



The Sexual Adjustment Process of Cancer Patients and Their Partners: A Qualitative Evidence Synthesis

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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 was 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 toward 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 behavioral 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.

Keywords Sexual adjustment · Cancer · Qualitative research

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 medicalized 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

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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 in 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, theoretical level, this information has not yet been brought together in a systematic way, leading to a theoretical model about how couples are adjusting toward these sexual changes and challenges. Furthermore, most intervention studies addressing sexual adjustment in couples are theoretical in nature (Badr & Krebs, 2013; Canada, Neese, Sui, & Schover, 2005; Kalaitzi et al., 2007; McCorkle, Siefert, Dowd, Robinson, & Pickett, 2007). 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 was 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 and 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 healthcare 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, and 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 Fig. 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 McKibbin, 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 reuse 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.

As can be seen in Fig. 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.

Purposeful Sampling and Analyzing

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 (Campbell et al., 2003; De Casterlé, Gastmans, Bryon, & Denier, 2012). 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

Meta-ethnography steps according to Noblit and Hare (1988)

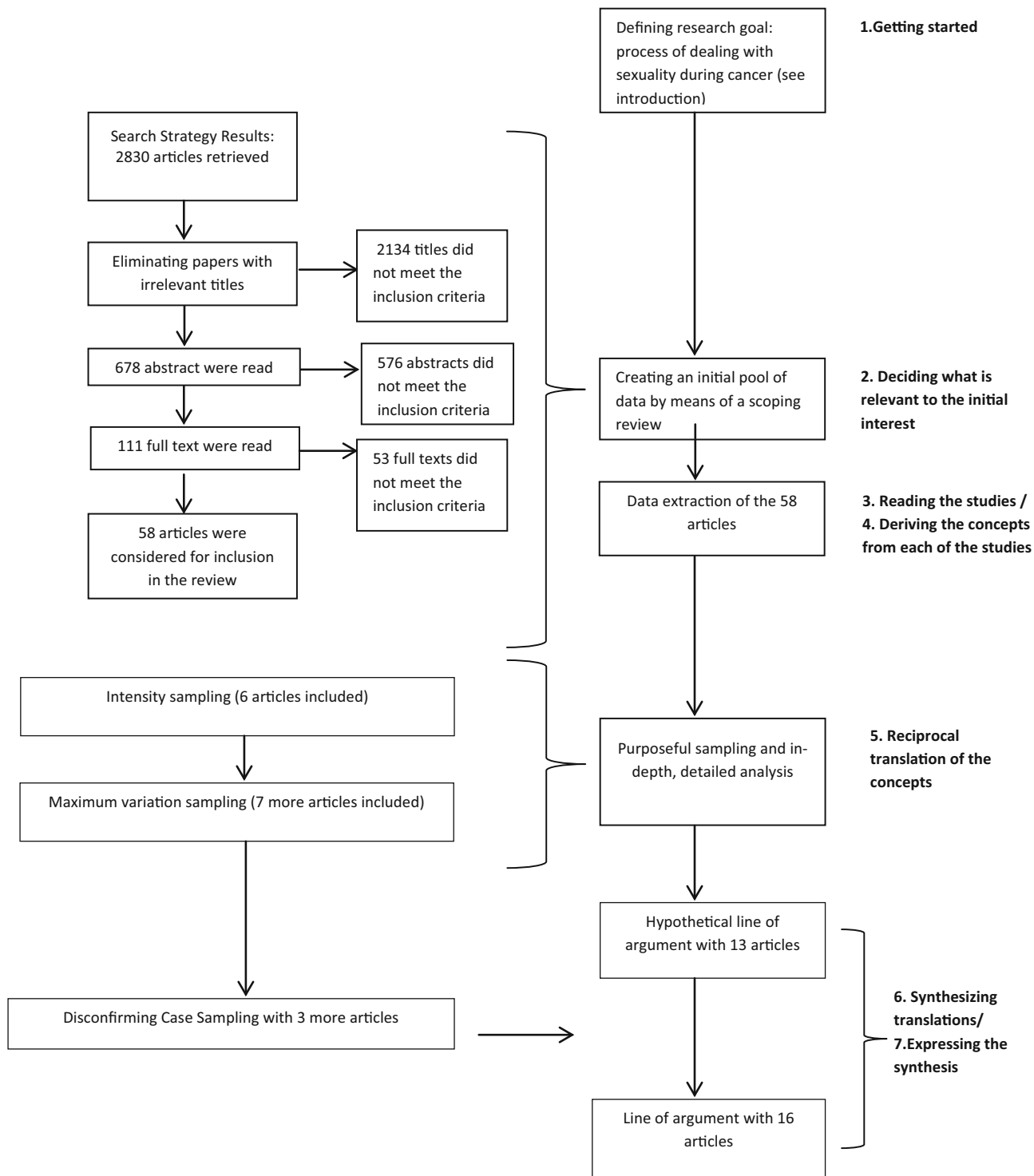


Fig. 1 Schematic overview of the methodology

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 years Average age of partners: 61 years Ethnicity: Euro-Canadian or American heritage, 1 who was Afro-American Type of cancer and treatment: prostate cancer, all undergoing androgen deprivation therapy
Concepts	<i>Discomfort about sexuality</i>
Main theoretical arguments	<i>Avoidance of sexuality</i> <i>“The more romantic husband”</i> <i>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</i>

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 analyzing run simultaneously, we will present them both together in this methodology section. Table 2 represents visually the whole process of sampling and analyzing.

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 were 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; and 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 (Britten et al.,

2002; Noblit & Hare, 1988). 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 one 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 and Robinson’s (2012) study, this is formulated as avoidance of communication about the sexual changes. In the Juraskovas et al. (2003) study, 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 analyzed 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. 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 toward 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

Table 2 Example of the purposeful sampling process of the 16 articles

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

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

The non-discursive parts are the articles and concepts coming from the included papers as a result of intensity sampling

The discursive parts are the articles and concepts coming from the included papers as a result of maximum variation sampling

The bold parts are new findings resulting from reciprocal translation of the concepts of articles included by maximum variation sampling

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

Table 3 Characteristics of the included studies

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 years m = 64 years Primarily Caucasian and Asian 2 Latina	Prostate cancer Time since diagnosis 1–8 years
Boehmer and 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 years–70 years 14 white 6 African American 1 Hispanic	Diagnosed with early prostate cancer, but not yet treated
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 4–5 in-depth interviews Grounded theory	Social constructionist	18 men diversification in sexual orientation Average age = 65 years 4 Afro-American 14 Caucasian	Prostate cancer Radical prostatectomy = 11 Radiotherapy = 6 Hormonal therapy = 4 3.7 years since diagnosis (1–8.5 years)
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 females 7 males Average age: 53 years 18 Anglo-Australian 1 Filipina 1 Italian	3 brain tumors 4 prostate cancers 2 lung cancers 7 breast cancers 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 23 f 21 m 35 partners 18 f 17 m Average age: 54.6 years Anglo-Australian (91%)	A range of cancer types and stages 5 years 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: 50–59 years = 8 60–69 years = 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

Table 3 continued

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 a radical prostatectomy	Semi-structured interviews Interpretive phenomenological analysis	/	3 gay couples Age = 40–62 years	3–6 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 = 19–64 years	Cervical and endometrial cancer (stages I, II) Treatment: Surgery alone Surgery + external beam and brachytherapy Post-treatment (immediately to 2 years after)
Navon and Morag (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 = 57–85 years	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 years Anglo-Australian	Prostate cancer patients with prostatectomy Months since prostatectomy: 3–72
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 years 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 years 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 23 f/21 m 35 partners 18 f/17 m Age = 54.6 years Anglo-Australian (91%)	All types and stages of cancer

Table 3 continued

Source	Included through	Objective	Method	Epistemological background	Participant characteristics	Type of cancer/ treatment
Walker and 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 years f = 32–82 years Average age patients = 65.4 years Average age partners = 61 years 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 and 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 years f = 32–82 years Average age patients = 65.4 years Average age partners = 61 years 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
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 years f = 57.6 years White	Prostate cancer pre-surgery and post-surgery 30 % had erectile dysfunction preoperatively Most men had erectile dysfunction postoperatively
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 = 35–69 years	Breast cancer Time since diagnosis = 5 months–>10 years 39 % lumpectomy 61 % Mastectomy

(articles that 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 Tables 2, 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 Tables 2, 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 of the purposeful

way of sampling and analyzing—16 of the initial 58 articles were included in this synthesis.

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 three 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 Tables 2, 4).

Characteristics of the Articles

Sixteen 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, gynecological 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, 2012; Wilmoth, 2001; Wittmann et al., 2014). 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 adjust-

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

	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 toward struggling	Strategy leading toward 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	/

ment 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, 2013; Hartman et al., 2014; Juraskova et al., 2003; Oliffe, 2005; Ramirez et al., 2010; Ussher et al., 2013; Walker & Robinson, 2011, 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., 2010; 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 behavioral 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 “Appendix” for 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., 2010; Walker & Robinson, 2012). The suppressing of sexual needs by patients has been described by Walker and Robinson: 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., 2010). 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 normalized through techno-medicines such as operation tech-

niques or assistive aids (e.g., Viagra, lubricants) (Boehmer & Babayan, 2004; Fergus et al., 2002; Oliffe, 2005; Ramirez et al., 2010; 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-orientation, 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 (Hartman et al., 2014; Wittmann 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 toward restructuring, sexual struggling is mainly described in the form 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.

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 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 in 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 (Fergus et al., 2002; Gilbert et al., 2010).

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., 2010). 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 in Fig. 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.

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. For example, “minimization of sexuality,” as a sexual strategy, is also a helpful coping strategy 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 acknowledgment of its self-deceptive nature (Hartman et al., 2014; Navon & Morag, 2003). Wilmoth (2001) formulates this acknowledgment as the “taking hold” phase.

Some authors therefore interpret an immediate acceptance of sexual changes as provisional (e.g., Walker & Robinson, 2011). Walker and Robinson acknowledge that this immediate acceptance is based on assumptions and avoidance—concepts that could be linked with denial—but due to the cross-sectional

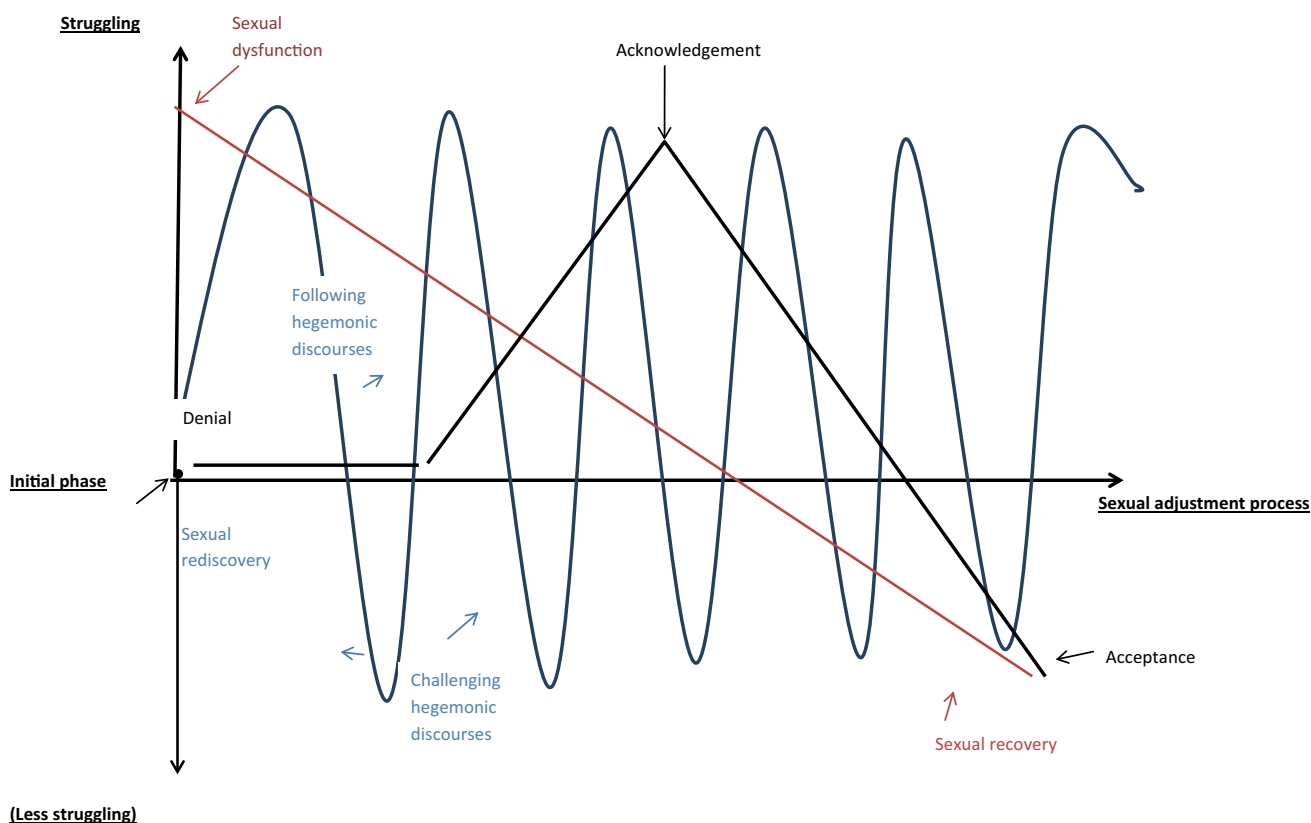


Fig. 2 Relationships between the concepts, according to the different pathways. The *black line* describes the pathway of grief and mourning, the *blue line* describes the pathway of restructuring, and the *red line* describes the pathway of rehabilitation (Color figure online)

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., 2010).

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 and 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 (Beck et al., 2013; Ussher 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 behavioral 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 and Robinson (2012), i.e., “allow time to pass and have patience” (Wittmann et al., 2014). One exception was the explicit acknowledgment 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 endpoint.

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 behavioral level. In these cases, challenging the discourses is a prerequisite to overcome the struggling and achieve good

sexual adjustment (Fergus et al., 2002; Hartman et al., 2014; Walker & Robinson, 2012). For example, Ussher, Perz, Gilbert, Wong, and Hobbs (2013) say 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 (Olliffe, 2005; Ramirez et al., 2010; Ussher et al., 2013; Walker & Robinson, 2012). 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 to 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 (Gilbert et al., 2010, 2013; Hanly et al., 2014; Ramirez et al., 2010).

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 toward 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 afterward (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’ behavior.

The advantage of the restructuring process is that it does take into account people who do not suffer from sexual dys-

function, 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 toward restructuring moves clearly away from an image of sexual dysfunction—often used in biomedical science—toward 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 to 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), although other clinical research reports some success with these aids (e.g., Titta, Tavolini, Moro, Cisternino, & Bassi, 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 to 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).

Toward 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 reintegration 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 behavior, 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 behavior should be accompanied with a change in 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 that there is not so much of a polarization 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 toward a rediscovery or even a transcendence of sexuality during cancer (according to the restructuring process). Interventions could thus follow a “strength-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 prioritize 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 (Badr & Krebs, 2013; Canada et al., 2005), as it shows us that patients and partners are continually shifting between challenging and following dominant discourses. Indeed, Ramirez et al. (2010) 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) toward 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 analyze 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 analyzing 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 toward 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.

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Compliance with Ethical Standards

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

Ethical Standard 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.

Appendix

List of articles that were included in the study but not used in the meta-synthesis.

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See Table 5.

Table 5 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 joint interviews Grounded theory methodology <i>Epistemological background:</i> /	17 heterosexual couples f = 57 years m = 64 years Primarily Caucasian and Asian 2 Latina Prostate cancer Time since diagnosis 1–8 years	<i>Pathway of grief</i> Accepting means to develop realistic expectations about sexuality Accepting means the acknowledgment that railing against the current situation was a waste of energy Accepting not only one's own feelings, but also partners' feelings <i>Pathway of restructuring</i> Couples who valued sex primarily for relational intimacy were more likely to successful 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 and Babayan (2004)	Understanding couples' reaction to potentially losing sexual capacity because of prostate cancer	Separate semi-structured interviews Grounded theory methodology <i>Epistemological background:</i> /	21 patients 13 partners Age = 37–70 years 14 white 6 African American 1 Hispanic Diagnosis with early prostate cancer, but not yet treated	<i>Pathway of restructuring</i> 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 greatly 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

Table 5 continued

Source	Objective	Methodological choices	Participant characteristics	Main theoretical arguments and concepts
Fergus et al. (2002)	Exploring prostate cancer patients' beliefs, values and sexual performances regarding masculinity with respect to prostate cancer treatment	Series of 4–5 in-depth interviews Grounded theory <i>Epistemological background</i> Social constructionist	18 men Diversification in sexual orientation Age = 65 years 4 Afro-American 14 Caucasian Prostate cancer Radical prostatectomy = 11 Radiotherapy = 6 Hormonal therapy = 4 3.7 years since diagnosis (1–8.5 years)	<i>Pathway of grief</i> Angry because of lack of preparedness for sexual dysfunction <i>Pathway of restructuring</i> 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 successful 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 <i>Epistemological background:</i> Material discursive framework	20 partners 13 f (11 heterosexual, 2 lesbian) 7 male (heterosexual) Age: 53 years 18 Anglo-Australian 1 Filipina 1 Italian 3 brain tumors 4 prostate cancers 2 lung cancers 7 breast cancers 1 mesothelioma 2 metastases	<i>Pathway of restructuring</i> Sticking to coital imperative Altered body image No renegotiation 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

Table 5 continued

Source	Objective	Methodological choices	Participant characteristics	Main theoretical arguments and concepts
Gilbert et al. (2013)	Exploring the post-cancer experiences of embodied sexual subjectivity for cancer patients and partners	Semi-structured interviews Theoretical thematic analysis <i>Epistemological background:</i> Poststructuralist approach	44 patients (23 f, 21 m) 35 partners (18 f, 17 m) Age: 54.6 years 68 heterosexual 11 gay/lesbian 1polysexual Anglo-Australian (91 %) A range of cancer types and stages 5 years post-diagnosis	<i>Pathway of restructuring</i> Sexual disembodiment Reinventing 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 <i>Epistemological background:/</i>	21 men Age: 50–59 = 8 60–69 = 13 95 % heterosexual 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	<i>Pathway of grief</i> Avoidance of physical intimacy for their wife Suppressing: denial behavior Minimizing side effects Emotional struggles (anger, depression, disappointment, a sense of loss) Accepting, getting on with life Early referral for sexual changes would have reduced anxiety <i>Pathway of sexual rehabilitation</i> 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 <i>Epistemological background:</i> /	3 gay couples Age = 40–62 3–6 months after radical prostatectomy	<i>Pathway of grief</i> Communication breakdown Avoiding initiating in sex accepting sexual status as the new normal <i>Pathway of restructuring</i> Emphasizing intimacy, embracing plan B are helping sexual adjustment <i>Pathway of sexual rehabilitation</i> 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

Table 5 continued

Source	Objective	Methodological choices	Participant characteristics	Main theoretical arguments and concepts
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 <i>Epistemological background:</i> /	20 patients (heterosexual) Age 19–64 Cervical and endometrial cancer (stage I, II) Treatment: surgery alone Surgery + external beam and brachytherapy Post-treatment (immediately to 2 years after)	<i>Pathway of grief</i> 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 <i>Pathway of restructuring</i> 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 <i>Relationship history</i> Broadness of sexual repertoire before diagnosis helped coping with sexuality <i>Pathway of sexual rehabilitation</i> Impact of treatment modality on the experienced difficulties with sexuality
Navon and Morag (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 <i>Epistemological background:</i> /	25 patients Age = 57–85 years Advanced prostate cancer Hormonal therapy 6 months to 3 years	<i>Pathway of grief</i> Revulsion Disguise, diversion and avoidance strategies Minimization: downplaying the matters' gravity Strategies have advantages and disadvantages. There are changing patterns over time

Table 5 continued

Source	Objective	Methodological choices	Participant characteristics	Main theoretical arguments and concepts
Oliffe (2005)	Exploring men with localized prostate cancer experiences of impotence following prostatectomy	In-depth semi-structured interviews Ethnography <i>Epistemological background:</i> Social constructionist	15 men with a current female partner Age = 57.6 years Anglo-Australian Prostate cancer patients with prostatectomy Months since prostatectomy: 3–72	<i>2010 Pathway of restructuring</i> Phallogentric 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 <i>Epistemological background:</i> /	30 females Age = 70 years Heterosexual 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 years post-diagnosis	<i>Pathway of restructuring</i> 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 Resisting the norm, and then return to it <i>Pathway of sexual rehabilitation</i> Orchestrating ostomy management techniques makes them able to resume intercourse

Table 5 continued

Source	Objective	Methodological choices	Participant characteristics	Main theoretical arguments and concepts
Ussher et al. (2013)	Exploring the renegotiation of sex in couples with cancer	Semi-structured interviews Theoretical thematic analysis <i>Epistemological background:</i> Material discursive	44 patients (23 f, 21 m) 35 partners (18 f, 17 m) Age: 54.6 years Anglo-Australian (91 %) All types and stages of cancer 68 heterosexual 11 gay/lesbian 1 polysexual	<i>Pathway of restructuring</i> 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 Renegotiation through effective communication: honest and open A relationship that normally involved a lot of non-coital intimacy made it easier to renegotiate Adopting the coital imperative: refiguring the body through technomedicine Following hegemonic discourses leads in the majority of cases to struggling
Walker and Robinson (2011)	Exploring how prostate cancer patients and their partners adjust to changes associated with androgen deprivation therapy	Interviews, unstructured interviews Grounded theory methodology <i>Epistemological background:</i> /	18 heterosexual couples (m 47–83 years) (f 32–82 years) Age patients: 65.4 years Age partners: 61 years Euro-Canadian or American heritage, 1 who was 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	<i>Pathway of grief</i> 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 Satisfied with the decision to stop sexuality <i>Pathway of restructuring</i> Expanding the definition of sex beyond intercourse <i>Pathway of sexual rehabilitation</i> Several techniques to maintain sexuality: new activities, altered initiation patterns, novel sexual tools and techniques

Table 5 continued

Source	Objective	Methodological choices	Participant characteristics	Main theoretical arguments and concepts
Walker and Robinson (2012)	Exploring struggles couples with prostate cancer faced when adapting sexually to side effects of androgen deprivation treatment	Unstructured interviews Grounded theory methodology <i>Epistemological background:</i> /	18 heterosexual couples (m 47–83 years) (f 32–82 years) Age patients: 65.4 years Age partners: 61 years 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	<i>Pathway of grief</i> Acknowledge loss and grief Allow time to pass Talk to each other about grief Avoid talking Ignore sexual thoughts Withdrawing <i>Pathway of restructuring</i> 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 from prostate cancer	Interviews preoperatively and 3 months postoperatively Analytic induction <i>Epistemological background:</i> /	8 couples (7 heterosexual, 1 homosexual), 2 singles Age m = 60.2 years Age f = 57.6 years White Prostate cancer pre-surgery and post-surgery 30 % had erectile dysfunction preoperatively Most men had erectile dysfunction postoperatively	<i>Pathway of grief</i> 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 Grief is a process variable in this recovery Accepting aids helped adjustment capacity to communicate will help grieving process Acceptance is sign of resilience <i>Pathway of sexual rehabilitation</i> 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 <i>Epistemological background:</i> /	18 white women, heterosexual Age = 35–69 years Breast cancer Time since diagnosis = 5 months to 10 years 39 % lumpectomy 61 % mastectomy	<i>Pathway of grief</i> 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

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