USING COGNITIVE INTERVIEWS TO EVALUATE THE FOUR-ITEM DYADIC SEXUAL COMMUNICATION SCALE IN COUPLES WHO MIGHT BENEFIT FROM A PALLIATIVE APPROACH

by

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Abstract

Much of the sexuality research with people who have life threatening diagnoses and their intimate partners has focused on sexuality of people with cancer. Sexuality research with people with progressive chronic illnesses tends to focus on functional sexuality of the patient, neglecting other issues and aspects of the couple experience such as dyadic sexual communication. The purpose of this study was to use cognitive interviews to evaluate the appropriateness and acceptability of the four-item Dyadic Sexual Communication Scale (DSCS), and to understand perspectives on sexuality and dyadic sexual communication in couples who might benefit from a palliative approach. This qualitative study used the approaches and methods of cognitive interviewing for data collection. Four couples aged 30-90 from Vancouver Island, BC participated in face-to-face interviews using think-aloud as well as probing techniques. Cognitive Aspects of Survey Methodology (CASM) and grounded theory techniques were used for data analysis. Although the DSCS items were comprehensible to most participants, two items caused serious confusion pertaining to word choice and sentence structure. On the other hand, DSCS scores may identify couples who are struggling with dyadic sexual communication. Evaluating dyadic sexual communication may reveal a couple's overall relational well-being, and may elicit socially desirable responses such as satisficing. In the context of progressive chronic or debilitating illness couples were *fixating on function*, *exploring alternatives*, and *communicating (non)mutuality*. Nurses are encouraged to educate themselves about sexuality in order to be prepared to discuss the topic with people who might want more support. More sexuality research is needed with the four-item DSCS and with couples who might benefit from a palliative approach.

Acknowledgements

Thank you, SV, who woke me to the fact that a man in a wheelchair, who spoke using a tablet, who was fed and excreted using tubes, and who was completely dependent on others for his physical care was sexually active. “My wife worries I will have a heart attack or fall down when we have sex.” They both laughed and I was in awe and embarrassed that I had never considered this possibility. My one encounter with you sent me on this amazing journey of discovery.

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Chapter One: Introduction and Background

Palliative care research seeks to enhance quality of life by using a wide variety of designs and measures. Self-report measures “represent one of the most efficient and inexpensive research methods available to collect representative, high quality data from large numbers of research participants” (Murdoch et al., 2014, p. 1), and are a common way for researchers to gather data from patients, families, and palliative care practitioners. Self-report measures rely on research participants’ willingness to answer all questions in an honest manner, that is, every question answered and with a response that resembles current reality (Preisendörfer & Wolter, 2014; Tourangeau & Yan, 2007). When either of these conditions is not fulfilled, the survey results are subject to reporting errors, which calls into question the validity of the study results.

Sensitive questions in surveys are particularly prone to survey error. According to Preisendörfer and Wolter (2014), “many questions in surveys are not socially neutral in their content and context, but are ‘socially loaded’ and therefore connected with a more or less serious tendency to misreport” (pp. 126-127). Socially loaded questions can evoke an internal editing process for research participants who may not want to tell the truth about their thoughts and actions in the context of a research survey (Guéguen, 2015).

Questions about sexuality are deemed sensitive, and questions about sexuality with people who have a life-threatening diagnosis might be considered extra-sensitive. There has been an increased research focus in the past fifteen years on the sexuality of individuals and couples, with a particular focus on cancer sites that are perceived to impact sexuality such as the breast (Holmberg, Scott, Alexy, & Fife, 2001) or the prostate (Garos, Kluck, & Aronoff, 2007). The past eight years has seen a broader research emphasis on sexuality in a range of cancer types (Gilbert, Ussher, & Hawkins, 2009) yet research in sexuality tends to sit in isolation from general quality of life surveys. In other words, patients and/or partners are recruited for projects that explicitly focus on sexuality (Ananth, Jones, King, & Tookman 2003; Lemieux, Kaiser, Pereira, & Meadows, 2004) wherein researchers and participants are fully aware that sexuality is being evaluated. On the other hand, general quality of life surveys that encompass broad domains of physical, emotional, and social well-being tend to neglect sexuality. Where sexuality is evaluated, questions are often merely dichotomous (yes/no), or measures are developed for the specific survey (Hawkins et al., 2009), resulting in "instruments that lack reliability and validity. This increases measurement error and makes the results of the study questionable" (De Santis & Vasquez, 2010, p. 180). For example, the Functional Assessment of Chronic Illness Therapy (FACIT) (www.facit.org) quality of life instruments have been adapted for use with a variety of life-limiting and chronic diseases, and include an item on satisfaction with sexual life. The questionnaires have shown reliability and validity (Webster, Cella, & Yost, 2003) but have also demonstrated an item nonresponse rate of up to 29% for the sexual life item (Dupont et al., 2009).

Errors in measurement can occur because research participants are often not asked about their experience of survey measures. The development and evaluation of self-report measures is a complex, time-consuming process usually accomplished in consultation with professionals in the particular domain (Stulhofer, Busko, & Brouillard, 2010). Target populations of patients or families are starting to be included in the development and evaluation of self-report measures but many gaps remain regarding the study of sexuality with people who have life-threatening or chronic progressive diagnoses.

Statement of the Problem

In the last two decades the research community has begun to investigate sexuality by engaging people with cancer and often their intimate partners. Where traditional palliative care has focused predominantly on the quality of life of cancer patients and their families, palliative care research also has tended to focus on quality of life for this population. Sexuality is an important quality of life issue. When researchers conjoined the study of sexuality with people who have a life-threatening diagnosis they started with people who have cancer. Indeed, even now most of the fulsome mixed methods sexuality research in the context of life-threatening illness tends to focus on the experiences of this population. As the understanding of palliative care has expanded to more of a palliative approach that explicitly focuses on other progressive chronic illnesses early in the disease trajectory, it would seem important to measure sexuality as a quality of life issue in this population.

Unfortunately, most sexuality research with people who have progressive chronic illnesses has an "overwhelming emphasis on genital and functional sexuality" (Hordern, 2008, p. E10; see also Arrington, Cofrancesco, & Wu, 2004; McClelland, 2012). Indeed, Merghati-Khoei, Pirak, Yazdkhasti, and Rezasoltani (2016) reviewed the literature pertaining to sexuality in people with a number of chronic diseases: diabetes; cancer; and cardiovascular, renal, bowel, lung and rheumatic diseases. Although there is mention of patients' experiences, every section of the review principally addresses sexual (dys)function regarding activity and performance. In addition, the aforementioned literature focuses on patients alone and neglects the intimate partner. This is not to say that patient perspectives should not be investigated but rather that there is a dearth of chronic disease research that focuses on the couple.

Another issue to consider is that survey questions about sexuality are often seen as unduly sensitive and invasive, thus potentially causing participants to feel uncomfortable, embarrassed, or anxious (Mitchell et al., 2007). In addition, uncomfortable feelings may lead participants to censor or alter their answers, a social desirability response that can lead to response errors (Tourangeau & Yan, 2007).

Finally, sexuality self-report measures that have prior evidence of reliability and validity (quantitative) or appropriateness and acceptability (qualitative) in one population may not obtain the same objectives with other populations (Murtagh, Addington-Hall, & Higginson, 2007). A sexuality self-report measure that has been deemed valid and acceptable to people with cancer and their intimate partners may not achieve the same results with people who have a different progressive chronic illness and their intimate partners. Because of these differences it is important to evaluate sexuality self-report measures in couples who might benefit from a palliative approach.

Background and Need

These are the early days of evaluating sexuality in general quality of life surveys with people who have a life-threatening diagnosis and their intimate partners. The work of an Australian research team currently publishing the greatest quantity of literature regarding sexuality post-cancer provides an example of the growth of sexuality studies. Hawkins et al. (2009) began with a mixed methods general quality-of-life survey in the context of cancer, which included measures for anxiety, depression, and caregiver burden, but also dichotomous and ‘created’ sexuality questions; participants were recruited for a general survey and sexuality questions were embedded in the survey. In the context of cancer-caring the studies report on gendered roles (Ussher, Sandoval, Perz, Wong, & Butow, 2013), relationship changes (Ussher, Wong, & Perz, 2011), and communication with health professionals (Gilbert, Ussher, Perz, Hobbs, & Kirsten, 2010). In addition, three articles feature analyses about sexuality in the context of cancer with a particular focus on intimate partners, whose experiences and needs are often invisible both in the care environment and in research (Gilbert et al., 2009; Gilbert, Ussher, & Perz, 2010; Hawkins et al., 2009).

Next, Ussher and colleagues recruited participants explicitly for sexuality research by conducting a “mixed-method study examining [patient and partner] changes to sexuality and intimacy in the context of cancer” (Ussher, Perz, Gilbert, Wong, & Hobbs, 2013, p. 456). The studies reported so far include patients’ and partners’ accounts of talking about sex with health professionals (Gilbert, Perz, & Ussher, 2014), health professionals’ accounts of talking about sex with patients and partners (Ussher, Perz, Gilbert, Wong, Mason, Hobbs, & Kirsten, 2013), Q-methodology for conceptions of sex and intimacy after cancer (Perz, Ussher, & Gilbert, 2013), and perceptions of sexual changes and renegotiations for patients and partners (Ussher, Perz, & Gilbert, 2015; Ussher, Perz, Gilbert, Wong, & Hobbs, 2013). Fulsome mixed methods research has revealed much about the experiences of patients with cancer and their intimate partners.

Sexuality research focusing on people who might benefit from a palliative approach, such as people with progressive chronic illnesses, would recruit participants further ‘upstream’ in the illness trajectory and investigate the issue from the perspective of many different illnesses. The focus of the research would align with the palliative care mandate of patient- and family-centered care with an emphasis on quality of life issues rather than mere sexual functioning (Leung, Goldfarb, & Dizon, 2016). Dyadic sexual communication is one such quality of life issue that has been studied quantitatively with patients with cancer and their intimate partners (Garos et al., 2007; Perz & Ussher, 2015; Perz, Ussher, & Gilbert, 2014; Seidler, Lawsin, Hoyt, & Dobinson, 2016). The most common dyadic sexual communication scale used in palliative/cancer research is the Dyadic Sexual Communication Scale (DSCS); indeed, it is the only scale of its type in Fisher, Davis, Yarber, and Davis’ (2011) *Handbook of Sexuality-Related Measures* (3rd ed.). The

13-item DSCS has been used in the context of sexuality after cancer with prostate cancer patients and partners (Garos et al., 2007), and a range of cancer patients and partners (Perz et al., 2014; Perz & Ussher, 2015).

The fact that the 13-item DSCS has been used in cancer research demonstrates that patients and partners are willing to participate and to answer questions about sexuality. However, the 13-item DSCS has not been evaluated for appropriateness and acceptability for people with progressive chronic illnesses who are in need of a palliative approach. Again, almost all of the sexuality research in the context of progressive chronic illness is focused on the patient’s sexual function leaving other quality of life issues such as dyadic sexual communication and the intimate partner’s perspective under-investigated in this population.

A modified version of the 13-item DSCS, the four-item DSCS, was created in order to accommodate “frequent evaluations” (Catania, 1998, p. 129) during longitudinal research. The four-item DSCS, which may be a more practical sexual communication measure in a broad or longitudinal quality-of-life survey, has never been used or evaluated in research with people with progressive chronic illness and their intimate partners. Therefore, the four-item DSCS needs to be evaluated for appropriateness and acceptability by couples who might benefit from a palliative approach.

Definitions of Terms

Palliative care. Palliative care is often described as the services provided by specialized health care professionals to people at end of life. The World Health Organization offers a more comprehensive definition:

> Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the

> prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (WHO, 2017)

The WHO definition introduces the idea that palliative care is an approach, and that quality of life, symptom management and the relief of suffering are the focus for patients and their families.

Palliative approach. A palliative approach considers "people facing chronic, life-limiting conditions at all stages, not just at the end of life" (Canadian Nurses Association, 2015, p. 2). Because 'palliative care' began with a focus on end of life, many people still associate it with that stage alone. Although this is no longer the case theoretically, in practice palliative care often equates to end of life care. A 'palliative approach,' on the other hand, shifts the scene further back in time or 'upstream' (Sawatzky et al., 2016) such that a primary or chronic care team, as well as the focus on person-centered care, quality of life and relief of suffering are available much earlier in the disease process, sometimes immediately after diagnosis. In addition, whereas until relatively recently palliative care has predominantly focused on cancer patients, a palliative approach explicitly draws attention to other progressive chronic illnesses such as renal disease, obstructive pulmonary disease, heart failure, and neurological diseases (Bacon, 2013).

Sexual quality of life. An emphasis on quality of life has been the focus of a palliative approach to care and research with people who have progressive chronic illnesses. Although most of the sexuality research with this population focuses on genital and functional sexuality, the concept of sexual quality of life encompasses biomedical and psychosocial aspects of sexual health. McClelland (2012) defines sexual quality of life as "sexual responses, cognitions, and attitudes, as well as dimensions related to intimate relationships and a sense of one's physical body as capable and entitled to experiencing sexual sensations" (p. 246). People experience the world in many ways: from an individualistic, intra-psychic perspective; an interpersonal, relational perspective; and as beings situated in a certain culture (Mitchell et al., 2011). Sexual quality of life measures broaden the focus of investigations beyond biomedical sexual (dys)function to encompass many psychosocial domains (Arrington et al., 2004).

Sexuality. The term 'sexuality' is often used as a construct for a variety of activities and theories. The WHO definition of sexuality is embedded in a 2015 World Health Organization document, "Defining Sexual Health: Report of a Technical Consultation on Sexual Health":

> Sexuality is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles, and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical, religious and spiritual factors. (WHO, 2015, p. 5)

The word "normal" does not appear in the definition, perhaps aligning with Tiefer (2012) who endorses "the absence of norms for sexual desire and activity" (p. 27), thus engendering an open, flexible approach.

Intimacy. Intimacy can "describe sexual acts, but at the same time also denotes something 'more' or other than sex: in particular, other than intercourse" (Sandberg, 2013, p. 262). Indeed, most authors agree there are enough words available to describe sexual intercourse: penetrative sex, penetrative intercourse, coitus, penis-vagina intercourse (Ussher, Perz, Gilbert, Wong, & Hobbs, 2013), and so intimacy can be reserved for other actions such as “sharing and closeness between partners,… encompassing touch and intimate communication” (Hordern, 2008, p. E11), “a quality in a mutual relationship, and as feelings of emotional closeness” (Palm & Friedrichsen, 2008, p. 6), and “a set of processes through which both partners expose themselves in verbal and nonverbal ways, trusting that the other person will be understanding and not betray trust” (Rolland, 1994, pp. 328-9). Intimacy, for the sake of this study, refers to close, private actions between partners, naked or fully clothed; actions undertaken for pleasure, comfort, or attachment.

Appropriateness and acceptability. Fitzpatrick, Davey, Buxton, and Jones (1998) state that “appropriateness requires that investigators consider the match of an instrument to the specific [research] purpose and questions” (p. iv) and that acceptability “addresses how acceptable is an instrument for respondents to complete” (p. iv). This study will evaluate whether the four-item DSCS asks questions that match the experience of couples who might benefit from a palliative approach, and whether this population is willing to complete the measure.

Purpose of the Study

Purpose statement: The purpose of the study was to evaluate the appropriateness and acceptability of the four-item Dyadic Sexual Communication Scale and to gain perspectives on sexuality and dyadic sexual communication in couples who might benefit from a palliative approach.

Description of the study: In order to evaluate the appropriateness and acceptability of the four-item DSCS, cognitive interviews were conducted with 4 couples who might benefit from a palliative approach. Members of the couple were interviewed separately to evaluate each of the four items using scripted concurrent probing techniques as well as reactive/spontaneous probes as needed. In addition, the measure as a whole was evaluated with scripted and reactive retrospective probing. Further details are outlined in the Methods section.

Research Questions

1. For couples who might benefit from a palliative approach, what are their perceptions of each item of the four-item DSCS, and the measure as a whole?

2. What are the couples' perspectives on sexuality and dyadic sexual communication?

Relevance and significance. People with progressive chronic illnesses and their intimate partners might benefit from a palliative approach in order to begin addressing sexual quality of life issues early in their disease trajectory. Sexuality and dyadic sexual communication are quality of life issues that have received scant attention in the research with this population. The four-item DSCS is a survey measure that can be used in generalized quality-of-life surveys, yet it remains to be seen if the DSCS is appropriate and acceptable to couples who might benefit from a palliative approach.

Outline of Thesis

The thesis is organized into five chapters: Chapter One describes the project domain, the statement of the problem, the background and need, key terms, and research questions. Chapter Two outlines the search and retrieval strategies used for the literature review, along with a comprehensive examination of the relevant research. Chapter Three describes the methods and procedures used in the project including recruitment, inclusion criteria, sampling, data collection and analysis, ethical considerations, and issues of trustworthiness. Chapter Four describes the results of the cognitive interviews and Chapter Five provides a discussion of the results in the context of current literature, study limitations, considerations for nursing education and practice, recommendations for future research, and a conclusion.

Chapter Two: Literature Review

The literature review was undertaken in order to understand sexuality research with people who have life-threatening and progressive chronic diagnoses. The search and retrieval strategies will be reviewed, followed by the findings of the review. The following concepts guided the research: a palliative approach to care and research, palliative care research, sexuality research in cancer and other progressive chronic illnesses, and sensitive survey questions.

Search and Retrieval Strategies for Literature Review

The initial extensive literature review was conducted over the course of four months, November 2014 through February 2015, followed by bi-monthly supplemental searches until completion of the thesis in May 2017. Multiple databases were accessed via the Trinity Western University electronic library: CINAHL (*Cumulative Index to Nursing and Allied Health Literature*), MEDLINE, PubMed, OVID, Science Direct, Web of Science, NIH RePORTER, NLM Gateway, Clinical trials.gov, Cochrane Library, and the Joanna Briggs Institute (JBI) (see Appendix A). Google Scholar was often successful when the databases failed to locate a specific article. Searches were restricted to English language articles for which a full-text was available. All articles for which there was no full-text available in the library databases through TWU or the Internet were excluded. Key terms included “sexuality or intimacy” and “partner or couple or spouse or caregiver” and “palliative or terminal or neoplasm.” The most productive search was the backward and forward citation function in Web of Science and Google Scholar. All of the most pertinent articles were entered in this search engine and every abstract reviewed for pertinence. Abstracts of 250 articles published from the 1950s to the present were reviewed in order to obtain a general historical perspective. Five articles referred to sexuality in partners of palliative patients; thirteen articles referred to sexuality in partners and/or couples where the patient has cancer. Four articles were kept for their historical significance (expert opinion pieces regarding sexuality and terminal illness): two oft-cited seminal articles that referred to sexuality in palliative patients (Ananth et al., 2003; Lemieux et al., 2004), and two literature reviews with thoughtful definitions of terms. The most pertinent articles range from 2007-2015 (see Appendix B). Regarding research methodology, there are 15 qualitative, five quantitative and one mixed-methods study.

Ongoing supplemental searches were conducted throughout the project to delve further into measurement evaluation, data collection, and analysis using cognitive interviewing techniques, and a palliative approach.

Literature Review

Palliative care research. Palliative care research aims at discovering ways to reduce suffering for patients and families. The Canadian Institutes of Health Research (2005) declare, “the key to change lies in rigorous scientific research that will provide the evidence for informed decision-making by clinical practitioners and policy makers” (n.p.). This may be accomplished by using methods both qualitative (Gilbert et al., 2009; Lemieux et al., 2004; Matzo & Hijjazi, 2009) and/or quantitative (Ananth et al., 2003; Garos et al., 2007; Perz et al., 2014) that ultimately aim at improving the quality of life of patients and families. In addition, the dictates of evidence-based practice compel research projects that emerge from the target population (Alexander, 2010; White & Hardy, 2010). In other words, education or intervention in the palliative care environment must use palliative care patients and families in the research realm in order for results to be valid for the intended population (Gysels et al., 2013). Unfortunately, as Kavanaugh and Campbell (2014) state “conducting studies at the end of life is often challenging for researchers due to the sensitive nature of the research, the vulnerability of the participants and the inherent methodological complexities” (p. 14). Palliative care research consists of a potent combination of sensitive topics such as the realm of death (as well as other topics) with a unique and possibly distressed population. In addition, palliative care research has the same methodological challenges as any other type of research, for example with participant recruitment and retention.

Sexuality research in couples who might benefit from a palliative approach. Sexuality has been studied in people with chronic illnesses such as cardiovascular disease (Assari, Lankarani, Ahmadi, & Saleh, 2014; Mosack, Hill, & Steinke, 2015), respiratory disease (Collins, Halabi, Langston, Schnell, Tobin, & Laghi, 2012; Kaptein et al., 2008), kidney disease (Kim et al., 2014; Sabanciogullari, Taşkın Yılmaz, Güngör, Söylemez, & Benli, 2015), and neurological disorders such as Parkinson’s disease (Jitkritsadakul, Jagota, & Bhidayasiri, 2015; Varanda et al., 2016) and multiple sclerosis (Kolzet et al., 2015; Marcket al., 2016). Most studies use quantitative survey methods and focus solely on sexual (dys)function investigating “arousal, sexual drive, vaginal lubrication/penile erection, ability to reach orgasm, and satisfaction from orgasm” (Sabanciogullari et al., 2015, p. 177). The terms ‘sexuality and intimacy’ or euphemistic terms such as sexual health, sexual life (Sabanciogullari et al., 2015), sexual well-being (Verschuren, Enzlin, Dijkstra, Geertzen, & Dekker, 2010) may appear in the title of an article, but inevitably the study is investigating function and performance. Although it is important to understand the physical impacts of disease on sexual functioning, purely quantitative methods neglect the lived experience of people with chronic diseases. In addition, all of the above studies investigate sexuality from the perspective of patients alone and do not include partners. Again, this is important information but as Verschuren et al. (2010) note:

> Some studies have indeed studied the impact of chronic disease on sexual functioning but

> have neglected relationship issues; other studies have focused on the effect of the chronic disease on the relationship, but have neglected sexual issues. Future research should strive to combine all three domains—disease, relationship, and sexuality. (p. 165)

The most fulsome mixed methods research pertaining to all three domains is found in the realm of cancer patients and partners; a literature search with the terms ‘sexuality’ and ‘palliative’ inevitably reveals the longstanding link between palliative care and cancer care. Thus, a review of sexuality research with partners and people who have a life-threatening illness such as cancer can provide a vision for future sexuality research in couples who might benefit from a palliative approach. The term ‘people who have progressive chronic illness’ will also be used to describe this population.

Sexuality research with people who have a life-threatening diagnosis and their partners. The investigation of sexuality has been accomplished in the last decade with quantitative and qualitative investigations; the latter research method predominates. A range of responses characterizes sexuality in the face of a life-threatening diagnosis: complete cessation of all sexual or intimate activities, ongoing struggle, or redefining and renegotiating the intimate relationship.

Complete cessation. One end of the range of responses is the cessation or diminishment of sexuality, which may be a longstanding position, “a story of celibacy” (Gilbert et al., 2009, p. 529), or a response to end-of-life issues. Walker and Robinson (2011) commented that for many couples “no sexual activity was defined as not engaging in any sexually intimate contact with the intent to produce sexual pleasure and included not only intercourse but also any activity that may be typically thought of as foreplay” (p. 882). Partners at this end of the range tend to be older (Drummond et al., 2013; Gilbert, Ussher, & Perz, 2010; Walker & Robinson, 2011), have a relationship history of negative sexual and communication experience (Gilbert, Ussher, & Perz, 2010), and focus on survival, where sexuality is seen as frivolous (Holmberg et al., 2001; Hordern, 2008; Walker & Robinson, 2011). In addition, consistent in much of the partner research, the partner is exhausted from caregiving (Gilbert et al., 2009; Hawkins et al., 2009; Taylor, 2014). Indeed, according to Ussher et al. (2012) “disrupted schedule was the single significant predictor of changes to the sexual relationship” (p. 80).

The dual role transitions for both members of the couple: lover to patient and lover to caregiver, often impacts the couple’s ability to continue to view their partner as a viable intimate companion. There is a belief that it is inappropriate to have sex with a person with a life-limiting disease (Hawkins et al., 2009) because the patient may be child-like due to care needs and therefore considered asexual (Gilbert et al., 2009). Indeed, the patient often has no desire, is disfigured (Taylor, 2014), incontinent, unwell, in pain, heavily medicated, tired, experiencing sweats, surgical consequences, and hampered by medical equipment (e.g., port-a-cath) (Gilbert et al., 2009).

Partners and patients express a wide range of emotions in regards to the cessation of sexuality. Some reactions seem positive and healthy: immediate acceptance (Walker & Robinson, 2011), reconciled (Gilbert et al., 2009), relief (Drummond et al., 2013) and a sense of sexuality being irrelevant, although Drummond et al. (2013) question whether positioning sexuality as ‘irrelevant’ is a coping mechanism for people who are considered by society to be asexual. For many people, the cessation or diminishment of sexuality and intimacy evokes negative thoughts and emotions such as anger, confusion, loneliness, frustration, sadness, loss (Gilbert et al., 2009), rejection, waste (Drummond et al., 2013), shame, remorse, and guilt (Taylor, 2014).

Renegotiation. At the other end of the range of responses some couples have figured out how to stay connected and to redefine and/or renegotiate their sexuality. Their language verges on transcendence: “humility,” “generosity of spirit,” “being really very close,” “part of one another,” “being accepting,” (Ussher, Perz, Gilbert, Wong, & Hobbs, 2013), but also “desire,” “fun,” “laughter,” “romantic” (Walker & Robinson, 2012), and “courage,” (Palm & Friedrichsen, 2008).

The couples in this group are facing disability and/or death for one of them and they actively choose to commit to the relationship by continuing to emphasize intimacy. Most couples talk about “close(ness)” (Palm & Friedrichsen, 2008; Taylor, 2014; Ussher, Perz, Gilbert, Wong, & Hobbs, 2013; Walker & Robinson, 2012), and many claim that their intimate life is better than before the diagnosis (Gilbert, Ussher, & Perz, 2010; Taylor, 2014; Ussher, Perz, Gilbert, Wong, & Hobbs, 2013). For most, sexuality and intimacy remain as important as ever but the physical expression has changed (Lemieux et al., 2004; Ussher, Perz, Gilbert, Wong, & Hobbs, 2013) in that very few couples desire or are able to engage in penetrative intercourse. The partner has a fully functioning body able to engage in most desired activities (barring their own health problems), whereas the patient may have deficits; many urges and body parts cannot be relied on to perform as in the past. But certain actions are possible, including: touching, holding, looking, cuddling, spending time (Ussher, Perz, Gilbert, Wong, & Hobbs, 2013), “mutual masturbation, self-masturbation, manual stimulation by patient, oral sex, massage, the use of vibrators, kissing and hugging” (Gilbert, Ussher, & Perz, 2010, p. 1005). In other words, activities that used to fall under the category of “foreplay” are now considered to be “real sex,” with one patient claiming it was “like being teenagers” (Ussher, Perz, Gilbert, Wong, & Hobbs, 2013, p. 457).

Open communication is the hallmark of the couples that were able to renegotiate their sexuality and intimacy. “All of these couples reported having intentional conversations about their sexual relationship. Honest communication seemed to help them increase clarity about each other’s expectations and allowed them to avoid making inaccurate assumptions about one another” (Walker & Robinson, 2011, p. 885). Perz et al. (2014) state that “sexual communication [is] a significant predictor of sexual functioning…[and] a key factor in sexual renegotiation” (p. 14). This makes sense since the ability to “make the effort” to have hard conversations, and to see these conversations as “something that has had to be done” (Gilbert, Ussher, & Perz, 2010, p. 1004), likely helps couples continue to invest energy in their intimate and sexual lives.

Struggle. Somewhere in the middle of the range of responses, between cessation and renegotiation of intimacy or sexuality, are the couples that are “struggling and sexually dissatisfied” (Walker & Robinson, 2011). These couples struggle with nonmutuality because of the “assumption that it was important for them to be equally contributing to all areas of the sexual relationship” (Walker & Robinson, 2011, p. 454). Some areas of nonmutuality or lack of balance in the couple’s sexual relationship included desire, affection, actions, initiation and effort (Walker & Robinson, 2011), and, most importantly, communication styles (Milbury & Badr, 2013).

Communication efforts for this group were consistently negative or nonexistent. Some couples “never discussed sex before cancer and did not discuss it now” (Ussher, Perz, Gilbert, Wong, & Hobbs, 2013). Efforts were “blocked,” certain feelings were “forbidden,” and “the silence surrounding sex within coupled relationships provided room for misunderstandings to flourish” (Taylor, 2014). In one study, protective buffering, “the degree to which individuals hide concerns and negative feelings and avoid arguments with their partner” (Manne & Badr, 2010, p. 944), was associated with less intimacy and more distress, and a demand-withdraw communication style, coupled with sexual difficulties, was associated with depressive symptoms (Milbury & Badr, 2013). Ineffective communication styles and attempts hindered couple well-being and total quality of life.

Dyadic sexual communication. A couple's ability to discuss sexual matters, hereafter known as dyadic sexual communication, emerges as one of the most important aspects of sexuality in the face of a life-threatening diagnosis. Couples that are able to discuss sexual matters, even in the context of a life-limiting or progressive chronic diagnosis, often redefine and renegotiate their sexual and intimate lives thus engendering joy and closeness, indeed, that "relationship closeness develops from communication" (Manne & Badr, 2010, p. 950). According to Cupach and Comstock, (1990) "satisfaction with sexual communication was significantly and positively associated with sexual satisfaction, dyadic adjustment, dyadic satisfaction, dyadic cohesion, affectional expression, and dyadic consensus" (p. 179). In other words, dyadic sexual communication impacts couple's sexuality and overall relational well-being.

Dyadic sexual communication has been evaluated for a variety of reasons, using a variety of measures; most sexual communication scales are used to evaluate how couples communicate about sexual *health* behavior, such as HIV/AIDS prevention strategies (Milhausen et al., 2007; Quinn-Nilas et al., 2015; Rojas-Guyler, Ellis, & Sanders, 2005). The 13-item (DSCS) was created in 1986 by Dr. Joseph Catania (1998) in order to measure participants' perceptions of the "discussion of sexual matters with their partners" (p. 129). The measure has been used to evaluate sexual health communication (Catania, 1998; Catania, Gibson, Chitwood, & Coates, 1990), but is predominantly used to evaluate the quality of couples' communication about sexual matters. The measure has been used with women with provoked vulvar pain and their partners (Smith & Pukall, 2014), and with gay male couples (Starks & Parsons, 2014). In addition, the DSCS has been used in the context of sexuality after cancer with prostate cancer patients and partners (Garos et al., 2007), and a range of types of cancer (Gilbert et al., 2009; Perz et al., 2014; Perz & Ussher, 2015). According to Garos et al. (2007), partners' depression was a significant predictor of lower dyadic sexual communication scores, and according to Perz et al. (2014), higher dyadic sexual communication was a significant predictor of partners' sexual functioning (Perz et al., 2014).

Sensitive survey questions. The DSCS is a self-report measure that directly asks research participants about behaviors, feelings, values, and opinions regarding sexual communication. Questions of this nature may be deemed 'sensitive' in three conceptual domains: intrusiveness, threat of disclosure, and social desirability (Tourangeau & Yan, 2007). Intrusive questions delve into topics that are considered to be 'taboo' or extremely private; questions about sexuality, religion, or income, for example, may offend respondents of all ages and cultures (Tourangeau & Yan, 2007). Questions that ask about illegal or illicit ideas or actions trigger possible self-protective responses lest an outside third party gain access to disclosures (Catania et al., 1990). Social desirability bias triggers participants to answer questions according to desires to control the perceptions of others or to safeguard one's self-perception (McCallum & Peterson, 2012). Questions about sexuality are 'risky' (Hordern & Street, 2007c), and deemed sensitive in that they are seen as 'intrusive' akin to an "invasion of privacy" (Tourangeau & Yan, 2007, p. 860).

Sensitive questions are especially prone to response error. This is problematic because errors can introduce overall bias and thus compromise the quality of the data. Tourageau and

Yan (2007) describe three types of response errors: (a) overall response rates wherein the sample of people who choose to participate may have vastly different characteristics from ‘non-responders’, (b) item nonresponse rates wherein certain questions are not answered, or (c) response quality wherein people may not “answer the questions truthfully” (p. 682).

There has been a great deal of research addressing response errors in sensitive survey questions. Mode of administration has been extensively investigated, comparing audio computer-assisted survey instruments (ACASI), self-assessment questionnaires (SAQ), face-to-face interviews, and random-response technique (RRT) (Langhaug, Sherr, & Cowan, 2010). Unfortunately there is no consensus regarding the most effective mode of administration to reduce errors. Langhaug et al. (2010) report “ACASI can significantly reduce reporting bias” (p. 362), whereas Hamilton and Morris (2008) report “the mode of survey administration did not appear to influence disclosure” (p. 842). Other factors that can ameliorate response errors include the use of instruments that are valid, reliable, and evaluated by similar research populations; the use of language that is appropriate for the population; assurances of privacy and confidentiality (Weinhardt, Forsyth, Carey, Jaworski, & Durant, 1998); and a confident, competent, experienced interviewer who is able to put people at ease (Mitchell et al., 2007). In addition, although there is a perception that people will not answer survey questions about sexuality, Hamilton and Morris (2008) report that nonresponse is low for sexual behavior questions whereas “item non-response rates for income questions are on the order of 25–30%” (p. 856). People are willing to answer questions about sexuality in surveys as long as the questions are pertinent to them and they are assured of confidentiality.

Palliative care research is conducted with a foundational focus on improving quality of life for patients and their loved ones. When using pre-existing sexuality measures that have been deemed valid and reliable in a variety of ways with a variety of populations, the measures must then be tested with people who have life threatening or progressive chronic illness. Cognitive interviewing is a way to evaluate the validity of a specific measure with a specific population. This technique goes beyond merely discovering semantic or terminological problems with questions but can also evaluate the content that is meaningful to participants.

The 13-item DSCS has been deemed valid for a variety of purposes and with a wide variety of populations. In addition, the measure has been used to evaluate dyadic sexual communication in cancer research thus showing that partners and patients are willing to answer the questions and that significant correlations can be documented. Unfortunately, the appropriateness and acceptability of the measure (and the four-item DSCS) has never been evaluated. In other words, the measure has been deemed valid in many studies, and the measure has been used and has revealed important information about dyadic sexual communication, but the experience of the measure has not been investigated. For example, what do people with a life-threatening or progressive chronic illness think about the measure? Does it ask about sexual communication in a way that is meaningful to these people? If the measure is deemed appropriate and acceptable to a sample of these people then the validity of the measure is enhanced, thus adding to the validity of a study where the measure is used. On the other hand, if the measure is not deemed appropriate and acceptable to this population then the palliative research community must consider the usefulness and validity of the measure in this context.

Chapter Summary

In this chapter, literature pertaining to a palliative approach to care and research, palliative care research, sexuality research in cancer and other progressive chronic illnesses, and sensitive survey questions was reviewed. Although sexuality in the cancer context has been well researched, studies specifically describing the experiences of sexuality for couples who might benefit from a palliative approach was very limited. The ability of partners and patients to discuss sexuality, also known as dyadic sexual communication, was shown to be a potent mediator for couples' overall relational well-being. The DSCS is a self-report measure that directly asks sensitive survey questions that may be deemed intrusive or taboo and therefore subject to response errors. Although the study of sexuality in the context of life-threatening and progressive chronic illness is rife with methodological complexities, for example reporting errors and the use of survey measures that may not be appropriate or acceptable to the study population, there are sound evidence-based approaches to address these challenges.

Chapter Three: Research Design, Method, and Procedure

This qualitative study used cognitive interviewing (CI) techniques to evaluate the four-item DSCS with partners and patients who might benefit from a palliative approach. The purpose of the study was to determine the appropriateness and acceptability of the measure, as well to explore the perspectives on dyadic sexual communication for this population. In order to understand these phenomena the following research questions were addressed: 1. For couples who might benefit from a palliative approach, what are their perceptions of each item of the four-item DSCS, and the measure as a whole? 2. What are the couples' perspectives on sexuality and dyadic sexual communication? This chapter includes a description of the study design, and includes discussions in the following areas: (a) rationale for the research approach; (b) recruitment and sampling techniques; (c) methods of data collection; (d) data analysis techniques; (e) ethical considerations; and (f) issues of trustworthiness. The chapter concludes with a brief summary.

Design

The research was designed based on the approaches and methods of cognitive interviewing. CI, a powerful method used in the development and evaluation of self-report measurement instruments, is designed to assess respondents' understanding and process of answering items in a questionnaire. The fundamental purpose of CI is to understand how a question performs in a specific social context (Miller, Willson, Chepp, & Padilla, 2014). It seems self-evident that questions about sexuality, for example, would elicit different responses from a 15-year-old and a 90-year-old; CI reveals respondent understanding and thought processes in answering a survey question. The power of CI accumulates from the wealth of information gained wherein respondents' "overt and hidden processes…thoughts and feelings, ideas and interpretations" (Gomes et al., 2013, p. 2836) are revealed verbally and often nonverbally during the interview process. The resultant verbal data and field notes can be used to evaluate the measure, the four-item DSCS, and the topic of interest, dyadic sexual communication.

Method

Recruitment. Recruitment started after receiving ethics approval from the Trinity Western University Research Ethics Board on February 3, 2016 (see Appendix C). The passive method of distributing posters (see Appendix D) in a wide variety of locations on Vancouver Island was the initial approach. Other recruitment strategies included: a newspaper article, a radio program appearance, an announcement on social media (Facebook and Craigslist), presence at a Health and Wellness Fair, and information lectures using a PowerPoint presentation at local support groups (see Appendix E). In addition, a website with recruitment information was created after requests from many potential participants: http://sexualityresearch.bravesites.com. I purposefully "friended" three people on Facebook: a natural health consultant, a sexual health educator, and a sexual health educator/sexological bodyworker. All have many "friends" and contacts in many communities on Vancouver Island and they "liked" or "shared" my page and website. I also approached several support groups in person and via email and received offers to speak at three: Prostate Support, Stroke Recovery, Women's Health. Finally, I spoke about the research and handed out my business card at every opportunity: my appointments at alternative health practitioners and my local general practitioner, a family birthday party (where I knew several same-sex couples would be present), the book launch of a local sexual health practitioner (seeking couples with alternative lifestyles: polyamory, bondage, dominance, submission, and masochism [BDSM] practitioners), a violence prevention class, a cultural safety class (seeking First Nation's couples—with the permission of the local Chief), and a fellow chaperone on the high school band trip. Participants contacted me by phone or took advantage of being in the same place at the same time to let me know of their interest. A follow-up phone call or face-to-face conversation ascertained inclusion and exclusion eligibility and provided an opportunity to describe the study.

Table 1 *Recruitment details*

	Posters	Newspaper article	Radio Program	Support Group	Social Media	Word of Mouth
Queries	2	1	0	2	10	2
Eligible couples	0	0	0	1	1	2

Participants. Participants self-selected by responding to the recruitment strategies outlined in Table 1.

Inclusion criteria. The inclusion criteria included being part of a couple (the husband/wife or common-law partner) where the patient has a chronic illness and may benefit from a palliative approach. Both members of the couple had to agree to be interviewed separately for up to one hour each in a face-to-face interview, and both had to be 19 years of age and older. Participants were required to read and write English, and they had to currently reside on Vancouver Island.

Exclusion criteria. The exclusion criteria included cognitive impairments, such as a diagnosis of dementia, in either the partner or the patient. For purposes of feasibility, people in an institutional setting were excluded.

Sampling. Purposeful sampling was used to recruit patients with any progressive chronic or debilitating illness that might benefit from a palliative approach, and couples in heterosexual/non-heterosexual, and monogamous/polyamorous relationships. However, variation was limited by having to rely on a convenience sampling approach since this topic can make recruitment challenging (Catania et al., 1990; Dunne et al., 1997; Fenton, Johnson, McManus, & Erens, 2001; Langhaug et al., 2010; Mithcell et al., 2007).

CI considers sampling in a qualitative way by using purposive sampling of a small number of participants. Given the typical range of 6 to 20 participants in studies that use CI (Gomes et al., 2013; Izumi, Vandermause, & Benavides-Vaello, 2013; Ryan, Gannon-Slater, & Culbertson, 2012; Willis, 2005), the initial goal for this study was to recruit 4-5 couples then, based on feasibility and richness of the data, up to a maximum of 10 couples. The low end of the range addressed what was feasible with this potentially difficult-to-recruit population in the context of a Master's thesis. Four couples were interviewed for this study.

Data Collection

Data were collected during face-to-face interviews in patients' homes; three couples shared a home, one couple lived separately. Each couple determined who would be interviewed first. In three instances the patient was interviewed first; in one instance the partner was interviewed first.

Taylor and de Vocht (2011) consider the complexities of interviewing couples about sexuality in the context of life-threatening illness. Joint interviews allow the couple to co-create the experience of talking in a research environment about their most intimate thoughts, feelings and actions. On the other hand, the presence of the partner may evoke socially desirable responses "that are perceived to be acceptable to the partner, or are consistent with the partner's perceived (or known) position" (Taylor & de Vocht, 2011, p. 1577). Separate interviews allow the possibility of uncensored, personal responses that may be unacceptable to, or private from, the partner. Unfortunately, separate interviews remove the people from their 'coupled relationship' and may leave a lingering sense of anxiety or distress because of secretiveness and unknown disclosure.

I chose to interview the couple separately since my data collection method, cognitive interviewing, customarily features a solitary participant. I concur with Taylor, a palliative care nurse, who chose to interview separately since participants "might speak of their fears or frustrations to a nurse, preferring not to share these with their partner quite so explicitly for fear of causing further distress" (Taylor & de Vocht, 2011, p. 1578). Partners and patients had the opportunity to debrief, both together with the researcher, immediately after both interviews were completed in order to realign their coupled relationship and to provide feedback about being interviewed separately.

Conscious of the sensitive nature of sexuality research I maintained an awareness of my way of being and appearance during the interviews. I was friendly but not flirtatious; careful to not seem to favor one member of the couple over the other. I dressed conservatively in a long sleeved white t-shirt, covered with a blouse, and long beige pants for each interview. I wore my hair tied back and minimal makeup.

I maintained an awareness of my social privilege as a 52-year-old university educated, white woman. I was conscious of a possible heteronormative stance since I am a cis-gendered (comfortable with the gender of the body into which I was born), heterosexual woman in a monogamous committed marriage. This aligns with Charmaz (2017) who states "methodological self-consciousness requires scrutinizing our positions, privileges, and priorities and assessing how they affect our steps during the research process and our relationships with research participants" (p. 35).

Cognitive Interviewing. CI data collection approaches can involve a passive interviewer who encourages a participant to perform a "think-aloud" while answering survey questions, or an active interviewer who asks "probe" questions. Current CI approaches outside of a cognitive lab often consist of both methods. Probes can be scripted (in advance) or reactive (during the interview); concurrent (probes after each question) or retrospective (probes after the complete survey has been administered); or any combination thereof. Examples of CI probes included: (a) "What did you think about when answering this question?" (b) "What does the term 'satisfying' mean to you?" All CI methods have adherents and opponents, advantages and disadvantages: "think-aloud" is seen as more natural but requires more effort from participants; probing is seen as somewhat intrusive but can help participants focus (Miller et al., 2014).

During the interviews, demographic information was obtained first (see Appendix F) and then the four-item DSCS was administered (see Appendix G). The first couple/participants were given a piece of paper with the five-point Likert scale (1 "strongly disagree," 2 "disagree," 3 "neither agree nor disagree," 4 "agree," and 5 "strongly agree") as I read the four statements. However, the first patient had vision difficulties and so I read the response options with each question. This technique was highly inefficient requiring numerous repetitions of the DSCS statements thus leading to the possibly erroneous finding that the participant was having trouble understanding the question. All subsequent interviews were based on an interview guide with each item of the four-item DSCS and the Likert scale on four separate sheets of paper. Each item was evaluated separately using concurrent verbal probing with scripted probes plus reactive probes for issues that came up during the interview (Willis, 2005). Retrospective verbal probing was used to evaluate the measure as a whole. Each participant had the opportunity to speak freely at the end of the interview. The interviewer's guide contained demographic questions, the four-item DCSC with the Likert scale plus scripted probe questions, and final retrospective questions about the measure and the experience of the interview (see Appendix H).

All interviews were audio-digital recorded and field notes were hand-written during and/or immediately after the interview. In one case the audio file was full toward the end of the interview and the final few statements were written as verbatim as possible. I transcribed all interviews listening to each interview and correcting the transcripts numerous times to ensure verbatim transcripts.

Measure. The four-item DSCS (see Appendix G) is a short form of the original13-item version, which was created in 1986 by Dr. Joseph Catania (1998) in order to measure participants' perceptions of the "discussion of sexual matters with their partners" (p. 129). The original measure featured a six-point Likert-type scale with "strongly agree" and "strongly disagree" as anchors, was administered by an interviewer, and used a "sum across all items for a total score" (Catania, 1998, p. 129). The 13-item DSCS has been used in two studies investigating sexuality after cancer, with prostate cancer patients and partners (Garos et al., 2007) and with patients with a range of cancers and their partners (Perz et al., 2014; Perz & Ussher, 2015). The measure has acceptable internal consistency reliability with Cronbach's alpha's of 0.83 for cohabitating couples (Perz et al., 2014), 0.89 for women with provoked vulvar pain and their partners (Smith & Pukall, 2014), and 0.73 for gay male couples (Starks & Parsons, 2014). Although the original DSCS was interviewer-administered, current use of the measure features either a postal or on-line questionnaire (Garos et al., 2007; Perz et al., 2014; Perz & Ussher, 2015; Quinn-Nilas et al., 2015; Smith, & Pukall, 2014; Starks & Parsons, 2014) with couples completing the questionnaire separately.

Two shortened and modified versions of the 13-item DSCS were developed in order to accommodate frequent evaluations during longitudinal research. The four-item version was examined in the National AIDS Behavior Survey (NABS), and the six-item version was developed for the AIDS in Multi-Ethnic Neighborhoods (AMEN) study. The four-item DSCS contains items 2, 8, 10, and 12 from the 13-item version. Although Catania (1998) states "reliability was good" with a Cronbach's alpha = 0.62 (p. 129) this may be contested given that Tavakol and Dennick (2011) state 0.70 to 0.95 represent an acceptable range. The four DSCS items derived from the original measure and numbered sequentially are as follows: (1) "Some sexual matters are too upsetting to discuss with my sexual partner." (2) "My partner has no difficulty in talking to me about his or her sexual feelings and desires." (3) "Talking about sex is a satisfying experience for both of us." (4) "I have little difficulty telling my partner what I do or don't do sexually." There is no evidence cognitive interviewing has been used with the 13-item or four-item DSCS. The four-item DSCS has not been used or tested in palliative care research and its appropriateness and acceptability to people who might benefit from a palliative approach has not been examined. The measure is used with Dr. Catania's permission.

Data Analysis

Cognitive interview data consists of verbal reports therefore an appropriate analysis method must be chosen to align with the study design and the nature of the research questions. Importantly, the verbal reports generated in order to design and pretest a survey measure would be handled differently from verbal reports evaluating whether the published measure is appropriate and acceptable to a specific population. Given the nature of the research, couple narratives were created so the verbal reports were situated in the context of the dyad (the couple) throughout the analysis. In other words, participants' verbal reports were considered as standalone entities but couples' verbal reports were most often considered as a dyadic entity. This early commitment to couple-level analysis ensured that all analysis took place in a context and not in isolation.

For the first research question content analysis methods were used to understand participants' perceptions of the four-item DSCS. First, a 'sum across all items' (Catania, 1998) was compiled for each participant and then each couple in order to analyze, report and describe the DSCS scores. Next a standardized coding scheme (Collins, 2007), Cognitive Aspects of Survey Methodology (CASM) (Miller et al., 2014; Willis, 2005) was used to determine if participants understood what each survey item was asking, to explain their thought processes in answering, and finally to provide a response to the item. The CASM process is easy to report and can be replicable across national and perhaps multi-national populations (Collins, 2007) thus contributing to the validity of the measure.

Data analysis began after each interview with a summative note guided by the Cognitive Aspects of Survey Methodology (CASM): a) comprehension, b) retrieval, c) judgment, and d) response; along with "a detailed question by question review" (Miller et al., 2014, Chapter 6, Section 2, para. 1). 4 X 8 tables were created to compile the data (four CASM items by eight participants) (See Appendices K-N). Comprehension refers to participants' ability to understand what the question is asking. Is the participant able to read and answer the question without asking for clarification of terms or wording? For example, item #2 states; "My partner has no difficulty in talking to me about his or her sexual feelings and desires." This item consists of many factors: perceptions about the experiences of another person (my partner), and a positive experience that is worded negatively ('no difficulty' can mean that something is easy but the question is not worded that way). Using item #2 as an exemplar to investigate the three remaining CASM domains (in italics), what strategies do participants use to *retrieve* the answer to the question about their partner talking to them about sexual feelings and desires? How do participants *judge* the importance and relevance of the item's many foci (perceptions of another's experience, item wording)? And finally, what is the actual *response* to the question (Ryan et al., 2012)? Thick description was used for the CASM summaries that were compared across partners, across patients, and within couples, in order to address the way each category of participant comprehended/retrieved/judged/responded to each item.

After completing the CASM analysis the CI data was further analyzed with an inductive-interpretive approach. According to Willis and Artino (2013) CI has been "reconceptualized as a sociological/anthropological endeavor, in that it emphasizes not only the individualistic mental processing of survey items but also the background social context that may influence how well questions meaningfully capture the life of the respondent" (p. 354). In other words, initial data analysis using a standardized coding scheme, the CASM framework, did not fully capture participants' perspectives nor the potent spoken and unspoken interactions that had taken place amidst and between responding to the four-item DSCS. Guided by grounded theory methods described by Kathy Charmaz (2014), the CASM tables were set aside for a few days in order to re-enter the transcripts with fresh eyes and a new approach. Double-spaced paper copies of each transcript were coded using pen and paper, moving line-by-line, and using gerunds. Gerunds are the noun forms of verbs that encourage the researcher to code for active processes rather than static descriptions of topics. In the example below the coding is active: connecting, shouting, choosing, assuming, wondering (see Table 2), providing "ready grist for seeing sequences and making connections" (Charmaz, 2014, Chapter 9, Section 3, para 17).

Table 2 *Example of coding using gerunds and memo writing*

Quote	Line 245: "Are you shattered honey from all those nasty questions?"

Coding	Connecting with his wife using (?) sarcastic humour.
Memo	In front of me from across the house he is shouting and choosing words for my benefit or to shake me a bit. His voice is very loud, he reasserts his place in the domain, and he is assuming “nasty” questions have been asked because he does not know the questions and therefore has only his imagination and conversations they had before I arrived. He is wondering: has she revealed too much? He is concerned about her well-being: using a term of endearment (honey) to call out to her and wondering what might have occurred while she was with me—that I could shatter her with my questions. I wonder if he is worried that my coming and interviewing them separately may “damage” something for her or between them.

Moving quickly and intuitively through each line, short codes were written, occasionally pausing to write longer memos when a particularly potent action was noted. Initial coding was followed by focused coding whereby repetitive or potent codes were used to “synthesize, analyze, and conceptualize larger segments of data” (Charmaz, 2014, Chapter 6, Section 1, para 3). The end-point in grounded theory is often to generate a theory of how the world “works” in a certain context. For the sake of feasibility, theory development was not the goal of this study. Grounded theory was not used to guide the development of the research project and although constant comparison did not guide the data collection, it did guide data analysis in the constant movement between the transcripts and the emerging codes.

Ethical Considerations

Trinity Western University, Research Ethics Board, permission was obtained February 3, 2016 (see Appendix C). Additional ethics amendments were approved March 25, 2016 and May 5, 2016 in order to expand recruitment strategies. November 15, 2016 an ethics amendment was filed to extend the recruitment period from December 31, 2016 to February 3, 2017 to align with the one-year mark of the application. An REB Renewal was approved February 23, 2017 to extend the study period for the completion of the writing of the thesis (see Appendix I).

Inclusion and exclusion criterion were assessed during an initial telephone call with one member of the couple. Once the couple agreed to be interviewed (via acceptance by the person who made the phone call) a mutually acceptable date, time, and location was chosen. Upon entering the home and making initial introductions, the informed consent process was completed with both members of the couple signing separate consent forms in each other's presence; each participant was given a copy of the consent form (see Appendix J) and a $5.00 honorarium gift card to keep regardless of their ongoing participation. The participants were aware they would be interviewed separately, they could decline to answer any questions, and they could stop the interview at any time. They were also aware that confidentiality was paramount; details from each interview would not be shared with the partner, and a self-chosen pseudonym would be used in reporting the results of the research.

The handheld recording device and paper notes were stored in a locked file cabinet. Transcripts of interviews were stored in a password-protected computer. The raw data was accessible only to my thesis supervisory committee and me and will be stored for seven years for possible secondary analysis.

Interviews with people who have a life-threatening or progressive chronic illness can be upsetting, while interviews about sexuality can be embarrassing. Extra training was undertaken in preparation for the study: Psychosocial Care of the Dying, a week long intensive course sponsored by Victoria Hospice; Intensive Sex Therapy Training, a week-long intensive course sponsored by The University of Guelph; and a Sexual Attitude Reassessment (SAR) 4-day intensive workshop at The Haven, Gabriola, BC. Active listening and compassionate presencing skills gained in 30 years of nursing practice were used during the course of the interviews. A list of local palliative care and sexuality resources was offered to each couple.

Issues of Trustworthiness

The integrity of a research project begins with the discovery of the necessity of the investigation as evidenced by a gap in the current literature, progresses through the application of the chosen research methods, and finally manifests in the reporting of the research results. Trustworthiness is used as one of the standards of quality in the preparation, organization, analysis, and reporting phases of qualitative research (Elo, Kääriäinen, Kanste, Pölkki, Utriainen, & Kyngäs, 2014). According to Miller et al. (2014), "in cognitive interviewing reports, credibility is demonstrated by a researcher's transparency and reflexivity" (Chapter 6, section 3, para 1). Trustworthiness was established for this project in the detailed, transparent explication of all phases of the research project. Reflexive journaling and peer de-briefing with my thesis supervisor were used from the first seminal ideas regarding sexuality with people who have a life-threatening or progressive chronic illness and continued through the writing of the final analysis.

Chapter Summary

In summary, this chapter provided details about the research design and methods of this project. Cognitive interviewing methods were used in order to evaluate the four-item DSCS and to understand participants' perspectives on dyadic sexual communication. The participant sample consisted of four purposefully selected couples who might benefit from a palliative approach. CI methods guided the data collection process. For the first research question, content analysis methods were used to understand the perceptions of the four-item DSCS, and for the second research question grounded theory methods were used to understand the perspectives on sexuality and dyadic sexual communication. Ethical principles were considered, and issues of trustworthiness, such as transparency and reflexivity, were accounted for in the explication of self-reflection and an audit trail.

Chapter Four: Results

The purpose of the study was to determine the appropriateness and acceptability of the four-item DSCS, as well to understand the perspectives on sexuality and dyadic sexual communication in couples who might benefit from a palliative approach. The four-item DSCS has never been evaluated with this population and it was believed that using cognitive interviews would reveal valuable information about the measure and about dyadic sexual communication for partners and patients. This chapter presents the results obtained from cognitive interviews with eight participants (four couples).

Seven findings emerged in relation to research question one:

1. The ‘sum across all items for a total score’ has the potential to reveal couples that may be struggling with sexual communication.
2. Participants comprehended most of the items with the following exceptions: the word ‘satisfying’ was seen as not applicable in the context of talking about sex for the oldest couple in the sample; item four was problematic for two participants.
3. Participants thought about their relationship history and usual way of being with each other as a retrieval strategy to respond to the items in the measure.
4. There were some gender differences with all of the women and one man expressing confidence about their ability to understand their partner’s thoughts and feelings.
5. Half of the participants perceived the DSCS measure as a whole to be asking about sexual function, with only two participants identifying sexual communication.
6. The four-item DSCS was deemed to be an appropriate and acceptable measure containing introductory level questions that do not probe too deep but that might be difficult for people not used to talking about sexuality.

7. Two participants engaged in satisficing, giving repetitive, simple answers to probe questions.

Three themes were constructed in relation to research question two:

1. Fixating on function
2. Exploring alternatives
3. Communicating (non)mutuality

Following is a presentation of the study results using thick description to support each finding. Participant demographics will be provided, followed by couple narratives using pseudonyms and couple-number based on the order of recruitment. Individual and couple DSCS scores will be described. Research question one will be answered using CASM analysis of CI data. Research question two will be answered using data analysis principles from grounded theory.

Description of Participants

Four couples were interviewed separately resulting in eight individual cognitive interviews (see Table 3). All couples declared themselves to be in a male-female dyad. (There was an implicit assumption that the couples were heterosexual although this specific question was not asked during the interview.) Three couples were married; one couple lived separately in different communities by mutual choice, but declared a commitment to each other and were raising her 9-month-old child. Ages ranged from mid-thirties to mid-eighties (a range will be given to aid in de-identifying participants). Relationship duration ranged from 3 to 26 years.

Table 3 *Demographics*

Characteristics	Patient	Partner
Gender		
Female	1	3
Male	3	1

Age		
30-40	1	1
40-50	1	1
50-60	1	
60-70		1
70-80		1
80-90	1	
Marital status		
Married	3 couples	
Living separately	1 couple	
Diagnoses		
Multiple Sclerosis	2	
DVT (May-Thurner's)	1	
Prostate cancer		1
Depression		3
Parkinson's Disease	1	

Couple Narratives

Since this study had a small sample size and recruited couples who might benefit from a palliative approach, couple narratives were written in order to understand the reasons for inclusion in the study and to contextualize the results. The narratives were based on recruitment and demographic data as well as from details obtained during the course of the interviews. Although none of the patients were receiving palliative care services all might benefit from a palliative approach given their diagnoses of progressive chronic or debilitating illness and current impacts on quality of life. All couples stated healthcare professionals had never asked them about sexuality although two couples sought counseling for other reasons related to the impact of the illness. (The following concepts will be referred to below: Activities of Daily

Living—ADLs—include self-care activities such as bathing, dressing, and eating; Instrumental Activities of Daily Living—IADLs—include functional activities such as housework, meal prep, and paying bills.)

Couple One. Samantha was a 40-50 year old woman who was diagnosed with MS 11 years ago. Her husband Joe was a 60-70 year old man who had depression. The couple was married and had been together 26 years. She had been ill recently and coughed often during the interview although she declined numerous offers to stop the interview. Samantha needed assistance with most ADLs and was able to walk holding onto surfaces although she became short of breath walking from living room to bedroom. Joe was responsible for all IADLs: housework, cooking, cleaning. The house was modified to accommodate Samantha's reduced mobility: handrails along the hall from living room to bedroom, a commode at the bedside, and an open-concept shower to accommodate a chair. This was the only couple that requested a formal debriefing session following the second interview; we all met in the living room for a 16-minute debrief after Joe's interview.

Couple Two. Jack was a 50-60 year old man who had been experiencing complications from DVT (May-Thurner's syndrome) and chronic pain secondary to the injury for 6 years. Although DVT is traditionally considered an acute condition and not a progressive chronic illness, Jack was told he could die at any time because although the left iliac vein was stented twice he "continued to clot above and below the stent." He described himself as a "workaholic, type A personality" who was now unable to work or exercise, both of which he had loved, due to complications from the original DVT. He started a Fentanyl patch for chronic pain the week of the interview. His wife Tracey was a 40-50 year old woman who was being treated for depression. The couple was married and had three school-aged children. Jack could complete most ADLs. A computer station was created at his bedside to enable him to “keep up with [his] field” while he maintained almost complete bed rest. When asked about psychosocial or sexuality supports in the healthcare system, Jack referred numerous times to the lack of “a total package” to support his comprehensive needs. Tracey stated Jack’s illness “turned our roles around” whereas before his injury she was a stay-at-home mother, after his injury and debility she had to return to work as a teacher in addition to maintaining the home and caring for the children whenever Jack was immobilized by pain or sedation.

Couple Three. Julia was a 70-80 year old woman diagnosed 3 years ago with Parkinson’s disease (PD). Paulo was an 80-90 year old man treated for prostate cancer 19 years ago. The couple was married. Although my recruitment material called for people with a serious illness neither Julia nor Paulo considered themselves seriously ill. Nonetheless, both could benefit from a palliative approach. They were both independent with ADLs for the most part although they assisted each other as necessary. Julia did not drive due to PD symptoms and the home was modified with handrails to assist with mobility.

Couple Four. Tadeauz was a 30-40 year old man diagnosed with MS 10 years ago. His partner Theory was a 30-40 year old woman who was being treated for depression; they were raising her 9-month-old son. The couple lived separately but both declared they had been together for 3-4 years. This is the only couple that met many years after the patient’s diagnosis. In other words, the new partner was fully aware of the patient’s disease condition before they became an intimate committed couple. Tadaeuz was independent with ADLs (including self-catheterization) and most IADLs. Although he was still driving he occasionally used walking aids when out in the community. Tadaeuz stated he was unable to work and needed frequent naps throughout the day to maintain his strength and emotional well-being.

Description of DSCS Scores

All participants willingly answered all four DSCS items, which allowed for the calculation of a “sum across all items for a total score” (Catania, 1998, p. 129) capturing individual and couple scores (see Table 4). No participant chose “strongly disagree” for any of the items, except for item one that had reverse coding. The lowest individual and couple scores were achieved by Couple Two, Jack and Tracey, who were both surprised that the other agreed to participate in sexuality research. Jack and Tracey never had the same response to any of the items, either agreeing where the other disagreed or the opposite. Although Jack stated he was more open to talking about sexuality than his wife he actually achieved the lowest score of all participants and chose “neither agree nor disagree” more than any other participant, perhaps aligning with his tendency to, in his words, “match her level of what she was trying to attempt to mention to me or talk to me.” Jack used the word “match” numerous times throughout the interview to describe how he comports himself with individuals and groups. At the end of the interview, but still in private, I gave Tracey a printout of the PowerPoint presentation of the current literature pertaining to sexuality in serious illness (see Appendix E). When I reviewed the three common responses: complete cessation, struggling and dissatisfied, and renegotiating and redefining intimacy, she said, “That’s would be us” when I described ‘struggling and dissatisfied.’ Her immediate identification in this category may align with their DSCS scores.

Two male patients, Paulo and Tadaeuz, both of whom repetitively declared themselves to be very open to talking about sexuality, not inhibited, and not having forbidden topics, achieved the highest possible individual score of 20. Both men discussed their inability to have penetrative intercourse thus confirming their openness and demonstrating sexual health in the face of what is often labeled as sexual dysfunction. The highest cumulative couple score was Couple Four, Tadaeuz and Theory, the youngest couple, who both stated they love talking about sex and were very eager to participate in the research. Tadaeuz stated he had not had penetrative intercourse in ‘seven [or] eight years’ and since the couple had been together for 3 ½ years this means the couple entered the relationship fully aware “traditional sex” (Tadaeuz’s term) would not be possible. Tadaeuz emphasized numerous times the importance and joy of ‘talking’ since his physical capacity had changed. Hence his excitement when I asked at the end of the interview what the measure seemed to be about. “Specifically *talking,*” he said. Indeed, his interview was the longest of the eight at 1 ½ hours.

Table 4 *DSCS scores and sums across all scores*

	#1 Some sexual matters are too upsetting to discuss with my sexual partner. (reverse scoring)	#2 My partner has no difficulty in talking to me about his or her sexual feelings and desires.	#3 Talking about sex is a satisfying experience for both of us.	#4 I have little difficulty in telling my partner what I do or don’t do sexually.	Individual Score; higher scores=better sexual communication
Patient 1 Samantha	Actual answer: 2 Reverse score: +4	4	5	5	18
Partner 1 Joe	1 +5	4	4	4	17
Patient 2 Jack	3 +3	2	3	3 to 4 3.5	11.5
Partner 2 Tracey	2 +4	4	2	2	12
Patient 3 Julia	2 +4	5	3	3	15
Partner 3 Paulo	1 +5	5	5	5	20
Patient 4 Tadeauz	1 +5	5	5	5	20
Partner 4 Theory	2 +4	4	5	4	17

CASM Evaluation of the Four-Item Dyadic Sexual Communication Scale

The four elements of a CASM evaluation: comprehension, retrieval, judgment, and response will be used to describe participants' cognitive processes in responding to the four-item DSCS as well as the concurrent and scripted probe questions. (For more detail: 4 X 8 tables were created to compile the data (four CASM items by eight participants) (See Appendices K-N)).

Comprehension. Participants understood most of the items; they followed instructions and understood what each statement was saying. One participant misunderstood item one, which had reverse coding, and one participant understood the negative wording of item one but then repeated his response on item two which was positively worded. One participant perceived that item two was asking about his partner's sexual history before the couple met. Two participants (Couple Three, Julia and Paulo) struggled with the term "satisfying" in item three; both stated the term did not apply in the context of talking about sex. For almost half of the participants talking about sex was for addressing and resolving problems: "It's satisfying in the respect that we can get something resolved" (Tracey). Julia noted, "Talking about sex is not difficult for us but as satisfying, that's the catch." Item four was the most problematic item in the measure. Most participants had to repeat the statement several times to understand what it was asking. Two participants struggled for up to ten minutes trying to understand the item. It appeared as though they used all of their cognitive energy understanding the item and perceived it was asking about things they have not revealed to their partner: infidelity or private sexual activities.

Retrieval. Most participants thought about their relationship history and usual ways of being together and talking with each other. Although interviewed separately three couples gave corresponding neutral or agree/strongly agree answers in noting their relational pattern of openness and being able to talk about sexual matters, thoughts and feelings, and activities. In other words, during probing both members of the couple gave the same story of good sexual communication. Couple Two, Jack and Tracey, also gave the same story but they described poor sexual communication. When answering the DSCS items they differed on every item in stating they had dissimilar relational styles and that this was consistent over time: one was open and one was conservative. Many participants cited specific examples to illustrate their understanding of the item and to retrieve their response. For example, in response to item two Julia stated, "Well… some of the hiccups when we discovered that we uh we couldn't have penetrative sex, he was quite comfortable with that, and able to discuss it."

Judgment. All of the women and one of the men stated they knew their partner well and were confident about their responses whereas three of the men talked about knowing themselves but were not certain about their partner's inner world; they expressed hope that their responses were consistent with those of their partner. Joe responded to item two but when probed was not confident about his interpretation since "Well that I'm not in her head. You know there's, everybody has their own mind. So though we will discuss things sexually…but to actually be inside her head is impossible." Almost half of the participants stated that 'talking about sex' (item three) was for resolving problems, or clarifying something.

Response. Most participants were able to map their judgment of the item onto a response category on the Likert scale, although Joe stated the scale "doesn't fit, you know and I don't know how you'd put it in that category. In the one to five. My answer, to the question." This was in response to the first item in the measure and he was able to use the scale with each of the subsequent items. Theory was unsure about the degree of her agreement with item four: "I would go in that four, five [on the Likert scale]. I'm just gonna go with four." She later stated she did not want to pick five because that meant there would be no room for improvement in their sexual communication.

CASM Summary

Overall the items and terminology were well understood by most participants with a few exceptions. There were a few response errors: one participant misunderstood the reverse coding of item one, and one participant understood the reverse coding for item one but answered item two as though it was also reverse coded, which was not the case. Item two seemed to have a gender bias with more women than men expressing confidence about their answer. There were comprehension difficulties with two of the four DSCS items (items three and four) for participants over age 60. Item three was confusing for both members of the oldest couple in the sample (age 70-90) owing to the word “satisfying” in the context of talking about sex. Item four was the most problematic item in the measure as noted above under comprehension. The two participants who struggled with the item were not of the same gender and were not a couple.

Participants’ Perceptions of the Four-Item DSCS Measure as a Whole

All participants were willing to respond to all of the items in the measure. This is not surprising given that all participants had agreed to be interviewed about sexuality. Most participants found the items easy/okay; two participants said they found the items difficult—they were used to doing research and being the ones asking the questions in a survey. Two participants were very excited to be participating in sexuality research and found the measure to be “fun” and “fascinating.”

When asked what the survey was asking about a minority of participants correctly identified communication/sexual communication as the topic under study. Half of participants (one female and two male patients, and one female partner) stated sexual function, or sexuality and coping after a serious diagnosis although none of the items ask about specific bodily abilities or the impact of illness. Given that three patients expressed this understanding it could be that they were more conscious of the impact of illness on their bodily functioning. In addition, the recruitment materials and the demographic section at the beginning of the interview were explicit about diagnoses so this focus may have been transferred onto the measure, particularly by the patient living with the illness.

All participants agreed the four-item DSCS was appropriate, acceptable, and relevant for couples where one has a serious illness. Participants thought the measure would "start a conversation," with "introductory" questions but that the questions "skirt around the issue" and do not get "to the nub of things." Three participants used the word "deep/er." The measure is not deep, does not ask deep questions about sexual/physical details, sexual frequency, or measures the couple has taken to cope with the impact of illness. When asked if they had wanted or hoped for this line of questioning all stated they had no specific hopes or desires for this line of questioning. Two participants stated the measure might be difficult for "people who are not used to talking about these things" (Theory). For Julia "some of [the items] were difficult, others were fine. "Because as I was saying we're a different generation." Numerous times throughout the interview she talked about sex as a taboo topic for her generation.

> If you get us older guys it's going to be really tough… because we were brought up where sex wasn't discussed. We just didn't discuss it with your friends, you didn't discuss it with your parents, it was not an open topic so in the a-- older age group I think it would be really difficult. (Julia)

In addition, she and her husband, the oldest participants in the study, found the term ‘satisfying’ to be confusing in the context of talking about sex; none of the younger participants expressed this problem.

Overall, participants were willing to respond to all of the DSCS items, perceived the items to be introductory-level, not touching on deeper questions about sexual communication, and easy to answer for most people. Gender and being from an older generation may have had an impact on the responses.

Satisficing

While transcribing interviews and categorizing results in the CASM tables it became apparent that two people used repetitive phrases throughout the interview to respond to items and probes rather than providing detailed, or at least varying, answers. A careful, detailed review of the audio recordings, field notes, and written transcripts was undertaken paying particular attention to participants’ vocal intonations, jottings about body language, and overall way of being during the interviews in order to discern patterns of repetition. I was confused by their willingness to participate in the research but to use repetitive phrases for many of their answers. A review of the literature pertaining to sensitive survey questions introduced the term ‘satisficing.’

Satisficing is a cognitive short-cut participants take during survey administration, especially with sensitive survey questions. Defined as participants not “investing cognitive or sensorimotor effort in answering the questions” (Couper, Tourangeau, Conrad, & Zhang, 2013, p. 325), satisficing responses can provide misleading data. A participant giving the same answer to each question or explaining their thinking with a simple heuristic does not provide complete information about the measure under investigation. Two participants seemed to engage in satisficing during the interviews and in responding to the survey items. The measure was asking about dyadic sexual communication and rather than addressing specific topics such as sexual feelings and desires or upsetting matters they both chose to answer using simple, repetitive phrases. Samantha and Paulo repeated certain phrases many times raising the possibility they did not want to invest energy in thinking carefully about the specific item at hand and other possible meanings. Samantha stated, “we always talk,” and when probed for what she was thinking when answering a question replied, “just the way we talk all the time,” and “how much we talk.” Samantha also blocked further questioning by repeating certain end-of-question phrases such as “that’s about it,” “cause it’s true and that’s all I thought about,” and “that’s about it I guess.” For the sake of the survey she opted for a quick easy phrase to elaborate many of the probes for what she was thinking. Samantha’s satisficing was likely secondary to her recent illness. Her partner Joe stated, “it took her out so bad the other day that I thought she was gone. I thought I was losing her. She was just totally delirious: no control at all, couldn’t even lift a finger.” Samantha was coughing during the interview but declined many offers to stop.

The initial CASM analysis did not reveal Paulo’s satisficing; this was likely because of novice researcher skills although the field notes point out his repetition of the “totally open” phrase even while his arms and legs were crossed for most of the interview. I also noted that it was a struggle to interview him—I worked hard and he sat straight and still. This was in profound contrast to his wife, Julia, who was genuinely open: giving advice, encouragement, and detailed information freely. Paulo stated, “we are terribly open,” and when probed about what he was thinking to answer an item stated, “we’ve always been totally open.” He repeated a variation of this phrase three times during the interview. In answering the second item in the measure he chose the same answer as the first item (which was reverse coded) and when I hesitated he admitted, “I didn’t read [the scale].” I was uncertain about Paulo’s reasons for satisficing; he stated he was “totally open” with his wife but was closed to me. Although he stated he did not have any expectations about the content of the interview he noted the DSCS items “don’t really hit at any in- inhibitions do they? So they …skirting around the issue doesn’t really pose any hard questions in terms of inhibitions.” When I asked what a “hard question” would be he stated, “Well a hard question there’s more to the nub of things: what are you doing about the effect of the serious illness to counter it?” Perhaps he perceived the measure as simplistic because it did not ask about “the nub of things.” For some people the DSCS questions might be too ‘introductory’, never capturing the most important way that couples have adapted their sexuality in the face of a life-threatening or progressive chronic illness. Or inference-based, repetitive responses may be the best recall strategy for people in long-term relationships (both Samantha and Paulo had been married to their partners for 26 years).

Thematic Findings

Following are the findings constructed from grounded theory approaches to answer research question two: understanding partners’ and patients’ perspectives on sexuality and dyadic sexual communication.

Fixating on function. Even in the midst of a progressive chronic illness many participants were almost single-mindedly focused on functional sexuality. Descriptions of sexuality were given in terms of performance, frequency, male erections, and orgasms. Joe wondered if the interview would address “physical/mental problems during sexual performance” because they’ve “had to change certain ways because of physical ail-- ailments and things like that. So it’s a little more laborious, little harder on both of us.” Techniques and approaches that worked in the past no longer served their altered needs and bodies. Tadaeuz worried he would be asked questions about, “you know do I please women? And ho-- do I perform?” He admitted it had been seven or eight years since he could have an orgasm in the “traditional way” (his term) inside a woman and although he had many new modes for pleasure and closeness he acknowledged his “male ego” had been triggered in anticipation of the interview. He felt that North American pornography contributed in part to his feelings of inadequacy. A man is a “tool…a hammer or screwdriver;” his part of the performance was to please a woman by remaining erect and her part of the performance was to vocalize during orgasm.

> But that gets into our psyche and then we start to think that and then we get this illness, and then suddenly we’re thinking, ‘Oh my God I am the most useless limp hammer that can’t even get one nail in.’

Illness impacted performance, which in turn impacted the way a man felt about himself. Jack stated his injury “makes me feel that I am less of the man I was going into the hospital.” Indeed, his self-worth was linked to his endurance—his ability to maintain an erection—something that his wife Tracey noted was a side effect of the injury and the pain medications. “He feels like he’s medicated all the time…he would get more erections than he does now…that’s kind of affecting him.” Tracey in turn had stressors of her own: his illness “turned [their] roles around” so she worked full time and he stayed home. He was often immobile, in pain, or heavily medicated so she cared for their three school-aged children and maintained the household. She started an antidepressant and stated she was entering menopause. She admitted she didn’t “have the libido…I’m a slow-to-warm-up girl.” Both Jack and Tracey stated that frequency of sex was their main issue although Jack perceived scheduling and the need to find a “cycle” would solve their problems. Tracey on the other hand got right to the point, “we want to make sure he ejaculates” because the sexual encounters were so infrequent and she admitted the encounters were “more important to him,” that she wanted him to get “the maximum benefit,” and therefore she did not speak about her own needs. “I’m not picky on what he’s doing or that kind of thing or like <changes voice to sound strangled> ‘Oh that’s that’s not working!’ Or ‘don’t touch me there!’ or you know that kind of thing.” Tracey admitted she was grateful for antidepressant medication because she was “not so emotional and like I am I’m more even-keeled because I was all over the place before that and I always it felt like I was always just like on the verge of crying a lot of times.” She was aware and content that this was a temporary measure to help her cope. Both Tracey and Jack expressed some level of awareness that his orgasms were the price to be paid for a heightened level of closeness in the aftermath. Orgasm “reset” his system so that he could “just not be in pain and be with my wife and everything is collapsed down to the world around that so. And then we enjoy the after-effect of that you know and the closeness of the… in your relationship” (Jack).

Exploring alternatives. Once the need to have sex for procreation was no longer an issue, sex could be seen as a mechanism for pleasure and closeness. And once illness impacted the ability of men to have an erection thus rendering penetrative intercourse impossible, couples explored alternatives to penetrative sex in their intimate and sexual relationship. Paulo and Julia (Couple Three) discovered that penetrative intercourse was impossible following his surgery for prostate cancer 19 years ago. To him it was a “blip,” to her a “hiccup” and then their voyage of discovery began. They joined support groups in their town and online, and they participated in a research project aiming to understand sexuality after prostate cancer. They tried pills, penile pumps, and once a penile shot although this had unforeseen consequences; Julia could hardly contain her laughter during the interview when she shouted, “It looked like a snake!” They finally chose to abandon medical interventions and paraphernalia in favour of focusing on activities that featured the parts of their bodies that were still in good working order: their minds, their hands and mouths.

> I said [to Paulo], "The trouble with us is that we need to take a page out of our kid's book. We need to get really good at oral sex. We need to get good at masturbation and they're very good at it so maybe we could learn." (Julia)

Julia talked about being raised in a generation that did not talk about sex but after the cancer diagnosis this taboo could no longer hold them "because there's no other alternative." They would have to talk to each other as they continued to experiment with sexuality. She thought that the current generation of 'kids' might have an easier time after a cancer diagnosis since the threat of AIDS and other STIs meant that penetrative intercourse was more risky than being called a 'bad girl' or getting pregnant and so individuals may have already experimented with alternative forms of pleasure and closeness.

Alternative forms of intimacy mentioned by participants consisted of holding hands, dancing, hugging, cuddling, snuggling very tight, and touching. Most participants mentioned kissing; indeed Tadeauz emphasized that with Theory he had "never known anyone that kissed that well and liked to kiss that much…We literally couldn't get through a single movie without ending up pausing it because we needed to kiss more." Theory stated they both had a creative side and found sexual inspiration in art and music. She loved the erotic stories he wrote and the collages he compiled from photos of her skin. Both talked about staring into each other's eyes. Theory stated, "And uh I've never had anybody where I just stared into their eyes for, I don't know, a *looong* time… like the rest of the world completely disappears." Tadaeuz concurred,

> We can just hold each other tightly, stare into each other's eyes, and that you know, there's there's that and I suppose in terms of procedure: like to look into each other's

> eyes is an important component. To really feel like we're with each other and not just two bodies hugging the bits: it's really her, it's really me.

Participants have open eyes and open ways of being in order to talk about every intimate subject resulting from the sexual vagaries of an aging or ill body. Many participants talked about being open and uninhibited about every subject, indeed that talking about sex was like talking about anything at all—if something needed to be talked about then partners made time to be fully present with each other. Julia stated that being together in close physical proximity and being active together, "they're not sex but they are much more meaningful to *me* particularly at this stage."

Communicating (non)mutuality. Most couples spoke about dyadic sexual communication in terms of mutuality and attachment: 'we are open; we are similar; we can talk about anything.' They used 'we' and 'together' language and emphasized their similarities, their areas of alignment, and their feelings of safety in revealing most sexual matters. Theory stated she was not alone with her concerns because she could share her inner distress with her partner. "When…I have my own *thing* and then now it becomes a a we-thing." There is a sense that these couples felt they were 'together.' Paulo stated, "We solved a lot [of sexual concerns] together," and his wife Julia emphasized their joy in each other's presence: "hiking together…dancing together…doing things together and being together is very important. And hugging we use- very frequently um sleep curled up together." Implicit in these statements is the time spent in each other's presence, wanting the presence of the other for pleasure and closeness, and the importance of having a shared experience. Importantly, two couples in this group were on disability incomes and one couple was retired; they had no predetermined schedules and all of their time was available to them.

One couple, Jack and Tracey, emphasized their differences and stated they were careful how they spoke to each other about sexual and other topics. Jack worried about the validity of the research project given that he and his wife “wouldn’t be at the same baseline” because he “wouldn’t have a problem discussing [sexuality] but she might have a little problem discussing something that was a sensitive issue.” In the context of their separate interviews they both highlighted their different styles of initiating and responding to sexual communication. They both described him as ‘open’ and her as ‘conservative.’ Tracey stated, “he’s a little more adventurous than I am, I’m pretty conservative.” Both perceived they needed to be careful how they spoke to each other about any topic that might have potency. Jack would ‘match’ his communication style and wording to the things he knew about his partner and his past experiences of bringing topics to her. “Most of the time my personality-wise is to uh find a comfortable um topic and position that would suit her needs at the least path of resistance for her.” Tracey for her part didn’t say things or ask questions because she might not want to hear what he had to say since “it’s usually something I’ve done wrong or something you know something he’s frustrated with.” But she also kept many of her thoughts and feelings to herself “out of love for him.” Tracey acknowledged she felt tired and stressed from working fulltime and running a household in the years since he became ill but she did not want to talk about her feelings and needs because he might feel bad or guilty. Unlike the couples above who had time together because of income not related to employment, this was the only couple that depended on outside income—Tracey was the only participant in this study who was employed fulltime. Numerous internal and external stressors contributed to their feelings of difference and alienation from each other.

When talking about sexuality some couples continued to ‘fixate on function’ even as bodies and capacities changed over time. Other couples accepted the altered functions and ‘explored alternatives’ that contributed to their maintaining pleasure and closeness as a couple. When talking about dyadic sexual communication most couples were ‘communicating mutuality’ when they emphasized their similarities whereas one couple was ‘communicating (non)mutuality’ when they focused on their differences.

Chapter Summary

This chapter presented the results of the study. The results were organized by research question. Using the four principles of CASM analysis: comprehension, retrieval, judgment, and response, confirmed the appropriateness and acceptability of the four-item DSCS for couples who might benefit from a palliative approach. Most items were well understood by most participants. Most participants answered the questions carefully and thoughtfully although two participants engaged in satisficing behavior by providing repetitive and simple answers. This response may have been due to illness or the perception that the survey measure was too simplistic. Three themes were constructed from the data using grounded theory approaches to understand participants’ perspectives on sexuality and dyadic sexual communication in the face of a progressive chronic illness. Some participants were ‘fixating on function,’ continuing to pursue performative sexuality in the midst of relational tension and reduced physical capacities. Some participants were ‘exploring alternatives,’ accepting new physical limitations while discovering new ways to experience pleasure and closeness. Participants were ‘communicating (non)mutuality’ in emphasizing either their similarities or their differences as a couple.

Chapter Five: Discussion, Considerations, Recommendations, and Conclusion

This is the first study of its kind to use cognitive interviews to evaluate the four-item DSCS, and to gain insight into the perspectives on sexuality and dyadic sexual communication, with people who might benefit from a palliative approach because of progressive chronic illness and their partners. The specific research questions addressed were: 1. For couples who might benefit from a palliative approach, what are their perceptions of each item of the four-item DSCS, and the measure as a whole? 2. What are the couples' perspectives on sexuality and dyadic sexual communication? The chapter will be structured around the results reported in Chapter 4, including the findings pertaining to the DSCS in relation to research question one: (1) participant perceptions of the DSCS, (2) interpretations of DSCS scores, (3) comprehension issues of the DSCS, (4) gender differences in judging a partner's thoughts and feelings, (5) interpretations of retrieval strategies used by participants, (6) social desirability bias and satisficing. There will also be a discussion of the thematic findings in relation to sexual scripts theory. This will be followed by strengths and limitations of the study. Conclusions arising from the findings will be presented, followed by considerations for nursing education and practice, and recommendations for future research.

The Four-Item DSCS

This study demonstrated that participants were willing to respond to all of the items in the four-item DSCS even though the measure contained sensitive survey questions of a potentially intrusive nature (Tourangeau & Yan, 2007). This finding seems to support the acceptability of the measure, however it is important to consider that most of the participants in this study were eager to participate in sexuality research and therefore this may not be a representative sample of people with progressive chronic illnesses and their partners (Tourangeau & Yan, 2007). The literature bears this out in that people who participate in sexuality research are often more sexually unconventional, experienced, and sensation-seeking than people recruited from the general population (Dunne et al., 1997; Fenton et al., 2001). Indeed, the additional fact that only heterosexual couples were interviewed is also a limitation of the study.

Tabulating a sum-across-all-scores to obtain individual and couples scores for the DSCS items and measure as a whole seemed to demonstrate that it does not take many items to quantify good vs. poor dyadic sexual communication. Assuming that the four-item measure is similar to the 13-item measure in how it reflects the domain under investigation, it may be more practical to use the shorter version in comprehensive or longitudinal quality of life surveys. The sum across all items score seemed to identify the couple that was struggling with "the discussion of sexual matters with their partner" confirming the original finding (using the 13-item measure) that the measure "discriminated people reporting sexual problems from those not reporting sexual problems, with the problem group reporting poorer sexual communication than the no-problem group" (Catania et al., 1998, p. 129). In this study, Couple Two both talked about difficulties communicating about sexual matters, feelings, desires, and preferences—all of which were evaluated in the measure.

In addition, individual and couple scores seemed to match the descriptions of experiences thus lending some credence to the measure's ability to differentiate good vs. poor dyadic sexual communication, but it is difficult to understand the value of the scores in this small sample. Does a score of 11 equate to poor communication and 20 to good communication? Couple Two had summative scores of 11.5 and 12 out of a possible 20 for the four-item DSCS, and although these were the lowest scores in this sample, the scores may best be understood by considering similar scores in another study that used the four-item DSCS. The NABS study used a modified version of the measure, and the mean score of 13.48 (*SD* = 2.14) for a "White National" sample (n = 843) (Catania, 1998) seems to suggest that the couple with the lowest scores in this study ranked as more similar to the general population than to the other couples in this study who scored in the high teens and up to 20, the highest possible score. In other words, it is possible that the high scores in this study were attained by people who were different from the general population in their eagerness to participate in sexuality research (as noted above). The comparison of scores across studies must be viewed with caution since the primary purposes and samples of this study and the NABS study were quite different; the NABS study examined correlates of extramarital sex with multi-ethnic samples of 18-49 year olds (Catania, 1998).

Although the measure was comprehensible to participants, most thought the measure as a whole was asking about sexual function and only a minority identified 'communication' as the topic under study, suggesting that the measure may not be an appropriate match for evaluating dyadic sexual communication (Fitzpatrick et al., 1998). On the face of it the four-item DSCS matches the purpose and questions under investigation but retrospective probing revealed participants' emphasis on sexual function. It is possible that situating the measure in an interview that was explicitly investigating 'intimacy and illness' (the title on all recruitment materials), and asking about the measure after obtaining demographic information about disease diagnoses and how illness may have impacted their lives may have led participants to the erroneous belief that the measure was explicitly about (dys)functional bodies. Another possibility to consider is the overwhelming emphasis in research and in the culture at large on genital and functional sexuality (Hordern, 2008). In other words, regardless of the content or purpose of a sexuality measure, most participants might respond based on a (dys)functional foundation. On the other hand it was only during retrospective probing that participants stated that the measure was about sexual function. During measure administration and concurrent probing it was apparent participants answered questions about dyadic sexual communication in their use of communication terms such as talk, discuss, mention, tell, and say, and so the measure likely is an appropriate match for investigations about this domain. Further validation research is needed to confirm this finding.

Even though the measure as a whole was comprehensible to most participants, two items caused particular difficulty in the CASM domain of comprehension due to word choice and syntactic complexity. As noted in the Results section: the word "satisfying" in item three caused difficulties for two participants, and the overall syntax of item four caused confusion for two participants. The fact that 25% of the participants (2/8) had comprehension problems with two of the four DSCS items seems to call into question the appropriateness of the measure for the domain under investigation. A comparison of the original DSCS wording of the two items with two modified versions reveals changes that may increase the comprehensibility of the two problematic items (Catania, 1998) (see Table 5).

Table 5 *Original and adapted wordings for DSCS items three and four*

	Original DSCS wording	Adaptation for NABS study	Adaptation for AMEN study
Item Three (Item 10 of the 13-item DSCS)	Talking about sex is a satisfying experience for both of us.	Is talking about sex with your spouse fun for the both of you?	Talking about sex with my primary partner is usually fun for the both of us.
Item Four (Item 12 of the 13-item DSCS)	I have little difficulty telling my partner what I do or don't do sexually.	Do you find that it is easy for you to tell your spouse what you do or do not like to do during sex?	It is easy for me to tell my primary partner what I do or don't like doing during sex.

The NABS and AMEN adaptations have the appearance of items that have been tested using cognitive interviewing although no reports of this process were found. The main change with item three is the substitution of the word "fun" for the word "satisfying." Certainly the item is more comprehensible but seems to be asking about different ideas given that almost half of the participants in the present study stated that ‘talking about sex’ was for resolving problems, or clarifying something. Item four has two substantial changes: the terms “little difficulty” have been changed to the singular term “easy,” and “what I do or don’t do sexually” has been changed to “do or do not like to do during sex” and “do or don’t like doing during sex.” Again, the adapted versions are more comprehensible but do not seem to be asking the same thing as the original; the term “sexually” in the original seems to include more possibilities than “during sex” in the adaptations. Yet the broad general possibilities of the original seemed to be the main cause of confusion in the current study. More research would be needed to evaluate the construct validity and equivalency of the items in the adaptations (Sousa, Matson, & Dunn Lopez, 2016). There may be a lingering concern about validity and reliability of the 13-item measure since the two difficult items retain the original wording, and the measure is being used in many current sexuality studies (Garos et al., 2007; Perz et al., 2014; Perz & Ussher, 2015; Seidler et al., 2016). Perhaps the 13-item measure is more stable to variances in item interpretation. More research would be needed to test this supposition.

The judgment portion of the CASM analysis suggested the possibility of traditional gender differences in that all of the women felt confident answering questions about their male partner’s inner world of thoughts and feelings and only one man, Paulo, attested to the same. In addition, three of the four women stated that some aspect of sexual function such as orgasm or frequency of activity was more important for their male partner than for them. McCabe, Tanner, and Heiman (2010) similarly found gendered responses during cognitive interviews about sexuality terminology discerning themes such as the importance of sex for men, male physicality versus female emotionality, and the negation of women’s sexual desire and pleasure.

It seems as though a couple’s ability to talk about sex might be an indication of the overall relational well-being of the couple. Perhaps one of the most interesting findings and one of the possible strengths of the measure was revealed when analyzing participants’ explanations of their retrieval process in answering each item. Most participants stated they answered the items by thinking about their partner and their overall way-of-being with each other over time. This perception aligns with Timm and Keiley’s (2011) observation that unlike most marital topics, sexuality is “emotionally intense… [and so] being able to communicate in highly intimate and intense situations is not a function of learning the right technique; rather it is likely a function of individuals being able to stay engaged with each other and hold on to themselves in the process” (p. 217). In other words, excellent dyadic sexual communication seems to transfer to more relational domains than merely talking about sex such that even difficult or absent sexual activity has less of an impact on the relationship (Litzinger & Gordon, 2005). Indeed, Pazmany, Bergeron, Verhaeghe, Van Oudenhove, and Enzlin (2015) state, “as proposed by several dyadic-level theories, [sexual] communication can serve as a strategy to strengthen the relationship, as a way to build intimacy and/or to enhance positive interactions between partners” (p. 525). The ability to talk about sexual matters is a possible barometer of the overall relational ability to talk about anything at all and to maintain relational well-being.

Another thing to consider is the lack of timeframe or reference period for past behavior (a.k.a. retrospective self-report) attached to the items under investigation. In the original and as administered in this study the four-item DSCS had no recall timeframe in contrast to some quality of life measures that ask about the last two days (Cohen et al., 2017), or sexual function measures that ask about the last 30 days (Fortune-Greeley et al., 2009). Pertaining to ‘autobiographical memory’ Schwartz (2007) states “respondents have to rely on partial recall and extensive inference strategies when asked to report on their past behavior and experiences" (p. 16), especially for mundane or frequent behavior, particularly over a long period of time (i.e., a 26-year marriage). This makes sense since even though people may not have engaged in sexual communication in the last few days or months they can likely recall occasions over time. Unfortunately, when a recall time frame is not stipulated respondents may assume periods from weeks to years when formulating their answers (Greenfield & Kerr, 2008). Indeed, cognitive interview reports often reveal participants using some other timeframe even when one is stipulated in the survey (Fortune-Greeley et al., 2009). For couples who have not been sexually active for a long period of time, the measure might still capture an element of the couple-relationship over time. The lack of recall timeframe may be an advantage in providing a general overview of dyadic sexual communication for the couple. Indeed, participants stated they thought about their partners when answering and answered the items according to their overall way of being with each other—one is left with the idea that couples had highs and lows but that they were able to envision their overall relational style.

It is important to note that the tendency to describe overall relationship communication may not identify people who are not sexually active since none of the items actually ask about behavior. Couples could be celibate and still answer the items in a positive way based on their general communication style over time rather than specifically related to sexual communication. In fact, I found this to be true when I was working as a clinical research assistant gathering survey data from caregivers of patients receiving palliative homecare and had the opportunity to briefly trial the four-item DSCS. Following the preamble to the measure most partners stated, "We don't do that anymore." Nonetheless when I administered the items all participants answered the questions; not one person insisted that the measure was not applicable to them.

This was likely some combination of social desirability bias and altruism; wanting to please me and also ensuring I got all of the information I needed to do my job. But I also perceived that partners were able to cast themselves back in time—perhaps to better times—and find a way to make sense of the items. The choice of strongly agree or disagree to an item seemed to make sense in the context of their longstanding way-of-being with each other.

Social desirability bias was a concern given the sensitive nature of the survey questions. It is possible that participants altered their answers for some reason and did not tell the truth about their experiences. But what would be the most socially desirable response to questions about sexuality and dyadic sexual communication for people with progressive chronic illness and their partners? What activities or ideas would be over-reported and what would be under-reported, the two aspects of social desirability bias that may lead to reporting errors? Tourangeau and Yan (2007) cite the work of Paulhus and offer some possible insights: self-deception or egoistic bias, wherein participants brag or claim positive characteristics about themselves; and impression management, wherein participants focus on making a good impression for the researcher. It is possible that the two participants who engaged in apparent satisficing may have provided a socially desirable response: 'we always talk about everything,' in order to portray themselves as open, uninhibited people with strong healthy relationships in the context of a research interview explicitly focused on the context of intimacy and illness. As to impression management, quite a few participants talked about other research they had read or participated in possibly as a way to demonstrate their intelligence or to find common ground with the researcher. On the whole it seemed as though most participants thought carefully about the DSCS items and provided careful truthful responses. If the participants were trying to make an impression then I was left with the impression that patients and their partners had weathered good times and bad times in the face of progressive chronic illness, that sexuality remained important, and that they were genuinely committed to each other. Much of this aligns with couples research in illness that shows that some couples feel closer following a life threatening diagnosis (Gilbert, Ussher, & Perz, 2010; Rolland, 1994).

The above sections focused on the first research question with discussions of matters pertaining to the four-item DSCS and to research using sensitive survey questions. The following sections focus on the second research question with discussions of matters pertaining to thematic findings regarding sexuality and dyadic sexual communication.

Sexual Script Theory

The thematic analysis found that many couples, even in the context of a progressive chronic or debilitating illness continued to fixate on function with their emphasis on genital and performative sexuality. Some couples, for whom “traditional sex” was no longer possible due to the male partner’s inability to attain an erection, talked about exploring alternatives such as holding, kissing, and looking into each other’s eyes. Some couples used “we” and “together” language consistently throughout the interviews emphasizing their similarities and thus communicating mutuality, whereas one couple emphasized their differences communicating (non)mutuality. These findings are consistent with a study by Mitchell et al. (2011) using scripting theory to understand participants’ perceptions of sexual function in the context of illness. Sexual scripts are conscious and unconscious, individual and group ways of engaging in social interactions. According to Mitchell et al. (2011),

> Sexual scripts are employed at three levels: at the cultural level, scripts operate rather like instructional guides, setting out the requirements for specific roles; at the interpersonal level individuals adapt, shape and improvise cultural scenario scripts into their own

> context-specific ones; and at the intra-psychic level individuals rehearse their own scripts through internal dialogue. (p. 541)

In other words, men and women, husbands and wives, ill people and healthy people have been 'given' or have created for themselves a script about how to act in and how to interpret certain situations. Mitchell et al. (2011) conducted qualitative interviews with 32 people, purposefully sampling people who sought treatment for sexual difficulties, people who had chronic illnesses that may lead to sexual difficulties, and people randomly chosen from a physician's waiting room. The participants were asked to describe satisfactory/unsatisfactory sexual relationship/activity. Mitchell et al. (2011) identified three sexual scripts: the biomedical script, the relational script, and the erotic script, acknowledging that there is often a combination of scripts at play but that one may predominate. In the current project, the biomedical script was prominent for two couples, Jack and Tracey, and Joe and Samantha, with their emphasis on functional and genital sexuality, and references to erections and orgasms; indeed, "the biomedical script viewed penetration as the only activity that really mattered" (p. 544; see also McPhillips, Braun, & Gavey, 2001) and physiological difficulties were the biggest 'threats to ideal sex.'

When the biomedical script was no longer feasible other scripts may have predominated. In this study the male partners in two couples, Paulo and Tadeauz, admitted they were unable to have penetrative intercourse because they were unable to have an erection secondary to complications from disease or treatment for disease. Both declared themselves to be "open" and uninhibited about sexuality and, interestingly, both men attained the highest possible DSCS score of 20. Paulo and his wife Julia emphasized the relational script with their focus on being together, indeed according to Paulo, "It's like we found a lot of things we like to do together naturally.” And for Julia, “I think doing things together and being together is very important. And hugging …we sleep curled up together. So those sorts of things are, they’re not sex but they are much more meaningful to *me* particularly at this stage.” Tadeauz and Theory seemed to be following the erotic script with their focus on pleasure, recreation, variety, and excitement in their use of erotic writing, artwork, and photography. Rich data was gleaned from cognitive interviews such that even in this small sample of four couples all three of Mitchell et al.’s (2011) sexual scripts were evident.

Strengths and Limitations

Eight people (four dyads) completed cognitive interviews of the four-item DSCS; this is an acceptable sample size for an introductory CI study. The study participants had an age range from 30-90 providing multi-generational perspectives of the DSCS as well as sexuality and dyadic sexual communication. In addition, couples’ relationship duration ranged from 3 to 26 years allowing for perspectives of newly formed and well-established couples. One couple met after the patient had been living with a progressive chronic illness and therefore the new partner was aware of sexual (dys)function early in the relationship. This aspect of the relationship provided a unique lens on sexuality research and is in contrast to most couple’s research in the context of illness conducted post-diagnosis.

Limitations of the current study include the small sample size of heterosexual couples from Vancouver Island, BC who self-selected to participate in sexuality research. Although the recruitment strategies sought people with any “serious illness” very few progressive chronic diseases were represented. It is important to consider other sources of diversity that may impact how people interpret and respond to questions about their sexual communication. Not represented in this study: (a) people espousing sexual diversity such as people identifying as

LGBTTQQIP2SAA (lesbian, gay, bisexual, transgender, transsexual, queer, questioning, intersex, pansexual, Two-Spirit, asexual, and ally) (Hulshof-Schmidt, 2012), and (b) people presenting cultural and ethnic diversity. As a result, it is not known if the four-item DSCS is appropriate and acceptable to people identifying as LGBTTQQIP2SAA or who are from other cultural or ethnic backgrounds.

Concluding Observations

Cognitive interviewing techniques were used in this qualitative study in order to understand perceptions of the DSCS and perspectives on sexuality and dyadic sexual communication of four Vancouver Island couples who might benefit from a palliative approach. The following eight conclusions were drawn from this study:

1. DSCS scores might differentiate between couples that admit to poor vs. good sexual communication. In this study the couple with the lowest scores both talked about difficulties with sexual communication, whereas the couples with higher scores stated they could freely talk about sexuality. It is important to consider that the low scores in this study were similar to the mean score for a large general sample in a different study revealing the possible differences between people who are willing or eager to participate in sexuality research and the general population.
2. People who are willing or eager to participate in sexuality research are likely different from the general population. The one willing-but-surprised-their-partner-agreed-to-participate couple provided a possibly more realistic glimpse into the experience of sexuality and dyadic sexual communication for most couples in the context of progressive chronic or debilitating illness. The three eager-to-participate couples in this

study were able provide a window into some of the ways couples have coped or thrived in the context of progressive chronic or debilitating illness.

3. It is possible that there is something special and potent about a couple's ability to talk about sexuality since the skills used to persevere through this most intimate topic may transfer to other sensitive topics. It is possible the ability to talk about sensitive topics would be valuable in the context of progressive chronic or debilitating illness.
4. It is possible that for heterosexual couples, regardless of the focus of the inquiry, questions about sexuality are filtered through a lens of sexual function even when genitals no longer function in the customary way.
5. Although cognitive interviewing captured difficulties with word choice and grammatical syntax of two DSCS items, data from think-aloud and probe questions suggested that participants were able to describe the quality of their dyadic sexual communication.
6. There were gender differences in judging confidence about understanding a partner's inner world of thoughts and feelings with more women espousing this stance.
7. The lack of timeframe for the DSCS might have allowed couples to provide a synopsis of overall relational way-of-being with each other separate from specific occasions of sexual communication.
8. Sexual scripts theory provided a rich, optimistic interpretation of couples' responses to sexuality in the context of a progressive chronic or debilitating illness.

Although the realm of nursing education and practice were not a focus in this research project nonetheless nurses provide care to couples who might benefit from a palliative approach to care. If the key principles of a palliative approach consist of an explicit focus on life threatening and progressive chronic illnesses, early in the disease process, with care being provided across the care-continuum by primary, acute, chronic, and long-term care practitioners (Bacon, 2013), then nurses can provide an essential service that could contribute to enhanced quality of life and sexual quality of life for people who are ill. The eight conclusions lead to the following considerations for nursing education, practice, and future research.

Considerations for Nursing Education

Nursing education can be understood as education being provided to and by nurses. It is well documented in the literature that nurses are hesitant to talk to patients or couples about sexuality or sexual quality of life. Nurses often position “knowledge, confidence and comfort as barriers to discussion of sexuality” (Ussher, Perz, Gilbert, Wong, Mason, Hobbs, & Kirsten, 2013, p. 1379; see also Reynolds & Magnan, 2005). There is a belief that sexuality is somewhat irrelevant for people who are ill (Matzo & Hijjazi, 2009). Nurses can extend their sexual health education by informing themselves about alternative sexualities (Pillai-Friedman, Pollitt, & Castaldo, 2015; Williams, Thomas, Prior, & Christensen, 2015), and sexual orientations other than heterosexual (Lindroth, 2016; Moser, 2016; Munson & Cook, 2016). For example, when I attended the Intensive Sex Therapy Training at the University of Guelph, a counselor talked about a woman who enjoyed BDSM practices in her relationship but since she had a lung removed she was unsure about how much pressure could be used in rope play. In my 30-year nursing career I had never heard of nor even considered such a concern. I wondered, “Who could she talk to about her health and her sexuality so she could be safe and satisfied?” I also experienced the sudden moral and professional responsibility to educate myself about sexuality in the context of illness.

The results showed that sexuality was important for the couples in this study who were dealing with the challenges of progressive illness. It is important for nurses to recognize that they do not need to be sexual health experts; education is the key to gaining knowledge and confidence in providing person-centered sexual quality of life assessment and care (Jonsdottir et al., 2016; Ussher, Perz, Gilbert, Wong, Mason, Hobbs, & Kirsten, 2013). The results of this study also indicate that in addition to a comprehensive biomedical sexual health curriculum, psychosocial domains such as couple communication and sexual scripts theory should be offered to nurses. The biomedical script that emphasizes sexual function and release is often the focus of concern for couples but relational and erotic sexual scripts are also common. In addition, it would be important for nurses to know that this study seems to indicate, regardless of physical impairments, any conversation about sexuality often triggers thoughts and feelings about sexual function. In other words, no matter what the sexual topic at hand, hetrosexual couples often initially adopt the biomedical sexual script. Encouragingly, nurses can inform couples that even when the biomedical script is no longer a viable option couples can still maintain a sexual relationship by adopting a relational or erotic script. Sexual assessment and communication models such as PLISSIT or BETTER (Hordern, 2008) can assist nurses in starting to ask questions about sexuality.

Findings from interviews with four couples who might benefit from a palliative approach highlighted the importance of sexuality for these couples, and the importance of nurses' attaining an understanding of biomedical, relational, and erotic sexual scripts that may be informing couples' responses. Some couples may only perceive the biomedical script with the emphasis on genital and sexual function and not be aware of other ways of expressing sexuality—nurses can provide education about alternative ways of being with each other.

Considerations for Nursing Practice

The findings of this study revealed possible differences between couples who are able to talk about sexuality and those who are struggling with dyadic sexual communication. According to the literature there appears to be three ways that couples respond in regards to sexuality in the context of progressive chronic or debilitating illness: (1) couples are celibate (represented in the literature but not in this study); (2) couples figure things out for themselves by seeking information from other sources such as online or support groups (Gilbert et al., 2014), or in relationship like Paulo who stated, “I’m happy to deal with my problems myself with my wife’s support”; and (3) couples continue to struggle with sexuality and dyadic sexual communication (Gilbert et al., 2009; Ussher, Perz, Gilbert, Wong, & Hobbs, 2013; Walker & Robinson, 2011). Since all three types of responses are likely represented in the population and in most areas of nursing care it might be possible for nurses to hone efforts to support couples (or the individuals in the dyad) by figuring out which response a certain patient tends to espouse. People who are celibate might say something along the lines of, “We don’t do that anymore,” whereas people who have figured things out might be willing and eager to talk about sexuality. People who continue to struggle might be hesitant but willing to talk. I wish to suggest that although all patients should have comprehensive sexual health assessment and intervention (as needed), it is the couples who are struggling that are most in need of support. In my experience in nursing practice and research the people who are celibate likely will not want to talk about sexuality, whereas the people who have figured things out might want to talk at length about their successes and challenges. Nurses should be cautious about over-sampling this latter, eager group, as happened in this study, thinking comprehensive sexual health care for the general population is being provided. In other words, if a nurse perceives that all patients assessed fall into only two categories: not wanting to talk or eagerly wanting to talk, then the couples who are struggling might be overlooked.

It might be important for nurses to recognize that the couple in this study who were struggling with sexuality and dyadic sexual communication are likely more similar to the general population of people with progressive chronic or debilitating illness than people who are eager to discuss sexuality. Indeed, they were the only couple that expressed frustration at not getting the "total package" consisting of biomedical and psychosocial care pertaining to sexuality. Jack provides some perspective:

> If you don't help or sort of give them the ability to see some information or a book or something like that. Or make the professionals aware of that, and it doesn't have to be from, it can be the outlying, so it could be a [social worker], it could be a counselor, it could be a psychiatrist, it could be other areas outside of that. It's a total package you know from that so. It would help a lot of people because I'm using up almost 100% of my stuff just to keep an even keel.

Jack wanted healthcare professionals to provide sexuality information because he was using all of his "stuff"—likely his physical, psychological, and emotional energy—to cope with his daily life. Most of the literature reviewed shows that people want to be asked about sexuality (Gilbert et al., 2014; Matzo & Hijjazi, 2009) and some studies show that people who are having difficulties are unlikely to ask for help (Flynn et al., 2012; Gilbert et al., 2014). Nurses need to be ready to assess and possibly address patients' and partners' sexuality concerns and understand how to refer them on for sex therapy or medical intervention (de Vocht, Hordern, Notter, & van de Wiel, 2011). While there is a time and place for the specialist assessment and care by a sex therapist or sexual medicine physician, most people are best served by the health care professional they visit on a regular basis. In fact, patients prefer to talk to the practitioners with whom they have already developed a relationship rather than a referral to a specialist (Hordern & Street, 2007a, 2007b), a preference that is addressed with a palliative approach to care.

Findings from interviews with four couples who might benefit from a palliative approach highlighted the importance of nurses' recognizing that some couples are able to solve problems on their own and some couples may want to be asked about and supported to find resources to improve this area of their life.

Recommendations for Future Research

Despite the limitations, the results of this study demonstrate the importance of studying dyadic sexual communication in couples who might benefit from a palliative approach. This study contributes to nurses' understanding of the DSCS and of couples' sexual communication in the context of progressive chronic or debilitating illness. More research is needed about the four-item DSCS. Recommendations include:

- Testing the appropriateness and acceptability of the measure with people who have a variety of progressive chronic or debilitating illnesses; and with people who have diverse sexual and cultural identities
- Testing the four-item vs. the 13-item for content validity; and the original four-item vs. the adaptations for comprehension
- Testing the measure with and without recall timeframes

Moving forward, researchers can take the lead from studies investigating sexuality after cancer and repeat the work with patients and partners with progressive chronic illnesses. For example, why not recreate the Perz et al. (2014) study examining psychosocial predictors of sexual functioning after cancer with people with Chronic Obstructive Pulmonary Disease (COPD), Congestive Heart Failure (CHF), renal failure, or Parkinson's disease? This study used the13-item DSCS as well as the Changes in Sexual Functioning Questionnaire, Hospital Anxiety and Depression Scale, Medical Outcomes Study health survey short form, Brief Dyadic Adjustment scale and the Silencing the Self Scale. In addition, future studies should consider following couples longitudinally, evaluating dyadic sexual communication and disease progression, for example. More research is needed to understand what individual and couple DSCS scores mean. What does it mean when one partner has a significantly lower or higher score than the other? What does a score mean when administered to an individual but not the partner, in research examining patient experiences alone, for example? What does it mean when a couple has different responses to the same items: one agrees where the other disagrees to a certain statement as was seen with Couple Two, Jack and Tracey, above? Cognitive interviewing could be used to further elucidate participants' perceptions of the measure and could also be used to investigate couples' perceptions about the meanings of the scores.

The results of this study suggested that the DSCS seemed to capture couples' overall relational way of being with each other. A different measure, the Dyadic Adjustment Scale (DAS), specifically measures the "quality of marriage" (Spanier, 1976), and has been used in combination with the DSCS in a number of studies evaluating relationship quality and dyadic sexual communication in cancer (Lawsin & Ballard, 2016; Reese, Porter, Somers, & Keefe, 2012), and female sexual dysfunctions such as provoked vulvar pain (Smith & Pukall, 2014), and dyspareunia (pain during sexual intercourse) (Pazmany et al., 2015). Future studies should be conducted using these two measures in patients with progressive chronic or debilitating illness and their partners for purposes of discriminant and convergent validity in order to enhance the construct validity of the measure.

In this study one couple formed a relationship after the patient received and lived with a progressive chronic or debilitating diagnosis. This couple espoused the erotic sexual script. It is possible that an illness that impacts sexual function necessitates fairly high-level sexual communication at the outset of the relationship. Indeed, Tadeauez stated, “That’s where things can certainly go more smoothly. I was quite nervous too cause another one of my criterias: cause no hurt, and reveal my diagnosis to whoever I’m dating so there’s no surprises. And Theory took it very well.” More research is needed with couples who entered a committed relationship post-diagnosis.

Findings from interviews with four couples who might benefit from a palliative approach highlighted the importance of future research endeavors pertaining to the four-item DSCS, sexuality, and dyadic sexual communication. The measure and its adaptations need to be tested with diverse populations and with other foci such as the measure’s ability to capture overall relationship quality. More research with couples who met post-diagnosis may reveal differences in relational and sexual communication.

Conclusion

The purpose of the study was to use cognitive interviews to evaluate the appropriateness and acceptability of the four-item Dyadic Sexual Communication Scale (DSCS), and to understand perspectives on sexuality and dyadic sexual communication in couples who might benefit from a palliative approach. The results suggest that the four-item DSCS is an appropriate and acceptable measure given that participants were willing to respond to all of the items, perceived the items to be introductory-level, not touching on deeper questions about sexual communication, and easy to answer for most people. This finding lends support for the inclusion of the measure in quality of life surveys wherein people may be surprised to find the items in the survey but may not find them to be overly intrusive. Low DSCS scores may identify couples that are struggling with dyadic sexual communication, whereas high scores may indicate good dyadic sexual communication, or may be skewed by people who are eager to volunteer for sexuality research. The results suggest there is a possibility that measuring dyadic sexual communication offers insight into overall relational well-being although, again, high scores may point to a sampling bias. Social desirability bias was a concern with apparent satisficing behavior noted. Thematic findings of fixating on function, exploring alternatives and communicating (non)mutuality were contextualized by sexual scripts theory identifying biomedical, relational, and erotic scripts. These scripts may lend understanding to the way couples cope in the context of a progressive chronic illness.

These are the early days of investigating sexuality and dyadic sexual communication with couples who might benefit from a palliative approach. It is hoped that the results of this study may encourage nurses to educate themselves about the topics and willingly discuss sexuality and sexual quality of life with individuals and couples. It is possible the four-item DSCS may be a valuable measure for use in comprehensive and longitudinal quality of life surveys in order to evaluate couples' dyadic sexual, and overall relational communication quality.

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Appendices

Appendix A: Table Outlining the Preliminary Literature Review

Date	Database Searched	Key words used	Result
November 2014	CINAHL	Sex*	125,931
		Sexuality*	17,323
		Intimacy*	1,606
		Closeness*	642
		Intercourse*	3,071
		Pleasure*	1,220
		Palliative*	25,124
		End of life*	14,450
		Cancer*	134,018
		Terminal*	22,330
		Sexuality*, palliative*	55
		Sexuality*, end of life*	71
		Sex*, end of life*	614
		Sex*, palliative*	443
		Sex*, cancer*	7,110
		Sexuality*, cancer*	1,062
		sex* or intimacy* or closeness* or intercourse* or pleasure*	128,285
		palliative* or end of life* or cancer* or terminal*	172, 448
		sex* or intimacy* or closeness* or intercourse* or pleasure* AND palliative* or end of life* or cancer* or terminal*	8, 196
		sex* or intimacy* or closeness* or intercourse* or pleasure* AND palliative* or end of life* or cancer* or terminal* NOT pediatric*	8, 038
December 3, 2014	CINAHL	Sexuality* AND palliative* or terminal* or end of life* or hospice* AND spouse* or partner*	22
December 5, 2014	Ovid	Palliative AND Sexuality	190 2 new articles

December 6, 2014	MEDLINE	Sexuality* or intimacy* or closeness* or intercourse* or pleasure* AND palliative* or end of life* or cancer* or terminal* NOT pediatric	2982
December 6, 2014	MEDLINE	sexuality* or intimacy* or closeness* or intercourse* or pleasure* AND palliative* or end of life* or cancer* or terminal* AND spouse* or Partner* or caregiver*	791
December 17, 2014	CINAHL	palliative* or end of life* or cancer* or terminal* AND sex* or intimacy* or closeness* or intercourse* or pleasure* or sexuality*	
		Limit: Jan 1950 to Dec 1959	None
		Jan 1960 to Dec 1969	None
		Jan 1970 to Dec 1979	None
		Jan 1980 to Dec 1989 (significance revealed by title/abstract)	118: 24 experience of the cancer patient 5 nurses attitudes about sexuality and cancer 3 assessment and treatment of sexuality in cancer pts 1 SAQ development 1 sexuality program for pts and partners (only mention of partners) 2 sexuality and dying pt (1981, 1983—both by P.B. Taylor, a nurse counselor)
December 18, 2014	MEDLINE	Sexual* or Sexuality* or intercourse* AND Cancer* or terminal* or palliative* NOT pediatric	1026
		Limit: Jan 1980 to December 1989; Remove sexual above	164 (23: sexual function/behavior; 9: experience of sexuality for cancer pts; 7: assessment treatment re sexuality cancer pts; 3: nurses' attitudes; 2 Dying person's sexuality—see Phyllis Taylor above)

		Limit Jan 1990 to Dec 1999	404
		Jan 2000 to Dec 2009	906
		Jan 2010 to present (Dec 2014)	750
December 18, 2014	CINAHL	Sexual* or Sexuality* or intercourse* AND Cancer* or terminal* or palliative* NOT pediatric	
		Limit Jan 1950 to Dec 1960	0
		Jan 1960 to Dec 1970	0
		Jan 1970 to Dec 1980	0
		Jan 1980 to Dec 1990	69 (based on title alone—31 pertinent—1 partners
		Jan 1991 to Dec 2000	368
		Jan 2001 to Dec 2010	1293
		Jan 2011 to present (Dec 2014)	718
December 18, 2014	CINAHL	Sexuality* AND Cancer* or palliative* AND couple* or partner* or spouse* or caregiver*	252 --67 related to sexuality/cancer/ partner --3 related to sexuality/partner/ palliative *1 Norwegian * 1 literature review *1 HCP perspectives --2 sexuality/palliative—unable to obtain
January 8, 2015	CINAHL: searching for theses	Sexuality* AND Cancer* or palliative* AND couple* or partner* or spouse*	237 1 appropriate thesis: Lion, E. (1990) “Sexuality of the dying: what dying participants, their spouses and their caregivers teach us about the sexuality of the dying.” (Alas, found the obituary for this nurse-educator. Sent request for access to the thesis via “contact” on her weebly page. Used my TWU email address.) No response as of April 30, 2015; Bridget Taylor (2012) discusses this thesis in her thesis; Lion used a typewriter and apparently no electronic copy exists.

January 9, 2015	Pubmed	Sexuality* AND Cancer* or palliative* AND couple* or partner* or spouse*	291: 33 related to sexuality/cancer/ partner 1 related to sexuality/ palliative/partner; French Nothing new in English
January 9, 2015	Science Direct	Sexuality* AND palliative* AND couple* or partner* or spouse*	464; duplicates; one new in French
January 9, 2015	Web of Science	Sexuality* AND palliative* or cancer* AND couple* or partner* or spouse*	180; 21 appropriate—all duplicates
January 17, 2015	NIH RePORTER	Sexuality	75: 3 with palliative focus: 2 sexuality after cancer diagnosis; 1 sexual distress after diagnosis
January 17, 2015	NLM Gateway	Sexuality and palliative	64: none appropriate (many studies mention HIV/AIDS—does this fall under the palliative umbrella?)
January 17, 2015	Clinical trials.gov	Sexuality and palliative Sexuality and cancer	13: none appropriate (found our study: #21 under palliative search term) 964 found: of the 1st 100 trials: 25 sexual function/rehab following cancer; 13 communication/intervention after cancer; 2 QOL after cancer
January 17, 2015	Cochrane Library	Sexual* and palliative*	39: 2 interventions for sexual dysfunction after cancer
January 17, 2015	JBI	Sexuality* and palliative*	56: 1 intervention to improve QOL and sexual function after cancer
January 23, 2015	CINAHL	Sexuality* AND palliative* or neoplasm* AND quantitative research*	23: 15 duplicates; 3 new
January 30, 2015			53 articles deemed most appropriate for review
February 1, 2015			4 more articles
February 22, 2015			Down to 23 most relevant articles

March 1, 2015		Focus on sexuality, partners, palliative with a few seminal articles that focus on patients	19 articles
March 2, 2015	Web of Science	Backward and forward (2 generations) analysis of each article based on sexuality/partner and palliative in abstract	2 new pertinent; 2 partner/palliative by the team: Perz, Ussher, Gilbert, Hawkins and others
March 4, 2015	CINAHL then Web of Science	Need more male partners and/or quantitative research Sexuality* and Palliative* or neoplasm* and quantitative Use Perz et al., 2014 (quantitative): Forward Backward (163 citations)	30; either not appropriate or duplicates 0 3 new quantitative; 2 with male partners; 1 both gender partners
April 10, 2015	CINAHL then select all databases	Sexuality* AND Palliative*	177: duplicates or not appropriate; one new by Bridget Taylor—not appropriate
June 24, 2015	CINAHL	Cognitive interview and Survey	899 13 articles chosen
July 13, 2015	CINAHL	survey and cognitive interview	140 7 articles chosen
August 19, 2015	CINAHL	Sexuality* or Sexual* AND Palliative*	125 one new 2015 article (Ussher, Perz, Gilbert LP0883344; this research took place in 2012-2013)
September 2015	CINAHL	Sensitive and survey and questions	188 4 articles chosen
September 2015	Google Scholar and grey literature	Vulnerable research participants	4 articles chosen

Appendix B: Table Outlining the Most Relevant Articles/Books Listed in Chronological Order

Author/APA Reference: Ananth, H., Jones, L., King, M., & Tookman, A. (2003). The impact of cancer on sexual function: a controlled study. *Palliat Med, 17*, 202-205.

Research Methodology: Quantitative; cross-sectional

Measures: Derogatis Sexual Function Scale; General Health Questionnaire (GHQ12); EuoQol; frequency of sexual relations; 10-point visual analogue for strength of sexual and emotional relations with partner, and general sexual satisfaction.

Sample: Patients with cancer: 64 palliative; 56 oncology; 67 general practice (comparison group)

Research Hypotheses: "Sexual difficulties are more common in patients undergoing treatment for cancer than matched controls and such difficulties increase with progression of disease" (p. 202).

Relevant Findings: Hypothesis confirmed. High recruitment response: approximately 75% in all three groups; patients are willing to discuss sexual difficulties.

Author/APA Reference: Lemieux, L., Kaiser, S., Pereira, J., & Meadows, L. M. (2004). Sexuality in palliative care: patient perspectives. *Palliative Medicine, 18*(7), 630-637.

Research Methodology: Qualitative; naturalistic inquiry

Sample: 10 palliative patients; 3 partners: not recruited but present for interview

Research Question: To explore palliative patients' sexuality: what it means for them, the impact of illness, barriers to sexual expression and discussions with healthcare providers.

Relevant Findings: Emotional connection and intimacy more important than intercourse; sexuality remains important; many barriers to sexual expression in institutional settings: lack of privacy, feeling unsafe, and size of hospital bed. Patients want to discuss sexuality: only one of ten had done so. Participating in research interview seen as a therapeutic intervention.

Author/APA Reference: Willis, G. (2005). *Cognitive interviewing : A tool for improving questionnaire design* [e-book version]. doi: http://dx.doi.org.ezproxy.library.uvic.ca/10.4135/9781412983655

Source type: Book

Relevant Findings: The evolution of cognitive interviewing techniques for survey design and evaluation. The practice: think-aloud +/- probing; (dis)advantages of both techniques—best strategy some combination of the two; analyzing cognitive interview data.

Author/APA Reference: Garos, S., Kluck, A., & Aronoff, D. (2007). Prostate cancer patients and their partners: Differences in satisfaction indices and psychological variables. *The Journal Of Sexual Medicine, 4*(5), 1394-1403.

Research Methodology: Quantitative; mail survey

Measures: Beck Depression Inventory-II; Life Satisfaction Index; Index of Sexual Satisfaction, Relationship Assessment Scale, **Dyadic Sexual Communication Scale**, Sexuality Scale, Client Satisfaction Questionnaire

Sample: 77 prostate cancer patients, 57 women partners; (norming samples from a variety of studies using above scales)

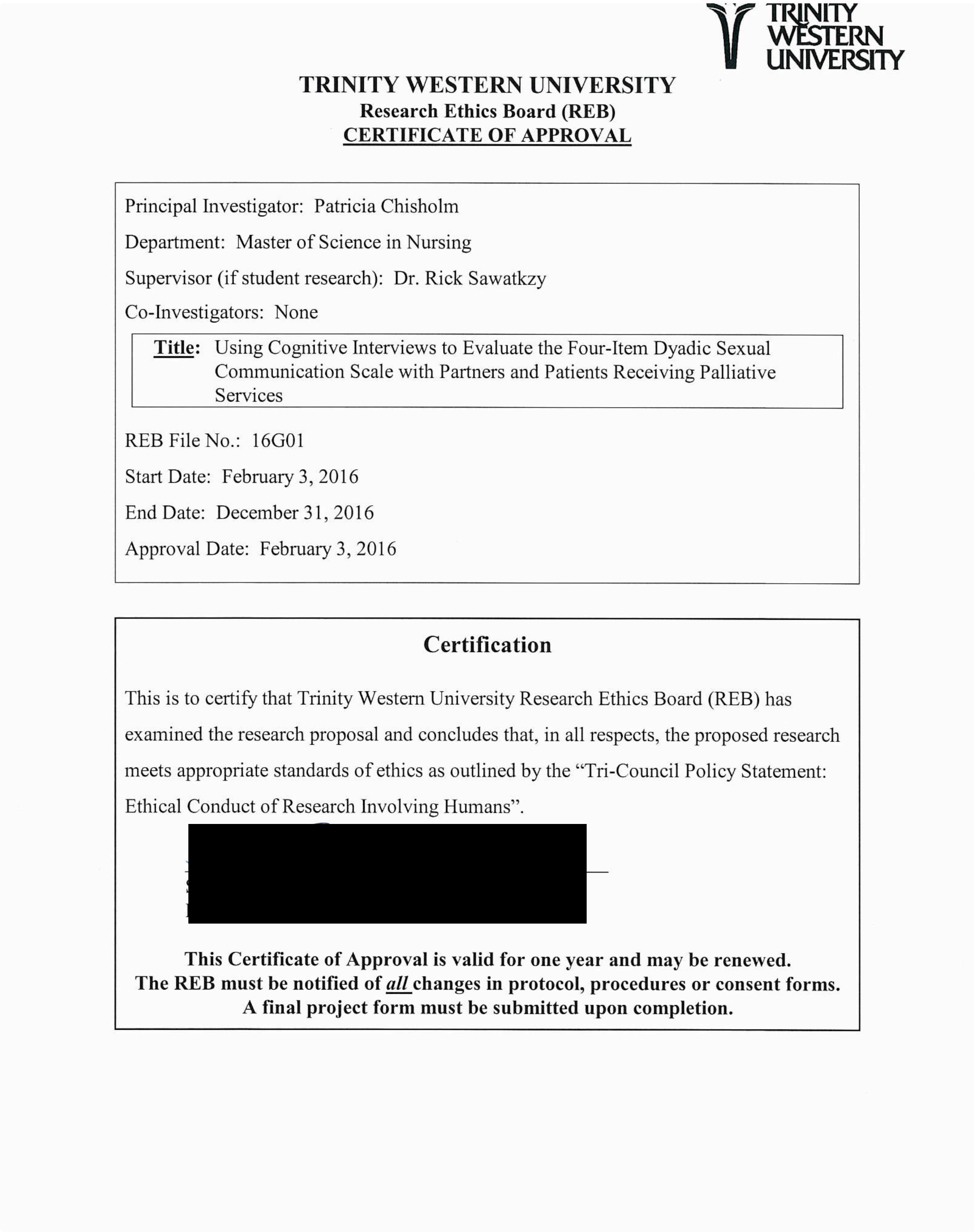
Research Hypotheses: To evaluate prostate cancer patient and partner relationship and sexual adjustment; hypothesize that partner depression, both general and sexual, impacts patient well-being on a number of measures.

Relevant Findings: Prostate cancer patients and partners had more depression, sexual dissatisfaction, and poorer sexual communication than the general population. "Partners' level of general depression and depression concerning their sex lives were significant predictors of patients' relationship satisfaction, perceived quality of communication about the sexual relationship, and sexual satisfaction after controlling for patients' general and sexual depression" (p. 1394).
Author/APA Reference: Tourangeau, R., & Yan, T. (2007). Sensitive questions in surveys. *Psychological Bulletin, 133*(5), 859-883. **Research Methodology:** Seminal literature review **Relevant Findings:** Overview of sensitive survey questions: definition of the term, response errors, and possible strategies to reduce reporting errors.
Author/APA Reference: Hordern, A. (2008). Intimacy and sexuality after cancer: A critical review of the literature. *Cancer Nursing, 31*(2), E9-E17. **Research Methodology**: Literature review **Sample:** Articles from 1970 through 2004; 421 articles reviewed **Relevant Findings**: Definitions of sexuality and intimacy not well-articulated; research emphasis on sexual function, younger patients, and survival over sexuality; patients want information, support and practical strategies; health professional attitudinal barriers: believe sexuality conversations inappropriate or embarrassing; cite time constraints and lack of knowledge; three communication models: ALARM: not useful due to functional focus; PLISSIT: innovative in its era (1970s) now dated and outmoded; BETTER: developed for oncology nurses.
Author/APA Reference: Gilbert, E., Ussher, J. M., & Hawkins, Y. (2009). Accounts of disruptions to sexuality following cancer: The perspective of informal carers who are partners of a person with cancer. *Health (London, England: 1997), 13*(5), 523-541. **Research Methodology**: Qualitative; semi-structured interviews; material-discursive perspective **Sample:** 20 partners of a person across a range of cancer types ("part of a larger cross-sectional project evaluating needs and experiences of informal cancer carers" (p. 524)) **Research Question: "**How do partners of a person with cancer account for changes in their sexual relationship post-cancer? More specifically, how do constructions of the caring role and sexuality impact on partners' experiences of their sexual relationship post-cancer?" (p. 526) **Relevant Findings**: Sexuality and sexual relationships are disrupted: patient has no desire, caring is exhausting, patient now seen as asexual or a child, reluctance to initiate encounters; Responses to disruptions: acceptance, renegotiation, anger or loneliness.
Author/APA Reference: Hawkins, Y., Ussher, J., Gilbert, E., Perz, J., Sandoval, M., & Sundquist, K. (2009). Changes in sexuality and intimacy after the diagnosis and treatment of cancer: The experience of partners in a sexual relationship with a person with cancer. **Research Methodology**: Qualitative; critical realist epistemological stance **Sample:** same sub-sample as Gilbert et al. (2009) above: 156 (of 300) partners answered open-ended questions in the larger study; 20 selected for in-depth interviews **Research Question:** Examine experiences of sexuality and intimacy in partners of a person with cancer. **Relevant Findings**: Status of current sexual relationship: cessation or decreased frequency of sex

and intimacy or renegotiation of same; Reasons for changes: impact of cancer treatment, exhaustion, person with cancer seen as a 'patient'; Partners' positive feelings: acceptance, affection, devotion; negative feelings: sadness, disgust, frustration; only 20% had discussions with healthcare professionals.
Author/APA Reference: Gilbert, E., Ussher, J. M., & Perz, J. (2010). Renegotiating sexualityand intimacy in the context of cancer: The experiences of carers. *Archives of SexualBehavior, 39*(4), 998-1009. doi: 10.1097/NCC.0b013e3182759e21 **Research Methodology**: Qualitative; material discursive framework **Sample:** same as above two studies—authors do not say if it is the same 20 partners; it is possible the interviews were done once with the same 20 people and the analyses focused on different factors **Research Question: "**How do carers who are the intimate partner of a person with cancer renegotiate their sexual relationship following the onset of cancer and the caring role? What factors are associated with successful or unsuccessful renegotiation?" (p. 1000). **Relevant Findings**: 1/3 Redefining sexual intimacy: self-masturbation, manual masturbation, oral sex, vibrators, massage, touching and kissing; 2/3 who did not renegotiate maintain the coital imperative; positive communication leads to renegotiation; negative communication blocks renegotiation.
Author/APA Reference: Ussher, J. M., Perz, J., Gilbert, E., Wong, W. K. T., & Hobbs, K. (2013). Renegotiating sex and intimacy after cancer: Resisting the coital imperative. *Cancer Nursing, 36*(6), 454-462. **Research Methodology**: Qualitative; semi-structured interviews; social constructionist stance **Sample:** 44 people with cancer (23 men, 21 women) and 35 partners (18 women, 17 men) 86% identify as heterosexual **Research Question:** "To examine renegotiation of sex and intimacy in the context of cancer, across a range of cancer types and sexual orientations in people with cancer and their partners" (p. 455). **Relevant Findings**: Resisting the coital imperative: redefining sex and embracing intimacy; adopting the coital imperative: refiguring the body through techno-medicine; the intersubjective nature of sexual renegotiation. **Note:** This is a new project for the team of Ussher, Perz and Gilbert (and colleagues). All previous references refer to a project focused on family caregivers; here the focus is changes and constructions of sexuality after cancer.
Author/ APA Reference: Miller, K., Willson, S., Chepp, V., Padilla, A. (Eds.). (2014). *Cognitive interviewing methodology*. [Kindle for Mac version]. Retrieved from Amazon.ca **Research Methodology:** Book **Relevant Findings:** Authors advocate for transparency and careful reporting of cognitive interview verbal data. Using an interpretivist framework to investigate participants meaning-making processes from within a certain sociocultural environment. Thorough instructions regarding data collection, analysis, and reporting.
Author/APA Reference: Perz, J., Ussher, J. M., & Gilbert, E. (2014). Feeling well and talking about sex: Psychosocial predictors of sexual functioning after cancer. *BMC Cancer, 14*, 228-228.

Research Methodology: Quantitative **Measures:** Changes in Sexual Functioning Questionnaire (CSFQ-14), HADS, Medical outcomes study health survey short form (SF-12), Brief Dyadic Adjustment Scale (DAS), **Dyadic Sexual Communication Scale**, the Silencing the Self Scale (STSS), ratings of sexual importance and activity **Sample:** 657 people with cancer (535 women, 122 men) and 148 partners (87 women, 61 men) **Research Questions: "**How important is sexuality post-cancer? What are the changes in sexual functioning reported before and post-cancer? What psychosocial factors are associated with reductions in sexual functioning post-cancer? What is the relative contribution of psycho-social factors in predicting reductions in sexual functioning?" (p. 3). **Relevant Findings**: Reductions in sexual functioning after cancer; dyadic sexual communication a significant predictor of sexual functioning for women with cancer and men and women partners.
Author/APA Reference: Perz, J., & Ussher, J. (2015). A randomized trial of a minimal intervention for sexual concerns after cancer: A comparison of self-help and professionally delivered modalities. *BMC Cancer, 15*(1), 1-16. **Research Methodology:** RCT with mixed method analysis **Measures:** Medical Outcomes Study Health Survey Short Form (SF-12); Hospital Anxiety and Depression Scale (HADS); Silencing the Self Scale (STSS); Brief Dyadic Adjustment Scale (DAS); **Dyadic Sexual Communication Scale;** Changes in Sexual Functioning Questionnaire (CSFQ-14) **Sample:** Subsample of Perz et al. (2014) above: of the 657 above 394 people with cancer and 93 partners indicated they would be willing to participate in future research; for this study, 88 people with cancer and 53 partners participated **Intervention:** Participants randomized to SH: self-help condition given written information about sexual changes after cancer; or HP: health professional condition given same written information plus one counseling session by telephone or Skype **Relevant Findings:** Both conditions found the information useful; quantitative analysis found no improvement in any measures.

Appendix C: Research Ethics Board Certificate of Approval



TRINITY WESTERN UNIVERSITY
Research Ethics Board (REB)
CERTIFICATE OF APPROVAL

Principal Investigator: Patricia Chisholm

Department: Master of Science in Nursing

Supervisor (if student research): Dr. Rick Sawatkzy

Co-Investigators: None

Title: Using Cognitive Interviews to Evaluate the Four-Item Dyadic Sexual Communication Scale with Partners and Patients Receiving Palliative Services

REB File No.: 16G01

Start Date: February 3, 2016

End Date: December 31, 2016

Approval Date: February 3, 2016

Certification

This is to certify that Trinity Western University Research Ethics Board (REB) has examined the research proposal and concludes that, in all respects, the proposed research meets appropriate standards of ethics as outlined by the "Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans".

[redacted]

This Certificate of Approval is valid for one year and may be renewed.
The REB must be notified of *all* changes in protocol, procedures or consent forms.
A final project form must be submitted upon completion.

Appendix D: Recruitment Poster

Intimacy and Illness Research

- **Do you or your intimate partner receive health care for a serious illness?**
- **Do you live on Vancouver Island?**

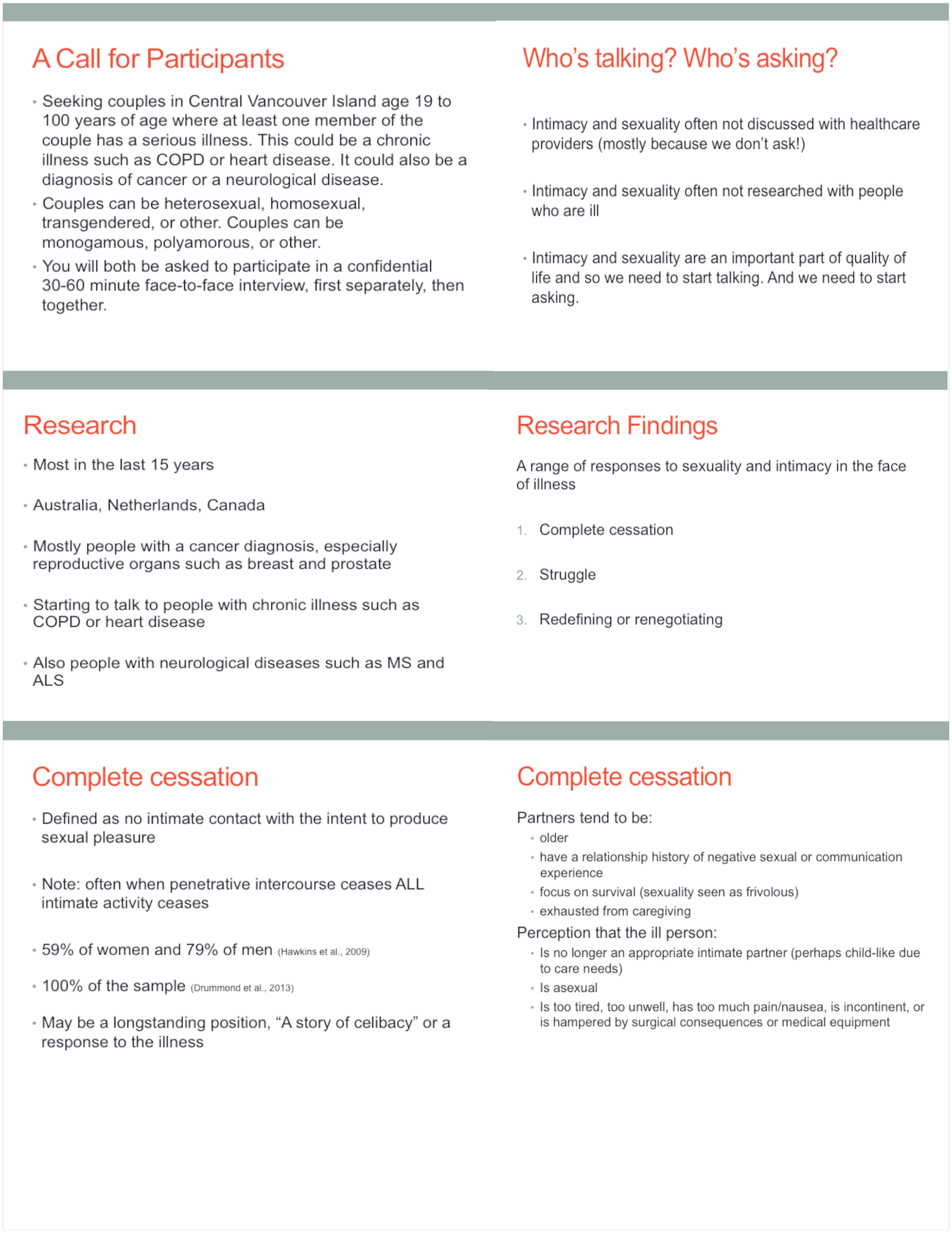
If you <u>and</u> your partner would be willing to talk to a nurse-researcher for 30-60 minutes about your intimate life:

Patricia.Chisholm@

250-000-0000

sexualityresearch.bravesites.com

Appendix E: PowerPoint Presentation



A Call for Participants

- Seeking couples in Central Vancouver Island age 19 to 100 years of age where at least one member of the couple has a serious illness. This could be a chronic illness such as COPD or heart disease. It could also be a diagnosis of cancer or a neurological disease.
- Couples can be heterosexual, homosexual, transgendered, or other. Couples can be monogamous, polyamorous, or other.
- You will both be asked to participate in a confidential 30-60 minute face-to-face interview, first separately, then together.

Who's talking? Who's asking?

- Intimacy and sexuality often not discussed with healthcare providers (mostly because we don't ask!)
- Intimacy and sexuality often not researched with people who are ill
- Intimacy and sexuality are an important part of quality of life and so we need to start talking. And we need to start asking.

Research

- Most in the last 15 years
- Australia, Netherlands, Canada
- Mostly people with a cancer diagnosis, especially reproductive organs such as breast and prostate
- Starting to talk to people with chronic illness such as COPD or heart disease
- Also people with neurological diseases such as MS and ALS

Research Findings

A range of responses to sexuality and intimacy in the face of illness

1. Complete cessation
2. Struggle
3. Redefining or renegotiating

Complete cessation

- Defined as no intimate contact with the intent to produce sexual pleasure
- Note: often when penetrative intercourse ceases ALL intimate activity ceases
- 59% of women and 79% of men (Hawkins et al., 2009)
- 100% of the sample (Drummond et al., 2013)
- May be a longstanding position, "A story of celibacy" or a response to the illness

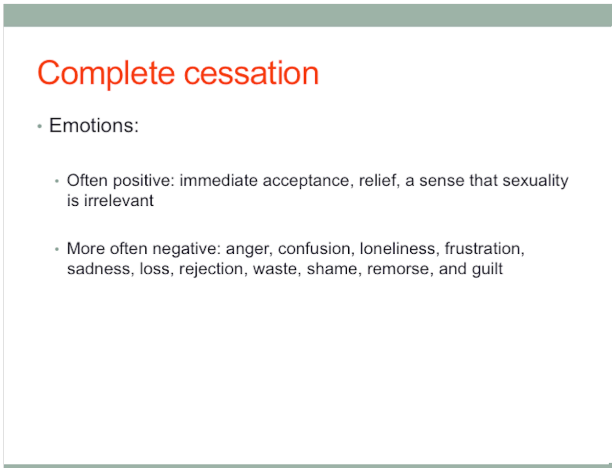
Complete cessation

Partners tend to be:

- older
- have a relationship history of negative sexual or communication experience
- focus on survival (sexuality seen as frivolous)
- exhausted from caregiving

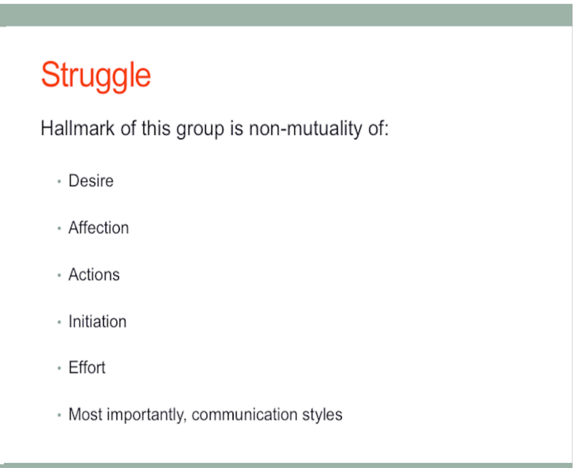
Perception that the ill person:

- Is no longer an appropriate intimate partner (perhaps child-like due to care needs)
- Is asexual
- Is too tired, too unwell, has too much pain/nausea, is incontinent, or is hampered by surgical consequences or medical equipment



Complete cessation

- Emotions:
  - Often positive: immediate acceptance, relief, a sense that sexuality is irrelevant
  - More often negative: anger, confusion, loneliness, frustration, sadness, loss, rejection, waste, shame, remorse, and guilt



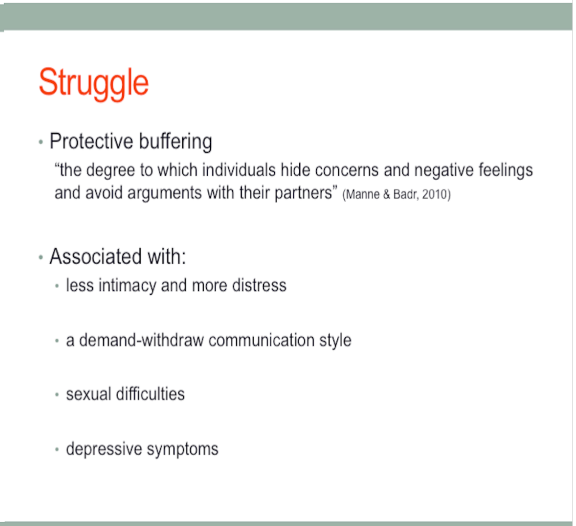
Struggle

Hallmark of this group is non-mutuality of:

- Desire
- Affection
- Actions
- Initiation
- Effort
- Most importantly, communication styles

Struggle

- Communication styles
  - Consistently negative or non-existent
  - Never discussed sex before and never discuss it now
  - Efforts blocked
  - Certain feelings forbidden

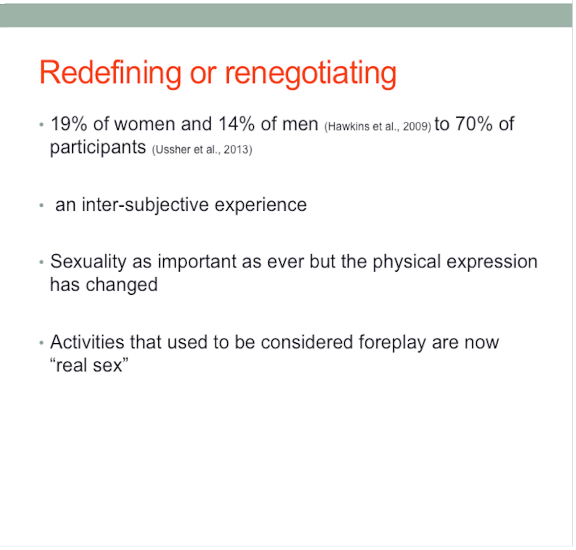


Struggle

- Protective buffering
  "the degree to which individuals hide concerns and negative feelings and avoid arguments with their partners" (Manne & Badr, 2010)
- Associated with:
  - less intimacy and more distress
  - a demand-withdraw communication style
  - sexual difficulties
  - depressive symptoms

Redefining or renegotiating

- Humility
- Generosity of spirit
- Part of one another
- Desire
- Pleasure
- Fun
- Laughter
- Romance
- Closeness



Redefining or renegotiating

- 19% of women and 14% of men (Hawkins et al., 2009) to 70% of participants (Ussher et al., 2013)
- an inter-subjective experience
- Sexuality as important as ever but the physical expression has changed
- Activities that used to be considered foreplay are now "real sex"

Redefining or renegotiating

- Touching
- Holding
- Looking
- Cuddling
- Mutual masturbation
- Self-masturbation
- Oral sex
- Massage
- Vibrators (& other toys)
- Kissing
- Hugging
- Like being teenagers

Redefining or renegotiating

- Communication styles:
  - Intentional conversations about sexual relationship
  - Honesty
  - Desire to have the hard conversations
  - Openness

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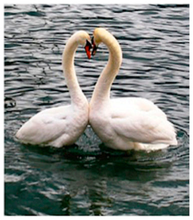
Want to participate in research?

Patricia Chisholm RN
Nurse Researcher

Intimacy and Illness Research

sexualityresearch.bravesites.com



Appendix F: Demographic Data

1. Is the person you care for your: husband; wife; common-law partner?

2. What is your marital status?

3. Do you live with this person? How long?

4. How long have you been together?

5. What is your age?

6. What is your gender?

7. Do you have any medical conditions?

Appendix G: Four-Item Dyadic Sexual Communication Scale

Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly Agree
1	2	3	4	5

1. Some sexual matters are too upsetting to discuss with my sexual partner.
2. My partner has no difficulty in talking to me about his or her sexual feelings and desires.
3. Talking about sex is a satisfying experience for both of us.
4. I have little difficulty in telling my partner what I do or don’t do sexually.

Used with permission.

Appendix H: Interview Guide; Cognitive Interview Probe Questions

A packet of papers is handed to the participant. Each item is typed on a single sheet of paper along with the Likert scale as shown above, for a total of four papers with items and scale. Dyadic Sexual Communication Scale questions are asked one at a time. Concurrent probing after each item; retrospective probing following the completion of the measure/domain.

Item:

1. What did you think about when answering this question?
2. (Tell me more about that.)
3. Question 1: what does the term “sexual matters” mean to you? What does the term “upsetting” mean to you?
4. Question 2: What do the terms “sexual feelings and desires” mean to you?
5. Question 3: What does the term “talking about sex” mean to you? What does the term “satisfying experience” mean to you?

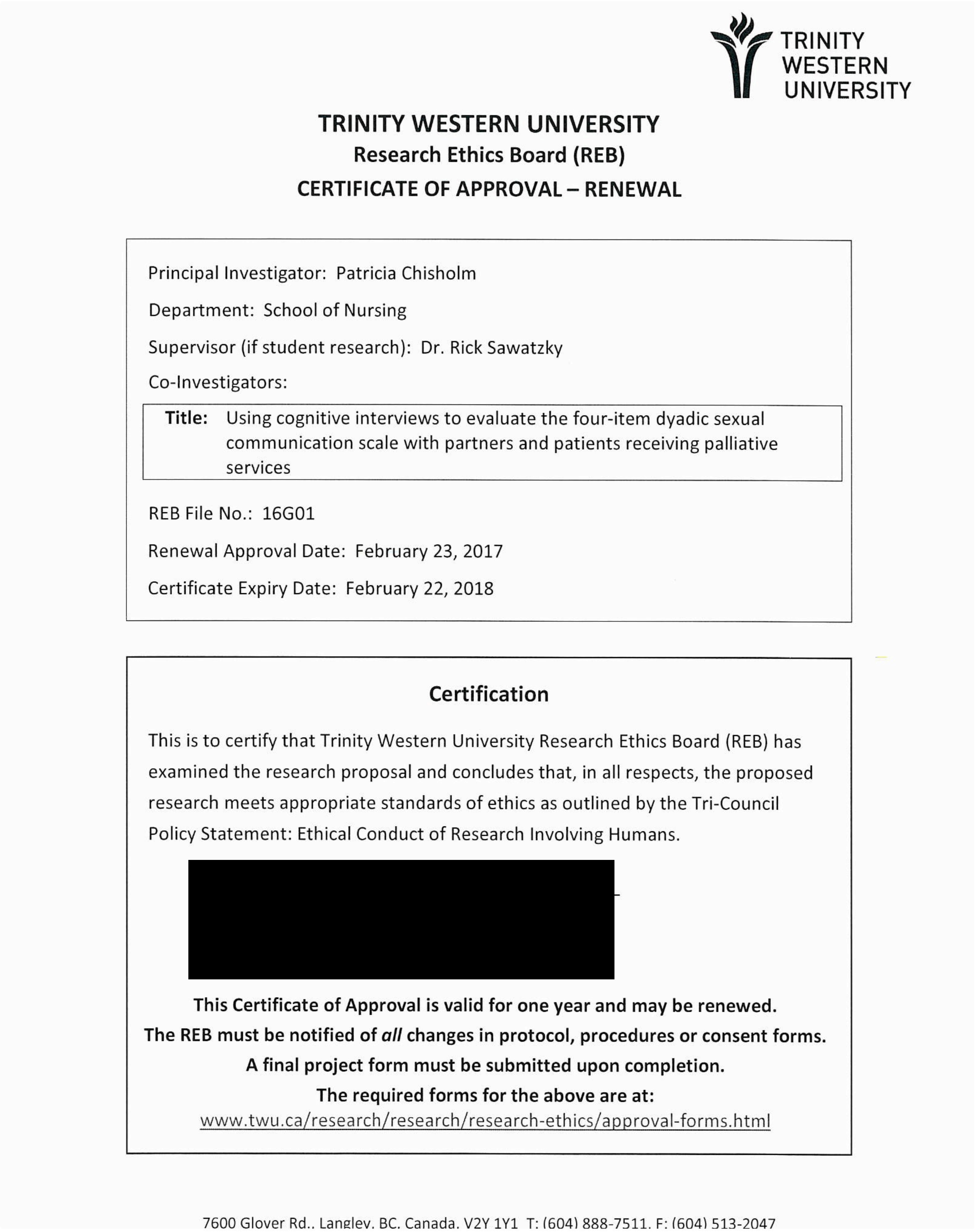
Domain

6. In your own words, what do you think this group of questions is asking about?
7. Could you please tell me if these questions are relevant to partners caring for someone who is seriously ill? Why? Why not? What kinds of questions should I be asking?
8. Would you say you answered according to how things are now, how things used to be between the two of you or in some other way?

Conclusion (if not addressed spontaneously earlier in the interview)

9. What does “sex” mean to you? “Sexuality”? “Intimacy”?
10. How did it feel to answer these questions?
11. Is there anything else you would like to tell me?

Appendix I: Research Ethics Board Certificate of Approval--Renewal



TRINITY
WESTERN
UNIVERSITY

TRINITY WESTERN UNIVERSITY
Research Ethics Board (REB)
CERTIFICATE OF APPROVAL – RENEWAL

Principal Investigator: Patricia Chisholm

Department: School of Nursing

Supervisor (if student research): Dr. Rick Sawatzky

Co-Investigators:

Title: Using cognitive interviews to evaluate the four-item dyadic sexual communication scale with partners and patients receiving palliative services

REB File No.: 16G01

Renewal Approval Date: February 23, 2017

Certificate Expiry Date: February 22, 2018

Certification

This is to certify that Trinity Western University Research Ethics Board (REB) has examined the research proposal and concludes that, in all respects, the proposed research meets appropriate standards of ethics as outlined by the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans.

[redacted]

This Certificate of Approval is valid for one year and may be renewed.
The REB must be notified of *all* changes in protocol, procedures or consent forms.
A final project form must be submitted upon completion.
The required forms for the above are at:
www.twu.ca/research/research/research-ethics/approval-forms.html

7600 Glover Rd., Langley, BC, Canada, V2Y 1Y1 T: (604) 888-7511, F: (604) 513-2047

Appendix J: Consent

Project Title: Intimacy and Illness research

Principal Investigator: Patricia Chisholm
Master of Science in Nursing (MSN) Student
School of Nursing Trinity Western University
7600 Glover Road Langley, BC V2Y 1Y1 Canada
Patricia.Chisholm@mytwu.ca (250) 000-0000

This research is related to Patricia Chisholm's MSN thesis.

Faculty Advisor for this study: Dr. Rick Sawatzky
School of Nursing
Trinity Western University
7600 Glover Rd Langley, BC V2Y 1Y1 Canada
rick.sawatzky@twu.ca (604) 513-2121 x3274

You have been asked to participate because you have serious illness or you are the husband/wife or common-law partner of someone who is seriously ill. Your participation in this study is entirely voluntary and will in no way affect the care that you or your loved one will receive from the health care system. You may decide not to participate or may withdraw from the study at any time without consequences or explanation. You are free to refuse to answer any questions.

PURPOSE

The purpose of this study is to examine intimacy and sexuality with people who are seriously ill and their partners. Studies have shown that intimacy affects quality of life, that we are just starting to understand what this means for couples where one is seriously ill, and that some couples want to talk about sexuality with a health professional. Research of this type will provide valuable information about patient and partner experiences and ways to improve sexuality resources for people who are seriously ill.

PROCEDURES

We are asking for your consent to participate in a face-to-face interview that will last approximately one hour. Each member of the couple will be interviewed separately and then come together for a few minutes to discuss any remaining thoughts or feelings. You will each be asked to complete two forms: a demographic data form (for example: age, length of relationship), and the four-item Dyadic Sexual Communication Scale. The Principal Investigator will ask a series of guiding questions and engage in a conversation with you around your experiences of the scale, and sexuality and intimacy in relation to serious illness. The interview will be arranged at a time of your convenience and will be audio recorded and typed by the Principal Investigator.

POTENTIAL RISKS FOR PARTICIPANT(S)

There is a low risk of emotional distress or embarrassment when talking about intimacy or sexuality. Patricia has been a nurse for 30 years in a variety of settings and has taken a Sex Therapy Training program through the University of Guelph. If you are distressed, Patricia will use empathy and active listening skills. In addition, a list of local sexuality resources can be made available to you upon your request.

POTENTIAL BENEFITS FOR PARTICIPANT(S)/SOCIETY

People who are seriously ill and their partners often want to talk about their intimacy and sexuality. Sometimes they have never been asked about this. You may find the interview to be therapeutic. In addition, the findings will inform healthcare professionals about the experiences of intimacy and sexuality when one member of a couple is seriously ill. The findings of the study will be published in a peer-reviewed journal, and presented at a nursing conference.

RIGHTS AND COMPENSATION

By signing this form, you do not give up any of your legal rights. There will be no costs to you for participation in this study and you will receive a $5 honorarium gift card as a token of appreciation for your participation in the study. Should you choose to withdraw from the study, you can keep the gift card.

CONFIDENTIALITY

All information obtained in this study is confidential. I will not discuss your interview with your partner. Only the Principal Investigator and Faculty Advisor will have access to the information. You will each be assigned a code number and fake name so you cannot be identified. All study information (e.g., interview materials, notes, and audio tapes) will be kept secured in a locked file cabinet that only I can access. All typed transcripts will be stored in an encrypted folder on a password-protected computer. These records will be kept for seven years for possible secondary analysis.

WHAT HAPPENS IF I DECIDE TO WITHDRAW MY CONSENT TO PARTICIPATE?

Your participation in this research is entirely voluntary. You may withdraw from this study at any time. If you decide to enter the study and to withdraw at any time in the future, there will be no penalty or loss of benefits to which you are otherwise entitled. If you choose to withdraw from the study, all data collected about you during your enrolment in the study will be retained for analysis.

CONTACT FOR INFORMATION

If you have any questions or desire further information with respect to this study, you may contact Patricia Chisholm (Principal Investigator) or Dr. Rick Sawatzky (Faculty Advisor) using the contact information provided at the beginning of this consent form.

CONTACT FOR CONCERNS

If you have any concerns about your treatment or rights as a research participant, you may contact Ms. Sue Funk in the Office of Research, Trinity Western University at 604-513-2142 or sue.funk@twu.ca

SUBJECT CONSENT TO PARTICIPATE

I have read and understood the subject information and consent form and am consenting to participate in the study "Intimacy and Illness."

- I have had sufficient time to consider the information provided and to ask for advice if necessary.
- I have had the opportunity to ask questions and have had satisfactory responses to my questions.
- I understand that all of the information collected will be kept confidential and that the result will only be used for research and evaluation objectives, such as in presentations, publication in book chapters and scientific journals.
- I understand that my participation in this study is voluntary and that I am completely free to refuse to participate or to withdraw from this study without changing in any way the quality of care that I receive.
- I understand that I am not waiving any of my legal rights as a result of signing this consent form.
- I understand that there is no guarantee that this study will provide any benefits to me.
- I have read this form and I freely consent to participate in this study.
- I have been told that I will receive a dated and signed copy of this form.

By signing below you are indicating you consent to participate on the study and that your responses may be kept for further use after the completion of this study.

Signature of participant: Date *(dd/mm/yy)*

Printed Name: ____

____

Signature of researcher: Date *(dd/mm/yy)*

Printed Name: ____

Appendix K: CASM Table Item One

CASM Table Item One: Some sexual matters are too upsetting to discuss with my sexual partner.

	Comprehension	Retrieval	Judgment	Response
Samantha (Pt 1)	Immediate answer: "not at all!"; determines it is asking about their communication style over time	Recalling memories "We always talk; I'm just thinking; when we've let something go by it doesn't happen" Repeats: "we always talk"	"We always talk; nice; lucky" Thinking about partner, their past, their usual way of being	Immediate understanding and answering the item "Not at all!"
Joe (Prtnr 1)	Understands the item; determines it is asking about topics	Reviewing topics "I was trying to think of things I wouldn't talk to her about…that's where my head went: what would I not want to talk to her about."	Not confident in his answer. "Uh, or maybe I should say that I neither agree or disagree because it doesn't fit, you know [mmm] and I don't know how you'd put it in that category. In the one to five. My answer, to the question. What do you think?" Eventually reveals details: "I'm into monogamy so I don't have things to hide in that respect."	Answers right away: "I guess I'd have to say strongly or disagree, one of the two. I guess I think it'd be strongly disagree I guess." After probing for meaning he wonders about changing his answer: Retains his original response after debating between two choices, choosing, pondering a different choice, asking for advice, then finally choosing
Jack (Pt 2)	Concerned that he and his wife would not be at the same baseline; wonders about answering all of the questions in the set—this is the	Rests on 'my wife and I are different'—I wouldn't have a problem but she would have a problem	Paying attention to the instructions while reading the questions from a piece of paper in front of him; worried about	After asking numerous questions and establishing an understanding of the process, and after I re-take

	first question so he is trying to understand the instructions		establishing a "baseline"; attempts to pre-empt me telling me how he and his wife may differ; answering before I even ask the question	control of the interview, reading the item and asking him to choose from the scale, he responds, "I would probably choose a three"
Tracey (Prtnr 2)	Takes her time deciding; "I would probably say disagree." Determines it is asking about topics and their communication style over time	Reviewing topics "areas in the past that would be too difficult" Recalling memories "we had things we had to work through"	Answering carefully and thoughtfully; reveals their ability to talk about times when she was "not trusting" when he was "too rough" or "too selfish"	"I would probably say disagree."
Paulo (Prtnr 3)	Immediate answer: "that would be number one" determines it is asking about their communication style over time	Recalling memories "We're terribly open with each other and discuss whatever we need to and we have no inhibitions about it…always"	Does not waver from 1st answer; thinking about their couplehood; inferring their openness means they can discuss "whatever we need to and we have no inhibitions about it"	"that would be number one"
Julia (Pt 3)	Said she disagreed with the item which would imply that there are no sexual matters that are upsetting but she states: "I was thinking of a few things I wouldn't discuss because it wouldn't be good for him so we just leave it."	Thinking of topics she would avoid "I was thinking of a few things that I wouldn't discuss because it wouldn't be good for him"	Agrees there are a few matters: "a few, not many" For example, the orgasmic sexuality is not important to her: "I would never tell him that; he knows instinctively but I wouldn't verbalize it…I don't want to go there; I don't	"I disagree"

			want to test it.”	
Tadeauz (Pt 4)	Understands the item; chooses an item from the scale; “I can’t think of anything so number one.” After a short discussion wonders what five/strongly agree would look like: “I don’t talk to her about anything and we just do it in the dark.”	Recalling his philosophy: “I’m very open sexually.” Making inferences: I’m open and so I could talk about any sexual matters.	Thinking about himself: he is open; she knows I am open. I know myself, she knows me and so I can infer that any topic would be okay, i.e. not upsetting; thinking perhaps more about if there would be any difficulty vs what might be upsetting. I can talk about anything; later he does talk about withholding; not talking about his desire—does this qualify?	“I can’t think of anything so number one.” Later: “I don’t know what five would even be. It’s like: I don’t talk to her about anything and we just do it in the dark?”
Theory (Prtnr 4)	Understands the item; chooses two items from the scale “I am more drawn to one and two”	Recalling memories; could talk about any topics it’s more about timing; not during sex; can talk later and not “ruin the moment”	Is drawn to the disagree end of the scale: “more drawn to one and two”; chooses two/disagree because “to say I never feel apprehensive about bringing something up wouldn’t feel completely right.” Re-reads the item and affirms she chose correctly	“I am more drawn to one and two.” I ask her to choose “Well I mean I’ll I’ll go with two…I know that I could talk with him about anything um but to say I never feel apprehensive about bringing something up wouldn’t feel completely right so I will go with two.”

Appendix L: CASM Table Item Two

CASM Table Item Two: My partner has no difficulty in talking to me about his or her sexual feelings and desires.

	Comprehension	Retrieval	Judgment	Response
Samantha (Pt 1)	Immediate answer	Thinking about partner	Thinking about partner and it's true and that's all. She got lucky, he's her angel of glory	Simple answer; does not seem to refer to the question but more about partner's way of being with her
Joe (Prtnr 1)	Uncertain how to answer; "On this thing? No? Is that what it was, no difficulties?"	Thinking about partner; has only limited knowledge about what she thinks or feels	From a theoretical standpoint talks about the limitations of knowing his partner's "own mind	I would agree generally
Jack (Pt 2)	Understands the question	"that would be a harder topic for her to talk about me but in the opposite way I don't but the the feedback would not be a problem so I would try to match her level of what she was trying to attempt to mention to me or talk to me or um desire" Thinking about: baseline, bell curves, outliers, data set—how are my points lying? "I'm a visual person." "Looking at 3D	Talks about his way of answering the question—it's about him figuring it out. Talks about his past, talks about his fantasies. He can talk, not as acceptable to her—watches for feedback: verbal, nonverbal cue-points. Then starts talking about "we" we have issues, we've noticed. Eventually talks about her needs: physical	Talks about partner: she would have a problem, I don't; he would "match" her level of what she was saying. I ask him to choose. "Trying to figure it out, baseline, it, what would be hers what would be ours. I would say…I would probably…I would be um, I would go more two than three." "I

		scattergraph in my brain…outliers, different perspectives, orthogonal views. That's how I do my analysis and work."	touching, kissing caressing. Then back to talking about himself and his injury—Venn diagram—used to be 80% overlap not 20%. Then talks about sex: "once we have physical intimacy it sort of resets	would sort of disagree with that she would have a difficulty in talking to me about that." "I wouldn't have difficulty."
Tracey (Prtnr 2)	Understands the question	Thinks about partner; thinks about the past. "He's pretty open so I just thought about how he is in the past in talking to me about things."	Gives an example of partner's sexual feelings: Feels like half a man; it's difficult to have sex.	I agree I would say four
Paulo (Prtnr 3)	Chooses the same answer as the first item; I query him; does not read the item with the scale that is in front of him; acknowledges this and apologizes	Thinks back to the previous item and gives the same answer: "we're terribly open with one another."	Makes an inference: because we are open, we can talk about everything so we can talk about this too	Chooses an answer, interviewer is pretty sure he does not intend this, asks him if he is sure; he reads the paper and chooses "number five this time. I didn't read it; terrible; glad you mentioned it"
Julia (Pt 3)	Understands what the item is saying	Thinking about partner; thinking about specific instances in the past/long term memory:	Recalls specific instance: Hiccups: "when we discovered that we couldn't have penetrative	Initially talks about partner: "He definitely doesn't [have difficulty] he's quite

			sex, he was quite comfortable with that." He's pragmatic even about her disease	comfortable." I direct her to the scale: strongly agree.
Tadaeuz (Pt 4)	Cites Statistics Canada—does not apply-- Initially chooses number two because he has "wanted more"; turns out he has wanted more about her sexual history not her current feelings and desires. I urge him to NOW, he re-reads, this is confusing. Not sure how to align the item and the scale: "no difficulty would be a one right? Or am I agreeing strongly that they have no difficulty?" Has failed exams in English {ESL?}worries about grading her too low. Chooses five	Thinking about partner; has difficulty with memory	Recalls previous conversations about past sexual history; she says it is not memorable but he wants to know more. Talks about himself, his sexual experiences, likes to document them. (She is not like me in this way.) Acknowledges it is not resistance on her part; he is open and wants open. I urge him to think about NOW. Talks about himself and his openness, his needs; she is responsive to his needs. Making an inference that this would be true since he is so open she would not meet any resistance.	Hesitates, talks about her memory (capacity) otherwise no (her ability to talk now); chooses number two. Talks about himself—he is different from her: cherishes his sexual history whereas she does not. I urge him to talk about NOW. Re-reads; this is confusing me; unsure about the scale and the item; has failed exams in English; worries about giving her a low grade; finally five. Talks about himself: I'm inquisitive, I've been the same all along, partner doesn't make me feel like my questions are a

				burden. "So definitely five I guess. I agree that there's no difficulty."
Theory (Prtnr 4)	Understands the item; chooses an answer from the scale	Thinking about recent conversations with partner; no problem communicating his feelings and desires: verbally, non-verbally and through writing	He can tell about feelings and desires but she can tell when he might be withholding; his desire's higher; she perceives he might think he is burdening her or being selfish with his own desires; withholds physically	Immediate: "Four/agree"

Appendix M: CASM Table Item Three

CASM Table Item Three: Talking about sex is a satisfying experience for both of us.

Pseudonym	Comprehension	Retrieval	Judgment	Response
Samantha (Pt 1)	Understands item	Thinking about their relational distant and recent past communication	“Thinking about how much we talk. We communicate quite a bit which is nice.” “Every topic yes but sex as well.” The same before and after her diagnosis.	“Strongly agree” (5)
Joe (Prtnr 1)	Understands item; gives an answer, asks how he should rate it: “numbers?” when probed asked for item to be repeated. Provides details, then “shit I’ve lost the questions again”	Thinking about past occasions: during a pornography movie	“We don’t talk about it that often.” “It has to be satisfying because humor and honesty are involved so I don’t think there’s dissatisfying.”	“I think so…Numbers?... number four.” (4)
Jack (Pt 2)	Understands item	Thinking about specific things he has said: “I had a good dream, we had fun, this is what we did.”	Using talk with sexual contact, “but it wasn’t a goal or a necessary means to an end, more sharing of information…she’ll respond but will not initiate.” He would find it satisfying, will share information with sexual content; she will not initiate but will respond: she’ll laugh	“Um that would be mutual, I would say three.” (3)

Tracey (Prtnr 2)	Understands item	Thinking about past conversations about their sexual lives together: fixing things, counsellor, “want to do it once a week”	“It’s satisfying in the respect that we can get something resolved.” “same cycles over and over again…frustrating.” Talking about their sexual life together: frequency, agreements made and not kept.	“I would disagree with that one.” (2)
Paulo (Prtnr 3)	Takes time making sense of the question; uncertain about the term ‘satisfying.’ Next uncertain about the terms ‘talking about sex’—asks for clarification. Interviewer continues to ask his thoughts. He makes connections between key terms, decides what the item is saying and answers according to the scale.	Uses all his cognitive energy making sense of the question. Answer seems more theoretical than personal.	There is a process to understanding what the question is asking. Starts by making inferences: “I don’t know if you term it satisfying as such…to me it’s like talking about anything” such as the weather or something on the radio. Coaxed by interviewer. “I’m getting my head around the word satisfying.” Coaxed by interviewer. “When you say talking about sex, is it discussing aspects of the relationship, or are we talking about pornography? What what are we talking about?” When asked what he thinks: “I would’ve thought it was meant to be talking about one’s interaction with	He finally decides what the question is asking. “I would agree it’s being talking about sex is clarification of thought…or the physical aspects of it. I suppose in the sense that you’re clarifying something that is satisfactory that you are both on the same wavelength so I mean do you call that satisfying? I’d agree strongly.” (5)

			your partner."	
Julia (Pt 3)	Takes time making sense of the question; uncertain about the term 'satisfying' "Talking about sex is not difficult for us but as satisfying, that's the catch."	Thinking about current patterns: "we only talk when there's a problem, thinking to the distant past: when we were newly married it was a satisfying experience, now it really doesn't matter." Comparing distant past to recent past; it was a focus then not as much of a focus now. States this may be due to age: "at this stage"	"We only talk about sex when we have problems to solve." Not a focus: "our lives are much more enjoying being with one another." Some things are more important than sex	"I'm going to have to go neither agree nor disagree…maybe I have to change the answer…It's a bit difficult that one." (3)
Tadeauz (Pt 4)	Understands item	Recalling occasions when they talked about their past intimate/sexual encounters.	"Talking about sex for me because of my condition is even more rewarding than the act. The act can be five minutes, the act of talking about it: three hours of pleasure of reliving how I felt that close to her."	"five" (5)
Theory (Prtnr 4)	Understands item	Thinking about their relational communication	"we both enjoy talking about that…it's a top topic."	"strongly agree" (5)

Appendix N: CASM Table Item Four

CASM Table Item Four: I have little difficulty telling my partner what I do or don’t do sexually.

CASM	Comprehension	Retrieval	Judgment	Response
Samantha (pt 1)	Understands item	Making inferences: “just the way we talk all the time. There’s no secrets between us.”	Makes inferences about the relationship in general; the perception there are no secrets—that the item may be talking about secrets.	“Very true!” when asked to use the scale: “Strongly agree”
Joe (prtnr 2)	Making sense of the question; making connections between terms. “That’s a strange item because she knows everything I do sexually. “I was trying to reach an understanding in my mind just what the question meant because I don’t do anything she doesn’t know. The doing something means what we do in the bedroom, there’s not any other activity going on.”	Uses much cognitive energy understanding the item. Making inferences: “I don’t do anything she doesn’t know.” Not giving specifics.	Making sense of the question; asking for clarification of concepts (“So is the insinuation that I would hide something? Is that the insinuation.”) Interviewer asks if he would like it read again—says yes. “What I do or don’t do…I see if you were out cheating or something.” Asks for clarification and repetition: “I have little difficulty telling her what I do? Is that what the question was?”	“Well I agree. I don’t know what the word strongly means but I definitely agree.”
Jack (pt 2)	Understands item	Recalls specific conversations from the past.	Thinks about their relational pattern in the past: “I will tell and then she will respond where it’s not a strongly agree is that she may not initiate.” Talks about	Definitely a loaded question in that one…I would…I would sort of between three and four.”

			his ability to 'tell' in other social situations: "I'll say what I really want to say."	
Tracey (prtnr 2)	Understands item; repeats item as she responds to probe (tell me more).	The way she communicated in the past—before his injury—is different from how she communicates now	She is aware that she censors herself; his experience ("we want to make sure he ejaculates") is more important than hers "It's not that I have difficulty, it's that I don't want to displease him." "I want him to get maximum benefit and so I'm not picky on what he's doing." "I feel like I'm doing it out of love for him because I know it's important to him and it doesn't really matter to me all that much."	"Oh probably…I would say disagree."
Paulo (prtnr 3)	Understands item	Makes inferences; no specific examples sexually just that they are on the same wavelength. From the beginning they "clicked," "did what came naturally." Had to talk about "abilities" after his diagnosis and treatment for prostate cancer.	Makes inferences: "We've always been totally open and reasonably inhibited. So we're both on the same wavelength so that makes things easy." "We found a lot of things we like to do together naturally."	"I would strongly agree with that."

Julia (pt 3)	Making sense of the question: "Do you mean what I do alone?" I repeat the item; she chooses an item from the scale.	Much cognitive energy spent trying to understand the item. Thinks of present way of being once she decides what the item is saying.	Finds the item "tough," wonders about one possible interpretation ("what I do alone"), trying to "figure out whether it was what I do by myself rather than what I do with him. What I want sexually from him or what I don't want. And I ruled that out because it didn't seem that was the question…Seemed to me that you were asking me what I do privately but I don't do privately at this stage because it's not that important."	"All your questions are tough." "I'm going in the neutral again."
Tadaeuz (pt 4)	Understands item	Refers to the information he has given over the course of the interview.	Making inferences about his ability to talk about anything; his openness.	"Five. I've covered that a lot."
Theory (prtnr 4)	Understands item; talks to herself about the intent: "Right so that's little difficulty meaning it's not that difficult."	Compares the past and the present; currently has a baby (baby-brain), lack of sleep, more about timing.	Lists some barriers to fully agreeing with the item: timing, sleeplessness, don't feel pretty/good about myself. Any difficulties are her internal states: worry. Makes inferences referring back to their usual style: That's "One of the good things about being able to talk to your partner about anything really…when I have no issue with them but I have my own	"I would go in that four, five. I'm just gonna go with four." Later states did not want to pick five because that means there's no room for improvement.

			thing and then now it becomes a we-thing." "So hearing somebody when they're telling you something that's bothering them it's really important. And being able to give as much reassurance as possible."	