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# Cancer, Sexual Quality of Life, and the Dyad: A Qualitative Study

Gabriela E. Gutierrez

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LOMA LINDA UNIVERSITY
School of Behavioral Health
in conjunction with the
Faculty of Graduate Studies

# Cancer, Sexual Quality of Life, and the Dyad: A Qualitative Study

by

Gabriela E. Gutierrez

A Dissertation submitted in partial satisfaction of
the requirements for the degree
Doctor of Philosophy in Systems, Families, and Couples

March 2019

Each person whose signature appears below certifies that this dissertation in his/her opinion is adequate, in scope and quality, as a dissertation for the degree Doctor of Philosophy.

____________________________________________, Chairperson
Jacqueline M. Williams-Reade, Associate Professor of Counseling and Family Sciences

Rose Hartzell-Cushanick
Rose Hartzell-Cushanick, Professor of Human Sexuality, San Diego State University

Lena Lopez-Bradley
Lena Lopez-Bradley, Assistant Professor of Counseling and Family Sciences

____________________________________________
Winetta Oloo, Associate Professor of Counseling and Family Sciences

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# ABBREVIATIONS

| | |
|---|---|
| MFT | Marriage and Family Therapist |
| MedFT | Medical Family Therapist |
| BPSS | Biopsychosocial-Spiritual |
| QOL | Quality of Life |
| SQOL | Sexual Quality of Life |
| IPA | Interpretive Phenomenological Analysis |
| P1-6 | Participant One through Six |

# ABSTRACT OF THE DISSERTATION

Cancer, Sexual Quality of Life, and the Dyad: A Qualitative Study

By

Gabriela E. Gutierrez

Doctor of Philosophy, Graduate Program in Systems, Families, and Couples
Loma Linda University, March 2019
Dr. Jackie Williams-Reade, Chairperson

As the rate of survivorship continues to increase within oncological care (White, 2007), more attention is being focused on the quality of life and long-term outcomes of cancer survivors (American Cancer Society, 2014). Sexual quality of life (SQOL), which includes both sex and intimacy, have been identified as primary sources of stress among patients and their partners across cancer types (Manne & Badr, 2008; 2010; Manne, Badr, & Kashy, 2012); however, reproductively related cancers, such as breast and gynecologic cancers have especially posed unique challenges to both patients and their partners (Jonsdottir, et al., 2016).

It is widely known that cancer has historically been researched through a medically dominated lens, in which psychosocial issues such as SQOL are either studied through a biological approach, or completely neglected altogether. Further, literature has continued to find that partners of patients have been correlated in predicating patient psychological adjustment outcomes (Jonsdottir, Jonsdottir, & Klinke, 2018; Traa et al., 2014); however, dyadic analyses, in which both patients and partners are studied as a unit, are virtually non-existent.

Through the utilization of Interpretive Phenomenological Analysis, while being informed by both Symbolic Interactionism and the Biopsychosocial-spiritual Model as guiding frameworks, this study seeks to answer the question: “What practices are couples utilizing in negotiating sex and intimacy amidst a cancer diagnosis?” This dissertation aims to gain holistic understandings and authentic accounts of participant’s lived experiences enduring SQOL negotiations amidst a reproductively related cancer diagnosis. Implications are discussed for three audiences: future couples, integrated healthcare teams, and marriage and family therapists.

# CHAPTER ONE

# INTRODUCTION

As the rate of survivorship continues to increase, cancer is not the death sentence it once was, and is more often becoming a chronic illness (White, 2007). Because of this, "more attention is being focused on the quality of life (QOL) and long-term outcomes of these cancer survivors" (American Cancer Society, 2014). As cancer research has begun to shift its focus to quality of life issues and positive psychological adjustment to life with a diagnosis, sexual dysfunction (Cormie et al., 2014), and relationally negotiated distresses surrounding sex and intimacy have been quickly identified as primary stressors for both patients and their partners across cancer types and phases of illness (Manne & Badr, 2008; 2010; Manne, Badr, & Kashy, 2012).

Literature has acknowledged both the importance of incorporating sex and intimacy based conversations into the cancer treatment process, as well as prioritizing dyadic accounts as to how cancer is experienced (Traa, De Vries, Bodenmann, & Den Oudsten, 2014). Despite this knowledge however, relatively scant literature has privileged dyadic accounts of the cancer process, and even less research has explored how dyads are experiencing sex and intimacy with a cancer diagnosis (Hughes, Hertlein, and Hagey, 2011). This qualitative study seeks to understand authentic accounts as to how couples are negotiating sex and intimacy among a reproductively centered cancer diagnosis by privileging both patient and partner voices. Further, through the accounts of the dyadic experience, this study seeks to gain better understandings as to how healthcare practitioners across disciplines can provide more competent and collaborative care to foster holistic outcomes.

## Defining Sex and Cancer

### *Sex and Intimacy*

It is imperative that prior to the remainder of this paper, that various terms be defined. Sex and intimacy are variably broad terms that can encompass numerous meanings and subjective interpretation. Because of this, sex, sexuality and intimacy will often be used interchangeably or as a unit of terminology in order to cater to the varying language utilized within the literature that informs this study. For the purpose of this paper, the researcher will favor the term "sexual quality of life" (Southard & Keller, 2008), in order to capture sex and intimacy as an all-encompassing term. Further, the researcher privileges the following definition that captures the essence of a sexual quality of life as presented by Hughes (2009). She states:

> The World Health Organization (2002) described sexuality as including pleasure, sexual activity, eroticism, and sexual orientation. It is a broad term that encompasses love of one's self as well as love of another, body image, intimacy, relating to another, pleasure, and reproduction (p. 241).

It is important to the research that a fluid defining of sex and intimacy are used, as I seek to not impose pre-defined meanings of what sex and/or intimacy may or may not look like for a participant, and that the research remain as participant-near as possible, which includes their preferred language, and interpreted meanings.

### *Women's Cancer and Survivorship*

This study will be focused on women's reproductively centered cancers including breast and various gynecological cancers. Because of this it is necessary to understand why reproductive related cancers were chosen exclusively, and what this means in contextualizing why this is important to this study. The term cancer in itself is simply "a name given to a collection of related diseases" (National Cancer Institute, 2015). American Cancer Society (2015) provides and equally broad description as they explain, "Cancer is not just one disease. There are many types of cancer…[it] can start any place in the body. It starts when cells grow out of control and crowd out normal cells." The definition of cancer is purposely vague as different cancers may act as completely different diseases in the body, which can manifest drastically different physiological symptoms as well as emotional responses to those cancers.

Although sexuality and intimacy affect both male and female patients across cancers (Ussher et al., 2013), both reproductive and non-reproductive, reproductively centered cancers tend to have more homogenous psychological effects as patients and their partners may produce meanings directly associated with their affected parts (Arrington, 2008; Barlow, Hacker, Hussain, & Parmenter, 2013; McDaniel, Doherty, & Hepworth, 2014; Thorne & Murray, 2000; Ussher et al., 2013). Further, women specifically have had to battle a unique and long history with socially constructed realities surrounding women's sexual identities that differ from those experiences of men (Thorne and Murray, 2000). As will be described more in depth later in this paper, the homogeneity of perspective is crucial to the methodology of this study.

Lastly, the term survivorship will be commonly referred to throughout this paper, and is important to define as the definition has been recently expanded within the field of oncology. According to the American Cancer Society's "Cancer Treatment & Survivorship: Facts and Figures" (2016), a cancer survivor

> …refers to any person with a history of cancer, from the time of diagnosis through the remainder of their life…There are at least three phases of cancer survival: the time from diagnosis to the end of initial treatment, the transition from treatment to extended survival, and long-term survival (p. 1).

It is important to mention, however, that statistics pertaining to probability of survivorship often refer to life that is predicted to extend 5 years or more after the diagnosis of a cancer disease (American Cancer Society, 2016; National Cancer Institute, 2016). For the purpose of this paper, the preliminary definition will be used, as sexuality and intimacy have been identified as significant stressors at multiple points of survivorship, including patients in active treatment that do not meet the criteria for an acute diagnosis (Barlow, Hacker, Hussain, & Parmenter, 2013).

## ***Staging***

Throughout this paper, references to various stages of cancer will also be mentioned. According to the American Cancer Society (2015), staging has been defined as a "process of finding out how much cancer is in a person's body and where it's located. It's how the doctor determines the stage of a person's cancer." Although staging cancer is a complex process defined through numerous medical terms, National Cancer Institute (2015) has provided simplified definitions of each stage. The definitions are as follows:

- Stage 0: Abnormal cells are present but have not spread to nearby tissue. Also called carcinoma in situ, or CIS. CIS is not cancer, but it may become cancer.
- Stage I, II, and III: Cancer is present. The higher the number, the larger the cancer tumor and the more it has spread into nearby tissues.
- Stage IV: The cancer has spread to distant parts of the body.

Each stage is determined by how many lymph nodes have been affected, or how a tumor or metastasis has been measured, also known as the TNM system (tumor, node, and mets). For the purpose of this paper, the complexity of defining staging will remain basic.

## Background

Cancer has a broad history in both research and literature. Dating as far back as 3,000 BC where descriptions of cancer have been found in ancient Egyptian scriptures, to the 19th century that provided the field of medicine its foundation in scientific oncology (American Cancer Society, 2014), tremendous progress in oncological pathology has been made. Currently, there are 15.5 million Americans with a history of cancer, and alive as of January 2016—this means that approximately 4.6% of the American population consist of cancer survivors with an estimated 1,688,780 cases of new diagnoses in 2017 (American Cancer Society, 2016). Although cancer remains a leading cause of death (second to heart disease), the death rate has declined by 25% since 1991. Survivorship has increased in numerous cancers, including breast and prostate cancers, which are the most frequently diagnosed cancers among women (breast) and men (prostate) (American Cancer Society, 2016; National Cancer Institute, 2016).

As female reproductive cancers will be the focus of this study, it is important to contextualize the chronic nature and potential of longevity for these cancers. The cancers that will be included in this study will be breast and gynecological cancers. Although overall survivorship does vary depending on age, gender, and race, The American Cancer Society, The National Cancer Institute, as well as Cancer.net have provided general statistics for survivorship. According to the American Cancer Society (2016), breast cancer, if staged at a 0 or 1, is close to 100% 5-year survival rate, while a stage 2 is about

93%. Gynecological cancers, which include, but not limited to ovarian, vulvar, and cervical vary in survivorship rates; all have 90% or higher survival rates if caught in early stages, such as a 0 or 1, and even a stage 2 in some cases (National Cancer Institute, 2016). Some gynecological cancers, however, are difficult to detect at early stages. Ovarian cancer, for example, only has 15% of its cases detected at very early stages (i.e. Stage 0 or 1) (American Cancer Society, 2016). Overall, however, reproductively related cancers typically have very high survival rates, which often designate these cancers as chronic illnesses.

### ***Chronic Illness and Quality of Life***

Cancer has historically been a topic largely focused on acute phases of cancer, and therefore, biological components of treatment and research have been prioritized and mainstreamed. However, as the rate of survivorship continues to increase, current research has consequently begun to take more serious interest in psychological related consequences posed by a chronic illness diagnosis (Colby & Shifren, 2015). Additionally, because cancer research has most often focused on patient outcomes, intimate partners, who also commonly double as caregivers, are left completely neglected (Badr & Krebs, 2012). Both patient and partner are then finding themselves needing to rediscover and redefine their lives and relationships that incorporate cancer's long-term presence and long-lasting effects.

The nature of cancer is chronic for many; therefore, especially couples find themselves grappling with numerous changes to their once familiar relationships. This leaves couples susceptible to negative relational and psychosocial side effects. Bal, Yilmaz, and Beji (2012) attest to this; however, they have found that healthy intimate and sexual identities have been an essential antidote in combating many of cancer's negative side effects. By prioritizing intimacy and sexual health, couples were able to produce various positive outcomes including positive associations with ones body, higher levels of individual and relational self-esteem, and overall positive adjustment to the cancer experience (Altschuler, 2015). Although discussed in more depth later on in this paper, the literature has confirmed that patients diagnosed with cancer do not experience illness as an individual or singular process, but rather, couples often experience cancer as a unit (Traa, De Vries, Bodenmann, & Den Oudsten, 2014). This means that patients can be, and often are, highly influenced as to how they experience cancer based on how their partners are also experiencing cancer. Due to this knowledge, it would be fruitless to study quality of life outcomes without a dyadic unit of analysis.

### ***Sexuality and Intimacy in Oncological Research***

Although voices of intimate partners have been a significantly neglected component of cancer research and the cancer experience (Gilbert, Ussher, & Prez, 2013), it is important to acknowledge that issues surrounding intimacy and sexual wellbeing have been scattered into oncological literature for some years now, but recognizing sexual quality of life as a valid entity of its own only dates back as recently as 2002 (White, 2008). Dutch gynecologist and psychologist, Woet Gianotten brought light to these post treatment quality of life concerns when she coined the term "oncosexology" (Gianotten, 2003). Despite this fairly recent introduction into oncological literature, research continues to provide often limited and incomplete depictions as to how these concerns are actually being experienced by patients, as well as their partners. As this topic will be addressed thoroughly later in this proposal, it is necessary to introduce how sex and intimacy is currently being presented in oncology literature.

It is widely known that cancer has been a historically medically focused disease, and therefore medical domains have dominated what we know surrounding all facets of the cancer experience, including psychosocial issues such as sexuality; however, although issues of sexuality and sexual wellbeing are being addressed, they are being done so from primarily biological perspectives (i.e. sexual dysfunction) (Hyde, 2006). Because of this, it is no surprise that dyads are rarely the unit of analysis for understanding how patients are not only experiencing cancer, but the meanings they attribute to themselves based on those experiences, which often include negative associations to the sexual and intimate parts of their individual and couple-hood identities (Brandao, Schulz, & Mena Matos, 2013).

It is important to acknowledge that researchers across disciplines (i.e. nursing; clinical psychology; family science) have begun to not only recognize sex and intimacy as a part of quality of life concerns, but also have also repeatedly confirmed that patients find conversations surrounding sex and intimacy as important aspects of their care (Cormie et al., 2014; Jonsdottir, 2015; Wang et al., 2013). Although this information is significant, we have yet to extend beyond these limited discoveries. Further, primary research in this area is being conducted internationally, while very little research is being conducted domestically. For example, researchers such as Jane Ussher, Janette Perz, and Emilee Gilbert, who are all Australian based researchers within the field of clinical psychology, have provided significant contributions to onco-sexology and related research. They have emphasized, and pioneered in many ways, that cancer forces meaning making processes especially in regards to constructions of femininity and masculinity with reproductive based cancers (Gannon, Guerro-Blanco, & Abel, 2010; Olson, 2015; Ussher, Perz, Gilbert, Wong, & Hobbs, 2013). Additionally, they have consistently and continually found the importance of treating oncology patients relationally by incorporating and privileging partner influence; however, similarly to the majority of current research, despite the acknowledgement as to the importance of a partner's role in a patient's life, dyads have not been utilized as a unit of analysis across the literature. This will be discussed thoroughly in the following chapters.

Unfortunately, despite advances in knowledge such as these, scant oncological research has been done through family sciences, and even less has been done in understanding dyads and their intimate identities amidst a diagnosis. Further very little research in this area is being produced here in the United States, which speaks to what we prioritize and define as "health." Through our silence, we are subsequently silencing our patients and their partners and therefore lack understanding of what they need in regards to how sex and intimacy may play a part in their definition of health and quality of life. This is especially relevant when speaking to reproductively based cancers, as meaning making of ones self, will inevitably be linked to ones sexual identity (i.e. Olson, 2015). Ussher, Perz, Gilbert, Wong and Hobbs (2013) best articulate this issue as they state:

> Although there is a growing body of research examining psychosocial correlates of changes to sexuality after cancer, including the influence of relational context, little attention has been given to renegotiation of sexual practice or intimacy, which has led to a plea for research examining successful strategies used by couples to maintain sexual intimacy in the context of cancer…there is a need for further research on sexual renegotiation after cancer, from the perspective of both people with cancer and their partners, across a range of cancer types (p. 455).

It is clear that in order to truly capture what quality of life may mean to patients, as well as how patients perceive obtaining positive psychological outcomes, researchers must consider the embodiment of the intimate relationship, which would inherently include both patients and their partners (Barlow, Hacker, Hussain & Parmenter, 2014).

The last crucial component that is offered through oncological research, is understanding the role of the clinician. Just as primary caregivers/spouses have been found to heavily influence patient's psychological adjustment outcomes to illness, clinicians also act as influential figures as to how patients learn to make sense of, prioritize, and negotiate their intimate relationships (Fitch, Beaudoin, & Johnson, 2013; Hughes, Hertlein, & Hagey, 2011; Penson et al., 2000). McDaniel, Doherty, and Hepworth (2014) speak to this as they argue that a primary reason clinicians are not bringing up topics of sexuality is due to embarrassment and the vulnerable nature of this topic. It is unfortunate, that more often than not, these conversations are not being initiated by healthcare providers, across disciplines, despite the knowledge that sex and intimacy are not only important topics for patients to discuss in order to facilitate positive psychological adjustment to life with and after illness, but also because patients have repeatedly reported wanting to talk about it (Fitch, Beaudoin, & Johnson, 2013; Loaring, Larkin, Shaw, & Flowers, 2015van der Riet, 1998; Wang et al., 2013).

Currently, research in oncological care has confirmed that sex and intimacy are crucial components to quality of life outcomes for patients and their partners; however, we have yet to transcend beyond this level of research. It is our responsibility to move this knowledge forward by actually engaging in these conversations with not only patients, but also their partners, and learning more about what patients may need from their healthcare providers to ensure more whole qualities of life. As confirmed through the literature, healthcare providers can significantly contribute to survivorship outcomes simply through the conversations we prioritize. It is the responsibility of the healthcare provider to not only research what patients need, but to learn, listen and implement these needs to reach standard levels of care. This can be done by privileging both patient and partner voices and initiating conversations, in practice and research, that emphasize dyadic sexual and intimate identities among a chronic cancer diagnosis.

## Objective

The overarching question of this study seeks to uncover how couples are negotiating sex and intimacy in chronic phases of cancer. The objectives were formed based on the current literature and developmental stage of research in this area. Currently, the literature is clear that sex and intimacy are important components to patient's qualities of life; however, few studies have researched beyond this knowledge and we are still lacking understanding as to what patients are actually doing to negotiate these important components as well as how healthcare providers may be influencing these negotiations. Further, virtually no studies have included partner's voices despite them being recognized most often as primary caregivers, as well as their influential impact on treatment outcomes. Therefore, the primary objectives of this study are:

1. To understand couples authentic lived experiences in regards to the negotiation of sex and intimacy with a cancer diagnosis.

2. To uncover if patients are experiencing their healthcare providers as operationalizing current literature recommendations surrounding the inclusion of sex and intimacy in oncological care.
3. To contextualize illness within psychosocial understandings by privileging the dyadic experience inherent in navigating sexuality with a chronic cancer diagnosis.

Through these objectives, this study aims to both understand and provide authentic depictions as to the current lived experiences and meaning making processes of couples living with cancer as it relates to their sexual and intimate relationships. Further, this study wishes to contribute to the literature by evaluating from patient perspectives if they experience their healthcare teams as operationalizing the research as to the importance of sexuality in oncological care.

## Rationale

Previous research has validated three essential components as fundamental in securing overall wellbeing and quality of life for those living with chronic illness. The three elements are:

1. Relationships and intimate bonds are an essential aspect to survivorship among those living with cancer (Bennett, 2005; Rokach, Findler, Chin, Lev, & Kollender, 2013).
2. The voices of the intimate partners have been silenced and must be privileged in future research (Barlow, Neville F. Hacker, Rafat Hussain & Glenda Parmenter, 2014).

3. Positive association with ones sexuality has been found to be a predictor of overall happiness and assists in maintaining a healthy quality of life (Laumannn, Gagnon, Michael, & Michaels, 1994; Santos, Ford, Santos & Viera, 2014).

The sexual and intimate relationship, dyadic analysis, and evaluating the perceived operationalization of current literature and research as to the importance of sexuality in oncological care, are all essential in not only contributing to future research, but also enhancing patient care. Although various studies have repeatedly confirmed the importance of incorporating sexuality into oncological care, virtually no studies have sought to know, neither from the perspectives of the patients nor the clinician, if these knowledge's are being translated into practical application. Secondly, various meta-analyses have affirmed that the dyad has been found to play an integral role in QOL outcomes; however, research seeking to understand *couples* lived experiences is extremely scant. Most, if not all, of the research pertaining to cancer and intimacy focuses solely on the diagnosed patient and ignores partner experiences all together. This is surprisingly also true for "dyadic research," as very little research actually incorporated partner's voices into dyadic-centered studies. It is for these reasons that the above rationalizations intentionally guide the progression of this study.

# CHAPTER TWO

# CONCEPTUAL FRAMEWORK

Much of today's research within the family sciences, struggles linking research to theory (LaGurman & Kniskern, 2013; vee & Dollahite, 2001); subsequently, there seems to exist an even larger gap between research and practice (Karam & Sprenkle, 2010; Sprenkle, 2003). According to Sprenkle (2003), research in family therapy has often suffered due to the bifurcation between "art and science" (p. 85). Although there has been a historical conflict between the subjective nature of theory, and the scientific conception of objectivity, the family sciences have been progressively moving away from the positivistic positioning of "objective truths" and closer towards a post-positivist world (Thomas & Wilcox, 1987; Lavee & Dollahite, 2001; Lebow, 2014). As a result, family researchers are more openly disclosing the interpretive processes that exist in research study (Williams, Olson, & Knapp, 1989; Lebow, 2016).

Making explicit the ties between research and theory serve multiple purposes; Lavee and Dollahite (2001) express that researchers are more often recognizing that empirical study is less of a "truthful reality," and more of a theory-laden exploration. There then exists an inherent reciprocity between research and theory. Further, Lavee and Dollahite argue "…that better developed theory will facilitate more relevant research, and that research which is more directly linked to theory will allow us to better understand families, and thus allow for more appropriate, empirically based recommendations for therapists, educators and policy makers" (p. 362). This point is especially relevant for qualitative study, as it often seeks to describe, or offer explanations of particular phenomena and experiences that are not typically quantifiable, or even generalizable, as qualitative research does not always seek to universalize results.

In the following section, the two theoretical frameworks that guide this study, Symbolic Interaction and the Biopsychosocial-Spiritual Model, will be defined and explained. Both frameworks were chosen as this study is guided by the idea that meaning making, especially that of sexuality and intimacy, is a product of social construction and pathology (Foucault, 1986); simultaneously, various researchers have critiqued constructionist based frameworks when speaking to medically centered issues, as they can minimize the role biology provides in participant's accounts of their experiences (Giles, 2006). Therefore, the Biopsychosocial-Spiritual Model will also be used in order to acknowledge the inherently biological nature of cancer, and contextualize psychosocial problems as possible outcomes due to the impact of their biological counterparts.

## Symbolic Interactionism

Symbolic interaction holds a long history within the world of research, which has American philosophical roots and is derived from pragmatism (Cooley, 1902; Longmore, 1998). This in itself is unique to this theoretical orientation; however, symbolic interactionism is also unlike other theoretical perspectives, as numerous philosophers and sociologists across disciplines (versus a sole creator) contributed to the inspiration and influence of what we have come to know as symbolic interactionism today. Interestingly, despite its lengthy history, the name "Symbolic Interaction" was not coined until 1937 by American sociologist Herbert Blumer (1962; 1966; 1969), nearly 20 years after actively being utilized as an established research perspective. As meaning making processes are an underlying goal to this study, it is also essential to acknowledge that regardless of illness, sexuality itself and the meaning we assign to it, are products of dominant discourses that have pre-constructed pathologies that then inform the way we see our sexual identities (Foucault, 1986), and how those identities then interact with other variables such as illness. In order to contextualize the assumptions that guide this study, this section will serve to explain the complex history and foundations of symbolic interactionism while also addressing the assumptions and objectives of this theoretical orientation.

### *History and Prominent Figures*

Symbolic interaction has been a primary theoretical orientation since the 1920's, and is still one of the most widely utilized and recognized conceptual frameworks today (Boss et al., 1993; White, Klein, & Martin, 2015). As various intellectuals, moralists, idealists, and philosophers all contributed to the beginnings of symbolic interaction, it was American pragmatists that were of the upmost influence (Boss et al., 1993). Some of the most prominent pragmatists included William James, Josiah Royce, Charles Peirce and John Dewy. These men made four major contributions to the foundation of symbolic interactionism. They were:

1. The static, predetermined, and inherently structured pictures of reality, should be replaced with dynamic, emergent, historical world-in-the-making view.
2. Social structure was an emergent process.

3. Rejected both idealist attempts to root knowledge in perception and materialist attempts to locate meaning solely in objects and insisted that meanings emerge from the interaction between subject and object.
4. Commitment to progress and democratic values and saw science both as a methodology for achieving advancement and as a model for democratic organization (Boss et al., 1993, pp. 136-137).

It was during this time that sociologists were eager to show how meaning making was socially created based on the society in which they lived (Deegan, 1987), rather than simply being passive recipients in a pre-determined, unchanging world (Boss et al., 1993).

As symbolic interaction began to take momentum, the field of family studies also took special interest in this orientation. Prominent contributors included Charles Horton Cooley, George Herbert Mead, Robert E. Park, Ernest W. Burgess, Herbert Blumer and William Isaac Thomas, among a few others; each of which offered different, yet significant ideas, which added to the development of this theoretical approach. Mead, for example, who is arguably the most influential figure for symbolic interactionism (Boss et al., 1993; White, Klein, & Martin, 2015; Charmaz, 2014) introduced many foundational ideas including the concept that meaning and consciousness were developed through gestures, in which language was the most complex, yet most affirming way people were able to anticipate how others perceive them (Mead, 1956). Based on Mead’s philosophy, the notion of a pre-existing world is essential; it is through learned language and gestures that we are able to realize our roles in an already existing society, and anticipate how others then perceive us in those roles. It was through this theorization that the idea of social norms became familiarized and introduced into family sciences.

Lastly, it is necessary to understand the contributions provided by Herbert Blumer (1962; 1966; 1969) who not only coined the phrase “Symbolic Interaction” in 1937, but also maintained its utility and contributed to the theory by emphasizing the importance of interpretation (White, Klein, & Martin, 2015; Charmaz, 2014). White, Klein, and Martin (2015) expand on Blumer’s theoretical contributions as they argue, “…we cannot understand a behavioral response unless we know what meaning the situation and stimulus have for an actor…the researcher must understand the meanings actors assign to the situation and action” (p. 72). This emphasis on assigned interpretation reaffirms the subjective negotiation of roles people characterize for themselves in a larger society. It is a noteworthy contribution as it truly legitimized qualitative methods (Boss et al., 1993) by recognizing the need for a more in depth research methodology through modes such as interviewing and participant observation (Blumer, 1969; Boss et al., 1993).

### ***Assumptions of Theory***

As symbolic interaction is the result of various schools of thought, it is inevitable that even today, there are numerous interpretations of symbolic interactionism itself. Despite these varying adaptations, there are foundational assumptions of the theory that underlie this perspective. Because pragmatism was a primary framework in which symbolic interaction arose, there are seven relevant assumptions that lie within three major themes that encompass the symbolic interactionist perspective. Those assumptions are:

Theme 1 (Importance of meanings for human behavior):

1. Human beings act toward things on the basis of the meaning that the things have for them.
2. Meaning arises in the process of interaction between people.
3. Meanings are handled in and modified through an interpretive process used by the person in dealing with things he or she encounters.

Theme 2 (The importance of self concept):

4. Individuals are not born with a sense of self but develop self concepts through social interaction.
5. Self concepts, once developed, provide an important motive for behavior (ie. Values and beliefs).

Theme 3 (Assumptions about society):

6. Individuals and small groups are influenced by larger cultural and societal processes (i.e. discourses).
7. It is through social interaction in everyday situations that individuals work out the details of social structure. (Boss et al., 1993, pp. 143-144).

Through the integration of the historical foundations of symbolic interaction with these overarching assumptions, it can be ascertained that the primary objective of the symbolic interactionist perspective is to “focus on the connection between symbols (i.e. shared meanings), and interactions (i.e. verbal and nonverbal actions and communications)…[and] understand how humans, in concert with one another, create symbolic worlds and how these worlds, in turn, shape human behavior" (Boss et al., 1993, p. 135). More currently, Charmaz (2014) offers a thorough explanation of symbolic interaction, in which she states:

> Symbolic interactionism is a dynamic theoretical perspective that views human actions as constructing self, situation, and society. It assumes that language and symbols play a crucial role in forming and sharing our meanings and actions. Symbolic interactionism views interpretation and action as reciprocal processes, each affecting the other. This perspective recognizes that we act in response to how we view our situations. In turn, our actions and those of other people affect these situations, subsequently we may alter our interpretations of what is, was, or will be happening (p. 262).

The symbolic interactionist perspective offers itself in unique ways that differentiates itself from other frameworks. For example, symbolic interactionism is highly interactional within its current time and space (Bengston, Acock, Allen, Dilworth-Anderson, & Klein, 2005). Because of this temporal flexibility, and its ability to theoretically shift based on the era in which it exists, this makes it an active and current guiding approach to research. Despite its older roots, this theoretical approach is still one of the most widely used conceptual frameworks for research in the social sciences (Bengston et al., 2005). Further, it has played a significant role in legitimizing qualitative research through introducing value to data that extends beyond solely quantifiable analysis. Through its focus on the meaning making experience, and groundbreaking ideas on identity co-construction, it has acted as a foundational pillar for numerous post-modern conceptual frameworks that guide many current research studies today.

## ***Conclusion***

As with any theoretical orientation, however, symbolic interaction has been heavily critiqued. Giles (2006), for example, argues that constructionist approaches, such as Symbolic Interaction, are inadequate theoretical frameworks for guiding research that pertain to biological concerns. In his article, Giles focuses on sexual desire, and argues that social constructionists often minimize the role biology plays in creating sexual desire, and attribute sexuality and desire as purely constructed phenomena. Gordon and Silva (2015) rebuttal this point as they argue that constructionists and interactionsists do take biology into account in that culture not only influences meaning surrounding biology, but that biology can shape culture. However, although symbolic interactionism does not necessarily seek to minimize the biological experience, it is also not informed by it. As Symbolic Interaction lends itself to understanding the meaning making experience that underlie dyadic negotiations, the Biopsychosocial-Spiritual Model will also be utilized as a guiding framework in order to provide a focus on the inherent psychosocial consequences that are directly informed by biological problems.

## The Biopsychosocial-Spiritual Model

As Symbolic Interaction provides significant guidance to this study in that it assists in better understanding how couples may process negotiation and how they make meaning of those negotiations based on the systems that they are a part of, symbolic interaction does not offer a perspective that considers the way illness specifically may operate on couples and how an illness narrative unique to each couple may influence those negotiations. The Biopsychosocial-Spiritual Model, which will be defined and discussed within this section, allows this study to be guided through a lens that accommodates the distinctive consequences, challenges, and outcomes that result both directly and indirectly from the chronic illness experience. Through descriptions offered by Engel (1977), Rolland (1984; 1994), McDaniel, Doherty, and Hepworth (2014), and Wright, Watson, and Bell (1996), the biopsychosocial-spiritual perspective will be utilized to conceptualize this research. Some adaptations that consider the challenges and contexts specific to chronic illness will also be included in this conceptual framework.

### ***Biomedical to Biopsychosocial***

The biopsychosocial approach, as pioneered through Engel (1977) captures the human essence of seemingly medical or scientific based problems. This model is unique in that it considers the psychological and emotional consequences that are directly correlated from historically biologically centered illnesses, including cancer. McDaniel, Doherty, and Hepworth (2014) speak to this as they promote a holistic and integrated approach to treating illness, in which foundations of this practice assume that there are no biological problems without psychological consequences and vice-versa. McDaniel, Doherty, and Hepworth describe the biopsychosocial model as "acknowledging the hierarchal, interdependent relationships of the biological, psychological, personal, family, and community and larger systems…any medical condition [that] reverberates across multiple systems" (p. 9). Thus, this model recognizes the integration of mental health components within typically medically focused issues.

Although today the practice of medicine is heavily influenced by biopsychosocial language (i.e. patient-centered care), this now standard perception of care is still a fairly recent, and developing approach (Frankel & Quill, 2005). Engel introduced the biopsychosocial model as a response to the extremely limiting nature of the biomedical model, in which a pre-existing separation between mind and body dominated the field

(Engel, 1980). The discipline of medicine encompassed a focus on "physical or infra-human systems" (Engel, 1996, p. 426), while simultaneously neglecting psychological and social outcomes that were direct results of biologically based problems. Although introduced in the latter part of the 70's, Engel (1996) continued to expand on humanizing science in a three part series titled "From Biomedical to Biospsychosocial." He continued to emphasize that biomedically focused science did not, and could not, capture the wholeness or complexity of ones diagnosis as physicians have always depended on patient's self reports specific to what motivated them to seek medical treatment. Therefore one of the key underpinnings of the Biopsychosocial Model is that "disease and illness are seen as mutually influencing one another both psychologically and physiologically; not simply as independent properties of mind or body" (Frenkel & Quill, 2005, p. 414).

Following the introduction of the biopyschosocial perspective, Engel (1980) commenced a practical clinical application of this approach, as he introduced the Biopsychosocial Model itself. His purpose was to display not only the importance of viewing diagnoses from broader standpoints, but to view patients in the context of their psychological and social problems (Engel, 1980). Further, Engel sought to change the way providers approached patient care, as he believed a more humanized approach was crucial to treating patients and contextualizing medically based problems without the assumption that any level of illness was negotiated void of psychosocial impact (Engel, 1980; Epstein, 1999; Frenkel & Quill, 2005).

Engel (1994) was adamant about preserving the human experience especially within science-focused research. Engel explains that this undertaking is "…what *biopsychosocial* is all about. Scientists, after all, are human beings, science is a human activity, and the inner life of the scientist is integral to what is publicly presented as science" (p. 434). In a system (i.e. healthcare institutions, or biological systems) that can be extremely dehumanizing to a patient, it is vital that healthcare professionals are able to treat the person with the illness rather than only treating the illness itself. Engel (1994) concludes his article with a quote from Albert Einstein, in which he felt truly encapsulated the spirit and significance of the biopsychosocial approach. Engel writes:

> Einstein (1950) identified the paradox for biomedicine when he wrote: "The whole of science is nothing more than a refinement of everyday thinking" (p. 59): in effect, humans had already evolved to the point of being able to evaluate the validity of what others have to say long before we devised how to be "scientific" about it. Biopsychosocial medicine opens the door to doing just that (p. 449).

Being able to recognize the amalgamation of both biomedical as well as psychosocial components as the make up to both the patient's and the partner's intimate identity, as they live with cancer is obligatory.

Through his biopsychosocial model Engel truly pioneered the humanization of patient care, as he emphasized the importance of viewing patients as whole beings functioning within and informed by the systems that they are a part of (Engel, 1980; von Bertalanffy, 1969). The prevailing biomedical perspective at the time posed numerous limitations as Engel sought to transcend beyond the reductionist approach to both science and practice. It is important to note that the current approach to oncological care favors this standpoint (i.e. Diacony, Maxim, Timofte, & Livadario, 2014; Ng et al., 2016); this is especially salient when speaking to reproductively based cancers, as it is essential to place patients in the context of the systems that they are a part of in order to not only understand their diagnoses more holistically, but to better grasp how patients may negotiate treatment as they deem which problems hold more or less significance. Cancer poses an especially unique approach to these negotiations, as patients are often living with illness for extended periods of time. The next section will provide a description as to a view of the biopsychosocial approach that is inclusive of the distinctive variables that chronic illness possesses.

## *Biopsychosocial-Spiritual (BPSS)*

Since Engel's introduction to the biopsychosocial perspective, there have been some adaptations made to the model in order to further understand the complexities of the human experience during illness. One of the major adaptations made was the addition of spirituality, which ultimately created the Biopsychosocial-Spiritual (BPSS) model. Although there are a number of academics that can be credited for the development of this model (e.g. King, 2000; McKee & Chappel, 1992), it was Wright, Watson, and Bell (1996) that mainstreamed the BPSS model within the field of family therapy, and modeled it as a systemic perspective that focused on the values and beliefs of families to make sense of relational problems due to illness. This version of the model will be the second guiding framework for this study.

Although, Engel's original Biopsychosocial Model has provided an essential bridge between medical and behavioral health fields, and has become a principal concept within medical family therapy, the addition of spirituality to the biopsychosocial model is a significant and important improvement that is necessary not only for this study, but integral in providing relationally based research outcomes, and implications for current and future family therapy practice situated in medical settings. It is important to note that

Wright, Watson, and Bell (1996) adapted the spiritual addition specifically for systemic practice within family sciences, and as a way of promoting holistic care in "healing the whole person" (Delbridge, Taylor, & Hanson, 2014). Similarly to Engel, as he created the Biopsychosocial Model as a response to the limiting nature of the Biomedical Model, Wright, Watson and Bell also endorsed the BPSS model as a response to Engel. They argued that the BPS model was too individualistic and should be more inclusive of patient's sociocultural beliefs (Wright, Watson, & Bell, 1996).

As the BPSS model has some variation across disciplines, Wright Watson and Bell promoted an emphasis on belief and value systems. It is important to mention that although the word "spirituality" was chosen as in adapting the BPS model, spirituality was defined broadly in that it extended beyond religion. Wright, Watson and Bell promoted the notion that "core beliefs are central to an understanding of the spiritual perspective" (Lehr, 2001, p. 102) when working with families and illness. Further, Wright, Watson and Bell (1996) posited that they "began to realize that it was the beliefs about a problem that were the problem when families experienced difficulties with an illness" (p. 4), in which a naturally hermeneutic process was occurring in how families made meaning of themselves and their successful or unsuccessful interactions with illness. This perspective is crucial to this study as it seeks to further understand the meaning making negotiations of a relational illness experience.

As the BPSS model, as adapted by Wright, Watson and Bell, contains a family-science specific orientation, it would be remiss to exclude the BPSS Model and ignore what it has contributed to our field in research and practice. Further, speaking to this study specifically, it is also important to consider that although the term "spirituality" can have varried meaning, its underpinnings are religious. That being said, sex and religion have an extensive and complex history (Turns, Morris, & Lentz, 2013) and it would prove negligent to not assume that chronic illness, and sex and intimacy are not somehow influenced by, or have the ability to impact, a couple's negotiations amidst a diagnosis. Although not all people may identify with a particular religion or spiritual-self, it is still essential to identify that sex, and dyadic negotiations surrounding sexual morality, especially within the context of monogamous relationships and marriage, are highly influenced by religious doctrine (Jones, 1996). The BPSS model then allows this research study to hold these assumptions while being guided by its lens.

### *The Biopsychosocial Model and Chronic Illness*

As previously discussed, since Engel's first conceptualization of the biopsychosocial model, some significant adaptations have been integrated in order to make this perspective more holistic. As spirituality was added in order to create the more inclusive Biopsychosocial-Spiritual Model, other adaptations that sought to have deeper understandings of the human experience during chronic illness, have also come to fruition. The following section will describe a second significant adaptation, which did not necessarily change the structure of the BPSS Model, but rather deconstructed this perspective in order to be inclusive of the unique developmental stages of illness and its impact on various human experiences and phases of life.

As chronic illness poses unique challenges to patients both individually and relationally (Rolland 1987; Sheilds, Finley, Chawla, & Meadors, 2012), the Biopsychosocial-Spiritual Model was adapted as a family systems approach in order to contextualize patient needs. Interestingly, prior to the adapted BPSS model, Rolland (1987) supported this notion as he argued, “In the arena of physical illness, particularly chronic disease, the focus of concern is the system created by the interaction of a disease with an individual, family, or other biopsychosocial system” (p. 1). The systems that patient’s can be a part of are both environmental and temporal. When speaking to biopsychosocial approaches and chronic illnesses such as cancer, time, developmental phase, and the life cycle itself must be considered.

As Engel created the Biopyschosocial Model in order to provide more holistic care and obtain more complete depictions of patient’s problems, Rolland (1987) also offers an avenue for more complete understandings as to patient’s experiences of illness through the consideration of time—or more specifically, temporal developmental phases of chronic illness. Rolland states, “The concept of time phases provides a way for the clinician to think longitudinally and to reach a fuller understanding of chronic illness as an ongoing process with landmarks, transitions, and changing demands” (p. 3). Shields et al. (2012) also support the idea that chronic illness especially provides patients with unique means of making sense of their illness experiences based on the type of illness, age, gender, amount of familial/communal support, and developmental stage of the illness. Further, they argue that chronic illness does not only pose new ways of conceptualizing ones illness experience, but this extends to caregivers, who are often spouses and other close family members (Levine, Halper, Peist, & Gould, 2010).

Including the specific addition of chronic illness is crucial to this study especially as it relates to how couples are negotiating sex and intimacy into their constructed illness narratives. Taking into consideration the distinct variables chronic illness poses on how patients not only make sense of their identities at diagnosis, but over time, as well as how chronic illness also shapes meaning in immediate familial caregivers (and particularly spouses), it remains imperative that not only chronic illness be explicitly discussed and included in this conceptualization, but that the dyad is prioritized as a voice that represents shared and interactional negotiation of meaning formation.

## Conclusion

The above section defined and described both symbolic interactionism as well as the biopsychosocial model. Further, some empirical evidence was used in order to support the rational as to the selection of each of these frameworks. Symbolic Interaction and the Biopsychosocial Model were presented separately in order to highlight their individual contributions to this study in regards to sex, intimacy, and cancer. It is important to note, however, that the intersectionality between symbolic interactionism and the biopsychosocial framework is crucial in that each framework lends itself in a way that the other does not. This is being done in order to capture a more holistic and complete approach to this qualitative study.

As confirmed by the literature, both perspectives are essential to this area of research. White, Faithfull, and Allan (2013), for example, found that in order to best address patient’s needs, the integration of both interactionalism or constructivism as well as the biomedical perspectives are necessary in understanding sexuality as it is impacted by cancer. Furthermore, other current researchers (i.e. Giles, 2006) have found that by utilizing only one of these two theoretical frameworks, often produce not only one-dimensional understandings of the intersectionality between cancer and sexuality, but provide results that are often too abstract for medical fields (i.e. the experience of meaning making), or too limiting for behavioral health clinicians (i.e. the often-rigid biomedical model). In doing this, researchers can severely miss integral aspects of a patients experience that are obstructed within each of these frameworks (Gilbert, Ussher, Perz, Wong, Hobbs, & Mason, 2013).

# CHAPTER THREE

# LITERATURE REVIEW

Understanding the impact cancer has on couple’s intimacy is an important topic that seeks to not only inform patient’s future experiences of cancer, but also offer implications as to the way practitioners (medical and family therapists) are treating and perceiving their patient’s needs. In order to ensure a clear understanding of these implications, as well as how this study may contribute to the existing literature, it was imperative that an in-depth review of present research and literature was performed. A search for literature surrounding cancer and intimacy was conducted, and approximately 130 articles were reviewed. Of those 130 articles, fifty were empirical studies that incorporated both variables (i.e. cancer and intimacy), and examined the relationships between them. The remaining articles were comprised of both empirical and theoretical literature, but reviewed each phenomenon separately.

Through this paper, a comprehensive review of the literature will be discussed in order to grasp the current state of the field as it pertains to the implications drawn from present research surrounding cancer and intimacy. Because differences exist across disciplines, this paper will first discuss the background and rational in this area of research in order to a) clarify defining key terms, and b) situate context in regards to how implications are being decided. The second portion of this paper will then summarize key findings as well as the implications for both future research, and practical application based on those findings. Lastly, this paper seeks to address how this research project will then contribute to the literature, and propel practical application as well as future research. Further, this paper will propose what impact this study will have on both medical and mental health professionals by considering how couples are negotiating sex and intimacy as they concurrently live through the cancer experience.

## Background and Rationale

Within the current state of the literature, it is apparent that patients find sexuality and intimacy as an important, yet neglected, component of their cancer treatment (Gilbert et al., 2013; Wang et al., 2013). As many cancers are more often becoming a chronic illness, and patients are living longer lives (White, 2007), healthcare providers must begin prioritizing issues surrounding long-term needs and tending to quality of life issues that remain with patients long after the cancer is over—this includes the sexual and intimate relationship. Historically, chronic illnesses such as cancer have focused on immediate biological outcomes; however, as cancer is not the “death sentence” it once was, it has become apparent that varying psychological and social consequences are an immediate concern as many patients must return to their lives after cancer treatment is over (Engel, 1977; McDaniel, Doherty, & Hepworth, 2014). Further, a significant portion of past cancer research, and how it pertains to quality of life issues, has primarily focused on the individual patient (Loaring, Larkin, Shaw, & Flowers, 2015; Traa, De Vries, Bodenmann, & Den Oudsten, 2014). It is becoming increasingly evident, however, that significant others and spouses should be included in well-being focused studies—not only because cancer is a relational experience, but because the wellbeing of primary support systems in our lives are often associated with the perception of personal wellbeing as well (Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008). It is important to note that this point is especially salient for women, as some studies have found that regardless if women are in the position of patient or caregiver, their expectations to assume household tasks remain the same (Cohen, Mabjish, & Zidan, 2001); this may be due in part to the already existing uneven distribution of tasks between men and women. Despite these gendered implications, it is surprising that dyadic studies are a fairly novel idea, even within past research studies that have been centered on cancer and intimacy. Much of the research has been "patient focused" and often ignores the experiences of the partner. As newer studies surface however, partners are being recognized more often as they often hold dual roles as a patient's primary support system and caregiver (Rokach, Finler, Chin, Lev, & Kollender, 2013).

Of the empirical studies reviewed, an overwhelming majority rationalized research surrounding cancer and intimacy as being a significant issue of quality of life. Articles varied as to what defined quality of life. One research study, for example, defined quality of life as overall life satisfaction (Saati, 2013). Saati, who conducted a research study on breast cancer survivors, explained that chronic illness presents unique challenges that can shift depending on the developmental stages of the illness. She pointed out that because over "90% of women diagnosed with breast cancer live beyond 5 years" (p. 39), both the developmental phase of the illness, as well as which phase a woman may be in her own life (i.e. age, marital status, etc.), can determine what may constitute "quality of life" for that patient. This is especially important when speaking to sex and intimacy as different stages of life present challenges associated with ones personal context. Bal, Yilmaz, and Beji (2012), validated this sentiment as they also recognized the unique needs that may arise depending on a woman's developmental stage. In their qualitative study for Turkish women with gynecological cancers, one woman, aged 32 years, reported, “It’s too early for me to have menopause and to feel old, and more interestingly it’s too early to leave off my femininity. It’s too early for me to leave my husband without a wife and my daughter without a mother” (p. 88). Other concerns reported in this study were topics such as motherhood, appearance (i.e. hair loss), and grieving a feminine identity.

As articulated above, there are varying criteria as to what constitutes quality of life. Although some articles may not have explicitly used the term quality of life, a similar rational was presented as to the reasoning for conducting research regarding sex and intimacy as it relates to cancer. In a theoretical nursing article, for example, Hughes (2009) speaks to the experience of familiarity and normality, as reasoning’s to address sex during the cancer experience. She laments that, “We talk about everything with our patients—bowel and bladder habits, nausea and vomiting—but we do not address sexuality issues” (p. 241). According to Hughes, we, as healthcare professionals, are failing to address the wholeness of ones identity by silencing topics such as sexuality and intimacy. For example, Hughes points out that sexual dysfunction is a common side effect and concern for many patients undergoing cancer treatment; Inevitably, psychological repercussions often arise as patients as a result of these dysfunctions. Patients and their partners are subsequently forced to negotiate issues such as lowered self-esteem and poor body image. In an Australian qualitative study on cancer and body image, Barlow, Hacker, Hussain, and Parmenter (2013) support Hughes’ call to action as they report that some cancers require highly invasive surgeries on reproductive organs. For women living with vulvar cancer for example, parts of the vagina are often removed which can lead to severe psychosexual consequences. Some of these consequences can include “levels of mood distress, a sense of loss of normality, and disturbed self-image” (p. 1857).   Barlow, Hacker, Hussain, and Parmenter specifically speak to the unique, long-term challenges that women will face as the survival rate for women diagnosed with cancer is between 93%-96%.  This means that even after cancer treatment is over, the impact of cancer will still inform these women as they must re-learn normality with the parts of themselves that remain—both physically and psychologically. It is apparent that, as healthcare professionals, we hold the responsibility to initiate conversations with our patients surrounding the re-negotiation of intimacy with cancer.  Unfortunately, these conversations are failing to occur, and this silencing produces messages of abnormality, and contributes to maintaining stigma to these parts of our patient’s identities.  Unless this is implemented in practice, it is a possibility that we are contributing to prolonged negative psychosexual outcomes, and reducing opportunities for positive adjustment and quality of life.

### ***Sexuality and Intimacy***

There is no question that cancer produces psychological consequences, and for women, one’s sexual identity, with or without illness, has paralleling effects.  It is necessary to acknowledge, however, that psychological wellbeing is highly influenced by what we as a society deems as culturally normal and healthy.  In considering how symbolic interactionism guides the view of sexuality among cancer patients specifically, it is also noteworthy to acknowledge how it perceives sexuality and intimacy as an overall construct.  Although there is some contradiction and critique as to the validity of constructivism and social construction as an explanation to sexual desire (Giles, 2006), constructivists believe that what we have come to know regarding our sexuality is a result of cultural influence and the formation of sexual scripts (Hyde, 2007). As with much of our behavior, sexual behavior is seen as a set of commonly accepted symbols (Gecas & Libby, 1976; Longmore, 1998). Longmore argues that, “The symbolic meanings associated with sexuality affect how we think about ourselves, how we relate to others, and how other think and relate to us” (p. 44). Especially for women, Thorne and Murray (2000) reason that a lengthy history surrounding the shaming of the female sexual identity in particular, has contributed to how women are currently informed in regards to how they make meanings of their sexuality and their bodies. Gergen (2009) supports this, as he believes most of what we know comes from cultural negotiations of some sort. In regards to sexual scripts, Gergen purports that “research on sexual scripts is most interesting, however, in its demonstration that what might be seen as biologically determined behavior is significantly fashioned through cultural convention” (p. 107). A significant amount of the literature surrounding sex, intimacy and cancer parallels this school of thought as it has been recognized that biology and cultural convention are intersected (Gecas & Libby, 1976).

These psychological effects do not go without relational impact; this is especially true for couples facing renegotiation in regards to sex and intimacy amidst a chronic diagnosis as couples have identified these as primary causes for relationship distress (Cormie et al., 2014). As patient’s grapple with their changing identities, the significant figures in our patient’s lives also endure role shift, new interactional negotiations, while managing their own processes of grief and loss (McDaniel, Doherty, & Hepworth, 2014; Rokach, 2013). When speaking to implications for future research and practice, it is essential to understand in what capacity are these terms being referred. As numerous definitions qualify as “quality of life” the same is true for “sex” and/or “intimacy” as they can have varying criteria. Many of the articles that were reviewed, looked to the World Health Organization also known as WHO (e.g. Hughes, 2009; Rasmusson, Plantin, & Elmerstig, 2012; Weinstein Dunn, 2015). Rasmusson, Plantin, and Elmerstig summarized the definition according to WHO (2002), as they articulated, “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, behaviors, practices, roles and relationships” (p. 363). Weinstein Dunn (2015) on the other hand deconstructs both terms of sexuality and intimacy separately. Pointing out that these terms are often used interchangeably, Weinstein Dunn first provides a blanketed definition, where sexuality and intimacy are generally used to describe “connectivity between behavior, activity, partnership, function, and attitude” (p. 68). However, she continues to define intimacy more specifically, and utilizes Hordern’s (2008) premise in distinguishing intimacy from sexuality. Weinstein Dunn offers that intimacy “…has been described as the sharing and closeness between partners, encompassing touch and intimate communication” (p. 68). Hughes (2009) confirms the complexity of how sexuality is defined, as it is multifaceted. “Sexuality is genetically endowed, phenotypically embodied, and hormonally nurtured” (Hughes, 2009, p. 241). Southard and Keller (2009) referred to this complex phenomenon as “sexual quality of life” which is all encompassing—from self-connection, to connection to others, the ability to have voice and choice and the ability to trust your body. Despite the complex and varying criteria of sex and intimacy, there are common themes across definitions that are necessary to highlight.  Sexuality and intimacy is an experience that is both biological and psychological in nature, and when introduced to a cancer diagnosis, much of the trust and choice one was once privileged to will often change.  The connections to oneself, as well as a partner are also susceptible to change and loss.

It is important to note that for the duration of this proposal, sexuality and intimacy will often be used interchangeably in order to honor the varying language used through the existing literature that guides this study; however, as articulated in the previous chapter, the study will privilege the language of the participants in order to capture the authentic lived experiences of each couple.  Lastly, sexual dysfunction will be considered different from sexuality/intimacy as it refers to a biologically based experience, while sexuality/intimacy speak to the psychosocial constructions of those experiences.

### *Culture and Social Scripts*

This section, which addresses culture as personal context, is both a rationalization to study as well as a recognized implication for future research.  When discussing the implications of any research study, it is important to not only clarify key terminology and defining criteria, but also address possible contextual factors that may explain or account for some of the research outcomes.  In this project specifically, both sexuality and cancer are influenced by contextual variables as they are informed by the cultural norms and gendered scripts associated with them.  Hyde (2006), for example, argues that both cancer and sexuality are actually socio-political in nature, and are not allotted the privilege of being purely private experiences.

In her study, Hyde (2006) found that perceptions surrounding cancer and sexuality are constantly informed by the world in which we live. For example, Hyde offers that feminist theory identifies that sexuality is often a source of "female oppression leaving woman in a dependent position" (p. 317). Another study found that at certain stages of an acute diagnosis, conversations surrounding sex and intimacy were not considered a priority to couples at all (Olsson, Athlin, Sandin-Boko, & Larsson, 2013). Olsson, Athlin, Sandin-Boko, and Larsson found that many studies implied that cancer was a "complex and long-lasting physical and psychological problem for the individual" (p. 3503). In this case, research and clinical application regarding sexual health are necessary, however, for those with diagnoses that offer shorter life, other priorities such as strength, and other biological components of the disease became a central focus.

Although much of the research considering cultural variables have been published based on Westernized perspectives, other international studies have asked for healthcare providers to also consider expanding sexual health issues identified by those living in traditional cultures, such as those from the Middle East. Two separate studies (Bal, Yilmaz, & Beji, 2012; Cohen, Mabjish, & Zidan, 2011), offered numerous suggestions to guide future research, as implications should be considered based on the patient that is being treated. This includes a timeline from treatment, developmental stage of life (including ages, gender and roles), as well as any other co-existing physical problems such as expedited menopause (Bal, Yilmaz, & Beji, 2012). These developmental stages may look differently for a woman of a Westernized culture than that of an Eastern culture. Cohen, Mabjish, & Zidan (2011) speak to this as they argue, "Culture may strongly affect the processing of medical information, as well as reactions to symptom, or a diagnosis of illness" (p. 191). This could include perceived spousal support, expectation and intimacy. These factors are imperative to consider before implementing an intervention informed by current implications, as they cannot be generalized to all patients. It is necessary to mention, that although the methodology that will be utilized for this study recruits participants from a lens that favors homogeneity (rather than sample based on diversity), it is crucial that researchers must take into account personal factors that may vary how certain couples from non-westernized cultures may interpret questions surrounding sex and intimacy, as well as how they co-create their shared meaning making processes and negotiations surrounding their sexual qualities of life.

All the above positions are critical to address as many medical professionals still see cancer as a primarily biomedical diagnosis, and often miss opportunities to initiate important conversations that may generate positive psychological outcomes for the patients we serve. This serves as an important reminder that we must not only initiate conversation, but that these conversations will be conducted differently based on whom we are speaking with. Conversations surrounding a female's experience of cancer, for example, may have different components than that of a male's experience. A young woman's meaning surrounding her sexuality may have different implications than that of a woman who is post-menopausal. The same goes for the stage of cancer one may be diagnosed with. How we progress forward through the actualization of implications provided by the existing research should be tailored to each patient's personal context. It is not enough to merely recognize the importance of these conversations, but clinicians must also consider patient's personal histories that will then determine appropriate interventions for corresponding developmental phases of ones life.

## *Dyadic Negotiations*

The primary objective of this study is to explore and understand the negotiations that couples are facing and addressing in regards to intimacy amidst a cancer diagnosis. As this study is guided by the BPSS model and the symbolic interactionist perspective, it becomes not only necessary to address the nature of dyadic negotiation itself, but to also acknowledge that negotiations, especially those surrounding sex, intimacy, and illness, are heavily influenced by sociocultural (Olekalns & Smith, 2013) and sexual scripts (Greene & Faulkner, 2005). This section will provide a brief background of dyadic negotiation by reviewing both the general literature in this area, while also providing a short overview of the available literature that surrounds dyadic negotiations as influenced by oncological factors as well as and gender and sexual scripts.

### General Dyadic Negotiation

In order to perform an ethical and competent study that serves to understand couple's negotiation processes, it is important to first understand what literature is already being written in this area. There are many components that affect not only the outcomes of dyadic negotiations, but the process of them as well. Many factors including various cultural contexts, power structures, gender, social cues and conditions, cultural norms, etc. influence how negotiations are enacted, as well as the results of those negotiations (e.g. Mazei et al, 2014; Olekalns & Smith, 2013; Wei & Luo, 2012). According to their study on creating shared value systems, for example, Olekalns and Smith (2013) explained that social context, although significant, is only a partial explanation in the negotiation process for shared values and beliefs. Rather, they found that distribution of power within a dyad has been found to be a primary variable in predicting what will ultimately be negotiated between them (e.g. Giebels et al., 2000; Mannix & Neale, 1993; Wolfe & McGinn, 2005). Supporting this idea, Wei and Luo (2012) found paralleling results in a prior study; however, they pointed out that social influence and power are not necessarily exclusive to one another and should be considered as interdependent as they often impact and influence the other.

Power has been a complex variable within this literature as it is a fairly subjective, and often ill-defined term (i.e. power of each individual negotiator versus the power within the dyad). Individual power, as a variable, can be impacted by the various statues we hold; however, when introducing illness into a dyad, the illness may (or may not) re-distribute power differently than if illness were not present. Interestingly, however, some literature has claimed that women, regardless if they are identified as a patient or the caregiver, are still are often positioned in the less powered position, and still held to the expectations that existed prior to the illness/diagnosis (e.g. Cohen, Mabjish, & Zidan, 2001; McDaniel & Cole-Kelly, 2003).

## Gender and Sexual Scripts

As described above, social factors, and other sociocultural contexts, highly influence negotiation patterns and outcomes. Because one of the sample criterions of this study is heterosexuality, it is necessary to understand not only power dynamics in negotiation, but also how gender assigns and predicts power, and thus influences negotiation outcomes. Further, because this study is looking specifically at female patients with male partners, gender is an explicit factor to this study and negotiation is inevitably impacted by the social constructions of gender itself. In fact, in a recent meta-analysis seeking to better understand gender's impact on systemic/economic negotiation outcomes, Maze, Huffmeier, Freund, Stuhlmacher, and Hertel (2015) claimed, "gender differences are among the most enduring issues in negotiation research" (p. 85). It is important to note, that the topic of gender and sexual scripts is extremely broad, and can serve as a topic that stands on its own; therefore, for the purpose of this section, a few key articles were chosen to help further understand and explain dyadic negotiations as impacted by gender and the sexual scripts assigned to them.

Before reviewing the available research on this area, it is necessary to briefly define sexual scripts. "Sexual scripts" is a theory that was introduced in 1973 by Simon and Gagnon (1986), which is grounded in the context of "cultural scripts [that] relate to gender roles within heterosexuality" (Beres, 2013, p. 77). It is based heterosexually in order to contextualize gender in relation to its counterpart (i.e. male versus female). Through this theory each gender holds a certain position of power, however, males have tended to hold the most power in terms of sexual scripts as they are often encouraged to be an "initiator," while women are often conditioned to be "gatekeepers" (Byers and Heinlein, 1989). Interestingly, in some of the negotiation research that was reviewed for this section, the initiating negotiator often held the most power within that dyadic process, and was most often predicted to gain their desired outcome (Olekalns and Smith, 2013). However, in sexual script theory, sexual negotiation can be experienced in a different ways, and both initiation and gatekeeping offers its own "power" so-to-speak. Regardless, Beres (2013) argues that dominant discourses, which are reflections of current systemic power structures, are the most influential factor on heterosexual sexual script negotiation. She explains:

> Discourses reflect understandings of how sexuality is constructed, and underlying beliefs about the nature of sexuality… These discourses make available particular subject positions for actors to take up and open up particular spaces for action. The spaces available vary depending on one's social location. In heterosex men have available different forms of action than do women (for example). When a heterosexual couple negotiates their sexuality these spaces of action produce various possibilities for them as a couple…Dominant discourses of heterosexuality, such as the male sexual drive discourse, construct heterosex in a way such that sex is male desired and where the goal of heterosex is to satiate men's desires, leaving women the passive participants in sexual activity (p. 82).

It comes as no surprise that when negotiating sexuality within the context of cultural and sexual scripts, power is an inherent part of that process, in which men are, more often than not, the active holders of that power.

As previously mentioned, a recent meta-analysis was performed seeking to understand the role of gender and its predictability to negotiation outcomes (Mazei et al., 2015). They found that, overall, research has provided mixed views on whether gender is a significant variable in predicting negotiation outcomes; however, most studies did tend to show that male negotiators more often received their desired outcome over women. Interestingly, however, after performing their meta-analysis, Mazei et al. found that although gender differences did often favor toward men, ultimately, negotiation outcomes were contextual and were subject to change. In the next section, we will discuss the addition of illness as a contextual variable, as it is essential to assess if a chronic diagnosis provides a social location that competes with gender in regards to power and negotiation outcomes.

## Chronic Illness and Dyadic Negotiation

In reviewing negotiation literature, and congruent with sexual scripts theory, studies are continuously confirming that women are often positioned as passive and disempowered and are not often favored in negotiation outcomes. Despite these findings, however, Mazei et al. (2015) argued, "gender differences in negotiations are contextually bound and can be subject to change" (p. 85). It is crucial to question however, is this always true when it comes to a chronic diagnosis, and more specifically, cancer?

In searching for this literature, there were no studies that were found that utilized chronic illness as a moderating/mediating variable in order to understand its impact on power and negotiated outcomes; however, there is literature that discusses power dynamics that exist between the caregiver and patient relationship, as well as some limited research that has sought to understand couples experiences of dyadic negotiation during the cancer experience at various times. Gardner (2008), for example, performed a dyadic analysis in which he sought to explore "patterns of relationship, support, and communication in married or partnered couples where one partner is diagnosed with advanced and terminal cancer" (p. 135). As his study also utilized the symbolic interactionist framework, the study operated under the assumption that negotiations were constructed within the dyad. Because of this, the study focused on outcomes regarding what couples were already doing together to foster "dyadic accommodations" through an assumption of an already existing, egalitarian and shared negotiation system. Therefore, this study did not acknowledge possible unequal distributions of power, or other variables that may influence negotiation outcomes. Despite this, the researcher did include these limitations and encouraged implications for future study to consider the impact of gender, and also for researchers to also take into account the differences between how caregivers and patients process illness to further understand dyadic experiences with cancer.

Although Gardner's study was informative as to how couples negotiate making meaning of terminal phases of cancer as a unit, it neglected to recognize the unique roles that manifest within the dyad due to adapting to a chronic illness. For example, McDaniel, Doherty & Hepworth (2014) argue that patients and caregivers have separate and unique experiences of the illness as their roles and responsibilities to the illness, and to one another, differ. Although both roles have influence on a dyad, the influence each role contributes may not necessarily be equal. Close family members or partners, who most often double as caregivers (McDaniel & Pisani, 2012), often experience the illness in covert ways, in which their experiences are often silenced or dismissed. This is starkly different to how a patient both experiences illness and is experienced by others. McDaniel, Doherty, and Hepworth (2014) explain that "The physically well member is often a 'hidden patient' whose needs or suffering is not expressed…but the observable and present needs of an ill person can lead therapists, as well as the caregivers themselves, to minimize the caregivers needs" (p. 258). In this way, caregivers are placed in a more disempowered position in contrast to their patient counterpart, which can present a different power dynamic between a dyad.

As studies in this area are rare and do not provide explicit implications regarding illness as a mediating variable, there are some studies that allude to understanding dyadic negotiations amidst a chronic illness. In one study, for example, Seidler, Lawsin, Hoyt, & Dobsin (2016) sought to explore the barriers and facilitators to sexual communication in male cancer survivors. They found that an illness of this caliber, although not necessarily terminal, had the power to shift priorities and worldviews. The men were more apt to creating a shared process with their female partners where they partners may have been “previously taken for granted” (p. 672). Although not the explicit focus of this study, it is the closest research study that I have been able to find that addresses both gender and cancer as variables in which the illness acted as a catalyst to dyadic change in regards to both the negotiation process between the couples (i.e. the process became more egalitarian) as well as the meaning making of sexual scripts.

It is clear from the lack of research in this area that dyadic negotiations need to be better understood. It is essential to not only know what couples are doing to create shared meaning, but how these negotiation processes came to be. Further, it is essential to recognize that patients and caregivers, although may have some shared experiences of cancer, also have differing roles, in which each member may interact with illness differently, and thus may influence the dyad to differing degrees amidst a diagnosis. Lastly, social context, social location, and already existing power dynamics may contribute to how negotiation processes manifest, as well as how negotiated variables, such as sex and intimacy, result in outcome.

## Conclusion

There are several explanations as to why spotlighting current research on intimacy and the cancer experience is important and necessary. Most articles justified that intimacy was an integral component in ensuring quality of life and overall wellbeing to not only the patients themselves, but to their partners as well. As there were multiple rationales offered, there were also varying definitions as to what constituted meanings of quality of life, sexuality, and intimacy. Each definition provided a different understanding and guiding perspective as to why these factors are essential and to what capacity they were impacting patient’s experiences. Another integral component was that of personal context. A patient’s personal context is necessary to consider when determining how implications of research may impact them. Context can help patient’s define what a positive quality of life may look like for them, as well as inform how healthcare professionals are initiating conversations with differing patient’s living with unique needs. This is especially important when broaching on often vulnerable or embarrassing concerns such as how sex and intimacy are being impacted or shifted through the cancer experience.

Despite slight differences in defining terminology, the current literature is unanimous in that intimacy is an important component to quality of life and psychological wellbeing. Research is also unanimous in that the current state of the field is not adequately translating literature into practice, and that there are necessary changes that are needing to be made within the healthcare setting. A call for a paradigm shift in regards to how research is being conducted has also been offered in order to gain more holistic understandings of patient’s authentic experiences.

## Implications

There are many questions to be asked as to how research surrounding cancer’s impact on couple’s intimacy can influence both the mental health field and the medical field. Through existing, published research, as well as this current research project, the ultimate hope is that healthcare will breed better outcomes for the patients who are affected by our approaches to treatment. As rational for this research has been thoroughly discussed, and preliminary implications have been introduced, this section will serve to elaborate on those implications, as well as summarize what the literature has suggested for future directions in regards to medical and mental healthcare. This paper will conclude with how this project can be incorporated as an addition to current research, and offer shifts in healthcare beyond what is already being proposed.

## *Current Literature and Research*

As previously stated, approximately 50, of the 130 articles reviewed, allowed for an extensive and accurate portrayal of the current state of the literature surrounding cancer's impact on intimacy and sex. It is noteworthy to consider the context surrounding these articles as a large majority have been written and published through nursing journals. The current implications, which focus on nursing outcomes, make this evident. Further, only three of these studies were published through health psychology, while only one was published through Journal of Marital and Family Therapy, and another was published through the Sex and Marital Family Therapy Journal. It may also be important to note that a significant amount of the research was conducted internationally, while local, national research was nearly non-existent. This disparity speaks to where the field of family therapy sees itself in relation to biological illnesses, (this is especially true for the United Sates) and although our field often boasts holistic care, very little of our research actually speaks to chronic illnesses, despite the dire need to address relational concerns, which have been made apparent through nursing literature for years.

Despite the significant lean and influence from the field of nursing, a literature review was conducted. Through this analysis, five predominant themes were raised in regards to implications for both research and practice. Those themes are:

1. The need for nurses to initiate conversations surrounding sexuality and intimacy.
2. Recognizing barriers to creating more holistic healthcare
3. Incorporating multidisciplinary healthcare.
4. A focus on dyads—both in practice and research analysis.
5. Addressing the unique contexts that inform patients. (i.e. Developmental stages of illness or other descriptive variables impacting patients).

These themes will be thoroughly reviewed and elaborated upon; some themes may overlap with others. It is important to remember that these implications reflect the nature in which these studies were published, as many of the outcomes speak to nursing or other related medical fields; however, it is because of this disparity that a gap has been easily identified, and a clear need for integrated healthcare provides a space for mental health professionals to advance our field.

### *Initiating Conversations*

An overwhelming majority of the articles concluded that nurses needed to initiate conversations surrounding sexuality and intimacy. At this time, there is not a lot of space being created by nurses to allow patients or couples to address their concerns pertaining to sexual functioning, or sex and intimacy. There have been numerous studies that concluded that patients felt they received little to inadequate information regarding what to expect about sexuality (Wang et al., 2013). Wilmoth, Hatmaker-Flanigan, LaLoggia, and Nixon (2011) found that especially for cancers that were associated with reproductive organs (i.e. ovarian cancer), patients were wanting to engage in conversations that allowed them to be aware of what to expect in regards to “effects of surgery [and] chemotherapy on their sexuality” (p. 707). Not only will these conversations create a sense of security for patients, but Wilmoth et al. also believe that it should be a standard of practice, so that healthcare providers can initiate an anticipatory guidance for patients during and after their treatment process.

Beyond the patient’s need, providers should be able to recognize the psychosocial and emotional side effects of cancer treatments as they impact sexuality and intimacy. In a study conducted in Australia, Usher, Perz, Gilbert, Wong, and Hobbs (2013) found that healthcare professionals can minimize distress when they help patients and their partners anticipate and buffer the effects of an inevitable re-negotiation of intimacy that occurs after cancer is over. Because many cancers enter into chronic phases, it presents unique developmental needs that form throughout time (Rolland, 1987). In order to ethically practice holistic care, sex and intimacy should be topics being discussed, or at least introduced, by healthcare professionals.

## Barriers

These examples are among only some of the research that has concluded the need to urge nurses to begin initiating conversations surrounding how cancer may be impacting patient’s lives. Despite this overwhelming need, one may wonder why these conversations are not being had. In a recent study (Ussher et al., 2013b), researches sought to answer this very question. Why are medical professionals not initiating conversations surrounding sex for patients living life after cancer? Ussher et al. found that there were a number of reasons that could be contributing. Some of those barriers could be as practical as "structural constraints, such as a lack of time, experience, privacy or education" (p. 1371). These reasons are unfortunate since this study revealed that primary sexual concerns were directly linked to cancer treatment, which included both sexual dysfunctions as well as created meanings about one's identity such as body image, and self-esteem. Nurses themselves identified that they knew these were issues needing to be had, but admitted some reasons being associated to just being too difficult. Some nurses attributed the challenge to lack of education (i.e. it may be the job of a therapist or a counselor), while others found it embarrassing, or did not want to embarrass a patient by being too assuming. It is absolutely unfortunate that discomfort is seemingly the primary reason that these very necessary conversations are not being had.

Another international study found paralleling results (Rasmusson, Plantin, & Elmerstig, 2012). This research revealed that nurses are in the unique position of being able to bring up issues surrounding sexual functioning or intimacy related concerns in a way that is natural for patients. However, despite this privilege, nurses are still hesitant to discuss sex with their patients. Interestingly, patients reported that their physicians were the primary source of any sexually related resources, but information was still severely inadequate. The study revealed that nurses were possibly being blinded and influenced by social scripts and pre-existing taboos. These covert internalizations were preventing them from initiating conversations as they were deeming them embarrassing or uncomfortable without consulting with patients beforehand. Rasmusson, Plantin, and Elmerstig concluded, "…that nursing personnel's view of the patient is governed by existing social taboos” (p. 366). Nurses were unknowingly totalizing patients by their illnesses and not recognizing them as whole individuals who may have sexually related concerns.

### ***Integrating Mental Health***

Initiating conversations is an important component to holistic care; however, barriers such as discomfort, essentializing patient identities, and lack of confidence to bring up conversations only encourage the silencing of important conversations and serve to maintain a stigmatizing identity on patients and their partners living with cancer. However, as previously mentioned, perhaps two of the primary factors contributing to the hindrance of initiating these conversations are lack of education and time. As many studies have recognized the need to address psychological wellbeing and quality of life, as well as encouraging nurses to utilize a biopsychosocial perspective, very few of the articles actually integrated mental health practitioners as possible solutions to combat these barriers. Only two of the articles reviewed, suggested the support of mental health practitioners in medical settings. Weinstein Dunn (2015) pointed out that although nurses should be available for conversations concerning sexual health, they should also be encouraged to facilitate referrals to other mental healthcare providers or sex therapists. This collaborative approach relieves pressure from the medical staff to focus on their own scope of practice and knowledge, and to refer to other practitioners who have other skill sets. Further, differentiating defining key terms such as sexual dysfunction, sexuality and intimacy, become increasingly salient as they may speak to different required educational knowledge’s and corresponding skill sets.

As Weinstein Dunn (2015) recognized the necessity of facilitating referrals, Badr and Krebs (2012) also pointed out the differences in care when a multidisciplinary team was not only considered, but available to patients. As both education an time are factors for providing patients with adequate care, having a mental health care provider to initiate conversations surrounding psycho-social needs can be crucial. One study on Latino men living with prostate cancer were found hesitant to even address their sexual concerns with medical staff and preferred either building their own communities or having a group centered for men with similar problems to speak with (Maliski, Connor, & Litwin, 2012). A mental health care provider could be an essential figure in facilitating this process.

As previously articulated, many research studies called on nurses to initiate conversations surrounding sexual health, intimacy, and other relational concerns that may be affecting patients and their partners as a result of the cancer process. However, there are unique knoweledges and skills that mental healthcare providers hold that could be vital in supporting medical staff through these conversations. Mental health clinicians can offer time and the educational background to engage in these conversations, as well as utilizing attunement to incorporate other contextual variables that may be influencing patients. Specifically, marriage and family therapists are especially attuned to systemic contexts and relational concerns that can be impacting a patient's experience, as well as being impacted by the developmental and changing nature of chronic illness. As couples, or other significant relational figures live through the cancer experience, dyadic analysis allows researchers to capture fuller and richer accounts of the experiences of patients and their loved ones. Especially for issues surrounding sexual health, a dyadic approach allows both researchers and clinicians to understand how couples are negotiating meaning surrounding their intimate identities as they are impacted by cancer.

### ***Dyads and Dyadic Research***

Of the studies reviewed, many, if not most, acknowledged the importance of addressing intimate partners in the context of chronic phases of cancer. Some recognized the importance of the partner's role either as a caregiver or support system, or in many cases pointed out how cancer in chronic stages will inevitably produce subsequent relationally centered outcomes. Despite this acknowledgement, however, very few studies actually produced dyadic studies (i.e. both partners as being the unit of analysis). This lack of relational research could be in large part due to the fact that the primary literature surrounding cancer and couple's negotiations of intimacy among their diagnosis stems from nursing journals. Although sparse, there were a few articles that did include patients and their partners as participants in their research, making for true dyadic research.

Dyadic analysis has become an important component in research, especially surrounding couples living with chronic illnesses. Traa, De Vries, Bodenmann, and Den Oudsten (2014) for example found that when responding to cancer, patients often react as a unit (i.e. as a couple or family) rather than as an individual. As many researchers rationalize their studies based on the notion of "quality of life," Traa, De Vries, Bodenmann, and Den Oudsten found that quality of life was often interdependent between patients and their significant others, which are often their partners. The perception of seeing cancer as relational is also validated through the coining of the term: the “we disease” (Acitelli & Badr, 2005; Kayser, Watson, and Andrade, 2007).

Although few, there have been meta-analyses performed (e.g. Badr & Krebs, 2012; Badr et al., 2016; Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008) that have also supported the idea of dyadic analysis as it recognizes the relational nature of chronic illness.  This is especially true for cancer, as numerous types of cancer are rapidly becoming considered chronic, versus acute, illnesses (Tritter, & Calnan, 2002).  One of the primary implications for future research lies in dyadic analysis that should be including the partner or spouse as they have been recognized to correlate with perceived support and quality of life (Badr & Krebs, 2012; Badr et al., 2016), and overall positive psychological outcomes.  Badr and Krebs (2012) who performed a meta-analysis on psychological outcomes found that cancer patients often identify their partners as they primary source of support.  Because of this, “coping with cancer has been characterized as a dyadic affair” (p. 1688).  Badr and Krebs call to future researchers to ensure that research remain consistent on relational outcomes by performing dyadic analysis, which will ensure that couples remain the unit of analysis throughout a study.  This call to research is a significant one because, as previously stated, although almost all articles reported the necessity of partners included in patient outcomes, as well as how cancer impacts units rather than individuals, very little of the research actually incorporated partners as part of the unit of analysis.  Reese, Porter, Casale, Bantug, Bober, and Shwartz (2016) for example sought to understand and develop a couple-based intimacy intervention to breast cancer, however, only patients were interviewed.  Interestingly, the results of the study incorporated the “couples” understanding of the cancer experience, despite not including partners as participants, and having an individual based analysis. Resse found that “Clinically, these findings suggest the importance of understanding and addressing both the woman’s challenges in adjusting to breast changes and her partner’s reactions when helping a woman cope with sexual concerns post–breast cancer” (p. 1094). As with numerous of the articles reviewed, these results, among others, were reported without interviewing partners of patients diagnosed.

Of the articles that were reviewed only two articles (Loaring, Larkin, Shaw, & Flowers, 2015; Traa, De Vries, Bodenmann, & Den Oudsten, 2014) actually examined the couple as the unit analysis, despite much of the research claiming couple-related outcomes and implications. As found in the Traa, De Cries, Bodenmann, and Den Oudsten article, Loaring, Larkin, Shaw, and Flowers found similar results in that they were able to provide more complete and accurate outcomes and implications as they were truly based on the needs of both patients and their partners. By including partners in the unit of analysis, implications regarding care for both patient and partner could be offered. Because of this, Loaring et al. found that psychological support could be strengthened for both patients and partners. This is especially pertinent for issues surrounding sexuality and intimacy as perceived support contributed to increases in self-esteem, body image, and the ability to maintain couple connection through “physical, verbal, and relational dialogue between the woman and her body, as well as the woman her body, and her partner” (p. 435).

Although dyadic research is currently scarce, some theoretically based articles that spoke to the importance of dyadic analysis. Sheilds, Finley, Chawla, and Meadors (2012) for example found that there was a significantly higher positive psychological outcome when partners were incorporated into treatment. Studies that included relational units of analysis seemed to produce better and more accurate results, however they also found that unfortunately, “the research on family interventions for medical problems is largely in the developmental phase” (p. 275). Loaring, Larkin, Shaw, and Flowers (2015) also validated this sentiment in that although relational literature is growing, and especially that of patient and partnered experiences in regards to sex and intimacy, studies are still severely lacking in relational units of analysis, as they argue that “ few studies have included both partner’ views of post treatment sexuality and body image” (p. 427). As articulated by Traa, De Vries, Bodenmann, and Den Oudsten (2014), “…a solely individualistic view, where patient and partner experience cancer separately…seems outdated” (p. 86). Future research must include significant others to be primary units of analysis in order to get more complete and accurate data (Badr & Krebs, 2012) surrounding the cancer experience and its effects on intimacy, relationships, and quality of life as a whole.

## Current Study

Through this literature review, there were two primary themes that have been highlighted across the existing literature. Those themes were: research paradigm and encouraging a holistic approach to improve quality of life outcomes (i.e. normalizing sexual qualities of life through initiating sexually based conversations). In regards to the research paradigm, in order to honor this shift, this research study will be conducted through qualitative understanding patients needs based on their experience during these chronic phases of cancer. This research study will also accommodate the need for the paradigm shift, as it will use dyadic analysis. All units of analysis will be couples in order to grasp the experience of both patient and partner, privilege voices of the couple as a unit, and study the phenomenon of intimacy as it is impacted by cancer through a relational and systemic lens. Secondly, this study further encourages holistic care, as it will be taking an integrated approach to care. While most of the studies offered implications for exclusive healthcare populations (i.e. solely medical healthcare professionals, or solely mental health care professionals), this study will recognize how through the collaborative care approach, standard of care may be maximized by incorporating the skills and strengths of each profession. This position is an important one as many of the "calls to action" for nurses required knowledge and interventions that may be out of their scope of practice or knowledge. A mental health care professional may be able to contribute interventions and initiate conversations in a way that medical professionals cannot. As reviewed in some articles, some possible limitations to proposed implications recognized lack of skill in this area, as well as lack of time. These are two things that mental health professionals can offer to care already being provided by nursing and other medical staff.

## Conclusion

Through this paper, implications for future research, as well as directions for practical application were discussed. This was done through providing a comprehensive review of the literature in regards to background and rationalization for this area of study, as well as a summarization as to the implications as suggested by existing research. This current research project seeks to implement these suggestions, and also contribute to furthering these implications by incorporating two significant additions: dyadic analysis and an integrated care perspective.  It is the hope of the researcher that healthcare providers, both medical and mental health, will be able to foster collaborative healthcare in order to raise the standard of care that is provided to patients.  Lastly, it is through this integrated lens that the researcher hopes to encourage and practice more holistic care by viewing the wholeness of a patient's identity, which inevitably includes the perspectives and experiences of significant loved-ones as well.

In regards to research, a large majority of studies have attempted to understand sexuality and cancer through a predominantly quantitative lens (Hyde, 2006).  However, Hyde argues that quantitative research has not been able to accurately account for cultural scripts that inform a participant's experience.  Klaeson and Bertero (2008) support this sentiment as they call for a shift in paradigm.  This call to action not only speaks to healthcare application, but also the type of research that is being done. As more research in this area is being conducted, qualitative and mixed methods are increasing in utilization.  This shift has been a beneficial one as more complete stories of how patient's are experiencing intimacy amongst a cancer diagnosis are unfolding, and researchers are then able to have more holistic and practical understandings as to how to implement these shifts into clinical application.

# CHAPTER FOUR

# METHODOLOGY

This study will be conducted qualitatively and will utilize Interpretive Phenomenological Analysis (Smith, Flowers, & Larkin, 2009). This section will serve to provide background of the chosen methodology, while also explicating the intention and rational in choosing Interpretive Phenomenological Analysis (IPA). Prior to this description, the research objectives of this study will be outlined.

Although explained later in this section, it is important to note that the overarching research question, as well as the wording of this question, was chosen intentionally in order to honor IPA’s research methods. The overarching question to this research project is: How are couples diagnosed with cancer negotiating sex and intimacy amidst a diagnosis? The objectives of this project are to:

1. To understand couples authentic lived experiences in regards to the negotiation of sex and intimacy with a cancer diagnosis.
2. To uncover if patients are experiencing their healthcare providers as operationalizing current literature recommendations surrounding the inclusion of sex and intimacy in oncological care.
3. To contextualize illness within psychosocial understandings by privileging the dyadic experience inherent in navigating sexuality with a chronic cancer diagnosis.

## Interpretive Phenomenological Analysis

Interpretive Phenomenological Analysis (IPA) is a fairly new methodology that made its mark in a 1996 publication by Jonathan Smith. IPA was created as a response from the need of identifying an approach that was rooted in psychology, while also able to capture an experiential essence to qualitative research. This was particularly salient as many other methodologies have not historically been rooted in psychology, but rather stem from other disciplines and are then adapted within the social sciences (Smith, Flowers, & Larkin, 2009). Because the foundation of IPA is psychological in nature, it allows for the unique focus on exploring how people make sense of themselves in the world they live in. Further it allows people to explore their personal epistemologies and understand how they have learned to form meaning based on their interpretations of the world in which they live (Smith, Flowers, & Larkin, 2009).

There are three key areas that inform IPA and allow for the theoretical perspective that this methodology offers its research. Those areas are: phenomenology, hermeneutics, and idiography. As IPA is most considered a phenomenological approach, IPA extends beyond phenomenology although holds many of its primary principles. Phenomenology, being a philosophical study of human experience, most strongly informs IPA as it seeks to find “a means by which someone might come to accurately know their own experience of a given phenomenon” (Smith, Flowers, & Larkin, 2009, p. 12). Phenomenology lends itself to IPA in that it centralizes its focus on experience and perception (Husserl, 1927;1982). This contribution guides IPA researchers into viewing persons as relational beings who are informed by and embedded in a world of relationships, objects, language, and culture (Smith, Flowers, & Larkin, 2009; Merleau-

Ponty, 1962; Sartre, 1948). Phenomenology not only inspired the ability to understand the human experience, but offers that our experiences are contextual based on the world in which we live.

Although phenomenology provides a significant foundation for the human perspective and its relationship to the world in which we live, IPA recognizes that as researchers, we are ultimately interpreting the accounts of our participants, in which those accounts are also interpretations of personal experiences. This notion of a "double-interpretation" is something that phenomenology alone does not address, which is why the role of hermeneutics is crucial to IPA research. Hermeneutics in itself is a theory of interpretation. Hermeneutics is a crucial component to IPA particularly as it informs the data collection and analyzation process. It informs how questions are asked, received, and how content and context may be interpreted in the coding process. The hermeneutic circle significantly informs IPA as it provides the researcher with a specific lens in understanding the context in which someone has interpreted an experience. Rather, "to understand any given part, you look to the whole; to understand the whole, you look to the parts" (Smith, Flowers, & Larkin, 2009, p. 28).

The final key component to IPA is idiography. According to Smith, Flowers and Larkin (2009) "idiography is concerned with the particular" (p. 29). This concept speaks to the generalizability of IPA research in that it does not intend to generalize findings to a population, but rather to deeply understand, explore and describe a particular phenomenon amongst a particular sample of people. Because of this, the depth of analysis can be more tedious than other methodologies as it requires meticulous attention to detail within the data. Similarly to other theories, such as grounded theory, IPA requires analysis to be detailed and systematic. Unique to IPA, however, because it is informed by idiography, it allows for single case studies, which means that research studies conducted with IPA often have extremely small samples—including only a single participant. Bromley (1985), for example, advocates for what is called a quasi-judicial approach, which seeks to produce "highly circumscribed accounts of persons in situations, giving rise to low level generalizations within relatively narrow areas of scientific and professional interest" (p. 8). However, it is important to note that although IPA research warrants for in-depth and "particular" research; the particular is inevitably a part of what makes up what we know as universal (Warnock, 1987). Therefore, IPA studies help understand generalizable ideas, but from a specific (or particular) perspective.

These three key components come together to form IPA's primary objective, which is to uncover a detailed understanding of the human lived experience within a particular sample based on how they make sense of themselves in a particular context (Smith, Flowers, & Larkin, 2009). Hence, IPA looks to phenomenology to understand lived experience, hermeneutics to acknowledge that both lived experiences and the inquiry of those experiences are interpretive, and idiography, which situates participants in particular contexts. Additionally, one of the unique components to IPA is its overt attention to the subjective nature of research and therefore the acknowledgement of the active role the researcher holds in shaping the data. This means that the element of "interpretation" goes beyond the participant's interpretations of his or her own lived experiences, but also takes into account the researcher's context, which then informs how he or she will make sense of the data.

Due to IPA's overt positioning in regards to the subjective and interactive nature of the research process, it is necessary to acknowledge that IPA exhibits numerous qualities that overlap into the realm of social constructionism. It is important to note, however, that Smith, Flowers, and Larkin (2009) adamantly state that although IPA subscribes to social constructionism, it does not do so as strongly as other methodologies (i.e. Discourse Analysis, or Foucauldian Discourse Analysis). This distinction is important as it separates IPA from other similar methodologies. The core difference lays in the fact that IPA research maintains its focus on lived experiences, or rather, "a person's relatedness to a given phenomenon" (p. 195) as the topic of study, while the phenomenon itself acts simply as a unit of analysis. Conversely, in other methodologies, the social construction of knowledge, or the interaction between a phenomenon and larger social contexts, for example, remain the focus of study while the experiences of participants may be seen solely as a unit of analysis, which serve to support these other more primary topics. Similarly to other qualitative approaches, IPA shares overlap with competing methodologies; yet its central objective to thoroughly understand and explore participant's authentic accounts of their lived experiences, distinguish it from its other methodological counterparts.

## IPA Rationale

IPA, although distinct to some methodologies, bare similarities to others. Although an older approach, Grounded Theory, for example, is often compared to IPA, as both methodological approaches honor the essence of qualitative work through inductive reasoning, in depth investigation, and category saturation. However, IPA was found as the best fit for this research project for numerous reasons. For example, it was important to consider the developmental stage of this research. Grounded Theory, which seeks to develop and generate theory, may be too premature for a study of this nature. So few research articles have explored couples as the unit of analysis (Loaring, Larkin, Shaw & Flowers, 2015) that attempting to develop a theory without preliminary research could provide inaccurate and incomplete results that are only sparingly informed. At this point in time for research in family therapy literature, it would be more informative to gain in depth understandings as to how patients create meanings and significance of their intimate relationships in relation to a cancer diagnosis, and how those meanings motivate other relational behaviors and outcomes.

Further, it may be important to note that Smith, Flowers, and Larking (2009) have pointed out that many research projects begin as IPA studies, and once preliminary knowledge is uncovered from that, are often continued with a secondary grounded theory study. Because of the current state of the literature, an IPA study would allow for participant's authentic voices to be heard, and to generate truly dyadic results from the perspectives of both patients and partners. Through IPA, participant's voices are allotted a more active role in data collection than in other methodological approaches. Using Grounded Theory, for example, can often be more selective of what participants are allowed to share as questions are often shaped by the emerging theory, or the researcher's need to build upon a conceptualization. IPA would allow for a more authentic collection of participants experiences, understandings, and relational reactions to sex and intimacy and how it is shaped by the cancer experience. Although both methodologies could produce equally exciting research, this project is not seeking to build a theory in understanding why patients are experiencing the phenomenon of intimacy as it relates to cancer. Rather, this research is seeking to describe how patients understand their lived experiences, and how those understandings are informing how they choose to navigate intimacy with cancer.

Lastly, IPA was chosen for its explicit intention in guiding studies related to human sexuality and related topics. Smith, Flowers and Larkin (2009) argue that sex and sexuality are key areas of IPA research. They express how IPA allows "the participant to talk about the way they think about an issue, rather than using a priori hypothesis to make assumptions about how people think, as much of traditional health psychology does" (p. 135). This perspective is especially important when understanding the way we make meanings of ourselves as it is so heavily dependent on the pre-constructed pathology of sexuality (Foucault, 1986).

## Method, Theory, and Proposed Outline

In this last section, a potential outline of this study will be created and described. The processes for sample collection, recruitment, data collection procedures, and analysis will be discussed. Additionally, this outline will not only describe the practical outline utilizing the IPA approach as articulated by Smith, Flowers, and Larkin (2009), but also how each of these components will be guided and perceived through the conceptual framework of symbolic interactionism. As each step of this research process will be conducted utilizing the IPA approach, it is important to note, this project will be guided by the researcher's conceptual frameworks, Symbolic Interactionism and the biopsychosocial-spiritual approach, and may differ from similar studies, as it is informed by the researchers own subjective realities and interpretations.

### ***Sample Collection***

Sample collection and recruitment will primarily be guided by the methodology and existing literature. The literature has stated that patients in chronic phases of cancer are more appropriate participants than those with acute diagnosis, as these patients tend to focus on immediate biological needs (Olsson, Athlin, Sandin-Bojo, & Larsson, 2013). The methodology asks that participants meet a criteria of homogeneity, and that the researcher focus on participants who are able to allow the researcher to remain close to the objective of IPA research, which is to “Focus on personal meaning and sense-making in a particular context, for people who share a particular experience” (Smith, Flowers, & Larkin, 2009, p. 45). One of the key components in generating a sample for IPA research is that the sample represents a perspective rather than a population. In virtually all of the existing research participants have been selected through a singular population (i.e. breast cancer patients *or* prostate cancer patients, etc.); however, this study will be able to explore multiple cancers as long as they meet the inclusion criteria. They are: patient must be an adult (18 and over) female within a chronic phase of cancer, a current patient at Loma Linda University Cancer Center, must have a reproductive related cancer (breast and/or gynecological), patient must be in a self-identified meaningful, monogamous, and an heterosexual relationship, as the dyad or couple will be the unit of analysis and should have some interest in knowing more about how their sexual quality of life interacts with the illness experience. These inclusion criteria honor the IPA approach in a number of ways. Most importantly, it maintains homogeneity within the sample through: the classifications of cancer, consistency within the gender of the patient, exploring heterosexual couples across cases, and the physical location of sample. Further, the sample chosen corresponds with IPA's sampling for perspective (versus population) through the intentional selection of female patients with male partners as literature has historically explored women's and men's perceptions of female sexuality; this perception is magnified as the element of illness threatens empowered female sexual qualities of life (e.g. Burwell, Templeton, Kennedy, and Hunter, 2008). Lastly, this study will be sampling dyads, which is not only a direct response to the gap in the existing literature, but also highlights IPA's methodology for perspective based sampling.

As previously suggested, sample size is often very small. IPA suggests a student project should be between "three and six participants" (Smith, Flowers, & Larkin, 2009, p. 51). The small sample size is due in part that meeting the requirements for IPA results is often a much more difficult task for large sample sizes, rather than a sample size being too small. However, as is the case for defining homogeneity, sample size for a Ph.D. level project will once again be determined by the project itself. The primary objective to maintain in IPA regarding a sample is that the researcher will be able to be able to uncover detailed accounts of individual's experiences in particular contexts. Results of an IPA study should "…provide rich, transparent, and contextualized analyses of the accounts of the participants" (p. 51).

### *Recruitment*

According to Smith, Flowers, and Larkin (2009), participants are often recruited via referral, opportunities, or snowballing. The recruitment process is not typically a long one as sample sizes for IPA are often smaller than other approaches as it requires detailed case-by-case data collection, and in depth understandings of “particular phenomenon in a particular contexts” (p. 49). Recruitment through the IPA approach also focuses on homogenous samples, however it is important to note that “how homogeneity is defined, depends on the study” (p. 50). It can be troublesome to make inclusion criteria so exclusive that the sample becomes small because of issues with recruiting rather than having a choice as to who will be a part of the study. In the context of this study, the homogeneity will be determined by a number of factors: (a) patients will be from Loma Linda Cancer Center, which will ensure that the context of care and environment are controlled by this specific location, (b) patients must be in an active heterosexual relationship because couples will be the unit of analysis, (c) patients must be in chronic phases of cancer (i.e. have not been given a timeline for life), and lastly (d) patients must be adult females, with adult male partners.

Recruitment can happen in a number of ways as typically done at the Loma Linda Cancer Center. At this time, recruitment will consist of flyers and physician referrals/recommendations. Flyers will be IRB approved as well as approved by the executive director at the cancer center. In regards to potential participants that are recommended through physician referrals, the researcher will perform a phone screening in order to ensure that participants meet inclusion criteria.

The researcher has reached out to the executive director of the cancer center in order to ensure appropriate and ethical steps for sample recruitment. Further, the head of research for the cancer center has also been consulted with, and will continue to be a part of the process to ensure ethical recruitment as determined by the cancer center. Lastly, surgeons and nurses have been notified of this future study in which most have agreed to also include flyers as a part of the intake process once flyers have been approved; Following IRB approval, a formal in-service will be done for all medical staff so appropriate referrals can be made. Steps for recruitment will mimic the procedures that have been determined for all previous clinical trials as outlined by the cancer center.

## ***Data Collection and Procedures***

Although IPA has clear guidelines surrounding data collection, this section will also be highly guided by the theoretical frameworks of this study: symbolic interactionism and the Biopsychosocial Model. As the methodological approach will guide the design, the conceptual frameworks will guide the content and direction. For an IPA study specifically, both the methodological approach as well as the theories guiding the study will contribute to the contextualization of the analysis and results.

### **IPA**

"In terms of devising a data collection method, IPA is best suited to one which will invite participants to offer a rich, detailed first-person account of their experiences…These facilitate the elicitation of stories, thoughts and feelings about the target phenomenon" (Smith, Flowers, & Larkin, 2009, p. 56). In order to capture these rich and detailed accounts of participants lived experiences of a particular phenomenon, it is most common practice to conduct face-to-face and one-on-one interviews. This means that focus groups and the like are not as common as a significant theoretical underpinning of IPA research is centered around the relationship between research and participant in terms of gaining individual accounts of a participant’s personal context and then comparing these accounts across cases at a later time. The contextualization of data is reflective of the participant, as well as how the researcher interprets the unique interpretation of context and phenomenon (i.e. double interpretation) by the participant’s already lived experiences.

Interviews through IPA are often done in a semi-structured format. Questions informed by this methodology are typically questions that are focused on the topic of the research, but the research question itself is rarely asked. This is large in part due to the fact that central research questions tend to be abstract in thought, and often are posed with a subjective intention, which can only be interpreted “correctly” by the researcher him/herself. Therefore it is aimed to “set up the interview as an event which facilitates the discussion of relevant topics, and which will allow the research question to be answered subsequently, via analysis” (Smith, Flowers, & Larkin, 2009, p. 58). The nature of the questions are semi-structured in the sense that there may be an “interview schedule” as the researcher has a pre-determined, and conceptually informed idea about what should be covered in the interview that would allow the primary research question to be answered, however, the interview itself is ultimately co-created, as the purpose of the interview is to gain authentic accounts of participant’s lived experiences, and IPA researchers ought to privilege what participants are prioritizing to share.

## Symbolic Interaction and the Biopsychosocial-Spiritual Model

Regarding the interview process, IPA is specific as to how interviews should be conducted, and that in order to gain focused and authentic accounts of participant's meaning making processes, it is important to conduct interviews on a one-to-one basis (Smith, Flowers, & Larkin, 2009). This is especially important for conducting dyadic interviews, as an IPA researcher seeks to gain deep and genuine understandings of the worlds participants are a part of and how they have made meanings of themselves in those worlds. In dyadic analysis, the researcher recognizes that responses, reactions, and sense making can be a relational process; therefore interviewing the unit alone will hopefully provide a close account of the couple's meaning making process and an authentic glance into how couples already interact. In cancer, being guided biopsychosocially allows the researcher to appreciate the various systems that exist outside the medical setting that can significantly contextualize how a patient makes meaning of a certain phenomenon, especially one pertaining to sexual quality of life. This is particularly salient for chronic phases of cancer as Hagedoorn, Sanderman, Bolks, Tuinstra, and Coyne (2008) emphasize the need to consider the impact of primary figures in patient's lives, which is most often an intimate partner, who highly contributes to meaning making processes surrounding QOL. They articulate that dyadic analysis is crucial for cancer research, and therefore practice, because perception and reactions of a patient are highly dependent on that of their partners.

> To an important extent, patients and partners are interdependent in that cancer impacts on their shared life, both emotionally and practically. Thus, the partner influences the adjustment of the patient, and conversely, the patient's diagnosis and treatment of cancer affects the adjustment and emotional well-being of the partner as well (p. 1).

When speaking to Symbolic Interaction, it is important to mention that it is guided by the assumption that participants live in, and are informed by, a pre-existing world. In order to gain these detailed accounts, symbolic interaction can inform one-on-one interviews by prioritizing the collection of information that pertains to the processes that couples have already gone through rather than a focus on the active construction of meaning. A focus group or group interview process, for example, may hinder this process as it introduces new ideas and foreign contexts that do not normally exist during a couple's negotiating process. Although the interview itself can be seen as presenting new variables into a couple's already existing world, the IPA interviewer is to remain intentional on questions that can still gather genuine recalling's of the unique meaning making process that exists between that couple. Therefore, in holding the perspective that reactions to a particular phenomenon (i.e. cancer and intimacy) is in fact a relational process (Gergen, 2009a; 2009b; Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne), then an IPA researcher would most often utilize the one-on-one interview in order to ensure that the relational responses being reflected in that interview are as closely due to the couples already existing process of meaning making.

The Biopsychosocial-Spiritual Model and Symbolic interaction further lend themselves in other significant way as they provide guidance as to what questions will and will not be included in participant interviews. Symbolic interaction, for example, seeks to understand "the primary connection between symbols (i.e. shared meanings) and interactions (i.e. verbal and non-verbal actions and communications)" (Boss, Doherty, LaRossa, Schumm, & Steinmetz, 1993, p. 135); therefore questions will be geared toward understanding how couples have learned to make their own meanings based on the worlds that inform them. The biopsychosocial approach, however, lends itself more subtly as it underlines the awareness that couples are not solely negotiating shared meaning about sex and intimacy, but are doing so in a world that is unique to the illness experience, versus other couples who negotiate meanings of sexuality without illness. These views remain congruent with the IPA methodology as this research platform is geared to understand sense making, and the meaning formation of a particular phenomenon in relationship to its existing and/or perceived realities. For this study, those variables are sexual qualities of life as is relates to the chronic illness and cancer experience.

As symbolic interactionism, the biopsychosocial approach, and IPA are conjointly informing the questions being asked, and IPA typically calls for semi-structured interviews, it is recommended that questions be constructed prior to the interview. Questions will be informed by symbolic interaction and the biopyschosocial perspective, which will both serve to understand the shared meaning making experience that exists in the interaction of the dyad, while understanding psychosocial issues as they have been shaped by illness. Examples of questions that are informed by both the methodology as well as the conceptual framework are:

1. Please tell me how you define sex and intimacy?
2. Do you find sex/intimacy an important part of your relationship?
    a. Has it become less/more important since the cancer experience?
3. How has your health team contributed to how you negotiate sex and intimacy after being diagnosed?

### ***Analysis***

As with data collection, the analysis of this research study will incorporate influence from both the methodology as well as the conceptual framework. As articulated through Smith, Flowers, and Larkin (2009) IPA consists of 6 specific steps in analyzing the data. Those steps are:

1. Reading and re-reading
2. Initial noting
3. Developing emergent themes
4. Searching for connections across emergent themes
5. Moving to the next case
6. Looking for patterns across cases (pp. 82-101).

During data collection, it is essential that transcripts are produced, as analyzing data needs to occur utilizing verbatim wording by participants. The goal of IPA is to generate results that are as accurate and close to participants lived experiences as possible, which also include the researchers transparent disclosures surrounding conceptual interpretation and contextualization of the data.

The first step in IPA is to ensure that participants are the focus of the analysis; therefore it is necessary to immerse oneself into the original data (i.e. recorded transcript). The primary purpose of this step is to re-enter the "participant's world" (p.82) even after time has passed since the interview was first conducted. The second step is the most "detailed an time consuming" (p. 83). This step is used to begin finding parts of the data that are of interest to the researcher, or anything that may be able to aide in answering the research question. The conceptual framework will also aide in determining what parts of the data are “interesting” as these conceptual perspectives are tools used to inform researchers of key words and phrases that are theoretically relevant to the research. The primary purpose of this step is to ensure “a growing familiarity with the transcript, and moreover, it begins to identify specific ways by which the participant talks about, understands and thinks about an issue” (p. 83).

The second step requires the most attunement to the researchers interpretations of the data, which also includes contextualizing and formulating both descriptive and “conceptual comments” (Smith, Flowers, & Larkin, 2009, p. 88). Descriptive comments are those that are usually just highlighting participant’s words verbatim, or a comment about if something may be “good or bad,” or a “negative or positive experience.” Although there may be some level of researcher interpretation in descriptive comments, they are usually minimal compared to the conceptual comments. Conceptual comments are typically annotated in the form of further questioning, or comments that are an attempt at conceptualizing the data through other components that may be remembered during the interview. The purpose of conceptual questions is to help the researcher come back to the data with guiding ideas and perspectives. Symbolic interaction, for example, will play a role in what questions may come to mind during analysis. As a researcher becomes more familiar with the data, questions guided by symbolic interaction may arise surrounding further exploration about role development, or a particular attunement to the various worlds or contexts that couples are a part of in and outside of the hospital. These contexts may help answer or link thoughts surrounding role formation or meaning making based on how a patient or partner perceives his or her role. This guided focus may inform how the data is perceived, or how particular phrases may hold more significance than others.

The third step in analyzing data is to develop emerging themes. The emerging themes are a result of the original data in addition to the growing commentary provided by the researcher as he or she becomes very familiar with the data. The emerging themes are developed through the grouping of exploratory notes (i.e. descriptive and conceptual comments). At this point the methodology is the primary guiding framework, as step two is a accumulation of conceptual and practical understandings of the data. The third step requires the researcher to be even more cognizant of the interpretations of the data, as each step of analysis “does indeed take you further away from the participant and includes more of you” (p. 92). However, the exploratory commentary should have a combination of participant’s verbatim comments, as well as contextualizations from the researcher, which aids in creating robust themes.

Step four is about connecting themes in order to create final structures or categories of those themes. Steps five and six are similar to step 4, but acts as a “meta-analysis” in many ways as the researcher now is finding common narratives and categories across cases. At this point finalized categories will emerge that are representative of the researchers entire sample, and results should reflect authentic and rich accounts of participant’s lived experiences through the understanding of how they have made sense and meanings of their personal contexts. The results will also reflect the interpretive nature of each participant’s experiences, as well as the researchers understandings of those interpretations.

### *Credibility*

As qualitative study has only been recently seen as a credible form of research, it is imperative to discuss the validity and trustworthiness of my study.  Historically qualitative work has been criticized by the research world as it has been argued that it lacks the ability to reliably prove the validity of its findings (Guba & Lincoln, 1994).  As best stated by Lincoln and Guba (1985) “The human instrument provides an easy way to obtain member checks to make apparently non-credible data credible" (pp.239-240).  In order to ensure the credibility of this study, I will utilize and perform member checking where I will be able to send the first level of coding back to participants who agree to be a part of this process.  This can be done by e-mailing participants verbatim transcriptions and interpreted themes (as described below).  Participants can confirm or correct how I have made sense of their experiences.

In order to confirm accuracy of the participant’s language is record all interviews. After recording, I will transcribe each interview verbatim which will include inflection and document body language and other notable observations in memos after each interview.  After transcribing the participant’s exact words, I will perform my first level of coding in which I intend to send to each participant in order to verify that I have fully captured, correctly interpreted meaning making, and that I have most accurately represented their experiences.  It is imperative that my study upholds the highest level of credibility in order to provide the most authentic results.

Lastly, I plan to send a clean version of the initial transcripts to be coded by another, unaffiliated researcher, in order to ensure the correct themes of this study, and that these themes are correctly and fully saturated.  After the second researcher completes his or her coding, we will compare the similarities and/or differences in our findings and collaborate on finalizing themes. These final saturated themes will once again be sent to participants to provide them yet another chance to provide input to ensure the authenticity of my results.

## Results

The purpose of these results is to explicate answers to the overarching question of this study. This question is: What practices are couples, who are living with cancer, currently engaging in regarding their sexual and intimate relationships? I am also seeking to answer the sub-question of how literature is currently translating into practice through the perspectives of diagnosed couples. This will help healthcare professionals know what steps are couples doing on their own to secure intimate bonds, what healthcare professionals are doing that either encourage or discourage the prioritization of sexual and intimate relationships, as well as what healthcare providers may need to do more of in order for conversations surrounding sex and intimate concerns are being addressed. Ultimately, literature and research have only provided theoretical validation as the importance and significance of sexual relationships and identity as it pertains to the cancer experience, but almost no information is being given as to the practical implication of current research. These results hope to provide those answers.

Because I am utilizing Interpretive Phenomenological Analysis (Smith, Flowers, & Larkin, 2009), IPA does favor a particular way of presenting results. Although IPA does not claim to have strict rules as to how any one researcher may present their data, it is highly suggested that because “your reader was not alongside with you during that process…you must present your results in a full narrative account which is comprehensible, systematic and persuasive to that reader who is coming to your study for the first time" (Smith, Flowers, & Larkin , 20009, p. 109). Because its emphasis on actual participant narrative, I will then be providing both a thematic structure, which will be supported by participant narratives. It is a top priority to present the results as authentic and most closely representative to the participant experience.

## Limitations

There are two limitations that I foresee happening within this study. The first is the plausible lack of diversity within the sample I am able to collect. As I am honoring the homogeneity called for by the methodology being used, the sample is limited to the Loma Linda Cancer Center, which may not provide a truly diverse sample. Although the methodology itself does not intend to be generalizable to other populations outside of the sample, participant's demographics will be limited to those that are represented by the cancer center. This could mean that there is a lack of diversity within socioeconomic status and race, among other demographics.

The second plausible limitation is that of the self-selection process itself. It may be noteworthy to keep in mind the type of patients and couples that are already naturally attracted to this study. It may speak to the level of risk the couple feels they are at, the severity of their problems, as well as how much they may already value the presence of an intimate relationship. I hold the assumption that couples who are not already open to the idea that sexuality and intimacy are important aspects of the cancer experience may not apply for this study.

## Conclusion

IPA has a clear outline that has pre-determined much of what the research process will look like, however this methodology does take into account the conceptual framework that guides the researcher.  A strong conceptual framework is essential for an IPA research project, and the intersection of Symbolic Interactionism and the Biopsychosocial Model is an appropriate fit for IPA.  As both IPA and symbolic interaction have a central focus on meaning making and the influences of personal and particular contexts, as well as researcher interpretation, these two approaches are a congruent match, and are appropriate frameworks to guide a qualitative study such as this one.

# CHAPTER FIVE

# UNDERSTANDING DYADIC NEGOTIATIONS REGARDING SEXUAL QUIALITY OF LIFE AMIDST A CANCER DIAGNOSIS: A QUALITATIVE STUDY

## Abstract

Utilizing an Interpretive Phenomenological Analysis approach, this study explored the negotiations of six heterosexual couples in regards to sexual quality of life amidst a reproductively related (gynecologic or breast) cancer diagnosis. Face-to-face semi-structured interviews were used, as this study collected dyadic data exploring the authentic lived experiences of female patients and their male partners. Research has validated the importance of sexual quality of life and its effect on patient adjustment outcomes. Further, studies have found that partners are highly influential in patient's overall wellbeing during and after cancer. Despite this knowledge, virtually no studies have collected nor analyzed data dyadically. In answering the question, "What practices are couples utilizing in negotiating sex and intimacy amidst a cancer diagnosis?" three overarching themes were found across the six couples: increasing intimacy, depending on prior values, and sharing responsibility. Implications are discussed for three audiences: future couples, integrated healthcare teams, and marriage and family therapists.

# Introduction

As the rate of survivorship continues to increase, cancer is not the death sentence it once was, and is more often becoming a chronic illness (White, 2007). Because of this, more attention is being focused on quality of life (QOL) and long-term outcomes of cancer survivors (American Cancer Society, 2014). As cancer research has begun to shift its focus to quality of life and adjustment to life with a diagnosis, issues related to sexual quality of life (SQOL) have been identified as primary stressors for both patients and their partners across cancer types and phases of illness (Cormie et al., 2014; Manne & Badr, 2008; 2010; Manne, Badr, & Kashy, 2012; Wilmoth, Hatmaker-Flanigan, LaLoggia, & Nixon, 2011).

Literature has acknowledged both the importance of incorporating sex and intimacy based conversations into the cancer treatment process, as well as prioritizing dyadic accounts as to how cancer is experienced (Traa, De Vries, Bodenmann, & Den Oudsten, 2014); however, despite this knowledge, relatively scant literature has privileged dyadic accounts of the cancer process, and even less research has explored how dyads are experiencing sexual quality of life with a cancer diagnosis (Hughes, Hertlein, and Hagey, 2011). Thus, this qualitative study seeks to explore the primary question: What practices are couples utilizing in order to negotiate sex and intimacy amidst a cancer diagnosis? Through answering this question, the study will gain authentic accounts as to the lived experiences of couples that are negotiating sex and intimacy amidst a reproductively centered cancer diagnosis while also privileging both patient and partner voices. Further, this study seeks to gain better understandings as to how healthcare practitioners across disciplines can provide more competent and collaborative care to foster relational and holistic outcomes.

## Background

### *Cancer as a Chronic Illness and Survivorship*

There are currently 15.5 million Americans living with a history of cancer, as of January 2016 (American Cancer Society, 2019). This number of overall survivors represents approximately 4.8% of the American population (National Cancer Institute, 2018; American Cancer Society, 2019). Further, according to the American Cancer Society (2019), 1.7 million new cases of cancer are projected to be diagnosed in 2019. As this study is exploring women with breast and gynecologic cancers, it is crucial to acknowledge that breast cancer is the most frequently diagnosed cancer among women with 268,600 new cases projected in 2019, while 110,070 new cases of gynecologic cancer were diagnosed among women in 2018 (American Cancer Society, 2019).

Although cancer remains a leading cause of death (second to heart disease), the death rate has declined by 27% since 1991 (American Cancer Society, 2019). Overall, reproductively related cancers typically have very high survival rates, which often designate these cancers as chronic illnesses (National Cancer Institute, 2018). For both breast and gynecologic cancers, if caught in early stages (0-2), have above a 90% survivorship rate of five years or more (National Cancer Institute, 2016). Due to increasing survivorship, it is important to consider what this may mean as to cancer's impact on SQOL and for the couples surviving them. Recent studies have confirmed this need as both gynecologic and breast cancer survivors reported among the highest for sexual dissatisfaction during and after the cancer process (Almont, 2018).

### *Chronic Illness and Quality of Life*

Cancer has historically been a topic largely focused on acute phases of cancer, and therefore, biological components of treatment and research have been prioritized and mainstreamed. As the rate of survivorship continues to increase, however, current research has consequently begun to take more serious interest in psychologically related consequences posed by a chronic illness diagnosis (Colby & Shifren, 2015). Additionally, because cancer research has most often focused on patient outcomes, intimate partners, who also commonly double as caregivers, are left completely neglected (Jonsdottir, Jonsdottir, & Klinke, 2018; Badr & Krebs, 2013). Both patient and partner then find themselves needing to rediscover and redefine their identities and relationships that incorporate cancer's long-term presence and lingering effects.

The nature of cancer is chronic for many; therefore, especially couples find themselves grappling with numerous changes to their once familiar relationships with sexual quality of life being deemed among one of the most important, especially regarding reproductive related cancers (Jonsdottir et al., 2016). This leaves couples susceptible to negative relational and psychosocial side effects. Bal, Yilmaz, and Beji (2012) attest to this, as they have found that healthy intimate and sexual identities have been an essential antidote in combating many of cancer's negative side effects. By prioritizing intimacy and sexual health, couples are able to produce various positive outcomes including positive associations with ones body, higher levels of individual and relational self-esteem, and overall positive adjustment to the cancer experience (Altschuler, 2015). Patients often report that they do not experience illness as an individual or singular process, but rather, couples often experience cancer as a unit (Traa, De Vries, Bodenmann, & Den Oudsten, 2014). This means that patient adjustment outcomes can be are often significantly influenced by how their partners are also experiencing cancer (Jonsdottir, Jonsdottir, & Klinke, 2018). Despite this knowledge, as confirmed in current literature, dyadic studies that include both patient's and their partner's voices are practically non-existent. This study finds it appropriate and necessary to then examine and explore the shared lived experiences of these couples by collecting and analyzing dyadic data.

### *Sexual Quality of Life in Oncological Research*

It is widely known that cancer has been a historically medically focused disease, and therefore medical domains have dominated what we know surrounding all facets of the cancer experience. Sex and intimacy are also often predominately researched from biological perspectives (i.e. sexual dysfunction), in which psychosocial and relational aspects of sexual quality of life are frequently neglected (Huyghe, 2016; Hyde, 2006; White, 2008). Mental health research can fill this gap in the literature by contributing new understandings of not only patient experiences with cancer, but by including dyadic data that accounts for the relational influences on patient adjustment.

As the need to address SQOL has steadily progressed in oncological literature, the term "oncosexology" was coined in 2002 (Gianotten, 2003), and the field of oncosexology arose. Research across disciplines (e.g. nursing; clinical psychology;

family science) have begun to not only recognize sex and intimacy as a part of quality of life concerns, but have also continuously confirmed that patients find conversations surrounding sex and intimacy as important aspects of their care (Almont, 2018; Cormie et al., 2014; Jonsdottir, 2015; Wang et al., 2013). The field of oncosexology is novel, but needed in order to inform clinicians and patients alike as to various interventions that may help both normalize individual and relational experiences with illness, while also minimizing the psychosocial impact cancer often takes on their hosts and partners.

As oncosexological research is scant, especially so in the United States, internationally based research is being done and making significant contributions to the field. Ussher et al., (2013), an Australian based research team for example, speak to the idea that cancer forces meaning making negotiations, in regards to constructions of femininity and masculinity within reproductively based cancers (Gannon, Guerro-Blanco, & Abel, 2010; Olson, 2015; Ussher et al., 2013; Ussher, Perz, Gilbert, Wong, & Hobbs, 2013). They have also consistently found the importance of treating oncology patients relationally by incorporating and privileging partner influence (Brandao, Schulz, & Mena Matos, 2013; Ussher, Perz, Gilbert, Wong, & Hobbs, 2013). For those in relationships, meaning making negotiations of oneself is an often, symbiotic process. Ussher, Perz, Gilbert, Wong and Hobbs (2013) best articulate this issue as they state:

> Although there is a growing body of research examining psychosocial correlates of changes to sexuality after cancer, including the influence of relational context, little attention has been given to renegotiation of sexual practice or intimacy, which has led to a plea for research examining successful strategies used by couples to maintain sexual intimacy in the context of cancer…there is a need for further research on sexual renegotiation after cancer, from the perspective of both people with cancer and their partners, across a range of cancer types (p. 455).

It is clear that in order to truly capture what quality of life may mean to patients, as well as how patients perceive obtaining positive psychological outcomes, researchers must consider the embodiment of the intimate relationship, which would inherently include both patients and their partners (Barlow, Hacker, Hussain & Parmenter, 2014). Family sciences, and related mental and behavioral health fields, can contribute to oncological research in this way.

### *Sexual Quality of Life and Healthcare Practitioners*

The last crucial component within oncological literature is understanding the role of the clinician. Just as primary caregivers/spouses have been found to heavily influence patient's psychological adjustment outcomes to illness (Badr & Krebs, 2013; Hagedoorn, 2008; Traa et al., 2014), clinicians also act as influential figures as to how patients learn to make sense of, prioritize, and negotiate their intimate relationships (Fitch, Beaudoin, & Johnson, 2013; Hughes, Hertlein, & Hagey, 2011; Penson et al., 2000). McDaniel, Doherty, and Hepworth (2014) speak to this as they argue that a primary reason clinicians are not bringing up topics of sexuality is due to embarrassment and the vulnerable nature of this topic. It is unfortunate, that more often than not, healthcare providers are not initiating these conversations. Moreover, family therapists often neglect both initiating and engaging in SQOL conversations despite the need for therapeutic facilitation, and the repeated desire to address SQOL needs (Fitch, Beaudoin, & Johnson, 2013; Loaring, Larkin, Shaw, & Flowers, 2015; van der Riet, 1998; Wang et al., 2013). Unfortunately, behavioral health clinicians have repeatedly reported that they do not feel knowledgeable, comfortable, or confident enough to speak to or treat SQOL concerns, which has created a significant barrier to this aspect of care (Fitch, Beaudoin, & Johnson, 2013; Jones, Johnson, Wenglein, & Elshershaby, 2018; Jonsdottir et al., 2016; Juergens, Smedema, & Berven, 2009; McDaniel, Doherty, & Hepworth, 2014; Ussher et al., 2013; Kazukauskas & Lam, 2010); this, coupled with the lack of research in this area, sustains the continuance of underserving our patients in this area.

## Method

### *Research Methodology*

Interpretive Phenomenological Analysis (IPA) (Smith, Flowers, & Larkin, 2009) was the methodology used to guide the data collection and analysis of this study. Although newer than some of its phenomenological counterparts, IPA contains unique and necessary characteristics that made it an appropriate choice for this study. Firstly, this approach is rooted in psychology (versus another field, which is then adapted to the social sciences) and was created with the specific intention of exploring and understanding the meaning making processes and lived experiences of its participants (Smith, Flowers, and Larkin, 2009). IPA is a phenomenological approach, which means that it seeks to explore participant's experiences and relationships with a particular phenomenon; however, it also emphasizes the subjective and interpretive nature of not only our lived experiences, but the experiences of research as well (Pringle & McLafferty, 2011). IPA makes explicit the inherently hermeneutic process, or "double interpretation," of research in that it recognizes that not only are participant's accounts of their experiences interpretations of their own lives, but that the researcher also takes an interpretive role in data collection and analysis.

For this research study, the two primary topics were regarding illness and sexual quality of life. IPA is an appropriate methodology as it became established in the field of health psychology in which sex and sexuality are a key area of IPA research (Smith, Flowers and Larkin, 2009). Further, IPA is an approach that utilizes research to respond to cultural norms that create meaning for its participants and "is particularly suited to researching sex and sexuality in that it can challenge understandings which are based around 'othering' people, or medicalizing and pathologizing behaviors" (p. 143). This point is especially salient for those diagnosed with cancer as not only are the participants interacting with the phenomenon of cultural understandings of sex and intimacy, but also through the lens of their illnesses. Overall, IPA is an appropriate methodological approach in privileging patient voices in order to understand how to make empowered decisions about their lives as it is impacted by a particular condition.

### ***Subjectivities***

Because IPA is interpretive in nature, it is important to be transparent and explicit about the setting and context of both the data collection site and the researcher herself. The researcher is a Latina/Chicana, 5th year doctoral student studying marriage and family therapy at a private religious academic medical institution in the southwest United States. The researcher works as a Medical Marriage and Family Therapist at the institution's cancer center from which the data was collected; however, none of her own patients were recruited for this study.

### ***Participants***

The participants consisted of six couples (six female patients and six male partners totaling 12 participants) that received care from the local medical institution. Participation criterion was set in order to understand the cohesive experience of a particular group of people as in line with the IPA methodology (Smith, Flowers and Larkin, 2009). In this case, women with reproductively related cancers with male partners were the targeted population. Of the six couples, four were married and two were not. All participants were heterosexual and over 18 years of age. The ages of the couples were varied with the youngest couple both being 28 years old, and the eldest couple being 67 years old (partner) and 59 years old (patient). Although the hospital is religiously affiliated, the patient population is varied. It is important to note that all participants in this study identified as Christian with one couple specifying their denomination as Catholic *(See Table 1).* Additionally, in regards to the classification of cancer diagnoses, of the six couples, five were gynecological, and one was breast; although the study garnered predominately gynecological cancers, the type of cancers varied across women. Similarly, the stages of each cancer also varied between one and three; none of the patients were in stage four.

**Table 1.** Demographics.

Dyadic Demographics of Patient and Partner Participants (n =12)

| Participant | Age | Ethnicity | Religion | Marital Status (years together) | Type of Cancer | Staging |
|---|---|---|---|---|---|---|
| Patient 1 | 59 | Native American | Christian | Married | Endometrial | Stage 1 |
| Partner 1 | 67 | White | (non-specified) | (40 years) | | |
| Patient 2 | 28 | Hispanic/White | Christian | Married | Cervical | Stage 2 |
| Partner 2 | 28 | Asian/White | (non-specified) | (7 years) | | |
| Patient 3 | 44 | Hispanic/Native | Christian | Committed | Cervical | Stage 2 |
| Partner 3 | 41 | Hispanic | (non-specified) | (4 years) | | |
| Patient 4 | 45 | White | Christian | Living together | Cervical | Stage 3 |
| Partner 4 | 41 | Hispanic (other) | (non-specified) | (17 years) | | |
| Patient 5 | 49 | Hispanic | Catholic | Married | Ovarian/Uterine | Stage 1 |
| Partner 5 | 53 | Hispanic | (non-specified) | (34 years) | | |
| Patient 6 | 48 | White | Christian | Married | Breast | Stage 3 |
| Partner 6 | 51 | White | (non-specified) | (5 years) | | |

### ***Recruitment***

Due to the sensitive nature of the interview, the vulnerable population to be recruited, as well as the dual role the researcher held during the time of recruitment (current Marriage and Family Therapist and lead investigator), the IRB and the research team determined the most ethical avenue for recruitment.  In order to protect patient confidentiality, the recruitment process was limited to either medical staff referral or self-referral via posted fliers. Although discussed further in the limitations portion of this paper, it is appropriate to acknowledge that the recruitment method may have contributed to limiting the types of couples willing to participate in this study.  For example, through staff referral, it was found that although patients would express interest in the study, their male partners would not agree to participation. Thus couples that did self-refer may be reflective of couples that already maintain a certain level of comfort with the research topic, and within their relationships.

The inclusion criteria were for female patients who were over the age of 18 in self-identified meaningful, monogamous, and heterosexual relationships, who were diagnosed with a reproductively related cancer (gynecological and/or breast cancer). Patients and their partners could not be past or present patients of the researcher.  If potential participants were interested in the study, the researcher would follow up with that couple to screen for appropriateness, and answer any questions about the study they may have. Participants were given a $10 gift card for their participation.

### ***Data Collection***

Once participants were screened and approved for the study, participants were given an informed consent in which the risks and benefits of the study were thoroughly explained. Interviews were done in English and participants (both the patient and their partner) participated in an hour-long, dyadic, face-to-face, semi-structured interview that was audio recorded and later transcribed verbatim. Examples of questions that were asked are: “How would you define sex?” “How would you define intimacy?” “Did your sexual quality of life change after being diagnosed with cancer? If so, in what ways?” “Is sex equally important now as it was before cancer?” “In what ways do you express intimacy when intercourse is unable to happen?” The student researcher was the only person to conduct these interviews.

### ***Analysis***

Utilizing the IPA methodology, analysis was performed as described by Smith, Flowers, and Larkin (2009). IPA holds an emphasis on small case-by-case sample sizes as the researcher is meant to engage in a thorough, iterative and inductive analysis of each case and then across cases (Smith, Flowers, & Larkin, 2009; Smith& Osborn, 2008). Although the analytic process is flexible, the authors describe and detail six steps that serve to guide the researcher. Those six steps are: (a) reading and re-reading; (b) initial noting; (c) developing emergent themes; (d) searching for connection across emergent themes; (e) moving to the next case; (f) looking for patterns across cases. These steps were followed for each case and across cases by the researcher.

As IPA recognizes the interpretive nature inherent in researching, numerous measures were taken to ensure trustworthiness and credibility throughout the data analysis phase. During initial noting, the recorded interview audio was used to guide the researcher to interpret and interact with transcripts throughout the process. As themes began to emerge, the researcher utilized extensive memo note taking to ensure any possible bias was addressed and minimized. Further, a research assistant engaged in the same process as coding was done separately along with corresponding memo note taking to reduce bias. Additionally, all coded and de-identified transcripts were sent to the original participants to ensure that coding interpretation and analysis was reflective of their experiences and that their words were accurately understood. Transcripts and preliminary data analysis were sent to all six couples in which five responded; participants stated that their data was accurately interpreted and were satisfied with all stages of coding. Through collaboration with the participants and a research assistant the results were finalized.

## Results

This section will be used to explore and describe the primary question of this study: What practices are couples utilizing in order to negotiate sex and intimacy amidst a cancer diagnosis? The analysis produced three themes and those themes are: increasing intimacy, relying on prior values, and sharing responsibility. Each of these themes is supported by sub-themes, which will be outlined throughout this section.

## *Theme 1: Increasing Intimacy*

Of the three themes, increasing intimacy was the most common practice that couples engaged in to negotiate their sexual quality of life while enduring cancer together. Often times the act of sexual intercourse became a lost option, especially while the women were in active treatment for their cancers, and even post-treatment as well. When intercourse was no longer an avenue that couples could use to express their closeness or love for one another, implicit negotiations occurred between couples in which they sought intimacy in other ways.

### **Sex and Intimacy as Separate Terms**

Every dyadic interview started with two questions: "How would you define sex?" and "How would you define intimacy?" Across all couples, sex was defined as the physical act of intercourse. The term intimacy was described slightly differently across couples, but there was a common consensus that although intimacy was a component of sex, the term itself was independent of intercourse. As one of the patients described the difference between sex and intimacy, she stated, "They [intimacy and sex] go hand in hand…[but] we definitely can have intimacy without sex for sure" (P2).

As sex was described as "intercourse," the term intimacy was defined in numerous ways across participants. Some examples of intimacy were described as: "being together," "cuddling," "sharing," "love," "beyond the physical," "kissing and hugging," "showing each other affection," "desire," "a bond," "playing together," "anything leading up to the sex," "romance," and "an interaction with each other." These examples were taken from all six couples in which some of the terms were shared by multiple couples, while others were unique to each couple; however the overall essence of intimacy seemed to be a special connection that was shared and reserved solely for the couple themselves.

## Intimacy Increases as Sex Decreases

Although natural negotiations took place between each couple, none of the couples reported having an explicit conversation as to how they would negotiate sexual quality of life when sex was no longer able to happen; yet, every couple was able to adapt to the sexual and intimate changes that cancer demanded of them. During the interview every couple was asked if they found sex and/or intimacy to be more or less important to them since being diagnosed with cancer. It was found that the importance of the role of sex decreased, especially for the women/patients, while simultaneously the role of intimacy significantly grew across couples. Although both women and men expressed their grief for their past sex lives, intercourse as a whole became insignificant, while the goal of staying alive and maintaining togetherness became central for these couples.

The data supported this as it continued to find that as the role of sex decreased, the role of intimacy increased. Although this study attracted couples that were already overall strong couples, many of them reported finding even more closeness by enduring the illness together. Closeness, a bond, and admiration for the other are all examples of forms of intimacy that were increased despite the decrease of sex. One partner, for example, reported, "…the bond has become more important I would say. I think our bond is probably as strong as ever maybe…we definitely have a bond that's holding us together” (P6). Another partner affirmed intimacy’s role as an integral part of surviving cancer together as he stated:

> I think intimacy is what got us through it. That was our rock. The intimacy, you know going through this stuff, our intimacy with each other…that’s what makes us say were going to take care of this were going to do it were going to go for it (P1).

Lastly, it is important to observe that while some couples may use sex as a barometer to determine the quality of the relationship, these couples broadened their ideas of sexual quality of life and intimacy. As one partner simply put it, “So…sex. We’re saying sex. Boom were saying our thing is physical. Boom. Physical ain’t jack. Physical ain’t nothing…. maybe that starts the ball rolling, but the intimacy’s a whole different ball game” (P1).

### *Theme 2: Relying on Prior Values*

As previously mentioned, the relational roles in regards to sex and intimacy came organically, and were never explicitly negotiated. As intercourse became rare, if occurring at all, couples had to not only find ways of staying connected to one another, but also remain dedicated to the relationship without sex, which the couples reported was their primary way of expressing love, desire, specialness, and attraction, prior to cancer. In lieu of a familiar sexual quality of life, the data uncovered that couples heavily relied on their value and belief systems to remain dedicated to the relationship through cancer. The two central values that emerged from the data were mostly derived from personal religious beliefs and gender role expectations.

### Religious Beliefs

All couples within this study identified as devout to a particular religion. The faith that each person held, significantly contributed to the motivation and sustainment of dedication within the relationship or marriage. One partner described his values as informed by religion as he described:

> I think a lot of this has to do with me as a person, and my beliefs, and my religion, and stuff like that because she... because a lot of people struggle through this. For me, I made a commitment to her in front of my family and God and stuff like that. I feel like I would almost be not only deserting her but deserting who I am. (P2).

His wife affirmed this sentiment as she articulated that sexual quality of life extended beyond the physical act of intercourse in their marriage; both intimacy and spirituality were crucial in maintaining shared values and togetherness. She shared:

> Oh, absolutely…bring [God] in, plus the cancer. You…have to view your sex life from a biblical perspective, because if you don't it's very easy to wander, let your mind wander, let fantasies start happening and things like that, or just having sex and focusing on, 'I need an orgasm. I want an orgasm.'"

Due to cancer's ability to threaten intimacy between couples, she and her husband leaned on their religious beliefs in order to remain mindful as to the intention sex and intimacy hold for them as a couple. Similarly, another patient turned to her religious beliefs in order to remain both empowered over her illness, while remaining close to God and her husband. She expressed, "I think intimacy is the bond that connects a man and a woman and I think that was created to for the purpose…to love one another and create that bond that God wanted us to have" (P6).

## Gender Expectations

The other characteristic that seemed to be common across couples was the role of gender in a relationship and how it guided interaction with one another. Many of the women, for example, operated the way they did based on their perceived notions regarding men's needs for sex. One patient stated:

> I think this is so important, because, for a man, that is a huge part of, and when they're not physically sick, I can see how that could affect them, and then lead to looking at porn and all these types of different things that then can lead to infidelity and then separate someone. (P2).

Contrarily, the men reported that sex was not nearly as important to them as assumed, but rather it was their responsibility as men to support their female counterparts during and after the cancer. One patient attested to this as she explained her fear of her husband possibly leaving her for her inability to engage in intercourse, but to her surprise, he did not. She shared, "…and [he's] like 'no, I'm not going to do that to you—I want you to heal' you know, and he just… you know; he was...very kind" (P1). Many of the partners validated this sentiment. One partner expressed:

> We have to be able to recognize, me as... as, as a man, and not being the patient, that she's first, because she's the patient, not me. Me as a man, I can do [things] myself…and just protecting her…that she doesn't feel mistreated. (P5).

He continued to explain, despite lacking a more traditional sex life, his sexual needs come second to his wife's biological needs, and that "as a man, I have to respect that."

### *Theme 3: Sharing Responsibility*

The last theme that emerged was that of shared responsibility. It is important to differentiate that "sharing responsibility" was not a singular event in which a particular responsibility was shared between the couple; rather, there were two separate, yet symbiotic, processes occurring in which each partner showed their engagement to the illness and relationship.  To elaborate, shared responsibility was motivated, and thus enacted, differently between the female patients and male partners.  The females, for example, found themselves feeling the need to maintain normality within their marriages; therefore, their sense of responsibility lied within upholding their roles as wives or partners in order to prevent being totalized by the illness.  For the males, their sense of sharing responsibility was to learn how to take on the role of caregiver in order to ensure a joint experience of the illness and that the women did not feel alone.  It was apparent that although shared responsibility was its own theme, the roles each partner adopted were different between the men and women.

### Female Patient's Upholding of Partnership

As the women in these couples were the ones diagnosed, many of them felt responsible for the changes occurring within their families and marriages; this was especially true regarding sexual quality of life, or the lack there of.  Although in some ways it proved to be a strength within the marriages that the women perceived the responsibility in taking care of their husbands emotional and physical needs as a mutual one, it was also an attribute that was detrimental to the women as well.  The women often internalized the burden of blame as to the reduction in (or ceasing of) intercourse frequency, among other marital changes.  Due to this perception, the women developed a sense of obligation to their partners in which they would often sacrifice their bodies and endure excruciating pain to follow through with the act of intercourse in order to fulfill these perceived obligations to their male partners.  One patient detailed her obligation to engage in intercourse, as she recounted:

> Anytime we have intercourse I get cuts and so I just don't even want to and I try to because I know that men have needs and he has needs. And so every, I would say like once every month or six weeks we'll try intercourse and I would grant him and bear it, but it's never without a lot of pain... essentially I mean, and then even just on the times when we can be intimate, I have to…it's like a process, it's like, I mean suiting up for a blizzard. (P6).

Another patient validated this sentiment as she voiced her fears as to the possible consequences of not being able to give her husband intercourse due to her cancer.  She explained, "We ain't having sex. If we ain't doing anything, how long is he gonna hold on? Or is he gonna be like, 'She's gonna get worser. I'll just find somebody else'" (P3).

Although it seemed that perceived obligation was the predominant catalyst in convincing the women to engage in intercourse with their male partners despite their own pains and discomforts, the motivation behind these obligations was actually a strength to the couple.  The women often acknowledged their partner's need for reciprocated caregiving, versus feeling entitled to being cared for without giving anything back to their partners.  Beyond intercourse, patients often expressed verbal affection, other forms of physical intimacy (i.e. cuddling, kissing, holding hands) as a means of gratitude.   It is important to note that although the mutual responsibility was appreciated, once the perceived obligation became explicit as a motivation for intercourse, partners often would encourage their female counterparts to cease engaging in any activity that may cause pain or discomfort.

As seen through these examples, the mutual responsibility the women upheld was both positive and negative.  It was positive in the sense that partners also need to be taken care of during a time of illness; however, it was negative in the sense that unbeknownst to the male partners, the women’s own sense of self-blame often encouraged the women to uphold a sexual standard at the sacrifice and health of their own bodies. It is necessary to make this process explicit both for the couples as well as the Marriage and Family Therapist (MFT) as it will serve to be a crucial point of intervention.

**Male Partner’s Adaption and Responsibility to Illness**

As the women utilized sex and intimacy to attempt to maintain a sense of normality and familiarity within the couple, the men found themselves learning to take on an additional role, which was to be both a husband and caregiver. As the women attempted to not be totalized by their cancer by keeping sex and intimacy as unchanged as possible (among other partnered duties), the men attempted to share their relationships or marriages with the illness by acknowledging and adapting to the changes cancer posed on them. One partner described his perception of the shift in sexual quality of life as he stated, “For me, sex wasn't even a thought. It was just my main concern was her health and making sure that she was okay, not just physically, but emotionally” (P2). Another couple spoke to this shift as not only happening during treatment, but after the cancer was biologically over. One female patient described her experience in beginning a hormone therapy that was intended to reduce the risk of a cancer reoccurrence. Consequently, this medication also caused severe vaginal dryness, which then inhibited the ability to resume intercourse. The patient described this scenario, and shared how she would have chosen to take the risk rather than to position her husband in having to choose to adapt to the illness over a “normal sex life.” She stated:

> And so I've said, I don't want it, why don't we just give up on the hormone therapy…and he's never once even wavered like, ‘Yeah, I think sex is more

> important than your life.’ So I really appreciate that. I really, really appreciate that. (P6).

The patient turned to her husband and continued, “I mean that and, I don't tell you that, but I really appreciate that, but I mean I wish I didn't have to keep doing this just to stay alive.” Despite the wife’s willingness and desire to maintain a “normal” sex life, the husband adapted to the changes cancer had imposed onto their sexual quality of life.

## Discussion

As current literature has found, addressing sexual quality of life is crucial for both patients diagnosed with cancer and their partners (Loaring, Larkin, Shaw, & Flowers, 2015; Ussher, Perz, Gilbert, Wong, & Hobbs, 2013). Repeatedly, patients have spoken to the importance, yet neglect, of sexual issues within cancer populations (Jonsdottir, et al., 2016; Wang et al., 2013). Further, research has found that partner’s influence on patient adjustment and overall wellbeing is significant yet virtually non-existent within oncological literature (Altschuler, 2015; Hughes, Hertlein, and Hagey, 2011). In answering this need, the purpose of this study was to then understand how couples negotiate sexual quality of life amidst a cancer diagnosis by exploring the practices they engage in. The research uncovered that although none of the couples engaged in explicit conversations regarding these negotiations, through the above themes, every couple collaborated as a dyadic system to find solutions that not only helped them endure cancer together, but stay dedicated, connected and bonded throughout. Sexual quality of life for these couples changed meaning as it shifted from a more intercourse-focused perspective to intimacy-informed one. Although the term “intimacy” was unique to each couple, the research uncovered that how intimacy was defined and expressed was heavily dependent on the dyad's already existing strengths and unique creativeness, as they were forced to utilize intimacy in ways they did not have to when intercourse was still an option for expression of love, attraction, and connection.

## *Clinical Implications*

Within this research study, it was imperative to explore clinical implications, not only from the data collected from the researcher's questions, but also from the perspective of the participants as well. All research interviews ended with a small set of questions that allowed couples to provide open input as to what they felt would better help future couples negotiating sex and intimacy once they have been diagnosed with cancer. Based on the participant's own experiences, successes, and challenges, the dyads offered many suggestions; however there were two primary recommendations that were given across all dyads. The first recommendation was for the couples themselves in order to remain better connected and cohesive throughout their journeys with cancer, while the second proposal was for the healthcare team to take a more holistic and whole person approach.

### Couples

For the couples, the dyads had suggestions to get through cancer as bonded as possible. They warned that these suggestions were merely opinions, but came from a place of learning from their own unique challenges. The women/patients offered recommendations to both patients and partners. For future patients they emphasized that it was important to appreciate their partner and to recognize that the partners are also experiencing the illness through the patient. Although different, it is important to avoid neglecting or minimizing the partner’s experiences. For the partners, the patients begged for future partners to be patient with the patients, especially in terms of sexual quality of life. One couple’s conversation began with the husband/partner saying:

> Be there for them [the patient], help them with their needs, make sure that they know that they're loved, and that you appreciate them and try and help them with whatever you can…And complement them still so that they know that you find them attractive and loved and they're still your husband or wife and you love them so much and yeah stay committed to them. (P6).

His wife affirmed this message and also shared to other future patients, “I think I have had to reassure him that it is the medication- [and not him].

The partners also offered wisdom to future patients and partners. The central theme was that partners should be understanding, patient, and not afraid to ask their significant others questions. They offered that future couples need to communicate with honesty and transparency in order to maintain their sense of togetherness and integrity. One of the male partners detailed:

> All communication [is necessary]. What is my concern as a partner, and what am I concerning you as a patient? What do I need to know about your illness, and what you need to know about what I'm gonna be going through. How long's it's gonna take? What they're gonna do. What is going to happen? What time? Do we want to let the family, uh, know? Do we wanna let our kids know? Those are things that we went through… (P5).

Another partner shared the same sentiment as he simply said, “Communication was probably the biggest one, just on my end because I deal with things a lot differently than she does” (P3). Lastly, one patient reminded us that responsibility for communication is also that of the patient as she affirmed, “Yeah. You have to ask what the other person needs, wants, [and] feels” (P4).

## Integrating Behavioral and Medical Health

Congruent with past and present literature (e.g. Engel, 1977; McDaniel, Doherty, & Hepworth,2014; Rolland, 2018; Williams-Reade, Freitas, & Lawson, 2014) this study also found that psychosocial-spiritual needs are prevalent among patients and their families enduring chronic illnesses. It is long overdue that MFT's be incorporated in multidisciplinary healthcare teams to address the systemic and relational needs of oncological patients. The dyads within this study spoke to this through their own recommendations for their healthcare teams that they felt would provide more cohesive and holistic care. Across dyads, both patients and participants agreed that sexual quality of life was an important issue to discuss; however, all couples shared that although they believe a space should be initiated by the medical doctor to discuss sexual related concerns, they did not want these conversations happening with their doctors. The need for a behavioral health team member is expressed by one patient as she describes the conversations she attempts to have with one of her doctors. She says:

> I honestly think she is really one of the most compassionate doctors I've ever seen; however, it's just like you have to put on your researcher hat…she has to put on her doctor hat and I tell her, I'm like, "Look, I feel depressed. I have gained 15 pounds. I don't feel like my body looks the same or looks like it used to. I don't like it…Anyways, long story short…I tell her my intimate life, it's no good, but she can't recommend that I don't take the medication…she suggested that I go to my OB…She's sad for me, but she can't do anything about it. (P6).

Couples recognize that each discipline has its expertise, and it is therefore necessary to bring in a behavioral health professional that has time and knowledge to help this area of cancer care. As another simply put, "It's not an issue with [the doctors]… It's not a medical issue" (P4). Couples expressed that they were open to the therapist working alongside the medical team, but made it clear that the medical doctor should focus on healing the cancer, while the MFT, or related behavioral health professional, would focus on the psychosocial and spiritual aspects of care. Lastly, patients and their partners disclosed that they felt it was the healthcare team’s responsibility to initiate an option for discussing sexually related concerns, but it should be up to the couple to initiate a follow up for that discussion to honor patient autonomy.

## MFT Points of Intervention

Emerging literature renders a call for action to behavioral health practitioners as psychosocial interventions for patients and their families living with chronic illnesses need to be addressed and implemented (Rolland, 2018). The participants in this study expressed that MFT’s in particular play a crucial role in patient care and adjustment outcomes as they address not only the patients themselves, but also the systems and relationships that they are a part of. There are various points of intervention that MFT’s can apply in therapy with their patients to tend to some of the needs expressed by couples negotiating sex and intimacy while enduring cancer. MFT’s working with chronic forms of cancer and its impact on sexual quality of life should consider the practical application of the following interventions: (a) encouraging explicit and transparent conversations between patients and partners; (b) acknowledging and normalizing the possibility of decreased intercourse; (c) assisting couples in defining intimacy that is unique to themselves, while identifying new ways of being intimate as they adapt to the changes the cancer may pose on their SQOL; (d) externalizing the cancer from the patient and encouraging shared responsibility over the illness; (e) participating in integrated healthcare to ensure more holistic outcomes that cater to the biopsychosocial and spiritual needs that couples may present.

## ***Limitations and Future Directions***

This research study had some noteworthy limitations. The first limitation is regarding the participant sample itself. All of the couples within this study exemplified various successful negotiations regarding adaptions to the illness and their sexual quality of life, despite reporting that no explicit conversations regarding these negotiations were had. All of the couples within this study experienced naturally occurring negotiations that maintained their closeness through the illness process, which may not be representative of all couple's experiences. Because the processes of negotiation within this study were often implicit, future research may aim to generate more explicit negotiation procedures and understandings.

The second limitation is regarding the recruitment criteria itself. As this study sought patients with fairly positive prognoses, it may have limited the types of couples who applied to participate in this study. Further, due to the vulnerability of the participant population, the sensitive nature of this research topic, as well as the naturally occurring negotiations that existed within this sample, it is appropriate to consider that the types of couples that were willing to participate in this study may embody particular strengths, or may have already engaged in explicit meaning making processes in which other couples may not have. Further, couples who are grappling with less positive prognoses may bring fourth other relational challenges that were not explored within this study. Lastly, the criterion that did not allow the researcher's own patients to participate in the study may have also contributed to this limitation, and future research may benefit from exploring couples in therapy in order to be exposed to other possible challenges and barriers that may exist in couples seeking to improve their sexual quality of life.

The second area of limitation was the lack of diversity within the sample, both in terms of ethnic diversity and diversity across cancer type. It is important to note that this sample, in terms of religious identification and ethnicity is representative of the local research area, but not necessarily the United States at large. Although IPA methodology does call for a homogenous sample, future research would benefit from recruiting from a wider racial and faith/non-faith based population. In regards to illness, the study sought to explore the experiences of both gynecological as well as breast cancers; however, due to limitations in recruitment, the study sample trended toward gynecological cancers. Because the researcher was not permitted to recruit patients directly (in order to protect patient confidentiality) the recruitment predominantly depended on medical staff participation and referral. Due to unknown variables, gynecological medical staff garnered more recruitment than the breast clinic staff. Lastly, it is important to note that no analysis was done in order to understand if differences in experiences and perception of sexual quality of life differ between stages. Future IPA studies may wish to incorporate this analysis to ensure further homogeneity of the sample.

Lastly, it is necessary to highlight that although this study explored the narratives of female patients with male partners, future research may want to explore other couple types (e.g. same-sex couples or male patients with female partners); changing the sample demographic may produce different outcomes and uncover new needs that are reflective of that participant pool. Additionally, as previously mentioned, because much of negotiation processes are implicit, future research may also consider including an individual component along with dyadic data collection. For example, the researcher may want to collect both dyadic and individual accounts in order to gain more in depth understandings of both the relational and individual processes of negotiation that may not be shared during a dyadic interview.

## Conclusion

Within oncosexologocial research, dyadic data collection is virtually non-existent. The purpose of collecting data dyadically was to witness and understand the shared experiences, negotiations, and meaning making processes that exist within the couple's interaction as both illness and sexually related challenges tend to exist relationally and are not exclusive to the individual partner (Baik & Adams, 2011; Hawkins et al., 2009; Kayser, Watson, & Andrade, 2007; Rolland, 2018). The research found that cancer significantly impacts sexual quality of life, and although none of the couples reported explicit conversations, organic and implicit negotiations were made across couples to accommodate for the changes cancer posed on them. Primarily, couples found that their need for intimacy increased as their ability to engage in intercourse dissipated. Both patients and partners also found themselves negotiating role expectations, which were primarily motivated by prior existing values or other societal discourses. Lastly, this study reveals the critical need for research to move forward by utilizing a multidisciplinary approach. Through integrated healthcare, teams can maximize impact in supporting the biological psychological, social, and spiritual challenges cancer poses on patients, their partners, and their sexual quality of life.

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# CHAPTER SIX

## IMPLICATIONS AND DISCUSSION

The literature has remained consistent in that, not only are conversations surrounding sex and intimacy are important aspects to a perceived satisfaction in overall quality of life, but also that patients have expressed wanting to discuss it as a part of what to expect during and after treatment (Wang et.al., 2013; Fitch, Beaudoin, & Johnson, 2013). This means providers, and especially MFT's, have the responsibility to learn how to assist couples in both negotiating the relational aspects of sexual quality of life (SQOL) needs, but also providing support in practical application.

Although more oncosexological research is needed to better serve our patients in this area, it is necessary to highlight a few discoveries that were uncovered within this study, that also support the current literature at large. These topics are important to address as they inform how healthcare teams can better address sexual quality of life concerns in future practice. Firstly, numerous studies (e.g. Ananth, Jones, King, & Tookman, 2003; Hawkins et al., 2009; Hordern & Street, 2007) have found that that patients feel the responsibility of initiating conversations regarding sexual quality of life lie in the hands of the healthcare provider. Ussher et al. (2013) also confirmed that patients often neglected to address sexual quality of life concerns, despite having the desire to initiate the topic, unless prompted by their practitioner. This was also uncovered and validated within this research study as well. Another significant discovery is that although oncological research is unanimous as to the importance of the role of the primary caregiver (who is most often a spouse or other close family member), scant research has privileged their voices in understanding patient's lived experiences, and perceptions to positive psychological adjustment to their illness. Moreover, despite current literature emphasizing the significant impact intimate partners have on patient's overall quality of life (Brandao, Schulz, & Matos, 2013), as well as the need to involve partners in future oncosexological research, (Hughes, Hertlein, and Hagey, 2011; Jonsdottir, Jonsdottir, & Klinke, 2018; Traa, De Vries, Bodenmann, & Den Oudsten, 2014), virtually no research in this area has followed through with these recommendations in which dyadic analysis was performed. Much of current research has continued to neglect partner voices in data collection.

This study served as a response to these calls to action in order to address the needs repeatedly requested by both researchers and patients across numerous studies as cited throughout this manuscript. Further, this study was able to ascertain beyond the importance of sexual quality of life concerns amidst a diagnosis, but also engage in the understanding as to the practical application for patients, partners, and the healthcare teams serving them. The subsequent sections in this paper will provide the following: summarize the findings of this study, provide a discussion as to the local and meta implications of the study, and it will also describe possible future direction, both in research and in practice, that are informed by the results of this dissertation project.

## Summarized Findings

This study was able to uncover understanding and practical application for three audiences: couples, multidisciplinary healthcare teams, and marriage and family therapists. For couples, the dyads in the study emphasized the need for open, honest and transparent conversations. This would allow couples to not only share responsibility over the illness, but it would allow the couple to negotiate shared solutions and to collaborate in understanding how to support each person within the couple. For the healthcare team, the dyads recognized the need for multidisciplinary healthcare teams, as cancer is a biopsychosocial and spiritual (BPSS) phenomenon. The patients felt that combining expertise would allow for all aspects of cancer to be treated, and more importantly, that these aspects are treated concurrently. Lastly, marriage and family therapists (MFT's) were recognized specifically in order to treat the systemic and relational needs of patients, which is highly important to SQOL concerns that involve both people (or more) in the relationship.

The results of this study also generated three main themes. They are: increasing intimacy, relying on prior values, and sharing responsibility. Each of the primary themes also generated subthemes that served to both deconstruct each primary theme, as well as to gain more in depth understandings as to the authentic, lived experiences and shared negotiations of patients and their partners. For MFT's especially, each of these themes is crucial in providing informed interventions and meeting the standard of care. Incorporating behavioral health components into medically dominated environments is still a novel movement, but the results of this study parallel the findings of current research in that the need to view cancer as a biopsychosocial-spiritual experience is necessary; this requires having multiple disciplines treating our patients. The findings of this study contribute to the current literature in that it not only echoes the current need, but also provides preliminary application and intervention that may be utilized by MFT's and other related behavioral health fields.

Lastly, the study also allowed for the privileging of both patient and partner voices in that they may provide their own clinical implications by drawing upon their own expertise based on their lived experiences. Additionally, based on the dyadic data collected, interventions for marriage and family therapists were identified. The relational and systemic nature of cancer makes the role of the MFT crucial. Points of intervention include: encouraging explicit conversations between patients and their partners, acknowledging the decrease of intercourse, assisting the identification and increase of intimacy in other areas beyond intercourse, and externalizing the cancer from the patient while encouraging shared responsibility over the illness.

## Meta Findings

There were three primary objectives of this study. They were:

1. To understand couples authentic lived experiences in regards to the negotiation of sex and intimacy with a cancer diagnosis.
2. To uncover if patients are experiencing their healthcare providers as operationalizing current literature recommendations surrounding the inclusion of sex and intimacy in oncological care.
3. To contextualize illness within psychosocial understandings by privileging the dyadic experience inherent in navigating sexuality with a chronic cancer diagnosis.

These objectives served to expand upon existing literature by providing a more in depth understanding as to not only the biopsychosocial-spiritual nature of cancer, but also highlighting the unique needs that reproductively related cancers pose on patients, their partners, and sexual quality of life. Further, this study sought to gain preliminary understandings as to what practical steps patients can take in negotiating SQOL amidst their diagnosis. As recommended by the literature, this study also evaluated the current treatment approach within the local institution in which the data was collected. This was done in order to gain understanding as to where research can be operationalized into practice in regards to any gaps in SQOL concerns in patient care. As supported by the data, patients reported overall satisfaction in their care; however, patients also vocalized the need for more holistic approaches to care, which would require more integration among a multidisciplinary team.

## ***BPSS and Multidisciplinary Care***

The BPSS perspective was found to be a central theme as reflected in the results of this study. It not only speaks to the complex nature of the cancer experience, but it also informs the need for a multidisciplinary approach, as well as the interventions that may be used for behavioral health clinicians serving this population. As articulated throughout the duration of this paper, and also confirmed through the results of this study, the researcher continues to hold the guiding belief that all problems are biological and psychological in nature. As emphasized by McDaniel, Doherty, and Hepworth (2014), there are no biological illnesses without psychological consequences, and the reverse is also true. This sentiment was strongly reflected through the data, and was found to be the primary basis for clinical implication. The dyads in this study acknowledged the unique impact cancer imposed on their lives as its chronic nature provided psychological, social, and spiritual challenges. As the couples found their relationships changing, implicit negotiations occurred as patients and their partners attempted to adapt to the illness. It is the hope of the researcher that the results reported through this study, which both support and contribute to current literature, might promote the advocacy for more proactive integrated healthcare while also normalizing the multidisciplinary approach.

### *BPSS and Sexual Quality of Life*

In terms of sexual quality of life, the BPSS approach is also necessary. As reflected in this study SQOL extends beyond biologically centered concerns such as sexual dysfunction. The couples spoke to their psychosocial and spiritual understandings that, although implicit, guided their negotiations with one another. As reflected in the results of this study, the couples drew upon aspects such as religious views, gender expectations, past strengths, and guiding values, in order to navigate how intimacy would still survive amidst an illness that forced both physical changes and emotional challenges. Across couples, the definition for intimacy extended beyond the physical, and the couples reported that they would often draw upon their intimacy in order to counteract the harmful influence that cancer can impose on couples. It is for these reasons that it is necessary to take a BPSS approach in cancer care so we may recognize patient needs beyond biological understanding.

## *Conclusion*

It is the belief of the researcher that objectives in this study were met and through its results is able to contribute to the larger body of literature both in social sciences, and oncological study. Through its objectives, this study was able to accomplish numerous tasks that will provide a foundation for future research in this area. This study garnered innovative results as it gathered dyadic data, produce integrated implications for multidisciplinary healthcare in the field of oncosexology, provide practical application for both patients and their partners, and also provide concrete interventions that are relational and systemic in nature for the utilization of the marriage and family therapist, or other related behavioral healthcare provider. This study is among the first to provide results of this nature through the lens of family science research in the field of oncosexology, and seeks to bridge future medical and behavioral health research.

## Proposal Changes

During the course of the research some changes were implemented. The proposed sample size was 10-20 couples or 20 to 40 participants; however, due to the challenges in recruitment as well as the sensitive nature of the study, garnering a larger sample size was not possible. Therefore the sample size concluded with six couples, or 12 participants. Further, changes in recruitment also ensued as confidentiality issues were highlighted. Due to the vulnerability of the population, the IRB found it necessary that recruitment was referral based only. This meant that patients could either self refer, or patients would have to be recruited by the medical team, but the researcher was not permitted to approach patients without a referral. Although the researcher is a current employee of the site in which participants were recruited, and thus has access to the patient population, the dual role of researcher was addressed in order to avoid any conflict of interest as well as maintaining the highest standard of confidentiality and protection to the prospective participants as possible. Lastly, due to these restrictions in recruitment, an appeal to expand recruitment was submitted and approved; however, recruitment at the new site was never pursued due to lack of time.

## Strengths and Challenges

The primary challenge to this study was the recruitment of the participants. As mentioned above, due to the sensitivity of the research topic as well as the vulnerability of the population to be recruited, recruiting a larger sample was challenging. Much of recruitment relied on the participation of the medical staff (nurses and doctors), which was voluntary. It was also challenging as medical health and behavioral health integration is still, in some ways, excluded or becomes secondary in patient care. Behavioral health intervention maintains a novel role in healthcare settings and therefore is not often understood in language and terminology nor its position in patient treatment. In order to address these issues, in-services for medical staff were conducted to understand the primary barriers to recruitment. The primary barrier stated by both nursing and surgical staff was the issue of time, and because of this many patients were not informed of the research study. Another significant barrier was the limitation within the recruitment criteria itself in which patients were not recruited from the researchers own current or past patient pool. This may have produced a significant change in sample size, as rapport seemed to be a primary influence in patient’s willingness to participate in a study of this nature.

Despite these challenges, this study possesses various strengths. The primary strength of this research project is that it is among the first of its kind not only in regards to dyadic data collection, but also its implications of study, which provided tangible interventions for marriage and family therapists. This is important to recognize for our felid, not only because practical interventions are identified, but also because it addresses the systemic and relational needs of patients during the cancer experience, which has been historically perceived to be a centrally biological phenomenon. Patients have continuously identified cancer as a biopsychosocial and spiritual experience, and have also highlighted sexual quality of life a necessary yet neglected corner of research. This study acknowledges these concerns, and sought to initiate understanding and practical application to address patient needs.

Another strength this study offers is that it not only considers implication regarding multidisciplinary teams, but also incorporated active engagement from both the behavioral and medical health fields. Although there were some barriers to recruitment, it is unique to oncological literature to incorporate assistance through multiple disciplines. The barriers in this study are informative to future studies as we seek to learn from and minimize them. Through this research, it has inspired the local institution to initiate engagement in future collaborative and multidisciplinary research.

## Future Practice and Research

Based on the findings of this study, a call to action regarding more integrated health has been uncovered and confirms the need to address often neglected psychosocial-spiritual concerns (McDaniel, Doherty, and Hepworth, 2014; Rolland, 2018), which includes sexual quality of life (Ratner, Richter, Minkin, Foran-Tuller, 2012). Although this study was not intended to provide generalized implications, the interventions that are identified in this study may be able to be used in settings similar to the one in which this data is collected.  Similarly, it was the intention of the research to be able to be applied within the institution in which this data was collected.  Although the local institution does already offer an integrated approach its application is still in preliminary stages of collaborative healthcare and can maximize patient care through more integrative and multidisciplinary policy.

Overall, although this study has its limitations, it has contributed to social science literature by exemplifying dyadic data analysis, which is fairly uncommon to oncological research. As well, its implications are meant to propel marriage and family therapists, and related behavioral health clinicians, forward by attempting to bridge a typically medically dominated topic into the social sciences by acknowledging that illness experiences also grapples with psychosocial and spiritual needs.  This research also intended to provide more holistic and whole person outcomes in order to advance our standard of care to our patients as we recognize the relational nature of chronic illnesses such as cancer.  Moving forward, it would be fruitful to consider other populations within oncosexology literature such as couples enduring other forms of cancer, both reproductive and non-reproductive (e.g. prostate, colorectal, etc.), varied couples (e.g. same sex couples, or male patients with female partners), or case conceptualizations that may further educate both behavioral and medical health fields as we progress together in exploring and answering the inherently integrated needs of our patients.

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# APPENDIX A

# SEMI-STRUCTURED INTERVIEW QUESTIONS

## Semi-Structured Interview Questionnaire

1. How do you define “sex?”

    a. How do you define “intimacy?”

2. What role does sex and/or intimacy serve in your relationship?

3. Do you find SQOL an important part of your cancer experience?

    a. Has SQOL become more/less important to you since the cancer diagnosis?

4. How has your sex life changed due to/since the cancer diagnosis and journey?

5. What messages, if any, does your healthcare team promote in relation to sex and intimacy amidst a cancer diagnosis?

6. In what ways has cancer changed your relationship?

7. In what ways has cancer impacted your sense of sexuality?

    a. Of yourself?
    b. Of your partner?

8. What conversations have you and your partner had, if any, regarding sex and intimacy?

9. What have you done to adapt to the changes that cancer may have posed on your relationship?

    a. Your sense of spirituality?

10. What advice would you give your healthcare team in regards to SQOL amidst a cancer diagnosis?

    a. What advice would you give to other couples enduring the same thing?