aspects of the sexual adjustment process.

We see the theoretical model as a first attempt towards a more in-depth analysis when accounting for the influencing factors mentioned above. For example, further research could perform a gendered analysis, focussing more on the way gender differences are depicted according to the three pathways.

CONCLUSION

Our synthesis points out that theoretical orientation has a significant influence on the claims the authors make about their results, and therefore this should be mentioned explicitly in the reporting of research. It also points out that, instead of a polarization of three different pathways of sexual adjustment, they could all be integrated to arrive at a complete and holistic approach to sexual adjustment during cancer.

Declaration of Conflicting Interests The authors declared the following potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding The study was financially supported by a grant from the Research Foundation Flanders (FWO)

Compliance with Ethical Standards As we did a secondary analysis of published articles, this article does not contain any studies with human participants performed by any of the authors.

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APPENDIXES

Appendix 1 Data extraction sheet of each of the included studies

Source	Objective	Methodological choices	Participant characteristics	Main theoretical arguments and concepts
Beck et al. (2013)	Understanding strategies that lead to successful adaptation and maintenance of sexual intimacy after prostate cancer treatment	Individual and conjointly interviews Grounded theory methodology *Epistemological background:* /	17 heterosexual couples f= 57 y m= 64 y Primarily Caucasian and Asian 2 Latina Prostate cancer Time since diagnosis 1 -8 years	*Pathway of grief* Accepting means to develop realistic expectations about sexuality Accepting means the acknowledgement that railing against the current situation was a waste of energy Accepting not only one's own feelings, but also partners' feelings *Pathway of restructuring* Couples who valued sex primarily for relational intimacy were more likely to succesfull adjust then those who valued sex for physical pleasure. Couples with intimacy as motivator were motivated to find alternative ways to be sexually active Flexibility: Couples who are willing to modify their old ways of having sex were able to maintain sexual intimacy Flexibility: Couples who were flexible in their communication were able to maintain sexual intimacy Persistence: months and years to rebuild a satisfying sexual relationship
Boehmer & Babayan (2004)	understanding couples' reaction to potentially losing sexual capacity because of prostate cancer	Separate semi-structured interviews Grounded theory methodology *Epistemological background:* /	21 patients 13 partners Age= 37 y -70 y 14 white 6 african american 1 hispanic Diagnosis with early prostate cancer, but not yet treated	*Pathway of restructuring* Erectile dysfunction as a threat to identity Worrying about future dysfunction Partners were stressing the existence of other relationship dimensions Current level of sexual function freatly influenced how they felt about the possibility of losing this function

				Dominant reaction was no anticipation of changed sexual practices, a reliance on medicine offering repair
Fergus et al. (2002)	Exploring prostate cancer patients' beliefs, values and sexual performances regarding masculinity vis-à-vis prostate cancer treatment	Series of 4 to 5 in-depth interviews Grounded theory *Epistemological background* Social constructionist	18 men diversification in sexual orientation Age= 65 y 4 Afro-American 14 Caucasian Prostate cancer Radical prostatectomy = 11 Radiotherapy= 6 Hormonal therapy= 4 3,7 y since diagnosis (1 -8,5 y	*Pathway of grief* Angry because of lack of preparedness for sexual dysfunction *Pathway of restructuring* identity struggles because of sexual losses over and above the desire for physical pleasure, that fuel strategies The sexual sacrifice as an erroneous assumption that sexuality was an isolated function Pressure to perform Virility and vitality Flaunting sexual prowess Baring an invisible stigma Effortful-mechanical sex not satisfactory Redefinition leads to less frustration The partner is an active participant in the redefinition process Disclosing as confronting a wall of socially constructed shame Discovering new sexual horizons Minimization as a succesfull strategy
Gilbert et al. (2010)	investigating the ways intimacy and sexuality are renegotiated during cancer, and what factors are associated with successful or unsuccessful renegotiation, from the perspectives of partners	Semi- structured interviews Grounded theory *Epistemological background:* Material discursive framework	20 partners 14 f, 7 male Age: 53 y 18 Anglo-Australian 1 Filipina 1 Italian 3 brain tumor 4 prostate cancer 2 lung cancer 7 breast cancer 1 mesothelioma 2 metastasis	*Pathway of restructuring* Sticking to coital imperative Altered body-image No renegociation of sexuality because of the assumption of sexuality is not to be talked about Resisting the coital imperative Including practices previously been marginalized Reconceptualizing sexual alternatives as the norm

				More intimacy as outcome of adaptation Both being complicit to discourses as resistant to them The possibility of being sexually intimate is associated with the possibility of alternative sexual practices , impeded by the adherence to the coital imperative, and influenced, impeded by communication problems
Gilbert et al. (2013)	exploring the post-cancer experiences of embodied sexual subjectivity for cancer patients and partners	Semi- structured interviews Theoretical thematic analysis *Epistemological background:* Poststructuralist approach	44 patients (23f, 21 m) 35 partners (18 f, 17 m) Age: 54, 6 y Anglo-Australian (91%) A range of cancer types and stages 5y post-diagnosis	*Pathway of restructuring* Sexual disembodiment Re-inventing sexuality Sexual re-embodiment Increased relational closeness Exploring non-coital sexual practices incorporating sexual changes into a new, expanded sense of self oscillating sexual subjectivity possibility of negative circular effect
Hanly et al. (2014)	Exploring factors influencing sexual adjustment of prostate cancer patients and partners.	semi-structured interviews Thematic analysis *Epistemological background* : /	21 men Age: 50-59= 8 60-69= 13 Localized prostate cancer = 19 Radical prostatectomy = 2 Initial treatment: 12 months ago = 6 less than 3 years ago= 13 less than 5 years ago= 2	*Pathway of grief* Avoidance of physical intimacy for their wife Suppressing: denial behavior Minimizing side-effecs Emotional struggles (anger, depression, disappointment, a sense of loss) Accepting, getting on with life Early referral for sexual changes would have reduced anxiety *Pathway of sexual rehabilitation* A good response to medical therapy leads to adjustment Lifestyle adjustment to accommodate the functional changes Coming to terms involved making life style changes, and integrating their

				post-treatment "new normal" sexual life.
Hartman et al (2014)	Exploring the experience of gay couples managing sexual dysfunction because of a radical prostatectomy	Semi-structured interviews Interpretive phenomenological analysis *Epistemological background:* /	3 gay couples Age= 40-62 3 to 6 months after radical prostatectomy	*Pathway of grief* Emphasizing health Age attributions Communication breakdown Avoiding initiating in sex accepting sexual status as the new normal *Pathway of restructuring* Emphasizing intimacy , embracing plan B are helping sexual adjustment *Pathway of sexual rehabilitation* Acknowledging change: Description of loss of libido, erectile function, sexual activity and orgasmic functions Degree of unpredictability of the side-)effects lead to struggling Trail and failure with assistive aids
Juraskova et al. (2003)	exploring dynamics and components of post-treatment sexual adjustment of patients following cervical and endometrial cancer	Semi- structured interviews Qualitative phenomenological approach based on grounded theory *Epistemological background:* /	20 patients Age 19-64 Cervical and endometrial cancer (stage I , II) Treatment: Surgery alone Surgery + external beam and brachytherapy Posttreatment (immediately to 2 years after)	*Pathway of grief* After surgery: still coming to terms with diagnosis Emotional detachment during first sexual experiences Fear with first resuming intercourse Afraid of resuming intercourse Reluctance to discuss feelings Discussing fear and anxiety leads to understanding *Pathway of restructuring* Identification of women with bearing children leads to struggling Self-renunciation of women providing partner with intercourse Struggling less profound when open communication and broader sexual repertoire prior to diagnosis Importance of partners in promoting a holistic healing *Relationship history* Broadness of sexual repertoire before diagnosis helped coping with sexuality *Pathway of sexual rehabilitation* Impact of treatment modality on the experienced difficulties with sexuality

Navon et al. (2003)	Examining coping strategies employed by advanced prostate cancer patients receiving hormonal therapy to learn from their experience about solutions to sexual needs	In-depth interviews Constant comparative method *Epistemological background:* /	25 patients Age= 57y-85y Advanced prostate cancer hormonal therapy 6 months to 3 years	*Pathway of grief* Revulsion disguise, diversion and avoidance strategies minimization: downplaying the matters' gravity Strategies have advantages and disadvantages. There are changing patterns over time *Pathway of restructuring* Believe to combat disease with masculine qualities
Oliffe (2005)	Exploring men with localized prostate cancer experiences of impotence following prostatectomy	in-depth semi-structured interviews Ethnography *Epistemological background:* Social constructionist	15 men with a current female partner Age= 57,6 y Anglo-Australian Prostate cancer patients with prostatectomy Months since prostatectomy: 3 -72	*Pathway of grief* *Pathway of restructuring* phallocentric representations resided beneath the seemingly rational justifications to choose life over potency Potency was legitimately dismissed through ageist constructions Stoicism precluded disclosure of problems Hegemonic constructions contributed to the expectant simplicity of impotence monitoring the penis by using assistive aids : a gap between the mythological ease and the real difficulty of achieving a functional erection. Disruption of essentialist constructions of male sexuality and impotency Redefining of intimacy Moving beyond libido to motivate sexuality Expressing sexuality through touch rather than penetration In between spaces of both rejecting and relying on hegemonic masculinity
Ramirez et al. (2010)	Examining the sexual challenges and adaptations made by female colorectal cancer survivors with ostomies	Interview study Grounded theory *Epistemological background:* /	30 females Age= 74 years White Non-Hispanic(N=22) Asian (N=3) Pacific Islander (N=2) African American (N= 2) Hispanic (N=1)	*Pathway of restructuring* Trying different assistive aids but failing: tremendous sadness Companioned model of marriage Cultural pressure to remain sexually active Restructuring: Intercourse not the centrifugal force Women resist cultural imperatives for specific forms of sexual activities

			Colorectal cancer survivors with ostomies At least 5 y post-diagnosis	Resisting the norm, and then return to it *Pathway of sexual rehabilitation* Orchestrating ostomy management techniques makes them able to resume intercourse.
Ussher et al. (2013)	Exploring renegotiation of sex in couples with cancer	Semi-structured interviews Theoretical thematic analysis *Epistemological background:* Material-discursive	44 patients (23f, 21 m) 35 partners (18 f, 17 m) Age: 54, 6 y Anglo-Australian (91%) All types and stages of cancer	*Pathway of restructuring* Hegemonic constructions of sex are central to the experience of sexuality after cancer Resisting the coital imperative: redefining sex and embracing intimacy Non-coital intimacy as producing increased closeness in the relationship Renegociation through effective communication : honest and open A relationhip that normally involved a lot of noncoital intimacy made it easier to renegociate Adopting the coital imperative: refiguring the body through technomedicine Following hegemonic discourses leads in the majority of cases to struggling
Walker & Robinson (2011)	exploring how prostate cancer patients and their partners adjust to changes associated with androgen deprivation therapy	Interviews, unstructured interviews Grounded theory methodology *Epistemological background:* /	18 heterosexual couples (m 47-83 years) (f 32 -82 years) Age patients: 65,4 y Age partners: 61 y Euro-Canadian or American heritage, 1 who was Afro-American Prostate cancer, undergoing Androgen Deprivation Therapy	*Pathway of grief* Accepting a relationship without sex, in exchange for life-extending treatment. Avoiding communication about the sexual changes they experienced. Avoiding topics by focusing to other areas in their life Accepting because of anticipation of sexual problems Struggling and having a sense of loss Grieving the loss of the relationship : disappointment and grief Open and honest communication as a key to success Couples are not necessary static in regards to adaptation

			Time since diagnosis: 8 months to 15 years Duration of ADT: from 4 months to 13 years	Satisfied with the decision to stop sexuality *Pathway of restructuring* Expanding the definition of sex beyond intercourse Reporting improvement of the sexual relationship *Pathway of sexual rehabilitation* Several techniques to maintain sexuality : new activities, altered initiation patterns, novel sexual tools and techniques
Walker & Robinson (2012)	Exploring struggles couples with prostate cancer faced when adapting sexually to side effects of Androgen Deprivation treatment.	unstructured interviews Grounded theory methodology *Epistemological background:* /	18 heterosexual couples (m 47-83 years) (f 32 -82 years) Age patients: 65,4 y Age partners: 61 y Euro-Canadian or American heritage, 1 who was Afro-American Prostate cancer, all undergoing Androgen Deprivation Therapy Time since diagnosis: 8 months to 15 years Duration of ADT: from 4 months to 13 years	*Pathway of grief* Acknowledge loss and grief Allow time to pass Talk to each other about grief Avoid talking Ignore sexual thoughts Witdrawing *Pathway of restructuring* Assumptions, judgements and persistence without flexibility exacerbates the struggle Embracing new experiences , flexibility in thoughts and behavior overcomes struggling The key factor is that the restructuring has to be mutual Improvement of sexual relationship after cancer is possible
Wittmann et al. (2014)	To examine a proposed conceptual model of couples' sexual recovery of prostate cancer	Interviews preoperatively and 3 months postoperatively Analytic induction *Epistemological background:* /	20 couples Age m= 60,2 y Age f= 57,6 y White Prostate cancer pre-surgery and post-surgery 30% had erectile dysfunction pre-operatively Most men had erectile	*Pathway of grief* Preoperatively : Overestimation of erectile recovery Expecting sexual rehabilitation Anticipatory grief about potential losses Postoperatively: Frustration Lost confidence Couples: loss and grief: cancer first loss, surgery-related sexual loss second

			dysfunction post operatively	Grief is a process variable in this recovery Accepting aids helped adjustment capacity to communicate will help grieving process Acceptance is sign of resilience *Pathway of sexual rehabilitation* Functional sexual losses after cancer urinary incontinence as a barrier for sexual rehabilitation engagement in intentional sex regular sexual activity and willingness to experiment sexually using sexual aids helped the sexual rehabilitation
Wilmoth (2001)	To describe aspects of sexuality that were important to women after breast cancer treatment	Qualitative descriptive study Grounded theory method *Epistemological background* /	18 white women Age= 35y-69 y Breast cancer Time since diagnosis= 5 months - > 10 years 39% lumpectomy 61% Mastectomy	*Pathway of grief* Changing sexuality is depicted in terms of losses A process of adjustment labeled as taking in, taking hold, taking on The meaning making component of the taking hold process did not begin until the taking in of the diagnosis had been resolved

Appendix 2 List of articles that were included in the study but not used in the metasynthesis

1. Afiyanti, Y., & Milanti, A. (2013). Physical sexual and intimate relationship concerns among Indonesian cervical cancer survivors: A phenomenological study. Nursing & health sciences, 15(2), 151-156.
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CHAPTER 3

THE USE OF PURPOSEFUL SAMPLING IN A QUALITATIVE EVIDENCE SYNTHESIS: A WORKED EXAMPLE ON SEXUAL ADJUSTMENT TO A CANCER TRAJECTORY

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Published in BMC medical research methodology, 2016, 16(1)

ABSTRACT

Background

An increasing number of qualitative evidence syntheses papers are found in health care literature. Many of these syntheses use a strictly exhaustive search strategy to collect articles, mirroring the standard template developed by major review organizations such as the Cochrane and Campbell Collaboration. The hegemonic idea behind it is that non-comprehensive samples in systematic reviews may introduce selection bias. However, exhaustive sampling in a qualitative evidence synthesis has been questioned, and a more purposeful way of sampling papers has been proposed as an alternative, although there is a lack of transparency on how these purposeful sampling strategies might be applied to a qualitative evidence synthesis. We discuss in our paper why and how we used purposeful sampling in a qualitative evidence synthesis about 'sexual adjustment to a cancer trajectory', by giving a worked example.

Methods

We have chosen a mixed purposeful sampling, combining three different strategies that we considered the most consistent with our research purpose: intensity sampling, maximum variation sampling and confirming/disconfirming case sampling.

Results

The concept of purposeful sampling on the meta-level could not readily been borrowed from the logic applied in basic research projects. It also demands a considerable amount of flexibility, and is labour-intensive, which goes against the argument of many authors that using purposeful sampling provides a pragmatic solution or a short cut for researchers, compared with exhaustive sampling.

Opportunities of purposeful sampling were the possible inclusion of new perspectives to the line-of-argument and the enhancement of the theoretical diversity of the papers being included, which could make the results more conceptually aligned with the synthesis purpose.

Conclusions

This paper helps researchers to make decisions related to purposeful sampling in a more systematic and transparent way. Future research could confirm or disconfirm the hypothesis of conceptual enhancement by comparing the findings of a purposefully sampled qualitative evidence synthesis with those drawing on an exhaustive sample of the literature.

INTRODUCTION

An increasing number of qualitative evidence synthesis papers are appearing in the health care literature (Hannes & Macaitis, 2012; Walsh & Downe, 2005). Qualitative evidence synthesis methods have the potential to generate answers to complex questions that provide us with novel and valuable insights for theory development and clinical practice, hereby moving beyond review questions only related to the effectiveness of interventions and causation Noyes et al., 2011).

Over 20 different approaches to qualitative evidence synthesis have been developed (Hannes & Lockwood, 2011). Meta ethnography developed by Noblit and Hare (1988) is currently one of the most commonly used synthesis approaches. ((France et al., 2014; Hannes & Macaitis, 2012; Noblit & Hare, 1988) Meta-ethnography enables a systematic and detailed understanding of how studies are related, through the comparison of findings within and across studies, ultimately providing an interpretation of the whole body of research (Noblit & Hare, 1988). It has known a considerable uptake in the field of healthcare (de Sousa Pinto et al., 2013; Franzel, Schwiegershausen, Heusser, & Berger, 2013). Furthermore, it has the capacity to generate hypotheses for future testing or comparison with trial outcomes (Petticrew et al., 2013). In our review project, we opted for a meta-ethnographic approach to synthesize findings on the sexual adjustment of cancer patients and their partners across a number of qualitative studies. It was expected that this would allow us to generate a comprehensive model to understand patients and their partners' sexual adaptation after cancer.

We noticed that many of the meta-ethnographies published adopt a linear approach to synthesizing the literature, mirroring the standard template developed by major review organizations such as the Cochrane and Campbell Collaboration. Consequently, in most meta- ethnographic synthesis projects, a strictly exhaustive search and information retrieval strategy is used to collect data and relevant studies are assessed for quality before being included in the synthesis. The idea to work with comprehensive samples of the literature is strongly influenced by the risk of bias discourse, suggesting that non-comprehensive samples may introduce a selection bias in systematic reviews (e.g. Adams et al., 2011; Feder, Hutson, Ramsay, & Taket, 2006; Gough, Thomas, & Oliver, 2012)).

However, the usefulness of the review strategy promoted by organizations such as Cochrane and Campbell, and thus of exhaustive search techniques and sampling, has been questioned by a substantial proportion of members of the qualitative research community. It has been argued that exhaustive sampling is a highly rigorous and formalistic approach that risks to be too time consuming because the searches often retrieve very large data sets that are impractical to screen (Shemilt et al., 2014; Suri, 2011). Moreover, exhaustive sample risks to produce rather superficial synthesis findings, with a large number of studies that fail to go beyond the level of description (Patton, n.d.).

Consequently, some authors are proposing a more purposeful way of sampling papers as an alternative for exhaustive sampling(Hannes, Booth, Harris, & Noyes, 2013).

Purposeful sampling techniques for primary research have been well described by Patton (2001, p. 230) who has provided a definition of what purposeful sampling means (Patton, 2001).

> "The logic and power of purposeful sampling lie in selecting information-rich cases for study in depth. Information-rich cases are those from which one can learn a great deal about issues of central importance to the purpose of the inquiry, thus the term purposeful sampling. Studying information-rich cases yields insights and in-depth understanding rather than empirical generalizations."

Applied to the meta-level, purposeful sampling in a qualitative evidence synthesis has often been promoted as a solution for pragmatic constraints of time, resources, access to information and expertise (Hannes & Lockwood, 2011; Suri, 2011). However, several review authors specializing in qualitative evidence synthesis have also provided a more theoretical background to the choice for purposeful sampling. One of the core arguments supporting a purposeful sampling approach is that it is not meant to be comprehensive in terms of screening all potentially relevant papers, mainly because the interest of the authors is not in seeking a single 'correct' answer, but rather in examining the complexity of different conceptualizations .It follows that these types of reviews require variation to enable new conceptual understandings to be generated.(Dixon-Woods, Agarwal, Jones, Young, & Sutton, 2005; Gough et al., 2012; Karin Hannes et al., 2013). Noyes et al. (2011) further claim that authors of qualitative evidence syntheses are mainly concerned with 'aiming to find sufficient cases to explore patterns and so are not necessarily attempting to be exhaustive in their searching'(Noyes et al., 2011). To guarantee a sufficient level of conceptual richness, review directions may be divergent and iterative, rather than linear (Barroso et al., 2003). This thus contradicts the classic prospective approach of exhaustive searching (Walsh & Downe, 2005).

Although several qualitative researchers have recommended purposeful sampling in the context of qualitative evidence synthesis, the published literature holds sparse discussion on how these strategies might be applied to a qualitative evidence synthesis (Suri, 2011). Suri (2011) has made a worthwhile attempt to address this issue by examining the adaptability of the 16 purposeful sampling strategies in primary research described by Patton (2001) to the process of qualitative evidence synthesis (see table 1).

Table 1*:* purposeful sampling strategies by Patton (2002), adapted by Suri (2011)

Purposeful sampling strategy	Purpose (Patton, 2002)	Purpose in qualitative evidence synthesis (Suri, 2011)
Extreme of deviant case sampling	Learning from highly unusual manifestations of the phenomenon of interest	Focusing on how things should be or could be, rather than how things are Suitable for realist syntheses
Intensity sampling	Information-rich cases that manifest the phenomenon intensely, but not extremely, such as good students/ poor students, above average/below average.	To develop a comprehensive understanding of the phenomena that is been researched in the synthesis
Maximum variation sampling	Identifying key dimensions of variations and then finding cases that vary from each other as much as possible. Identifies important patterns that cut across variations	To identify essential features and variable features of a phenomenon among varied contexts To construct an holistic understanding of the phenomenon
Homogenous sampling	Picking a small, homogeneous sample. Reduces variation, simplifies analysis, facilitates group interviewing	To overcome the critique of “mixing apples and oranges”:i.e. to overcome the epistemological incommensurability of different qualitative methods To describe some particular subgroup in-depth Suitable for participatory syntheses
Typical case sampling	Illustrates or highlights what is typical, normal, average	To study how common themes recurring in the published literature might be related to the relative strengths and weaknesses of the typical methodologies or theories underpinning the typical studies
Critical case sampling	Permits logical generalization and maximum application of information to other cases	To assist stakeholders in making informed decisions about the viability of a certain innovation
Snowball sampling	Seeking information from key informants about details of other information-rich cases in the field	To identify studies that are highly valued by different stakeholders To identify studies outside the academic mainstream
Criterion sampling	Selecting all cases that meet some predetermined criterion of importance	To construct a comprehensive understanding of all the studies that meet certain pre-determined criteria
Theoretical sampling	Selecting cases that represent important theoretical constructs about the phenomenon of interest	Research synthesis who employ constant comparative methods or grounded –theory approaches
Confirming sampling	Selecting cases that are additional examples that fit already emergent patterns	To advocate a particular stance for ethical, moral and/or political reasons Suitable for openly ideological synthesis
Disconfirming sampling	Selecting cases that do not fit. They are a source of rival interpretations as well as a way of placing boundaries around confirmed findings	To shake our complacent acceptance of popular myths and generalizations in a field

Stratified purposeful sampling	Sampling within samples where each stratum is fairly homogeneous	To examine variations in the manifestation of a phenomenon as any key factor associated with the phenomenon is varied. In a research synthesis, this factor may be contextual, methodological, or conceptual.
Opportunistic sampling	Adding cases to a sample to take advantage of unforeseen opportunities after fieldwork has begun	To be used in a research area which is at its exploratory stage or when the synthesis does not have an insider status in the relevant field of research Suitable to participatory syntheses where the synthesis purpose evolves in response to the changing needs of the participant co-synthesists
Purposeful random sampling	Adds credibility to sample when potential purposeful sample is larger than one can handle. Reduces judgment within a purposeful category	To locate most of the primary research reported on a topic and then randomly select a few reports from this pool for in-depth discussion
Sampling politically important cases	Selecting a politically sensitive site or unit of analysis	To gain attention of different stakeholders and the synthesis findings get used. Suitable for synthesis of hot topics, in which several stakeholders are interested
Convenience sampling	Involve selecting cases that are easy to access and inexpensive to study	Not a recommendable technique, because its neither purposeful, nor strategic
Combination or mixed purposeful sampling	To use a combination of two or more sampling strategies to select evidence that adequately addresses their purpose	To facilitate triangulation and flexibility in meeting the needs of multiple stakeholders

Despite this promising effort by Suri (2011) to theoretically present the different options of sampling for synthesis, researchers who claim to have used a purposeful sampling approach often fail to create a transparent audit trail on the review process. In addition, early pioneers such as Campbell and colleagues (2003) who explored purposeful sampling remain close to a positivist sampling strategy, opting for an arbitrary, random sampling technique to select a subset of papers to extract (Campbell et al., 2003). Noblit and Hare (1988), the initiators of the meta-ethnographic approach, introduce the idea of sampling purposefully without developing it further(Noblit & Hare, 1988).

This indicates that there is a unilateral focus on exhaustive sampling methods, as well as a lack of transparency on how to effectively use and report on purposeful sampling techniques. Therefore, we discuss in this paper why and how we have used purposeful sampling in our qualitative evidence synthesis. The following issues will be addressed: (a) how purposeful sampling procedures have been integrated into our review procedure; (b) how this purposeful sampling has led to the development of a line-of-argument, and (c) what sort of challenges and opportunities we encountered in the instrumental outline of the procedure.

METHODS

We used Suri's (2011) description of 16 possible purposeful sampling strategies for qualitative evidence synthesis as a starting point for deciding on which type of sampling strategy we would apply in our synthesis (see table 1)(Suri, 2011). Suri (2011) urges authors to carefully identify sampling strategies that are conceptually aligned with the synthesis purpose, that are credible, that sufficiently address the synthesis purpose, and that are feasible, ethical and efficient.

However, we found that Suri did not offer a 'grab and go' option that was the perfect match for building a theoretical model, which was the aim in our qualitative evidence synthesis about sexual adjustment after cancer. Little guidance is thus available for the practical implementation of theoretical sampling. Following the example of theoretical sampling guides in primary research, we choose to see theoretical sampling as an umbrella approach, i.e. a combination of different purposeful sampling techniques (Draucker, Martsolf, Ross, & Rusk, 2007; Charmaz & Bryant, 2010).

We have therefore chosen a combination consisting of (a) intensity sampling at first, then a (b) maximum variation sampling and finally (c) disconfirming case sampling. This combination of sampling techniques was chosen as these aligned with the different steps of analysing towards a theoretical construct, and in accordance with Corbin and Strauss, who also connected specific sampling strategies to different types of analysing (Corbin & Strauss, 2008).

In what follows, we describe and discuss how these sampling procedures have been integrated into our review procedure. As well we describe why we used the specific sampling technique in alliance with a specific step in the analysis.

1. Scoping review

Initially, we compiled a database of potentially relevant articles based on a scoping review. Scoping is an exploratory and systematic way of mapping the literature available on a topic (Hannes et al., 2013). Scoping exercises are perceived as the ideal way of doing preparatory work for an exhaustive systematic review. In our case, we have used them for building an archive of data for our qualitative evidence synthesis.

We searched 4 major databases: Medline, Psychinfo, Cinahl and Dissertation Abstracts. A search string was developed for each database with the support of a specialized team. For each database we added a methodological filter to these search strings in order to extract qualitative research articles (McKibbon, Wilczynski, & Haynes, 2006; Wilczynski, Marks, & Haynes, 2007; Wong, Wilczynski, Haynes, & Hedges Team, 2004). For example, the research string we used in Medline was ((interview* or qualitative or experience*) and (cancer and sexual*). Studies included had to be written in English and be carried out between 1994 and 2014, for pragmatic reasons.

The qualitative studies retrieved were qualitative studies matched against the following inclusion criteria.

A. Type of studies

We considered all sorts of qualitative designs. Opinion pieces and editorials were excluded. The study reports should be qualitative in nature.

B. Phenomenon of interest

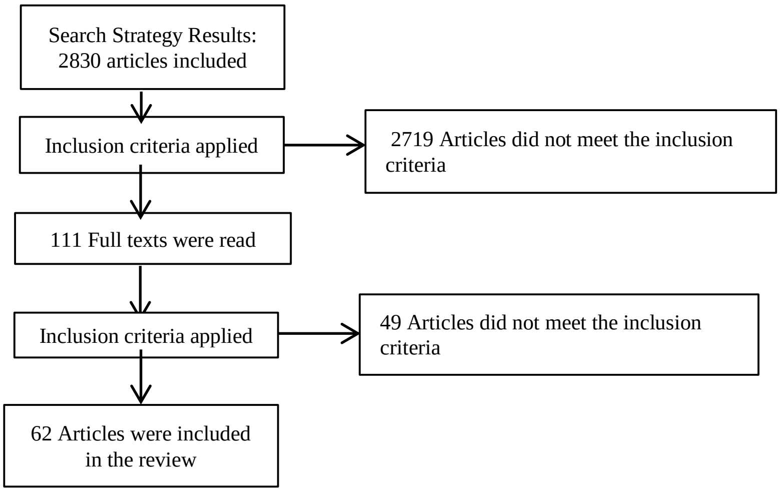
Studies should (partially) focus on the relational aspects of sexuality, namely the sexual intimacy of patient and partner, in a context of a cancer diagnosis.

C. Type of participants

We included articles where the cancer patient and/or the partner was the unit of analysis.

First one researcher (CB) applied the inclusion and exclusion criteria to the retrieved abstracts. A full text was requested for each of the relevant studies. These studies were further assessed by the same researcher, rechecking them against the same inclusion and exclusion criteria. As can be seen in figure 1, a total of 58 articles were included in our pool/ archive of data.

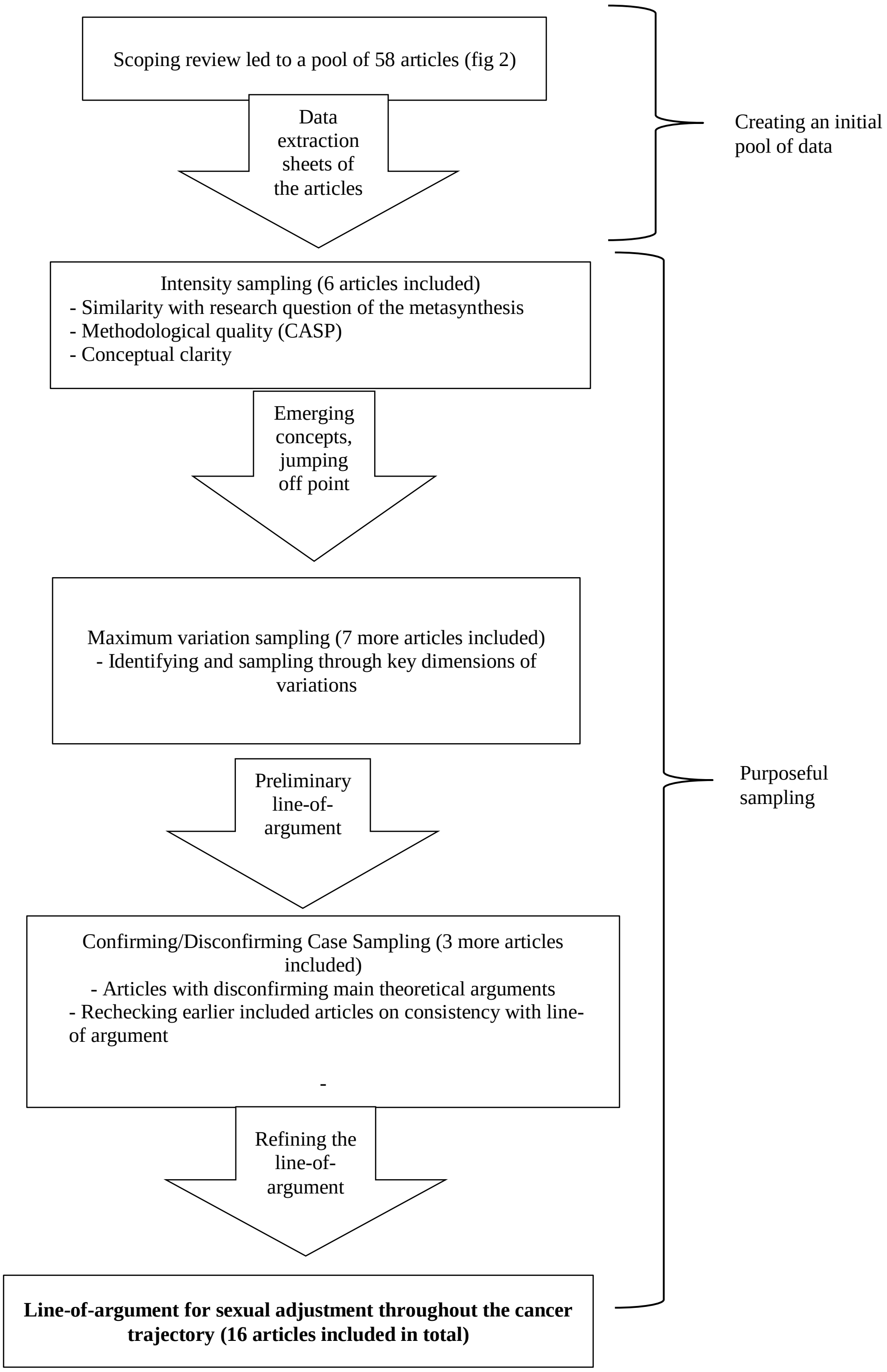
Fig. 1 Flow Chart of the scoping review



The quality of the 58 studies was appraised using the CASP (Critical Appraisal Skills Program) tool , as this proved to be the most feasible instrument to appraise qualitative studies (Hannes, Lockwood, & Pearson, 2010). The appraisal of the quality of the research articles was not meant as an inclusion tool in scoping, but was used later on as a parameter for intensity sampling (see further).

The pool of 58 data was used to initiate purposeful sampling –i.e. (a) intensity sampling, (b) maximum variation sampling, and (c) confirming/disconfirming case sampling (see figure 2).

Fig. 2 Overview picture of the purposeful sampling guidance



In order to prepare for the purposeful sampling phase, we constructed a standardized extraction form for each of the 58 articles to highlight the specific characteristics identified, i.e. the data collection, method, research question/goal, sampling characteristics and main theoretical arguments. By summarizing the methodological and theoretical basis of the primary studies we could easily compare the differences between studies. This facilitated our choice in purposefully sampling papers. Table 2 shows an example of a descriptive data extraction sheet of one of the studies included.

Table 2: example of descriptive data extraction sheet

	Walker (2012)
Data collection	Interviews together as a couple, unstructured interviews
Method	Grounded theory methodology
Research question/ goal	To present the struggles that these couples faced when trying to adapt sexually to the side effects of prostate cancer treatment
Sample characteristics (Age, sex)	18 heterosexual couples (m 47-83 years) (f 32 -82 years) Age patients: 65,4 y Age partners: 61 y Ethnicity: Euro-canadian or American heritage, 1 who was Afro-American Type of cancer treatment: Prostate cancer, all undergoing Adrogen Deprivation Therapy
Concepts	*an uncomfortable feeling about masturbation* *the avoidance of the topic of sexuality by the partners* *the more romantic husband ….*
Main theoretical arguments	*Whether couples choose to maintain sexual activity or cease engaging in sexual activity, they BOTH encounter a variety of struggles and for both choices, these struggles can be successfully overcome*

2. Purposeful sampling

a. Intensity sampling

"Intensity sampling in a research synthesis would involve selecting studies that are 'excellent or rich examples of the phenomenon of interest, but not highly unusual cases (Patton, 2001)".

The reason why we chose this sampling technique as the first technique is because we believed that the starting point of the literature synthesis would influence the further analysis, so it was important to choose rich examples of the phenomenon of interest, but not highly unusual cases.

The first task was to translate the theoretical definition of intensity sampling into some concrete inclusion factors. The first factor was the degree of overlap between the research question of the article and those of the qualitative evidence synthesis, because the content of the article had to parallel the intended content of our meta-ethnography closely. The second factor was the methodological quality of the paper, evaluated by means of the CASP. High-quality articles are usually more likely to provide rich, textual accounts to draw information from (Carroll, Booth, & Lloyd-Jones, 2012). A third factor we assessed was the conceptual clarity of the article(Toye et al., 2013). Conceptual clarity means the presence and clarity of concepts for translation, and is integral to a meta-ethnography which requires clear concepts as data.

We did this intensity sampling until a "jumping off point" was reached (Thompson, 1999). This point is reached when the concepts and categories emerging from the papers are saturated, meaning that no new concepts are derived from reading further articles. We retrieved this jumping off point after including 6 articles (see Fig 2). From that point on, we wanted to deepen the concepts further by investigating the relation between the different concepts, by means of maximum variation sampling.

b. Maximum variation sampling

"A maximum variation sample is constructed by identifying key dimensions of variations and then finding cases that vary from each other as much as possible. This sampling yields: '(1) high-quality, detailed descriptions of each case, which are useful for documenting uniqueness, and (2) important shared patterns that cut across cases and derive their significance from having emerged out of heterogeneity (Patton, 2001)

Presuming that different study characteristics illuminate different aspects of a phenomenon, maximum variation sampling can be utilized to construct a holistic understanding of the phenomenon by synthesizing studies that differ in their study designs on several dimensions (Suri, 2011). This type of sampling fits the stage of analysis as the aim is to uncover a many different key dimensions as possible.

The different concepts derived from the intensity sampling, defined the key dimensions that served as a basis for selecting additional papers. These papers vary from each other in these particular dimensions, e.g. theoretical underpinning of the articles (see further for an example of these key dimensions). Maximum variation sampling led us to the construction of a preliminary line-of-argument, after including 7 more articles (see Fig 2) which was then further refined by using confirming/disconfirming case sampling.

c. disconfirming case sampling

"The disconfirming case sampling contains a selection of articles that do not fit [the emerging patterns]. They are a source of rival interpretations as well as a way of placing boundaries around confirmed findings"(Suri, 2011).

Disconfirming case sampling fits this stage of analysis, as we want to verify and deepen the preliminary line of argument.

We selected new articles based on deviant theoretical assumptions. Disconfirming articles were thus also selected through the data extraction sheets of each paper, namely by reading through the main theoretical aspects of the studies. Papers that featured theories and concepts opposing the ones we had already included in our preliminary line-of-argument were further considered for in-depth analysis. We included 3 more articles for this sampling technique , which makes the total number of included articles 16 (see Fig 2).

We have now addressed how to potentially introduce purposeful sampling into a review project. However, it has been suggested that a purposeful sampling procedure is subject to a permanent dialogue with the analysis of the data (Dierckx de Casterlé, Gastmans, Bryon, & Denier, 2012; Froggatt, 2001).In what follows, we will discuss what sort of contribution purposeful sampling has made to our findings and the model we have developed, by means of a worked example.

RESULTS : Illustration of the purposeful sampling techniques using a worked example

In a meta-ethnography, a popular way of analysing data is the translation of the concepts or metaphors of one study into another, while preserving the structure of relationships between concepts within any given study (Britten et al., 2002). We will thus show how we sampled different studies and how this influenced the translation exercise based on an example of three example concepts from three articles included in our review. Note that the decision to work with three concepts only was taken to increase the clarity of the procedures we describe in this paper, not to describe all the actual results and complete line-of-argument.

1. First step: Arriving at a “jumping off point” through intensity sampling

We will illustrate these decisions of intensity sampling by describing the inclusion of 3 articles (Gilbert, Ussher, & Perz, 2010; Juraskova et al., 2003; Walker & Robinson, 2011) which - according to our parameters described above - have a great degree of overlap with the research goal, a high methodological quality and strong conceptual clarity.

On the articles that were included through intensity sampling, we performed a reciprocal translation of the concepts, which is the translation of one study’s findings into another, using metaphors and overarching concepts (Noblit & Hare, 1988). In what follows, we give a worked example of how we did this reciprocal translation for 3 concepts identified in the initial set of studies considered for the synthesis, as this is a necessary step towards the illustration of the subsequent sampling methodology. In order to be explicit about how the concepts compared to one another, we created a table into which we placed and compared the concepts of each paper (See table 3). Each row of the table represents a key concept. In the left column, we labelled the rows with concepts that encompassed all the relevant concepts from each paper.

Concepts	Walker (2011)	Gilbert (2010)	Juraskova (2003)
Sexual struggling	Having a sense of loss	Altered body image	Reduced vaginal lubrication
Exacerbation of struggling	Avoiding communication about the sexual changes	Sticking to a coital imperative	Receiving radiotherapy combined with external radiation and brachytherapy
Sexual adjustment	Accepting the decision to stop sexuality	Renegotiating the practices of sexual intimacy	Sexual adjustment and quality of life

Table 3: Intensity sampling: Example of reciprocal translation of 3 concepts

The first concept we retrieved through intensity sampling is " sexual struggling", encompassing the different ways of struggling with the sexual changes due to cancer. In Walker's study (2011) it is formulated as having a sense of loss (Walker & Robinson, 2011). In the study of Gilbert (2013), this is formulated as patients having an altered body image (Gilbert et al., 2010). In Juraskova's study (2013) it is formulated as "reduced vaginal lubrification" (Juraskova et al., 2003).

Another overarching concept that we retrieved was "exacerbation of struggling", encompassing strategies, situations, characteristics that were leading to an increasing struggling with the sexual changes. In Gilbert's study (2013), this is formulated as "sticking to the coital imperative", which means that intercourse is the most normal and natural form of heterosexuality, and condemns those who cannot perform as dysfunctional. In Walker's study (2012), this is formulated as avoidance of communication about the sexual changes. In Juraskova (2003), exacerbation of struggling is the case when the patients are " Receiving radiotherapy combined with external radiation and brachytherapy".

A third overarching concept we found was the "sexual adjustment" to changes due to having cancer, encompassing the different ways of adaptation to sexual changes. Gilbert's study (2010) describes that there is "a renegotiation of the practices of sexual intimacy" , which means that the couple included sexual practices that had previously been marginalized in relation to sexual intercourse. Walker (2011) formulates this adjustment as "accepting the decision to stop sexuality". Juraskova (2003) formulates it as "sexual adjustment and quality of life".

The articles were sampled by the main author, but all articles included by intensity sampling were read and analysed by two authors (CB and MS). After a certain point which we call the "jumping off point", we began to discover certain key dimensions of variation between the studies, which we explored further through maximum variation sampling. In the worked example that we explain here was the discovery that the studies varied on the scientific approach they took on, resulting in a different interpretation of the overarching concepts. To illustrate this: Gilbert (2010) used a social-constructionist lens to investigate sexual adjustment, Walker (2011) used a more psychological approach to investigate the subject, and Juraskova (2003) underscores more the biological aspects of sexual changes after cancer. Through the maximum variation sampling, we thus want to further explore how these different approaches lead to different interpretations of the phenomenon.

2. Second step: Apply a maximum variation sampling strategy to construct a preliminary line of argument

To explore the consequence of variation on the key dimension, we used maximum variation sampling to include studies that varied on the above cited dimension (i.e. scientific approach, socio-, psycho, or biological perspective). In this worked example, we show through the inclusion of three more papers ((Fergus, Gray, & Fitch, 2002; Hanly, Mireskandari, & Juraskova, 2014; Hartman et al., 2014) how we arrived – through comparison of the papers- at a preliminary line of argument.

The sampling was also done by one researcher, but the articles were read and analysed by 2 researchers. As a result of this maximum variation sampling and constant comparison between the papers, could develop relationships between the different concepts and constructing a preliminary line of argument (see table 4).

First, with regard to the concept of struggling, we found that articles who work with a psychological approach, describe the concept of struggling on an emotional level, analog with the stages of grief (anger, depression,..) while the sociological articles describe it more on a level of identity, analog with the theory of biographical disruption . Articles who have a more biological approach reduce the struggling on a level of sexual dysfunction.

Second, with regard to the concept of exacerbation of struggling, articles who work with a psychological approach again describe a stage of the grief theory , which is denial. Sociological oriented articles work with the adherence to hegemonic discourses, and biological oriented articles use certain characteristics of the cancer treatment as barriers towards adjustment.

Table 4: maximum variation sampling

Note 1: The discursive parts are the concepts coming from the included papers as a result of maximum variation sampling

Note 2: The bold parts are new findings resulting from maximum variation sampling

	Walker (2011) + *Hanly (2014)*	Gilbert (2010) + *Fergus (2002)*	Juraskova (2003) + *Hartman (2014)*
Struggling	Having a sense of loss + *Anger, depression* **Grieving about sexual changes**	Altered body image + *Identity struggle* **Sexual changes as biographical disruption**	Reduced vaginal lubrication + *loss of libido* **Sexual dysfunctions**
Exacerbation of struggling	Avoiding communication about the sexual changes + *Minimization of side effects* **Denial as one of the grief stages**	Sticking to a coital imperative + *Flaunting sexual prowess despite erectile function* **Following hegemonic discourses of sexuality**	Receiving radiotherapy combined with external radiation and brachytherapy *+ unpredictability of the side-effects* **Characteristics of the cancer treatment**
Sexual adjustment	Accepting the decision to stop sexuality + *Accepting sexual changes* **Acceptance of sexual changes**	Renegociating the practices of sexual intimacy + *Redefinition of what sexuality means* **Sexual rediscovery**	Sexual adjustment and quality of life + *Using Viagra leads to sex similar to before cancer* **Sexual recovery**
Line of arguments	**= Sexual adjustment as a grieving process**	**= Sexual adjustment as a cognitive restructuring process**	**= Sexual adjustment as a rehabilitation process**

Third, with regard to the concept of sexual adjustment, articles who are psychological oriented again use a stage of the grief theory to encompass this adjustment, which is acceptance. Sociological oriented article worked with a "rediscovery" of what sexuality is. The changes are thus not merely accepted, rather they are incorporated in a new definition of the self and sexuality. Biological oriented articles worked with "sexual recovery" , which –in contrast to the sociological oriented articles- means that there is no difference in what sexuality means , but a reuptake of sexual activity , similar to what it was before the cancer.

Our preliminary line of argument consisted of three different pathways the articles worked with. First, there are articles following the grief theory to describe the adjustment process In this case, sexual changes are depicted in terms of losses, and the adjustment occurs through the process of grief and mourning.

Second, there are articles following the "restructuring theory" during illness. Unlike the case of grief theory, where the patient and partner are working through some emotional stages, in the restructuring pathway patient and partner are more cognitively dealing with sexuality after cancer through the development of a new sexual paradigm. Flexibility is the central aspect of this adjustment.

Thirdly, there are articles following the pathway of sexual rehabilitation. This pathway is embedded in a more positivistic paradigm where the adaptation does not emphasize psychological changes or cognitive restructuring, but sexual changes as a bodily dysfunction that needs treatment and behavioural strategies.

3. Refining the preliminary line of argument by means of disconfirming case sample.

To test, refine, and deepening our preliminary line-of-argument, , we included 3 articles out of the pool of 58 articles that consist of a theory and concepts opposing the preliminary line-of argument. We will give an example with including 1 article (see table 5).

Table 5: disconfirming case sampling

	White (2014)	Navon (2003)
Main theoretical arguments	The women colluded with the medicalization of their bodies which helped their adjustment	Despite the deceptive nature of the strategies of this patients, they are considered to be beneficial and even essential. However, their effectiveness diminishes over time due to the increasing salience of their self-deceptive nature

In this phase of sampling, we worked together with a researcher who was not involved in the analysis process before (JB). This is because we wanted to have a fresh and "unambiguous view" of our line of argument. This researcher, together with the first researcher, read the articles and tested them against the line of argument.

In our preliminary line-of-argument, we assumed that the three pathways of adjustment all followed a linear pattern from the struggling towards the adjustment. However, Ramirez (2009) counter argues this linear approach by stating that patients could refine their definition of sexuality, but could also return to it at a certain moment (Ramirez et al., 2009) . These disconfirming findings led us to re-analyse the included articles, where we came eventually to the conclusion that the sexual adjustment as a cognitive restructuring process does not have a linear pattern with an endpoint, but rather makes on oscillating movement between following hegemonic definitions of sexuality, and challenging them.

4. **Challenges and opportunities**

In the process of conducting a qualitative evidence synthesis through purposeful sampling, we encountered several challenges. But this process also created a few opportunities that would not have occurred if we had used an exhaustive sampling and analysis strategy. In what follows, we discuss how we have bridged obstacles and maximized benefits in terms of the opportunities arising.

First, it proved to be difficult to define what exactly to look for, since the concept of e.g. an intensity sample on the meta-level could not readily been borrowed from the logic applied in basic research projects. In an original research project, as opposed to a qualitative evidence synthesis project, purposeful sampling can often easily be conducted, for example by using a brief questionnaire as a screening tool to search for participants with specific characteristics (Draucker et al., 2009). However, with research reports, this is more difficult in practice. We chose to search for literature by means of electronic databases with the use of search strings. Finding a specific search string to detect a specific information-rich research report which meets the sampling criteria would be difficult, because the search terms are usually based on population and setting characteristics as well as the topic of interest, rather than on conceptual or theoretically interesting leads.

Therefore we decided to conduct a scoping of the literature prior to applying a purposeful sampling technique. The scoping review was intended to create a pool/ or archive of primary research reports that are easily accessible and can be used later as material for purposeful sampling . In fact, our purposeful sampling strategy did not start at the level of data-collection. It was initiated at the level of data extraction and analysis. The consequence of this decision was that the sampling procedure was rather labour-intensive as we had to perform a scoping review before the actual mixed purposeful sampling could start.

We illustrated through our worked example that using purposeful sampling techniques also has several advantages.

First of all, although some researchers argued that reducing the number of included articles by means of purposeful sampling could result in neglecting important data (Dixon-Woods et al., 2005; Sherwood, 1999), we showed throughout this worked example that the opposite can be true. With the use of this combination of three purposeful sampling techniques – intensity sampling, maximum variation sampling and confirming/disconfirming case sampling - we arrived at a line-of-argument.

Because of this emphasis on conceptual robustness instead of generalization of the data, we were more sensitive to “deviant data”, i.e. data that may not have been picked up when synthesizing information from an exhaustive sample of the literature, because review authors are generally more focused on detecting commonalities between articles. When using an exhaustive sampling technique, researchers will arrive at results that describe the “greatest common devisor” of all included papers.

Furthermore, deviant data that has been derived through maximum variation sampling and confirming/disconfirming case sampling may add new perspectives or a new space of understanding to the line-of-argument, while sampling randomly may run the risk of preventing enhanced insight and knowledge.

Moreover, the combination of sampling techniques – instead of a random sample or just one method of purposeful sampling- could enhance the quality and diversity of the papers being included, and could make the results more conceptually aligned with the synthesis purpose. This would further enhance the possible impact a qualitative evidence synthesis could have on informing healthcare practice (Sandelowski, 2004).

Such an approach, however, demands a considerable amount of flexibility from review authors, mainly because inclusion criteria may change progressively during the process. This fact, together with the experience described above of doing a labour-intensive scope of the literature, goes against the argument of many authors (Hannes & Lockwood, 2011) that using purposeful sampling provides a pragmatic solution or a short cut for reviewers who have limited time for searching and screening. However, we felt we did gain some time in the analytical process, since the number of articles from which data were extracted was modest in number. This strategy is therefore recommended for authors who are left with a high number of relevant articles after screening for inclusion.

However, the choice of using this particular combination of sampling techniques should also be motivated from a theoretical perspective. Authors who want to build a theoretical model out of the qualitative evidence synthesis could use this scheme of sampling methods, as it aligns well with the different stages of analysis, and is parallel to what Corbin and Strauss suggested for primary research (Corbin & Strauss, 2008)

CONCLUSION

In this paper, we addressed two different needs:

Firstly, we met the need for a transparent worked example of how to apply purposeful sampling techniques to a qualitative evidence synthesis. We believe that this paper can help other researchers to make decisions related to purposeful sampling in a more systematic and transparent way.

Secondly, we gave evidence for the beneficial effects of using purposeful sampling techniques in a qualitative evidence synthesis. Although purposeful sampling is a time-consuming activity that requires a lot of resources and flexibility from the researchers, it creates potential to arrive at a rich conceptual model that can be useful for clinical practice. Future research could confirm or disconfirm the hypothesis of conceptual enhancement by comparing the findings of a purposefully sampled qualitative evidence synthesis with those drawing on an exhaustive sample of the literature.

Competing interests: We did not have financial or non-financial competing interests.

Authors' contributions: CB carried out the qualitative evidence synthesis and wrote the first draft. KH guided the philosophic discussion that contributed to the methodological development of the paper. JB conceived of the study, participated in its design and helped to draft the manuscript. All authors read and approved the final manuscript.

Acknowledgements : We would like to thank Drs. Marlies Saelaert for making substantial contributions to the analysis and interpretation of the data of our meta-synthesis. We also would like to acknowledge the Flemish fund for Scientific research (FWO) for financially supporting this study.

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PART III

PATIENTS AND PARTNERS EXPERIENCES ABOUT SEXUAL AND INTIMATE INTERACTIONS DURING TERMINAL ILLNESS

CHAPTER 4

THE MEANING AND EXPRESSION OF SEXUALITY IN TERMINAL CANCER: THE EXPERIENCES OF PATIENTS, PARTNERS, AND BEREAVED PARTNERS

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Submitted

Abstract

Sexuality may remain a significant concern in terminal cancer, although its meaning and expression might have changed. There is a lack of knowledge about sexuality during the final stage of life. We performed an Interpretative Phenomenological Analysis with a multi-perspective design, exploring in depth how patients and their (bereaved) partners experience sexuality during terminal cancer. 23 interviews were conducted with 18 participants (7 patients, 6 partners, 5 bereaved partners). This study resulted in a rich description of how the expression of sexuality in the context of terminal cancer is related to the experience of sexual losses, imminent death, the progressive deterioration of the patient's body and changing identity in terms of sexual role, and how the partner and patient negotiated all these worries with each other. These results might help healthcare providers to work with patients with terminal cancer and their partners to discuss their concerns about sexuality.

INTRODUCTION

Couples faced with cancer inevitably experience changes in the significance they attach to sexuality and in the expression of their sexuality. Indeed, a diagnosis of cancer requires couples to rediscover their relationship, including their sexual relationship (Beck, Robinson, & Carlson, 2009). Although there is a growing amount of literature focusing on the challenges in the field of sexuality during and after cancer (for a review: see Benoot, Saelaert, Hannes, & Bilsen, 2017), so far very few studies have focused on experiences of sexuality when faced with terminal cancer. The scarcity of available research suggests that the sexuality of patients with advanced or terminal cancer changes considerably (Lemieux, Kaiser, Pereira, & Meadows, 2004) and is more compromised than it is in curable diseases (Ananth, Jones, King, & Tookman, 2003). Physical factors such as immobility, general malaise and the physical weakness related to advanced cancer may decrease sexual desire and the spontaneity of sexuality, and negatively affect body image (Leung, Goldfarb, & Dizon, 2016). Environmental conditions (e.g., a single hospital bed, a lack of privacy in in-patient settings) may also create barriers to the expression of sexuality between partners (Manne & Badr, 2008). Confronted with these challenges related to sexuality, couples vary greatly in their reactions. It has been shown that at the end of life some couples connect, some disconnect and others reconnect in their intimate and sexual relationship (Taylor, 2014). Details of how partners negotiate with each other about these sexual challenges that might lead to sexually (re)connecting or disconnecting are still unclear.

Although the content and meaning of sexuality might change, it has been shown that it remains important until the end of life for a lot of couples (Ananth et al., 2003; Lemieux et al., 2004; Taylor, 2014). Research has identified a need for closeness or intimacy in this final stage of life (De Vocht, 2011) that is sometimes even stronger than before the illness (Mercadante, Vitrano, & Catania, 2010). Moreover, a perceived increase in the quality of life through sexual expression was also found (Matzo, Pope, & Whalen, 2013).

Besides their importance for couples' quality of life, experiences with sexuality towards the end of life might also have an impact on the experiences of the bereaved partner after the patient's death. Although other studies concerning sexuality at the end of life recommend further investigating this topic to inform professional practice (Taylor, 2014; Kadwell, 2016), this has not yet been done.

Patients and partners generally prefer their healthcare providers to take the initiative in addressing sexual issues, even in an advanced stage of disease (Ananth et al., 2003; Cagle & Bolte, 2009; Lindau, Surawska, Paice, & Baron, 2011). However, discussing sexuality in the context of terminal illness continues to be challenging and difficult for healthcare providers (Dyer & das Nair, 2013; Hordern & Street, 2007; Lindau et al., 2011). Healthcare providers often feel responsible for doing so, but at the same time, the topic may evoke conflicting feelings such as fear and embarrassment (Saunamäki & Engström, 2014). They also frequently claim that they lack the skills to initiate a conversation about sexuality (Higgins, Barker, & Begley, 2006), resulting in denial, ignorance, or avoidance of conversations about this sensitive topic (Hordern & Street, 2007). Moreover, healthcare providers report having some theoretical knowledge about the sexual consequences of cancer treatment, but claim to have no knowledge about how patients and partners experience these sexual consequences (Canzona et al., 2016; Reese et al., 2017). They are more inclined to address 'functional' aspects of sexual issues (e.g. erectile dysfunction or vaginal dryness) than emotional and relational aspects, although these are the aspects that couples themselves would prefer to be addressed (Hordern & Street, 2007). This lack of skills and knowledge is even more prominent in case of terminal cancer, leading to health care providers having certain assumptions about sexuality in this stage, e.g. that sexuality is not or no longer important (Gleeson & Hazell, 2017; Hordern & Street, 2007). This lack of knowledge also extends to intervention studies: so far, those aiming to enhance sexuality in couples have only focused on early-stage cancers (Badr & Krebs, 2013).

Therefore, the current study aims to explore in depth how patients and their (bereaved) partners experience sexuality during terminal cancer.

The concept of sexuality

Our conceptualisation of sexuality aligns with the principles of a biopsychosocial model (Bancroft, 2009), and is based on our findings in a qualitative evidence synthesis we recently completed (Benoot et al., 2017). These findings suggest a holistic interpretation of sexuality, encompassing biological, psychological and social aspects. This approach is also recommended elsewhere, but is not consistently or frequently used in qualitative and quantitative research (Hordern, 2008). In this study, we have focused on the relational dimension of sexuality, i.e., how biological, psychological and social aspects of sexuality are expressed in the interactions between patient and partner. In order to reflect this dimension, we choose to use the term "sexual expression" in the results section, as this concept best reflects all possible forms of sexual interaction between partners. We deliberately choose to not include the term "intimacy" in our definition, as we wanted to avoid the risk of using this as a "euphemism" for sexuality, thereby implicitly agreeing with the general assumption that sexuality is not a suitable topic to be discussed, expressed or studied in the final stage of terminal cancer.

METHOD

We used Interpretative Phenomenological Analysis (IPA) (Smith & Osborn, 2015), a qualitative research approach that is widely used in health psychology (Loaring, Larkin, Shaw, & Flowers, 2015). IPA is one of the several approaches described as phenomenological psychology, whose central concern is to give a rich description of people’s world of experience. IPA is intellectually connected to hermeneutics and theories of interpretation (Packer & Addison, 1989; Smith & Osborn, 2015) rather than to the descriptive approaches, as it postulates that the participant always interprets his/her own experience, and that the researcher always interprets the participants’ interpretation. This is called a “double hermeneutic” (Smith & Osborn, 2015). IPA is also committed to an idiographic analysis of cases rather than jumping to generalizations. Therefore, IPA studies often involve semi-structured interviews with a small, homogeneous sample (Smith & Osborn, 2015), where the participants share a mutual perspective on a specific experience. More recently, IPA researchers have begun using more complex designs to explore an experience from more than one perspective, i.e., a multi-perspective design (e.g., Loaring et. al, 2015; Borg Xuereb, Shaw, & Lane, 2016). In the current study this ‘multi-perspective design’ was used, combining three different perspectives, namely patients’, partners’, and bereaved partners’ experiences of expressing sexuality during the last stage of terminal cancer. When starting from the idea that our understanding of phenomena in the world is always partial (Moran, 2000), combining perspectives can give us a fuller understanding of a studied phenomenon. Patients can inform us about the perspective of the ill person, partners about the perspective of a partner in a relationship with the sick person, and bereaved partners on their experiences in the relationship with the ill person until the very last moments of life as well as their experiences of the loss of the relationship with the ill person after he or she died.

Recruitment and data collection

Data collection started in November 2014 and lasted until March 2016. Participants were sampled from palliative and oncology units in university and regional hospitals, ambulant palliative home care and support groups for couples with cancer/bereaved partners to ensure sufficient diversity in the selected population. Nurses and physicians working in the aforementioned settings approached patients and partners with the invitation to participate. In total, 18 participants, (7 patients, 6 partners and 5 bereaved partners) were included in the study. All participants were competent to give informed consent. Patients (3 female patients, 4 male patients) were aged 34 to 60 years old, partners (5 female partners, 1 male partner) were aged 31 to 75 years old, bereaved partners (2 female bereaved partners, 3 male bereaved partners) were aged 49 to 56 years old. Most participants (n=16) were heterosexual (two male participants were homosexual). Patients were diagnosed with different types of cancer: i.e., colon cancer, prostate cancer, lung cancer, ovarian cancer, mouth cancer and a brain tumour. The relationship duration of the participants varied from 2 to 40 years before diagnosis. All participants were married or cohabiting and all bereaved partners had been married to or cohabiting with the patient at the time of death. The majority of the interviews took place between two weeks and nine months before the patient’s death. Two patients were still alive when data analysis was finished. The time between the death of the patient and the interview with the bereaved partner varied between three months and two years.

The sample size of this study exceeds the average range for an IPA study (Reid, Flowers, & Larkin, 2005). However, we believe that – as sexuality appears to be a difficult subject to study and get (rich) stories about – it was necessary to include more respondents to acquire a sufficiently detailed interpretative account of the topic.

Patients and partners were recruited individually, and when both the patient and the partner of a couple participated, the interviews were conducted separately. We chose this option because we considered that participants might be willing to disclose things to the researcher that they would not disclose in presence of their partner, especially concerning sensitive issues such as sexuality and death (Taylor & de Vocht, 2011). Separate interviews have proven to work well for exploring different perspectives on sensitive experiences (Lindau et al., 2011; Loaring et al., 2015). We also learned during recruitment that several participants only agreed to participate in the study on the condition that their partner did not participate and sometimes even that their partner was not informed about their participation in the study. Semi-structured interviews were conducted by the first author – a female sexologist. The interview started with broad questions about experiences with diagnosis and treatment in order to help participants to feel at ease and enable them to tell their story (see interview guide, Table 1). Gradually, the questions began to focus on sensitive topics such as their experience of sexuality. The interview guide was used flexibly and the interviewer used prompting and probing techniques. Interviews took between 1.5 and 3 hours.

Table 1 Interview questions for patients, partners and bereaved partners

Patient interviews	**Partner interviews**	**Bereaved partner interviews**
Please can you tell me something about the moment you received the news of having incurable cancer?	Please can you tell me something about the moment you received the news of your partner having incurable cancer?	Please can you tell me something about the moment you received the news of your partner having incurable cancer?
Can you describe how you have gone through the course of the illness together until now?	Can you describe how you have gone through the course of the illness until now?	Can you describe how you went through the course of the illness together until your partner died?
What does sexuality mean for you at this moment?	What does sexuality mean for you at this moment?	What does sexuality mean for you at this moment?
How would you describe your sexual life with your partner since your diagnosis?	How would you describe your sexual life with your partner since the diagnosis?	How would you describe your sexual life with your partner after the diagnosis?

Altogether, the 18 interviews gave rich data on experiences of intimacy and sexuality during the terminal stage of disease and after the patient's death. To enhance the rigour of our research, we did member checking in the form of a second interview with 5 participants (2 patients and 3 partners), with whom we performed a "cooperative exploration", which means we sought new insights together based on the reflection of both the interviewer and participant – a key feature of hermeneutic phenomenological research (Bradbury-Jones, Irvine, & Sambrook, 2010) – by conducting a second interview with 5 participants. That enabled us to test the validity of our categories, interpretations and conclusions and also enabled the participants to provide additional information, and led to a final amount of 23 interviews with 18 participants.

Analysis

The data were analysed using IPA (Smith & Osborn, 2015) with the support of the computer program NVivo 10 (QSR International, 2012). A more detailed overview of our analysis process can be found in Table 2, where it is explicated more clearly how we use an idiographic approach to analysis, by beginning analysing each interview in depth and only slowly working up to more general categorization or claims.

Table 2 Analytical process using IPA and a multi-perspective analytical procedure

1. Immersing to the data by re-listening to the interview and reading the manuscript several times, writing down initial ideas and make notes of anything that appeared significant and of interest as close to the participants' descriptions as possible, without denying that interpretation is part of the process (Larkin et al., 2006).
2. Line by line analysis of each individual interview, i.e. coding of the understandings of each participant, paying close attention to language.
3. Identification of emergent patterns, first within each individual interview, then cross-case analysis within each group (i.e. group for patients, group for partners, group for bereaved partners), emphasizing both convergence and divergence, commonality and nuance.
4. Cross-analysis between the different groups, looking for similarities and differences, as well as creating super-ordinate themes to capture the different perspectives..
5. Development of a structure, to illustrate the relationships between the themes.
6. Member checking.
7. Development of a narrative to facilitate reading.

In accordance with the IPA approach and its double hermeneutics, we used multiple levels of interpretation: we did not only look at the content of the participants’ meaning making, but also at the words they chose to communicate this meaning making (e.g., what words or metaphors they used to describe sexuality, where they had difficulties in describing their experience). This because IPA researchers realize that the connection between people’s talk and their thinking and emotional state is complicated, that people struggle to express what they are thinking and feeling, and that the researcher has to interpret people’s mental and emotional state from what they say (Smith & Osborn, 2015). We believe this is particularly important in research about sexuality (Wiederman, M & Whitley, B., 2002, P. 532). The first author asked critical questions when analysing the transcripts of the participants: “What is the person trying to achieve here? Do I have a sense of something going on here that maybe the participants themselves are less aware of?” (Smith & Osborn, 2015, p. 53).

Moreover, IPA follows the interpretative phenomenological approaches that one cannot and should not bracket the researchers’ experience and understandings, which means setting aside one’s assumptions about the phenomenon, thereby trying to be as non-influential and neutral as possible (Finlay, 2009). Instead, researchers need to come to an awareness of their pre-existing beliefs, a critical self-awareness of their own subjectivity, foregrounding this subjectivity so as to begin the process of separating out what belongs to the researcher rather than the researched. For example, the first authors’ professional background, as a sexologist, was critically reflected upon, in the way that her fore-structures about sexuality affected the interpretation of the data.

The analysis process was a cyclical process. When we constructed higher order themes across the groups, we consistently went back to the individual transcripts to check whether these themes could be found there as well. The whole analysis process, carried out by the first author, was supervised by the co-authors on a regular basis. The goals of this were to enhance reflexivity and to check the plausibility and coherence of the interpretations being made by letting the first author present her analysis and her rationale for the interpretations. The co-authors looked at the data from different perspectives as researchers and health workers: JB as a public health scientist and nurse, PE as a clinical sexologist and therapist and LP as a health scientist and general practitioner.

Ethics

This study was approved by the ethical committee of the Academic Hospital of the Vrije Universiteit Brussel (B.U.N. 143201420594). Data collection was carried out after participants gave informed consent and data analysis was done with care and concern while strictly guaranteeing the privacy and confidentiality of the participants.

RESULTS

The analysis gave a rich description of patients' and partners' interwoven experiences of losses of sexual expression, imminent death, the unreliable and deteriorating body of the patient and changing sexual roles, how they make meaning of these experiences and how partners negotiated about these experiences. This negotiation process did not only unfold by negotiating *about* sexual expression, but they also negotiated *through* sexual expression. The analysis also showed that this negotiating process did not stop when the patient died, but continued during the bereavement period in the form of internalized conversation.

Making meaning about the loss of sexual expression

All participants experienced losses in their sexual relationship over the course of terminal cancer. This even continued after the patient's death, during the period of bereavement. This theme describes how participants experienced these losses of sexual expression and how they made meaning of these losses and negotiated this with each other. The importance and meaning of sexual expression within their relationship before the diagnosis seemed to influence the intensity of the feelings attached to these changes. The more importance participants attached to sexual expression in their relationship, the more they described the changes with an emotional undertone, and the more they tended to see the sexual changes as losses that were difficult to replace with other "intimate" interactions.

> In terms of sexuality: (gestures with hands) … there's nothing, the psychologist says intimacy is important too, and we do have that: a cuddle, a hug sometimes, we do all that, but it's not the same for me. (Partner, m)

Participants who attached less importance to sexual expression in their relationship made meaning of these changes in a different way: they described the changes more neutrally, using words like "different" and "less". They were not very conscious of what the changes brought to their relationship, stating that other aspects of their intimate relationship were more important, such as being able to communicate about intimate things they only shared with their partner.

> To be honest we were more of a couple who had sex on weekends and holidays, if you see what I mean, not all that physical really. Good conversations, we did have those, that's intimate too, isn't it… so yes, the fact that that's over, it's not really on my mind (Partner, f)

The way they gave meaning to sexual expression also had an influence. Patients and partners who saw their sexual expression predominantly as a physical act of intercourse, for pleasure and excitement, tended to make meaning of sexual changes as losses, mostly in terms of frequency. Those who saw sexual expression as a way of finding closeness made meaning of the changes in sexual expression by trying to find other ways of connecting. When they succeeded in finding new ways of relating to each other, they described this as an experience that brought them closer to each other as partners and made them stronger as a couple.

> It was no loss that we couldn't make love any more, I'd say, it was better actually, at the end we were cuddling all the time, I'd stroke her arm and her head, we carried on kissing a lot … (Bereaved partner, m)

Meaning making about the loss of sexuality was also done by looking at the broader picture of the quality of the relationship: as patients and partners were facing imminent death, they tended to make evaluations of the overall quality of their relationship. Feelings varied from thankfulness to disappointment with their relationship. In most stories, the sexual changes tended to get lost in the evaluation of the overall quality of the relationship, either in a positive or negative way.

> I'm convinced that we have a unique relationship, and I have come to realise that since I got ill: we have gone through so much, but we still support each other and talk to each other, and do fun things and daft things and crazy things. (Partner, f)

> I really married the wrong person, I should have realised beforehand, but sometimes you don't know, do you, what someone is like… (Patient, f)

For a few participants, however, the overall quality of the relationship seemed to suffer from their prominent struggle with meaning making about sexual losses. The loss became for them one of the major difficulties to deal with during the last stage of life, making them questioning the overall quality of their relationship.

> Actually, it is a bit of a problem for me in our relationship… a big difference in libido… I always thought it was a shame, it sowed a lot of doubts in my mind… and certainly now, because I kind of feel like… well, all that is over, but it's like I'm not ready for that yet, and that does make it difficult for me. (Partner, f)

Lastly, some participants also made meaning of the loss of sexual expression by putting it in the context of imminent death. When the expected time together was limited, some (bereaved) participants told us that their mindset was focused on prolonging their time together for as long as possible, and that they had no need to express their sexuality at all.

> If you get a death sentence ten days after your operation, you stop asking too many questions about sexuality and all that. The longer I could keep him here, the better, as long as he was

> okay, those were my main concerns and it stayed that way throughout those six months. (Partner, f)

For bereaved partners, making meaning of the loss of sexual expression appeared to be an existential loss, irrespective of the importance or meaning they attached to sexual expression in their relationship or the general quality of the relationship. They talked about missing hugs from the patient and holding them tight and described these as irreplaceable losses. Participants negotiated with each other about the importance and meaning of sexual expression in their relationship. In the example underneath, the patient and partner are emphasizing the relative importance of sexuality in the context of age.

> My husband says the same thing himself, he says he if it was ten years ago, I would have really had difficulties with it in my mind, er, that things wouldn't be as easy any more, that I wouldn't be able to do it, I'm lucky, he says, it's not that he doesn't find it that important any more but he says it would have been even worse back then. (Partner, f)

Meaning making about imminent death through sexual expression

In the accounts of the participants, sexual expression was one of the non-verbal and indirect ways of communicating with each other about their feelings about approaching the end of life. These feelings about imminent death varied during the course of the illness, and so did the way of expressing their sexuality. One of the women told us she wanted to show her sick partner that they were a united front against the disease, and that she wanted to affirm this unity by having passionate sex.

> We have a lot of sex. For me it's more out of consideration for him, not so much because of my libido but to show affection, to show I'm there for him. (Partner, f)

Another patient recalled that they were both in shock after the diagnosis of an irreversible illness, which led them to avoid all kinds of physical contact. She said: "We didn't touch any more, we stopped looking each other in the eye." The grieving process could also influence sexual expression in a positive way. One bereaved partner (f) experienced that being aware of the impending death made her and the patient more aware of the little things in life, which meant that they enjoyed their expression of sexuality even more. Particularly at the very end of life, one patient was so preoccupied with her illness and death that she became more introverted, due to the inherent aloneness of dying. This made her less attentive to reaching out for her partner.

> Yes, for him sometimes, I give him less affection than he gives me, because I'm preoccupied with my illness and that I haven't got much time left, so sometimes I do forget (Patient, f)

Some participants recognized that their particular state of mind was not always congruent with that of the partner, and therefore their way of expressing sexuality was different and experienced as disturbing. One patient tried to pick up his way of life as it had been before the illness and, as a consequence, he wanted to have the same kind of sexual expression with his partner as before his diagnosis. He explained that his partner, however, was still struggling to accept the terminal cancer, seeking solace in physical intimacy such as hugging.

> We hug a lot now, more than I'd like, but it's really important to her, I've never been much of a hugger so I don't know why I should change now. All that hugging gives me the impression that I'm going to die any moment. I say to her then, please act normal! (Patient, m)

Participants said they were attentive to reading and recognising their partner's emotional state through their expressions of sexuality.

> Like this morning, for example, we were both awake, it must have been about quarter past seven, he came to me and I was sitting up in bed because my back hurts, and then he came and lay down in my bed, with his head on my lap, and then I know, ok, you need to be comforted and held for a bit, and then I stroke his back and head … (Patient, f)

Especially during the last moments of life, patients and partners did communicate *through* sexual expression. Bereaved partners told us how they communicated their feelings through touching, caressing and cuddling when verbal communication was no longer possible because of the patients' inability to speak, or when "everything had already been said" and words thus lost their value. Here, sexual expression was the ultimate way of expressing their grief.

> On the very last day, it was one of those times when I was having difficulty coping again, and my partner saw me. I said "I'm tired, I'm sorry", I felt guilty for crying, I make it more difficult for him as well when I do that, and then he said… – if you could feel this… (cries) – he said, (pats the sofa cushions)… "come here" and he made a bit of space in his bed… and he did this (pats the cushions again) and I lay down beside him,… you can't describe it…………. (Bereaved partner, m)

After the patient's death, the bereaved partner's grief continued to interfere with their way of sexual expression. For most bereaved partners, the feelings about the recent death of their partner suppressed or tempered their expression of sexuality. Most of them were not sexually active and not – or not yet – interested in initiating a new (sexual) relationship. One bereaved partner told us how he mourned about the loss of the patient by trying to embody their previous ways of sexual expression, through internal dialogue and role playing.

> Actually, I have a double identity too now, you see, I play my partner and I play myself, so I lie in bed the way my partner used to do, for example, and then I'm lying there like that, and I let him cuddle me and things. (Bereaved partner, m)

Another example of how meaning making about death and sexual expression interfered, was the story of a 31-year-old partner, whom we interviewed again three months after bereavement. She had started a new (sexual) relationship two months after the death of her husband. She explained that she was able to do that because she had started to disconnect herself from her husband from the diagnosis onwards, and did so progressively during the two years of illness.

Negotiating sexual expression with an unreliable and deteriorating body

This theme describes how participants experienced the impact of the progressive deterioration of the body and the seriousness of the physical implications of terminal cancer on their sexual expression, as well as how they negotiated sexual expression in such a context. When participants talked about the consequences of the declining body on their sexual expression, they mentioned several aspects.

Most of all, they mentioned physical limitations such as shortness of breath, absence of erection, a decrease in libido, pain, a change of smell and taste due to chemotherapy, or a loss of control over the body and bodily functions (e.g., incontinence) that influence their way of expressing sexuality. Participants negotiated this sexual expression by trying different positions or other ways of having sex such as oral sex instead of intercourse, or by talking together about the physical limitations and how to deal with these. This continuous renegotiation was sometimes described as “clumsy searching” but frequently they approached it with humour.

> He also said his sperm smelled different because of the chemo, so he was afraid to come inside me. He thought it couldn’t be healthy. I said then it did not matter to me, I could not smell it. Bereaved partner, f

> Yes, his body was changing physically as well, actually, he no longer got erections, but we were pleased to find he did still get morning erections, and we would celebrate, I’d say “Wow, do you see that? It’s party time” I’d say. And he’d say, “Oh yeaaah …” (Bereaved partner, m)

This was a continuous process of adaptation, as the terminal phase of cancer was characterized by a progressive weakening of the patient’s body. This continuous changing of the patient’s body made the body unreliable in a sense: partners described how they would continually check whether the patient was comfortable, that they were not in pain, etc. This often led to less spontaneous, more inhibited way of sexual expression.

> We were going to have sex, but it must have been too early, at least I think so, because he got a really bad headache and got sick, and now that’s always at the back of my mind, sex is so inhibited although it used to be spontaneous, I’m always checking: do you feel okay? Does it hurt? Are you dizzy? (Partner, f)

Every patient and partner had to quit sexual intercourse at some point due to physical decline, but for most patients and partners, other forms of sexual expression were introduced. This occurred even after the death of the patient, as this bereaved partner said he still interacted with the dead body of the patient, by hugging, kissing, or lying next to the body in bed.

> I found it too difficult not to kiss him there (in the mortuary), I did it anyway, I really held him tight and kissed him, even there. (Bereaved partner, m)

The stories of the participants made clear that the extent to which their bodies were attuned influenced the way and ease with which the couple was able to adapt their expression of sexuality to the possibilities of the deteriorating body. Some participants said that before the diagnosis, their ways of expressing their sexuality had become a familiar form of physical communication and interaction as the relationship evolved, in which they knew the characteristics and limitations of each other's body and desires. When the patient's body was weakening because of the terminal stage of cancer, they learned that these learned and habitual ways of physical and intimate communication needed to be changed, and thus these suddenly became conscious acts again that they had to renegotiate. Participants who had succeeded in changing their way of sexual expression in response to previous physical transitions (e.g. because of normal physiological ageing or previous illness) found it easier to do so in these new circumstances.

> If you're with an older partner, your sexual pattern has completely changed anyway. He already had prostate problems, so we have learned that it isn't because you take a different approach to sexuality that it doesn't exist. It has already been different for us for years. For example, he found it more difficult to come and masturbate in recent years because of his prostate problem, but that didn't necessarily reduce his drive. We did still touch each other, and I was more active in that than he was. That's how it evolved. So, in that sense nothing much changed. (Bereaved partner, m)

One partner, who had only recently met the patient before the cancer, experienced difficulties in modifying the way of sexual expression with the patient. She said they needed to renegotiate their sexual behaviour verbally, with the help of a psychologist.

> He had had COPD with his lung cancer for three years, at the most serious level, so he can't make any exertion. At first, that was hard, because we didn't know how to approach each other. He felt inadequate towards me, and I felt he was pushing me away. We couldn't talk about it at first. We hadn't been together long either. Then, we spoke to a psychologist and she helped us express it. Since then, we talk about it and we say, a kiss or cuddle is more than enough. (Partner, f)

Reconstructing sexual roles during terminal cancer

Participants described how the changes in their sexual expression lead to an identity crisis related to their sexual roles, and how they tried – together with their partner – to reconstruct their sexual roles. Participants talked about their own identity crisis and search for new opportunities in a very implicit way, but could describe their partners' identity crisis more explicitly.

Patients struggled with their identity due to their terminal cancer, the fact that they felt ill and changing sexual roles. The normative expectation and socio-sexual script that equates masculinity with sexual prowess and virility, and femininity with attractiveness and passivity, resulted in patients who mentioned feeling insecure about their bodily appearance, their feeling of loss of masculinity or femininity, their feelings of inferiority to their partner, and a fear of provoking disgust in their partner.

> And then my partner said, looking in the mirror, "look at me, I'm not that bad, am I?" It did upset him, but then he'd put on a lot of weight, swollen up, and that did bother him. "What do I look like, what must you think of me?" he'd say. (Bereaved partner, m)

Partners also struggled with identity issues, being caught between being a good caring partner and being someone with sexual needs. The normative expectation that 'healthy' partners should support their dying partner can result in partners conceal their own sexual needs and refrain from sharing them. Partners expressed this by stating that they were aware of the patient's feelings, adapting themselves to the patient's circumstances, which sometimes resulted in being conflicted about their own sexual needs. They used expressions such as 'not putting pressure on the patient'. They did not verbally communicate about their own conflicted sexual needs with the patient, but tried to deal with their needs on their own.

> If she says she's not in the mood, I understand, no way will I try to force anything or upset her or… no, she's the one who's sick, but I do get frustrated sometimes. (Partner, m)

> I don't think you should pressurize your partner, because it's not easy for him either to deal with that as well, he's got enough problems. So touching, cuddling, intimacy, I content myself with that. (Partner, f)

Bereaved partners reported about their own identity struggles related to feeling caught between being a loyal partner to the deceased patient and being a *single person with personal sexual needs.* For bereaved partners, thoughts of possibly embarking upon new sexual relationships was tinged with feelings of guilt.

> He was always a good husband, always… I'd feel I was letting him down, being a bad wife, is that odd? On the other hand, so many years to go on my own… he didn't like being alone, but neither do I. (Bereaved partner, f)

Participants tried to help partners in rethinking their sexual roles. One the one hand, partners tried to reassure the patients that they accepted the patients' body, that the declining body was of no importance to them, that they still wanted to be physically intimate with the patient. Partners also communicated their acceptance and love of the patient's weakening body non-verbally, through sexual expression, thereby making clear that the body was still cherished.

> When she got a colostomy bag, she said to me, I'm no longer a woman, why are you still with me and so on… and I said, you're my wife, I'm there for you, for better or for worse, you've always been there for me too, so why wouldn't I be there for her, however bad it gets? (Bereaved partner, m)

On the other hand, some patients also recognized how their partners were trying to conceal their sexual needs, and they tried to help their partner to rediscover their sexuality by giving permission to the partner to look for new ways of sexual expression with other persons than the patient, sometimes even before the patient's actual death.

> Sexuality has always been an important element for him. I know he misses it, but of course he won't say so. I've said to him, it's fine by me if you want a 'friend with benefits', but I'd rather not know. (Patient, f)

Bereaved partners also tried to reconstruct their identity in terms of sexual role by having internalized conversations with their deceased partner about a (possible) new partner. They reassured the deceased partner that another hypothetical relationship could never be equal to their relationship. This was a way of trying to solve the duality between someone who is loyal to the dead partner and someone with personal sexual needs:

> That was my new girlfriend you saw just then, I really get on well with her, she lives next door and now we have a relationship, it can happen, can't it, some people say it's too early but what does too early mean, if we are both okay with it, but she knows too that I have a wife and a girlfriend, I'm never going to have two wives. And [my deceased wife] knows too that she will never be replaced, I tell her that regularly. (Bereaved partner, m)

DISCUSSION

This study resulted in a rich description of how the expression of sexuality in the context of terminal cancer is related to the experience of sexual losses, imminent death, the progressive deterioration of the patient's body and the changing identity in terms of sexual role, and how the partner and patient negotiated all these worries with each other. The results clearly show that it is not because a patient is dying that sexual expression disappears from their life. A lot of patients and partners reported constantly and actively negotiating different ways of relating and communicating with each other, including sexually. This shows that, at the end of life, the meaning and expression of sexuality are changeable and malleable to what is still possible based on the physical and mental state of the patient. The results also show the relevance of the patients' and partners' context in adapting to the sexual changes of the terminal cancer: the importance and meaning they attach to sexuality and sexual expression influences the way patients and partners make meaning of their loss of sexual expression; the extent to which their bodies are attuned influences the way and ease with which patients and partners are able to adapt their sexual expression to the weakening body, but also how normative expectations about masculinity and femininity and the related socio-sexual scripts have an impact on how terminal cancer influences the identity of patients and partners in terms of their sexual roles. The results also show that the meaning making and negotiation of how to continue to express sexuality in a partner relationship, as well as the reconstruction/restructuring of their sexual role, continues during the very final moments of life and even after the patient's death. In the bereavement phase, most of this renegotiation happens internally, through an internal dialogue with the deceased patient.

This qualitative study adds to the literature by paying attention for the multi-layered ways in which people give meaning to and express their sexuality during the final stage of life. Whilst recognizing the main story of loss, this article also presents evidence for a plurality of reactions and approaches to sexuality in terminal cancer. More specifically, our results include a plea for a sex-positive framework for addressing sexuality in oncology and palliative care. "Positive sexuality" is a term mainly used in research into adolescent sexuality (Harden, 2014) and that has also been taken up by the World Health Organisation (WHO, 2006). "Positive sexuality" tries to encapsulate notions of diversity and empowerment in the definition of sexuality, moving away from an emphasis on dysfunction and risks. "Positive", here, refers to the strengths, wellbeing, and happiness sexual expression can entail. Our results confirm the value of a positive way of expressing sexuality in the last days of life, how it can colour the memory of bereaved partners, and how sexual expression during the course of terminal cancer can also be rediscovered and might even turn it into a transcendent experience of relational growth.

This holistic, multi-layered way of depicting sexual expression also corresponds closely with the aim of IPA for a rich description of the experiences, and IPA explicitly adheres to this rather holistic vision, as it sees a person as “an experiencing, meaning making, embodied and discursive agent” (Eatough & Smith, 2006, p. 486). Each of the themes also depict a distinctive dimension of sexual expression: a psychological, biological and social dimension of sexual expression.

The first theme, *making meaning about the loss of sexual expression,* illustrates a more psychological dimension of sexuality. By depicting the sexual changes in terms of losses, and by showing how participants made meaning of these losses, this theme corroborates many other qualitative studies following this psychological dimension and depicting this process of meaning making – mostly indirectly – as grieving and mourning, by mainly describing several emotions related to sexual loss, such as disappointment, frustration, fear, and a sense of loss and grief (Hanly, Mireskandari, & Juraskova, 2014; Juraskova et al., 2003; Walker & Robinson, 2012). These articles also describe how participants try to make meaning of the losses of sexual expression by accepting these losses, developing realistic expectations towards these losses, and trying to put these losses in perspective (Beck, Robinson, & Carlson, 2013; Hanly et al., 2014). One article in line with this psychological dimension also resonates with the findings of the current study by describing how couples who place a greater value on sex for relational intimacy adjust better to the sexual challenges due to cancer than couples who place a greater value on sex for physical pleasure rather than relational intimacy (Beck et al., 2013).

The second theme, *making meaning about imminent death through sexual expression,* can also be situated within the psychological dimension. However, it also clearly linked with the biological dimension by its emphasis on the body as a medium through which meaning making occurs. Indeed, the findings within this theme show that patients and partners also negotiate *through* sexual expression. This is mostly apparent in the case of making meaning about the imminent death, when verbal communication has lost its value because it is not sufficient to express their feelings, or when it became impossible because of the physical limitations due to the illness of the patient. In other words, our results show that the expression of sexuality is an example of nonverbal, bodily communication of important relational messages at the end of life. Remarkably, although there is some research that describes the value of nonverbal communication at the end of life (Manusov & Keeley, 2015) we did not find any qualitative studies that explicitly described how patients with cancer and partners tried to communicate through sexual expression. Moreover, most of the qualitative research on sexuality and cancer tend to emphasize the negotiation *about* sexuality rather than describing how couples negotiate *through* sexuality (Benoot et al., 2017; Beck et al., 2013; Ussher et al., 2013). This could be partly because in a lot of qualitative articles with a social-constructionist stance, the body is treated as a symbol of society, as a cultural text, as socially influencable, mainly emphasizing its passivity, rather than showing that bodies are active agents as well, and can also produce meaning (Jackson & Scott, 2001; Ussher, 2002).

The third theme, *negotiating sexual expression with an unreliable and deteriorating body,* illustrates a more biological dimension of sexual expression, by emphasizing the impact of the progressive deterioration of the body and the seriousness of the physical implications of terminal cancer on the expression of sexuality. These findings could also be found in qualitative articles with a more realist theoretical background, that are more descriptively describing the physical consequences of cancer or cancer treatment on the way patients and partners are experiencing sexuality (e.g., Wittmann et al., 2014). Our results add to the existing knowledge by describing the specific situation of the progressive deterioration of the body, which requires a continuous adaptation of sexual expression from patients with terminal cancer and their partner, in accordance with the evolving physical limits of the patient's body.

The fourth theme, *reconstructing the sexual role during terminal cancer,* illustrates a more social dimension of sexual expression, by emphasizing the normative expectations and socio-cultural scripts surrounding sexuality and illness that lead to patients' and partners' identity crisis related to their sexual role, and how this affects their renegotiation and reconstruction of their expression of sexuality. Other qualitative studies, embedded in a more social-constructionist paradigm, also emphasize some social and cultural forces that shape the sexual experiences during a cancer trajectory, such as the 'coital imperative', in which sexual interaction is equated with penetrative intercourse (Ussher et al., 2013); 'the companionate model of marriage', where regular intercourse is seen as the core affective bond and where there is cultural pressure to stay sexually active (Ramirez et al., 2010), or the repositioning of the person with cancer as childlike or as an asexual 'sick patient' (Gilbert, Ussher, & Hawkins, 2009). Our findings add to this by mainly describing the tension between the normative expectations of being an ill person, a (bereaved) partner of an ill person and the normative expectations of being a person with sexual needs. Importantly, it describes how the partner helped to reconstruct the person's sexual identity. These results confirm findings from other studies in which couples challenge those normative assumptions (Beck et al., 2013; Ussher et al, 2013). By including the societal context in our analyses, we also respond to the critics of the biopsychosocial approach for excluding the social context of sexuality, and still following a biomedical discourse of sexuality, in which sexuality was reduced to fertility, menopause, erectile dysfunction or the capacity to have intercourse (Hordern & Street, 2007; Chamberlain, & Murray, 2009).

The strengths and limitations of the study

One of the strengths of this study lies in its uniqueness, exploring the experiences of sexual expression in the very last months and weeks of life. Although this was recommended in other studies concerning sexuality in advanced illness (Taylor, 2014), it is still an underrepresented topic in the literature. We did this by recruiting patients – or their partners – in the last months or days of their life (only 2 patients lived longer than expected), as well as bereaved partners who could talk about their experiences until the very last moment of life. Moreover, the experiences of the bereaved partners may give some deeper, contextualized insight into earlier, sparse research into how marital interactions during the final phase of life can influence the grieving experience (Holdsworth, 2015).

Another strength of this study is its focus on the patient *and* the partner, and on the relational aspects of sexuality that unfold between them. Although there is an increasing awareness of the applicability of a systemic perspective to study the relational context in severe illness, particularly in couples (Taylor & de Vocht, 2011), and although a new discourse of relationship-centred research has been proposed (Beach & Inui, 2006), the research that follows this systemic discourse is still in its infancy (Li & Loke, 2014).

Moreover, in contrast with the IPA guidelines that recommend using purposeful sampling to find a closely defined group (Smith & Osborn, 2015), we were only able to recruit participants through the help of directors of palliative centres and thus ended up with a convenience sample. This was due to the challenging task of finding participants willing to talk about such a sensitive topic, or healthcare professionals who were willing to mention the study to patients and (bereaved) partners. A consequence of this sampling method is that it was not possible to examine the role of several possible influencing factors in depth. For example, although the focus of the second theme was on the deterioration of the body during terminal cancer, sampling or analysing could not be done based on the type of cancer.

Implications for research and practice

The results of this study can be used to inform other phenomenological studies that would like to investigate experiences and meaning making in cancer (or other terminal illness), by recommending that aspects of sexuality should not be left out. Although, in theory, phenomenological approaches explicitly address the dimension of the body in the experiences (Eatough & Smith, 2006), most studies surprisingly leave out the sexual part of this embodied experience (de Vocht, 2011): For example, a phenomenological study on making new meanings after treatment for oral cancer included neither communication, kissing nor oral sex in the description (Roing et al., 2009).

Furthermore, sexuality has been recognized as an important component that needs to be addressed in care settings working with people with terminal illness (*National consensus project for quality* *palliative care,* 2012). By doing this research and providing information and deeper insight in how patients and partners may experience sexual expression at the end of life and during bereavement, we try to encourage healthcare providers working with patients with terminal cancer to provide opportunities for patients and their partners to discuss any concerns they might have about their sexuality (Lemieux et al., 2004; Leung, Goldfarb, & Dizon, 2016; Taylor, 2014). If there is no acceptable forum for people to voice the experiences of loss, grieving, etc. described above, these grieving feelings can become disenfranched, which mean that they "cannot be openly acknowledged, socially validated or publically mourned" (Doka, 2002, p. xv), and thus remain hidden.

Our results do not only encourage healthcare providers to listen to and explore patients' or partners' stories of loss of sexual expression: they also invite healthcare providers to approach sexuality from a different angle than the dominant negative discourse of sexuality, centred around dysfunction and inability due to illness, by taking up the aforementioned term "positive sexuality". The task for healthcare providers is no longer to eliminate dysfunctions caused by cancer and to reduce risks, but rather to support patients and partners in dealing with loss due to changes in how they can express their sexuality, and to support re-negotiation in a way that is meaningful for each person. This also entails helping patients and partners to find new ways of expressing their love in sexual behaviour, not despite the inabilities but thanks to the abilities and possibilities that are still there.

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CHAPTER 5

INTIMACY DURING TERMINAL ILLNESS: DYNAMIC MEANING MAKING OF LIVED AND ANTICIPATED RELATIONSHIP LOSSES.

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Submitted

ABSTRACT

Background While terminal cancer brings challenges to relationships, it has been shown that satisfying intimate relationships protect patients and partners from the distressing consequences of illness and may positively influence the surviving partners' experience of bereavement. So far, very little research has focused on the experience of intimacy in patients with terminal cancer and their partners.

Methods A qualitative study was done, using Interpretative Phenomenological Analysis, combining the perspectives of patients, partners and bereaved partners. 23 in-depth interviews held with 18 participants (6 patients, 7 partners and 5 bereaved partners).

Results Our findings provide important input to improve the conceptualisation of intimacy in research, by showing that creating intimacy during terminal cancer is a dynamic process that is constantly in motion, resulting from patients and their partners trying to create meaning of their lived anticipated relationship losses. As results show in detail how this is a continuous, evolving and dialectic process of negotiation and interaction, that even continues after the patient's death, the current findings help to develop a more nuanced view than the current dualistic approach that evaluates interactions as either promoting or undermining the level of intimacy in a relationship.

Conclusions The results invite healthcare providers who work with terminally ill patients and their partners, to be aware that there are multiple - sometimes paradoxical and indirect- ways to create intimacy, and to remember that non-disclosure can be part of the grieving process about relationship losses and might even help the couple to create meaning together.

INTRODUCTION

The terminal stage of cancer brings many challenges to patients and their partners. Patients, living with their end of life awareness, experience their life as increasingly unpredictable, are in an unconquerable struggle to maintain control (Rydahl-Hansen, 2005), commonly experience substantial pain (Weiss, Emanuel, Fairclough, & Emanuel, 2001) and often suffer from clinical depression (Breitbart et al., 2000). Partners on their turn often suffer by worrying about the imminent loss of their partner and about their ability or inability to continue their role as caregiver (Manne & Badr, 2008; McLean, Walton, Rodin, Esplen, & Jones, 2013). In addition to these experiences specific for patients and partners, both patient and partner must cope with several "relational challenges" that are inherent to the progression of the illness, such as negotiating difficult choices regarding end-of-life care, coping together with anticipatory grief, role and life-style changes, and talking about the ill partner's legacy (Manne & Badr, 2008; McLean & Jones, 2007; Tie & Poulsen, 2013). Because they are no longer able to socialize as a couple, patients and partners might feel they have lost their identity as a couple (Rolland, 1994). Moreover, since illness diminishes patients' self-esteem, there is the threat of "falling out of love" with oneself, which might also play out relationally (Weingarten, 2013). The couple dynamic might also change in such a way that it feels more like that between a parent and child from which all adult intimacy has disappeared. As a result, some – but not all – couples' relationship risk deteriorating during terminal cancer (Koop & Strang, 2003; Weingarten, 2013). It has been shown that a couple is particularly vulnerable to relational difficulties as the patient's health starts to deteriorate during terminal cancer (Persson & Sundin, 2008). More specifically, 33 to 50% of both partners reported experiencing relational distress when one of them was terminally ill (McLean & Hales, 2010).

Relational distress in couples with terminal cancer is often characterized by loss of intimacy reported by both partners (Tie & Poulsen, 2013). Intimacy was found to be important in couples confronted with terminal cancer. Intimacy is not only considered as a basic human need (Manne & Badr, 2008), it also predicts the distress level of each partner. A satisfying intimate relationship tends to result in lower levels of distress, depression, anxiety and psychological morbidity (Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008) when being confronted with the distressing event of a serious illness. It also reduces the burden related to caregiving (McLean et al., 2013), is associated with posttraumatic growth of the patient during the illness (Canavarro, Silva, & Moreira, 2015), and contributes to a dignified end of life (Guo & Jacelon, 2014). Intimacy might also impact the experience of the bereaved partner following the patient's death (Dumont, Dumont, & Mongeau, 2008; Holdsworth, 2015; Kissane et al., 2003). As a consequence, researchers suggest that intimacy might be a better concept than e.g., depression or quality of life (QOL), to use as an outcome for studies of well-being in the context of end of life (Mohr et al., 2003). However, researchers only very recently started studying how terminal illness affects the intimacy of a couple (Altschuler, 2015). Researchers are encouraged to focus much more on what happens in the marital system when serious illness occurs (Wright, 2005), as well as to consider the impact of relationship attributes – such as intimacy – on the bereavement experiences of spouses (Fasse et al., 2014).

As a consequence of this scarce research, there is also a lack of knowledge about specific therapeutic methods for helping couples to regain intimacy in terminal cancer. We found very few intervention studies on couples at the end of life (McLean et al., 2013; Mohr et al., 2003). This is in high contrast to the abundance of interventions for couples coping with early stage cancer (Ferrell & Wittenberg, 2017). Therefore, the aim of this study is to gain more insight into the experience of intimacy in patients and partners who are dealing with terminal cancer.

Methods

We used Interpretative Phenomenological Analysis (IPA) (Smith & Osborn, 2015) a qualitative research approach that has been widely used in health psychology (Loaring, Larkin, Shaw, & Flowers, 2015). Although IPA is not a prescriptive approach, it provides a set of flexible guidelines, which can be adapted by individual researchers in light of their research aims (Eatough & Smith, 2006). IPA follows the central aim of phenomenology, which is to give a rich description of peoples' lived experiences, but adds to that two types of interpretation, by postulating that the participants interpret their own experience, and that the researcher interprets the participants' interpretation. This is called a "double hermeneutic" (Smith & Osborn, 2015).

Traditionally, IPA studies often involve semi-structured interviews with a small, homogeneous sample (Smith & Osborn, 2015) where the participants share a perspective on a similar experience. More recently, IPA researchers have begun using more complex designs to explore an experience from more than one perspective (Borg Xuereb, Shaw, & Lane, 2016; Loaring et al., 2015). This study uses this "multi-perspectival design", combining three different perspectives, namely patients', partners', and bereaved partners' experiences of intimate interactions during terminal cancer. When starting from the idea that our understanding of phenomena in the world is always partial, combining perspectives can give us a fuller and richer understanding of the phenomenon. Patients can inform us about the perspective of the ill person, partners about the perspective of a partner in a relationship with the sick person, and bereaved partners on their experiences in the relationship with the ill person until the very last moments of life as well as their experiences of the loss of the relationship with the ill person after he or she died.

Concept of intimacy

Most of the research into intimacy during illness focuses on the effect of the illness on intimacy as *an experience* (Berg & Upchurch, 2007; Li & Loke, 2014; McLean & Jones, 2007). A different approach would be to focus on *how* partners interact with each other when coping with illness and ultimately death, thus to look for the mechanisms, i.e., intimate interactions that account for an experience of intimacy during this life phase, which are still unclear (McLean & Jones, 2007; Shields, Finley, Chawla, & Meadors, 2012).

Therefore, our study is guided by the conceptualisation of intimacy as a relational *act,* as something people *do*. Weingarten (1991, p. 287) conceptualizes intimate interactions as follows: "Intimate interaction occurs when people *co-create meaning* and are able to *coordinate their actions* to reflect their mutual meaning-making. Meaning can be shared through writing, speech, gesture or symbol. Refraining from meaning-making and providing, imposing, rejecting and misunderstanding meaning are associated with non-intimate interaction"(Weingarten, 1991).

We chose to use this conceptualization of (non-)intimate interaction because it also accommodates symbols and gestures, which is especially useful in the terminal phase, when patients are often unable to communicate verbally, but often do communicate poignantly without words.

As a consequence, our research question is as follows: 'What are the intimate (or-non-intimate) interactions between a patient and partner when dealing with terminal cancer?'

Recruitment and data collection

Data collection started in November 2014 and lasted until March 2016. Participants were sampled from palliative and oncology units in university and regional hospitals, from ambulant palliative home care, and from support groups for couples with cancer/bereaved partners to ensure sufficient diversity in the selected population. Nurses and physicians working in these settings approached patients and partners with the request for their participation. Nurses or physicians were asked to recruit patients or partners of patients, diagnosed with incurable cancer and with an estimated "life expectancy" of 6 months, according to the current definition of terminal cancer (Llobera et al., 2000). Bereaved partners, also recruited by nurses or physicians had an ill partner, who died between 3 months and 2 years ago. Although recent grief theories tends to deemphasize the importance of time since loss, this 2 year time-frame has been often used in research (Holland, Currier, & Neimeyer, 2006). In total, 18 participants, (six patients, seven partners and five bereaved partners) were included in the study (see table 1 for an overview of the participants). The participant's ages varied from 31 to 71 years old and most of them (n=16) were heterosexual, while two male participants were homosexual. The relationship duration varied from 2 to 40 years before diagnosis. The majority of the interviews took place between two weeks and nine months before the patient's death. Two patients were still alive at the time of finishing the analysis.

Table 1: Overview of the interviews with the patients, partners and bereaved partners

Patient/partner/bereaved partner	Type of cancer	Patient deceased … weeks after the interview (with patient or partner of patient)	Time between death of the patient and interview with the bereaved partner
Patient (f, 41y)	Colon cancer	2 weeks	
Bereaved partner (m, 64y)	Prostate cancer		3 months
Patient (m, 47y)	Lung cancer	3 months	
Partner (f, 41y)	Lung cancer	3 months	
Partner (m, 58y)	Brain tumor	6 months	
Patient (m, 40y)	Brain tumor	Still alive	
Partner (f, 36y)	Brain tumor	Still alive	
Bereaved partner (m,56y)	Ovarian cancer		1,5 years
Bereaved partner (f, 58y)	Colon cancer		2 years
Bereaved partner (f, 65y)	Brain tumor		1,5 years
Partner (f, 31y)	Lung cancer	2 months	
Patient (m, 34y)	Lung cancer	2 months	
Patient (m, 45y)	Lung cancer	4 months	
Partner (f, 40y)	Lung cancer	4 months	
Partner (f, 75y)	Mouth cancer	3 weeks	
Patient (m, 60y)	Prostate cancer	9 months	
Bereaved partner (m, 49y)	Brain tumor		4 months
Patient (f, 71y)	Brain tumor	3 months	

The sample size of this study exceeds the average range for an IPA study (Smith & Osborn, 2015). However, we believed that – as intimacy appears to be a difficult subject to put words to – it was necessary to include more respondents to acquire a detailed enough interpretative account of the topic and to reach data saturation on the subject.

Patients and partners were recruited individually, and where couples wanted to participate, interviews were conducted separately. We chose this option because we considered that participants might be willing to disclose things to the researcher, they would not disclose in presence of their partner, especially concerning sensitive issues such as sexuality and death. Separate interviews have proven to work well for exploring sensitive experiences (Taylor & de Vocht, 2011). We also learned during the recruitment that several participants only agreed to participate in the study on the condition that their healthy or ill partner did not participate and sometimes even that their partner was not aware of them participating in the study .

In-depth interviews were conducted by the first author, a female sexologist. The interviews were conducted at the preferred location of the participant. The interview started with broad questions on experiences with diagnosis and treatment in order to help participants to feel at ease and enable them to tell their story. The interviewer used prompting and probing, and encouraged the respondents to reflect on their feelings. Interviews took between 1.5 and 3 hours. The interviews were audiotaped and data were transcribed verbatim.

To enhance the rigor of our research, we did member checking with four participants (one patient, three partners) with whom we performed a "cooperative exploration", a key feature of phenomenological research (Bradbury-Jones, Irvine, & Sambrook, 2010). That enabled us to test the validity of our categories, interpretations and conclusions and enabled them to provide additional information. Altogether, the 23 interviews produced rich data on the experience of intimate interactions during terminal cancer.

Analysis

The data were analyzed using IPA (Smith & Osborn, 2015) with the support of the computer program NVivo 10. A more detailed overview of the analysis process, together with a worked example, can be found in table 2. The analysis was a cyclical process. When we constructed higher order themes across the groups, we consistently went back to the individual transcripts to check and see if these themes could be found there as well, until there was a degree on data sufficiency on all themes.

The whole analysis process, carried out by the first author, was supervised by the co-authors on a regular basis, with the goal of enhancing reflexivity, checking the plausibility and coherence of the interpretations being made, by letting the first author present her analysis and her rationale for the interpretations. The co-authors looked at the data from different research perspectives: JB as a health scientist and nurse, PE as a sex researcher and sex therapist, and LP as a health scientist and general practitioner.

Table 2 Analytic process using a multi-perspective analytical procedure

	Phases of the analytic process	**Worked example**
1.	Immersing to the data by re-listening to the interview and reading the manuscript several times, writing down initial ideas and make notes of anything that appeared significant and of interest	“We’re best friends, I’ve already told him, you’ll have to find another woman, because you need someone, don’t you, our four-year-old daughter can’t fulfil his needs, he can’t talk to her. I told him not to stay alone for the rest of his life, he’s a bit of a loner, I say to him, if you like someone, don’t start thinking ‘no, I won’t’”. (Patient, f, 41y) *Initial ideas of this fragment that were written down: “ Here the patient wants to express to her partner that he can go with his life by engaging to a new relationship. Underlying this message, it seems like she is ready to say goodbye to life and specifically saying goodbye to their relationship.*
2.	Line by line analysis of each individual interview, transforming initial ideas into more specific themes i.e., coding of the understandings of each participant in terms of psychological concepts.	Example of how initial ideas are transformed into more specific themes. “the patient wants to express to her partner that he can go with his life by engaging to a new relationship. Underlying this message, it seems like she is ready to say goodbye to life and specifically saying goodbye to their relationship.” ➔ “Making meaning of a relationship loss” by “Letting go of relationship”
3.	Identification of emergent patterns, first within each individual interview, then cross-case analysis within each group (i.e., group for patients, group for partners, group for bereaved partners), emphasizing both convergence and divergence, commonality and nuance.	1. *Identification of emergent patterns within individual interview* Extract in the same interview “I felt we already were a really good couple, but since I became ill I’ve become convinced we have a unique relationship, we’ve been through so much, and still we continue to support each other and talk, and do fun things and act crazy, we’re on the same wavelength with that, we don’t argue anymore” (Patient, f, 41y)” - “Making meaning of relationship loss by “ emphasizing holding on (what they still have) - Vs. “Making meaning of a relationship loss” by “Letting go of relationship” → **Divergence between both “codes:** Interpreted as : there is a continuous push and pull noticeable between expressing “holding on” and “letting go”. 2. *Cross-case analysis within each group (group of patients)* “Yes, to start with, disbelief and sadness, it’s

	finished here, I’m going to have to start saying goodbye, but then I got a hold of myself pretty quickly, but it still comes in waves, time and again, now thinking I’ll be all right for a while, then thinking about death again, actually it’s like that the whole time.” (Patient, m, 47y) → **Confirmation of the continuous push and pull between expressing “holding on” and “letting go”.**
4. Cross – analysis between the different groups, looking for similarities and differences, as well as creating super-ordinate themes which capture the different perspectives. Themes were chosen based on their prevalence and the weight placed on them by participants.	*Cross-analysis between the different groups (in this case with bereaved partner)* “I have a double identity too now, you see, I play *(name of deceased patient)* and I play myself, so I lie in bed the way *(name of deceased patient)* did, for example, and then I’m lying here like this, and I let him cuddle me and so on.” (Bereaved partner, m, 64y) → Discovering the similarities between the groups by seeing how meaning making through holding on continues as well during bereavement phase
5. Development of a structure, to illustrate the relationships between the themes.	A table is produced that shows the higher order themes and the subthemes
6. Doing member checking.	we did member checking with four participants (one patient, three partners) That enabled us to test and refine the validity of our interpretations and conclusions and enabled them to provide additional information.
7. Development of a narrative to facilitate reading.	

Results

The analysis offered detailed insight into how the transition to a terminal phase included a redefining of the couple’s relationship, in which the dying person and the partner experienced lived and anticipated relationship losses, how the intimate interactions between patients with terminal cancer and partners are focused around their co-creation of these relationship losses, and how this experience of relationship losses and meaning making continued to exist after the patients’ death. All themes and subthemes can be found in table 3.

Table 3 Themes and subthemes

Themes	Subthemes
1. Relationship losses	*The experience of* lived and anticipated relationship losses
2. Intimate interactions	Co-creating meaning on relationship losses
	Active collaboration or indirect/ nonverbal meaning making
	Different ways of negotiating about holding on/letting go
3. Meaning making of relationship losses after the patient's death	Continuing to make meaning through emphasizing holding on-letting go after the patient's death
	Memories of intimate interactions during terminal cancer: a feeling of completeness or unfinished business

Relationship losses

Subtheme 1: Experience of lived relationship losses and anticipated relationship losses. Participants report experiencing lived and anticipated relationship losses. "Lived" relationship losses refer to partner's actual experiences of changes due to the debilitating and organisational consequences of the terminal cancer. Both partners experienced these "lived" losses as a disruption of the different roles they previously had in their relationship, i.e., roles that are narrowed down to their current role of patient and caregiver. The changes they describe also affected their usual sexual, recreational habits and routines, and the work-life balance they had as a couple.

> *"You have to give up your active lifestyle, he can't manage that anymore, so you see, as a partner, that's why a lot of things have changed, for him and for me, I do still go to work, and I have taken over a few things myself because he can't do them anymore, so, well, it's a case of finding a new balance, really." (Partner, f, 41y)*

Patients and partners also described "anticipated relationship losses", i.e., losses they expected to be confronted with in the (near) future, such as the expected death of the patient, and thus the definite loss of the relationship. Patients and partners referred to mourning about the loose of future perspectives concerning their intimate relationship, such as having children or growing old together.

> *"…but the most difficult thing is that we don't have that future anymore, we were planning to buy a house together, and then have children, and now we can't do all that anymore, we needed to stop planning, as my life is just going to stop soon" (Patient, m, 47y)*

Patients and partners experienced two types of relationship losses – lived and anticipated –interwoven with each other. However, most participants said that the anticipated relationship losses prevailed over the lived relationship losses., This partner, who played down the experience of the loss of sexuality – a lived relationship loss – in comparison to a greater "anticipated" loss:

> *"If you get a death sentence, ten days after your operation, you stop asking questions about sexuality and all those kinds of things. The longer I can keep him with me the better: that is the thing that matters to me most." (Partner, f, 31y)*

Because of the advanced illness and the consequent progressive decline of the patients' body, some patients and partners described how "lived experienced losses" became more salient. For them it' s as "a cascade of losses". They had to redefine their relationship continuously in as the patient's condition progressively declined. The quotation below illustrates how a partner tried to deal with the anticipated relationship losses, but how the experience of a cascade of lived relationship losses interfered with this anticipatory grief.

> *"You have to enjoy every moment there is, they say, because it will soon be over… we do try, but he has to be able to, it has to be physically possible to do something together… we've been doing this for a year now, in and out of hospital, it has never really stopped, and it just keeps going from bad to worse." (Partner, f, 41y)*

Subtheme 2: Making meaning of these relationship losses by emphasizing holding on –letting go
Patients and partners dealt with these losses in a myriad of ways, and each person had their own unique way of coping. Participants tried to make meaning of their lived and anticipated relationship losses by emphasizing either "letting go" or "holding on".

With "letting go", they gave their healthy partner permission to engage in another romantic relationship and tried to accept the loss of relational habits (e.g., their sexual relationship) that were not possible anymore.

> *"We're best friends, I've already told him, you'll have to find another woman, because you need someone, don't you, our four-year-old daughter can't fulfil his needs, he can't talk to her. I told him not to stay alone for the rest of his life, he's a bit of a loner, I say to him, if you like someone, don't start thinking 'no, I won't'". (Patient, f, 41y)*

With "holding on" , participants emphasized the aspects of the relationship that still existed. They highlighted the normal interactions in their relationship, still untouched by the illness. Participants confirmed the quality of the relationship and their love, and honoured their relationship history. They also tried to enrich their relationship, emphasizing and enjoying moments of togetherness.

> *I felt we already were a really good couple, but since I became ill I've become convinced we have a unique relationship, we've been through so much, and still we continue to support each other and talk, and do fun things and act crazy, we're on the same wavelength with that, we don't argue anymore" (Patient, f, 41y)*

In each interview, there was a continuous push and pull noticeable between expressing "holding on" and "letting go". Sometimes a participant changed during the interview from the "holding on" to the "letting go" position depending on the context. One participant said that this continuous push-and pull dialectic was also reflected in daily life:

> *"Yes, to start with, disbelief and sadness, it's finished here, I'm going to have to start saying goodbye, but then I got a hold of myself pretty quickly, but it still comes in waves, time and again, now thinking I'll be all right for a while, then thinking about death again, actually it's like that the whole time." (Patient, m, 47y)*

Intimate interactions

Subtheme 1: intimate interactions as co-creating meaning for relationship losses. Intimate interactions were centred on their co-creation of meaning for lived and anticipated "relationship losses". This meant that partners and patients were continuously in negotiation about this "letting go/holding on dynamic".

They shared the same meaning about relationship losses as an intimate experience, as "being on the same wavelength" or "finding each other" in their grieving. However, this experience of intimacy did not always take away the feelings of grief a person had. In the example below, a partner talks about being "emotionally affected' by co-creating meaning with her dying partner.

> *"On the days when he feels hopeful himself I get a boost from him. Other days it's really difficult, at the end of May for example, at the school party. Our daughter is in her first year of kindergarten. We saw her in the school play together for the first time, but it might be the last time we see her do that together. I find it really hard [sobs]. He hardly ever cries either, and if he does start crying, I know he's thinking about that and I break down too." (Partner, f, 31y)*

Participants also described circumstances, where they failed to co-create meaning with their partner, as rather non-intimate experiences that made them feel lonely and disconnected from their partner.

> *"Last week, when he gave me the feeling I was already dead, then – honestly – I've never felt as lonely as I did then. We've had other times during the illness when it was really, really difficult, but then I felt like we were sharing them." (Patient, f, 41y)*

Patients and partners tried to experience this intimacy by co-creating meaning around this holding on/letting go dialectic. In the quotation below, a patient calls this negotiating process an energy-absorbing process.

> *"Well, yes, and sometimes I just can't do it and vice versa. Sometimes she doesn't want to talk about saying goodbye, which is something that's really on my mind. But when we do find each other, we can literally hold each other tight again. But not when there is something in the air between us. It takes a lot of energy, clearing the air." (Patient, m, 60y)*

Subtheme 2 Active collaboration or indirect/nonverbal meaning making They talked explicitly, mostly short and delineated about the meaning of relationship losses . Partners described the few moments they talked more extensively relationship losses, as selected moments of privacy and quietness, such as taking a bath together.

> *"Really talking about it in detail? At times when we know the children are doing something else, so they can't hear what we're saying. But it does happen spontaneously. We enjoy having a bath together and those are times when conversations like that just happen." (Partner, f, 31y)*

More often, participants explained how actions to create meaning were far more implicit by communicating either indirectly or non-verbally. A patient described how she made meaning of her partner's nonverbal interactions – in this case, a specific glance from her partner – by interpreting it as "letting go".

> *"That was at that time, those five days when he distanced himself, he looked at me like some friends do – friends, acquaintances, you know – with a look in their eyes – how do I explain, it's like "oh poor you, you're going to die soon", and I can really do without it, I want us to carry on communicating the way we have always done, there are enough people who pity me." (Patient, f, 41y)*

Another partner preferred a non-verbal way of making meaning in certain instances, in this example by emphasizing "holding on".

> *"You don't always need to say anything to understand each other, I don't think. Yesterday, for example, just glancing at each other, and I think, we've still got each other, haven't we. And we enjoy it, sitting in the sun together, having a glass of wine." (partner, f, 65y)*

Subtheme 3 Different ways of negotiating about holding on/letting go Through the accounts of the participants describing these explicit and implicit conversations in which they tried to create meaning together, we found that this negotiation process about letting go/holding on was expressed in different ways: through imposing a meaning on each other, by taking in a complementary meaning then the partner; by rejecting the meaning of the partner, by not disclosing the meaning to the partner, or taking on the partner's meaning.

Although we present them – for analytical reasons – as separate actions, these different ways of co-creating meaning are each "links" in a complex process.

Imposing a meaning onto another: Participants described how they – or their partner – sometimes imposed the meaning of holding on or letting go by interpreting one of the partner's actions as either holding on or letting go. For example, a partner (71 y, f) recalled how her ill partner interpreted her suggestion to get palliative care at home as letting go, i.e. as her wanting to get rid of him, as wanting him to be "dead already". Another patient interpreted the "distant behaviour" of her partner as letting go, i.e. him saying goodbye to their relationship prematurely.

> *"Yes, I do lose my temper sometimes, like on Saturday, but that was the first time in ages, because I really thought it was too much, he was just too distant – and then I do sometimes dare to be hard on him, I said, otherwise I'll just ask them to put me down now, and that's that, you won't have to distance yourself." (patient, f, 41y)*

Adopting a complementary meaning: Participants also talked about taking a complementary position to the one their partner was expressing, which was formulated by a patient as "trying to convince them". Adopting a complementary meaning was an attempt to "mirror" the other, to share with the partner another way of looking at the relationship loss, thereby making the experience of that loss more complete. The partner in the quotation below explained how she emphasised the meaning of "holding on" during meaning-making of anticipated relationship losses, when her ill partner expressed "letting go" of their relationship.

> *"Then he said, that was our last New Year's Eve together. I can feel it, I've aged ten years. I can feel my body deteriorating. Then I said, love, don't say that, we might still have another year." (Bereaved partner, f, 58y)*

Rejecting the partner's meaning: Participants described how they rejected the partner's meaning. Unlike adopting a complementary meaning, there is no explicit alternative meaning offered instead.

> *"On the day of the diagnosis, when they told us nothing else was going to help, we came back and he went to sit in the sun and started reading a book, and I said, 'How can you do that? I can't!' And I ran away. I wandered around the streets like a headless chicken." (Bereaved partner, m, 64y)*

Not disclosing the meaning: Participants described times when they decided not to disclose their meaning towards their partner. They usually did so in an attempt to protect the other person from the potential risk of harm by talking about sensitive subjects. In the example below, a partner explained her decision not to disclose her feelings about her ill partner's effort to renovate their bathroom despite being in pain from lung cancer:

> *"I'm not going to start saying to him, (mimics a condescending tone): you seem to be having trouble letting go, no, that would make it even worse. The only thing I do at the moment is keep a bit of an eye on him, that he does not force himself, and if he wants to do something, I let him do so but I do keep an eye on him." (partner, f, 41y)*

Adopting the partner's meaning: Participants also described how their partner could make them see "the other side of the story" by expressing their meaning, which made them adapt to the partner's meaning. In the example below, a patient attuned to the meaning her partner was expressing non-verbally, i.e. holding on to their relationship.

> *"I'm preoccupied with being ill, and then sometimes I'm not able to pay as much attention to him, to the here and now… but he tells me. Like this morning, for example, he came to me and I was sitting up in bed because my back hurts, I was just sitting on my bed with my feet on the ground and then he came and lay down beside me, with his head on my lap, and then I know, ok, I need to pay a bit more attention to us too, and then I stroke his back and head." (Patient, f, 41y)*

Meaning making of relationship losses after the patient's death

The experience of relationship losses and meaning-making through holding on or letting go continued to occur in two ways after the patients' death: Firstly, the bereaved partner continued to make meaning after the patients' death in an internalized way. Secondly, the intimate interactions during the last moment of life took an important place in the memories of the partner, as well as playing an important part in the feeling of completeness, closeness, or unfinished business.

Subtheme 1 Continuing to make meaning through emphasizing holding on-letting go after the patient's death After the death of the patient, the push and pull between expressing holding on and letting go continued to exist for bereaved partners. This happened in two ways: on the one hand, this negotiation played out internally, in an imagined conversation with the deceased patient.

For example, a bereaved partner found a way to "hold on" to the relationship with the deceased patient by trying to embody their previous roles in the relationship, through internal dialogue and role playing.

> “I have a double identity too now, you see, I play *(name of deceased patient)* and I play myself, so I lie in bed the way *(name of deceased patient)* did, for example, and then I’m lying here like this, and I let him cuddle me and so on.” (Bereaved partner, m, 64y)

On the other hand, his negotiation also existed outwards, when other intimate relationships – even imagined ones in the future – are built. Another bereaved partner who started a new relationship played out the holding on-letting go dynamic with his new partner by affirming their relationship through involving the new partner in a “farewell ritual”, (letting go) while asserting that this relationship could never replace the previous one (holding on).

> *“She (new girlfriend) makes pottery and here she has made a pot especially for my dead wife, and we put a candle in it together. But she knows too – I say it to her – I have a wife and a girlfriend, I’m never going to have two wives.” (Bereaved partner, m, 56y)*

Subtheme 2 Memories of intimate interactions during terminal cancer: a feeling of completeness or unfinished business These last memories of intimate interactions were described as important and meaningful for the bereaved partner. In their accounts, it became clear these memories became of part of mourning their loss. When bereaved partners experienced that both ways of meaning-making – holding on and letting go – have been lived through during terminal cancer, they experienced this as a feeling of completeness, of closure.

> *“We really talked a lot in the last few months. My husband said: if I’m gone you have to get on with your life”. But in the last few months we often just sat on the patio, just enjoying life.” (Bereaved partner, f, 58 y)*

Inversely, when the bereaved partner felt that the intimate interactions during the trajectory were more focused, e.g. only emphasizing holding on, they experienced this as “unfinished business”.

> *“We couldn’t do without each other, certainly not during that illness, we were so intensely together, and now he’s gone, it’s terrible, I have the feeling we did not prepare for death. It’s like I lost an arm or leg.” (Bereaved partner, f, 65y)*

DISCUSSION

The results of this study show how the transition of a patient into a terminal cancer results in a reframing of relationship between the dying person and their partner. We found that the experiences of relationship losses contained “lived” and “anticipated” relationship losses. These are interrelated in a complex way, although the anticipated losses often prevailed over the “lived relationship losses”. This is congruent with what Rolland (1994) calls “emotional currency”, where concern about the patient's imminent death seem to devaluate the "ad-hoc" burdens experienced by the other partner(Rolland, 1994). This implies that in couples certain losses can thus become silenced.

The current study offers an insight into the different ways a dying person and partner make meaning together. We found that intimate interactions between patients with terminal cancer and their partners focus on their co-creation of meaning of lived and anticipated relationship losses. Patients and partners experienced relationship losses, and made meaning from them either by emphasizing what they have lost or are about to lose, (= letting go) and/or emphasizing what they have or want to have (=holding on). As participants are constantly switching between these two ways of meaning-making - described in the results as a continuous push and pull - they experienced moments where they held a different meaning than their partner: these moments were described as non-intimate. They also experienced moments where they shared the meaning about their losses: these moments were experienced as intimate. Thus it seems that in the terminal phase of cancer, patients and partners try to make meaning together with regard to their relationship losses, and that this meaning-making process implies a continuous negotiation about this letting go/holding on dialectic.

We also found that bereaved partners continued to make meaning of their memories of the last interactions. They made an evaluation of these interactions: If they had experienced and been able to express both letting go and holding on during the last stages of the illness, they tended to have more positive feelings such as closure and completeness. When this was not the case, bereaved partners felt regret about "unfinished business". Furthermore, bereaved partners continued to negotiate this "holding on/letting go" dynamic after the death of the patient, often through internalized conversation. This happened throughout – what Deford & Gilbert (2016) call –"a relational triad" which means that this meaning making occurred between the bereaved partner, the patient who has died, and a living other (DeFord & Gilbert, 2016).

Very few qualitative studies so far have investigated these interactions in the context of terminal illness (Berg & Upchurch, 2007; Li & Loke, 2014). This is probably due to a combination of both methodological challenges inherent to qualitative research and ethical challenges inherent to interviewing patients and their partners during terminal illness (Astedt-Kurki, Paavilainen, & Lehti, 2001; Gysels, Shipman, & Higginson, 2008).

The results of this study should be viewed within a new trend , still in its infancy, that proposes a discourse of relationship-centred research (Li & Loke, 2014; Lo et al., 2013; Lyons, Miller, & McCarthy, 2016). This is a critical response to most research that focuses on the individual, be it the patient or the patient's partner. This relationship-centred discourse considers couples affected by advanced illness as an interdependent emotional unit, such that their meaning making can be seen as *a shared* process, a pathway to greater intimacy. This is complementary to most research and theoretical work on meaning-making in the face of adversity and terminal illness that has emphasized intrapsychic processes (Park, 2010).

The present qualitative study provides important input to improve the conceptualisation of intimacy that has been used in research in the context of serious illness (Manne & Badr, 2008). Our findings demonstrate that intimacy in the context of terminal cancer is a dynamic process that is constantly in motion, as patient and (bereaved) partners are continuously trying to co-create meaning of their relationship losses due to the illness. The results show that intimacy is not an all-or-nothing phenomenon that certain individuals experience consistently while other individuals never experience it. It shows that intimacy is not a given, but rather ‘created’ in intimate “moments” during which partners seeking to create meaning in a continuous, evolving process of negotiation and interaction.

These results also imply that, while some of these interactions (e.g., when one partner rejects the meaning of the other) could be considered as non-intimate (i.e. as they may lead to divergent meanings resulting in a break between partners), these interactions are inherent in a process and can serve as a catalyst for eventually arriving to an experience of intimacy. Indeed, having and expressing a divergent meaning – which is considered non-intimate – could trigger the other to rethink his or her meaning about the relationship losses, thus ensuring flexibility. This flexibility may ensure that both poles of the dialectic, i.e., holding on and letting go, are lived through, so that a better balance between the fulfilment of the partner’s and patient’s needs may be reached, thereby leading to a sense of “closure” during the bereavement phase. Thus, the current findings might help to develop a more nuanced view than the current dualistic approach that evaluates interactions as either promoting or undermining the level of intimacy in a relationship (Manne & Badr, 2008). It demonstrates how we cannot evaluate a relationship of a patient and partner based on observable behaviour, but that we must rather look at the underlying process of meaning making that unfolds throughout a sequence of these behaviors.

Another important finding is that – although they are in continuous search for meaning-making – patients and partners indicate they do not always want to talk about relationship losses, but only occasionally and in a delineated context. This is congruent with the findings of Kvale (2007), who also postulates that cancer patients do not always want to talk about difficult emotions (Kvåle, 2007), and with Weingarten (1991), who suggests that intimate interactions cannot be judged by the degree or content of disclosure *per se*, but rather the extent to which the interaction carries a meaning that is shared, understood and constructed by both partners (Weingarten, 1991). The present findings, however, contradict studies which suggest that verbal, open and honest communication (i.e., disclosure) is seen as a prerequisite for an intimate relationship, and sometimes even as the definition of intimacy itself, and that non-communication and silence (i.e., non-disclosure) are detrimental to an intimate relationship (Manne & Badr, 2008; Zhang & Siminoff, 2003) It contributes to recent calls to develop a more nuanced view of couples' communication that acknowledges that there are multiple ways to talk about and make meaning of cancer, and that a tacit agreement to avoid emotionally difficult issues may also protect the couple from harmful feelings (Badr, 2017; Ekstedt, Stenberg, Olsson, & Ruland, 2014).

Limitations

we aimed – as is typical for an IPA study – for a degree of homogeneity and depth in our story – which is reflected in the fact that all patients had cancer and were terminal, the rather young sample of patients/partners/bereaved partners- the sample cannot be seen as representative for all couples dealing with terminal cancer. For example, it may be that the above meaning making might be particularly challenging for those couples who have limited capacity for intimacy with each other to begin with, and such couples are absent from our sample. Indeed, each relationship will have its pre-existing dynamics, strengths and vulnerabilities that will likely affect the way patient and partner communicate during illness (Morhardt & Spira, 2013). More research is thus needed into the pre-existing communication patterns and relationship quality that may influence how they make meaning (Badr, 2017).

The sample did not allow us to examine how gender might influence the preferences for and method of making meaning. Research suggests that while women tend to value the sharing of thoughts and feelings, men are more likely to express intimacy nonverbally (Lupton, 2012). This could also be an area for further research.

Finally, the scope of this paper is limited to marital relationships in which one partner has a terminal cancer, excluding other important relationships which might have different characteristics at the end of life (e.g., parent-child interactions). We did not investigate intimate interactions in patients and partners with a non-European background, or those faced with terminal illnesses other than cancer. Important variations might occur there, and as such our findings need to be validated in these subpopulations in future research.

CONCLUSIONS

Our results give healthcare providers and (psycho)therapists insight in the complexity of dealing with illness together as a couple, and the relationship-centeredness of our study can be translated into relationship-centred "care" (Ekstedt et al., 2014). Healthcare providers can see the couple or dyad as a unit of care and consider both partners' needs simultaneously. It shows the value of being interested and invested in both the patient and partner's efforts to make meaning, even behind the observable interactions. It can protect healthcare providers against an overly dualistic view and a judgemental position.If couples have non-intimate experiences, the current findings may encourage healthcare providers to help them see that they have a common source of distress, which is the experience of the relationship loss. The "sharing of the grieving of these relationship losses" can be a central aspect of an intervention during the terminal phase of an illness. This might help both partners in a couple to see each other's way of dealing with the illness as an inherent part of the process of dealing with loss. This awareness can be helpful to embrace and accept the differences in how the partner and patient make meaning. However, healthcare providers should be careful about stimulating disclosure as the current findings show that we need a more nuanced view of couples' communication and negotiation of meaning making. They should also acknowledge that there are multiple ways to talk, be aware that avoiding talking can also be a part of the grieving process and remember that non-disclosure can also help the couple to make meaning together.

List of abbreviations : No abbreviations have been used in the manuscript.

Declaration Ethical approval and consent to participate : This study was approved by the ethical committee of the Academic Hospital of the Vrije Universiteit Brussel (B.U.N. 143201420594) and data collection was performed after participants gave written informed consent and data analysis was carried out with care and concern while strictly guaranteeing the privacy and confidentiality of the participants.

Availability of data and materials: The datasets generated and/or analysed during the current study are not publicly available due to protection of the privacy of our participants, but are available from the corresponding author on reasonable request.

Competing interests: The authors declare that they have no competing interests

Funding: This study has been funded by a grant from the Flemish Research Foundation (FWO) G041413N

Author Contributions : CB conducted all in-depth interviews and analysed all data and wrote the first draft. PE supervised the analysis and gave feedback on the content of the manuscript. LP supervised the methodological process. JB conceived of the study, participated in its design and helped to draft the manuscript. ll authors have agreed on the final version and offered a substantial contributions to conception, design, and analysis of the study, as well contributed to drafting the article or revising it critically for important intellectual content.

Acknowledgements: We thank all participants because of their willingness to share their stories.

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PART IV

PALLIATIVE CARE NURSES ADDRESSING SEXUAL AND INTIMATE RELATIONSHIP ISSUES IN DAILY PRACTICE

CHAPTER 6

ADDRESSING SEXUAL ISSUES IN PALLIATIVE CARE: A QUALITATIVE STUDY ON NURSES ATTITUDES, ROLES AND EXPERIENCES.

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Published in Journal of Advanced Nursing, 2018 [epub ahead of print]

ABSTRACT

Aim: To explore palliative care nurses' attitudes, roles and concrete experience with regard to addressing sexual issues in their daily practice.

Background: Patients and their partners in palliative care might experience dramatic changes in their sexuality and want nurses to provide the opportunity to address them. Moreover, it is argued that the holistic philosophy of palliative care encourages nurses working in this area to include sexual issues in their daily care. It is, however, unknown how palliative care nurses address sexual issues

Design: A generic qualitative study was performed.

Methods: In total, 21 in-depth interviews were done with nurses from different facilities of palliative care networks in Flanders. Data were collected between September 2014 and September 2016 and thematic analysis was used to analyse the data.

Results: It was found that the way palliative care nurses addressed sexual issues was clearly influenced by their own interpretation of the philosophical principles underlying palliative care. The different interpretations of these basic principles create tensions for nurses about how to address sexual issues in the daily practice of palliative care, and nurses vary in their reactions to these tensions. The present findings show that palliative care nurses – when they were able to overcome these tensions – use a "sex-positive approach" that fits with their tendency to focus on quality of life.

Conclusion: Out of the results of this study, we made a list of good practices for palliative care nurses addressing sexual issues. This list can be used in nursing educational programs.

Keywords: Qualitative research, thematic analysis, terminal illness, palliative care, sexuality, couple, nursing, communication

SUMMARY STATEMENT

Why is this research needed?

- Patients in palliative care and their partners expect their nurses to instigate the discussion about sexual issues in the palliative phase.
- The holistic philosophy in palliative care encourages nurses to include sexual issues in their daily care as well.
- In general, discussing sexual issues with patients/partners is challenging for nurses, but it is unknown how nurses working in palliative care address sexual issues.

What are the key findings?

- The way palliative care nurses address sexual issues is clearly influenced by their own interpretation of the philosophical principles underlying palliative care.
- Different interpretations of the philosophy of palliative care create tensions about how to address sexual issues, and nurses vary in their reactions to these tensions.
- Palliative care nurses can use a “sex-positive approach”, aligning with their tendency to focus on quality of life.

How should the findings be used to influence policy/practice/research/education?

- The results show the usefulness of several interpersonal communication strategies, which might be added to the general models used in nursing care for addressing sexual issues.
- Recommendations on addressing sexuality in palliative care and how to use these in nursing educational programs are formulated.

INTRODUCTION

When entering the palliative stage of life, experiences in the realm of sexuality and their significance may change profoundly for patients and their partners (Ananth, Jones, King, & Tookman, 2003; Lemieux, Kaiser, Pereira, & Meadows, 2004; Leung, Goldfarb, & Dizon, 2016; Taylor, 2014; Vitrano, Catania, & Mercadante, 2011). For instance, the intense emotional reactions provoked by the experience of proximity to death may have an influence on the sexual experience of both patients and partners: some couples have sexual interactions to reinforce their emotional connectedness or to console each other, while others restrain from sexuality due to altered feelings or miscommunication (Taylor, 2014). Moreover, physical factors related to the palliative stage (e.g., immobility and general malaise) may decrease sexual desire and hinder the spontaneous expression of sexuality (4). Furthermore, social or environmental conditions (e.g. a single hospital bed or a lack of privacy in inpatient settings may also be barriers to the expression of sexuality(Lemieux et al., 2004; Shell, 2008).

Background

Although sexual issues are often surrounded by taboos in health care, patients and/or partners expect palliative healthcare providers to instigate the discussion about sexual issues related to their illness (Ananth et al., 2003; Flynn et al., 2012; Hordern & Street, 2007b; Leung et al., 2016; Stead, Brown, Fallowfield, & Selby, 2003). This is also in line with recommendations formulated in the National Consensus for Quality Palliative Care in the United States, where sexuality is recognized as an important component that needs to be addressed in palliative care (National Consensus Project for Quality Palliative Care, 2012). Moreover, the World Health Organisation (WHO, 2010) positions nurses at the forefront of the delivery of “sexual health care”.

However, research has shown that discussing sexual issues with patients/partners is still challenging and difficult for nurses (Hordern & Street, 2007; Lindau, Surawska, Paice, & Baron, 2011; Perz, Ussher, & Gilbert, 2014; Stead et al., 2003, Dyer & das Nair, 2013). Nurses feel responsible for doing so, but the topic often provokes conflicting feelings such as fear and embarrassment (Saunamäki & Engström, 2014). They also frequently mention a lack of knowledge and skills to adequately initiate a discussion about sexual issues (Higgins, Barker, & Begley, 2006). As a consequence, they often deny, ignore, or avoid dealing with sexual issues in their work (Hordern & Street, 2007b). In general, they feel more comfortable addressing the ‘medical(ised)’ aspects of sexuality (e.g. erectile dysfunction, vaginal dryness), than the emotional and relational aspects, as often preferred by the patients/partners involved (Hordern & Street, 2007).

It has been argued that the holistic philosophy and patient-centred approach in palliative care (Pastrana, Junger, Ostgathe, Elsner, & Radbruch, 2008) encourages nurses to include sexual issues in their daily care as well (Bowden & Bliss, 2009; Lemieux et al., 2004; Leung et al., 2016; Taylor, 2014). On the other hand, there are also reasons to doubt – in practice – that sexuality is likely to be addressed in palliative care, especially in advanced stages of disease: recent research shows that barriers to addressing sexual concerns may *increase* as the disease progresses (Reese et al., 2017). No empirical research so far has specifically investigated how nurses working in palliative care do address these sexual issues.

Therefore, the central research question of the current study was: : "What are palliative care nurses' experiences with sexuality in their daily practice?", and more specifically "What are their attitudes about sexuality in palliative care, their assumed roles towards addressing sexuality, and their specific experiences with addressing sexual issues in palliative care?"

METHODS

Aim

The aim of this research is to explore palliative care nurses' attitudes, roles and concrete experience with regard to addressing sexual issues in their daily practice.

Design

We performed a "generic qualitative study" , as our research questions did not fit neatly within a single established methodology (Kahlke, 2014). More specifically we chose "interpretive description" , a subgenre of generic study developed to address the need in nursing research for a pragmatic, contextualized qualitative approach that draws on experience from clinical practice, is translated easily into the practice setting, and also reflects nursing's unique mandate and epistemological foundations (Thorne, Kirkham, & MacDonald, 1997). The generic qualitative study is based on in-depth interviews, as we wanted to provide detailed information about the palliative care nurses thoughts, experiences and behaviour, and as in-depth interviews may provide a relaxed atmosphere in which to collect information- which might be necessary for sensitive subjects such as sexuality (Boyce & Neale, 2006). To analyse the data, we used thematic analysis (Braun & Clarke, 2006) .

Participants

Our study was conducted in Flanders, the Dutch speaking half of Belgium. Flanders has well-developed and varied palliative care services, formally coordinated by regional palliative care networks, consisting of residential palliative care units and palliative support teams in hospitals, palliative home care teams visiting patients at home or in nursing homes and palliative day care facilities offering ambulatory support during the day (see figure 1).

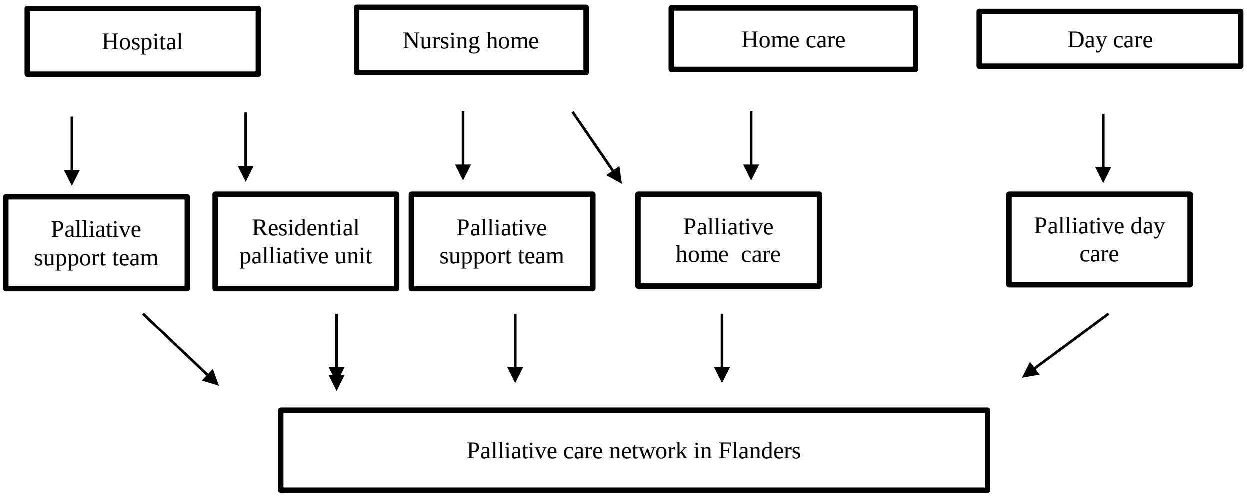


Fig. 1. Organisation of palliative care in Belgium

For this study, we recruited nurses working in these different facilities. Recruitment was done through the directors of these facilities. In total, 21 nurses were interviewed, based on willingness and availability at the time: two from palliative support teams in hospitals, six from residential palliative care units, 11 from palliative home care teams, and two from palliative day care facilities. All interviews were done in a private room at their workplaces. Table 1 gives an overview of the participating nurses' characteristics.

Table 1. Demographics of nurses (n=21)

	Palliative support team	Residential palliative care unit	Palliative ambulant care team	Palliative day care centre
Male	0	1	3	0
Female	2	5	8	2
Age Range	30-45	32-58	28- 57	40-55

Data collection

In-depth interviews were conducted with the palliative care nurses. At the start of the interview, we told the participants we were interested in how they addressed their patients and partners' sexual issues in everyday work. To open the topic, we shared with them Gilley's broad conceptualisation of sexuality in the context of palliative care, stating that sexuality includes both expression of emotional needs through physical intimacy and a more erotic interpretation (Gilley, 2000). We asked nurses about their experiences with addressing sexual issues, what they find difficult about it, what they find easy, etc. The interview guide was used flexibly and the interviewer used prompting and probing techniques (see appendix for interview guide).

All interviews took place between September 2014 and September 2016, and were done by a female sexologist (CB, first author of this article), who had no personal connection with the nurses. Interviews took between one and two hours, were audio-taped and transcribed *verbatim*. Data collection ended when saturation was reached; i.e., when additional data did not reveal new ideas.

Ethical considerations

This study was approved by the Ethical Committee of the Academic Hospital of a University (B.U.N. 143201420594) and data collection and analyses were carried out with care and concern while maintaining total privacy and confidentiality for the participants. To reach this goal all personal information was deleted before transcription and representation of the data, so that neither nurses, nor their working area could be traced.

Data analysis

We performed our analysis according to the six phases of thematic analysis offered by Braun and Clarke (2006). We identified themes at a latent level, which means that we interpreted the nurses' accounts, examining underlying ideas, assumptions, and conceptualisations/ideologies. In our case, we interpreted the nurses' accounts in relationship with the philosophical principles of palliative care (Pastrana, 2008; Giley, 2000). A detailed description of the different phases of analysis can be found in Table 2. The final thematic map is shown in figure 2.

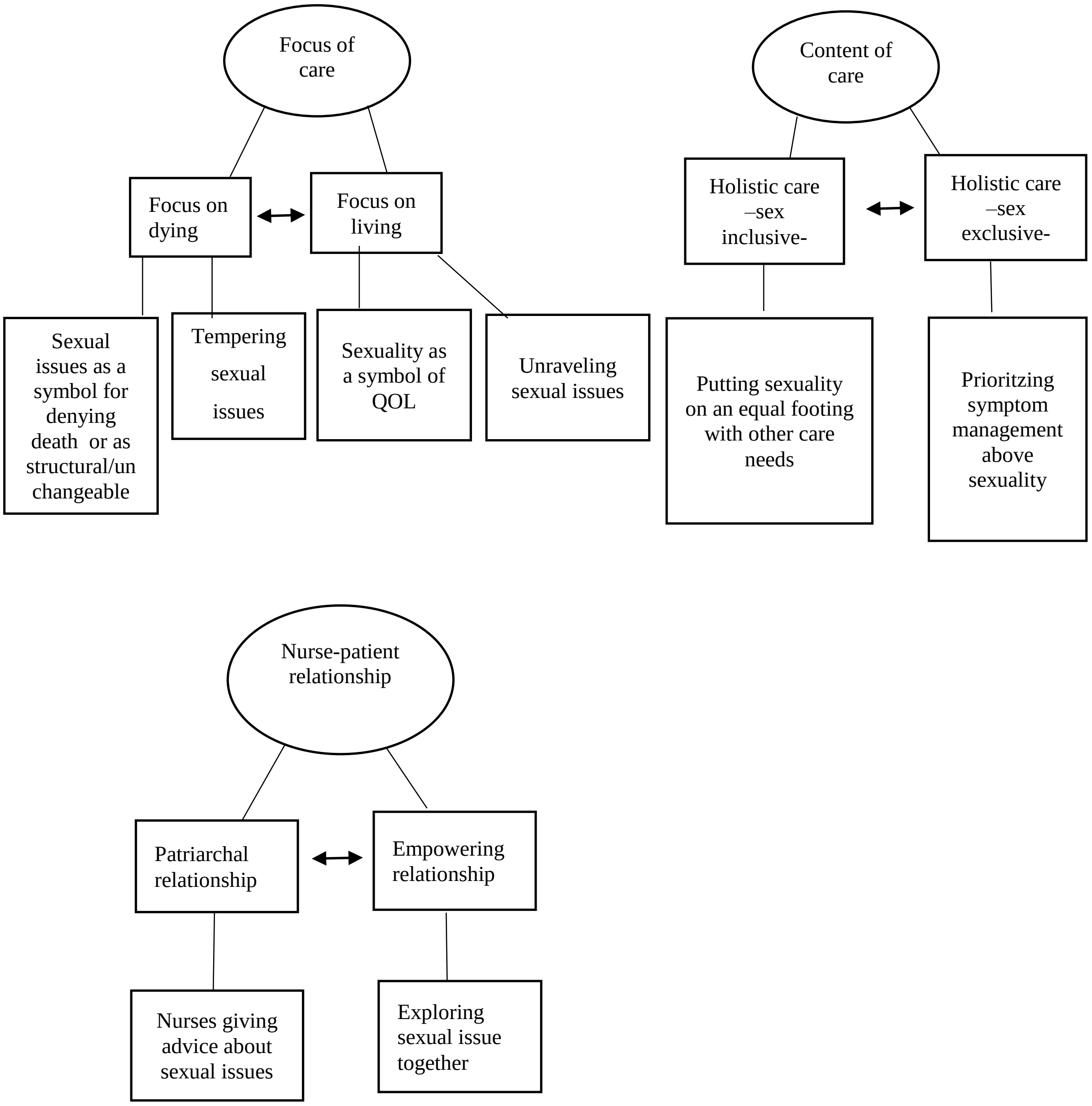
The first author (CB) did the analysis under supervision of a research team, which met regularly during the whole trajectory of the research process. During these meetings, the first author presented her rationale for data collection, analysis and her interpretation of the data, in order to enhance reflexivity and to check plausibility and coherence in her interpretation. The members of the research team looked at the data from a different research and health work perspectives: i.e., JB as a public health scientist and nurse, PE as a sex researcher and sex- and marital therapist and LP as a health scientist and general practitioner. We used NVIVO 10 to guide our thematic analysis.

Rigour

To ensure rigour in our qualitative study, we ensured that that the typical and atypical elements of the data were depicted in the descriptions, thereby providing a plurality of reactions to the subject. As well, we ensured that our data analysis was done by additional researchers (Sandelowski, 1986; Guba

& Lincoln, 1981). Also, we reported our study in a comprehensive and transparent way by the aid of the COREQ checklist (Tong, Sainsbury, & Craig, 2007), a checklist that aims to promite complete and transparent reporting amongst researchers.

Fig 2: Phase 5 in thematic analysis: defining and naming themes



Phase		Description of the process
1.	Familiarising yourself with your data	Reading and re-reading the data , noting down initial ideas (general ideas + specific ideas for coding)
2.	Generating initial codes	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code e.g. “Actually we listen to the patient and their partner, what they bring up, what they need. And if they talk about things like touch, intimacy, sexuality, we pick up on them. Then we ask more questions… and we might be able to work with it… but we don’t have any standard questions in palliative care.” *Initial codes for this fragment* No standard questioning in palliative care Addressing sexuality through active listening Being attentive to sexuality-related content during active listening Addressing sexuality depends on what the couple brings to the fore “ [working on sexuality] . When I see that someone only has another two weeks or a month maximum to live, we often feel here like, are you going to lift the lid on that and start meddling with things that people might not be able to cope with? Or, say the person dies before it is finished, you sometimes do more harm than good. When people die, it might sound strange, but a lot of those problems just solve themselves, you see.” *Initial codes for this fragment* Limited time to talk about sexuality Not taking the risk of bringing up sexuality Uncertain about the ability to handle sexual problems Problems may be solved by the death of the patient
3.	Searching for themes (detailed illustration of the coding tree available in supplementary files)	Collating codes into potential themes, gathering all data relevant to each potential theme E.g. No standard questioning in palliative care Addressing sexuality depends on what the couple brings to the fore Not taking the risk of bringing up sexuality → *Potential theme:* non-structural assessment of sexuality in palliative care Addressing sexuality through active listening → *Potential theme:* General communication techniques for addressing sexuality Limited time to talk about sexuality Problems are solved by the death of the patient Uncertain about the ability to handle sexual problems → *Potential theme:* dilemma of staying away or touching on the subject of sexuality

4. Reviewing themes Hypothesis that there are several principles of palliative care that each cause some tensions in addressing sexuality 1. Checking this hypothesis with the principle of empowerment (by going back in the data/codes) Dilemma about who has to take the initiative to initiate the subject of sexuality Dilemma on who is responsible for dealing with sexuality 2. Checking this hypothesis with the dilemma of staying away or touching on the subject of sexuality (by going back to the data/codes) This is a dilemma derived from putting the principle of “personal growth” into practice	Checking the themes work in relation to the coded extracts and the entire data set, generating a thematic map of the analysis e.g. *Potential theme:* non-structural assessment of sexuality in palliative care *Potential theme:* General communication techniques in palliative care for addressing sexuality General communication techniques: Checking themes with the entire data set: hypothesis that non-structural assessment and general communication techniques are derived from putting principles of palliative care into practice. Finding: Non-structural assessment in palliative care, + general communication technique (active listening) can be related to the **principle of empowerment** *Potential theme:* dilemma of staying away or touching on the subject of sexuality Checking theme against the above finding that palliative principles are put into practice: This theme gives us the hypothesis that putting the principles into practice causes some **tensions, dilemmas**
5. Defining and naming themes See figure X for a final thematic map/conceptual scheme Ongoing analysis to refine the specifics of each theme	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme e.g. The principle of empowerment: + Dilemma about who has to take the initiative to initiate the subject of sexuality Dilemma of who is responsible for dealing with sexuality The principle of empowerment→ the principle of palliative care related to the patient-nurse relationship When nurses find themselves responsible for addressing sexuality → a patriarchal relationship When nurses find addressing sexuality a shared responsibility → an empowering relationship
6. Producing the report	Selection of vivid extract examples, final analysis of selected extract, relating back of the analysis to the research question, producing a scholarly report of the analysis

Table 2 Phases of Thematic Analysis (Based on Braun & Clarke, 2006)

FINDINGS

We found that the way palliative care nurses addressed sexual issues was clearly influenced by their own interpretation of the philosophical principles underlying palliative care. These principles relate to the focus of care, content of care, and the nurse-patient relationship (see fig 2). Our findings suggest that different interpretations of these basic principles create tensions between nurses about how to address sexual issues in the daily practice of palliative care, and that nurses vary in their reactions and responses to these tensions. In the subsequent sections, we discuss these philosophical principles and their interpretations, as well the consequences for the way nurses address sexual issues.

Focus of care on living or dying: Unravelling or containing sexual issues?

A first philosophical principle underlying palliative care is that the focus of the nurses' care is to promote the 'quality of life' (QOL) of patients. When put into practice, this focus on quality of 'life', however, does not imply that nurses need to ignore the fact that the patient is dying. The search of a balance between living and dying creates tensions about how to address sexual issues, in two ways: the tension to see sexuality as a part of QOL or as a way of denying imminent death, and the tension between "unravelling" or "containing" sexual issues.

Firstly, there is the tension between interpreting sexuality either as 'a symbol/ part of QOL' or as 'a symbol of ignoring the reality of dying'. Nurses who saw sexuality as a part of QOL mentioned several advantages of sexuality for QOL: e.g. "it diminishes terminal agitation" or "it's an effective way of communicating when verbal communication is getting more difficult." This tendency to see sexuality as part of QOL was found more frequently where they rephrased it as "physical intimacy".

> Nurse, m, residential palliative unit, 48y: "terminal agitation will occur less when two people can feel each other's presence in the same bed… even if it just means lying under the same cover in the same bed, holding each other …"

These nurses often tried to live up to this point of view in their every day care by consciously providing opportunities for patients and partners to be sexually intimate: e.g., they tried to involve the partner in giving physical comfort to the patient; they adapted (hospital) infrastructure to create a facilitating environment for physical intimacy, e.g., by putting a second bed in the room or encouraging the couple to lie in bed together; ensuring privacy by knocking on the door before entering.

Other nurses, however, interpreted a couple's need/request to resolve sexual issues – especially when understood in a limited erotic sense, i.e., penetrative intercourse – as a symbol of the incapability of a patient/partner to “accept” the fact that they are dying; they regarded this need as incompatible with “a good death”.

> Nurse, f, residential palliative unit, 58y: “He did say that he needed sex, but couldn’t catch his breath in his wheelchair, let alone if he was supposed to be having sex in some way. That man was so determined, he didn’t want to adapt at all. I know it sent shockwaves through the team here.”

When confronted with questions about sexual issues, they tended (sometimes prematurely) to work towards acceptance of the sexual loss, instead of exploring feelings or expectations about these sexual issues.

> Nurse, f, home care organisation, 48y: “A woman said to me recently, although she was severely ill, that she missed sexual intimacy with her husband who no longer dared to have sex with her. Now that I think about it, I was too hasty with her, I had an immediate answer ready: “do you still cuddle? Yes? Well that’s nice too, isn’t it…”

Secondly, there is the tension between containing sexual issues and unravelling them as part of the “personal growth” inherent to QOL. Personal growth refers to the idea that unresolved issues – of which sexual issues may be one – can be (re)solved and offer partners/patients an opportunity for further growth.

According to this philosophical principle, nurses can help patients/partners to resolve sexual issues that are at stake at the end of life. However, when put into practice, there is the risk that unresolved sexual issues may impose a significant threat to a couples’ relationship or personal wellbeing. Nurses said they have to be attentive not to unpack problems when there is not enough time left to work them through – due to the imminent death of the patient – as by doing so they may risk preventing “a good death”. Thus, the fact that the patient is dying demands a balanced approach of psychosocial care, and this is especially so when it comes to addressing sexual issues.

> Nurse, f, palliative day care center, 40y: “The possibilities are often very limited. We don’t have the opportunity to intervene… usually all we can do is limit the damage. By looking after them as well as possible. That is palliative care.”

When nurses focused more on dying and thus on the limited time available, they reported being hesitant to unravel sexual issues. They tended to categorize sexual issues as structural problems deeply rooted in the history of a relationship or a person, that need more time and effort to resolve than the limited time they can work with the patient/partner. They mentioned feelings of “helplessness”, and tended to listen to stories about sexual issues rather passively, reassuring themselves that giving patients/partners the opportunity to express their concerns was the only matter that fell within the scope of their task.

> Nurse, f, home care organisation, 48y: "Yes. I let her tell her story (about her sexual issues) and acknowledged her but that was all, really. Afterwards she didn't come back to me with it and I didn't raise the subject again either."

When nurses focused more on the possibility of personal growth, they tended to be more open to actively exploring sexual issues with the couple. They did not shy away from sexual issues, but assumed that by exploring the issue together, for example by probing to help patients/partners to better understand what is going on with their sexuality, the acquired insights could help patients/partners to unravel sexual issues.

> Nurse, f, home care organisation, 57y: "If they say something like, my husband doesn't even touch me, I say: was it different before? Then they can realise themselves that… my husband was never really the touchy-feely type or much of a cuddling kind of person, if I have never said anything about it, it's going to be difficult to change him now. Or they might say, yes, actually I kept him at a distance, so he started to distance himself… maybe there is something I can do to change that… that's how people become aware of it themselves.

Content of palliative care: "Holistic sexuality-inclusive" or "holistic sexuality-exclusive"

A second philosophical principle underlying palliative care is that the content of the nurses' care is "holistic", i.e. that it comprises somatic, psychological, social/cultural and spiritual aspects. As sexuality is a multi-dimensional phenomenon, it is related to all these aspects. However, nurses' accounts revealed that the palliative phase is mainly associated with bodily deterioration and physical suffering, which creates tension about the question whether sexual issues are "a priority" or not.

When nurses said that they were giving sexual issues as much priority as other care needs, they negotiated with patients/partners about possible implications of certain medical or infrastructural interventions for their sexuality, e.g. as they found that sometimes patients/partners chose the intimacy of sleeping together over the possible discomfort this entails.

> Nurse, f, home care organisation, 38y: "In the beginning of my career, I thought I had to decide when to set up a hospital bed. Now, as a palliative care nurse, I find there is no point insisting because they already have to give up so much as a couple. So I leave it up to them. As long as

> the partner is prepared to get her husband into bed every evening, who am I to say it’s wrong and that they need a hospital bed. It’s important to them.”

Another example is how symptom management is sometimes adapted to enable sexual expression.

> Nurse, f, home care organisation, 28y: “I take into account the sexual implications if I am putting pain pumps in, because they make you drowsy, so I ask when the partner is home and if that is the time they want to spend together. And then I sort out the pain pump at a time that suits them, so they can have their intimacy.”

Being confronted with the tensions in holistic care described above, other nurses sometimes stated to rely on and work with a hierarchy of care in which symptom management was prioritized above sexual issues and management of them, reflecting their doubts about sexual issues being a priority, or stating that symptom management needs to come first, especially when time is limited.

> Nurse, f, home care organisation, 51y: “When there is pain for example or another symptom, that symptom is at the foreground. Then intimacy and sexuality are right down at the bottom of the pile. If someone is in constant pain, we try to do something about that. And then things like sexuality might come up afterwards. But as long as there is a complaint or symptom, there is no room for things like that.”

Nurse-patient relationship: From “giving advice” to “exploring the issue” together.

A third philosophical principle of palliative care emphasizes the empowerment of the patient/partner in the nurse-patient relationship. This means that patients/partners are seen as (co-)decision-makers, and that – instead of organizing care based on fixed procedures – nurses’ care is primarily led by the needs of patients/partners and at their pace. It moves away from only the professional having control, to give the patient/partner as much sense of autonomy as possible.

> Nurse, m, residential palliative unit, 48y: “Actually, we listen to the patient and their family, what they bring up, what they need. And if they talk about things like touch, intimacy, sexuality, we pick up on them. Then we ask more questions, and we might be able to work with it… but we don’t have any standard questions in palliative care.”

However, nurses also knew that patients/partners may be hesitant to broach sensitive subjects such as sexual issues. This leaves them with a tension to choose between proactively initiating an exploratory conversation about sexual issues or waiting for patients/partners to initiate the topic themselves.

Some nurses chose not to proactively initiate conversations about sexuality because they felt insecure or unqualified to do so or believed they lacked “expertise” in the field of sexuality. They assumed that addressing sexuality issues in palliative care meant that they had to give “advice” about sexual issues and suggest “solutions” to the concrete problems the patients’/partners put forward. They shifted responsibility for broaching sexual issues towards psychologists or GPs.

Furthermore, they mentioned not seeing patients/partners frequently enough to initiate conversations about sexual issues, being convinced that sensitive conversations – whether by patients/partners or nurses – are only possible in a close professional relationship.

Other nurses however acknowledged not having enough experience to give clear-cut specialised advice about specific sexual issues, and also didn’t find it necessary to do so. They assumed that addressing sexuality issues in palliative care meant that they “talk about”, “explore”, and “acknowledge” the emotions linked to sexual issues, together with the patient/partner.

> Nurse, f, home care organisation, 28y: “Then I ask: how have you always approached sex… To give them a bit of insight and so that they do… yes… feel like, do I still want to do that, how am I going to do it, and then we also always ask, can you do that yourself or do you need help… we can help… Do you have questions for us or is there something we can do about it? So, actually it’s the same for all issues, sexuality too, we have to approach things in the same way actually.”

These nurses also reported using facilitating techniques initiating discussion, such as taking sexual issues seriously, even if the patient/partner is laughing, or putting their observations into words.

> Nurse, f, residential palliative unit, 41y: “Talking about sexuality does come up too when we are washing patients, for example. They might say about their intimate body parts, “there used to be more life in it”. If you brush it off and laugh, an important moment is lost. But if you detect these things carefully and delve deeper, and ask if they need it, those conversations start.”

They mentioned that an open, responsive attitude on the part of the nurse and the intensity of the encounter is more critical than the closeness of the relationship or the frequency of encounters.

These nurses said they are also not free from uncomfortable feelings that may prevent them from identifying opportunities for addressing sexual issues, but when this happens, they often take a reflective position and discuss their hesitance with colleagues or in team meetings.

DISCUSSION

This study provides empirical data for the idea that addressing sexual issues falls within the remit of holistic palliative care, but also reveals that nurses experience difficulties and tensions when confronted with patients and partners' sexual issues in their daily practice.

More specifically, nurses reported being confronted with certain tensions that can be related to the basic principles of holistic palliative care. We found a tension about whether care should focus mainly on living than on dying, which resulted in tension for nurses about what to do, i.e. "unravel" or "contain" sexual issues. Furthermore, we found tension about the importance of sexual issues at the end of life, and how they related to other care needs (priority or not). Finally, we found tension about how "the empowerment of the patient/partner" was concretely translated within the nurse-patient relationship by taking more of an initiating or waiting attitude towards conversations about sexual issues. This study demonstrates how the underlying discourse from a specific nursing area might interact with the nurses' concrete attitudes and behaviour, thereby offering a broader perspective on the results of other studies on this subject, studies that mainly focus on personal factors such as assumptions, values and comfort or discomfort in individual nurses (Gleeson & Hazell, 2017; Magnan & Reynolds, 2006; Reese et al., 2017)

However, besides the philosophical principles of palliative care, several other important factors that may influence the nurses' way of dealing with these tensions emerged from our study: the type/kind of sexual issue, the organizational structure/context of the care and the possible "techniques" available to address the specific issue. Nurses seem less prone to translate palliative care principles into practice when it concerns more erotically explicit issues of sexuality than when the issues lean towards physical intimacy. This might be also due to stereotypes about the asexuality of old(er) and ill persons (Taylor, & Gosney, 2011). Nurses were also less prone to address sexuality according to the principles of palliative care when they perceive a lack of time and space to give appropriate care. Moreover, they tend to handle tensions more easily when the way of addressing sexual issues is close to their daily tasks as a palliative care nurse, e.g., letting the partner help with comfort care, or using communication skills such as empathic listening.

Although our sample contained a differentiation on gender, age and palliative care services, our analysis did not reveal differences on these factors. The research literature is also inconclusive/controversial whether nurses-related issues might influence nurses' attitudes towards sexuality (Kotronoulas, Papadopoulou, & Patiraki, 2009). Probably, it might be that the philosophic principles of palliative care might weight heavier on the attitude and experience of addressing sexuality than the type of palliative care service. More research might be needed to explore these differences in-depth.

Our results also show that palliative care nurses – when they were able to overcome the above described tensions – use a “sex-positive approach”. A sex-positive approach refers to a recent discourse emphasizing the pleasurable aspects of sexuality: it means being open, communicative, and accepting of individual differences regarding sexuality and diversity in sexual behaviour (Williams, Thomas, Prior, & Walters, 2015). It is clear that the philosophy of palliative care – with its focus on quality of life, on being holistic and by emphasizing the empowerment of the patient and partner in the nurse-patient relationship – aligns with this sex-positive approach.

In our results, this sex-positive approach is put into practice by nurses by “encouraging the couple to be ‘sexually’ intimate, by creating a positive-sex environment, by being open to actively exploring issues”. These results reflect how the tendency in the general (nursing) literature about serious illness and sexuality evolves from a predominantly “sex-negative” framework for conducting research about sexuality or informing practice (Hordern, 2008) to a more patient-centred, positive approach (Reisman & Gianotten, 2017). The current finding show that this positive approach can also be found in the attitudes and daily practice of palliative care nurses on the condition that nurses able to overcome the tensions between philosophy and practice.

What is more, the empowering discourse in palliative care teaches us that addressing sexuality is a “negotiated process” rather than a “unilateral way” of giving information (the nurse) and receiving information (the patient). Most literature emphasizes that informing patients and partners is the primary way to address sexual issues, and the general educational models for addressing sexual issues usually applied in the field of oncology/nursing care in general emphasize this “one-way” information-giving as well (Ayaz & Kubilay, 2009; Taylor & Davis, 2006; Reese et al. , 2017). The results of this study show the usefulness of more interpersonal communication strategies (e.g., exploring feelings, active listening, probing, negotiating), which might be added to the general models used in nursing care as effective ways of addressing sexual issues.

Limitations

The transferability of the data is limited. We partly recruited nurses based on their motivation to be interviewed for this study. This possibly leads to some bias, because of their explicit willingness to talk about sexuality. Our study further focuses exclusively on palliative care nurses working within the palliative care services as organized in Flanders, Belgium, excluding nurses caring for terminally ill patients within other work settings (e.g., nurses working on oncology wards) . Moreover, the settings in which palliative care is provided (i.e. ambulant and residential care) are diverse, and this might also have implications for the way palliative care nurses act, which we did not investigate in depth in this study. It might be interesting to do further research into the different groups of nurses working with terminally ill patients, as well researching how the different settings in which the care is delivered shape communication by health professionals in palliative care and practices surrounding sexual issues. However, the narratives of the palliative care nurses might transcend their immediate context and be transferable in other (West-) European states with a similar developed health care system.

More or less absent from the accounts of the nurses was there experience with and attitude towards different sexualities in palliative care. This might be because we did not explicitly asked questions about this topic, but the invisibility of this subjects in the accounts might suggest a heteronormative attitude that denies diversity in sexual identities (Simpson, Almack & Walthery, 2016) Thus it might also be worth exploring nurses' attitudes to or experience with different sexualities in palliative care as well. Also, we did not have in-depth data for other possible influences on the way nurses addressed sexual issues, such as the personal context of the nurse, the gender of the nurse vs. the gender of the patient/partner, the personality of the patient/partner, the nurses' experiences with their own sexuality, etc. All these could be further areas of investigation.

CONCLUSIONS

Palliative care nurses attitudes, roles and concrete experience with regard to addressing sexual issues was clearly influenced by their own interpretation of the philosophical principles underlying palliative care. The different interpretations of these basic principles create tensions for nurses about how to address sexual issues in the daily practice of palliative care, and nurses vary in their reactions to these tensions. Our results show that palliative care nurses – when they were able to overcome these tensions –use a "sex-positive approach" that fits with their tendency to focus on quality of life.

The findings of this study are useful for clinical practice, as the focus of our study goes beyond listing barriers to addressing of sexual issues – as often found in nursing literature (Dyer & das Nair, 2013) – towards showing *how* nurses deal with sexual issues. More specifically, we made recommendations on addressing sexuality in palliative care, which can be used in nursing educational programs in list form (table 3), which we retrieved from our data. We call them "good practices" as these are the attitudes and skills of nurses when they were able to translate the philosophical principles of palliative care into practice. These recommendations can be used in educational programs in palliative care, as well these can form the basis of evaluation and amendment in the light of experience. Further research might investigate whether the good practices of palliative care nurses are applicable in other contexts as well, for example in oncology healthcare.

Educational programs in palliative care can further use the findings of this paper to help nurses becoming more aware of how basic care principles (e.g. the philosophy of palliative care) influence their way of addressing sexual issues, which may enhance their reflexivity.

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Appendix Interview Guide palliative care nurses

Introduction

- Introducing the interviewer
- Introducing the aim of the research : “we want to explore palliative care nurses’ attitudes, roles and concrete experience with regard to addressing sexual issues in their daily practice”
- Introducing what we mean by sexuality : “sexuality includes both expression of emotional needs through physical intimacy and a more erotic interpretation (Gilley, 2000)”
- Collecting background information (age, years of experience, previous job…)

Questions

- *To explore the attitude to sexuality in palliative care*

    - (broader question): can you tell me about your motivation to become a palliative care nurse? What is most appealing about the job?
    - Is "caring for the sexuality of a couple" something that has to be addressed within your profession? How and when?

- *To explore the role and concrete experiences to addressing sexual issues*
- What are your experiences with addressing sexual issues?
- How are you generally assessing sexual issues in palliative care/ How do you find out if a couple has sexual issues?
- If couple has sexual issues, how do you address them? Do you refer to colleagues (psychologist, ..) or not? When?
- What is for you the most difficult part in addressing sexuality?
- What are the aspects of addressing sexuality that are easier to do?
- In what way is there a team approach regarding addressing/assessing sexual issues?
- What would you need to better support sexual issues in palliative care?

CHAPTER 7

" IT'S IN THE LITTLE THINGS ": HOW NURSES OFFER RELATIONSHIP SUPPORT TO COUPLES IN PALLIATIVE CARE

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Submitted

ABSTRACT

Palliative care nurses are often confronted with couples experiencing relational distress. Up to now there is little research about how palliative care nurses address such issues.

We performed a generic qualitative study among nurses in different palliative care settings in Belgium, consisting of in-depth interviews, observational studies and peer debriefing groups.

Nurses were found to clearly support intimate relationships between patients and partners by creating a couple-positive care environment. Relationship issues were mostly addressed via own creative assessment and communication skills during daily care, and backed up by team support. Nurses were rather hesitant towards explicit unravelling of relationship problems, in favor of providing emotional support and comfort. Although nurses' interventions with regard to relationship issues were often appropriate and useful, there is a need of an integral and relationship-centred nursing care conceptualization, making nurses' approach more visible and assessable for education and contributing to professional recognition.

INTRODUCTION

During the terminal phase of illness, one of the patients' and partners' greatest desires is to strengthen their intimate relationship (McLean & Nissim, 2007). In the last phase of life, relational concerns very often predominate in couples: patients and their partners wish to say goodbye, to be able to spend time with and confide in intimate others, to resolve longstanding conflicts and to feel that they are of value to intimate others (Sherman, 1998; Zaider & Kissane, 2011) There is also evidence that the well-being of seriously ill patients and their partners are intimately and inextricably linked (Hodges, Humphris, & Macfarlane, 2005; Murray et al., 2010) and that having a meaningful, intimate relationship is an important protective factor for the well-being of incurably ill patients (Berg & Upchurch, 2007; Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008; Rodin et al., 2007). However, being terminally ill also brings profound relationship challenges for couples, such as negotiating difficult choices regarding end-of-life care and coping with anticipatory grief, role and life-style changes, and talking about the ill partner's legacy in psychological and practical matters (Manne & Badr, 2008; Taylor, 2014; Tie & Poulsen, 2013). Some couples' relationships even risk deteriorating towards the end of life (Koop & Strang, 2003; Weingarten, 2013). More specifically, 33-50% of patients and partners experience relational distress during terminal illness (McLean & Hales, 2010).

A unique characteristic of palliative care is that patients and partners are considered as the unit of care, which implies that palliative care can offer couples the opportunity to reconcile conflicts and heal their relationship(s) (Altschuler, 2015).

Often palliative care nurses – because of their personalised care – are the first to be confronted with couples experiencing such relational distress. Indeed, palliative care nurses mention that enhancing the connection between patients and their partners is an important component of the psychosocial care they provide (Fan, Lin, Hsieh, symptom, & 2017, n.d.; Goldberg, 2010; Grande et al., 2009; Hudson & Payne, 2011) However, they also mention that they are not sufficiently trained to address relationship issues (von Heymann-Horan et al., 2017). The currently available recommendations on how to deal with these relationship issues are based more on theoretical speculations or clinical experience than grounded in empirical research (King & Quill, 2006). There is a clear lack of evidence-based work on supporting couples in palliative care, despite repeated calls by researchers to do so (McLean, Walton, Rodin, Esplen, & Jones, 2013). There are also very few intervention studies that focus on support for couples in the phase of advanced or terminal illness (McLean et al., 2013; Mohr et al., 2003; von Heymann-Horan et al., 2017) which is in high contrast with the abundance of interventions for couples coping with early stage cancer (Badr & Krebs, 2013). Moreover, the few existing intervention studies are meant specifically for psychotherapists working in palliative care, thereby overlooking nurses' key role in providing relationship support to couples. Especially in palliative care, including nurses is relevant because members of the palliative care team (i.e., psychologists, physicians, nurses) do not usually work within distinctly defined roles (O'Connor & Fisher, 2011). Moreover, to be effective, proposed interventions need to be adapted to and embeddable in the context of the daily care practice of palliative care nurses. Thus there is an urgent need to develop an empirical framework on how palliative care nurses can address relationship issues between patients and their partners in their daily practice in different settings. Such a framework could function as a basis for education and evaluation of interventions in daily practices. The aim of this paper is to contribute to the development of such a framework by answering the following research question: "How do palliative care nurses address relationship issues between patients and their partners in their daily practice"?

METHOD

We performed a generic qualitative research study (Caelli, Ray, & Mill, 2003) with data triangulation, consisting of an in-depth interview study, an observational study, followed by peer debriefing groups, in the palliative care setting in Flanders, Belgium. Generic qualitative studies are those that exhibit some or all of the characteristics of qualitative endeavour but rather than focusing the study through the lens of a known methodology, they combine several methodologies or approaches (Caelli et al., 2003).

Our generic qualitative study was conducted in Flanders, the northern, Dutch-speaking part of Belgium. Flanders has well-developed and varied palliative care services, formally coordinated by regional palliative care networks, consisting of residential palliative care units and palliative support teams in hospital settings, palliative ambulant care teams visiting patients at home or in nursing homes, and palliative day care facilities offering ambulatory support during the day (see figure 1).

1. In-depth interviews

The first part of this qualitative study consisted of in-depth interviews focussing on the experience of palliative care nurses dealing with relationship issues in their daily care practice.

For this study, we recruited nurses working in the different palliative care facilities described above. Recruitment was done through the directors of these facilities. In total, we interviewed 21 nurses, based on willingness and availability: two from palliative support teams in hospital settings, six from residential palliative care units in hospital settings, 11 from palliative ambulant care teams, and two from palliative day care facilities. All interviews were done in a private room at their workplaces. Table 1 gives an overview of the participating nurses' characteristics.

Table 1. Demographics of nurses (n=21)

	Palliative support team	Residential palliative care unit	Palliative ambulant care team	Palliative day care centre
Male	0	1	3	0
Female	2	5	8	2
Age Range	30-45	32-58	28- 57	40-55

We asked nurses about their experiences with addressing relationship issues and how they integrated this kind of support in their daily practices. The semi-structured interview, supported with an interview guide and used in a flexible way, gave much opportunity for the respondents to speak very openly.

All interviews took place between September 2014 and September 2016, and were done by a female researcher (CB, first author), who had no personal connection with the nurses. Interviews took between one and two hours, were audio-taped and transcribed *verbatim*.

2. Observational study

Additionally, we decided to perform two observational studies in a hospital unit and an ambulant care team, as a form of data triangulation. During our observations, we focussed on skills and actions that had not yet been revealed by the nurses during the interviews (Walshe, Ewing, & Griffiths, 2012). We were also interested in observing the extent to which concrete behaviour in the field corresponded to the attitudes that came up in the interviews.

The team in the palliative care unit consisted of 16 nurses (2 m, 14f). 2 of these nurses participated in the previous interview study. The ambulant care team consisted of 11 palliative care nurses (2m, 9f), of whom one had participated in the previous interview study.

All nurses were informed about the study, and written consent was obtained in advance. No nurses refused to participate in the study. We also informed the patients and partners about the study and asked them permission to observe the nurses in their presence and in their caring interactions with them. No patients/partners refused this.

Data were collected through ‘negotiated interactive observation’ (Wind, 2008). Observations were specifically focused on the nurses’ interactions with patients and their partners, aiming to address relationship issues in their daily care practice, in the way nurses talked about relationship issues during team meetings, in patient case reporting, and at informal moments (e.g. over lunch). We also screened the written notes that nurses use as a communication tool during shift changes for comments about relationship issues – e.g. notes about patients, their health and mental status, records of who visited the patient, the mental state of the close relatives, etc…During the whole period of observation, we also reflected on our observations with the nurses as an informal way of member checking.

The observations in the hospital setting and ambulant care setting consisted of 75 effective hours of observation in the hospital setting and 25 in the ambulant care setting over a period of 3 months. Immediately after the period of observation, all observation notes were written out in detail.

3. Peer debriefing groups

The results of preliminary analyses of the interview and observational data were presented and discussed in three palliative care teams, i.e., two residential palliative care units and one ambulant palliative care team. The first palliative care unit was the unit we observed (16 nurses, 2m, 14f), the second palliative care unit consisted of 11 nurses, and the palliative ambulant care team consisted of 11 nurses (3m, 8f). This type of research is similar to peer debriefing, which is, according to Lincoln & Guba, (1985, p. 308), "the process of exposing oneself to a peer in a manner paralleling an analytic session and for the purpose of exploring aspects of the inquiry that might otherwise remain only implicit within the inquirer's mind." However, what is different in our approach is that we held these peer debriefings at the end of our study and not during the data collection process, as Lincoln and Guba (1985) prescribe.

The nurses were invited to critically review the results and spontaneously started to reflect on their own nursing practice and why and how they addressed relationship support. The nurses gave feedback by either confirming or challenging the results and the assumptions and interpretations of the researcher. This enabled us to refine and deepen our analysis. These presentation and discussion sessions lasted two to two and a half hours each time. In total, 45 nurses actively participated in this peer debriefing session.

4. Data analysis

We performed our analysis according to the six phases of thematic analysis offered by Braun and Clarke (2006) (Braun & Clarke, 2006). A detailed description of the different phases of analysis, as well as the final thematic map at the end of the interviews, can be found in Table 2 and Table 3. We used NVIVO 10 to facilitate our thematic analysis.

First, we analysed the data from the in-depth interviews, which resulted in a list of preliminary themes, which were used to inform and narrow our focus in our observational study. Second, we analysed the data from the observational study together with the interviews. The themes derived from these analyses were presented to the three peer debriefing groups. The discussions in these peer review groups were used to refine these analyses to our final themes presented in the results.

We ensured that our data analysis was done in collaboration with additional researchers (Sandelowski, 1986; Guba & Lincoln, 1981): a nursing and health scientist (JB), a clinical sexologist (PE) and a general practitioner (LP).

Phase	**Description of the process**
In-depth interviews with palliative care nurses	This study started with collecting data through in-depth interviews with palliative care nurses
1. Familiarising yourself with your data	Transcribing, reading and re-reading the data, noting down initial ideas (general ideas + specific ideas for coding)
2. Generating initial codes	Coding interesting features of the data systematically using the entire data set (i.e., in-depth interviews, collating data relevant to each code e.g., Interview: I mention the imbalance: for example, I said recently to one partner, I know you need self-care too and that is why you don't always come to the hospital, but I notice that your partner really appreciates it a lot when you do come *Initial code for this fragment* *"identifying the imbalance in a couple's relationship"* "Yesterday, for example, I showed a partner what her contribution was to caring for the patient and that that was good and important. It was very important for that woman to feel what she had been able to do, even though the man now needs hospitalisation" Interview with a home care nurse *Initial code for this fragment* *" emphasizing strengths and resources"* *"offering credit for efforts being made"*
3. Searching for themes	Collating codes into potential themes, gathering all data relevant to each potential theme e.g., *denominating the imbalance in a couple's relationship* → Potential theme : rectifying imbalances in couples' relationships e.g. *" emphasizing strengths and resources"* *"offering credit for efforts being made"* → Potential theme: comforting patients and partners with difficult emotions regarding relationships
Observation study with palliative care nurses	Our observation is narrowed by exploring the potential themes derived from the interview study e.g., Potential theme: rectifying imbalances in couples' relationships → How do nurses rectify these imbalances in relationships in their daily practice?

	e.g. Potential theme: comforting patients and partners with difficult emotions regarding relationships → How do nurses comfort patients and partners with difficult emotions regarding relationships?
4. Reviewing themes There are several ways of addressing relationship support, each having their characteristic skills, dilemmas , difficulties and strengths	Checking the potential themes in relation to the entire data set (i.e., the data from the in-depth interviews as well as the observation data) e.g., Checking the potential theme: rectifying imbalances in couples' relationships against the data derived from observation → Observation: rectifying imbalances also encompasses the skills of nurses, encouraging, stimulating or tempting a couple to try out different behaviour e.g., Checking the potential theme: comforting patients and partners with difficult emotions regarding relationships → Observation: although nurses often comforted patients and partners, some nurses in palliative care find it difficult to see this as "real work"
Peer debriefing groups with teams of palliative care nurses	Discussing the themes derived from step 4 with the teams e.g., Several ways of addressing relationship support, each having their characteristic skills, dilemmas , difficulties and strengths
5. Defining and naming themes See table X for a final thematic map	Ongoing analysis to refine the specifics of each theme, using the data from the peer debriefing groups to refine these. e.g., Checking the potential theme: comforting patients and partners with difficult emotions regarding relationships + Observation: although nurses often comforted patients and partners, some nurses in palliative care find it difficult to see this as "real work" → Peer Debriefing: Palliative care nurses who are new to the job have to get used to comforting patients and partners, because it is "being present with them" , instead of "doing something".
6. Producing the report	Selection of vivid extract examples, producing a scholarly report of the analysis

Table 2: Worked example of the triangulation process and the different phases of analysis offered by Braun and Clarke (2006)

Themes	Subthemes
The process of addressing relationship issues	The process of pro-actively addressing relationship issues. The process of creating and adhering to a team approach towards relationship issues.
Different types of addressing relationship issues	Addressing relationship issues by creating a couple-positive environment. Addressing relationship issues by 'being there' and 'acknowledging feelings'. Addressing relationship issues by restoring misbalances in the couple due to illness. Addressing relationship issues by mediating unfinished business between patient and partner.

Table 3 Themes and subthemes

Ethical considerations

The study was approved by the Ethical Committee of the Academic Hospital of a University and data collection and analyses were carried out with care and concern while maintaining total privacy and confidentiality for the participants.

RESULTS

Two main themes were derived from our data: the process of how nurses address relationship issues, and the different ways nurses address relationship issues.

The process of addressing relationship issues

The process of addressing relationship issues includes two subthemes: the process of proactively addressing relationship issues and the process of creating and adhering to a team approach towards relationship issues.

The process of pro-actively addressing relationship issues

When it comes to addressing the relationship issues of a couple, palliative care nurses stated in the in-depth interviews that their care is primarily led by the needs of patients/partners and at their pace, which implies that nurses should not initiate a discussion on or address relationship issues themselves. At the same time, they mentioned that patients/partners may be hesitant to broach sensitive subjects such as relationship matters. Nurses themselves hesitated between not burdening the couple and addressing relationship issues within daily care. Moreover, the limited time left for patients when palliative care is introduced, implies that nurses cannot always put a wait-and-see attitude into practice, or wait until they have a closer relationship with the couples before addressing relationship issues. Instead they have to pro-actively respond to possible “cues”, about relationship issues they discover during their contact with patients and partners.

During our observation study, we saw nurses dealing with this dilemma in two ways:

Firstly, they did not use standardized assessment processes to detect relationship issues, but rather developed their own observation and communication skills to “get to know the couple better”, what is referred to as their “sensitive and fine-tuned antennas”. These skills, e.g. active listening and showing genuine interest, are simultaneously also a way of providing support with these relationship issues.

> A nurse sees how the partner is sitting in a chair far away from the patient. As his eyes fall on a wedding picture, he comments that it is a very romantic picture. The nurse and the couple start a conversation about their early days as a couple. The nurse directs the conversation by asking how they are dealing with the current situation as a couple…. During the conversation, the nurse emphasizes that they are doing well but that it must be hard. (Observation notes, ambulant care)

Secondly, we observed how palliative care nurses tried to proactively address relationship issues by integrating them in daily care. When entering a patient’s room or visiting the patient and partner at home, nurses usually started by (talking about) physical care and daily tasks, using these (conversations about) daily tasks and basic care as an opening or starting point to begin a conversation about relationship issues. Nurses reflected in the peer debriefing groups that they do this because of the ‘increasing work load’ and they defined themselves as “task-oriented persons”. They also stated that they have the opportunity during daily care to observe interactions within the couple and intervene when possible or needed, using this daily care as a rich information source. We observed that the pitfall of addressing relationship issues by starting from practical, daily care issues is that these conversations are often short and specific, and often fail to go to a deeper, existential level. In the example below, a nurse explains how she gave relational support while washing the patient.

> A man with a lot of pain had trouble washing himself. Nurse (m, 48y) says that from now on he will wash him so that the patient can spend the energy he saves, on being with his partner more, on enjoying each other’s company. His partner started to cry and said that she finds it so difficult that they have so little time together. The nurse told me afterwards that he reacted this way because he noticed that the partner was very nervous and tense. (Observation note, hospital unit)

The process of creating and adhering to a team approach towards relationship issues. Nurses working in ambulatory care and palliative units emphasized that addressing relationship issues presupposes a team approach. They also mentioned that team meetings are the ideal place to “blow off steam”, as dealing with these relationship issues is often an emotional burden for the nurses.

Throughout our observations, we saw how being reflexive as a team about the relationship issues was helpful to broaden the nurses’ individual perspectives, for example when a colleague reformulated the difficult behaviour of a patient towards his wife as a consequence of the illness instead of a personal trait.

> Nurse 1: Goodness, that patient is a pretty-bad tempered type of guy, shouting at his wife all day. Nurse 2: Yes, he told me how much he had had to give up in such a short time. It must be frustrating for him. (Observation notes, team meeting hospital unit)

It was also noticeable that – in contrast with discussions about medical and physical care problems – nurses do not use professional jargon to describe relationship issues in team meetings, such as “I gave some support in room three”. This makes the descriptions of their interventions less specific, leaving it difficult to have a profound insight into the details of the interventions they undertook.

During our observations, we also noticed differences between the team approach in ambulant care and the hospital unit:

In a hospital unit, nurses make sense of relationship issues by “putting the pieces of the puzzle together”: what each nurse contributes is often a fragment, a particular observation. However, by bringing these particular observations together, each nurse contributes to the broader picture of the relationship. In the peer debriefing groups of the hospital units, nurses confirm this fragmentary way of assessing and addressing relationship issues, and linked it to the short but multiple visits by the different nurses in a day. They call it a “complementary team approach”, not only in gathering the pieces of the puzzle but also in discussing relationship issues with patient and partners profoundly: nurses that are more skilled or have a better personal relationship with the couple can take up this role.

In ambulant care, one nurse often tells the whole story about the relationship, getting feedback from the other nurses. In the peer debriefing group of the ambulant setting, they explained this by the fact that only one nurse is assigned to each patient/couple to provide daily care, and the visits take often 1-2 hours, which means that one nurse often has a more complete insight the relationship. However, they also pointed out that it is a disadvantage that the other nurses only reflect from a distance and have no direct contact with the patient and partner themselves.

Different ways of addressing relationship issues

Regarding the content of how nurses address relationship issues, we found 4 subthemes, each describing a particular way of addressing relationship issues. For each type, we describe the goal, how palliative care nurses provide this particular type of support, what the difficulties are with providing this type of relationship support and how they overcome or fail to overcome these difficulties.

Addressing relationship issues by creating a couple-positive environment

In the in-depth interviews, palliative care nurses mention addressing relationship issues by creating a supportive environment: this means a safe base for patients and their partners in which nurses want to show couples that the patient and partner are treated equally in palliative care, and that maintaining/strengthening the quality of the couple's relationship is one of the goals of palliative care. This type of 'standard' relationship support is a more indirect way of addressing relationship issues and is a kind of "preventive" type of relationship support, as nurses mention delivering this type of support independently of whether the couple had relationship issues or not.

Throughout our observations, we noted differences between the palliative care unit and the ambulant setting. In the hospital unit, nurses started by creating a supportive environment for couples from the admission of the patient, preferably during intake, where they create an atmosphere of intimacy, acceptance and sameness, by emphasizing the couple's privacy in their unit. They also mentioned taking care to knock on the door every time before entering the room.

> "It starts at intake. We really say that this is their room, their territory, that we are not just going to walk in all the time. It's up to them to cal us. We don't disturb them all the time, we believe that is unacceptable." Interview, hospital unit

Some nurses also explicitly mentioned to the couple the advantages of palliative care for the quality of the relationship.

> Nurse says to patient that she will be able to look after them well, that they can ask any questions at all. Then says to wife that she will be able to visit more than in other hospital departments, that they might have a bit more space to be there for each other (Observation notes, hospital unit)

Palliative care nurses in a hospital setting reflected on the increasing safety and hygiene measures, which mean that if nurses want to create a "home-like" environment, they have to rely more on their personal qualities and creativity than environmental qualities. One nurse explains this as "having to rely even more on our fine-tuned antennas".

In the ambulant setting, nurses created an intimate, accepting atmosphere in a more implicit way, by showing a genuine interest in the couple's relationship history. They create the feeling of having time to listen to the couple's story using simple questions (e.g. "How long have you been together? How did you meet?").

Addressing relationship issues by being there and acknowledging feelings

Palliative care nurses tried to comfort patients and partners by "cooling down" negative emotions that relationship issues bring along. They do so by listening actively to patients or partners' stories, by acknowledging their feelings and emotions, and by normalizing these feelings and relationship issues in the context of the illness. They described this support as "just being there", "offering a genuine presence", "sharing difficult moments together". They also regularly emphasized the strengths and resources the couples have, offering credit for their efforts.

> "Yesterday, for example, I showed a partner what her contribution was to caring for the patient and that that was good and important. It was very important for that woman to feel what she had been able to do, even though the man now needs hospitalisation." (Interview, ambulant care)

Throughout our observations, we observed that the level of experience in palliative care seems to play a role in the nurses' perception of this role. Nurses new to the area of palliative care reported that this attitude of just "being there" felt contra-intuitive to them, as they were trained to "solve" things. These novice nurses did not see this as "work", often expressing their powerlessness in these cases.

> Nurse (< 5 y experience): "That man is not in pain or anything, in fact it's just psychological support at the moment, his wife is really suffering with her husband's worrying, so I don't know if I'm really needed there …" Nurse (> 5 y experience): "You can certainly do something meaningful there at the moment." Nurse (< 5 y experience) shrugs. (Observation notes, team meeting ambulant care)

In peer debriefing groups, nurses explained how they were trained – during their general education – to "perform", to offer practical solutions, and how most of them had to get used to the palliative care approach of "being". Nurses also admit sticking to this "being there" attitude, not with the goal of "calming people down", but because they feel too uncertain and insecure to explore the issue more proactively, to move ahead and foster progress, as they don't know where that might end. A consequence of this was that they often have the feeling of "being stuck". In extreme cases, this leads to a feeling of fatalism:

> “There’s not much we can do, listen a bit, the problem will solve itself anyway (with the patient’s death)” (Observation notes, team meeting ambulant care)

Nurses preferred to acknowledge feelings and be there in one-to-one conversations, i.e., either with the patient or with the partner alone. In our observations, it became clear that patients and partners also felt more comfortable talking about relationship issues when they were alone. For example, most conversations with the partners happened in the corridor of the hospital or home setting. Nurses in peer debriefing added that these one-to-one conversations could entail the risk of allying with one of the partners, especially when they offer “one-to-one” support. One way of overcoming these barriers was to take a more systemic attitude, even if it encompasses a one-to-one conversation. In the observations, we saw how nurses embraced such a systemic attitude, by acknowledging the painful emotions of both members of the couple rather than only acknowledging the emotions of one of them.

> Nurse says to crying spouse in the corridor that it must be hard for her when her husband gets so angry with her. He tells her it comes from a feeling of powerlessness, that she should put herself into his shoes, that it is not easy for him… (Observation notes, hospital unit)

This position requires more distance, neutrality and more empathy for both partners. Those nurses holding a relational-centred attitude tend to centre their focus on the patient and partner as a unit of care, instead of protecting the interests of one of them. They tried to see the relationship issue from a more distant (meta)perspective and tried to place themselves in both perspectives.

This difference of attitude became visible during a “patient case discussion”, where a nurse said she was trying to mediate between a patient and partner regarding the patient’s end of life decision (to have euthanasia).

> Other nurse responding to the case: “Well, why waste your time on that, you’re here for the woman, her partner hasn’t caught up yet, don’t get involved in it, the doctor isn’t going to refuse euthanasia just because her husband isn’t ready for it.”
>
> Nurse (who introduced the case): “Come on, they’re a couple, that’s one unit, if you don’t get the partner’s trust then you haven’t got the patient either.” (Observation notes, team meeting ambulant care)

Addressing relationship issues by rectifying imbalances due to illness

During the in-depth interviews, nurses explained how they addressed relationship issues by restoring balances in a couple relationship that typically became disrupted due to the illness. They talked about trying to restore imbalances of “holding on and letting go”, where patient and partner are on a different “wavelength” in terms of their preferences, wishes and expectations regarding the end of life. They also tried to rectify imbalances in “distance and closeness”, where the patient and partner have grown apart due to a long illness, or, inversely, when they have become too involved with each other, thereby risking exhaustion. Lastly, they talked about trying to rectify imbalances in “giving and receiving”, as because of the disabling effects of the illness, the patient only tends to be able to “receive”, while the partner is only able to “give”. Nurses emphasized that in order to restore these imbalances they have to use a different approach to just being there and acknowledging feelings. They described this way of offering support as identifying their observations of the couple’s behaviour. During our observations, we saw that nurses not only identify their observations, but also tried to interpret the behaviour in the context of the illness. This way, it appeared less judgemental.

> I mention the imbalance: for example, I said recently to one partner, I know you need self-care too and that is why you don’t always come to the hospital, but I notice that your partner really appreciates it a lot when you do come (Interview, hospital unit)
>
> Woman is in tears is with the nurse, says she does so much for her husband and he is just angry with her all the time: nurse says he know her husband does see what she does and that he’s grateful, that he has already said so to him (Observation, hospital unit)

Moreover, we observed also that rectifying imbalances encompasses the skills of encouraging, stimulating or tempting a couple to try out different behaviour, thereby fostering their mutual support and trying to mobilize the couple into a new balance. Nurses do so, for example, by stimulating the couple to express preferences, wishes and expectations regarding the end of life to each other. They do this by stimulating the couple to hold/caress/hug each other, by teaching the partner how to touch the patient in a way that is comfortable. The responsibility here lies more with the couple, and nurses state that their task here is to make the partners see and to “offer opportunities”.

> *Observation of conversation between partner and nurse:* “I have the impression he doesn’t realise he’s dying, he never really mentions it, and such a difficult conversation, you hold back a bit to see what he’ll say” C: “Oh, it’s okay to talk about it, you know, you can show your emotions.” Z: “Yes but he’s always been about getting on with things, I don’t think he has any space for grief” C: “But there is space for emotions here, you know, it will be good for him to (gestures non-verbally: to get it off his chest), because otherwise it gets bottled up.” *Observation note, hospital unit*

Nurses in the peer debriefing groups, as well in the in-depth interview, said that the biggest difficulty in assuming this restoring role is their reluctance to intervene in the couple as a system. They reported reluctance out of respect for the “individuality” of the couple or – in the short time that they have to get to know the couple – not knowing whether their observations are typical behaviour that is part of the couple's normal interactions or whether the behaviour is the consequence of the illness.

> **"**I find it difficult, let's say a couple who have been married for 50 years, and they come to us, and they're short with each other and mean and whatever, what can you do, can you try to bring that into balance of do you say, that's just the way they are and respect it. I find that difficult: how is it any of my business?" (Peer debriefing extract)

In order to deal with this difficulty, some nurses stated they pay particularly attention to the "story" of the couple, especially to how the couple was before the illness. Interventions as above need always to be "tailored to" their story and context, which implies that approaches such as stimulating and encouraging can never be seen as "techniques". Nurses formulated this continual balancing of their interventions as "precision work".

> "They do say: encourage the partner to take part in physical care to enhance the connection, but if the partner wants their freedom back, and then they hear that suggestion again here…, we do always try to listen to their story before we make suggestions like that" *Peer debriefing*

Addressing relationship issues by mediating unfinished business between patient and partner

Palliative care nurses mentioned in the in-depth interviews being confronted with having to mediate "unfinished business" between the patient and partner. This happens when there are unresolved issues or conflicts in a relationship and the couple – or one of them – feel the need to express old injuries from the past and work towards reconciliation.

Nurses used expressions such as "not insisting on reconciliation", "being careful" and "a risky business" to describe how they address this particular form of relationship issues. There was a consensus that they all use a hands-off approach towards these issues, with the tendency towards "covering up" instead of "unravelling". As a consequence, where there are conflicts, they mostly address them by "setting boundaries" to ensure the patient's comfort and "calm things down". They mentioned only starting to actively mediate these problems if both partners explicitly formulated their wish to do so.

This hesitant behaviour was also visible in our observational study, where none of the nurses actively mediated in relationship issues. In the interviews, as well as during peer debriefings, the main reason mentioned to adopt this hands-off approach was because of the limited remaining time for the couple. Although nurses in ambulant care settings were often called in much earlier in the course of the illness than in a hospital setting, they also experienced that these unresolved issues often come only to the surface at the very end.

> “We have to try not to make a mountain out of a conflict: ultimately we’re here for the couple’s comfort. If you start stirring up that kind of conflict, all sorts of nastiness comes up. It’s an open wound that you don’t have time to heal in the time that’s left”. (Peer debriefing extract)

Nurses also mentioned various other reasons for this hesitance, sometimes even contradictory ones. Some nurses said they avoided handling these issues because of a lack of skills and know-how to deal with these conflicts. They emphasized the unpredictability of a process towards reconciliation. It can turn out well, but it also be disastrous. These nurses expressed a need to be able to handle these situations better. Other nurses said their long work experience in the field told them to stay away from such unresolved conflicts. The more “experienced” nurses emphasized “the right to die with secrets” and said that “the comfort” of the patient should prevail. They often stated that this work does not belong to the context and aim of palliative care and that the patient and/or partner have to be referred for this to more specialized care. However, some nurses found that no issues are outside the context of palliative care, stating that – even if they were not able to work towards reconciliation, or to deal with the “facts” – they could also fall back on “being there”, talking and exploring the feelings these issues entailed instead of blocking conversations and referring couples to other healthcare providers.

DISCUSSION

This article gives a rich description of and insight into in the process and content of how palliative care nurses address relationship issues in their daily work.

Concerning the process of addressing relationship issues, the results show how palliative care nurses use specific observation and communication skills to simultaneously assess and support relationship issues, rather than relying on standardized processes and procedures. Furthermore, nurses integrate the addressing of relationship issues into their practical daily care, and even use this practical basic care as a tool to address relationship issues. The results show how nurses do this out of necessity, because of the limited remaining time for the couple, restrictions of the setting, “increasing pressure of work” and hesitance of the patient and partner to broach the subject. However they make a virtue of it, so that their support is inscribed in the empowering and holistic principles of palliative care, in line with the nurses’ practical-oriented approach. Moreover, the results also give detailed insight in how a team approach is used to address relationship issues. As for the content of addressing relationship issues, we have described different types of relationship support in detail with their main characteristics, difficulties and dilemmas. We show that the way this support is delivered is determined by a range of conditions and processes that reflect its complexity.

Our findings reveal that the personality and style of the individual nurse play a significant role in how relationship issues are addressed. However, the philosophical principles of palliative care, and especially the context in which palliative care is delivered, might be even more important.

Firstly, concerning the philosophical principles of palliative care, we might note that the different ways of addressing relationship support are all embedded in the general praxis of palliative care (Mount et al., 2006): ‘Creating a couple’s positive environment’ resonates with the praxis of ‘creating a supportive environment to promote quality of life’. ‘Being there and acknowledging feelings’ resonates with the praxis of ‘providing relief from pain and other distressing symptoms’. ‘Rectifying imbalances due to illness’ resonates with the philosophy of ‘living until you die’. ‘Mediating unfinished business between patient and partner’ resonates with the philosophy of ‘having a healthy closure, personal growth’.

Secondly, hospital and home care settings pose different challenges and opportunities to nurses regarding the process and content of how nurses address relationship issues.

A hospital setting implies that nurses are able to meet the couple and to observe their interactions on several occasions during the day. Moreover, the team approach leads to a multi-perspective shared view and a richer way of looking at and addressing relationship issues. Multiple meetings and patient debriefings per day give nurses occasions to blow off steam about relationship issues and work together to address them.

Ambulant care provided in the couple’s personal context gives nurses more opportunities to talk about relationship issues in a more personal atmosphere. It also facilitates the creation of a supportive environment, as the intimate environmental qualities can be maintained by letting the couple stay in their personal space. Lastly, nurses in ambulant care settings are often called in much earlier in the course of the illness than in hospital settings, which means they often struggle less with the limited time left for the couple, although this seems not the case for resolving relationship conflicts.

Another important finding in this paper is that nurses situate the process and content of addressing relationship issues in “the little things”. Firstly, because of the simultaneous assessment and support of relationship issues, as well as their integration into basic care, the interventions are described as “short”, and “specific”. This reference to “little things” is also reflected in nurses’ description of their interventions as “just offering opportunities, and not solving issues”, or “precision work”.

Whether this emphasis on “little things” is an opportunity or a barrier for addressing relationship issues is mainly dependent on the personal conviction or attitude of the nurse. Some nurses hold the belief that the little things are what make a difference for the couple, that the value of their work is in the details and that this is part of an empowering approach. This point of view is in line with other nursing research, that argues that “the little things” are imbued within nursing skills, and that by focusing on the little things, nurses are able to enact dignity in care and are able to offer tailored, personal care

(Macleod, 1994; Williams, Kinnear, & Victor, 2016). Other nurses seem to discount the value of the little things, however. They do not consider this relationship support as “work”, more frequently express “powerlessness” about addressing relationship issues, state that they perceive their role as a nurse as “solving things”, reflecting that they adhere to a more target-driven and goal-centred healthcare discourse (Pearcey, 2010). Moreover, in team meetings, nurses struggle with “the little things” and find it difficult to express them in a detailed and useful way to their colleagues, thereby sticking to general, superficial descriptions as “providing support”. Thus the way nurses address relationship issues often remains invisible, and risks being easily forgotten and overlooked because of its subtlety (Williams et al., 2016)

Another important finding is the hesitance palliative care nurses reported about working towards reconciliation between the patient and partner: Nurses are poignantly moving away from the ideal of ‘heroic dying’, which would include the closure of all interpersonal unfinished business (Kissane, 2004) to the preference of a peaceful end with good symptom control, a “good enough” approach. In general, it seems that nurses choose to avoid or comfort relationship issues rather than unravelling them. This opinion partly corroborates the work of other scholars. Stajduhar (2010) states that in palliative care, patients and partners might have more need for a sense of security than empowerment (Stajduhar, Funk, Jakobsson, & Öhlén, 2010). Langley-Evans and Payne (1997) concluded that the provision of comfort may be as important as more proactive one-to-one counselling (Langley-Evans & Payne, 1997). Milberg (2012) states that the task of palliative care is mainly to offer a secure base and that only when that base is secure enough can patients and partners start to explore their relationship at the end of life (Milberg et al., 2012).

However, in our results, a few nurses also expressed a need to be more proactive in handling situations of relationship conflict. These nurses were expressing another opinion previously voiced in the literature, namely that – while there is no harm in offering compassionate care regarding relationship issues in couples with advanced illness – it is perhaps more effective if nurses are able to explore them more actively, thereby fostering couple resilience (Zaider & Kissane, 2011)

Another important finding is that palliative care nurses tend to use a positive, stimulating approach towards supporting intimate relationships and that they go further than merely reducing distress in the couple, wanting to create more intimacy in a couple relationship. This is what Tie (2013) calls “reclaiming the partnership” and could be related to the philosophical principle in palliative care that focuses on affirming life and emphasizing quality of life. Others have suggested that this creation of a positive atmosphere is appreciated by both the patients, partners and staff (Skilbeck & Payne, 2003). However, it could also be questioned whether this focus on the positive aspects at the end of life is also not used with the aim of diverting attention away from the harder work, i.e., dealing with conflicts in palliative care.

More specifically, the results of this study show how a relational-centred attitude in nurses somehow requires a different attitude to a patient-centred attitude. Although the core of psychosocial care – trust, kindness, warmth, compassion and genuineness – might be still the same (Fan et al., 2017; Mok & Chiu, 2004), a relational-centred attitude requires more distance and neutrality. Zaider & Kissane (2011) confirm this by stating that supporting couples' relationships requires more of a meta-position from the healthcare provider. Working from this relationship-centred attitude might protect nurses from becoming over-involved with their patients. Our results also show how this relation-centred attitude infiltrates the whole process of addressing relationship issues, for example also in the way that questions are asked: questions such as "how did you meet each other" depicts the nurses' belief that illness is a couple affair. Moreover, the results show how a relation-centred attitude can avoid coalitions with one of the partners, which in turn prevents nurses from getting stuck between the partners.

Methodological considerations

The current study is unique due to its focus on the couple instead of other family relationships, such as parent-child, which is often the main focus in palliative care literature (Kissane, 2000). This is of added value as patients and partners might have different issues, and within the family, the partner usually has the largest impact on the well-being of the patient (Mohr et al., 2003).

Another strength of this study lies in the triangulation of in-depth interviews, observation study and peer debriefing respectively. Data triangulation is the ideal way to enhance credibility (Patton, 1990) because each method reveals different aspects of empirical reality and multiple methods of data collection provide "more grist for the research mill" (p. 1992). Indeed, we learned during the in-depth interviews that the nurses saw their actions and skills for supporting relationships as taken for granted, and thus difficult to explain. The observational research facilitated understanding of what they actually did and how their actions changed in response to situations. The peer debriefing was an opportunity to test and challenge our interpretation of our observations and findings, offering additional insights into the why and how of nurses' behaviour. Throughout our results, as well as in Table 2, the merit of the three different approaches is made clear.

One methodological consideration is the limited transferability of the study, as we did not include the whole field of palliative care in Flanders. We did not perform an observation of the palliative support teams in hospitals and palliative day care centres, due to financial and time restrictions.

Implications for research and practice

This study adds empirical and theoretical evidence that supports the importance of a "relationally-located conceptualisation" of dying in palliative care (Broom, Kirby, Good, Wootton, & Adams, 2012; Nebel, 2011) The World Health Organisation (WHO, 2002) recommends explicitly that close relatives of the patients should be included in the unit of care, and this study shows in detail how this philosophical principle is translated into practice by nurses. The current study might inform nursing praxis because it clarifies what exactly providing relationship support might entail in nurses' daily care practice. This is because there is often a lack of clarity about the terminology used to describe all concepts relating to "psychosocial support", e.g., emotional care, psychological support, and thus also relationship support, with an assumption that there is a shared understanding of these terms (Skilbeck & Payne, 2003). This study shows that this is not the case, by "dissecting" what relationship support can entail. The details of the study can give direction to what is important for the education of palliative care nurses in addressing relationship issues, which skills or attitudes they can cultivate, and what caveats they can expect. Moreover, by explaining the process of providing relationship support in detail and by making the little things visible (King & Quill, 2006), our results can help nurses overcome their tendency to refer to this as non-work, by becoming more conscious of their taken-for granted interventions, by being able to name these interventions, i.e. by cultivating a professional jargon which integrates concepts such as those described in our results (Williams et al., 2016).

Furthermore, we postulate that the processes described above for addressing relationship issues have inherent therapeutic qualities, making the nurses' way of addressing relationship issues look like 'brief therapeutic conversations' (Wright & Bell, 2009). This finding is a call to reconsider the educational programs for (palliative care) nurses, and – following a transdisciplinary paradigm – adapt several therapeutic skills to the palliative care nursing context. Further research might translate existing therapeutic frameworks (such as for example Emotionally Focused Couple therapy, Tie & Poulsen, 2013) to the skills of nurses, as well as the working context of the nurses. This could further be elaborated in an intervention study specifically applied to the praxis of palliative care nurses.

To conclude, the results of this study are a plea for a general prioritization of "relationship-centred care reflected in all aspects of the palliative care organization, i.e., from its philosophical fundaments to the specific description of what nurses do and how they do it.

Funding : This study has been financially supported by a grant from the Flemish Research Foundation

Declaration of Conflicting Interests :The Authors declare that there is no conflict of interest.

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PART V

GENERAL DISCUSSION

CHAPTER 8

GENERAL DISCUSSION

8.1. Introduction

8.2. Summary of the main findings

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CHAPTER 8 GENERAL DISCUSSION AND CONCLUSIONS

8.1. Introduction

The broad aim guiding this dissertation was to explore the expression and experience of intimacy and sexuality between patients and partners in the context of terminal cancer, as well as to explore how palliative healthcare providers address intimacy and sexuality-related issues in their work. First, this dissertation contains a qualitative evidence synthesis on the sexual adjustment process of cancer patients and their partners, as well as a detailed description of the use of purposeful sampling in a qualitative evidence synthesis, as this is an underdeveloped and new technique in meta-synthesis. Second, this dissertation explored the meaning of sexuality and its expression in terminal cancer, as well how intimate interactions during terminal cancer occurred, by means of a multi-perspective interpretative phenomenological analysis (IPA) study with patients with terminal cancer, their partners, and bereaved partners. Lastly, this dissertation explored how palliative care nurses addressed sexual and relationship issues in their daily practice, through a generic multi-method qualitative study.

In this discussion section, we will first briefly summarize the main findings of the dissertation (paragraph 8.2.). Second, we will address the strengths and challenges of the different methods used in this work (paragraph 8.3). Third, we will describe personal reflections about the different roles that the researcher adhered to, as well as about her professional background as a sexologist that affected the entire approach to this dissertation (paragraph 8.4.). Next, we will discuss the findings in the context of current research and palliative care practice (paragraph 8.5.). Finally, we will outline a number of recommendations and implications for both clinical practice and future research (paragraph 8.6.)

8.2. Summary of the main findings

In this paragraph, the results of the previous chapters are summarized in three separate sections, following the three aims of this dissertation.

The **first aim** of the dissertation is to synthesize evidence in a systematic way from primary qualitative research studies on sexual interactions during cancer, in order to arrive at a theoretical model of how patients and partners adjust towards the sexual changes during a cancer trajectory

Chapter 2: The Sexual Adjustment Process of Cancer Patients and their Partners: a Qualitative Evidence Synthesis

In chapter 2, we performed a qualitative evidence synthesis of a purposeful sample of 16 qualitative studies, using a meta-ethnographic approach in order to arrive at a theoretical model of the process of sexual adjustment during cancer. We found that the subsequent studies used different theoretical approaches to describe the sexual adaptation process. This led to three divergent sexual adaptation processes. First, the pathway of grief and mourning, depicting sexual changes in terms of loss, and where different stages of adjustment to these sexual losses are in line with stages known from grief work theory, such as denial, anger, and acceptance. Second, the pathway of restructuring, depicting the adjustment process toward sexual changes as a cognitive process with a strong focus on social and cultural forces shaping the values and experiences of sexuality. These forces create certain dominant discourses about sexuality, that couples either adhere to or challenge. Unlike grief theory, where the patient and partner work through different emotional stages, the patient and partner in this pathway sexually adjust to the consequence of cancer in a more cognitive way, by developing a new sexual paradigm. Third, there is the pathway of sexual rehabilitation, depicting sexual changes as a bodily dysfunction that needs treatment and specific behavioural strategies. This pathway is embedded in a more positivistic approach, where the adaptation process is depicted as a rather linear progression from having a sexual dysfunction towards the recovery of that sexual function. All three pathways each have their own opportunities and challenges. This also implies that, instead of polarizing three different pathways of sexual adjustment, all three could be integrated to arrive at a complete and holistic approach to sexual adjustment during cancer.

Chapter 3: The use of purposeful sampling in a qualitative evidence synthesis: A worked example on sexual adjustment to a cancer trajectory.

In Chapter 3, we gave a worked example of the use of purposeful sampling in our qualitative evidence synthesis, to meet the need for transparency on how to effectively use and report on purposeful sampling techniques. We described in detail how purposeful sampling procedures have been integrated into our review procedure. We found that translating the technique or concept of purposeful sampling to the meta-level could not readily be done by building on the logic applied in basic research projects. This purposeful sampling has led to the development of a conceptual model by combining three purposeful sampling techniques. This way of sampling has the advantage over exhaustive sampling of being more sensitive to ‘deviant data’, which enriches the conceptual model, and moreover purposeful sampling leads to results that are more conceptually aligned with the synthesis’ purpose. In this chapter, we also described the different challenges we encountered in the instrumental outline of the procedure, i.e. that it demands a considerable amount of flexibility and that it is labour-intensive, which goes against the argument of many authors that using purposeful sampling provides a pragmatic solution or short cut for researchers, compared to exhaustive sampling.

The **second aim** is to explore how patients with terminal cancer and their partners experience sexuality and intimacy.

Chapter 4: The meaning and expression of sexuality in terminal cancer: The experiences of patients, partners, and bereaved partners

In chapter 4, we performed an Interpretative Phenomenological Analysis (IPA) with a multi-perspective design of patients, partners, and bereaved partners, to explore how patients with terminal cancer and their partners experience sexuality. In total, we conducted 23 in-depth interviews with 18 participants (6 patients, 7 partners, 5 bereaved partners).

The analysis resulted in a rich description of patients' and partners' interrelated experiences of losses of sexual expression, imminent death, the unreliable and deteriorating body of the patient and the changing sexual roles that they have to adapt to, and how they negotiated these experiences with each other. This negotiation process did not only unfold by negotiating *about* sexual expression, but they also negotiated *through* sexual expression. The analysis also showed that this negotiating process did not stop when the patient died, but continued during the bereavement period in the form of internalized conversation.

The first theme in this chapter covers the meaning-making that surrounds the loss of sexual expression. All participants experienced loss in their sexual relationship over the course of terminal cancer, even continuing after the patient died, in the period of bereavement. This theme describes how participants experienced this loss of sexual expression and how they made meaning out of this loss and negotiated this with each other. The second theme covers meaning-making through sexual expression relating to imminent death. In the accounts of the participants, sexual expression was one of the non-verbal and indirect ways of communicating their feelings about approaching the end of life with each other. These feelings regarding imminent death varied during the course of the illness, and so did the way of expressing their sexuality. Especially during the last moments of life, patients and partners reported communicating *through* sexual expression, and also after the patient's death, the bereaved partner's grief continued to interfere with their search to find new ways of expressing their sexuality. The third theme covers the negotiating of sexual expression with an unreliable and deteriorating body. This theme describes how participants experienced the impact of the progressive deterioration of the body and the seriousness of the physical implications of terminal cancer on their sexual expression, as well as how they negotiated sexual expression in such a context. The stories of the participants revealed that the level of attunement of their bodies influenced the way and ease with which the couple was able to adapt their expression of sexuality to the possibilities of the deteriorating body. The fourth theme covers the reconstruction of sexual roles during terminal cancer. Participants described how the changes in their sexual expression led to an identity crisis related to their sexual roles, and how they tried – together with their partner – to reconstruct their sexual roles.

Chapter 5: Intimacy during terminal illness: Dynamic meaning-making of lived and anticipated relationship losses

In Chapter 5, we performed an Interpretative Phenomenological Analysis (IPA) with a multi-perspective design, to gain more insight into the experience of intimacy in patients and partners who are dealing with terminal cancer, and into how experiences of intimacy may affect the bereavement experience of the surviving partner. We conducted 23 in-depth interviews with 18 participants (6 patients, 7 partners, 5 bereaved partners).

This chapter offers detailed insight into how the transition to a terminal phase included a redefining of the couple's relationship, in which the dying person and the partner experienced lived and anticipated relationship losses. These are interrelated in a complex way, although the anticipated losses often prevailed over the lived relationship losses. The results show how the intimate interactions between patients with terminal cancer and partners are focused around their co-creation of meaning-making about these relationship losses. Patients and partners experienced relationship losses, and made meaning from them either by emphasizing what they have lost or are about to lose, (= letting go) and/or emphasizing what they have or want to have (=holding on). As participants are constantly switching between these two ways of meaning-making - described in the results as a continuous push and pull - they experienced moments where they attached different meaning to the relationship losses than their partner: these moments were described as non-intimate. They also experienced moments where they shared the meaning of their losses: these moments were described as intimate. Thus it seems that in the terminal phase of cancer, patients and partners try to make meaning of their relationship losses together, and that this meaning-making process implies a continuous negotiation of this letting go/holding on dialectic. The results also show how the experiences of relationship losses and meaning-making continued to exist after the patients' death. We also found that bereaved partners continued to make meaning from their memories of the last intimate interactions. They made an evaluation of these interactions: If they had experienced and been able to express both letting go and holding on during the last stages of the illness, they tended to have more positive feelings such as closure and completeness. When this was not the case, bereaved partners felt regret about “unfinished business”. Furthermore, bereaved partners continued to negotiate this “holding on/letting go” dynamic after the death of the patient, often through internalized conversation with the deceased partner.

The **third aim** of this dissertation is to explore how palliative care nurses address sexual and relationship issues between patients and their partners in their daily practice.

Chapter 6: Addressing sexual issues in palliative care: A qualitative study of nurses’ attitudes, roles and experiences

In Chapter 6, we performed a generic qualitative interview study to explore palliative care nurses’ attitudes, roles and specific experience regarding addressing sexual issues in their daily practice. In total, 21 nurses were interviewed: two from palliative support teams in hospitals, six from residential palliative care units, 11 from palliative home care teams, and two from palliative day care facilities.

This study demonstrates how the underlying discourse from palliative care might interact with the nurses’ personal attitudes and behaviour. More specifically, it shows how addressing sexual issues falls within the remit of the basic principles of holistic palliative care, but also reveals that nurses experience difficulties and tensions when applying these principles to addressing patients’ and partners’ sexuality related issues in their daily practice. A first philosophical principle underlying palliative care is that the focus of nurses’ care is to promote the ‘quality of life’ (QOL) of patients. When put into practice, this focus on quality of ‘life’, however, does not imply that nurses need to ignore the fact that the patient is dying. The search of a balance between living and dying creates tensions about how to address sexual issues, in two ways: the tension to see sexuality as a part of QOL or as a way of denying imminent death, and the tension between ‘unravelling’ or ‘containing’ sexual issues. A second philosophical principle underlying palliative care is that the content of the nurses’ care is ‘holistic’, i.e. that it comprises somatic, psychological, social/cultural and spiritual aspects. As sexuality is a multi-dimensional phenomenon, it is related to all these aspects. However, nurses’ accounts revealed that the palliative phase is mainly associated with bodily deterioration and physical suffering, which creates tension surrounding the question of whether sexual issues are ‘a priority’ to address or not. A third philosophical principle of palliative care emphasizes the empowerment of the patient/partner in the nurse-patient relationship. This means that patients/partners are seen as (co-)decision-makers, and that – instead of organizing care based on fixed procedures – nurses' care is primarily led by the needs of patients/partners and at their pace. However, nurses also know that patients/partners may be hesitant to broach sensitive subjects such as sexual issues. This leaves them with a tension to choose between proactively initiating an exploratory conversation about sexual issues or waiting for patients/partners to initiate a conversation about the topic themselves.

Besides the philosophical principles of palliative care, several other important factors that may influence the nurses' way of dealing with these tensions emerged from our study: the type of sexual issue, the organizational structure/context of the care and the possible skills available to address the specific issue. Nurses seem less prone to translate palliative care principles into practice when it concerns more erotically explicit issues of sexuality than when the issues lean towards physical intimacy. Nurses were also less prone to address sexuality according to the principles of palliative care when they perceive a lack of time and space to give appropriate care. Moreover, they tend to handle tensions more easily when the way of addressing sexual issues is close to their daily tasks, and corresponds with their skills as a palliative care nurse, e.g. letting the partner help with comfort care, or using communication skills such as empathic listening.

The results in chapter 6 show that palliative care nurses – when they are able to overcome the above described tensions – use a sex-positive approach. This approach is put into practice by encouraging the couple to be 'sexually' intimate, by creating a sex-positive environment and by being open to actively exploring sexual issues. It is clear that the philosophy of palliative care – with its focus on quality of life, on being holistic and emphasizing the empowerment of the patient and partner in the nurse-patient relationship – aligns with this sex-positive approach.

Chapter 7: "It's in the little things": How nurses offer relationship support to couples in palliative care

In Chapter 7, we explored how palliative care nurses address relationship issues between patients and their partners in their daily practice, using a generic qualitative study with data triangulation, consisting of an in-depth interview study (with 21 nurses from different palliative care facilities) an observational study in a hospital unit and an ambulant care team, and followed by 3 peer debriefing groups.

The results show how palliative care nurses use specific observation and communication skills to simultaneously assess and support relationship issues, rather than relying on standardized processes and procedures. Also, nurses integrate the addressing of relationship issues into their daily care practice, and even use this practical basic care as a tool to address relationship issues. The results show how nurses do this out of necessity – because of the limited remaining time for the couple, restrictions of the setting, hesitance of the patient and partner to broach the subject – but make a virtue out of it, so that their support is inscribed in the empowering and holistic principles of palliative care, and in line with nurses' practice-oriented approach. Moreover, the results also give detailed insight into how a team approach is used in addressing relationship issues.

Furthermore, the results described in detail four different ways of addressing relationship issues: (1) Addressing relationship issues by creating a couple-positive environment: this means creating a safe base for patients and their partners, by which nurses want to show to couples that the patient and partner are treated equally in palliative care, and that maintaining or even strengthening the quality of the couples' relationship is one of the goals of palliative care. (2) Addressing relationship issues by being there and acknowledging feelings: this means trying to comfort patients and partners by "cooling down" negative emotions that relationship issues bring along. Palliative care nurses do so by listening actively to patients or partners' stories, by acknowledging their feelings and emotions, and by normalizing these feelings and relationship issues in the context of the illness. (3) Addressing relationship issues by restoring misbalances in a couple's relationship due to illness: this means nurses try to restore imbalances of "holding on and letting go" in relationships where the patient and partner are on a different 'wavelength' in relation to their preferences, wishes and expectations regarding the end of life. Nurses also try to restore imbalances in 'distance and closeness', when the patient and partner have grown apart due to the longstanding illness, or, inversely, when they have become too tangled up with each other, thereby risking exhaustion. Lastly, nurses try to restore imbalances in 'giving and receiving': due to the disabling effects of the illness, the patient tends to be only able to 'receive', while the partner is only able to 'give'. In order to restore these imbalances, nurses denominate their observations of the behaviour of couples, trying to interpret the behaviour of couples in the context of the illness, and stimulate the couple to try different behaviour, thereby fostering their mutual support and trying to guide and mobilize the couple into a new balance. (4) Addressing relationship issues by mediating unfinished business between patient and partner: this means that nurses address unresolved issues or conflicts in a relationship in situations where the couple needs to express injuries of the past and work towards reconciliation. Nurses all report using a hands-off approach towards these issues, with the tendency to 'covering up' instead of 'unravelling', only starting to actively mediate these problems if both partners explicitly formulate their wish to do so. The main reasons to take this hands-off approach is because of the limited remaining time for the couple, because of a lack of skills and know-how, or because nurses let the comfort of the patient and partner prevail. The findings revealed that the personality and the individual style of the individual nurse play a significant role in the way relationship issues are addressed, but that the philosophical principles of palliative care, and especially the context in which palliative care is delivered, might influence the process and content of how nurses address relationship issues even more.

8.3. Methodological considerations, strengths and limitations

We conducted three different qualitative methods covering five types of data collections to answer our research questions. First, we conducted a qualitative evidence synthesis of a purposeful sample of papers, using principles of meta-ethnography. Second, we conducted an Interpretative Phenomenological Analysis (IPA study) with a multi-perspective design, in which we conducted in-depth interviews with terminally ill patients, their partners, and bereaved partners. Third, within a generic qualitative study, we conducted in-depth interviews with palliative care nurses, an observation study of palliative care nurses in a hospital and ambulant care setting, and peer debriefing groups with palliative care teams from both units. Each method used has its strengths and limitations. We will describe these strengths and limitations below. An important note is that, although we describe the rigour of each particular chapter and methodology, the approach we use is different for every method, as we understand that rigour is a theoretical issue and not a technical one, and that we therefore must select an approach to evaluating the rigour and quality of our methods that is methodologically congruent with our form of inquiry (Caelli, Ray, & Mill, 2003; M Sandelowski, 1993).

8.3.1. Qualitative evidence synthesis

The strength of using a meta-ethnographic approach to perform a qualitative evidence synthesis lies in the fact that a meta-ethnography enables a systematic and detailed understanding of how studies are related, through the comparison of findings within and across studies, ultimately providing an interpretation of the whole body of research (Noblit & Hare, 1988). A meta-ethnographic approach is also the ideal way of building theory, which has the capacity to generate hypotheses for future testing or comparison with trial outcomes (Petticrew et al., 2013). As our aim was to arrive at a theoretical model of the process of sexual adjustment during cancer, we might conclude that the aim and method of this study do correspond well.

However, the main strength of the methodology being used for this qualitative evidence synthesis lies in its innovativeness and transparency. First, our approach is innovative because of the implementation of the purposeful sampling techniques. In most meta-ethnographic synthesis projects, a strictly exhaustive search and information retrieval strategy is used to collect data. However, this exhaustive sampling has been questioned by a substantial proportion of members of the qualitative research community, as it is a highly rigorous and formalistic approach that risks becoming too time consuming because the searches often retrieve very large data sets that are impractical to screen (Shemilt et al., 2014; Suri, 2011). Moreover, exhaustive sampling risks producing rather superficial synthesis findings, with a large number of studies that fail to go beyond the level of description (Patton, 2001). Although several qualitative researchers have recommended purposeful sampling in the context of qualitative evidence synthesis, the published literature holds very sparse examples of those that have actually applied these techniques (Suri, 2011). Second, the use of purposeful sampling techniques made the results more conceptually aligned with the qualitative evidence synthesis purpose, which was to create theory. The emphasis was on conceptual robustness instead of generalization of the data: we were more sensitive to “deviant data”, i.e. data that may not have been picked up when synthesizing information from an exhaustive sample of the literature, because review authors are generally more focused on detecting commonalities between articles. Moreover, the combination of three purposeful sampling techniques – instead of a random sample or just one technique of purposeful sampling – could enhance the quality and diversity of the papers being included, and could make the results more conceptually aligned with the synthesis purpose. Third, by offering a worked example of our purposeful sampling techniques and the iterative analysis, it offers an opportunity for the general lack of transparency on how to effectively use and report on purposeful sampling techniques.

In the process of conducting a qualitative evidence synthesis through purposeful sampling, we also encountered several challenges. First, the sampling procedure was rather complex as we had to perform a scoping review before the actual mixed purposeful sampling could start. It also demanded a considerable amount of flexibility, and was labour-intensive, which goes against the argument of many authors that using purposeful sampling techniques provides a pragmatic solution or a short cut for researchers, compared with exhaustive sampling. Second, by opting for conceptual robustness rather than completeness of the data, it was an analytical choice to focus on the link between the theoretical approaches of the studies and the interpretation of the sexual adaptation process, thereby purposefully sampling for these concepts, and letting go of potentially other interesting angles of investigation, for example, analysing the articles from a feminist perspective, which can focus on the gendered aspects of the sexual adjustment process.

8.3.2. An Interpretative Phenomenological Analysis (IPA Study)

The strengths of this IPA study lies in the grounding of the data in examples and the accurate description of participants’ experiences. We ensured that the typical and atypical elements of the data were depicted in the descriptions, thereby providing a plurality of reactions to the subject of research. The credibility of the IPA study also lies in the member checking with five participants (two patients and three partners) with whom we performed a “cooperative exploration”. This means that the researcher and participants sought new insights together, based on the reflection of both the interviewer and participant. This method of member checking is aligned with the principles of interpretative phenomenological research (Bradbury-Jones, Irvine, & Sambrook, 2010).

Another strength of this methodology is the multi-perspective approach: combining perspectives can give us a fuller understanding of the phenomenon. Patients can inform us about the perspective of the sick person, healthy partners about the perspective of a healthy partner in a relationship with the sick person, and bereaved partners about their experiences in the relationship with the sick person until the very last moments of life, but also about how sexuality plays a role in their experiences of grieving after the patient's death. All these perspectives proved valuable and contributed to coming to an understanding of the impact of terminal cancer on the experience of sexuality and intimacy. A final strength of this IPA study lies in the detailed description of the methods, for example by adding worked examples of the analysis, which makes it easier to read. By providing detailed background information about the informants, we allowed readers to assess the transferability of the findings.

A challenge of this IPA study might be that we did not adhere strictly to the idiographic approach that an IPA methodology prescribes (Smith & Osborn, 2015). Indeed, a distinctive feature of IPA is its commitment to a detailed interpretative account of the individual cases included. IPA studies are therefore mostly conducted on small sample sizes, even sometimes case studies. Because it uses a rather large sample of 18 participants as well as including three different perspectives, our study tends to make more generalizations than an average IPA study would do. However, on the other hand, IPA is flexible in its guidelines and recently other IPA researchers have begun using more complex designs to explore an experience from more than one perspective (Borg Xuereb, Shaw, & Lane, 2016; Loaring, Larkin, Shaw, & Flowers, 2015). Furthermore, Chapters 4 and 5, clearly describe how we also analysed our findings in the spirit of the idiographic mode of inquiry by immersing each individual transcript and making a detailed line-by-line analysis of each individual interview, before doing cross-case analysis. Another challenge of this study was the convenience sampling, in contrast with the IPA guidelines that recommend using purposeful sampling to find a closely defined group (Smith & Osborn, 2015). This was due to the challenging task of finding participants willing to talk about such a sensitive topic, or healthcare professionals who were willing to mention the study to patients and partners. A consequence of this convenience sample is that it was not possible to examine the role of several possible influencing factors in depth: for example, some important cancer types were not included in the sample, and neither was there any inclusion of other cultural groups than those of Belgian origin. As a consequence, the sample cannot be viewed as representative of all patients and (bereaved) partners dealing with terminal illness, so one needs to be careful about generalising or transferring the findings. However, the founders of IPA encourage thinking in terms of theoretical rather than empirical generalizability (Smith & Osborn, 2015). In this case of theoretical generalizability, it is the reader who makes links between the findings of an IPA study, their own personal and professional experience, and the claims in the extant literature.

8.3.3. A generic qualitative study

A generic qualitative study means a study that exhibits some or all of the characteristics of qualitative endeavour, but rather than focusing the study by using the lens of a known methodology, it combines several methodologies or approaches, or it claims no particular methodological viewpoint at all (Caelli et al., 2003). The trend towards generic qualitative research, or research that does not claim explicit methodological or theoretical frameworks, is currently evolving but also highly contested, and gives rise to the question "What needs to be there for generic research to be as credible as qualitative research?"

First, we argue that the generic approach is congruent with the more pragmatic and contextual aims of both Chapter 6 and 7, with its emphasis on informing nursing praxis. Indeed, Thorne et al. (1997) points out that generic qualitative research is a qualitative approach that draws on experience from clinical practice, and can easily be translated into the practice setting (Thorne, Kirkham, & MacDonald, 1997). It is inscribed in the vision of nursing as an applied or practical science, without the limitations that tie many other sciences to theoretical or methodological orthodoxy (Caelli et al., 2003).

Second, our qualitative generic study is credible because of the transparency of the methodological steps being undertaken, the data analysis done in collaboration with the co-researchers (Guba & Lincoln, 1981; Sandelowski, 1986), and especially because of our extensive form of data triangulation. Data triangulation is said to be the ideal way to enhance credibility (Patton, 1999), because each particular method of data collection reveals different aspects of empirical reality, so multiple methods of data collection provide "more grist for the research mill" (p. 1992). Indeed, this is applicable to Chapter 7, where we learned during the in-depth interviews that the nurses took their actions and skills for supporting relationships for granted, and so found them difficult to explain. An observation study as a form of data triangulation turned out to be a very good additional way of data collection when one wants to uncover this taken-for-granted work of health professionals (Walshe, Ewing, & Griffiths, 2012). So the observational research facilitated understanding of what the palliative care nurses actually did and how their actions can alter in response to situations. Observation research is rarely used in palliative care research as a data collection method, even where the questions posed might indicate its suitability (Walshe et al., 2012). This is probably because of the combination of a challenging context and a time-consuming practice. The fact that this study integrated this observation method thus also makes it an innovative study. The peer debriefing – the third technique used in this generic qualitative study - was an opportunity to test and challenge our interpretation of our observations and findings, offering additional insights into the why and how of nurses' behaviour. The analytical table with the worked example in Chapter 6 and 7 enhances the transparency of how we combined the three ways of data collection.

There are also several challenges to our methodological approach. The first challenge encompasses the different samples of palliative care nurses in the interview study and the observation study. Although there is some overlap between the sample of the interviewed nurses (n= 21), and those observed (n= 27), most nurses who were interviewed did not participate in the observation study. This is because the idea of performing an additional observation study only came up after the interview study had been analysed. This limits our possibility to compare the differences and similarities of individual nurses' attitudes and behaviour. However, because of the considerable sample size (n= 21) of the interview study, and the similar context nurses are working in, we believe that the results of the interview study are transferable to the context where the observation study took place.

Second, the sample of nurses did not include general home care nurses. This was because we limited our research sample to specialist palliative care services that are developed in Flanders, Belgium, which are the palliative support teams and residential palliative units, the palliative ambulant care teams and the palliative day care centre. However, these general home care nurses, through their daily care and support to terminally ill patients and partners, might also be confronted with the same relationship issues and might also address these in a particular way.

Our study also focuses exclusively on palliative care nurses working within the palliative care services as organized in Flanders, Belgium. However, the narratives of the palliative care nurses might transcend their immediate context and be transferable in other (West) European states with a health care system that has developed along the same lines.

Another challenge of the sample is the convenience sample of nurses for the in-depth interviews. We partly recruited nurses based on their motivation to be interviewed for this study. This possibly leads to some bias, because it might be that these voluntarily participating nurses have an explicit willingness to talk about sexuality. This is especially the case for Chapter 6, as there is no triangulation in this chapter with observation methods which might compensate for this selection bias.

8.4. Personal reflections

In this part of the discussion, I reflect upon the different roles I adhered to as a researcher depending on the method I used, and in accordance to the sensitivity of the subject and the vulnerability of the population. More specifically, I will reflect about my role as a researcher performing in-depth interviews with patients and (bereaved) partners, as well as reflecting on my role as a researcher performing observational and peer review research in palliative care. Lastly, I will reflect on how my professional background as a sexologist affected the entire approach in this dissertation.

Reflections about my role as a researcher performing in-depth interviews with patients and (bereaved) partners

The way I took up my role as a researcher interviewing terminally ill patients and (bereaved) partners was influenced greatly by my previous experiences of performing in-depth interviews with a vulnerable population. As a novice researcher 6 years ago, I was confronted with burnout after doing research on the experience of cancer patients living alone. Trying to grasp the events that led up to this emotionally disturbing period, I wrote an auto-ethnography about the vulnerability of a novice researcher doing research on emotionally challenging subjects (Benoot & Bilsen, 2016). My point in this paper was that the supposed ‘affective neutrality’, the role that academic discourse prescribes for researchers to adhere to over the whole course of the research project, as well as in relationship with the participants, added up to the suppression of emotions of novice researchers, which contributes to their vulnerability. However, I ended that paper with the following quotation:

> “It is not the avoidance of emotions that necessarily provides for high quality research. Rather, it is an awareness and intelligent use of our emotions that benefits the research process” (Gilbert, 2001; p. 11).

As I meanwhile engaged in a new project, researching intimate relationships in terminally ill persons and their partners, I searched for ways to integrate emotions into the process of my research, yet I could find very few practical examples in the literature on how to deal with emotions in the research relationship in an appropriate and useful way. I found more insights into this matter when I started following a 4-year course to become a licensed psychotherapist alongside my research. I discovered there how the attitude and professional skills of a therapist – emphasizing the correct use of emotions in relationship with clients – can be applied to the research encounter as well, and how using these skills made me come to a much deeper understanding and more accurate representation of the experiences of participants, as well as ensuring the participants’ (the person being interviewed and the researcher’s) integrity and wellbeing. I tried to encapsulate these skills in the term ‘reflexive embodied empathy’, a practice in a research process that involves engaging, reflexively, with the embodied intersubjective relationship between a researcher and a participant (Finlay, 2005). This kind of empathy goes further than simply being a ‘technique’ such as repeating participants’ words and representing what has been said, as most handbooks about qualitative interviewing tend to suggest (e.g. King & Horrocks, 2010). Empathizing requires practice and skill (Finlay, 2005).

‘Embodied empathic reflexivity’ is a relational process, as the researcher needs to be open to being with the participant in a relationship (Finlay, 2005). It is also an embodied process, in which the researcher needs awareness of how the bodily relationship between participant and researcher is mutually constitutive. In order to establish this, I tried to be empathic to my participants' embodied experiences by using imaginative projection and bodily mirroring (Finlay, 2006). Here is an example of how I put this into practice during an interview with a female partner of a terminally ill patient. The woman was talking about her ill partner who was not very willing to talk about his imminent death. I noticed that she was telling this while pushing both her hands forward. I started mirroring this gesture, and for me it felt, while doing this, that I was hitting a wall, and I could feel a kind of loneliness and separation. I decided to share my experiences with the participant: "When you do like this (arm movement), for me, it feels like hitting a wall". She immediately confirmed this and started to talk about her isolation. This example shows that reflexive empathy is something that is done intentionally. As you are consciously stepping in to the experience, you are also able to consciously step out of it, thereby leaving the experience to the participant, in this case the partner.

This capacity to be empathic can be enhanced through reflexive awareness (Linda Finlay, 2006). Reflexive awareness is about recognizing the subjective individuality of the researcher and being thoughtfully and critically aware of how the researcher's emotions impact the research process. This is an example of how I was reflexively aware of my emotions: I interviewed a terminally ill man about his experiences of dying, and while I tried to grasp how he was making sense of his imminent death, he kept on talking on how he had painted his walls the previous Saturday. I recognized a feeling of resistance at that moment. Instead of reacting to my resistance by labelling his answers as superficial and not usable, I started exploring these feelings of resistance. What did it mean that I judged this as superficial, worthless data? I started to see that this resistance came from my own desire to unfold and unravel things, me becoming a researcher for this reason. By going deeper into exploring these values of mine, I began to see the man's behaviour not as superficial – that was myself speaking - but as a real coping mechanism, and later I coded these parts as "holding on to life". Here I see myself not as a researcher with a neutral presence but as a person with her own history, preferences, etc… I try to understand better what I am feeling, thereby exploring my unconsciousness and how the dynamic between me and the participant had created such emotional reactions. It became clear to me that being thoughtfully and critically self-aware of how my emotions affected my way of looking at the data, and even influenced my coding and analysing process. However, it is also important that in the case of reflexive awareness, the focus stays on the participants, and not on the researcher, preventing "indefinite navel-gazing"(Latour, 1988; p. 155).

When investigating sensitive aspects of people's lives, the boundaries between doing an interview and a therapeutic session can become blurred. So given the challenges of working in such depth, I had to be mindful of the ethical dimensions and duty of care at that time to ensure the participants' safety and wellbeing. I discovered that rather than relying on professional ethical codes to guide us through the process, I needed to grapple reflexively with ethical uncertainties and power issues that arise at particular, often unexpected moments during the encounters (Finlay, 2009). It is through such introspective, reflexive self-awareness that qualitative researchers can develop more open and attentive interviewing practices in which the interview is framed as 'communion' rather than 'conquest' (Ezzy, 2010).

Reflections about my role as a researcher performing observational and peer review research in palliative care

Being a researcher interviewing – and particularly observing - palliative care nurses demanded a different role than being a researcher interviewing patients and (bereaved) partners. My own professional background – as a sexologist –significantly influenced how my role was perceived in the field, as I was considered 'an outsider' with no experience regarding the nursing profession. Also, as the observation period 'only' lasted 3 months, this was experienced as too short to acquire a 'deep familiarity' with the field, which means getting emotionally, physically and socially close to the people being studied (Lofland, 1995). I considered this 'outsider perspective' – both at a professional and emotional level - partly as an advantage, as the aim of this observation was to describe the 'taken for granted behaviour' of the nurses. Being new to the field, and seeing everything from a certain distance, I could observe those structures and processes that were considered evident for the nurses. However, being an outsider meant also that I was in no way part of the team, and I experienced that palliative care nurses were also observing me, puzzling out what I was doing, sometimes even being suspicious about my presence, afraid that I was going to judge them. To tackle this, I often found myself = explaining what my role and aim as a researcher was, but also I shared with them my observations, asking them for feedback. So the fact that I was considered – and considered myself - as an outsider to the field did not imply that I was not interacting with the nurses. I experienced that openness and sensitivity towards the field, and being perceptive of what nurses were doing, was only possible into continuous interaction with them. This method of observation has been also described as 'negotiated interactive observation', a way of doing fieldwork in hospital settings that emphasizes the way we negotiate ourselves into the field (Wind, 2008).

Furthermore, during peer debriefing, where I presented my preliminary results to three different nursing teams, I felt that my position as an outsider, a sexologist and doctoral researcher, elicited some defensiveness in certain nurses, as if they wanted to protect their daily work from the critical but inexperienced outside observer. So my role as a researcher here was even more collaborative, to a point where I considered the nurses in the team as 'co-researchers', a term that Finlay (2009) also uses in her relational-centred approach, stating that the research relationship involves an interactional encounter in which both parties (in this case the researcher – the author of this dissertation - and the nurses) are actively involved (Finlay, 2009). It involves a constantly evolving, negotiated, dynamic, co-created research process to which both researcher and nurses contribute (p. 9). Much of what we learned in the peer debriefing arose within this intersubjective space between the researcher and the participants.

Reflections about my professional background as a sexologist

Certain philosophical research traditions would encourage researchers to set aside one's assumptions about the phenomenon they are researching, thereby trying to be as non-influential and neutral as possible (Finlay, 2009). However, our dissertation is inscribed in the constructivist and critical realist tradition (see introduction), both of which accept to a certain extent that knowledge and meaning is socially constructed (Benton & Craib, 2001; Haverkamp & Young, 2007). Moreover, we use a hermeneutic from of phenomenology in some parts of the dissertation, that acknowledges that the researcher interprets the participants' interpretation, and that one cannot and should not bracket the researchers' experience and understandings (Finlay, 2009). Instead, these approaches state that researchers need to come to an awareness of their pre-existing beliefs, a critical self-awareness of their own subjectivity, placing this subjectivity in the foreground so as to begin the process of separating out what belongs to the researcher rather than the researched. So my professional background, being a sexologist, gave me certain fore-structures about sexuality, which affected my way of doing research and my way of interpreting the data. More specifically, sexology is a science where interdisciplinary thinking is central, and sexologists are in continuous dialogue with different forms of sciences, from social sciences to natural sciences and psychology (Bancroft, 2009). This interdisciplinary lens might have been used during the meta-ethnographic analysis in Chapter 2 and 3, where I discovered how the theoretical lens of each author affected the way they interpreted the sexual adjustment process. This interdisciplinary lens might also been used in the way we approached the data in Chapter 4, where we also arrived at a holistic, bio-psycho-social approach to sexuality. Being a sexologist might also be visible in certain statements that were made throughout the dissertation with which we advocate the recognition of sexuality, also in the context of terminal illness, for example in the decision to not include the term 'intimacy' in our definition (although acknowledging that sexuality cannot be regarded in isolation from emotional and psychological intimacy), as we wanted to avoid the risk of using this as a "euphemism" for sexuality, thereby implicitly agreeing with the general assumption that sexuality is not a suitable topic for the final stage of life.

8.5. Discussion of the findings

The following paragraph provides some discussion of the findings of this dissertation in the light of current research. First, we will attempt improve the conceptualization of sexuality and intimacy that has been used in research in the context of serious illness, by putting these in the light of our findings. Then we will present the role of the palliative care nurses in addressing sexual and intimate relationship issues.

8.5.1. Towards a better conceptualization of sexuality

In Chapter 2, we performed a qualitative evidence synthesis, which pointed out that most qualitative articles concerning sexuality and cancer tended to emphasize the emotional, cultural and social aspects of sexuality, (i.e. their influence on the grief process and on the restructuring process) thereby neglecting the bodily aspects of sexuality (i.e. the sexual rehabilitation process). This pattern can be understood better when looking at the wider field of sex research. For decades, the most dominant discourse informing the literature, assessments and interventions is the biomedical discourse of sexuality – inscribed in essentialism - which translates sexuality into fertility, menopause, erectile dysfunction or the capacity to have intercourse (Hordern & Street, 2007). Studies inscribed in this discourse focussed mostly on how body image and physical changes impacted on cancer patients or other seriously ill patients' desire for and satisfaction with sexual intercourse, whilst not including the impact of these changes on other expressions, feelings or values of sexuality (e.g. Cavalheiro et al., 2012; Platell, Thompson, & Makin, 2004). Concerning the addressing of sexual issues, this discourse advocates the restoration of sexual relationships to prior states (Clarke, 2003). The potential risks are that certain people might be excluded from assessment and treatment: e.g. patients who are no longer physically able to engage in coital sex - which is often the case in the palliative context - (Ussher et al., 2013), patients whose reproductive organs are not affected by cancer and cancer treatment, as the predominant focus of the literature is on cancer that impacts coital sex and visible signifiers of gendered identity (Kadwell, 2016). However, these patients yet might still desire sex or at least want to talk about their losses. Therefore, in recent years, a counter-discourse embedded in social-constructionism and relativism has emerged in response to these limitations. Indeed, qualitative researchers tend to explore the experiences of sexuality by emphasizing the different cultural and social influences of the experience of sexuality. However, by opposing a biomedical interpretation, qualitative research also risks ignoring certain aspects of sexuality, i.e. its bodily aspects. The body is – in most of the qualitative papers about sexuality and cancer - treated as a symbol of society, as a cultural text, ignoring its materiality (Jackson & Scott, 2001). Moreover, these researchers adhere to the idea that 'sexuality is whatever it means to the patient' (Cagle & Bolte, 2009), thereby making of sexuality such a broad and inclusive concept that it risks losing meaning.

Chapter 4 tried to overcome this polarization between the biomedical and social constructionist conceptualization of sexuality by adhering to a holistic conceptualization of sexuality that encompasses biological, psychological and social aspects. This approach has been recommended elsewhere, but has not frequently been used in qualitative research (Hordern & Street, 2007). This holistic, multi-layered way of depicting sexual expression also corresponds closely with the aim of Interpretative Phenomenology to provide a rich description of the experiences, and IPA explicitly adheres to this rather holistic vision, as it sees a person as “an experiencing, meaning-making, embodied and discursive agent” (Eatough & Smith, 2006, p. 486).

The qualitative evidence synthesis in Chapter 2 also revealed how the theoretical approaches of the qualitative studies included influenced understanding of the sexual adaptation process during cancer. More specifically, it shows how the theoretical approach of a study influences whether sexual changes are depicted as a loss or rather as an opportunity for sexual growth. The qualitative articles following the pathway of grief theory, for example, mainly focus on the experience of sexuality as a loss, sometimes to a point where these articles risk being judgmental and based on the assumption that the loss of sexuality is a stressful event in all cases. Patients and partners who are not struggling with sexual side effects are then considered to be in denial (Hanly, Mireskandari, & Juraskova, 2014; Juraskova et al., 2003; Walker & Robinson, 2012; Wittmann, 2014). Articles with a more social constructionist background emphasize the empowering process, the strengths of patients and partners instead of emphasizing sexual dysfunctions, and emphasize rediscovery of sexuality as a possible outcome. With the qualitative study in Chapter 4, we also tried to integrate both visions, by recognizing the main story of loss, but also by presenting evidence of a plurality of reactions and approaches to sexuality in couples confronted with terminal cancer. More specifically, the results in Chapter 4 include a plea for a sex-positive framework for addressing sexuality in oncology and palliative care. ‘Positive sexuality’ tries to encapsulate notions of diversity and empowerment in the definition of sexuality, moving away from an emphasis on dysfunction and risks (Williams, Thomas, Prior, & Walters, 2015). ‘Positive’, here, refers to the strengths, wellbeing, and happiness that sexual expression can entail. Our results confirm the value of a positive way of expressing sexuality in the last days of life, how it can colour the memory of bereaved partners, and how sexual expression during the course of terminal cancer can also be rediscovered and might even turn it into a transcendent experience of relational growth. “Positive sexuality” is a term mainly used in research on adolescent sexuality (Harden, 2014) and that has also been taken up by the World Health Organisation (WHO, 2006) , who have defined sexuality in a positive way since 2006:

> “Sexuality is a central aspect of being human throughout life, which 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, legal, historical, religious and spiritual factors." (WHO, 2006)

8.5.2 Towards another conceptualisation of intimacy

The results of Chapter 5 provide important input to improve the conceptualisation of intimacy which has been used in research in the context of serious illness (Manne & Badr, 2008). Our findings demonstrate that intimacy is a dynamic process that is constantly in motion, as patients and (bereaved) partners are continuously trying to co-create meaning. The results show that intimacy is not an all-or-nothing phenomenon that certain individuals experience consistently while other individuals never experience it. It shows that intimacy is not a given, but rather 'created' in intimate 'moments' during which partners seek to create meaning in a continuous, evolving process of negotiation and interaction. The current findings might help to develop a more nuanced view than the current dualistic approach that evaluates interactions between patients and partners as either promoting or undermining the level of intimacy in a relationship (Manne & Badr, 2008). It demonstrates how we cannot evaluate a relationship of a patient and partner based on observable behaviour, but that we must rather look at the underlying process of meaning-making that unfolds throughout a sequence of these behaviours. Another important finding in Chapter 5 is that – although patients and partners are in a continuous search for meaning-making –they do not always want to talk about relationship losses, but only occasionally and in a delineated context. This is congruent with the findings of Kvale (2007), who also postulates that cancer patients do not always want to talk about difficult emotions (Kvåle, 2007), and with Weingarten (1991), who suggests that intimate interactions cannot be judged by the degree or content of disclosure *per se*, but rather the extent to which the interaction carries a meaning that is constructed, shared and understood by both partners (Weingarten, 1991). The findings contradict studies which suggest that verbal, open and honest communication (i.e. disclosure) is a prerequisite for an intimate relationship, and sometimes even as the definition of intimacy itself, and that non-communication and silence (i.e., non-disclosure) are detrimental to an intimate relationship (Manne & Badr, 2008; Zhang & Siminoff, 2003). It contributes to recent calls to develop a more nuanced view of couples' communication that acknowledges that there are multiple ways to talk about and make meaning of cancer, and that a tacit agreement to avoid emotionally difficult issues may also protect the couple from harmful feelings (Badr, 2017; Ekstedt, Stenberg, Olsson, & Ruland, 2014).There is a remarkable parallel here with some of the findings from Chapter 4, which describe how patients and partners make meaning about imminent death through sexual expression, emphasizing the body as a medium through which meaning-making occurs. This finding clearly illustrates the overlap between the concepts of intimacy and sexuality as mentioned in the introduction (see introduction 1.2.1). It appears that sexual expression can thus also be used as a way of intimately interacting, especially when verbal communication has lost its value because it is not sufficient to express their feelings, or when it has become impossible because of the physical limitations caused by the patient's illness. In other words, our results show that the expression of sexuality is an example of nonverbal, bodily communication of important relational messages at the end of life. This is a new contribution to the existing research about sexuality and intimacy in cancer: although there is some research that describes the value of nonverbal communication at the end of life (Manusov & Keeley, 2015) , we did not find any qualitative studies that explicitly described how patients with cancer and their partners tried to communicate through sexual expression.

8.5.3. Towards a better insight into how palliative care nurses address sexual and intimate relationship issues

Chapter 6 and 7 bring a unique insight into how palliative care nurses address sexual and intimate relationship issues, as the focus goes beyond listing barriers to addressing sexual and intimate relationship issues – as often found in the literature (Dyer & das Nair, 2013). Instead, the results of these chapters demonstrate *how* nurses deal with these issues. Few studies describe palliative care nurses' process and reflection regarding these supportive care practices explicitly and in such a detail (Strang, Henoch, Danielson, Browall, & Melin-Johansson, 2014).

Both Chapter 6 and 7 also show how the underlying discourse from palliative care interacts with nurses' personal attitudes and specific behaviour regarding addressing sexual and intimate relationship issues. Both chapters thereby offer a broader perspective on the results of other research into these subjects, research that mainly focuses on personal factors such as assumptions, values and comfort or discomfort of individual nurses (Gleeson & Hazell, 2017; Magnan, Reynolds, & Galvin, 2006; Reese et al., 2017). The palliative care philosophy entails the praxis of creating a supportive environment to promote quality of life (Mount et al., 2006), which is visible in the positive and stimulating approach palliative care nurses tend to take in addressing sexual and intimate relationship issues. Indeed, the sex-positive approach, also supported with the results of Chapter 4 (see above) has been also taken up by the palliative care nurses, who put this sex-positive approach into practice by encouraging the couple to be 'sexually' intimate, by creating a positive-sex environment, by being open to actively exploring issues. These results reflect how the tendency in the general (nursing) literature and praxis about serious illness and sexuality has evolved from a predominantly "sex-negative" framework for conducting research about sexuality or informing practice (Hordern, 2008) to a more patient-centred, positive approach (Reisman & Gianotten, 2017). This positive, stimulating approach is also visible in the way palliative care nurses address other relationship issues, where they also go further than merely reducing distress in the couple, and aim to create more intimacy in a couple relationship. This creation of a positive atmosphere was appreciated by both the patients, partners and staff (Skilbeck & Payne, 2003).

Additionally, the results of Chapter 6 and 7 show how a relation-centred attitude in nurses somehow requires a different attitude compared to a patient-centred attitude. Although the core of psychosocial care – trust, kindness, warmth, compassion and genuineness – might be still the same (Fan, Lin, Hsieh, & Chang, 2017; Mok & Chiu, 2004), a relation-centred attitude requires more distance and neutrality. Zaider & Kissane (2011) confirm this by stating that supporting couples' relationships requires more of a meta-position from a healthcare provider (Zaider & Kissane, 2011). Working from this relationship-centred attitude might protect nurses from becoming over-involved with their patients. Our results also show how this relation-centred attitude infiltrates the whole process of addressing relationship issues, for example also in the way that questions are asked: questions such as "how did you meet each other" depicts the nurses' belief that illness affects the couple as a unit. Moreover, the results show how a relation-centred attitude can avoid coalitions with one of the partners, which in turn prevents nurses from getting stuck between the partners.

Another characteristic of the sexual and relationship support palliative care nurses offer is that it lies in the details and remains close to their daily work. Palliative care nurses address sexual issues in a way that it is close to their daily tasks and basic skills, e.g. by letting the partner help with comfort care, or by using communication skills such as empathic listening. Those skills often do not require any expertise in the field of sexuality, but are inherent to the nurses' profession. The same goes for addressing intimate relationship issues, as nurses simultaneously assess and support relationship issues. Their interventions are also described as 'short', and 'specific' and integrated into basic care. This reference to 'little things' is also reflected in nurses' description of their interventions as 'just offering opportunities, and not solving issues', or 'precision work'. Other nursing research does also confirm that 'the little things' are imbued within nursing skills, and that by focusing on the little things, nurses are able to enact dignity in care and offer tailored, personal care (Macleod, 1994; Williams, Kinnear, & Victor, 2016).

However, Chapter 6 and 7 both also show several challenges palliative care nurses are confronted with when they try to address sexual and intimate relationship issues. First, because their sexual and relationship support lies in the details and is close to their daily tasks as a palliative care nurse, some nurses did not consider this relationship support as real work, because they assume they should 'solve' the sexual and relationship issues and give tailored advice. These nurses adhere to a more target-driven and goal-centred healthcare discourse (Pearcey, 2010). Moreover, because it lies in the details, the way nurses address relationship issues often remains invisible, even to themselves, and risks being easily forgotten and overlooked because of its subtlety (Williams et al., 2016). Second, palliative care nurses seem more prone to comfort sexual and relationship issues, e.g. by empathic listening, rather than unravelling these issues and working actively towards reconciliation. Indeed, other literature shows that palliative care nurses tend to move away from the ideal of 'heroic dying' which would include the closure of all interpersonal unfinished business (Kissane, 2004) to a preference for a peaceful end with good symptom control, i.e. a 'good enough' approach. Stajduhar (2010) states that in palliative care, patients and partners might have more need for a sense of security than empowerment (Stajduhar, Funk, Jakobsson, & Öhlén, 2010). Langley-Evans and Payne (1997) concluded that the provision of comfort may be as important as more proactive one-to-one counselling (Langley-Evans & Payne, 1997). Milberg (2012) states that the task of palliative care is mainly to offer a secure base and that only when that base is secure enough can patients and partners start to explore their relationship at the end of life (Milberg et al., 2012). However, other scholars do encourage nurses to explore more actively relationship issues, thereby fostering couple resilience (Zaider & Kissane, 2011).

8.6. Implications for practice and research

8.6.1. Recommendations for practice

In each of the chapters of this dissertation, there is a great focus on the practical implications of our findings, each time with some clear messages for health practitioners who might be able to assist people with cancer in dealing with their sexuality in a meaningful way. In this part of the dissertation, we want to synthesize all these, and come to a series of overarching recommendations related to relationship-centred care, the way of communicating about sexuality/brief therapeutic conversations, and adhering to a positive sexual framework. Although a great deal of the recommendations comes from the chapters that investigated palliative care nurses specifically, this synthesis of practical implications is mostly extrapolated to all healthcare providers working with patients with (terminal) cancer and their partners. Therefore, we use the term 'healthcare providers' in the paragraphs below, unless indicated otherwise.

From relationship-centred research to relationship-centred care

The relationship-centred research discourse (see chapter 2, 4, and 5) – that conceptualizes patients and partners as an interdependent emotional unit (Broom & Kirby, 2013; Nebel, 2011) - could be translated into a relationship-centred care approach, in which healthcare providers can see the couple or dyad as a unit of care and consider both partners' needs simultaneously (see Chapter 6 and 7).

First, and most of all, the results of this dissertation – as it is qualitative in nature - give healthcare providers more insight into the complexity and richness of the experiences of sexuality and intimacy from a couple perspective, which can help them better asses and understand the ways a particular patient is behaving. The results could also help them to give the patients and their partners insight into their own experiences.

Moreover, this way of relationship-centred care – in which the couple is approached as a unit - demands a somehow different attitude from the healthcare provider/palliative care nurse. As stated above, a relational-centred attitude requires more distance and neutrality. When healthcare providers take on a meta-position, they are more able to look behind the observable interactions between patient and partners, and look for the underlying efforts of making meaning together, which is a departure from a judgemental and dualistic view on the couple. If couples have non-intimate experiences, taking on a relationship-centred attitude may encourage healthcare providers to help them see that they have a common source of distress, which is the experience of the relationship loss. The 'sharing of the grieving for these relationship losses' can be a central aspect of an intervention during the terminal phase of an illness. This might help both partners in a couple to see each other's way of dealing with the illness as an inherent part of the process of dealing with loss. This awareness can be helpful to embrace and accept the differences in how the partner and patient make meaning.

Also, the diversity of meanings and expressions of sexuality that this dissertation demonstrates also means that addressing sexual issues is not a therapeutic goal for all patients and their partners. However, patients and partners also frequently conceal and avoid sexual problems, or regularly shift between struggling and not struggling with sexual issues, as our qualitative evidence synthesis points out. Consequently, healthcare providers should not restrict themselves to assessing potential sexual issues at one single point in the illness trajectory. Rather, it is the task of the healthcare provider to follow couples longitudinally and repeatedly address sexual and intimate issues, to distinguish patients and/or partners who do not prioritize sexual issues or do not experience sexual changes as a loss, and those who are hesitant to raise the topic.

Lastly, the holistic approach towards sexuality that is offered in this dissertation gives the healthcare provider different angles to look at the sexual issues that manifest. A first angle offers a more psychological dimension in which healthcare providers can help patients and their partners cope with the different emotions related to sexual loss, such as disappointment, frustration, fear, and a sense of loss and grief. Healthcare providers can help couples to create meaning for these losses by accepting the losses, developing realistic expectations towards them or by trying to put them in perspective. Healthcare providers should also take into account that sexual expression is also a way of meaning-making and coping with imminent death. They can guide a couple in unravelling this meaning-making behind their sexual behaviour. A second angle offers a more biological dimension in which healthcare providers can offer some information to the couple about the bodily implications of (terminal) cancer and its possible influences on sexual functioning. The healthcare provider can help explore how a couple can continue to be sexually active and how they might adapt their sexual behaviour to the circumstances. A last angle offers a more social dimension, in which healthcare providers can help patients and partners restore their identity related to their sexual role, by unravelling how this identity is subjected to different normative expectations regarding sexuality that exist in society. For healthcare providers, helping a couple to challenge the dominant discourses of sexuality that affect their identity is hard (Ramirez et al., 2009) and patients/partners tend to often return to these dominant discourses. In sum, a more continuous and profound training/counselling might be necessary to prevent patients and partners from struggling with these norms. A healthcare provider works in an eclectic way, by choosing the right angle that corresponds to the need of the couple, or by combining several angles, as they are not mutually exclusive.

Communicating about sexuality and relationship issues: recommending brief therapeutic interventions

Chapter 6 and Chapter 7 both give recommendations for palliative care nurses on how to communicate about sexuality and relationship issues. In both chapters, the emphasis lies on the added value of interpersonal communication strategies such as exploring feelings, active listening, probing, stimulating and encouraging communication, unlike most literature, which is restricted to offering information to patients and partners (Ayaz & Kubilay, 2009; Reese et al., 2017; Taylor & Davis, 2006), or most psychosocial intervention studies that are primarily psycho-educational in nature, focusing solely on teaching and advice (von Heymann-Horan et al., 2017). By broadening the scale of possible ways of intervening and supporting in the case of sexual issues, healthcare providers will be more able to work eclectically by choosing the right approach that corresponds with the patients' needs. Furthermore, we postulate that the processes described for addressing sexual and relationship issues have inherent therapeutic qualities, making the nurses' way of addressing relationship issues look like 'brief therapeutic conversations' (Wright & Bell, 2009) (Wright & Bell, 2009).This finding is a call to reconsider the educational programs for (palliative care) nurses, and adapt several therapeutic skills to the palliative care nursing context. For example, we propose that certain skills that are used in Emotional Focused Couple Therapy (EFCT) could be adapted to the palliative care context and taught to palliative care nurses. Internationally, Emotionally Focused Couple Therapy is the most popular form of therapy being used for couples facing terminal illness (McLean & Nissim, 2007; Tie & Poulsen, 2013).

It is an integration of an interactional and family systems approach, with an affective and experiential approach. One of the goals in EFCT is to facilitate awareness of primary, underlying emotions underneath the observable behaviour of a person, and then to encourage the overt expression of those primary emotions (Johnson, 2004). This form of therapy neatly fits the practical recommendations of Chapter 5, where ' the sharing of the grieving about relationship losses between patients and partners' are also encouraged as a central aspect of an intervention during the terminal phase of the illness. This grieving can be considered as a primary emotion, and sharing these emotions might help both partners to see these underlying primary emotions and accept how patients and partners differ in their observable behaviour, which is exactly one of the goals of EFCT (Johnson, 2004). Moreover, EFCT in the context of terminal illness also emphasizes the continuity of this therapeutic process after bereavement, saying that the living partner has the chance to carry that support on into the future, and emphasizing the importance of the last memories of the healthy spouse, which can either encourage or inhibit him or her to engage in new relationships (Tie & Poulsen, 2013). This ongoing support for bereaved partners is something that the results and recommendations of Chapter 4 and 5 both also emphasize. Lastly, the skills of EFCT might be especially applicable and useful in the palliative care context when nurses want to rectify imbalances between patients and partners due to illness (Chapter 7). Moreover, by explaining the process of providing relationship support and addressing sexual issues in detail and by making the little things visible (King & Quill, 2006), our results can help nurses overcome their tendency to refer to this as non-work, by becoming more conscious of the interventions they take for granted, by being able to name these interventions, i.e. by cultivating a professional jargon which integrates concepts such as those described in our results (Williams et al., 2016). The results also can help them overcome their insecurities about addressing sexual issues, as they demonstrate that nurses – or other healthcare providers - do not need to be 'sex-experts' in order to address these issues.

Further research might translate this therapeutic framework into a brief therapeutic training that is applicable to the skills of nurses, as well as to the working context of the nurses. This could further be elaborated in an training specifically applied to the praxis of palliative care nurses, which has been done for example by Bowles, Mackintosh, & Torn (2001).

A positive attitude towards sex and relationship in practice

As stated above, the different chapters of our dissertations all emphasize a relationship and sexual positive discourse, whether as a framework for research into something that was found in the nurses' attitudes and skills, or a recommendation of how to put this positive attitude in practice. To recapitulate, 'positive' refers to the strengths, wellbeing, and happiness sexual expression can entail, but also tries to encapsulate notions of diversity and empowerment in the definition of sexuality, moving away from an emphasis on dysfunction and risks (Williams, Thomas, Prior, & Walters, 2015).

First, healthcare providers can address sexuality using a strength-based approach (Thorne & Paterson, 1998) without being blind to the vulnerability of patients and partners. It means healthcare providers can choose to work with those aspects of illness that are healthy, transformative and positive instead of focussing on loss and suffering. Healthcare providers can also adapt to a positive attitude towards sexuality by pro-actively providing opportunities for patients and their partners to discuss any concerns they might have about their sexuality. If there is no acceptable forum for people to voice the experiences of loss, grieving, etc. described above, these feelings of grieving can become disenfranchised, which mean that they “cannot be openly acknowledged, socially validated or publically mourned” (Doka, 2002, p. xv), and thus remain hidden. Healthcare providers are also invited to approach sexuality from a different angle than the dominant negative discourse of sexuality, centred around dysfunction and inability due to illness, by taking up the aforementioned term “positive sexuality”. The task for healthcare providers is no longer only to eliminate dysfunctions caused by cancer and to reduce risks, or to help couples accept the limitations of their sex life. Additionally, a healthcare provider can also support patients and partners in dealing with loss due to changes in how they can express their sexuality, and to support re-negotiation in a way that is meaningful for each person. This also entails helping patients and partners to find new ways of expressing their love in sexual behaviour, not despite the inabilities but thanks to the abilities and possibilities that are still there.

The results of Chapter 5 and 7 show how we can move from practical recommendations on how to diminish the burden for couples, as most studies tend to do (Mclean & Nissim, 2007) to a focus on how to help a couple to regain the romantic, emotional partnership (Tie & Poulsen, 2013). Healthcare providers should thus put emphasis on the positive aspects of the couple’s relationship, which can help partners to adjust to a new way of being together, and facilitate new patterns of reciprocity. Chapter 5 gives more detail on how to accomplish this goal. It states that healthcare providers can help couples to see that they have a common source of distress, which is the experience of the relationship loss. This awareness can be helpful to embrace and accept the differences in how the partner and patient make meaning. However, healthcare providers should be careful about stimulating disclosure as the current findings show that we need a more nuanced view of couples’ communication and negotiation of meaning-making. They should also acknowledge that there are multiple ways to talk, be aware that avoiding talking can also be a part of the grieving process and remember that non-disclosure can also help the couple to make meaning together.

8.6.3. Recommendations for research

The results of our qualitative study exploring how patients with terminal cancer and their partners experience sexuality, show that it is not because a patient is dying that sexual expression disappears from people's lives (see Chapter 4). A lot of patients and partners reported actively negotiating different ways of relating and communicating with each other, including in a sexual way. It shows how at the end of life the meaning and expression of sexuality are changeable and malleable to what is still possible based on the physical and mental state of the patient and the partner. The results of this study can be used to recommend to other phenomenological studies aiming to investigate experiences and meaning-making in cancer (or other terminal illness) not to leave out or ignore aspects of sexuality. Although, in theory, phenomenological approaches explicitly address the dimension of the body in experiences (Eatough et al., 2006), most studies surprisingly leave out the sexual part of this embodied experience (De Vocht, 2011). For example, a phenomenological study on making new meanings after treatment for oral cancer, included neither communication, kissing nor oral sex in the description (Röing, Hirsch, Holström, & Schuster, 2009). The results of the current study can thus encourage further research to break with what has been called the "double-barred taboo" surrounding the combination of sexuality with terminal illness (Jaffe, 1977). Furthermore, the results of Chapter 5, as well as the results of the qualitative evidence synthesis, might encourage other researchers to integrate all aspects of sexuality – psychological, biological and social dimensions. This is especially so for papers in qualitative research following a social constructionist approach, where the dominant emphasis is on the cultural and social aspects of sexuality, thereby often neglecting the bodily aspects of sexuality. Further qualitative research should thus move away from a unilateral/unidimensional opposition against a medical approach of sexuality. Only then we can come to a holistic, biopsychosocial interpretation of sexuality.

Also, the qualitative evidence synthesis in Chapter 2 pointed out that the theoretical orientation of a study has a significant influence on the claims authors make about their results, and therefore authors should be encouraged to mention this theoretical approach explicitly in the reporting of the research.

Chapter 6 and 7 gave a rich description of how palliative care nurses addressed sexual and relationship issues in their daily practice. Although several contextual factors have been taken into account, such as the institution (out-patient care versus palliative care unit), as well as the philosophical principles of palliative care, other factors have not been explored, such as the personal relationship context of the nurse or their own experiences with sexuality, the gender of the nurses in combination with the gender of the patient/partner, as well as the personality of the nurse, patient and/or the partner. Moreover, more or less absent from the accounts of the nurses was their experience with and attitude towards different sexualities in palliative care. This might be because we did not explicitly asked questions about this topic, but the invisibility of this subjects in the accounts might suggest a heteronormative attitude that denies diversity in sexual identities (Simpson, Almack & Walthery, 2016). All these topics could be further investigated. Also, as already described in the section of the methodological challenges, further research could also include other nurses, for example general home care nurses or nurses working at an oncology ward, as these nurses, through their daily care and support to terminally ill patients and partners, might be also confronted with the same relationship issues and might address them in a particular way.

What is lacking in this dissertation is attention to the non-intimate dimension of sexuality: sexual violence, or more generally, intimate partner violence. We did not explore this in our qualitative interview study with patients and (bereaved) partners, nor did we explore this subject in depth with the palliative care nurses. The experiences of patients and partners have not been explored in the existing cancer, palliative care, and sex research. However, in some recent studies, healthcare professionals in palliative care raised particular concerns about sexual and intimate partner violence (Kadwell, 2016). For example, oncologists Schmidt, Woods, and Stewart (2006) noted multiple reports of intimate partner violence from patients in their oncology practice. They suspected that this violence prevalence is higher in patients with cancer but that practitioners, perhaps because they do not want to believe it happens in their practices, likely believe that the rate of violence is lower. Other researchers have also drawn attention to the need for further research to be conducted in these areas (Jayawardena & Liao, 2006). Intimate partner violence may be exacerbated at the end of life because patients and their partners often experience significant stressors associated with physical, emotional, social, and financial burdens (Wygant, Bruera, & Hui, 2014). Additionally, palliative care patients may be at high risk of ending up in an abusive relationship because they are generally more vulnerable and dependent and more isolated as a result of physical and functional deterioration (Wygant et al., 2014; Schmidt et al., 2006). Unlike some survivors of intimate partner violence, many cancer patients with advanced disease cannot leave their relationships. A better understanding and awareness of sexual and intimate partner violence at the end of life and how healthcare providers are dealing with these issues could help those healthcare providers support, counsel, and ameliorate the suffering caused by this “unspoken” trauma (Wygant et al., 2014).

Lastly, Chapter 4 and 5 of this dissertation show us the shortcomings of doing a cross-sectional study and demonstrate the necessity of using a longitudinal qualitative approach to see how sexual and relationship issues evolve as a function of the cancer trajectory, either from curative cancer to remission, or from curative cancer to advanced cancer, terminal cancer and bereavement.

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2013

‘Staying independent’: a qualitative study to explore the experiences of cancer patients living alone during their treatment, 13th World Congress of the European Association for Palliative Care (EAPC), Prague, Czech Republic, May 2013 (poster presentation)

2014

De psychosociale noden van alleenwonende patiënten met kanker, Tweedaagse Oncologie vereniging voor oncologieverpleegkundigen (VVRO), Leuven, Belgium, Februari 2014 (oral presentation)

The psychosocial needs of cancer patients living alone, Qualitative Cancer Conference ‘Taking Stock, Stepping Further’, Berlin, Germany, April 2014 (oral presentation)

Informal support needs of cancer patients who are living alone: A qualitative insight, 20th annual Qualitative Health Research Conference, Victoria, Canada, October 2014 (oral presentation)

A meta-synthesis about sexuality when having cancer: A worked example, 20th annual Qualitative Health Research Conference, Victoria, Canada, October 2014 (oral presentation)

“Novice Researcher syndrome” The emotional impact of doing qualitative research on sensitive topics, 20th annual Qualitative Health Research Conference, Victoria, Canada, October 2014 (oral presentation)

2015

Seksualiteit bij patiënten met terminale kanker en hun partners, Studiedag seksualiteit en intimiteit in de Palliatieve zorg, Forum Palliatieve zorg, Wemmel, Belgium, Februari, 2015 (oral presentation)

“Novice Researcher syndrome” The emotional impact of doing qualitative research on sensitive topics, 2-day Seminar of Undisclosed issues in Qualitative research, Jette, Belgium, April 2015

Informal support needs of cancer patients who are living alone: A qualitative insight; International Mental Health Congress, Lille, France, April 2015 (oral presentation)

“Novice Researcher syndrome” : The emotional impact of doing qualitative research on sensitive topics, International Mental Health Congress, Lille, France, April 2015 (oral presentation)

Seksualiteit bij patiënten met terminale kanker en hun partners, Symposium "cheek to cheek": kanker en palliatieve zorg: is er plaats voor intimiteit en seksualiteit? Stichting tegen Kanker, Brussels, Belgium, May 2015 (oral presentation at workshop)

De noden van alleenwonende patiënten met kanker ten aanzien van hun omgeving: een kwalitatief onderzoek, Derde Congres in de Psychosociale Oncologie, Cédric Hele instituut, Mechelen, Belgium, December 2015 (poster presentation)

Naar een theoretisch model van seksuele adaptatie bij kanker: een kwalitatieve metasynthese, Derde Congres in de Psychosociale Oncologie, Cédric Hele instituut, Mechelen, Belgium, December 2015 (poster presentation)

2016

Couples' sexual adjustment process to cancer: a meta-synthesis and qualitative study, 13th congress of the European federation of sexology (EFS), Dubrovnik, Croatia, May, 2016 (oral presentation)

Workshop Interviewing techniques in Qualitative Research, Interuniversity Symposium on Qualitative Research in Medical & Health Sciences, Leuven, Belgium, September 2016 (oral presentation at workshop)

2017

Workshop seksuele gevoelens in de psychotherapeutische relatie, Seminar of Belgische vereniging voor relatietherapie, systeemtherapie en gezinscounseling (BVGRS) ,Antwerp, Belgium, May 2017 (oral presentation at workshop)

Psychosociale ondersteuning van koppels op het levenseinde: Van een kwalitatief onderzoek naar de ervaringen van palliatieve verpleegkundigen naar een transdisciplinair trainingsmodel; Vierde Congres in de Psychosociale Oncologie, Cédric Hele instituut, Mechelen, Belgium, December 2017 (poster presentation)

2018

Workshop Seksualiteit in de palliatieve zorg: hoe gaan we van onmacht bij de zorgverlener naar een positieve manier van omgaan met seksualiteit? EPC-congres 'Macht, onmacht en overmacht in de palliatieve zorg', Jette, Belgium, Februari 2018 (oral presentation at workshop)

Integrity in qualitative research about sensitive subjects: integrating emotional reflexivity, European congress of Qualitative Inquiry, Leuven, Belgium, February 2018 (oral presentation)

Purposeful sampling in a qualitative evidence synthesis: a worked example; Three day international Workshop about systematic reviews of quantitative and/or qualitative evidence, Leuven, Belgium, March, 2018

Organizer of seminars

Organizer of the two day PhD training ‘Undisclosed issues in qualitative research’ in collaboration with the Doctoral School of life sciences and medicine and research group Crime and Society (CRIM) of the VUB; 9-10 April 2015

Organizer of the two day PhD training ‘ Undisclosed issues in qualitative research’ PART II; in collaboration with the Doctoral School of life sciences and medicine and research group Crime and Society (CRIM) of the VUB; 21-22 April 2016

Prizes

World congress of European Association for Palliative Care (EAPC, 30 May-2 June 2013): EAPC- best poster award: ‘staying independent’: a qualitative study to explore the experiences of cancer patients living alone during their treatment