UNDERSTANDING SEXUAL HEALTH IN BREAST CANCER SURVIVORSHIP: CAPTURING PATIENT, PARTNER, AND PROVIDER NARRATIVES TO ENHANCE BIOPSYCHOSOCIAL CARE

by

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A Dissertation Submitted to the Graduate Faculty of George Mason University in Partial Fulfillment of The Requirements for the Degree of Doctor of Philosophy Communication

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ABSTRACT

UNDERSTANDING SEXUAL HEALTH IN BREAST CANCER SURVIVORSHIP: CAPTURING PATIENT, PARTNER, AND PROVIDER NARRATIVES TO ENHANCE BIOPSYCHOSOCIAL CARE

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Breast cancer survivors experience a range of physical, psychological, and relational sexual health issues that affect quality of life. While other quality of life issues may improve two to three years after primary treatment, sexual health concerns have been reported in up to 50% of breast cancer survivors and are among the complications that can worsen across time (Denlinge & Ligibe, 2013; Ganz et al., 1996). Prior research indicates survivors want to discuss sexuality with medical providers; however, these conversations rarely take place (Sporn et al., 2014). Communication is critical as patients who do not discuss sexual health problems with providers are more disposed to sexual dysfunction (Murray, 2010). Rolland’s Family Systems Genetic Illness Model (2005) provides a framework in which to better understand the complex biopsychosocial nature
of sexual health experiences in breast cancer survivorship at various points across the life span.

This dissertation consisted of two phases and associated goals. In phase one, 305 breast survivors representing young, middle, and older adulthood completed an online survey to determine the impact of breast cancer on women’s sexual health experiences broadly and the potential for provider-patient communication about these issues. To capture a more comprehensive view of women’s sexual health experiences and concerns, in phase two, a subsection of these women \((n = 40)\) completed written reflections and participated in in-depth interviews guided by the Critical Incident Technique. To fully explore this, multiple perspectives were sought. Thirteen romantic partners of survivors completed the same process. Finally, interviews with a range of medical providers (gynecologists, oncologists, family medicine physicians, general medicine internists, behavioral health specialists, and nurses) were conducted \((n = 40)\). Interview transcripts were thematically analyzed using the constant comparative method. Survivor, partner, and provider narratives were then compared to identify similarities and discrepancies, which could inform efforts to enhance care.

Results reveal that survivors experience significant sexual health distress regardless of age or survivorship length, that willingness to communicate is related to sexual health outcomes, and that a range of providers have the opportunity to discuss sexual health with patients. However, over 70% of survivors reported they are not quick to make a medical appointment specifically to discuss their sexual health issues.
Phase 2 results demonstrated that women experience a range of biopsychosocial sexual health concerns. They reported various interpersonal and system level barriers to addressing those concerns. Providers and partners were not always aware of the full complexities of women’s concerns and the magnitude of the barriers they face. Women indicated a desire for providers to discuss sexual health earlier in the cancer continuum and to facilitate an in-depth conversation about sexual health that honors patients’ emotions. The groups reported varying perspectives about the helpfulness of certain provider social support behaviors, linguistic devices, and the act of incorporating the partner in a medical interaction about sexual health. In addition, women’s experiences varied according to developmental phase and length of survivorship such that older women and long-term survivors felt bias prevented providers from addressing their sexual health concerns.

This dissertation highlighted differences in perspective among survivors, partners, and providers that can impact a woman’s sexual health and the quality of sexual health care and uncovered multiple theoretical, methodological, and translational insights that can be applied to the study of sexual health and other sensitive health issues.
CHAPTER 1

Introduction

Breast cancer is the most common invasive cancer among women (American Cancer Society, 2007). Forty percent of female cancer survivors are breast cancer survivors (National Research Council, 2005) with over 2.5 million breast cancer survivors living in the United States (American Cancer Society, 2013). Due to advancements in detection and treatment, 89% of women diagnosed with invasive breast cancer are expected to survive five or more years (American Cancer Society, 2007). According to the Office of Cancer Survivorship (OCS) of the National Cancer Institute (NCI) and the National Coalition for Cancer Survivorship (NCCS), an individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life (NCI, 2004). Family members, friends, and caregivers are also affected by the survivorship experience and are therefore included in this definition (NCI).

In 1996 the NCI recognized the need for more comprehensive survivorship care and established the OCS to conduct and support “research that both examines and addresses the long- and short-term physical, psychological, social, and economic effects of cancer and its treatments” (NCI, 2013). Researchers investigating survivorship gather data to increase understanding and reduce the harmful effects of cancer diagnosis and treatment in an effort to enhance outcomes for survivors and their families (Aziz, 2004).
As the numbers of cancer survivors rise, this research will be particularly critical not only to oncologists, but to a range of primary care providers who will be required to understand and meet survivors’ complex needs (Hewitt, Greenfield, & Stovall, 2006).

To improve the quality of care for cancer survivors, researchers must recognize that patients’ needs vary at different points across the disease trajectory or cancer continuum (Rowland, Hewitt, & Ganz, 2006). Since the 1970s, the “cancer continuum” has been used to represent different points of the cancer trajectory—from prevention, early detection, diagnosis, treatment, survivorship, and end of life (Hewitt, Greenfield, Stovall, 2006). The cancer continuum specifies, for instance, that while patients in the diagnosis phase may have needs related to medical decision-making and adjusting to illness, survivors face different challenges such as managing late effects and coping with long-term psychosocial consequences of cancer. Though the categories on the continuum overlap and all processes are not discrete, the continuum allows researchers to view the unique challenges inherent in each phase of the cancer experience. The continuum therefore serves as an important framework to help identify gaps in cancer research and to isolate where resources are needed to enhance cancer care (Hewitt, Greenfield, & Stovall, 2006).

Survivorship is often a neglected phase of the cancer care continuum, both in research and practice (Ligibe & Denlinger, 2013). Despite growing interest in cancer survivorship, it is dwarfed by scholarship concerning cancer treatment (National Research Council, 2005). As a consequence, survivors’ voices are not fully represented and their distinctive needs are not fully understood. This oversight is concerning because
survivors and family members report difficulties speaking about the challenges of survivorship (Anllo, 2000), and this gap in the literature may serve to further silence them. Patients have reported that oncology professionals, devoted entirely to cancer care, do not address the full implications of cancer treatments into survivorship (Aziz, 2007).

The shift from oncology after often-intensive primary cancer treatments have ended may compound this problem further. Survivors have suggested that providers seldom talk openly about physical and psychosocial concerns related to cancer after primary treatment (Bober et al., 2009; Mellon, Northouse, & Weiss, 2006). Thus, once patients make this transition to cancer survivorship and return to receiving primary care, many cancer-specific quality of life issues may be neglected (Bober et al., 2009).

Research conducted to understand survivor experiences is important because quality of life for cancer survivors is of great concern both in managing challenges associated with this phase of the cancer continuum, but also in minimizing future risks of recurrence. Quality of life is a multifaceted construct that involves a person’s subjective sense of well-being in physical, psychological, and social domains (Al-Ghazal, Fallowfield, & Blamey, 2000). Researchers investigating quality of life are interested in each facet of health (Garman & Cohen, 2002). Therefore, quality of life is a biopsychosocial phenomenon that highlights the need to move from the traditional biomedical model of care, a strain of medical thinking that encourages health professionals to attend primarily to physical components of illness and can dehumanize patients, to a perspective of care that is more comprehensive of survivors’ health needs and concerns (Borrell-Carrió, Suchman & Epstein, 2004). The biopsychosocial approach
to care (Engel, 1977) suggests that physical, psychological, and social components of illness are interrelated, and the illness experience is best understood when these components are considered simultaneously (Borrell-Carrió, Suchman, & Epstein, 2004).

Research has uncovered that cancer survivors are at increased risk for a number of interrelated quality of life threats including anxiety, depression, stress, body image concerns, sexual issues, loss of fertility, fear of recurrence, fatigue, chronic pain, sleep disturbances, and relationship and family distress (Bakht & Najafi 2010; Ferrell, Dow, & Grant, 1995; Institute of Medicine (IOM), 2004; Knobf, 2007; Rustøen & Begnum, 2000). Survivors reported these sources of cancer-related distress long after primary treatments like surgery, radiation, and chemotherapy were completed (Helgeson, Snyder, & Seltman, 2004; Knobf, 2007). However, the majority of existing research focuses on the period between diagnosis and two years after treatment. This omission is troubling given many effects of cancer treatment occur well into long-term survivorship (Aziz, 2006). In an era where survivors are living longer, we have relatively little knowledge about how to address the concerns of patients who are post-treatment for a significant amount of time (Aziz, 2007).

Given this, it is critical to recognize that completing primary cancer treatment does not represent an end to disease-related suffering. Rather, it represents a shift from a reality of immediate risk to a reality that is more akin to the daily concerns of chronic illness (Institute of Medicine, 2006; Kim, Moran, Wilkin, & Ball-Rokeach, 2011; Polinsky, 1994). Studies have suggested the transition to breast cancer survivorship involves many quality of life challenges (Foster, 2012; IOM, 2004; Knobf, 2007; Shapiro
et al., 2001) that survivors, families, and providers must collaboratively manage long into the future.

The National Comprehensive Cancer Network, (NCCN) recognizing the complex picture of health in survivorship issued new Guidelines for Survivorship Care (2013) that cover eight distinct quality of life-related concerns present in survivorship: anxiety and depression, cognitive function, exercise, fatigue, immunizations and infections, pain, sexual function/fertility, and sleep disorders. While breast cancer survivors have reported that some of these quality of life issues improve two to three years after primary treatment (Ganz, Coscarelli, Fred, Kahn, Polinsky & Petersen, 1996), sexual health concerns are among the complications that can worsen across time (National Research Council, 2005). In fact, although many breast cancer survivors have reported adequate quality of life when assessed 5 to 10 years post diagnosis, sexual problems remain a concern for many survivors at this time (Bloom et al., 2004; Casso et al., 2004). Decreased sexual health has been reported in up to 50% of breast cancer patients (Ligibe & Denlinger 2013).

Sexual health is a sensitive and complicated topic for many survivors. It encompasses a number of quality of life dimensions such as physical pain and dysfunction, depression, anxiety, and relationship problems (Ligibe & Denlinger, 2013). Women have reported physical problems such as pain or difficulty reaching orgasm (Tuinman et al., 2010), psychological challenges like poor body image (Bakht, & Najafi, 2010; Valdivies et al., 2012), as well as relational issues with partners stemming from decreased intimacy and poor communication (Hawkins et al., 2009). Further
complicating the matter is the fact that physical, psychological, and relational sexual health challenges vary across the life span such that women may have different experiences, needs, and concerns depending upon their age or place in the life course (Oktay & Walter, 1991). These aspects of sexual health are interrelated such that considering one aspect (physical, psychological or social) in isolation would fail to capture the multidimensional nature of sexual concerns experienced in survivorship.

For instance, the relational dimension of sexual health is an integral quality of life issue that often goes overlooked. According to Mellon, Northouse, and Weiss (2006) cancer is an experience embedded in family relationships. The authors found that family adjustment is one of the strongest predictors of survivors’ quality of life. Likewise sexual health issues in breast cancer survivorship do not occur in a bubble and instead affect both the patient’s and the partner’s adjustment and coping (Lambert, Jones, Girgis, & Lecathelinais, 2012). Cancer survivors and partners alike have cited sexuality among their most pressing concerns years after primary treatment (Stilos, Doyle, & Daines, 2007). According to Meyerowitz, Desmond, Rowland, Wyatt, and Ganz (1999), breast cancer survivors of all ages who experience sexual health concerns also reported relationship difficulties. Thus, sexual health and relational functioning are linked and, therefore, should be scientifically examined incorporating a relational health lens. In light of this, while it is important to understand survivors’ sexual health, it is also critical to ascertain their partners’ perspectives to more fully understand and improve survivors’ sexual health experiences.

expanded to include genetic illness and renamed Family Systems Genetic Illness Model (FSGI) (Rolland, 2005), has been used across disciplines including by scholars in family health communication (e.g., Bylund, Galvin, & Gaff, 2010; Fisher, 2010, 2014; Fisher et al., 2014) and offers survivorship care researchers a rationale for examining sexual health narratives from a variety of scholarly perspectives. The FSGI model emphasizes the need to consider how unique biopsychosocial features of illness, developmental phases of the individual and the illness, as well as important family relationships shape health experiences. Rolland characterizes the interaction of the medical professional, the individual, the illness phase, and the family as the therapeutic quadrangle (1988). In other words, the perspectives of the patient, family member(s), and provider are interlinked and collectively play a role in survivorship care. In essence, the FSGI model suggests that to understand health experiences like sexuality one needs to capture the narratives of everyone involved and appreciate how and why their stories merge or differ.

Narrative Theory further supports the importance of capturing insiders’ perspectives. According to this lens, narratives are a primary mechanism through which we think and communicate about health experiences (Charon, 2007). Researchers can use insiders’ narratives to bring patient perspectives to the forefront in a biomedical world that has historically silenced them (Harter, Japp, & Beck, 2005). Narratives are useful tools to improve cancer care by encouraging provider empathy, reflection, and communication about the issues stories serve to illustrate (Charon, 2001). A narrative approach can help facilitate our understanding of sexual health in breast cancer survivorship by uncovering how sexual health experiences change as a result of cancer
and its treatments, and how those changes influence survivors’ sexual health outcomes.

Used jointly, Narrative Theory and the FSGI model provide an optimal framework in which to better understand the complex biopsychosocial nature of sexual health experiences in breast cancer survivorship at various points in the life span by capturing patient, partner, and provider perspectives. A more comprehensive exploration of research informing the study’s focus is presented in Chapter 2. This review of the literature further articulates the need to improve breast cancer survivors’ sexual health care by capturing their authentic and shared stories and the critical role medical providers play in cancer survivorship.
CHAPTER 2

Review of the Literature

Multiple bodies of research offer insights into the complex physical, psychological and social sexual health challenges of breast cancer survivorship and inform our understanding of how provider communication can be a significant factor in survivors’ sexual health outcomes. To gain a comprehensive view of survivors’ experiences and to ensure providers have the information they need to enhance biopsychosocial care, research that explores multiple facets of sexual health experience and health care communication must be carefully examined. Therefore, this review of the literature explores a) how social expectations and prevailing societal narratives prevent women from voicing their concerns; b) the biopsychosocial nature of survivors’ sexual health challenges including how those challenges may be experienced differently according to women’s place in the life course and how partners’ perspectives can deepen our comprehension of survivor sexual health concerns; c) the role provider communication behavior plays in survivors’ sexual health outcomes, and d) how narrative can enhance care by helping us understand sexual health experiences from variant perspectives.

Survivorship and the Cancer Continuum

To better appreciate the importance of capturing patient, partner, and provider narratives it is helpful to discuss aspects of survivorship that may discourage patients
from openly communicating about the issues they face during this phase of the cancer continuum. The survivorship phase of the continuum contains difficulties that are not often publically recognized (Hewitt, Greenfield, & Stovall, 2006). This may prevent women from voicing their concerns and can perpetuate suffering that could otherwise be alleviated or reduced.

During the survivorship phase patients may no longer experience the acute shock of diagnosis or make complex medical decisions regarding primary treatment of their cancers. However, the transition to survivorship involves many other physical, psychological and social trials. Survivors have experienced physical pain and dysfunction, depression and anxiety, and disruptions to their relationships as they work to cope with the effects of cancer and its treatment (Bakht & Najafi 2010; Ferrell, Dow, & Grant, 1995; IOM, 2004). When women transition to survivorship they often feel uncertain or fearful and have little information to guide them through recovery from treatment (Ganz, 2000). As a consequence, some women may feel surprised and unprepared to cope with survivorship issues. This may cause them to cope with that uncertainty by remaining silent when experiencing problems like sexual distress.

It has been suggested that women may also feel discouraged from voicing their concerns due to the social expectation that survivorship is a time for women to demonstrate resilience and serve as role models for other cancer patients (Oktay & Walter, 1991). Thompson (2009) explored women’s explanatory models across the cancer continuum and found that some breast cancer survivors felt guilty for talking about their cancer-related problems. Often patients reported they felt they had less right
to communicate about their suffering after transitioning to survivorship.

Thompson (2009) also discovered that when survivors were told about others who “breezed through” their cancer experience, they became fearful of being perceived as weak and felt pressure to behave in a way that mirrored their pre-treatment selves. This pressure may amplify survivors’ need to be “good patient(s),” and prevent them from disclosing their concerns to family members and medical providers (Thompson). This is troubling, as research has demonstrated that open communication regarding the lingering effects of cancer and cancer treatment can improve survivors’ quality of life issues (Schmidt, Tjornhoj-Thomsen, Boivin, & Andersen, 2005). Social expectations about survivorship reveal why gathering patient narratives regarding difficult health issues is so important. These expectations may prevent women from voicing their concerns to providers once their treatment ends and may also contribute to reasons that providers do not address these concerns. Narratives afford survivors with opportunities to give voice to their thoughts and feelings in a culture that explicitly or implicitly silences those stories.

The FSGI model recognizes the importance of these narratives’ in uncovering implications for cancer survivors’ sexual health. The FSGI model was developed to provide a foundation for psycho-education, assessment, and intervention with families coping with chronic illness across the life span and directs clinicians’ attention to various dimensions of patient experience including the importance of considering multiple perspectives when delivering patient care (Rolland, 2005).

The FSGI model emphasizes three dimensions that continually interact and are critical to understanding illness experiences: (1) unique biopsychosocial features of the
illness or disability, (2) developmental phase of the individual or the illness over time, and (3) the nature and influence of key family relationships (Rolland, 1998). Rolland’s model further suggests that all participants in an interaction exert influence on one another. The medical professional, the individual, the illness’ features and phase, and family relationships comprise a therapeutic quadrangle (1988). Rolland indicates each component of the quadrangle contributes in fundamental ways to patient health experiences. Therefore, each component should be considered in research and practice that attempts to understand and address survivors’ sexual health concerns – particularly when societal expectations discourage open communication about biopsychosocial complications of survivorship.

**The Biopsychosocial Nature of Sexual Health in Breast Cancer Survivorship**

The FSGI model suggests that it is important to recognize the biopsychosocial nature of sexual health for breast cancer survivors, meaning “how suffering and disease are affected by multiple levels of organization” (Borrell-Carrió, Suchman, & Epstein, 2004, p.576). From this perspective, physical, psychological, and social components of health are integral to patients’ experiences. Further, these dimensions are interrelated such that a patient’s true condition cannot be fully understood by considering these dimensions separately (Borrell-Carrió et al., 2004).

Sexual health is more than the presence or absence of physical dysfunction. It can be defined as a state of physical, psychological, and social well-being related to one’s ability to function sexually (World Health Organization, 2008). As such, physical, psychological, and social challenges are pieces of a puzzle that fit together to create the
overall picture of women’s sexual health. Further, these challenges vary across the woman’s life span. According to Ganz (2000), severity and significance of symptoms is related to breast cancer and its treatments may differ due to age and developmental differences.

Viewing sexual health from a biopsychosocial perspective includes an understanding of how the illness experience changes over time (Engel, 1977). Rasmusson and Thome’s (2008) study of female cancer survivors found that thoughts about diagnosis and prognosis dominated their cancer experience during treatment. Once treatment ended the women became “survivors” and demonstrated “difficulties aligning themselves to the emotional and/or physical changes in their life situation and a need for knowledge about sexuality and the importance of the relationship between the partners” (p. 216). Thus, exploring patients’ and partners’ perceptions of sexual health during survivorship is especially relevant as many couples are just beginning to actively communicate about this topic for the first time since diagnosis. To understand survivors’ experiences and enhance quality of care it is critical to investigate sexual health as a phenomenon containing physical, psychological, social, and developmental layers.

**Physical Sexual Health Challenges**

Most breast cancer patients receive a regime of multiple treatments including radiation, chemotherapy, surgery, and hormone therapy, which destroy cancer cells and prolong life. However, these treatments can also interfere with patients’ physical sexual health. The ability to function sexually comprises a variety of complex physiological processes, directed by the neurological, vascular, and endocrine systems (Bachmann &
Breast cancer treatments alone or in combination disrupt these processes resulting in symptoms such as fatigue, nausea, vomiting, hot flashes, sleep disturbances, susceptibility to infection, weight gain or loss, decreased arousal and sensation, inability to orgasm, and pain during intercourse (associated with vaginal dryness, thinning/inflammation of vaginal tissue or treatment-induced menopause) (Jolley, 2002; Molassiotis, Sylt, & Diggins, 2007; Vallance, Courneya, Plotnikoff, Yasui & Mackey, 2007). Treatment effects vary in their severity and longevity and can last months to years. Some may even be permanent (NCI, 2008b). Therefore, it is helpful to examine the short- and long-term effects of cancer treatment on survivors’ sexual function as these pertain to specific treatments.

Radiation therapy uses high-energy radiation to kill cancer cells (NCI, 2008b). It can cause painful burning sensations and skin changes (redness, rash, spider veins) to the breast, as well as decreased arm mobility and fatigue. Previous research has suggested the effects can interfere with survivors’ sexual desire and confidence (Hughes, 2000). However, these effects are often confined to the areas being radiated and usually resolve within six months after the completion of treatment. In rare cases skin changes and problems with arm mobility can become chronic (Hoeller et al., 2003). Additionally, surgical treatments (e.g., lumpectomy, single or double mastectomy) and reconstructive surgery can cause physical changes that affect a woman’s ability to function sexually. Negative effects of surgical interventions may take time to diminish. Some women have reported surgery-related sexual health problems begin to decrease two years after surgery (Ganz, Schag, Lee, Polinsky, & Tan, 1992). Often skin sensation decreases or cannot be
preserved after surgery (Bonanno & Choi, 2010). These procedures also reportedly cause moderate to extreme pain that can last more than a year (Bonanno & Choi). Oktay and Walter (1991) report that up to one third of mastectomy patients develop sexual problems related to pain and breast sensation.

Chemotherapy is associated with complications that can have significant consequences for long-term sexual health outcomes (Ratner, Foran, Schwartz, & Minkin, 2010). Physical side effects of chemotherapy include hair loss, nausea, sleep disturbances and weight gain, which may affect a woman’s sexual self-confidence and desire for up to two years after treatment is completed (Maggard, 2003). Chemotherapy patients often experience delays in ability, or the inability, to become aroused or achieve orgasm (Hughes, 2000; Tuinman et al., 2010). Alder and colleagues (2008) discovered that chemotherapy is predictive of long-term problems with arousal, orgasm, and sexual pain.

The difficulties with arousal, orgasm, and sexual pain can result from other chemotherapy-related effects on a woman’s sexuality. For instance, chemotherapy can cause natural hormone levels to drop dramatically and quickly, producing premature or worsened menopause, which can interfere with a woman’s arousability and ability to orgasm (Tuinman et al., 2010). Pain during intercourse can be the result of chemotherapy-induced or chemotherapy-worsened menopause and is associated with 1) vaginal dryness, 2) the narrowing of the vaginal passage (vaginal stenosis), or 3) vaginal thinning/inflammation (Ganz et al., 2002). Ganz and colleagues found women, irrespective of age, reported problems with pain and lubrication. They further reported that these problems existed well into survivorship.
Problems with arousal, orgasm, and pain have also often been reported among breast cancer patients treated with hormonal adjuvant therapy (Broeckel, Thors, Jacobsen, Small & Cox, 2002). Adjuvant hormone therapies are typically given after primary treatment (radiation, surgery, chemotherapy) is completed and are reportedly associated with the continuation of symptoms experienced during chemotherapy (Broeckel, et al.) Some adjuvant therapies block the production of hormones in women with hormone sensitive breast cancer and reduce the risk of recurrence. Women typically remain on the treatment regimen anywhere from 5-10 years (Rowland et al., 2009.)

Physical complications associated with breast cancer and its many treatments are also associated with psychological, social, and developmental implications. These connections should be explored to gain a holistic picture of sexual health in survivorship.

**Psychological Sexual Health Challenges**

Physical challenges intersect with psychological aspects of sexual health in important ways. Thompson (2009) suggests that illness experiences centered on the breast are different from other illnesses. Breasts can be integrally tied to a woman’s identity and perceptions of femininity. Thus, the impact of procedures such as mastectomy can be traumatic, causing mental distress and taking a toll on previous notions of self, body image, and sexual confidence (Carroll, 1981).

Many survivors have reported depression and anxiety that interferes with sexual desire (Kim et al., 2008). Women who experience cancer-related physical changes to reproductive and sex organs often suffered depression as they worked to cope with changes to sexual desire, function and the visual impact of treatments such as surgical
scars (Gorman & Rickard, 2009). Women have also experienced anxiety about engaging in sexual activity as a result of changes to physical sexual response after breast cancer treatment (Bolte, 2010). Many of these survivors are placed on selective serotonin reuptake inhibitors (SSRIs) to treat their depression and anxiety. However, SSRIs can cause or worsen sexual dysfunction. The incidence of sexual dysfunction with SSRIs ranges from 58% to 73% (Montejo, Llorca, Izquierdo, & Rico-Villademoros, 2001).

The physical influences of breast cancer have psychological consequences for both cancer survivors and their partners. Both women breast cancer survivors and their partners have expressed cancer-related mental distress years after primary treatment, rating sexuality among their most critical concerns (Stilos, Doyle, & Daines, 2007). They both indicated that feelings of sadness and rejection are hallmarks of decreased sexual health (Butler et al., 1998; Hawkins et al., 2009). Physical sexual health challenges (including pain and lack of arousal or sensation) and associated psychological distress are among the most negative influences on cancer survivors’ social/relational quality of life (Hughes, 2000).

Rolland’s FSGI model can also help researchers understand how social sexual health challenges are related to physical and psychological aspects of sexual health. For instance, it is possible that physical trauma of certain breast cancer surgeries (physical) cause declines in body image (psychological), which may interfere with physiological sexual response (physical). In turn, these negative health effects may seriously influence women’s social health by decreasing the desire for and participation in sexual intimacy (social). Much of the research to date supports this supposition (Hawkins et al., 2009).
Social Sexual Health Challenges

Illness-related physical, psychological, and social challenges are linked (FSGI model). Thompson (2009) suggests that the cancer-related symptoms, physical changes and psychological concerns breast cancer patients experience during and after cancer negatively affect their relational lives. For example, treatment-related fatigue is a symptom that has been identified as a side effect that may influence frequency of and satisfaction with sexual activity (Hughes, 2000). Physical pain has also been found to lead survivors to avoid intimacy and intercourse (Ratner et al., 2010).

In addition, the site of the disease, a woman’s breasts, can be integrally tied to a woman’s identity, sexuality, and perceptions of femininity. Shifts in body image have been reported to disrupt long-standing patterns of physical pleasure and intimacy with partners (Fobair, Stewart, Chang, D’Onofrio, Banks, & Bloom, 2006). Thus, problems with body image may cause tensions for relational development and maintenance (Bakht, S., Najafi, S. 2010; Valdivies et al., 2012). Relational consequences are complex and can vary according to the treatments survivors received. For instance, women who undergo lumpectomy surgical procedures have reported that partners show less negativity about their surgical scars and initiate sexual activity more than women who undergo mastectomy (Wimberly et al., 2005).

According to Hughes (2000) a couple's response to cancer treatment can be one of the most serious sexual consequences of cancer. Many couples have reported difficulty talking openly about sexual problems with each other or seeking help from professionals (Crooks, 2001). This, in turn, has been found to both the patient and the partner’s quality
of life (Hughes, 2000; Jones, Girgis, & Lecathleteinai, 2012). Hawkins et al. (2009) reported that when sexual intercourse stops, other forms of intimacy and affection also decline. Both survivors and partners have reported that sexual health issues cause isolation, sadness, and are accompanied by poor communication (Butler et al., 1998; Hawkins et al., 2009). Even after physical problems subside, psychosocial problems, relational conflicts, and poor body image may persist and linger well after successful treatment (Schag, 1993). Breast cancer survivors experience a range of interrelated physical, psychological, and social sexual health challenges. However, these experiences are not uniform across the life span. The FSGI model suggests that developmental differences must be accounted for to better illustrate survivors’ sexual health needs.

**Developmental Differences**

Developmental differences shape sexual health experiences in survivorship. Sexual health incorporates the personal beliefs and experiences that are influenced by age (Murray, 2010). The FSGI model suggests that illness-related challenges differ according to the developmental phases of illness (survivorship) as well as the developmental phase of each patient (Rolland). Some sexual health experiences among women with breast cancer appear to be consistent across age groups. For instance, while the prevalence of reported sexual complications has been found to decrease with age (Lester & Bernhard, 2009), women described chemotherapy-related effects (such as fatigue and weight loss/gain) that reduced their sense of femininity and sexuality regardless of pre- or postmenopausal status (Ganz et al., 1996). Women have also reported that pain
associated with vaginal dryness and atrophy impedes sexual activity and intimacy regardless of age (Early Breast Cancer Trialists’ Collaborative Group, 1994).

However, women have reported other divergent sexual health concerns across the life span. Roughly 25% of women diagnosed with breast cancer are younger and premenopausal (Schover, 2008). Recent communication-focused research indicated that women diagnosed in their thirties describe are especially concerned with their sexual health and their future relational lives in comparison to women diagnosed later in life (Fisher, 2014). Younger women have been found to be particularly vulnerable to distress caused by problems with sexual function and intimacy related to fertility (Wenzel et al., 1999). Premenopausal women often experience premature ovarian failure as a result of chemotherapy (Wenzel et al.). This has been found to lead to higher rates of depression (Avis & Crawford, 2004) and relationship problems (Baucom et al., 2005) for younger women struggling to cope with changes to their sexual and reproductive systems. According to Baucom and colleagues, younger women often receive more aggressive courses of chemotherapy than post-menopausal women, which may result in more severe physical sexual health challenges related to treatment such as nerve and tissue damage, pain, and diminished arousal.

The literature to date demonstrates that sexual health is a multilayered concept. To understand sexual health experiences researchers should consider the interconnected nature of physical, psychological, and social problems related to survivors’ sexual health. Furthermore, the implications of age and treatment type should be considered in
explorations of survivors’ biopsychosocial experiences. Doing so will provide a more complete view of sexual health issues.

Given women’s sexual health is often a relational experience, the perspective of their romantic partner warrants attention. The FSGI model suggests that significant relationships are an integral component of patients’ biopsychosocial health as they are affected by and influence patients’ illness experiences. Rolland suggests relational partners can deepen our understanding of patients’ quality of life concerns. As such, partner perspectives contribute important contextual knowledge critical to exploring survivors’ comprehensive sexual health concerns.

**Partners and the Biopsychosocial Nature of Sexual Health**

For partnered women, one of the most consistent predictors of sexual health in breast cancer survivorship is the quality of their partnered relationship (Meyerowitz et al., 1999). However, research examining sexual health after treatment from relational or social perspectives is lacking (Emilee, Ussher, & Perz, 2010). Rather, much of the current research focuses on individual effects of cancer on sexual health (Emilee et al.). To capture a complete picture of sexual health in survivorship partners’ perspectives should be considered.

The role of the partner is an important factor for women who engage in partnered sex or are in committed relationships (de Vocht, Hordern, & Notter, 2011). Flynn and colleagues (2011) reported that during their study on cancer patients’ sexual functioning, communication with partners, attitudes of partners, and other related concepts consistently emerged as primary factors contributing to patients’ sexual health outcomes.
Survivors’ perception of partners’ behavior and attitudes can influence women’s sexual health experiences. Huber, Ramnarace, and McCaffrey (2006) found that women who felt their partners were not bothered by surgical scars reported greater sexual confidence and feelings of femininity. The authors also discovered that women who perceived their partners were less emotionally involved in sexual activity reported greater emotional distress. This indicates that partners’ emotional involvement is a central component of women’s sexual, relational, and emotional adjustment after breast cancer treatment.

The FSGI model regards close relationships as a potential support resource, emphasizing relational partners’ ability to assist in understanding patient experiences and encouraging growth (Rolland, 2005). Research has demonstrated that partners are integral to survivors’ sexual health experiences (Murray, 2010) and that survivors have reported they want their partners to be included in clinical conversations (Flynn et al., 2012). Given sexual health is a shared experience for partnered women during survivorship, partners’ perspectives should be considered an asset in both research and clinical practice.

**Communicating about Sexual Health: The Clinical Interaction**

Research has suggested that shared involvement in clinical interactions can lessen the communication challenges within partnerships (Rasmusson & Thome, 2008). From a biopsychosocial perspective, partners are an integral component of sexual health experiences for many survivors and, therefore, should be included in research and practice aimed at alleviating sexual health concerns. However, using a biopsychosocial lens to view survivors’ sexual health concerns also means exploring how providers affect
survivors’ experiences regarding sexual health challenges. Poor provider communication has been found to perpetuate or worsen survivors’ sexual health issues (Kantsiper et al., 2009). Current research has suggested that survivors and providers seldom talk about the full biopsychosocial implications of sexual health in survivorship (Bober et al., 2009). Further, despite the fact that patients often reported wanting to discuss sexual health, providers are often uncomfortable talking about sexual health issues (Crooks, 2011). This suggests some patients’ and partners’ attempts to communicate about sexual health may be met with a silencing resistance.

However, providers are not alone in their discomfort with the topic of sexuality. Studies have indicated that sexuality is still a taboo subject matter for many patients and this may prevent them from disclosing their sexual health concerns (Arrington, 2000; Hordern & Street, 2007a). Hill and colleagues’ (2010) study of gynecologic and breast cancer survivors revealed that more 40% of survivors wanted to receive sexual health care, but only 7% of women reported initiating that discussion. Studies have consistently suggested that patients are reluctant to bring up the issue (Hordern & Street 2007a; Flynn et al., 2012; Perez, Ussher, & Gilbert, 2013).

Despite the prevalence of sexual distress after cancer treatment, it has been suggested that researchers examining these issues experience difficulty recruiting patients for sexual health studies, likely due to the sensitive nature of the topic (Jennings et al., 2014). This discrepancy contributes to the scarcity of evidence-based and medical training interventions (Newell, Sanson-Fisher, & Savolainen, 2002; Shell, 2002). This is concerning given the rising numbers of survivors and the discomfort with sexual health
topics reported by both parties, which makes these training interventions especially warranted.

Before training interventions can be designed we need to understand more about the experiences of all the primary participants involved. The FSGI model suggests that all participants in an interaction exert influence on one another. Therefore, we must gather multiple perspectives sexual health discussions in breast cancer survivorship to understand how medical interactions support or hinder sexual health outcomes. Understanding patient hesitancy and their preferences for communication with providers may be used to help providers more sensitively address patient needs. Capturing provider perspectives of sexual health care communication may shed light on how they talk and think about sexual health and generate information that can be applied to improving communication practices. To further elucidate the need for gathering provider perspectives on breast cancer survivor sexual health the following sections will explore the state of survivorship care today and its implications for patients’ sexual health outcomes.

The State of Survivorship Care

It is becoming increasingly difficult for oncologists to care for the growing number of cancer survivors (Kantsiper et al., 2009). To address this challenge, the American Society of Clinical Oncology published guidelines for treating breast cancer survivors, which stipulate that primary care providers (PCP) begin assuming greater responsibility for ongoing cancer care needs (Khatcheressian et al., 2006; Sisler, Brown, & Stewart, 2004). At the conclusion of primary breast cancer treatment many women are
discharged from oncology and referred back to primary care settings (Ganz, 2000). They no longer attend daily or 3-week visits to cancer treatment centers (Ganz). As the number of breast cancer survivors continues to increase, PCPs will encounter more patients and partners who are being transitioned back to primary care. PCPs need to be prepared to address the effects of cancer and its treatments on survivors’ quality of life. However, many report feeling unprepared to do so.

Kantsiperet et al. (2009) reported that PCPs are concerned that they do not have sufficient training to provide survivorship care and may be hesitant to take on responsibility for survivors’ ongoing care. In Kantsiperet and colleagues (2009) study, many PCPs rarely became directly involved in cancer-related aspects of care, relying on assumptions that breast cancer survivors were continuing to see oncologists, when in fact, although figures vary, women only visit oncology specialists once a year or less after primary treatment is completed (NCI, 2010). Many of these visits are scheduled primarily to monitor for disease recurrence and not to manage the long-term effects of cancer and its treatments (Nekhlyudov, 2009). Further, oncologists and patients alike have reported they believe PCPs should have a larger role in attending to comorbidities (such as sexual health problems) caused by cancer and cancer treatments (Nekhlyudov). Thus, PCPs would benefit from training that equips them to understand and address the biopsychosocial concerns of survivors and their family members.

However, PCPs are not alone in their difficulty with the topic of sexual health. Numerous studies have suggested that while oncologists are specialists in cancer care, they may not always address quality of life issues like sexuality with survivors.
Some patients have indicated their oncologists do not initiate conversations about
delicate aspects of psychosocial cancer care or that they handle those conversations
poorly (Bolte, 2010). Patients may have the opportunity to speak with a range of
providers about their sexual health concerns. Since little is known about women’s
preferences for provider specialty surrounding quality of life issues, research should
explore their preferences and examine multiple provider specialties, as the implications of
ineffective patient-provider communication may be profound.

High quality patient-provider communication during survivorship is needed as
patients and families navigate new information about risk, follow-up care, and
psychosocial effects of cancer and its treatments (Oeffinger, Nathan, & Kremer, 2008)
Unfortunately, patients have reported a number of unmet psychosocial needs in medical
interactions (Kantsiper et al., 2009), which have implications for patients’ sexual health.
Effective patient-provider communication can help facilitate improvements or enable the
continuation of care for sexual health issues in survivorship (Kantsiper et al.). Therefore,
it is important to explore which needs are currently unmet, why providers may experience
difficulties communicating about sexual health, and the ways in which providers’
communication affects survivors’ sexual health outcomes.

**Patient-Provider Communication and Survivors’ Unmet Psychosocial Needs**

Research suggests survivors and families are not receiving care that addresses
their complex biopsychosocial needs (Institute of Medicine, 2006; Kantsiper et al., 2009).
For instance, Bober and colleagues (2009) assessed survivor care along four dimensions
critical for survivor and family coping: monitoring for cancer recurrence, management of late effects, sexual functioning, and mental health. They discovered only 24% of medical providers met criteria for providing this multi-dimensional survivorship care. Mallinger’s (2005) work suggested that while breast cancer survivors may be satisfied with information related to treatment, they are less content with information related to long-term physical, psychological, and social effects of cancer and its treatments. Further compounding the issue is the fact that some providers have been found to underestimate the informational and psychosocial needs of breast cancer survivors and rarely include family members in discussions (Kantsiper et al., 2009). Bober and colleagues’ (2009) findings supported this, suggesting that providers do not routinely discuss psychosocial needs and family concerns with breast cancer survivors.

Sexual health concerns can be a topic with intense psychosocial implications. Studies have consistently revealed that women across the life span view their sexuality as an integral quality of life issue and want to discuss sexual concerns with physicians (Lindau, Gavrilova, & Anderson, 2007; Lindau, Schumm, Laumann, Levinson, O’Muircheartaigh, & Waite, 2007). Survivors reported a great need for information, support and assistance with the practical management of their sexual changes after treatment (Bober, 2009; Murray, 2010). However, an ample body of research has also suggested that providers are not having sexual health discussions with their patients.

Survivors have reported an unmet need for information regarding sexual side effects and available therapies (Flynn et al., 2011). In one study, 60% of survivors reported they’ve never had a physician-initiated conversation about the implications of
cancer and its treatment for their sexual health (Hill, et al., 2011). Stead, Brown, Fallowfield and Selby (2003) reported that 98% of providers surveyed believe sexual complications should be discussed. Yet, only 21% reported actually having these conversations with patients. Park and colleagues’ (2009) research concerning provider communication supported those findings, revealing that 62% of physicians never or rarely addressed sexual dysfunction with cancer patients.

Flynn and colleagues (2012) study of sexual health along the cancer continuum revealed that survivors believe that communication among patients, partners, and physicians is important. The authors reported participants also conveyed concerns surrounding asking providers about sexual problems, and expressed a desire to include their spouses in conversations about sexual health issues. They suggested that cancer-related sexual health issues can profoundly affect the lives of women and their partners, but couples rarely get the chance to address their concerns with providers. While providers may find sexual health communication difficult, patients reported it is helpful have those discussions.

**Patient-Provider Sexual Health Communication - Challenges and Relevance**

Despite evidence supporting the need to address multiple aspects of cancer survivors’ quality of life, providers can experience difficulties communicating about the full spectrum of sexual health complications for several reasons. De Vocht, Hordern, and Notter’s (2011) research with various health care professionals in cancer care suggested that sometimes providers do not see patients as sexual beings. Therefore, they only occasionally brought sexual health into conversations. Horden and Street’s (2007a) study
of a range of health care providers revealed that providers take a biomedical approach to cancer communication. They reported the assumption that a patients’ main concerns are physiological processes so when sexual health is discussed, many providers have a limited view of patients’ intimacy and sexuality and do not initiate conversations about the psychosocial aspects of sexual health (Bober et al., 2009).

This approach is contrary to cancer patients’ beliefs about the importance and nature of sexual health discussions (Horden & Street). Both patients and partners have reported that a person-oriented approach is a critical factor in their interactions with health care providers. If they do not perceive that “the professional ‘sees’ the person they are, including their emotional layer and a real life in the world ‘out there’ with everything that comes with it, they will be very hesitant to disclose personal issues” (de Vocht, Hordern, & Notter, 2011, p. 615).

The delivery of biopsychosocial care is hindered by other challenges associated with the topic of sexuality. Some providers have suggested they are uncomfortable with topics like sexual health and are unwilling to discuss them (Murray, 2010; Solursh et al. 2003). Hordern and Street’s (2007b) work with a range of cancer medical professionals found that sexuality and intimacy are often seen as taboo and outside of the realm of medical problem-solving.

These findings reflect the challenges patients and families report in medical settings. Often survivors and families have reported that providers do not inquire about their sexual health concerns and express difficulty communicating with providers regarding sexual health topics (Institute of Medicine, 2006; Kantsiper et al., 2009). These
oversights are problematic for multiple reasons. Clinical communication regarding survivors’ sexual health is critically important. Medical professionals have the ability to ease concerns about sexuality and intimacy after breast cancer (Can et al., 2008). Two decades of studies in oncology have demonstrated that physician behavior is related to patients’ quality of life (Ong, Visser, Lammes, & de Haes, 2000). Oncologists’ inability to recognize and attend to cancer patients’ perspectives has been shown to lead to increased uncertainty (Maguire, 1988), depression (Fallowfield, Hall, & Maguire, 1990), and overall poor psychological adjustment to cancer (Rainy, 1985). Poor patient-provider communication has been associated with poor psychological outcomes for survivors such as reduced adjustment and anxiety (Arora, 2003). When medical professionals fail to appreciate the biopsychosocial nature of patients’ health concerns and do not initiate or elicit patient perspectives it may negatively affect patient quality of life issues.

For instance, it has been shown that patients who do not have opportunities to discuss sexual problems with healthcare providers are considerably more disposed to sexual dysfunction (Murray, 2010). Survivors reported a desire for their health care providers to be direct and bring up the topic because it is often difficult or embarrassing for patients and their partners to bring these topics up on their own (Murray). Importantly, cancer patients have also suggested they look to their doctor for signals as to whether it is proper to discuss topics with psychosocial implications during medical visits (Street, 1992). In oncology between 29% and 37% of patients indicated that they generally await a signal from their physician before discussing issues surrounding their relationship with their partner and their social functioning (Ong, Visser, Lammes, & de
Providers’ inability to broach the topic may have other implications for the patient-provider relationship and patient sexual health. Survivors reported interpreting a provider’s silence on sexual matters as insensitivity (Bolte, 2010). Sometimes the lack of information provided is construed as dismissiveness about the importance of patients’ sexual health concerns. Bolte suggested this dismissal increases survivors’ mistrust of medical professionals, and perpetuates sexual health distress.

However, research has also demonstrated that provider communication can positively influence patients’ quality of life outcomes. Hack, Degner, and Parker (2005) found that when providers communicate in ways that recognize and validate patients’ physical, psychological, and social concerns patients feel understood, comforted, and reassured. They further discovered this facilitates patients’ ability to follow through with treatment and self-care (Hack, Degner, & Parker). Levinson and Roter (1995) reported patients disclose more information regarding their emotional and social functioning when the provider has an appreciation for psychosocial features of care. By eliciting and exploring patients’ psychosocial concerns, providers can ease patient anxiety (Bensing, 1991). These findings may extend to sexual health concerns.

Providers have the potential to greatly enhance cancer survivorship care by communicating in ways that increase patients’ sexual health. Providers would be well advised to appreciate and attend to biopsychosocial concerns related to sexual health and to feel comfortable eliciting and discussing those concerns with patients and partners. However, current literature demonstrates that those conversations are not taking place. This oversight can lead to the continuation of sexual health distress. Capturing medical
providers’ perspectives regarding survivors’ sexual health challenges may help contextualize and deepen our understanding of how this issue can be better attended to in survivorship care. Understanding where patients’, partners’, and providers’ perspectives merge and differ will lead to a more comprehensive view of sexual health challenges in survivorship and suggest avenues to improve the quality of biopsychosocial care.

To capture these perspectives and contribute to quality survivorship care, a narrative approach is optimal. Narratives are means for patients, partners, and providers to make sense of sexual health in survivorship. They are a tool for researchers to expand knowledge within this realm and, at the same time, can be used to improve the quality of patient-provider communication.

Using Narrative to Understand Sexual Health and Improve Survivorship Care

Researchers have acknowledged that studies grounded in first-hand experience and analyzed from a psychosocial perspective hold great potential for unlocking the illness experience (Schneider & Conrad, 1983). Narratives can increase understanding of experience and improve survivorship care for several reasons. First, narratives are a primary means through which we make sense of our health experiences (Charon, 2007). Therefore, they are useful tools for improving our understanding of the biopsychosocial nature of sexual health in breast cancer survivorship. Second, narratives give voice to patient experiences that often go unheard. By eliciting narratives researchers draw out and emphasize patient perspectives in the midst of a medical culture that can mute them (Harter, Japp, & Beck, 2005). Third, narratives can facilitate empathy, reflection, and open communication (Charon, 2001) by drawing attention to basic elements of the illness
experience including the timeline of illness challenges, common or prototypical experiences of the ill, how people make sense of their experiences, the nature of interactions with healthcare providers, and the overall impact of illness on individuals’ quality of life (Groleau, Young, & Kirmayer, 2006). The information acquired through narrative inquiry can provide important insights, which can be applied to enhance survivors’ sexual health outcomes.

**Narratives and Understanding Health Experiences**

Storytelling has been found to transmit information, develop internal awareness, and communicate emotions since the time systems of language surfaced (Fisher, 1987). Narratives in essence are constructions of lived experiences. When narratives are formulated and communicated human beings make sense of actions, motives, as well as interactions, relationships, and feelings (Fisher, 1987; Klienman, 1988). According to Bolas (1987) narrative is the instrument human beings use to access what is referred to as the “unthought known.” It allows individuals to conceptualize and organize ambiguous, confusing, or frightening elements of existence. Schank and Berman (2002) suggested that “we construct and tell stories, in part, to teach ourselves what we know and what we think” (p. 294).

The construction of narrative can be enormously helpful when individuals are faced with health challenges. Illness isolates patients from previous notions of self. Healing requires finding a new sense of self amidst the altered physical, psychological and social realities of illness. In essence, managing health transitions requires the creation of new stories (Stanley & Hurst, 2011). These stories allow patients to make sense of
their suffering. As such, patient and partner narratives may reveal how they make sense of physical sexual health changes and how those physical changes are related to psychological and relational sexual issues in survivorship. Illness narratives are a rich source of information. They provide “biographic and social context of the illness experience and suggest coping strategies” that can be instructive for patients, families, and providers alike (Kalitzkus & Matthiesse, 2009, p.4).

Narrative is particularly useful when seeking to understand experiences like survivorship—experiences that cannot be neatly organized, are highly complex, and are often misunderstood or unvoiced. For instance, narrative theorizing helps researchers unpack the problem of continuity and disruption. Philosophers from Aristotle to Kenneth Burke have long held that a chief impetus to narrative is that of expectations gone awry (Harter, Japp, & Beck, 2005). Difficulties of continuity and disruption may be particularly salient for survivors and their loved ones experiencing sexual health challenges after treatment. Survivors and partners may have unique, sometimes contradictory, expectations regarding sexual health in survivorship. Illness narratives are a means for viewing the overall timeline of patients’ sexual health challenges and determining what influences the way patients experience and respond to disruption in their sexual selves.

**Narratives and Giving Voice to Survivors**

In the early 1980s scholars began to talk about the “narrative turn” in medical care (Kalitzkus & Matthiesse, 2009). Narrative has become increasingly accepted as a means to bring patients’ experiences or voice to the forefront illness experience, encouraging
physicians to view them as human or more than just their specific pathologies (Charon, 2006; Mattingly & Garro, 2000). Many medical professionals have come to regard narrative as a source for learning the distinct, patient-specific meaning of illnesses (Polkinghorne, 1988). Greenhalgh and Hurwitz (1999) wrote that in giving voice to the individual, narrative offers otherwise inaccessible meaning, context, and perspective on that patient’s health challenges. In essence, narratives bring to light individual health challenges as well as the complex system in which they are rooted. Because narrative underscores how individuals experience and interpret reality, rather than just what they do or what is done to them, they offer a valuable visual representation of emotions, thoughts, and communicative behaviors that are applicable when attempting to deliver high quality medical care (Loftus, 1998).

The narrative approach may offer added value when examining sexual health issues in breast cancer survivorship. These issues are often uncomfortable topics for patients and their partners. Many have reported remaining silent rather than try to engage providers in what they view as difficult or embarrassing conversations (Hughes, 2000). Geist-Martin, Ray, and Sharf (2003) pointed out that illness narratives “give voice to the concerns of persons who are usually not heard because of the stigma” (p.42). As previously discussed, in a society where sexuality is taboo it may be more difficult for patients to express themselves in this context (Arrington, 2000; Hordern & Street, 2007a). Further, it has been suggested that stigma associated with sexuality may create uncertainty and tension for partners attempting to voice their concerns, fears and experiences to each other (Emilee, Ussher, & Perz, 2010). Thus, giving patients and
partners the space and opportunity to tell their stories takes on an added layer of significance. Couser (1997) wrote that cancer is more than a medical story. He suggested cancer is a “feelings story” and noted breast cancer survivors’ narratives offer a more complete picture of cancer-related transitions including the emergence of sexual problems.

**Narratives and Healing – Improving Survivorship Care**

It has been generally accepted that narrative can offer increased understanding of illness (Kalitzkus & Matthiesse, 2009). However, many in the medical community are now beginning to apply narrative knowledge to improve patient care. Those who embrace narrative recognize that “the boundaries between narrative and scientific knowledge are permeable” (Czarniawska, 1997). Physicians do not simply evaluate symptoms objectively. They interpret signs by combining diagnostic criteria with the specific elements of the patient’s story. Grasping the narrative nature of illness and the subjective aspects of medicine are central to clinical work (Greenhalgh, 1999). Greenhalgh states that narrative allows a clinician to meaningfully draw on all aspects of evidence—his or her own experience, the patient’s individual social and cultural perspectives, and clinical research trials and observational studies—to arrive at an integrated clinical judgment.

Rita Charon, the physician and scholar who founded the Program in Narrative Medicine at Columbia University, suggests that medical practice should be “informed by the theory and practice of reading, writing, telling and receiving stories” (Charon, 2006, p. 4). She proposed that identifying, understanding, and knowing what to do with stories can improve patient-provider communication and enhance quality of care (Charon, 2001).
In accordance with the FSGI model, narrative approaches imply that delivering comprehensive clinical care requires physicians to consider the survivor as embedded within an unfolding narrative of patient experiences, relationships, and the challenges associated with certain phases of the cancer trajectory.

Narrative is a viable mechanism for helping providers learn about survivors’ biopsychosocial concerns because it has been found to encourage reflection (Greenlaugh & Hurwitz, 1999), increase comprehension and retention (Ragan, Mindt, & Wittenberg-Lyles, 2005), and facilitate the expressions of empathy, which are critical to encouraging patient disclosure (Fernandes-Taylor, 2010). Narratives may be particularly helpful when communicating about sexual health topics, which are sometimes difficult for patients and providers to discuss, and therefore, are not well understood (Murray, 2010). However, to achieve the long-term goal of improving survivorship care, narratives that are faithful to patient experiences must be captured.

Researchers who aim to understand the meaning individuals give to their illness often examine fundamental narrative elements of experience. Groleau, Young, and Kirmayer (2006) write that to understand patients’ perspectives it is necessary to uncover (1) the basic timeline of their illness so that changes to their health experiences can be contextualized; (2) the critical and the usual or prototypical experiences that epitomize those health changes including illness symptoms, feelings and communication with others; (3) how people with health challenges understand and explain their experiences; (4) personal reflections on interactions with health care providers, and (5) how patients characterize the overall impact of illness on their quality of life. The information acquired
through narrative inquiry can provide important insights, which can be applied to enhance survivors’ sexual health care and sexual health quality of life.

**Capturing Multiple Perspectives to Improve Sexual Health Survivorship Care**

Taken together, the FSGI model and the narrative theoretical approach provide the rationale and the means to gather multiple complex narratives of sexual health in survivorship. The FSGI model suggests the utility of capturing narratives that incorporate the physical, psychological, and social domains of sexual health concerns in breast cancer survivorship, including how developmental differences and unique aspects of patients’ treatment can influence their sexual health concerns. It also suggests that health experiences should not be conceptualized on the individual level. Rather, that the ongoing interactions between patients, the illness, significant relationships, and the medical provider shape the patients’ illness experience. As such, intimate relational partners and providers are integral to survivors’ sexual health outcomes. Capturing partners’ narratives of sexual health recognizes partners’ ability to assist in understanding patient experiences (Rolland, 2005). Providers’ narratives can inform our understanding of sexual health survivorship experiences as providers’ ability to understand and talk about the complex nature of sexual health may influence patients’ sexual health and quality of life (Kantsiper et al., 2009; Kalitzkus & Matthiessen, 2009). Gathering patient, partner, and provider narratives will improve our understanding of the sexual health challenges faced by survivors and produce valuable information that can be applied to improve biopsychosocial survivorship care in the future.
Research Questions

Although prior research demonstrates women want their providers to bring up the topic of sexual health (Flynn et al., 2012), sexuality can be uncomfortable for both women and providers to discuss (Arrington, 2000; Hordern & Street, 2007a). Providers report the need for more training in survivorship care, with sexual health being one of the least understood aspects of this phase of the cancer continuum (Flynn et al., 2012). As such, the overarching objective of this research was to produce a more comprehensive picture of survivors' sexual health experiences and the role medical providers play in enhancing survivors’ quality of life.

This study encompassed two phases and associated aims. The goal of phase 1 was to better understand the nature of women’s sexual health experiences broadly and the potential for provider-patient communication about these issues. As noted, little research exists that explores the presence of sexual health distress for women of various ages and survivorship lengths. Furthermore, little is known about which provider a survivor might prefer to talk to about sexual health or whether a woman’s willingness to communicate is tied to her sexual health outcomes. To explore these issues the following inquiries were posited:

**RQ1**: Do women of all developmental phases and survivorship lengths report sexual health concerns?

**RQ2**: Which provider do survivors consider their general health primary care provider?

**RQ3**: Which provider do survivors think they would approach if they had a sexual health concern?

**RQ4**: How is survivor willingness to discuss sexual health concerns related to survivors’ sexual health outcomes?
The next phase extended this knowledge by delving deeper into the quality of sexual health survivorship care and women’s needs. Phase 2 was intended to capture a more comprehensive view of sexual health including the timeline of women’s typical sexual health challenges after primary cancer treatment ends, how sexual health challenges are understood and explained, and the impact of cancer on sexual health and quality of life (Groleau, Young, & Kirmayer, 2006). These issues were also considered in relation to a woman’s place in the life span since a survivor’s age and length of survivorship.

To explore this, multiple perspectives were sought. Sexual health is a relational issue for partnered women; thus, the partner’s perspective was imperative to more fully understand this aspect of health. The provider’s voice was also needed to understand the challenges of addressing sexual health issues in diverse clinical environments (e.g., oncology, primary/family, and gynecological care). All three perspectives (survivor, partner, and provider) could then be compared to identify areas of similarity and variation critical to improving care. The following inquiries addressed these goals:

**RQ5:** What sexual health issues do developmentally diverse breast cancer survivors encounter that influence their quality of life during survivorship? (according to survivors, partners, and providers)

**RQ6:** What challenges/barriers do survivors encounter with regard to addressing sexual health concerns in a medical setting? (according to survivors, partners, and providers)

**RQ7:** What provider communication factors facilitate or impede a successful clinical interaction regarding sexual health (according to survivors, partners, and providers)?

**RQ8:** How do survivors’, partners’, and providers’ understanding of sexual health and sexual health communication in survivorship merge and differ?
CHAPTER 3

Methodology

This research attempted to capture the full complexity of women’s experiences to improve sexual health-related survivorship care. This was best accomplished using a mixed methods design. Specifically, a sequential explanatory design was used to accomplish this overarching directive (Creswell, 2009). A mixed-methods sequential explanatory design contains two phases. First quantitative data is collected and analyzed followed by qualitative collection and analysis (Creswell). The results of the quantitative data analysis provide a broad understanding of the research problem and the qualitative data analysis clarifies, explains, and builds on statistical results by exploring participants’ views in more depth (Creswell, 2003, 2009; Ivankova, Creswell, & Stick, 2006; Tashakkori & Teddlie, 1998). According to Kreps, (2012) mixed method studies like sequential explanatory designs can generate robust data that help scholars “translate raw health communication research findings into practical and usable health care/promotion interventions and policies.”(Kreps, 2012, p.8)

In this study the goal of phase 1 was to establish the significance of women’s sexual health concerns in survivorship, identify their preferences for providers, and demonstrate if communication willingness is tied to women’s sexual health outcomes. The goal of phase 2 was to further explore these patterns and associations by drawing out
the contextual complexities of women’s sexual health concerns, including their experiences communicating with different kinds of providers and their reservations about engaging in sexual health discussions in a medical setting. The study design and methodology including recruitment, sampling, participants, procedures, and data analysis plan are presented according to the phase of the mixed method design.

**Phase 1: Linking Factors to Women’s Sexual Health: Exploring Age, Survivorship Length, Provider Preference, and Willingness to Communication**

To understand survivors’ sexual health experiences an impartial record of the presence and degree of experiences should be obtained (Ricoeur, 1975). A quantitative approach is best suited to identifying relevant sexual health variables and seeking out possible relationships among those variables (Creswell, 2009). Survey research provides a numeric representation of attitudes, beliefs, and reported behaviors of a population by answering questions of “why, how much, how often, and who” (Creswell, 2009; Cooper & Schindler, 2006, p. 3). This survey established “who” by determining which providers women see as their primary care providers and who they would visit for sexual health distress, and answered “how” women’s willingness to communicate was related to their sexual health outcomes. It further determined “how” and “how much” by testing for a relationship between sexual health outcomes and willingness to communicate about sexual health.

**Recruitment**

Institutional Review Board (IRB) approval was obtained through George Mason University’s Office of Research Integrity and Assurance. Following IRB approval participant recruitment proceeded through various channels to maximize sample size.
potential. Study flyers were sent to cancer navigators and oncology social workers based in hospitals or medical centers including George Washington University Medical Center’s Survivorship Center, Beth Israel Deaconess Medical Center, Women’s Center - Chestnut Hill Hospital, and Providence Cancer Center. Non-profit organizations and social media organizations were also contacted. Study recruitment materials were distributed online or in-person during survivor support groups. Participating groups included the Sisters Survivor Network, The Pink Link, Lotus Foundation, Breast Cancer Partner, The Pink Paper, Beyond Boobs, National Cancer Survivors Day, Bay Area Young Survivors, and the 3B Foundation. Individual cancer researchers and survivor advocates/authors also wrote newsletters or blog posts concerning the project. Contributing writers included Nancy’s Point, Dr. Schover, and Barbara Musser of Sexy after Cancer.

**Sampling**

Purposive sampling was used to recruit women who satisfied the following conditions: Participants were 1) breast cancer patients who completed their last primary cancer treatment (chemotherapy, radiation, or surgery) and were 2) at least 18 years old. Further, to determine variations across developmental phases or age, representative samples from three age groups were sought: young adulthood (under 40), middle adulthood (ages 40-59), and older adulthood (ages 60+). Age group classification was informed by similar practices in previous developmental research within the context of breast cancer (Oktay & Walter, 1991; Fisher, 2014).
Participants

Three hundred and seventy-six participants initiated the survey. Thirty surveys were excluded for incomplete data. Survey settings were programmed to require an answer to every question; however, multiple potential participants exited the survey after answering up to three initial questions. Therefore, tests for missingness were not necessary as all participants included in the calculations completed the survey in full. Three survey responses were excluded for inconsistent medical demographics. Thirty-eight responses were omitted due to relationship status (they were single, divorced, or widowed). As a result, 305 eligible participants completed the survey. The sample distribution for age, cancer stage, and survivorship length were consistent with overall figures for breast cancer survivors nationally (ACS, 2013). Survivorship length here was defined as time lapsed since women’s last primary treatment for cancer (i.e., chemotherapy, radiation, and/or surgery). The majority of the respondents in this study were White (72.1%), college graduates (32.4%), in spousal relationships (67.9%), and heterosexual (93%). Table 1 presents complete sample characteristics for participants of Phase 1.

Table 1

Sample Characteristics

<table>
<thead>
<tr>
<th>Variable</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sociodemographics</td>
<td>N</td>
</tr>
<tr>
<td>Age Group</td>
<td></td>
</tr>
<tr>
<td>Young Adulthood (&lt; 40)</td>
<td>91(2.6)</td>
</tr>
<tr>
<td>Middle Adulthood (41-59)</td>
<td>186 (54.7)</td>
</tr>
<tr>
<td>Older Adulthood (60+)</td>
<td>28 (8.2)</td>
</tr>
<tr>
<td>Race</td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>245 (72.1)</td>
</tr>
<tr>
<td>Medical Demographics</td>
<td></td>
</tr>
<tr>
<td>----------------------</td>
<td>----------</td>
</tr>
<tr>
<td>Cancer Stage</td>
<td></td>
</tr>
<tr>
<td>Stage I</td>
<td>92 (27.1)</td>
</tr>
<tr>
<td>Stage II</td>
<td>105 (30.9)</td>
</tr>
<tr>
<td>Stage III</td>
<td>65 (19.1)</td>
</tr>
<tr>
<td>Stage IV</td>
<td>24 (7.6)</td>
</tr>
<tr>
<td>I don’t know</td>
<td>19 (5.6)</td>
</tr>
<tr>
<td>Currently on hormonal therapy</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>No</td>
</tr>
<tr>
<td>Survivorship length</td>
<td></td>
</tr>
<tr>
<td>0-11 months</td>
<td>93 (27.4)</td>
</tr>
<tr>
<td>1-2 years</td>
<td>85 (25.0)</td>
</tr>
<tr>
<td>3-5 years</td>
<td>62 (18.2)</td>
</tr>
<tr>
<td>5-10 years</td>
<td>48 (14.1)</td>
</tr>
<tr>
<td>+10 years</td>
<td>17 (5.0)</td>
</tr>
<tr>
<td>Treatments caused early menopause/ovarian failure</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>Don't know</td>
</tr>
<tr>
<td></td>
<td>Not applicable</td>
</tr>
<tr>
<td>Treatments caused lasting physical changes</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>No</td>
</tr>
</tbody>
</table>

*Notes: Total n=305. 1. Other includes, Asian, Native American, Native Alaskan, Pacific Islander*

### Procedures

Emails and flyers listed the study web site (http://bcsurvivor-sexualhealth.com/).

The web site included a link to complete the survey online via SurveyMonkey. The first page of the survey contained informed consent material. Participants clicked “agree” to
provide consent. Participants input sociodemographic and medical demographic information as well as provider preference and completed two brief instruments assessing sexual health and willingness to communicate about sexual health. On the last page of the survey participants were thanked and asked if they would be willing to participate in phase 2 of the project (see Appendix A for informed consent documents for both phases). If interested, they supplied their name, telephone number, or email address.

Measures

The following instruments were used to gather sociodemographic information, medical information, and provider preferences. Two scales were used to operationalize willingness to communicate and sexual health outcomes.

**Sociodemographic and medical information.** Participants provided demographic information related to age, marital status, race or ethnicity, education level, employment, and income. Participants supplied the following information related to their breast cancer diagnosis and treatment: diagnosis date, cancer stage, treatment type, and date of treatments. They also indicated if (1) they were or have taken adjuvant hormonal therapy, (2) if treatments caused early menopausal state or premature ovarian failure, and (3) if treatments caused lasting physical changes such as visible scars, current hair loss, or weight changes. Sociodemographic and medical information questions were adapted from Meyerowtiz, Desmond, Rowland, Wyatt, and Ganz’s (2008) exploration of factors influencing pre- and post-breast cancer sexuality. To collect information regarding survivors’ medical provider patterns, participants were also asked whom they considered
their primary general health care provider and which provider they would talk to if they had a sexual health concern (see Appendix B for instrument).

**Sexual health outcomes.** *Sexual Quality of Life – Female (SQOL – F).* The SQOL – F (Symonds, Boolell, & Quirk, 2005) was used to operationalize sexual health. The SQOL – F is an 18-item scale that addresses sexual health quality of life for females. The SQOL – F contains statements that address both the psychological and social dimensions of sexual health. Specifically, the SQOL – F assesses sexual confidence, emotional well-being, and relationship issues. For example, included are statements such as “When I think about my sexual life, I feel frustrated,” “When I think about my sexual life, I worry that my partner feels hurt or rejected,” and “When I think about my sexual life, I am satisfied with the frequency of sexual activity.” Each item is rated on a 6-point Likert scale ranging from "completely agree" to "completely disagree," in which a higher score reflects better SQOL. The authors found that all items were interrelated, suggesting an overall total score rather separate domain scores is preferable. Supporting this treatment of the data, principal component analysis revealed one factor accounted for the majority of variance in SQOL scores in this study. The SQOL – F demonstrated a Cronbach’s alpha reliability coefficient of 0.95. This scale has been found to accurately reflect women’s level of physical sexual dysfunction (2005). According to the data of the original validation studies women without a sexual dysfunction had mean scores on the SQOL-F of 80.1 (see Appendix C for instrument).

**Communication measure.** *Willingness to Communicate about Sexual Health Scale (WTCSH).* Wright, Frey, and Sopory’s (2007) Willingness to Communicate about Health
Scale (WTCH) scale gauges patients’ willingness and comfort communicating about their health. For this study the scale was adjusted to assess patients’ willingness and comfort communicating about sexual health concerns with providers and non-providers, creating the Willingness to Communicate about Sexual Health Scale (WTCSH). The original scale includes 10 items measured on a 5-point scale (from strongly agree to strongly disagree), higher scores indicating more willingness to communicate. For instance, the scale includes items such as “I am comfortable talking about health issues with my physician.” However, Wright et al. (2007) reported that five items on the WTCH were more stable across different samples. Therefore, these items were selected and included on the new WTCSH. Further, one question assessing participants’ comfort having their partner included in the sexual health discussions with medical providers was added. Principal component analysis extracted one factor for the WTCSH Scale. This suggested these items were driven by the same underlying construct. The WTCSH demonstrated an overall Cronbach’s alpha reliability coefficient of .80 (see Appendix D for the instrument).

**Data Analysis**

Frequencies and a hierarchical multiple regression were run using SPSS Statistical Software Version 20 to answer research questions 1 - 4. Regression analyses first controlled for sociodemographic and medical demographic information when testing relationships between the independent variable (willingness to communicate about sexual health) and the dependent variable (sexual health outcome). A hierarchical approach was used in order to ensure sociodemographic and medical demographic information did not
explain away the association between WTCSH and SQOL. Entering demographic variables into the model first guaranteed that they would get “credit” for any shared variability they may have with the predictor of primary interest, WTCSH. Any observed effect of WTCSH could then be said to be independent of the effects of demographic variables.

**Phase 2: Capturing Narratives: Survivor, Partner, and Provider Sexual Health and Related Communication Experiences**

The next phase of this research extended our understanding of the relationships established in phase 1 by investigating complex experiences reported by individuals who are central to survivors’ sexual health challenges. Multiple perspectives were gathered to offer a more holistic view using survivors’, partners’, and providers’ narratives.

**Recruitment**

*Patients and partners.* The recruitment procedures for survivors were embedded within the first phase (see phase 1). To recruit partners, women who completed the interview were asked at the end of their participation if they would be willing to invite their partners to participate. Women were told their partners’ participation was not required and that they should only ask their partner if they felt comfortable doing so. If and when a survivor decided she was comfortable, she supplied her partner with the study website and associated email address so that the partner could contact me. After recruitment, partners and received an informed consent form and writing prompt via email or the U.S Postal Service.
**Providers.** For phase 2 a range of medical specialties were targeted as informed by the results of phase 1. Provider recruitment was conducted in several departments at Fort Belvoir Community Hospital (FBCH). After approval by the FBCH Institutional Review Board, a resident physician and faculty physician from the Department of Family Medicine served as research partners and coordinated recruitment. The physicians were supplied with an information sheet for potential participants, a recruitment script, and a calendar. They invited providers to participate in an interview about their experiences/opinions regarding breast cancer survivorship care. The partner physicians gathered the participants’ scheduling preferences for an appointment with me, supplying a date, time, and location for the interview. The context of sexual health was purposefully excluded in order to avoid sensitizing participants to the topic. This was deemed important because the stigmatized nature of the topic might deter participation. This strategy also ensured the interviewees didn’t prepare answers ahead of time. This increased the likelihood that the interviews elicited a more accurate representation of the care currently being delivered.

**Sample**

The qualitative portion of the study was comprised of three participant populations—survivors, partners, and providers. The following paragraphs describe the sample characteristics for each population.

**Survivors.** Of the 305 survivors who participated in phase 1 of this study, 149 clicked they agreed to participate in phase 2 at the end of the survey. At the conclusion of phase 2 data collection, 40 women completed priming written reflections and participated
in in-depth interviews. The women ranged in age from 24 to 70 years old, with an average age of 49 (SD = 12.26). Women from the following age groups were represented: young adulthood (n = 12, M = 34.5, SD = 5.36), middle adulthood (n = 16, M = 49.5, SD = 3.59), and older adulthood (n = 12, M = 63.8, SD = 4.19). All women underwent some combination of surgery, radiation, and/or chemotherapy, completing primary treatment anywhere from 3 months to 25 years ago: 0-2 years (n = 13), 2-5 years (n = 14), and 5+ years (n = 13). All women participating in phase 2 were in heterosexual relationships. The majority were married (n = 34). Six women were in committed relationships.

The sample was predominantly White (n = 30) with a smaller number representing other ethnicities: Black (n = 6), Hispanic/Latina (n = 3), and Multiracial (n = 1). The majority of participants completed a college degree (n = 20) with the remainder completing various levels of education: high school graduate (n = 4), some college/vocational training (n = 7), or graduate schooling (n = 9). Most participants worked fulltime (n = 27) with fewer participants working part-time (n = 3), or not at all (n = 10). Almost half of participants reported a household income of over $100,000 (n = 17) with fewer numbers of women in lower income brackets $0-20,000 (n = 2), $21-40,000 (n = 5), $41-60,000 (n = 7), $61-80,000 (n = 3), $81-100,000 (n = 6).

**Partners.** Thirteen partners of women who participated in this research completed written reflections and in-depth interviews. Partners ranged in age from 41 to 73 years old, with an average age of 55 (SD = 9.82). Their girlfriends/spouses represented the following developmental phases: young adulthood (n = 1), middle adulthood (n = 8, M =
50.7, $SD = 6.36$) and older adulthood ($n = 4, M = 65.7, SD = 4.99$). Eleven of the 13 partners were married. Two were in committed relationships with survivors.

**Providers.** Providers from various departments FBCH were included in the sample. FBCH is operated by the Department of Defense and is located in Fairfax, Virginia in the Washington, DC metropolitan area. FBCH is a teaching hospital that cares for a military population, serving wounded, active-duty service members, retirees, and family members. Within its structure a wide variety of providers care for cancer survivors, similar to other health care institutions. In-depth interviews were conducted with 40 medical providers from a range of specialties: family medicine physicians ($n = 12$), gynecologists ($n = 11$), general medicine internists ($n = 3$), oncologists ($n = 3$), behavioral health specialists ($n = 4$), and nurses ($n = 7$). Nurses interviewed were specialists in several departments: family medicine ($n = 1$), gynecology ($n = 3$), general internal medicine, and ($n = 2$), oncology ($n = 1$). The participant group was evenly divided between male ($n = 20$) and female ($n = 20$). Providers had practiced medicine from 1 to 44 years, with an average 9.7 years of practice.

**Procedures**

During phase 2 data collection survivors, partners, and providers completed written narrative reflections and participated in in-depth interviews. The Critical Incident Technique (CIT) informed the written reflection prompt as well as the interview scripts (Flanagan, 1954). CIT is grounded in the narrative theoretical approach. It is a flexible set of principles, which help researchers understand how participants experience and behave in a certain situation as well as the meanings they attach to its significance (Keatinge,
CIT techniques during data collection often focus on solving specific problems by acquiring participants’ memories of an incident (Butterfield et al., 2005). Researchers have used this technique to identify effective and ineffective medical practices (Hosie et al., 2014; Schluter et al., 2008). CIT also represents a non-threatening method of capturing behavior, interpretations, and consequences of meaningful events (Keatinge, 2002).

In line with CIT, the writing prompt was designed to elicit a narrative surrounding a memorable moment or event the participant thought was a good example of how her sexual health had changed after breast cancer treatment. The narrative approach suggests that it is helpful for the researcher to first listen to the participant’s story before seeking to further refine their focus (Connelly & Clandinin, 1990). As such, the writing prompt used here allowed the participant to take the lead about the significance of the phenomenon under study. At the same time, researchers can also draw participants’ attention to several areas significant to the study foci when eliciting these stories (Phinney & Haas, 2010). Therefore, the prompt for this study contained instructions for participants to attempt to include the following information when relaying their story: the context of the moment or event (setting, time period, who else, if anyone, was involved); a basic description of what happened including what they or others said/did what they were thinking/feeling; and why this moment or event stood out to them as significant. The prompt indicated that participants could view the written reflection as an opportunity to give medical providers the information needed in order to understand their sexual health concerns. Partners of breast cancer survivors were given the same prompt but were instructed to write about
what they believe the survivor would view as memorable or important.

Survivors and partners emailed or mailed their reflections to me prior to the interview. The stories were used as a tool to prime myself and the participants for the in-depth interviews. Asking participants to write about their sexual health challenges prior to the interview provided participants the chance to reflect on their experiences through a less threatening medium before the interview took place. The rationale for collecting patients’ and partners’ stories prior to an interview is derived from other methodological approaches (e.g. the diary-interview method), which suggest their utility for gathering reliable information regarding sensitive topics (Zimmerman & Wieder, 1977). The written reflections also expanded my understanding of sexual health issues (thereby contributing to research question 5) and sensitized me to areas of significance prior to the in-depth interviews. As such, they were treated as a tool to improve the quality of subsequent interviews but were not analyzed as data.

The written reflection prompts and interview guides were pilot tested with the first three participants from each group sampled (survivor, partner, and provider) to verify that the methodological mechanisms were congruent with the research questions and modify the approach to enhance the rigor of the study (Morse et al., 2002). As a result of pilot testing, the wording of the writing prompts and several interview questions were altered as one mechanism to increase ensure the validity of findings.

Interviews were conducted using a semi-structured interview script containing mainly open-ended questions. Interviews with survivors and partners were conducted over the telephone. Interviews with providers were conducted in private offices in various
departments at FBCH. In this study, the CIT approach centered interview questions on participants’ individual experiences. During interviews with survivors and partners, I first drew participants’ attention to elements of their written narrative and then asked them to describe their sexual health issues, challenges addressing these issues in a medical setting, and provider communication behavior they viewed as helpful and unhelpful. Data analysis processes ran concurrently with data collection (Strauss & Corbin, 1998) so that the semi-structured script could be adapted across interviews. This allowed me to pursue emerging insights and served as a verification strategy. Executing these tasks simultaneously helped me be responsive and flexible when listening to participants’ thoughts and concerns (Morse et al., 2002). Thus, it better equipped me to substantiate developing ideas and identify new areas of exploration (Morse et al.)

In-depth interviews were conducted with survivors, partners, and providers. The interview guide included many of the same questions to be answered from the patient, partner, and provider perspectives, making comparisons possible across the three perspectives. However, while participant groups received the same foundational questions (which allowed comparisons between groups), the script’s reflexivity captured a multidimensional picture of each group of insiders’ experiences as directed by the participants themselves. Comparing multiple peoples’ perspective within the same relational dynamic (e.g., patient-provider-partner) is rarely done in health behavior research. Yet, obtaining all parties’ perspectives is critical to capture the health issue at hand and determine optimal communication practices for attending to them.
All interviews were audio-recorded and transcribed. The interviews for survivors averaged 83 minutes in length, resulting in 48 hours, 51 minutes, 19 seconds of recorded material and 823 single-spaced pages of data. Interviews with partners lasted an average of 42 minutes resulting in 9 hours, 26 minutes, 18 seconds of recorded material and 165 pages of single-spaced pages of data. Interviews with survivors and partners were conducted prior to provider interviews. This was done to allow for the emergence of additional areas of inquiry that needed to be included in data collection with providers. Given the repetition of several themes within the interviews with survivors and partners, it became clear that analysis should capture the reasons why providers do not bring up the topic of sexual health as well as their explanations for why they may believe sexual health is not a relevant conversation for some breast cancer survivor populations. Interview length with providers was an average 25 minutes generating 16 hours, 54 minutes, 12 seconds of recorded material and 370 pages of single-spaced data.

As interviews were conducted and transcribed a coding system was used to organize the data and allow for a clear presentation of results. Survivor interviews were represented with a numerical identification code (1, 2, 3, etc.). If the survivor’s partner participated in this study the survivor identification code was accompanied by an a (e.g., 1a or 2a). Partners’ identification codes were matched to their wives’ or girlfriends’ codes such that their code is identical except they were signified with a b. For instance, one couple was presented in the data as 3a (survivor) and 3b (partner). Medical providers were assigned a numerical code (1, 2, 3, etc.) and the letter p to distinguish them from survivor data. In addition, pseudonyms were created to replace the names of real people
referenced in the interviews (see Appendix E for semi-structured script for each population).

Analytical Process

Riessman (2008) suggests that thematic analysis is an analytical approach that can help highlight important experiences by categorizing thematic aspects of the narratives. In thematic analysis, a researcher categorizes data by identifying patterns (Keyton, 2006). I used the constant comparative method (Glaser & Strauss, 1967) to conduct a separate thematic analysis for each research question in phase 2. Further, analyses were separated by population (survivor, partner, and provider). Analysis of survivors’ interview transcripts was also divided by age group and survivorship length.

To conduct a thematic analysis, I first immersed myself in the data associated with each research question. Data immersion involves engaging in entire breadth of the data by reading and rereading transcripts, listening to recordings of interviews, and thinking about the ideas that are important to participants (Creswell, 2007). Subsequently, I initiated the first step of the qualitative coding process, which is open coding or initial coding (Tracy, 2013). This step involves examining the data and assigning words/phrases that epitomize their essence. As open coding continues general codes will be transformed into codes that are more specific and active (Tracy). Next, during second level coding, I critically examined the descriptive codes, looking for recurring or repetitive ideas, and began to organize, synthesize, and categorize codes into interpretive themes that made conceptual sense (Aronson, 1994; Tracy, 2013). As the process continued, codes were examined for thematic salience, which was determined here by recurrence, repetition, and
forcefulness (Owen, 1984). During thematic analysis properties were developed as I continually compared the data applicable to each recurring category/theme and constantly modified definitions to fit new data or broke them off to create new codes. This continued until categories/themes were easily distinguishable and succinct (Boyatzis, 1998; Glaser & Strauss, 1967). Themes for each group (survivor, partner, and provider) were also contrasted and compared to better understand the nature of women’s sexual health experiences and communication needs or challenges.

The presentation of results includes frequency counts for each theme. Typically frequency counts are not presented in interpretive designs using semi-structured interview scripts because all participants do not receive identical questions (Daly, 2007). However, there is an argument for including them when researchers want to demonstrate that some concerns feature more prominently in experiences than others (Daly). Given that participants were all asked the same foundational questions and taking into account comparative nature of this study, understanding the frequency with which themes appear across participant groups adds value to this analysis. As such, in this instance numbers are not misleading but may contribute to our understanding “of the shared and patterned experiences of participants” (Daly, 2007, p.234). The presentation of results was arranged in an order intended to best demonstrate the complex relationships between themes. To be included in the presentation of results a theme needed to be reported by at least 20% of participants.

To present the data, thematic findings for survivors, partners, and providers were categorized as action-oriented statements to present an explicit interpretation of their
“practical import” (Fisher, 2014; Morse et al., 2009, p. 1036; Sandelowski & Leeman, 2012, see Table 14.1). Themes were integrated into tables according to each group (survivors, partners, and providers) using the “ecological sentence synthesis” approach for intervention efforts aimed at enhancing patient care (see Banning, 2003). Discrepancies among survivor, partner, and provider themes that have the ability to negatively impact patient care were also presented in table format (see Tables 8, 13, & 17).
CHAPTER 4

Phase 1 Results

This study was conducted in two phases with distinct aims serving a larger goal: improving survivorship care. The goal of phase 1 was to link women’s sexual health outcomes with their age, treatment, and willingness to communicate with providers about sexual health issues as well as to understand who they regarded as primary and preferred health care providers with regard to general care and sexual health care. Research questions 1 - 4 were answered quantitatively.

Sexual Health Distress Prevalence

Research question 1 explored whether women of all ages and survivorship lengths reported sexual health concerns. As noted, the SQO-F scale was used to assess sexual health distress with a higher score indicating better sexual health quality of life. The mean SQOL score for this sample was 53.4 out of 100. According to the original validation studies, developmentally diverse “healthy” women without sexual dysfunction (FSD) acquired mean SQOL scores of 80.1 and women with diagnosed FSD scored an average of 59. This suggests that breast cancer survivors reported notably diminished SQOL as compared to their “healthy” peers. Their scores are in line with women diagnosed with FSD. The authors of the SQOL-F call for the instrument to be tested in patient populations with FSD-associated medical conditions. This result adds to that body
of literature. Furthermore, survivors reported sexual health issues regardless of age, race, and medical demographics (including survivorship length). There were no statistically significant differences in SQOL scores according to these factors. In other words, sexual health dysfunction is an experience for women that persists throughout survivorship and across adulthood.

Higher SQOL scores were seen if participants answered no to “did breast cancer and treatments cause lasting physical changes?” or they answered not applicable to “did the treatments you received cause an early menopausal state or premature ovarian failure?” Lower scores were seen among Black women. However, these differences are purely descriptive and not statistically significant. The mean SQOL scores are presented in Table 2.

Table 2

<table>
<thead>
<tr>
<th>Group</th>
<th>Mean SQOL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age Group</td>
<td></td>
</tr>
<tr>
<td>Young Adulthood (&lt; 40)</td>
<td>53.5</td>
</tr>
<tr>
<td>Middle Adulthood (41-59)</td>
<td>54.9</td>
</tr>
<tr>
<td>Older Adulthood (60+)</td>
<td>51.7</td>
</tr>
<tr>
<td>Race</td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>55.3</td>
</tr>
<tr>
<td>Black</td>
<td>46.0</td>
</tr>
<tr>
<td>Hispanic/Latina</td>
<td>53.5</td>
</tr>
<tr>
<td>Multiracial/Other</td>
<td>49.0</td>
</tr>
<tr>
<td>Cancer Stage</td>
<td></td>
</tr>
<tr>
<td>Stage I</td>
<td>56.0</td>
</tr>
<tr>
<td>Stage II</td>
<td>52.6</td>
</tr>
<tr>
<td>Stage III</td>
<td>49.9</td>
</tr>
<tr>
<td>Stage IV</td>
<td>57.5</td>
</tr>
<tr>
<td>I don’t know</td>
<td>63.5</td>
</tr>
<tr>
<td>Currently on hormonal therapy</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>53.7</td>
</tr>
<tr>
<td>No</td>
<td>54.6</td>
</tr>
<tr>
<td>Survivorship length</td>
<td></td>
</tr>
<tr>
<td>0-11 months</td>
<td>55.1</td>
</tr>
<tr>
<td>1-2 years</td>
<td>52.5</td>
</tr>
<tr>
<td>3-5 years</td>
<td>54.5</td>
</tr>
</tbody>
</table>
Medical Provider/Interaction Preferences

Research questions 2 and 3 were broadly aimed at gathering information about medical provider preference. Research question 2 asked which provider survivors considered general health primary care provider. The American Academy of Family Practice (2014) defines primary care providers as a patient’s comprehensive first contact and continuing care medical provider for general undiagnosed signs, symptoms, or health concerns. Research question 3 asked women which type of provider they would visit if they had a sexual health concern. Of the 305 participants, most survivors reported they considered their primary health care provider to be their family medicine physician ($n = 126; 41.3\%$), followed by their oncologist ($n = 95; 31.3\%$), and, lastly, their general internist ($n = 51; 16.7\%$). However, results for research question 3 indicated that if women had a sexual health concern in survivorship, they were most likely to visit their OBGYN to discuss it ($n = 117; 38.3\%$). Another 22% of women ($n = 67$) reported they did not know who to go to when they have a sexual health concern.

Two items from the WTCSH generated noteworthy results that are relevant to patterns of medical provider preference and utilization. First, over 70% ($n = 215$) of
women disagreed with the item, “I am quick to make an appointment when experiencing a sexual health issue.” These findings support the need to saturate clinician types in the interview phase of the study as women also reported relying on a variety of providers for their medical care. Even though 38% said they would visit their OBGYN to discuss sexual health issues, this finding indicates women might still be hesitant to make an appointment to discuss sexual health. Thus, they may never do so, even with their OBGYN. Not only should a variety of provider types be aware of sexual health issues in cancer survivorship, but they should also be prepared to engage in the discussion with survivors.

Second, when participants were asked if they were comfortable having their partner present in a medical interaction where sexual health was discussed, their responses demonstrated potentially important variations. Forty-seven percent ($n = 144$) agreed they would be comfortable with their partner’s presence. However, 32% ($n = 98$) reported they would be not comfortable. This division presented another opportunity for phase 2 (i.e., in talking to both women and partners their reasoning for wanting or not wanting a partner present could be better explained). Table 3 presents the statistics for medical provider/interaction preferences.

**Table 3**

**Medical Provider/Interaction Preferences**

<table>
<thead>
<tr>
<th>Variable</th>
<th>$N$ (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Who do you consider your primary health care provider?</td>
<td></td>
</tr>
<tr>
<td>General Medicine Internist</td>
<td>51 (17.0)</td>
</tr>
<tr>
<td>Family Medicine Physician</td>
<td>126 (41.3)</td>
</tr>
<tr>
<td>Oncologist</td>
<td>95 (31)</td>
</tr>
</tbody>
</table>
If you had a sexual health concern in survivorship who would you visit to discuss it?

<table>
<thead>
<tr>
<th>Provider Type</th>
<th>Count (Percentage)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nurse (NP or RN)</td>
<td>2 (0.7)</td>
</tr>
<tr>
<td>OBGYN</td>
<td>9 (3)</td>
</tr>
<tr>
<td>I don’t have a provider I consider primary</td>
<td>21 (6.9)</td>
</tr>
<tr>
<td>General Medicine Internist</td>
<td>10 (3.3)</td>
</tr>
<tr>
<td>Family Medicine Physician</td>
<td>40 (13.1)</td>
</tr>
<tr>
<td>Oncologist</td>
<td>58 (19.0)</td>
</tr>
<tr>
<td>Nurse (NP or RN)</td>
<td>6 (2.0)</td>
</tr>
<tr>
<td>OBGYN</td>
<td>117 (38.4)</td>
</tr>
<tr>
<td>I don’t know</td>
<td>67 (22.0)</td>
</tr>
<tr>
<td>Write-ins^a</td>
<td>11 (3.3)</td>
</tr>
</tbody>
</table>

Notes: Total n=305. a. Therapist/psychologist n = 7.

Connecting Willingness to Communicate and Sexual Health

Research question 4 asked if there is a relationship between willingness to communicate about sexual health and sexual health outcomes. After the exclusion criteria were applied to the existing sample the preliminary goal of 315 participants for a regression model including all the sociodemographic and medical information gathered data was not met. After considering previous research indicating particular demographic variables of interest (age, race, education, cancer type, and survivorship length) and the overall goal of the study, it was concluded that the remaining sociodemographics and medical demographics could be excluded from the regression model because patterns among the excluded variables were adequately assessed through descriptives. As a result, the hierarchal multiple regression model conducted included WTCSH, SQOL-F, and five demographic variables, for a total of six variables. Post-hoc power analysis concluded that with six predictors, a sample size of 305, observed ($R^2=.10$), and statistical significance set at ($\alpha=.05$), the observed statistical power for the regression is (.90).
The overall model using WTCSH to predict SQOL was significant, \( F(6,266)=4.924, p < .000, \text{adj. } R^2 = .080 \). WTCSH \((b = 1.45, p < .000)\) was positively associated with SQOL. After controlling for sociodemographic and medical demographics, WTCSH accounted for 8% of the variance in SQOL scores. The results established a small but significant relationship between willingness to communicate about sexual health and SQOL in that women with poorer sexual health were also less willing or comfortable talking about it with medical providers and people other than providers in survivorship. Coupled with the previous result (that even if women have a concern they may not be “quick” to make an appointment), this suggests the need to capture the nature of women’s hesitancy to talk about sexual health or why it may not be prioritized in their care.

Exploring this issue is an important aspect of improving their survivorship care and, thus, should be further explored in phase 2. Table 4 presents the results of the hierarchal regression.

<table>
<thead>
<tr>
<th>Table 4</th>
<th>Multiple Regression Results for SQOL</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Step 1</strong></td>
<td></td>
</tr>
<tr>
<td>Age Group</td>
<td>.50</td>
</tr>
<tr>
<td>Race</td>
<td>-.13</td>
</tr>
<tr>
<td>Education</td>
<td>.24</td>
</tr>
<tr>
<td>Cancer Stage</td>
<td>.70</td>
</tr>
<tr>
<td>Survivorship Length</td>
<td>.09</td>
</tr>
<tr>
<td><strong>Step 2</strong></td>
<td></td>
</tr>
<tr>
<td>Age Group</td>
<td>.72</td>
</tr>
<tr>
<td>Race</td>
<td>-.21</td>
</tr>
<tr>
<td>Education</td>
<td>-.00</td>
</tr>
</tbody>
</table>
Cancer Stage  |  1.0  |  1.1  |  .05
Survivorship Length  |  -.90  |  1.7  |  -.03
WTCSH  |  1.5  |  .27  |  .32***

Note: $R^2 = -.017$ for Step 1, $\Delta R^2 = .080$ for Step 2 (p<.000) ***

**Conclusions and Directions for Phase 2**

Overall these results provided important insights into the state of women’s sexual health and survivorship care that were further explored in phase 2. Phase 1 results suggested that survivors, regardless of age or survivorship length, experience sexual health quality of life that is significantly lower than what previous research has shown as typical of their “healthy” peers. As such, sexual health is not only critical to survivorship care but also of great concern to survivors of variant age and survivorship length. While the findings demonstrated the significance of sexual health in survivorship care, the results also indicated that how or whether it is addressed in the clinical setting is quite complex.

For instance, women reported a wide range of provider types as their general health primary care provider, which supports the notion that various providers have the opportunity to address the sexual health issues with breast cancer survivors. Yet, at the same time, women also reported not making an appointment right away to address such concerns and were divided about whether or not they want their partner present in such clinical interactions. Given the results also showed that women with poorer sexual health were also less likely to talk about it, collectively these findings are concerning. Previous research shows that the transition to survivorship can be an especially uncertain and confusing time (Hewitt, Greenfield, & Stovall, 2006) and, at the same time, sexual health
is a taboo topic in society. This reality may contribute to women’s sexual health needs not being met, particularly if they are not talking about it because they are not sure who to address their concerns with or those issues are not being proactively addressed by providers. Exploring these complexities further in phase 2 was critical to ensure that sexual health is not only discussed in clinical interactions, but is addressed in a helpful manner.

Phase 2 attempted to explain aspects of the quantitative results and better understand the nature of women’s sexual health experiences and clinical interactions. Quantitative results suggested the following mandates for the qualitative portion of this study. First, women of all ages and survivorship lengths should be included as they all reported SQOL that was significantly lower than previously identified “healthy” controls. Second, a variety of provider types should be included in the sample as women reported visiting a range of medical professionals in survivorship. Special attention, however, should be given to recruiting family medicine physicians (as the highest number of women identified them as their primary care providers) and gynecologists (as women indicated they would visit them to discuss a sexual health concern). Third, given the relationship between willingness to communicate and sexual health as well as the number of women who did were not quick to make an appointment to discuss a sexual health concern, it was important to explore this reticence qualitatively. As such, the fourth mandate involved including interview questions that captured provider, partner, and survivor perspectives regarding the presence of the partner in the medical visit and the role of the partner overall in affecting women’s sexual health outcomes.
CHAPTER 5

Phase 2 Results

Three aspects of sexual health formed the focus of analysis for each group of participants: (1) women’s sexual health concerns in survivorship (research question 5), (2) challenges of addressing sexual health in a medical setting (research question 6), and (3) providers’ helpful and unhelpful communication behavior in the clinical interaction (research question 7). Research question 8 explored how survivor, partner, and provider understanding of sexual health and sexual health communication in survivorship merge and differ. Analysis is presented according to three perspectives (survivors, partners, and providers) to provide a more comprehensive understanding of sexual health concerns and provider-patient communication about this aspect of cancer survivorship care.

The results for phase 2 are organized by research question (research questions 5 - 7) and, thus, broken into three sections with analytical insights to answer research question 8 (comparing the three perspectives) integrated at the end of each section. Section 1 outlines the results for research question 5 (including variations in survivors’ sexual health concerns according to developmental stage and length of survivorship). Survivors’ perspectives are presented first followed by an analysis of how their sexual health concerns varied by age and length of survivorship. This is followed by an analysis presenting partners’ views and then providers’ perceptions. Section 1 concludes with a
brief discussion of differences and similarities that emerged by comparing each group of participants’ reports. Section 2 and 3 follow the same format by respectively presenting analyses for research questions 6 and 7.

Research Question 5: Sexual Health Concerns in Survivorship

Survivors’ perspectives. Analyses of survivors’ experiences revealed six dominant sexual health concerns during breast cancer survivorship: suffering physical symptoms that affect sexual functioning, experiencing shock or confusion about changes to the body, battling feelings of powerlessness, struggling to renegotiate the sexual self, worrying about relationship with partner, and navigating communication problems with partners (see Table 5). Themes are presented in an order intended to best convey the interconnectedness of women’s physical, psychological, and social sexual health concerns.

Suffering physical symptoms that affect sexual functioning. Women described physical changes due to cancer and its treatments that impact their ability to function sexually \((n = 39)\). These physical symptoms included hot flashes or menopausal symptoms, decreased libido, difficulty or inability to achieve orgasm, moderate to extreme pain with intercourse created by dryness and thinning of the vaginal lining, breast tenderness or numbness, nerve pain, lymphedema, fatigue, and weight gain. One woman summed up the physical changes she experienced in the following way: “It’s like an avalanche of symptoms designed to keep us from having sex – delicate skin that bleeds, no libido, hot flashes like a million needle pricks, fatigue and nerve pain in my breasts. I just cannot do it anymore” (28).
Cancer treatment can cause a variety of physical problems for women. Chemotherapy and hormonal medications like tamoxifen and aromatase inhibitors can cause premature menopause. One menopausal symptom that troubled survivors was hot flashes. Hot flashes were described as one of the first “hurdles” in women’s attempts to engage in sexual activity:

I mean they’re not painful but they’re incredibly uncomfortable and they come and go without warning. They’re very intense and usually happen at night. We’ll try to have sex several times in one evening and we cannot even get going because every time we do it seems like I have one. We cannot even get past the first hurdle. (10a)

Women also reported weight gain and fatigue, as a result of their primary and adjuvant treatments, as other first level hurdles they had to overcome during their partners’ attempts to initiate intimacy. They described how these outcomes hamper their ability to function sexually:

Suddenly you feel kind of fat and sluggish and old and that’s certainly not conducive to a satisfying sex life, and it’s got nothing to do with my husband, but thinking about all this extra weight I’m carrying prevents me from thinking about what I’m supposed to be thinking about in those moments. (23)

Surgical interventions also caused significant physical barriers for women in a nonsexual way, but these symptoms ultimately impact their sex life. Several women reported suffering from persistent lymphedema, a building up of fluid in different parts of the body that can happen after surgery to remove lymph nodes. The condition can be very uncomfortable and distressing (Gebruers et al., 2015). One woman spoke about the way lymphedema diminished her ability to be intimate with her partner. She said:

I have lymphedema in my arms and I just cannot bear to be touched there, for him to even look at it. Even if I was in the mood all he has to do is touch my arm by mistake and I’m in tears. (39)
Of these changes, however, decreased libido, difficulty or inability to achieve orgasm, and moderate to extreme pain with intercourse were cited most frequently within the interviews. Women found problems with arousal and orgasm extremely frustrating. One survivor reported, “I feel like it takes forever and sometimes it’s not worth it. Let’s just get it over with . . . It was very easy before. It was easy and now it doesn't work” (24). These issues changed the way some women conceptualize sex. One survivor said:

> For me that orgasm, I cannot do it. Sex used to be an opportunity and now it’s just a test. I keep failing the test and I’ve been through enough. I can’t keep banging my head against the door just for a slim chance it will work this time. I know it won’t so what’s the point? (21)

Women also reported extreme vaginal pain when their partners tried to have sex with them. One woman said, “The thinning of the lining makes that very painful . . . I mean, it hurts so badly I would cry out and the pain wouldn’t stop until hours after we tried to have sex” (32). As result, women started to “dread” attempts at intercourse. They suggested crying or panic attacks became instinctual precursors to attempts at intimacy, which they would try to hide from their partners.

**Experiencing shock or confusion about changes to the body.** Experiencing physical changes that affected their sexual function was not the only challenge women described. These changes, or their severity, came as a complete surprise to survivors. Thus, the impact of the changes described in the previous theme was not just physical—it was also emotional. After primary treatment, many women described a sense of relief, as if they were “finally stepping off a roller coaster” (13a). However, that sense of relief turned to shock and confusion when they realized the extent of the “fall out” that would continue to remain. As such, a distinct challenge for women during survivorship was the
feeling that they were not adequately prepared for the many changes cancer and its treatments caused. Women reported shock due to pain during intercourse, confusion about the source of low arousal, and being blindsided by the poor results of their breast reconstruction ($n = 17$).

Pain was a common physical experience as noted in the previous theme. One woman told a story about her emotional reaction after she first experienced pain with intercourse:

We weren’t able to [have sex], because it was just so incredibly painful for me . . . There was nothing they [the doctors] told me about anything else that could be giving me pain during sex . . . So, I was just in the dark, and figured it was me. I was focusing on the wrong thing; I was obsessing over the pain, and it was my fault that I couldn’t focus on something else than the pain to make it [sex] possible. At that point, when I had no options, or I didn’t know what else it could be, like if it was an infection, I just lost it. I had a little emotional breakdown, in essence. (25)

Women were also confused by their low arousal/sensation levels. Often, they were unsure about the cause of these symptoms. This survivor spoke about her confusion:

One of the things I didn’t anticipate was loss of sensation. Not in my breasts but my clitoris and it almost feels numb and I didn’t anticipate that. So it’s hard to differentiate normal menopause from breast cancer, you know? Is [this] normal? What’s going on? (11a)

In the absence of readymade explanations women also reported fearing these symptoms were evidence that their breast cancer had returned and spread. This woman said:

I just didn’t know what to think. Things were changing. I immediately thought, “Oh no, the cancer has come back.” You think that whenever you prick your finger after treatment anyway and these symptoms were just so severe. It was hard to think it wasn’t a bad omen. (1a)

Many women reported that medical providers had not prepared them for the possibility they could experience pain or that it could be so severe. As a result, women
were shocked, confused, and surprised, which created fear, anxiety, and self-blame. As evidenced above, women disclosed two assumptions they made about the cause of these changes: 1) that somehow the changes were “their fault,” and 2) that changes may be due to another health condition or as a result of their breast cancer metastasizing to their reproductive organs. Apart from the implications of these changes for their physical sexual lives, this sense of shock/surprise created unnecessary psychological distress.

Lastly, women described feeling blindsided when the results of their breast reconstruction were not what they were expecting. One survivor stated:

I was more upset and surprised because I never really knew there could be anything less than wonderful outcomes from reconstruction . . . I was blindsided because my hopes were so high and that was really difficult to deal with. It’s been depressing. (19)

There are ranges of options for reconstruction after breast cancer. The selection of which can differ depending on women’s cancer type, treatment plans, lifestyle factors, body type, and individual preferences (Morrow et al., 2014). Each surgery carries risk such as extrusion of the implant, implant rupture, rippling, unevenness, and skin scarring and necrosis. Some of the women in this study viewed reconstruction as a small compensation for their loss. When it became evident the results of surgery were not in accord with their hopes it was very difficult for them to process. As one survivor indicated,

I’m embarrassed to admit it, but the reconstruction was my one very small silver lining. It was my only shining hope I could feel good about myself again, and no one told me that was not the real story – that my hopes would be dashed again. (1a)

**Battling feelings of powerlessness.** The surprise women experienced was not an
isolated event. Rather, it contributed to women’s overall sense of powerlessness. After the initial shock at the discovery of sexual health changes women described repeated attempts to engage in sexual activity or to address sexual health changes using various treatments. These attempts usually failed and left them battling a feeling of powerlessness, which manifested itself in two ways: (1) women panicked because they could not control their physical symptoms during attempts at intimacy and (2) they felt hopeless because they believed there was no way to effectively address their sexual health changes ($n = 13$).

Survivors reported that the awareness of physical symptoms triggered emotional responses, which further encumbered their ability to function sexually. One such emotional response was panic. After continual failed attempts to have intercourse women began to anticipate that future attempts would be painful and unsuccessful. In turn, women began to panic as intimacy was initiated. For instance, one woman noted:

“I’m becoming more aware of it, and seeing that my anxiety can trigger a hot flash, or it can trigger my nerves being very sensitive; and I don’t want to be touched, or touch anything. I just know there’s nothing I can do to prevent it. I’m helpless and then I freak out from there . . . all this because I cannot control what’s going to happen. I know it’s going to hurt and so I panic. I know I cannot change it. (25)

In this survivor’s case, anticipating pain associated with intercourse caused her to become so upset that she would panic, which in turn provoked physical symptoms like hot flashes and sensitivity. Women reported feeling a kind of “paralysis” stemming from their feelings of panic. In these instances, knowing that they would soon experience discomfort caused panic, which created a domino effect that further impaired multiple domains of their sexual encounters.
For some women these feelings became chronic and debilitating – especially when they believed their symptoms could never not be improved. Women described a sense of futility because they felt powerless to correct their sexual health issues. For example, one survivor shared how her attempts to treat her sexual health issues created feelings of hopelessness:

I’ve tried everything . . . all the creams and exercises and toys and I don’t think there are any real good solutions. You just do the best you can with what is out there and keep looking. I keep looking. I keep trying new stuff and it doesn’t make a whole lot of difference, and again this may be one of those things that this is as good as it gets and you work around it somehow, but ultimately there’s no hope. And when I think about that it’s hard not to cry. Nothing works. (23)

Women’s feelings of hopelessness increased as time went by. As this survivor said, “I had more doubts that I would ever be normal again. A couple of months after that [the first failed attempted at intercourse] I was like, ‘I don’t know if I’ll ever even have sex again’” (6a). Hopelessness seemed tied to women giving up attempts at intercourse. This woman reported, “There was a suppository that she [the physician] also mentioned, and I tried that and it didn’t work well enough and I tried it a couple of times for a whole month and then I just said ‘forget that’”(8a). Multiple women in this study reported they had not had intercourse in years. This theme also illustrates that the physical symptoms women experienced were physical and emotional in nature. These emotional effects were severe at their often-unexpected onset (as demonstrated in shock or confusion about changes to the body), but also continued to impact women’s quality of life as survivors faced the new long-term reality that those changes imposed.

**Struggling to renegotiate the sexual self.** The physical and emotional challenges detailed in the previous themes carry additional burdensome implications for survivors.
Namely, these challenges can require extensive revisions to the way women view themselves as sexual beings. The women in this study reported the following changes which they struggled with when attempting to renegotiate their sexual selves in survivorship: violations of prior self-scripts, diminished self-worth, and feeling like their body parts were foreign or disordered \((n = 20)\).

Many women struggled with the feeling that the woman they used to be was now lost. They reported they had been robbed of elements of their identity, which formed their ideas about who they were as sexual beings. Feeling sick or experiencing weight gain/loss or hair loss provoked this change in sexual identity. One woman talked about how breast cancer violated her prior self-scripts:

So I didn’t really think about it then, but afterwards, when you start to put the pieces back together like one of the realizations that I had was “Wait, I’m not physically who I used to be” . . . I used to be 120 pounds. That’s my weight. I'm a runner, but I’m different now. It bothers me because I don't feel as attractive – like who I used to be. (17)

Another woman said:

My hair used to be waist length. So that was a big part of my sexuality. My partner would touch my hair - that made me feel pretty. It was down my back and all that. I just don’t feel as womanly with short hair, and I get nervous that I look like a boy. (39)

Many survivors also reported severe drops in self-worth related to their view of themselves as women. One survivor said, “Every day since [the diagnosis], I look in the mirror and I look like a chopped up mess. So then who would want to touch me at that point” (30)? Another woman confessed, “I feel so unattractive . . . It's been really hard. There was some depression and I think the depression is related to the fact, that I don't like the way that I look” (1a). Women dissociated the changed parts of their bodies from
the whole or described themselves as “disordered” or “monstrous.” These women often also expressed very intense feelings of worthlessness and said they abandoned the idea that sexuality could be part of their lives “on any level any longer” (33). One woman described her feelings of disorientation in a manner that demonstrate the separation of the old self from the “new” self:

My torso is not my own. It looks like some sort of science fiction thing to me. Frankensteinied, like I’m looking in the mirror before my shower it just does not really look like how a woman’s supposed to look. (19)

As this woman suggested, breast cancer and its treatments alter important aspects of how “a woman defines herself, her sensuality, sexuality and her own identity” (7a). The overall impact of women’s sexual health was significant and their attempts to renegotiate how they viewed themselves were largely unsuccessful.

Worrying about relationship with partner. As the aforementioned thematic illustrations demonstrate, these powerful psychological and physical challenges are not experienced in an individualized vacuum and ultimately extended into survivors’ perceptions about their relational lives. In particular, women reported a range of concerns regarding how these changes affect the quality of their relationship with their partner. Women’s worries about their relationship emerged via several paths: women worried their partner did not find them attractive, they worried about implications of decreased intimacy with their partner, and they worried that their partner felt rejected or dissatisfied. They also struggled with guilt for not providing their partners with the kind of sexual relationship they thought their partner deserved ($n = 24$).

Women reported regularly ruminated about what their partners think of their post-
cancer bodies. One survivor said, “My husband doesn’t see me as a sexual woman anymore. He doesn’t get excited by seeing me naked anymore” (21). Another woman’s story echoed the same relational anxiety:

I would not keep my shirt on but I noticed that my husband, I don’t think he knew what to do with my reconstructed breasts. He was ignoring them . . . he tried to touch it [her breasts] just a little bit and it doesn’t really work for the two of us because it’s not my breast, I mean, I don’t know. So, after that, I keep my top and my bra on every time. (17)

Women reported these negative ideas were reinforced when their partners rejected their attempts at intimacy or made positive comments about the way other women look. This woman said, “He could be with any other woman” (36). She also sometimes showed her partner pictures of what she looked like before the surgeries to remind him that her “previous self is still there somewhere.” These insecurities may be heightened due to the difficulty some women had engaging in sexual activity. Another survivor shared how she worries her pain was affecting her sexual relationship with her husband:

I think I would be frustrated if I were him, too . . . I guess he knew [how uncomfortable I was] because he stopped approaching . . . and then there was no, none of that, like even making advances. I thought of my marriage. I feel like this old couple that, your typical old married couple, that are just together as roommates. (26)

This survivor described how the lack of a sexual relationship began to impact other forms of intimacy:

We are not willing or happy or excited about initiating any kind of sexual contact and even sometimes, even cuddling, I don't. I'm not as readily available that way, then he did even say to me a couple of weeks ago . . . I reached over and grabbed his hand and he was like, “Oh, my goodness. You haven’t done that [in] forever, months.” (1a)
When patterns like this continued, women became aware of the effect it had on their partners. One woman spoke about her partners’ feelings of rejection after a period of months in which she did not initiate sex or respond to his advances:

He had been really hinting around for a while . . . are you attracted to me? Do you want to make love? . . . I did say to him once I have enough to deal with and I think he was disappointed and his feelings were hurt because he felt like” so you’re saying sex now is something to deal with?” That made me feel terrible. (15).

Guilt was a prominent feature of women’s relational worry. Regardless of the partner’s behavior, many women said they feel guilty about the effect breast cancer and its treatments have on their sexual relationship. Women reported feeling that they have failed their partners in some way. One woman said, “It is a struggle to maintain a relationship that I can feel good about - feeling like I’m pleasing him and am an equal partner when I cannot have sex” (32). Another survivor described it this way:

It’s guilt. You want to please your husband and when you can’t, when you know that your situation is the reason that you can’t then - I don’t know. I just felt bad for him and I felt - I felt worse for him than I did for myself. (30)

At the same time, women reported feeling “stuck” or “trapped” because they know there are no easy solutions to their problems and often they said they are afraid to talk to their partners. They said many of these issues are acutely felt but “left unsaid.”

Navigating communication problems with partners. As the previous theme demonstrated, women reported worrying about the impact of sexual health changes on their relational lives. They also reported these concerns are often “left unsaid.” This is because women found it difficult to talk about their fears with partners. Survivors reported several communication issues that challenge their ability to have productive
conversations with their partners about sexual health: mistrust of partner’s automatic
scripts, avoidance, partner defensiveness, and partners’ unwillingness to seek help for
their sexual health problems \( n = 22 \).

One communication behavior that women found particularly upsetting was their
partners’ use of automatic scripts – assurances that everything is fine when the survivor
brought up a concern. One woman spoke about her attempts to talk with her partner after
noticing he was not looking at her during sex anymore: “He said ‘No. No. That’s not
ture.’ So that’s how he handles that and it really hurts. He says ‘It’s not the case. I love
you. End of conversation.’ Like no further” (37). Women sometimes believed partners
use this strategy to avoid talking about their true feelings.

According to survivors, their partners may feel it’s easier to avoid talking about
the problems they are experiencing. One survivor spoke about how her husband changes
the topic, pretends he needed to go to sleep, or makes phone calls when she brings up the
topic:

I think for him - I don’t know - he just goes into avoidance I think where there’s
always something you can put in between us or it so it doesn’t have to become a
fight or have to be addressed and then you feel sort of powerless to continue this.
(33)

When survivors were able to engage their partners in conversations about sexual
health problems they said those conversations ended abruptly due to partner
defensiveness. This woman reported:

My husband is very defensive and we don’t really communicate anymore and any
time I tried to communicate with him on issues like this, he takes it very, very
personally. As if he is not doing his job and so I just stopped trying to talk to him
about it. (21)
Several women struggled with balancing two demands in their communication: absolving their husband from responsibility and trying not to blame themselves. Often this task proved to be too difficult. What seemed to make this even more frustrating for women was that their partners were not interested in seeking professional help to address these issues. One woman said, “I’ve suggested marriage counseling prior to that, and we’ve been talking about having someone come into our house that would work on this and he’s refused that to” (33). When partners were resistant to seeking help, it appeared to exacerbate other sexual health concerns, especially existing feelings of powerlessness and frustration.

**Variations by age and survivorship length.** The analysis carefully attended to diversity in women’s experiences according to their developmental phase or length of breast cancer survivorship. Several important differences in women’s sexual health concerns were revealed among themes. Variations existed within *experiencing shock or confusion about changes to the body* and *navigating communication with partners*.

**Variations by age** were noteworthy with regard to menopausal symptoms and survivors’ experience of shock or confusion about this change. As noted, women in this study reported this experience (e.g., hot flashes). However, the nature of the surprise was different based on women’s developmental stage. Younger women were shocked because they were not told to expect this outcome and when they were informed they were merely told they would experience a temporary or permanent premature menopause but were not offered contextual information. Since they had never experienced the symptoms of estrogen depletion they didn’t think about what that would mean for their bodies. Several
pre-menopausal women suggested they were so focused on surviving cancer that it never occurred to them to research what menopausal symptoms entailed or ask the provider for further information. They were shocked by the severity of their symptoms and largely noted they did not have expectations for what menopause would mean for them beyond implications for their fertility.

Post-menopausal women were also shocked by the menopausal symptoms they experienced. However, this shock was based on the violation of a clear-cut set of expectations based on their prior experience with menopause. Most of the older adult participants did not expect to see much change from their current level of functionality beyond the re-emergence of hot flashes (in cases where they had subsided). Yet, their expectations were violated regarding pain, sensitivity level, and hot flashes. This survivor talked about the severity of hot flashes:

What I didn’t realize – I didn’t realize tamoxifen has side effects. For the first month after I started tamoxifen, I started to have hot flashes that were like needle pricks; hot needles it felt like going in and out, and in and out. And it was not like that in menopause. I had hot flashes then. And they felt uncomfortable, and then they’re done. (20)

Survivorship length also affected the nature of women’s shock or confusion. During the first two years post treatment, women reported when they reinitiated sexual activity they were astonished by the pain and difficulty they experienced. At this time symptoms were at their most severe. This is the time period in which many women made their first attempt at talking to a medical professional about the issue. During these appointments several women reported providers told them a certain level of arousal and lubrication should return, particularly after they completed adjuvant therapies. As such,
the women earlier in survivorship indicated they expected many of these issues to resolve after they finished adjuvant therapies, which are typically prescribed for 5 years (though new guidelines have extended that time period to 10 years for some women (Cuzick et al. 2015).

Women in this study who completed primary treatment five or more years ago reported shock as well. However, their shock stemmed from the fact that their symptoms didn't cease after time passed. Many of these women eventually stopped looking for strategies to improve their sexual quality of life. One long-term survivor said:

My depression builds over time. I start to realize nothing is going to change. It’s shocking. It still shocks me every day but I’ve stopped trying to do anything about. Everyone who told me things would get better, even a little better, were lying. (21)

Survivorship length differences were also evident in their experience of navigating communication problems with their partners. Women in their first two years of survivorship reported more anxiety about partner defensiveness as they began to initiate conversations about sexual health. Issues surrounding their partners’ unwillingness to seek professional counseling for these issues was also only reported by women in the first several years since primary treatment. While marred by tension, these women described engaging in ongoing attempts at communication with their partners. However, women in the long-term survivor group reported more avoidance accompanied by an overall feeling that they could not come to a resolution through communication and often settled into resignation.

I kept talking but nothing worked. Maybe we’ll stay together, maybe we won’t. I can do or say nothing to change what is happening. I’ve tried for so long I just cannot do it anymore, but it weighs on me so heavily sometimes I cannot breathe.
I’ll probably never say another word about it to him though. (32)

Table 5

The Survivor’s Perspective of Sexual Health Concerns

<table>
<thead>
<tr>
<th>This percentage of survivors</th>
<th>describe these sexual health concerns,</th>
<th>which are characterized by the following dimension(s).</th>
</tr>
</thead>
<tbody>
<tr>
<td>(n = 39, or 98%)</td>
<td>Suffering Physical Symptoms that Affect Sexual Functioning</td>
<td>Hot flashes, decreased libido, difficulty or inability to achieve orgasm, pain with intercourse, breast tenderness/numbness, nerve pain, lymphedema, fatigue, weight gain</td>
</tr>
<tr>
<td>(n = 17, or 43%)</td>
<td>Experiencing Shock or Confusion about Changes to the Body</td>
<td>Shocked by pain during intercourse Confusion about source of low arousal/sensation Blindsided by poor breast reconstruction results</td>
</tr>
<tr>
<td>(n = 13, or 33%)</td>
<td>Battling Feelings of Powerlessness</td>
<td>Panicked by inability to control physical symptoms during intimacy Hopelessness due to belief sexual health issues cannot be resolved</td>
</tr>
<tr>
<td>(n = 20, or 50%)</td>
<td>Struggling to Renegotiate the Sexual Self</td>
<td>Violations of prior self-scripts Diminished self-worth Feeling like their body parts are foreign or disordered</td>
</tr>
<tr>
<td>(n = 24, or 60%)</td>
<td>Worrying about Relationship with Partner</td>
<td>Concern partner does not find them attractive Worry about decreased intimacy with partner Fear partner feels rejected or dissatisfied Guilt for not providing partners with the sexual relationship they deserve</td>
</tr>
<tr>
<td>(n = 22, or 55%)</td>
<td>Navigating Communication Problems with Partners</td>
<td>Mistrust of partner’s automatic scripts Avoidance Partner defensiveness Partner’s unwillingness to seek help for sexual health problems</td>
</tr>
</tbody>
</table>
Partners’ perspectives. Partners recognized many of the same biopsychosocial sexual health concerns reported by survivors. The men described five sexual health concerns they perceived women experience: suffering physical symptoms that affect sexual functioning, experiencing shock or confusion about changes to the body, feeling insecure about changes to the body, worrying about the ways sexual health changes are affecting their partner, and experiencing difficulty talking to their partners (see Table 6). While these themes are similar to those presented according to survivors’ perspectives, the men’s accounts provide a more comprehensive picture of the issues of concern.

Suffering physical symptoms that affect sexual functioning. Partners reported physical symptoms affect survivors’ sexual functioning. Specifically, they reported that low arousal/inability to achieve orgasm and pain during intercourse are the most troubling issues they noticed for their mates \( (n = 10) \). One partner said:

> Even more devastating to our sex life, is the fact that the medication has effectively killed her libido. If we have sex it is more like her performing whatever act for me, without any desire to do so, or capability for her to enjoy it. Sex with someone who doesn't want sex is not enjoyable. (12b)

Even when sex continues many partners reported they are aware survivors’ desire and ability to enjoy themselves had changed. In some cases, this altered the dynamic of their sexual relationship. Several men reported being so frustrated with or hurt by this that they no longer want to have sex as often, even when it was an option. One man discussed how decreases in his wife’s libido were related to decreases in other intimate behavior. He said, “We talked about it and she said she just doesn’t feel a whole lot of desire and even as simple as holding hands, there is no intimacy” (8b). In these couples, even though intercourse may be physically possible, survivors’ low arousal changes the
way couples relate to each other sexually.

In addition to changes to women’s arousal levels, partners reported the pain women experience during intercourse is significant. When sex continues in these circumstances it creates a lot of uncertainty and discomfort for partners. Moreover, like the survivors, their husbands also reported experiencing guilt. This partner said:

She doesn’t always tell me the truth so I don’t know if you know if we’re in the middle of having intercourse and she’s in a lot of pain, or a little pain . . . I just don’t ever know so for me, the act of it gives me guilt and worry, so it’s tough (3b).

This man also talked about how the pain his wife experiences during intercourse is problematic: “I don’t know where the lines cross if they do, but there is an extra amount of sensitivity and there was dryness and things like that. You can’t really move forward, because it’s painful” (6b). Feeling unsure about survivors’ pain level slowly lead partners to initiate sex less often. At times, sex was so painful the couple eventually reached a place where they no longer had intercourse. This partner said, “You know everything has changed, and we haven’t made love for 10 years. It hurts her too much” (5b). According to partners, survivors’ inability to become aroused and their pain during intercourse upsets both partners and leads to partners’ hesitation to initiate or continue sexual encounters. It can also lead to the termination of traditional sexual intercourse.

**Experiencing shock or confusion about changes to the body.** Partners reported that what made these physical changes more traumatic for survivors was the fact that they were surprised by many of the symptoms. Similar to the survivor group, partners reported that the women experienced shock or confusion about some of these changes to the body. In particular, they suggested that women were surprised by the poor results of breast
reconstruction, the emergence and continuation of pain or difficulty with intercourse, and confusion as to whether sexual health symptoms could indicate another health problem \(n = 4\).

Like survivors, partner said they are aware of women’s surprise and disappointment with breast reconstruction. As one husband recalled,

I think she was looking forward to having the implants put in . . . . The plastic surgeon said, “You’ll really love them. It will be so much better. It’ll look better” and all those things. So we were both looking forward to her new breast being more natural and softer and all those things . . . . The results were pretty poor . . . and so her perkier breasts are kind of wrinkled and not very attractive to look at and so I think she was shocked and disappointed and she’s still dealing with that . . . she said, “If I knew they were gonna look like this I wouldn’t even have done it.” (1b)

Another partner said his wife was devastated by the results of her reconstruction. He reported:

It did not turn out the way they we were led to believe at all. For a couples years she didn’t do anything about it, not wanting to go through more surgeries, but when we started to have more [relationship] problems, she discovered specialists that have new ways of doing that kind of surgery. We have to travel across the country for that. It’s been 9 years and she’s now in that process and that’s not going smoothly either. They [reconstructed breasts] keep getting infected and other things. She lost a nipple. (13b)

This suggests the consequences of not being informed about the realities of reconstruction can be painful and can last for years.

Partners also talked about how challenges with intercourse shocked survivors and were both physical and emotional. They discussed how the long-term nature of these changes was unexpected. For instance, as one husband stated she didn’t realize,

That this continues, she will be unable to make love and that these treatments and drugs would have these horrible effects for so long, really permanently. I was surprised I think she was too, that things weren’t going to be the same. (5b)
Partners’ indicated that both people in the relationship can feel equally unprepared for sexual health outcomes in survivorship. They suggested they both were uncertain as to how long issues would last. As one partner said, since they didn’t realize the problems could arise in the first place, they also were not sure if it was permanent. He also mentioned that no one was willing to say that to them.

The partners described how uncertainty about the longevity of this health outcome ultimately extended fears about the future of the sexual relationship. According to one husband, it was very difficult for his wife. He said, “At times now it’s frustrating for her because she wants to, but cannot, and she wonders will it be this way forever. I think that bothers her a lot, wondering if there’s a future” (10b).

Partners also suggested that when survivors were unprepared for the changes they experienced, it led to confusion, fear, and worry. The men described how in the past the women attempted to cope with this by creating their own explanation for the cause of symptoms – explanations that caused even more anxiety. One man suggested:

When she was feeling some vaginal changes she was worried. I think she went to her GP to talk about that, and actually she sent her to a specialist. I think her [the survivor’s] thought was maybe it was cancerous, that something was going on with her cervix. (1b)

Like the survivors, the men described how not being prepared for sexual health issues leads to traumatizing fears of recurrence.

**Feeling insecure about changes to the body.** As demonstrated in the previous themes, physical changes were experienced emotionally and both aspects of these changes can seriously impact women’s overall sexual health. Men in this study reported
an awareness of these emotional challenges. They suggested one way cancer and its
treatments can alter a woman’s emotional well-being is through changes to her body
image. Specifically, they said women are noticeably preoccupied with changes and
reluctant to let their partners look at them anymore ($n = 8$).

Partners reported women regularly engage in negative self-talk. Several partners
said that much of their days are punctuated by survivors’ talk of their bodies. This partner
said, “She regularly comments since her breast cancer either that she is ‘broken’ or her
body has betrayed her” (9b). Partners suggested women are acutely aware of the ways
their bodies changed and detail their insecurities so frequently that the men have become
extremely concerned:

Definitely body image – she’s super active, very athletic. She’s always been in
great shape. The post menopause has given her a little extra weight. The scars on
her chests on both sides are daily – multiple times a day reminders of her trauma.
Her lymphedema on her right arm is – I mean everything – this is constant.
There’s never a day that goes by that there’s not a mention of either her body
image or her arm or her chest. That’s constant and very troubling. (3b)

Like survivors, partners said they are aware that changes to the body impact women’s
self-esteem. Their accounts mainly centered on partner concerns about women’s constant
disparaging remarks. However, they did not report the full complexities of revisions to
the sexual self as was reported by survivors. Further, most of their observations were
related to how body image problems were related to how the survivor and the partner
interacted or the future of their relationship. Partners noticed survivors demonstrated
other behavior that revealed the depth of their insecurities post cancer, namely, the
reluctance to reveal their bodies. One man said, “Sometimes she’ll keep her bra on
[during sex]” (1b). Another partner said, “The anti-depressants have caused weight gain.
So this is upsetting and disappointing her. The weight gain has left her more disappointed with her appearance than the mastectomy and so she doesn't want to show me her body anymore” (7b). Partners often said they feel at a loss for words when trying to help their mates deal with their feelings related to these changes. The men reported women are worried about how these changes affect their partners. However, partners’ awareness of this worry is also a source of stress for the partners.

**Worrying about the ways sexual health changes are affecting partner.** As reported in the previous theme, partners said survivors’ struggles with self-esteem are characterized by attempts to hide their bodies from their partners. According to partners, survivors worry about the ways in which other aspects of their sexual health changes are upsetting or unfair to their partners. In particular, partners suggested that women experience guilt over how their decreased ability to enjoy/participate in sexual activity impacts their partner and worry their partner will leave them \( n = 5 \).

Men reported they know survivors feel badly because they no longer enjoy sex as much as they did pre-cancer. One partner said, “Sexual drive had lessened and of course she even felt bad for me . . . . She just felt guilt because of her lack of libido and sexual drive” (1b). Partners reported that despite knowing they could not control what happened to them, survivors often have a tendency blame themselves for the issues they are experiencing. One partner said, “It does make her feel in a sense like it’s her fault. It’s not and we both know that. Sometimes I reiterate that, but somehow psychologically or emotionally, it’s always going to be there” (6b).

Several of the men also reported that this guilt leads the survivor to fear the
partner will end the relationship. This man said:

No matter what kind of conversation we had it got back to that question of whether or not I was going to leave her because of the sex issue which was not the case . . . still, she worries sometimes. (8b)

Overall, partners themes echoed survivors’ concerns. Both survivors and partners reported that women are acutely aware that their sexual health changes extend beyond themselves and might have repercussions for their partner. According to both parties, women worry that these changes make them less equipped to provide their partner with the kind of relationship he deserves.

**Experiencing difficulty talking to partners.** Both survivors and partners connected women’s worries about sexual health to difficulties communicating within the relationship. Partners suggested they often have difficulty talking about their worries. They reported that women frequently delineate their insecurities but beyond that they have trouble openly conversing about challenges in their sexual relationships. They suggested that survivors’ difficulty is evidenced through their use of avoidance ($n = 3$).

One partner suggested he sensed his wife evading the topic of sexual health:

She doesn’t talk about it either because . . . she just doesn't have the desire anymore and it’s an awkward conversation so she just probably avoids it to not, I guess, rock the boat. If anyone is gonna rock the boat it will have to be me. (5b)

However, other partners admitted that both parties are not open to discussing the issue, either because they know there was nothing they can do about it or it is too emotional to pursue. This partner said, “It [sexual health changes] impacts our communication because I think she may be, she’s tap-dancing around it or ignoring it because she doesn’t want to deal with it” (3b).
Another partner described how he believes his wife was feeling after several unsuccessful attempts to have sex over a series of months:

It really bothered her that I didn’t say anything about it earlier . . . she said she knew it was bothering me but she didn’t know how to talk about it either. We both sort of avoided the topic because it was too much to get into. (11b)

While women in this study acknowledged that many of their concerns were left unsaid, which may be reflected by partners’ reports of avoidance, women also suggested that partners regularly avoid the topic. In addition, when women made attempts to communicate they felt their efforts were thwarted by partners’ defensiveness, use of automatic scripts, or unwillingness to get help. These discrepancies, and others, are explored through comparing perspectives of survivors, partners, and providers at the end of this section.

Table 6

<table>
<thead>
<tr>
<th>The Partner’s Perspective of Survivors’ Sexual Health Concerns</th>
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<tbody>
<tr>
<td>This percentage of partners describe these sexual health concerns, which are characterized by the following dimension(s).</td>
</tr>
<tr>
<td>(n = 10, or 77%) Suffering Physical Symptoms that Affect Sexual Functioning Low arousal or inability to achieve orgasm Pain during intercourse</td>
</tr>
<tr>
<td>(n = 4, or 31%) Experiencing Shock or Confusion about Changes to the Body Surprised by emergence/continuation of pain with intercourse Fear sexual health symptoms could indicate another condition Blindsided by poor breast reconstruction results</td>
</tr>
<tr>
<td>(n = 8, or 54%) Feeling Insecure about Changes to the Body Preoccupied with dislike of changes to the body Reluctance to let partners see them naked</td>
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Providers’ perspectives. Medical providers reported that breast cancer survivors experience a range of symptoms that affect their sexual lives and that these changes may also cause significant tension within their relationships. Three themes emerged regarding women’s sexual health concerns: suffering physical symptoms that affect sexual functioning, struggling with the aftermath of breast cancer surgeries, and coping with changes in their romantic relationships (see Table 7). While the providers’ narratives resulted in fewer themes, the primary issues of concern do overlap with the survivors’ perspective, albeit at a less nuanced level.

Suffering physical symptoms that affect sexual functioning. Like survivors, providers also recognized that women experience a wide range of physical changes that impact their sexual functioning. They offered detailed descriptions of how these physical changes affect women’s sexual health. The physical changes that emerged from interviews with providers clustered within four areas: menopausal symptoms, weight gain, low libido, and pain during intercourse ($n = 30$).

Providers suggested that women can experience a range of symptoms related to breast cancer treatments, which cause premature menopause or the intensification of menopausal symptoms. One family medicine physician said, “With menopause they’re
going to get irritation, hot flashes, and their periods may stop completely” (16p).

Providers also pointed out that menopausal changes are likely more traumatic for younger women. This family medicine physician noted that older women may not find the changes “as scary.” He said, “A lot [older women] have already dealt with sexual challenges in the sense of lack of estrogen” (41p).

In addition to menopausal symptoms providers said some women experience weight gain. Weight changes were mentioned most often in the context of affecting a woman’s sexual response cycle – specifically her ability to become aroused. A psychiatrist told a story about one of her patients who struggled with this:

She ended up gaining a lot of weight during her treatment and so that’s actually been a very primary focus. It affects her ability to feel in the mood. This actually interferes with her response cycle and her ability to become aroused. (22p)

Providers from a behavioral background (in this case, psychiatry, psychology, and clinical social work) more frequently discussed how weight changes affect women’s arousal.

Providers are aware that breast cancer and its treatments cause reductions on women’s libidos. One family medicine physician said, “You know from a hormonal standpoint, if they’re on any kind of medications or chemotherapies, anything that can affect sex drive, libido” (21p). A gynecologist pointed out that, “A lot of them [survivors] can’t have hormones or hormone replacement so they’ve got dyspareunia, which is pain with intercourse” (11p).

While the awareness of physical effects was high, some providers reported assuming many of the sexual side effects caused by cancer and its treatments resolved
fairly quickly and that some women may not be concerned about them at all or at some point during survivorship. This family medicine physician talked about treating survivors who are a couple years post treatment, “Those effects are likely gone and I know this is bad, but being older maybe they just aren’t concerned about that anymore” (31p).

Providers did offer extremely detailed accounts regarding the physical changes women experience and how those changes can alter sexual functioning, yet descriptions of the potentially long-term psychological and relational impact of these changes were not as rich. The following two themes illustrate instances in which the psychological and relational implications of breast cancer were noted.

**Struggling with the aftermath of breast cancer surgeries.** When providers did report a psychological dimension of sexual health changes it was focused primarily on one aspect of the breast cancer experience, namely, the effects of breast cancer surgery. They recognized that surgeries for breast cancer (such as lumpectomies and mastectomies) create psychosocial distress that women struggle to cope with. Specifically, they reported that physical changes due to breast cancer surgeries can alter a woman’s sexual self ($n = 13$).

Providers recognized the profound symbolic importance of the breast for many women. One oncology nurse practitioner explained it this way:

> As women in our culture our breasts are kind of our womanhood. So for a lot of our mastectomy patients, or even lumpectomy depending on how extreme, it is a huge thing for them . . . they don’t feel as attractive anymore. So that affects a lot of women in the way they view themselves. (38p)

Providers reported a sensitivity to the loss or disfigurement of breast tissue and spoke of treating patients who struggled with surgeries. A family medicine physician told
one such story:

I remember there was a patient in medical school who identified herself with her breasts and that was where she found her womanhood. And what was interesting to me is from a sexual health perspective is that it didn’t really particularly matter to her husband. It didn’t change how he found her, it was really her confidence and her sense of self was lost, which I can easily see. I think that when you’ve had such a sensitive area undergo so many traumatic surgeries changing the way that area looks and also through the idea that cancer equals sickness so your breasts are sick. I can easily see that being an issue as far as how you identify with yourself. (27p)

Even though providers indicated that changes to the breast were unique and may be perceived more powerfully than would changes to other parts of the body, they also indicated that women may think the damage is worse than it is “from an empirical standpoint.” A gynecologist recounted one of his experiences with a patient he believed fits this pattern:

She’s like, “I’m so ugly” you know “I look terrible. I can’t wear this. I can’t wear that. I look horrible.” And I’m like “come on, how bad can it be?” and she actually said, “I’ll show you” and showed me. She lifted up her shirt and showed me the scarring to which I was like “Whatever. I’ve seen that before.” But for her it’s profoundly disfiguring. (14p)

While providers discussed the symbolic importance of breasts and the psychosocial implications of surgery on the breasts, many also minimized the implications for individual women. For instance, providers reported saying to women that the damage was not as bad as they thought. This has implications, which are discussed in research question 7.

**Experiencing distress in their romantic relationships.** Several providers recognized the relational component of sexual health changes. They indicated their patients had disclosed distress about changes in their romantic relationships. Relational
distress emerged in two different forms: women expressed concerns over decreased intimacy with their partner and women struggled with their partners’ reactions to their physical changes (n = 9).

Providers reported that survivors may be worried about their diminished capacity to have sex. One gynecologist talked about one of her patients who tried to cope with this:

She had gone through premature menopause in her 40s due to chemotherapy and she had done fine for about five years or so until sex had become really painful for her and she couldn’t have sex anymore. It was a big stress for her and for her marriage and for her quality of life. It was causing tension in her marriage. (34p)

These accounts echoed survivors’ and partners’ stories regarding the emotional impact of declining intimacy. This family medicine physician talked about one patient’s concerns:

“She said, if I could just feel like I want to have sex more than it would be better for my husband. I miss it and my husband feels rejected because I don’t feel those things anymore” (16p).

In addition to worrying about the consequences of a diminishing sexual relationship, providers suggested women are also deeply troubled when their partner’s reaction to their post cancer bodies is negative. One family medicine physician said women struggle because, “You may not feel sexually attractive anymore or your spouse may have a negative reaction to you that also can be devastating” (18p). Women also reported that any signal that their spouse may be unhappy with the state of their sexual lives can be very traumatic. This oncologist reflected on the issues she’s seen in her practice:
Divorce is really common when women are diagnosed with breast cancer. It’s really sad but it’s really common . . . A lot of spouses react negatively to these changes . . . They are just not as supportive as I’d like so even if they’re still having sex, since things about their partner may have changed sexually – her appearance, for instance, they have problems with it. (33p)

The distress that breast cancer and its treatment create in a romantic relationship is a central theme in survivor, partner, and provider narratives. However, it was far more comprehensive in the survivor narratives. The potential reasons for these discrepancies are further discussed below.

Table 7

<table>
<thead>
<tr>
<th>The Provider’s Perspective of Survivors’ Sexual Health Concerns</th>
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<tbody>
<tr>
<td><strong>This percentage of providers describe these sexual health concerns,</strong> which are characterized by the following dimension(s).</td>
</tr>
<tr>
<td><strong>(n = 30, or 75%)</strong> Suffering Physical Symptoms that Affect Sexual Functioning</td>
</tr>
<tr>
<td><strong>(n = 13, or 32%)</strong> Struggling with the Aftermath of Breast cancer Surgeries</td>
</tr>
<tr>
<td><strong>(n = 9, or 23%)</strong> Experiencing Distress in their Romantic Relationships</td>
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**RQ5: Closer Comparisons of Survivor, Partner, and Provider Perspectives.**

Several areas of similarity and variance emerged when comparing survivor, partner, and provider accounts of the sexual health issues women experience in survivorship. While all three groups recognized the biopsychosocial nature of the issues
facing women, different groups emphasized distinctive elements of women’s physical, psychological, and relational experiences. In addition, comparing the accounts revealed sources of possible misunderstandings that could impact quality of life and quality of medical care (see Table 8).

For instance, many survivors reported the fear that their partners are no longer attracted to them. They indicated this belief either stemmed from or was reinforced when they noticed their partners were reticent to look at or touch their breasts during sex. They reported that partners averted their eyes, closed their eyes, or carefully placed their hands in a position on their torsos – away from the women’s chest. This greatly disturbed many survivors. However, interviews with partners revealed the men are aware of women’s insecurities about their bodies. Partners reported sensing that women are uncomfortable having their breasts touched. These narratives present a fundamental disconnect. While survivors may perceive their partners are sending signals they don’t find them attractive, in some cases, this may be happening because partners sense the women’s discomfort and may be trying to avoid triggering negative feelings by focusing on other aspects of their sexual encounter. One partner explained it this way:

The big thing for me is I know she doesn’t really want me to touch, or even look at her chest in general. Like I said, I didn’t marry her because of her breasts anyway. She knows that. So, what I do is work around them. She’s less likely to get upset if I don’t draw attention to them by focusing on them. (4b)

Comparing perspectives also revealed that survivors, partners, and providers understand the serious effect partners’ negative reactions can have on women. It also uncovered that partners know how guilty women sometimes feel about the way breast cancer and its treatments have altered their sexual relationship. Some partners reported
that because they know how concerned women are about changes to their bodies, the men’s communication efforts are primarily aimed at easing women’s fears in this regard. For instance, one partner said, “She feels guilty. I kept talking about it and I was trying to calm her down. It’s not her” (5b). Many partners reported feeling at a perpetual loss for words as they tried to respond to survivors. They suggested it’s challenging to know how to reply when survivors start to question their appearance or their ability to have sex because they know how much their wives/girlfriends have suffered. They don’t want to upset them further by having that difficult conversation. Partners also reported guilt for being concerned about “their own sexual gratification” (13b) after their spouse or girlfriend survived cancer. Throughout the interviews, partners emphasized their gratitude for their significant other’s survival. One partner said:

    I married my wife because I love her. I didn’t marry her because of her breasts, and I want her in my life for the remainder of my life. So that is my big concern. I didn’t want to lose her. (2b)

    Partners’ awareness of survivors’ insecurities and guilt coupled with their own remorse and desire to protect survivors seemed to contribute to their use of automatic scripts when responding to women’s attempts to initiate conversations about their sexual health issues. While they are trying to be careful or protective of women, this approach can backfire. Survivors reported distrust for automatic scripts or assurances when they attempted to communicate with their partners. Women expressed frustration that their partners answered with blanket statements such as: “It’s going to be okay,” “You look great,” or “It doesn't bother me.” In certain cases, women felt like it was a way partners hid their true feelings. When women reported this interpretation of events they often
internally replaced what was said with their own worst fears such as, “He doesn’t know how to tell me he doesn't love me anymore” (21).

This comparison of reports suggests that understanding each other’s motivations for their behavior could minimize the relational distress women experience as a result of sexual health changes. This points to the need for strategies to help women and their partners express their thoughts and feelings in safe and supportive environments. Medical professionals may be in a position to assist couples in this regard. Unfortunately, several dimensions of the providers’ interviews shed light on potential discrepancies between the concerns survivors are reporting and how medical professionals perceive those issues.

Analysis revealed trends in providers’ perception of women’s sexual health concerns that may have implications for patient care. Shock or confusion about changes to the body was a major theme in both survivor and partners interviews. Yet, that theme did not recur in the provider interviews. In addition, providers appreciated how traumatic breast cancer surgery can be for women’s sexual selves, but several reported survivors’ negative thoughts and feelings were not based on anything “empirical” and suggested they communicated this to patients. Providers at times minimized the physical trauma which did not mesh with the survivors’ and partner’s descriptions. This divergence in views may have unintended effects in clinical interactions (this is further explored in subsequent RQ analyses).

Lastly, the majority providers reported that women experience physical symptoms that may affect sexual functioning. However, several providers did not recognize those symptoms and advanced different explanations for why sexual health concerns were not
present or commonly relevant to survivors. Additional analysis revealed the following provider explanations: older women are not as concerned with sex, long-term survivors don’t experience symptoms, survivors’ focus is on living but not sex, and survivors are happy with the results of their reconstruction.

A family medicine physician qualified his view of women’s sexual health concerns by saying when a woman is multiple years into survivorship, “those effects are likely gone and I know this is bad, but being older maybe they just aren’t concerned about that anymore” (31p). This assertion by providers stands in stark contrast to that of survivors and partners who described the long-term nature of these outcomes (their physical, emotional, and relational impact) and their belief that the change is permanent. Some providers assumed sexual health is not a long-term issue or something that concerns women regardless of age, whereas partner and survivor narratives revealed that it is.

This misconception on the part of providers may impede care. In some cases providers may not realize that all survivors are at risk for sexual health issues. Providers might assume that after the trauma of diagnosis and treatment women’s priorities shift away from sexuality. One gynecologist reported:

I’m not sure it’s really important for most women after something like cancer. I’ve seen some horrible stuff. I think their mindset must shift into a continuing survival focus and so that makes perfect sense to me. It’s not anywhere near the top of the list. (12p)

This assumption is problematic. While survival may be most women’s primary motivation, women in this study reported this does not equate to the dissolution of all other concerns.
These interviews also demonstrate that occasionally providers may have expectations regarding reconstructive surgery that don't always align with patient experience. A gynecologist reflected on the breast cancer survivors he’s treated in clinic: “Most patients have done fine. Many have had breast implants put in, and are very happy with them and the husband’s very happy and they’re doing fine . . . They return to their usual self”(1p). Some of these beliefs regarding the existence and nature of survivors’ sexual health concerns re-emerge as barriers to addressing sexual health in a medical setting are explored.
Table 8

*Variation across Perspectives: Survivors’ Sexual Health Concerns*

<table>
<thead>
<tr>
<th>Survivors reported these concerns, partners reported these concerns, and provider reported these concerns, which interact in the following ways, and suggest these actions points to enhance survivors’ quality of life.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Worrying about Relationship with Partner</strong>&lt;br&gt;Concern partner does not find them attractive</td>
</tr>
<tr>
<td><strong>Navigating Communication Problems with Partners</strong>&lt;br&gt;Mistrust of partner’s automatic scripts&lt;br&gt;Partner avoidance</td>
</tr>
<tr>
<td>Experiencing Shock or Confusion about Changes to the Body</td>
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<tr>
<td>Low arousal</td>
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<tr>
<td>Pain during intercourse</td>
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<tr>
<td>Reconstruction results</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Suffering Physical Symptoms that Affect Sexual Functioning</th>
<th>Suffering Physical Symptoms that Affect Sexual Functioning</th>
<th>Suffering Physical Symptoms that Affect Sexual Functioning</th>
</tr>
</thead>
<tbody>
<tr>
<td>Various</td>
<td>Various, with caveats</td>
<td></td>
</tr>
<tr>
<td>Various</td>
<td>While providers reported women can experience a range of physical issues, some indicated they do not believe issues affects survivor QOL for the following reasons: older women are not as concerned with sex, long-term survivors don’t experience symptoms, survivors’ focus in on living not sex, and survivors are happy with the results of their reconstruction.</td>
<td></td>
</tr>
<tr>
<td>Assumptions about when and why particular groups of women are not affected by sexual health changes have the potential to create health care disparities. Education efforts should be aimed at addressing these erroneous beliefs.</td>
<td></td>
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</tr>
</tbody>
</table>
Research Question 6: Barriers/Challenges to Sexual Health Care

Survivors’ perspectives. Analysis for research question 6 expanded our knowledge of sexual health concerns by exploring the barriers women encounter when trying to address those issues. Four themes emerged that represent challenges or barriers survivors reported when attempting to communicate about sexual health concerns in a medical setting: feeling inhibited by the taboo nature of sexuality, reluctance based on patient-provider demographic differences, believing providers cannot help them, and being unable to access timely or coordinated medical care (see Table 9). Themes were presented in an order intended to demonstrate how barriers range from micro/internal to macro/system level issues. They may stem from individual emotions, from interpersonal concerns, and from state of care or system level problems.

Feeling inhibited by the taboo nature of sexuality. Sexuality is a difficult topic for survivors to openly discuss. Many women reported feeling inhibited by the sensitive and personal nature of sexuality when thinking about discussing sexual health with medical providers. This inhibition emerged in three dimensions: 1) women expressed discomfort with the idea of talking to a medical professional because sex is taboo in their family or in dominant culture, 2) they outlined different ways psychological aspects of sexual dysfunction were stigmatizing, and 3) they indicated that talking about body parts or physiological processes was awkward (n = 16). These concerns prevented women from bringing up sexual health issues and discussing them in full.

It was initially difficult for some women to articulate why the subject of sexuality made them uncomfortable. Survivors were flummoxed because they reported in all other
respects they considered themselves direct, straightforward people. One woman demonstrated this:

I’ve never talked [about sex] and as close as I am to my doctor, I don’t think that’s something that I would talk to her about. I don’t know why. As I’m saying it to you, I have no idea why. But no, we’ve never talked about that. Maybe it was the way I was raised . . . I don’t think I’ve ever talked to anyone about sexuality even though I’m a very open person. (15)

Women referenced social norms in their family life to explain their hesitation – sex was not something that was discussed. Others indicated their families discussed sexuality freely when they were young, but that sexual dysfunction was something on a broader societal level, they felt encouraged to suppress. Women reported this discomfort was one reason they preferred their providers to broach the subject. One survivor said:

It’s hard to bring it up first. It’s hard to stop the exam and say, “Look, this is what I want to talk about” . . . I want somebody else to bring it up first. Just so I don’t think I have these bizarre feelings that no one else has . . . there’s a block in this society. That’s [bring it up] hard to do without their help. (24)

Discomfort with the topic of sexuality varied. Some women reported that the most taboo or stigmatized aspect of sexual health is the psychological or emotional components. One survivor suggested, “I think maybe my emotions toward all of those situations [body image issues and pain during intercourse], would be a little bit more uncomfortable to talk about” (25). Another woman reported:

It’s just the way I’ve been raised where you don’t bring up it . . . and people might think I’m crazy because I’m bringing up topics like that. The stereotype, you know, here’s this crazy emotional woman crying because no one thinks she’s pretty. (36)

Other women found sexual topics more uncomfortable in the context of discussing body parts and strategies to address physiological dysfunction:
I think the orgasm issue would be a difficult discussion . . . But I think also talking about different ways to achieve orgasm [would be difficult] . . . if the doctor was going to suggest, “Well, why don’t you use a vibrator . . .” I think those discussions would be difficult, talking about different sexual positions might be difficult. (21)

Women cited the term “orgasm” as a major barrier. One woman said she would not want to have that conversation: “I think any doctor asking about orgasms is embarrassing, challenging and I wouldn’t want that. It just feels like that’s awkward and weird” (16). This embarrassment represents a barrier to care as it can stop them from communicating with medical professionals.

**Reluctance based on patient-provider demographic differences.** Reluctance to talk was also tied to demographic differences between the patient and provider. Aversion to discussing sexual health with providers in certain demographic categories was a prevalent theme among survivors. In this case, two demographic differences were the source of women’s hesitation: biological sex of the provider and age of the provider ($n = 18$).

Survivors suggested that they feel more at ease talking about sexual health when the provider is a woman. One survivor said, “I’m more comfortable with a woman. Not that it’s weird to have a male doctor and it’s not weird for me [in general], but I’m more comfortable talking about certain things with a female” (39). Women suggested they are also doubtful a male provider could comprehend their experiences. One woman said, “I think having a man as a doctor makes it a little harder. Because I feel like he can’t relate to me as a woman, and what I’m going through” (2a). When discussing an already sensitive issue, differences in biological sex can create additional barriers for women.
Age was also a factor for women of all developmental phases. What seemed critical to willingness to communicate was similarity in terms of age. Younger women indicated that talking with older providers is uncomfortable because they feel like they’re talking to a parent. They reported a pressure to censor themselves in these situations. One woman explained: “It’s not something I would have wanted to discuss with the ‘dad’ kind of guy but maybe if there’s a gynecologist who was a little younger, I could see as a peer [that would be easier]” (17).

Likewise, older adults said they are less willing to discuss their sexual health issues with providers who are significantly younger than them. For instance, one survivor spoke about an instance in which her male provider referred her to another medical professional – a woman: “It was more like ‘I think you’ll be more comfortable talking to Dr. Howard, was her name. And she was very sweet. She was very young. And she didn’t have a clue” (24). Older survivors sometimes preferred providers from their own generation because they believe many younger individuals in the medical system do not appreciate that sexuality is a relevant concern for women, regardless of age. This survivor said she would not broach the topic with a younger provider because “I have a feeling that I was somewhat discounted just because of age” (27).

Although women reported hesitation to bring up their sexual health concerns when there was demographic discordance with the provider, they also reported that in these situations providers can attempt to ease their discomfort and suspicion by acknowledging the differences and conveying their earnest desire to help patients with their problems.
Believing providers cannot or will not help them. At times barriers were not based on discomfort with the topic or how that discomfort factors into conversations in particular patient-provider dyads. Women also suggested a barrier to communication is their belief that providers cannot help them with their sexual health issues. Women fashioned this belief from their own assumptions, prior research they conducted about the state of sexual health care, or prior interactions with providers. This belief manifested itself in three forms. Survivors reported there were no solutions to their sexual health problems, providers do not possess the requisite knowledge to help them address their issues, and providers do not listen to their concerns or view them as important \((n = 16)\).

Many survivors reported doing a lot of online research, attempting to communicate with providers about sexual health, and talking with other survivors about what has worked for them. For some, this led them to believe there was nothing available to address their concerns. Because of this, women reported feelings of hopelessness and did not see the utility of seeking medical care. One woman said:

Women’s sexuality is not very well explored and there’s so many factors that go into a woman’s satisfaction that it’s really hard to say “Okay it’s this. Okay it’s that. We’re gonna do this and you’re gonna be better” . . . So why bother? I went through the stage of “Somebody help me. There must be something” and now I’m just at the stage of there’s nothing and I’m just gonna do the best I can with what I have. But every once in a while I do throw a little pity party for myself. (34)

Women recognized the complexity of the issue. Women who sought care in the past reported that they would not repeat their efforts because they believe many providers do not have the knowledge needed to help them. One survivor told a story about her last appointment with a medical professional, her gynecologist:
During my chemo and after chemo I talked with my oncologist. Probably four months after my chemo I went back to my initial GYN and it was a disaster . . . he had nothing to tell me. In the doctor’s room it was just me telling him what I had been experiencing. I was very frank with him, “Yeah I can have sex finally but I don’t have a lot of moisture.” He just didn’t know what to do with me and I said to him, I finally said “Do you have any other patients my age who are on tamoxifen or have gone through cancer?” and he said “no” so I had to find a different doctor immediately . . . It became so clear to me he didn’t know what to say to me or how to find the answers for me. (6a)

This woman reported talking with her oncologist, family medicine physician, and gynecologist about her concerns but walked away convinced that they didn’t have the requisite information and were not willing to research the issues. She indicated the oncologist didn’t have the sexual health expertise, the gynecologist didn’t have the cancer expertise, and her family medicine physician suggested she talk to another provider. As a result, she did not return for further medical care. This pattern existed for other women in that previous medical interactions created barriers for women who were contemplating seeking help for sexual dysfunction.

Women indicated that previous interactions created the impression that providers would not listen to their concerns and would not think they were important. In turn, they became less likely to bring up the topic during clinical visits. One survivor described an experience with a provider that contributed to her current silence on the topic of sexual health:

He and I had a little bit of a [disagreement]. He wanted to put me on a fourth chemo drug and I said no to this drug because I did enough research to realize that this is not for me, and until this day we battle it out. [He said] I should have done it, and I’m like “No, I shouldn’t have done it” and I’m still here almost ten years. There was never enough comfort level and that’s what I’ve experienced with a lot of doctors. Because we never had a good relationship, had disagreements, and I felt he just doesn't listen, I got the feeling he wouldn't be a person I could talk to about this. (36)
Disagreements are not the only aspect of previous interactions that gave survivors the impression providers could or would not help them. Sometimes women reported that their provider’s demeanor during treatment lead them to think they should not ask about their sexual health symptoms in survivorship:

I do wonder if this is something this particular doctor is even concerned with. They’re concerned with your cancer, and keeping you alive, and keeping it from coming back. You kind of do wonder should I even be asking her about this or should I even be concerned with that or should I just be happy that they have medicine that can maybe help and just suck it up and live with it . . . . Sometimes I could tell, if I mentioned other quality of life issues after treatment, like fatigue, I mentioned once, she would just say, “Well, that’s a small price to pay for still being with us, isn’t it?” Then she smiled. I thought that was kinda odd. (8a)

Survivors repeatedly said they were very grateful to be alive. Cancer is a traumatic, life-altering event that made them re-evaluate their priorities. Some women reported that during treatment sex was not on their minds. However, “when the dust settled,” they reported a desire to reclaim their sexuality but felt sheepish about vocalizing those concerns. Survivors reported that interactions like the one above can reinforce the belief women that should suffer in silence and focus on the positive, or being alive.

**Inability to access timely or coordinated medical care.** The inability to access timely or coordinated care can also have a silencing effect on survivors. Survivors reported that time-based difficulties or the lack of coordinated care inherent in the current medical system poses challenges to effective sexual health communication in the clinical setting. They said the lack of communication between different providers, continual referrals, confusion about which provider to go to for sexual health concerns, inability to
access providers, and time constraints during appointments made it less likely that survivors could have their sexual health concerns attended to \((n = 21)\).

Women reported a lack of communication between providers. They suggested some providers assumed another provider was addressing their sexual health concerns. This woman talked about her experience talking to doctors after she first discovered intercourse was painful:

When I went to Dr. Smith and said “I don’t know what’s happening” he said, “Well didn’t Dr. Greene tell you all this?” and I said “No.” And then he said “Well you should talk to her.” And so I was supposed to go back to the primary care doctor, and I said, “Well I want you to talk to me” and he was uncomfortable; I could feel that he was uncomfortable. He ended up giving me to his nurse practitioner . . . . They all thought someone else had told me and, when I went to my surgeon and said, “How come nobody told me,” she said, “Well, because everyone reacts differently.” So I don’t know if that’s true or not. I never found out (12a).

Providers may not always talk to each other to coordinate patient care. This issue is exacerbated when providers relocate or retire. One survivor talked about her experience looking into whether or not a certain medication would be an effective and safe treatment for her pain during intercourse:

Well when my oncologist had first recommended Estrace he said, “We’ll get a follow up with some labs and all” and then no one else seemed to follow up with labs. It went from that oncologist, who had ordered it, and then he stopped his practice, and then I wanted to get it from my obgyn . . . . and he wasn’t gonna follow up with the labs with it . . . no one wants to get this for me and no one wants to follow up with labs. When I asked I was referred it back to the oncologist. I couldn’t get anybody to order Estrace. The obgyn didn’t want to order it. (35)

This confusion can create a situation where survivors are continually volleyed back and forth between providers. Women reported this can make them question their providers’ investment in their care. This survivor summarized it this way:
My obgyn told me to talk to my oncologist. If it keeps going I know they aren't talking to each other. I guess it’s because they’re too busy or they don’t care or, that, I guess neither of them have a clue what to do with me. (4a)

Although coordinated teamwork may be necessary to treat the complex needs of women during survivorship, when survivors were constantly referred to different providers it created confusion about which provider to see for their sexual health issues.

As this woman suggested:

I don’t know who to go to for what, because I may go to my medical oncologist and I’m there and say “oh by the way [I have this sexual health issue], and then they say “No. Do you go to your PCP or to a gynecologist.” You can’t keep up with it all. (10a)

While some survivors reported the abundance of unsuccessful medical appointments as the barrier, other women expressed the inability to get an appointment and appointment lengths were too short. One woman spoke about access issues stemming from her lack of insurance:

Knowing that I was uninsured, and I couldn’t go see a specialist, or go see a counselor, or go see somebody about and trying to figure out and get down to the bottom of it. It made it very easy for me to shut down, because I knew just wasn’t going to be a possibility if they suggested it. (25)

Even when insurance coverage was not an issue women reported they cannot see their providers in a timely manner. One woman said, “If you call some doctors [they say], ‘Oh, we’re booked.’ And you can’t get see them for another two months. Sometimes I can’t believe it. I need to talk to someone in the next week or so” (36). Survivors reported that long wait times hamper their ability to seek medical care because by the time they actually see the physicians so many quality or life issues have accumulated that there are
not enough minutes in the appointment to bring up the delicate topic of sexuality. Many survivors reported the system is not set up in a way that facilitates their care.

**Variations by age and survivorship length.** Women’s challenges addressing sexual health concerns were informed by their developmental phase and length of breast cancer survivorship. Two important distinctions were discovered that may impact patient care. They included *reluctance based on patient-provider demographic differences* and *inability to access timely or coordinated care.*

**Variations by age** were noted in that women in older adulthood found gaps in age between patient and provider challenging. They reported frustration that providers may view them as parental figures and therefore are uncomfortable having sexual health conversations with them. Alternatively, they suggested that many in the medical environment dismiss the possibility older adults could be concerned about their sexuality. When discussing her attempts to bring up sexual health with her provider one women said she got the message, “You shouldn’t be thinking about sex. You’re too old for that” (9a). This poses a significant obstacle for older women because it makes it harder for them to broach the topic with providers and also influences the helpfulness of that interaction. As this survivor said:

> I think if I was in my 20’s or 30’s it would be an expected part of it. That I would expect to have a continual, satisfying sex life. But I am at the age when most women are already through menopause and because of that it’s minimized. (11a)

She further suggested that her frustration with this attitude made her “less willing” to put herself through repeated attempts to address sexual health concerns. As such, these
perceived biases based on age negatively impacts women’s ability to access the care they need.

_Survivorship length_ shaped challenges for women. During the first year of survivorship many women had their first sexual encounters post primary treatment and were shocked by the pain and difficulty they experienced. After some time they began the process of collecting information and talking to providers. By two years post treatment many women entered the “trial and error” phase of their attempts to address their concerns with providers and began fighting the frustration of communication attempts being unsuccessful to various degrees. As this survivor said:

After that first year or so I really started to try to figure out what to do about it. One – two oncologists, one nurse practitioner, one gynecologist and one internist. So that’s five doctors and a nurse. It didn't really help because they all seemed to be uncomfortable or just not know what to do. So if there are bonafied professional sexual therapists or counselors out there I am completely unaware of them. (5a)

This is also the time when women reported struggling with navigating continual referrals and waiting for long periods of time to get appointments. It is important to recognize challenges women are having accessing timely and coordinated care during this period because it has implications for their future. Women who had been survivors for longer than five years regularly reported that their efforts diminished or ceased and that the longer sexual health distress continues, the harder it is to ask for help. According to one woman, “It’s so far out, the further you get, the harder it is to reinitiate or open that again after it's been non-existent” (10a).
**Table 9**

*The Survivor’s Perspective of Barriers to Addressing Sexual Health*

<table>
<thead>
<tr>
<th>This percentage of survivors</th>
<th>describe these communication barriers,</th>
<th>which are characterized by the following dimension(s).</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>(n = 16, or 40%)</em></td>
<td>Feeling Inhibited by the Taboo Nature of Sexuality</td>
<td>Sex is taboo in their family/dominant culture</td>
</tr>
<tr>
<td></td>
<td>Discomfort with psychological aspects of sexual health</td>
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<tr>
<td></td>
<td>Embarrassed to discuss body parts and physiological processed (e.g. orgasm)</td>
<td></td>
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<tr>
<td><em>(n = 18, or 45%)</em></td>
<td>Reluctance Based on Patient-Provider Demographic Differences</td>
<td>Male biological sex</td>
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<tr>
<td></td>
<td>Age differences</td>
<td></td>
</tr>
<tr>
<td><em>(n = 16, or 40%)</em></td>
<td>Believing Providers Cannot Help Them</td>
<td>No solutions to sexual health problems</td>
</tr>
<tr>
<td></td>
<td>Providers’ knowledge gap</td>
<td></td>
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<tr>
<td></td>
<td>Belief providers will not listen and view concerns as important</td>
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<td><em>(n = 21 or 53%)</em></td>
<td>Inability to Access Timely or Coordinated Medical Care</td>
<td>Lack of communication between providers</td>
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<td>leading to continual referrals</td>
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<td></td>
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<td>Inability to access providers</td>
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<td></td>
<td>Time constraints doing appointments</td>
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**Partners’ perspectives.** The barriers reported by partners and women overlap in many respects. Partners noted several challenges to communicating about sexual health in medical settings including a *reluctance based on patient-provider demographic differences, believing providers cannot help them, and the inability to develop relationships with providers* (see Table 10).
Reluctance based on patient-provider demographic differences. Like survivors, partners also reported their wives or girlfriends have trouble when there are demographic differences between patient and provider, namely a difference in biological sex (n = 5).

Partners suggested their wives or girlfriends are more comfortable with women providers because of the sensitivity of the issue and because they feel women may be more understanding of their experiences. This partner said he thought his wife would feel more relaxed if a woman provided sexual health care: “I think it is more helpful for my wife . . . she feels more at ease I guess if she talks about it with a female doctor” (3b).

Another partner said, “I think having a female doctor, she can talk a little bit more than having a male doctor . . . because she thinks they are more understanding” (8b). Several partners suggested that survivors had returned from medical appointments lamenting the fact that they saw a male provider that day. However, in contrast to survivor narratives, largely, partners did not report that the discomfort caused by demographic differences with a provider would ultimately prevent survivors from doing what they needed to do to receive care for their sexual health concerns.

Believing providers cannot help them. Similar to survivors, three partners also talked about how the belief that providers cannot solve sexual health problems complicates survivor attempts to address issues. Partners’ characterization of this theme emerged in one dimension: survivors’ belief that seeking medical care is futile because there is nothing her provider can do to help her (n = 3).

This partner offered his perspective on the dilemma that expands our understanding of the same theme from the analysis of survivors’ narratives:
Sometimes I think she’s frustrated because she feels like there’s nothing he [the provider] can do, but I think really she’s just tired of trying to find a solution. It drives me crazy because she’s given up and the doctors just don’t understand how hard it is. They don’t get her hesitation to believe them. (7b)

He later indicated he believes “the science is just not there for bullet proof solutions” and suggested his spouse knows this too. However, he reported she becomes despondent when providers talk to her about alternative solutions like over the counter lubricants. He said that she feels offering these alternatives is an attempt to placate her because there are no “real effective treatments.” This partner’s perspective allows us to view another layer of the phenomenon survivors described. According to partners, women’s belief that nothing can be done to help them may be partially informed by a “hopelessness”(4b) or “giving up”(7b) in addition to the assumptions, outside research, and prior interactions cited by survivors. These perspectives may also point to a disconnect between survivor and provider wherein the provider does not appreciate what is behind survivors’ reluctance to accept that providers are offering nonprescription treatments as legitimate strategies, which may help ease aspects of their symptoms to various degrees.

Inability to build relationships with providers. Some partners reported the inability to access medical care pose a greater challenge than beliefs about what a provider was or was not capable of doing to address sexual health issues. Partners indicated women have troubling building relationships with providers for one reason: they see too many types providers for short periods of time. According to partners, this creates a barrier because women are not given the opportunity to develop the trust needed to discuss sexuality with providers (n = 4).
Partners suggested the brevity of appointments and the abundance of provider specialists who deliver care pose a challenge for women. One husband talked about his wife’s experiences and their impact:

Doctors nowadays you get 15 minutes and you can only have one idea during that 15-minutes. Also, she goes to an Ob, a breast surgeon, her oncologist, her radiologist, there’s just so many people that she sees. It maybe even gives her confusion about who to trust and who to have that conversation with. Literally she’s has a half dozen doctors that she sees throughout the year. (3b)

Sometimes partners suggested this pattern of care poses problem for women who need to establish trust before discussing sexual health issues. One man said:

She’s pretty conscious of the psychological part of this [sex]. In other words, she’s not really vocal but I think once she felt comfortable with somebody [it’s easier]. She’s a hard one. She’s got a very strong external wall so it takes a long time with one provider, which she never gets because she sees lots of people in 5-minute bursts. But when that wall comes down she’ll open up. (6b)

Overall, partners identified several of the themes women also reported as barriers. However, while partners reported these challenges they largely did not suggest these issues would prevent women from accessing care or openly discussing their concerns.

Partners indicated that women had learned to become advocates for their own health care and even if they were uncomfortable they would still do what needed to be done to get the care they need (3b). These variations will be discussed further at the conclusion of this section.
Table 10

The Partner’s Perspective of Barriers to Addressing Sexual Health

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<th>This percentage of partners</th>
<th>described these communication barriers, which are characterized by the following dimension(s).</th>
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<td><em>(n = 4, or 31%)</em></td>
<td>Reluctance Based on Patient-Provider Demographic Differences</td>
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<tr>
<td><em>(n = 3, or 23%)</em></td>
<td>Believing Providers Cannot Help Them</td>
</tr>
<tr>
<td><em>(n = 5, or 38%)</em></td>
<td>Inability to Build Relationships with Providers</td>
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**Providers’ perspectives.** Providers reported multiple barriers to patients seeking sexual health care. However, they also delineated obstacles for providers attempting to deliver sexual health care to survivors. Examining how providers conceptualize impediments to care for survivors and for themselves adds another layer of complexity to this analysis. This information is critical to more efficiently devise strategies to enhance care.

First, the barriers providers reported for survivors are explored. Medical professionals suggested a variety of barriers complicate survivors’ attempts to address their sexual health concerns. These barriers emerged within four ideas: reluctance based on patient-provider demographic differences, feeling embarrassed by the taboo nature of sexuality, and coping with provider behavior which makes it difficult to address issues.
Reluctance based on patient-provider demographic differences. Providers suggested managing demographic differences can be difficult. They recognized that demographically discordant patient-provider pairings may make it less likely that women will feel comfortable seeking help for their sexual health concerns. In accordance with survivors’ accounts, they reported that differences in biological sex and age can be problematic for patients ($n = 16$).

A registered nurse said, “We have a lot of patients that request females only but we have several male doctors in the clinic. So I think that can play a role, not wanting to bring it up if you have a male provider” (23p). A male family medicine physician reported he notices what he perceives to be a trend in women’s preferences:

In general I feel like [survivors prefer] female providers. In my prior [practice] I know for a fact the female nurse practitioners did three or four times the number of Pap smears and women’s health visits than I did. I do maybe a few a week. There were times where they did a few in a day. (26p)

One oncologist suggested she has seen this pattern in her department, “I’m the only female oncologist – and they’ve walked out of another office and a couple have snuck into my office, closed the door and said “I know I just saw Dr. Smith but can I ask you this” (33p). Providers offered a variety of reasons they believe women feel uncomfortable with male providers. The most frequent reason was that women feel male providers won’t understand their concerns or are embarrassed bringing it up with men because it changes the dynamic from one of discussing a medical issue to one of conversing about a taboo and personal topic. However, a few providers cited another motivation. One male
gynecologist explained why he believes survivors feel more comfortable discussing

sexual health with women providers.

I know the patient would feel uncomfortable talking to me about it [sexual health concerns], and I think these patients – gynecology patients – maybe feel more comfortable talking to the female doctors and of course the female doctors and female care providers, whether they’re doctors or not, the patients get into a lot of the emotional stuff that I don’t. (1p)

While the majority of male providers reported they cultivate trusting relationships with patients in which psychosocial concerns are regularly addressed, several male providers indicated they believe many patients still feel more comfortable talking with women providers. While providers and survivors both reported that women might feel more at ease with women providers, providers were not always aware that there are steps they can take to address women’s discomfort with biological sex differences. As noted earlier, survivors said that acknowledging the potential difficulty posed by the demographic differences, emphasizing the provider is there to help them, and carefully listening to patient concerns can reduce that discomfort.

Younger providers also cited age as a potential barrier for women. One family medicine physician reported:

I look young for my age and so I think they have a hard time probably talking to me, as hard as I try to communicate like an adult. I get people who ask me if I just graduated, or if I’m a resident . . . . I’ve heard women before, struggle a little bit with me being their provider that way, and there’s not a lot I can do about it. (15p).

Providers said that some survivors may not believe younger providers are experienced or mature enough to discuss sexual health matters with. Younger providers also reported they are aware that certain topics are “off limits” to them because patients may not trust
them as patients have difficulty moving beyond the parent-child dynamic the age difference creates in their minds. Providers acknowledged that age discrepancies can pose challenges for women. However, they did not report one aspect of the age barrier emphasized by older women, namely, that many older women believe providers – especially younger providers – do not appreciate that sexuality is a relevant concern for them.

**Feeling inhibited by the taboo nature of sexuality** Providers also reported appreciating the fact that it can be difficult for survivors to get care for their sexual health concerns because of the taboo nature of sexual health. Their accounts centered on two aspects of this difficulty: patients from certain cultural background may have more difficulty talking about sexual health in the medical interaction and it is embarrassing to disclose the reason for their medical appointment before speaking with providers privately \((n = 20)\).

Providers said that sexuality is not something many women feel comfortable freely discussing. According to one gynecologist, “I think the biggest challenge is a lot of times women are reticent to bring it up . . . . Sex is embarrassing for many women. It’s not something that's talked about openly” (39p). Providers pointed to a number of cultural factors, which may influence a patient’s discomfort bringing up the topic. Another gynecologist spoke about this broadly:

> It depends on the patient’s cultural background too. Some patients are very open about it and others it’s like “This is not something you talk about.” That can be hard for patients that want help but also feel like they can’t talk about it. So it depends on what the patient brings to the table and their background. (6p)
Other providers cited more specific examples of cultural backgrounds, which based on their experience, can make discussing sexuality more challenging for women. An oncology nurse practitioner reported, “It depends on the way they were raised and how they associate sexuality. I guess people that have a very strong religious background – like Catholicism for instance – it’s not something that was discussed” (38p). Similarly, a family medicine physician reported how cultural norms in the southern United States informed his view of this challenge for survivors:

I don’t think it’s something that you really think about – you go to the doctor to talk about your sex life. I’m from the South. I think it’d probably be even worse down there. It’s taboo, inappropriate to speak about. It’d be like, “oh god no, why would I want to talk to my doctor about that”. (27p)

Providers suggested it is not only difficult to discuss sexuality once inside the clinic room. The taboo nature of sexuality also influences women’s attempts to access care before the conversation begins. This barrier is present from the first moment survivors interact with the medical system. One gynecologist reported a trend she said most providers are familiar with:

Coming in with that [sexual health] as a primary complaint. This is really an exceptional patient that presented herself and said “this is my primary problem” so I think a lot of women won’t necessarily present with that one primary issue and probably present like I said, through the back door with other little issues. It will come in as a “well woman” appointment. We have a nurse practitioner that’s dedicated to well women appointments and she’s says “They’re never well women.” People tell the person on the phone, “I’m coming in for a well woman” but really they have a lot of private or personal things they want to talk about. And for whatever reason, maybe just cultural or how they were raised or it’s so private they don’t want to talk about it then. They have to work up their courage. (13p)

Many providers reported that being reticent to disclose the reason for their appointment before talking to the provider is an additional barrier for survivors. A family
medicine physician explained the process women often navigate on their way to speaking to their provider:

First they have to call and make the appointment. Then multiple numbers of people will touch them from the time they come in the door. They imagine that the front desk has the reason for visit “Sex problems” or something like that, and then they come back and the nurse asks them “So why are you here today?” and they have to say, “Well sex problems.” The number of people that they end up having to talk to is large. They may not feel empowered to say, “It's just a personal issue. I just want to take it up with the doctor.” (15p)

The description paints a clear picture of the obstacles women need to circumvent before they even meet their provider face to face. Another oncologist echoed this concern. He reflected on this difficulty and the potentially unfortunate effect on patients’ quality of life:

They said they’re coming in for something completely different. So they tell the person on the phone “I’m coming in for a urinary tract infection” and they bring it [sex] up at the end of the appointment so like “Oh by the way” and that was real the reason why they were there. They’re just really uncomfortable saying it out loud. So you wonder if there are people that don’t even come in . . . like there’s probably women out there who are suffering that just don’t even come in. (35p)

Thus, these providers reported, the taboo nature of sexuality presents barrier for women attempting to discuss sexual health during the medical visit. However, they said it may also prevent women from coming into the clinic in the first place. These accounts align with survivors’ reports regarding their reluctance to bring up the topic of sexual health as well as with the hesitance to make an appointment to discuss sexual health reported by survivors in phase 1 of this study.

*Coping with provider behavior, which makes it difficult to address issues.*

According to providers, women must cope with more than their own discomfort with sexuality when attempting to address their concerns. Providers also reported their
behaviors can make it difficult for women to receive care for their sexual health issues. They discussed two behaviors, which may pose challenges for survivors: patients may receive conflicting medical advice and medical providers do not bring up the topic of sexual health \((n=9)\).

Providers reported they are aware that breast cancer survivors often see many different providers. As such, they suggested that conflicting medical advice is a side effect of that necessity and can create barriers to effective care. One gynecologist reported patients, “probably have gotten conflicting messages so they probably aren’t sure what the right answer is, just because my guess is probably they’ve been told different things by different providers. So they probably don’t know what to do” (11p). Survivors reported one reason they have been bounced back and forth between providers in the past was that providers don’t know what approach to take to address sexual health issues or they disagreed about the safety of different courses of treatment.

Several providers cited another element of their own behavior as a potential barrier for women. They suggested at times they simply failed to ask the question. One internal medicine physician talked about a time he treated a survivor in the clinic, who in retrospect he believed needed to talk about sexual health issues. When asked why he thought the patient didn’t talk with him about her issues he responded, “I think it was just really hard for her to ask and she was trying to build up her courage and couldn’t. So, I think part of it is that I didn’t ask” (20p). Importantly, providers recognized that women might be uncomfortable bringing up the topic of sexual health and that this barrier was previously reinforced when providers did not broach the topic themselves. However,
further analysis further explores if this sensitivity to the issue translates into practice. This is discussed at the conclusion of this section.

Table 11

The Provider’s Perspective of Barriers to Survivors Addressing Sexual Health

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<th>This percentage of providers</th>
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<tr>
<td>(n = 16, or 40%)</td>
<td>Reluctance Based on Patient-Provider Demographic Differences Male biological Sex Age differences</td>
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<tr>
<td>(n = 20, or 50%)</td>
<td>Feeling Inhibited by the Taboo Nature of Sexuality Embarrassed to disclose reason for visit before speaking with providers privately Patients from certain cultural background have difficulty talking about sexual health</td>
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<tr>
<td>(n = 9, or 23%)</td>
<td>Coping with Provider Behavior which makes it Difficult to Address Issues Patients receive conflicting medical advice Providers do not bring up the topic</td>
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While providers acknowledged the barriers survivors face when attempting to address their sexual health issues, they also described the challenges they experience that feed that dynamic in problematic ways. The following themes represent the issues providers report facing when providing patient care: coping with patient reluctance to discuss sexual health based on patient-provider demographic differences, time constraints that affect their ability to provide care, and feeling ill-equipped to address survivors’ needs (see Table 12).
Coping with patient reluctance to discuss sexual health based on patient-provider demographic differences. Providers recognized that demographic differences are a challenge for survivors. However, they also suggested that these differences pose challenges for them because they can sense survivors’ discomfort. Specifically, they reported that differences in biological sex and age are barriers for them in the delivery of care \((n = 10)\). Providers reported being taken aback or having had difficulty trying to devise communication strategies to overcome sex and age barriers.

While providers recognized that women might feel embarrassed or hesitant to discuss sexuality with male providers, providers also discussed how sex differences create an obstacle for them. One gynecologist expressed the frustration he sometimes feels trying to help women as a male provider:

> You know sometimes it catches me off guard because – I do so much women’s health. I’m still thrown off by women who don’t want to see a male provider. I do always kind of wonder in the back of my mind am I getting everything, just being a guy, doing medical care. I think most of the time I am but you know sometimes I’m surprised. Women show up and say “Oh it’s a male doctor? I’m not even gonna have him do my Pap” and they’re gone. And so I wonder if they would be willing to bring up some of this stuff with me. (35p)

Many providers had cases where they sensed the patient’s discomfort but didn't know what to do to help them feel more at ease. Often they reported this divide made them more reticent to ask the patient the question. One family medicine physician said, “I think the challenge that I have is trying to negotiate what I should ask and what I shouldn’t” (16p).

This divide can also be caused by age. According to this internal medicine physician:
I think the older women, like my mom— I think there’s difference. I think we have to look at those kind of things, how to connect. Because when I’m looking at her generation – she’s part of that baby boom generation so things were a lot more strict . . . and then I look at Angelina Jolie and that’s a whole different generation. They will talk about it openly, but older women, it’s hard for me. I have to be careful about the way I broach the subject. (17p)

Patients, partners, and providers all identified demographic differences as a barrier to addressing sexual health issues. In some cases this divide created a sense of uncertainty, which prevented all parties in the interaction from bringing up the topic of sexual health. This points to the clear need to provide medical professionals with communication strategies to help them navigate these challenges.

Time constraints that affect their ability to provide care. Time constraints were the most frequently cited barrier for providers. Providers overwhelmingly suggested that time constraints were the biggest challenge they face in the delivery of medical care. Time presented a problem for providers via several paths: the nature of the faced-paced clinic does not always leave time for them to review patient history before walking into the room, it makes them feel they only have enough time to discuss primary biomedical complaints, and it prevents them from having enough time to figure out if a patient is comfortable or to build rapport needed to make that conversation possible (n = 31).

Many providers said they find it challenging to deliver quality care within the time parameters they are given. One issue they identified is the fast-paced clinical schedule can prevent them from looking at a patient’s medical history before the visit. They suggested that if they knew the patient was a survivor ahead of time they would be sensitized to the possibility of sexual distress. However, in the everyday clinical
environment, this is sometimes not feasible. One family medicine physician spoke about
the speed of his average day:

Yesterday I had nine patients. I was just in clinic for the afternoon. Two or three
of those patients were actually assigned to me as their primary care provider and
the remaining six or seven were assigned to someone else. So even if I’d been
here a long time, I would likely know more about two or three patient’s history
but I would likely not know about the history of those other seven. I wouldn't
have time to look before going in and I wouldn't have that pre-existing knowledge
either. (20p)

Providers reported time restrictions are upsetting because it makes them feel as
though they cannot provide comprehensive care. One gynecologist told a story about an
instance in which not having the time to review survivor’s medical chart prior to the visit
prevented him from picking up on patient signals that sexual health may have been a
concern:

There were some things that I didn’t pick up on because when I went and saw her
– she came in for some other complaints. There were so many things I’m
surprised I didn’t pick up on it, and then afterwards I’m thought “I was so stupid”
I mean obviously. But I just didn’t know her history, because I didn’t have time to
look at it before going in, she wouldn’t disclose it. It’s not necessarily not all over
her charts unless you have the time to go digging to find it. (35p)

For many providers sexual health is a challenging topic to bring up. They reported they
would feel more comfortable broaching the topic if they were able to locate hints to its
relevance for individual patients. They reported one resource for this is the patient’s
electronic medical record. When they don't have time to use this tool properly, they
reported it can affect patient care.

Providers suggested that time restrictions make it difficult to address anything but
biomedical aspects of patients’ primary complaints. They indicated that unless a patient
makes an appointment only to discuss sexual health, it is challenging to factor that issue
into the appointment. For instance, one family medicine physician said unless sexual health is the stated purpose of the visit it simply would not be on his mind as a possibility:

If that’s the chief complaint, obviously we’re gonna discuss that. I would have to say though if its just a routine follow up, that probably would not be at the top of the list of things that I am gonna talk about if I’m just being honest, and that twenty minute appointment and a full clinic that just is not at the forefront of my mind, thinking about sexual health. (21p)

In addition to this lack of awareness, providers reported short appointments mean that they feel they have an obligation to use that time to investigate “long life” issues. This family medicine physician characterized his dilemma this way:

To be honest in the course of those visits with a short amount of time . . . I have to decide what is important enough from a mortality or a long life standpoint, what is important to address. If I think that there are – I don’t want to say – but deficiencies in that person. If I see someone is morbidly obese we’re probably gonna talk about her weight. But otherwise I try to target things towards what they want to talk about because I don’t have anywhere near enough time to address every possible quality of life issue going down the line, and I think that’s probably my biggest limiting factor. (15p)

This sentiment was repeated among oncologists. One oncologist suggested that in the hierarchy of survivorship care sexual health takes a back seat to other issues that require monitoring:

I think it’s more of a time issue. Because we’re focused on when did they get their mammogram, are they following up with their surgeon, and then what are the side effects they’re experiencing with their medication, and then also their mood because it affects their mood, and then it [sexual health] gets put off to the side. (8p)

Providers reported feeling that the modern day clinical timetable sometimes precludes them from addressing “nonessentials issues” unless the appointment is booked to focus on that concern. According to providers in this study, sexual health, is an issue
that requires a great deal of time to discuss. They also reported it is a discussion that includes a lot of psychosocial counseling and providers may see this as outside the scope of their role. One gynecologist explained his concerns about time and psychosocial issues this way:

Things have changed a lot in gynecology since I came along. We did surgery. It is a challenge because it’s [sexual health] not exactly what we’ve done historically, We took care of patients and treated them medically but we did not really get into all the touchy feely stuff... Not as these young docs – they get into all the stuff and – and let me tell you – most female – all female, I try not to – I’m not a sexist and I’m not a bigot or anything else. It’s just the facts. When they present patients they have all this information, and I think back Jesus. When I came along – when we discussed patients with our staff guys, you never talked about this. You talked about the disease process. I mean I hear more crap and I don’t get into it. I don’t feel I’m equipped to do that because I don’t have the time to frankly. I don’t have the time and that’s not my priority. (1p)

Providers reported that initiating a discussion about sexual health is like trailing off “into the weeds” or opening “Pandora’s box.” While many providers were not as opposed to addressing psychosocial concerns as the aforementioned gynecologist, many still suggested they don’t have time wander into that territory. One oncologist said it’s challenging to fully address sexual health because when you ask survivors “how things are in their relationship since treatment” you will get a “20 minute litany of their unfortunate side effects so you have to be careful.” She went on to say she knows one gynecologist who “doesn’t sit down during any visits or ask any questions. He’s learned to do that if you want a short visit – because if you ask a patient any [questions] – you’ve opened Pandora’s Box” (33p).
Providers consistently reported that time constraints are a major reason they prefer the patient to bring the subject up instead of broaching the topic themselves. This gynecologist described the way time constraints influence his preferences:

Time restrictions are probably the reason most providers don’t just say, “how’s your sexual health.” It’s uncomfortable and it takes time. Time is a big thing. It’s not a conversation that you can have in five minutes. There are other things on the docket. So I prefer the patient to bring it up. Now, I think if you’re really looking at what’s best for the patient? Yeah, it’s probably best that the provider bring it up. (11p)

When working under time constraints letting the patient introduce sexual health issues was reported to be a more “efficient approach.” Another gynecologist talked about what he learned about broaching the topic of sexual health with patients: “One thing I learned early on is that if you ask every women that comes in if they have dyspareunia everyone’s gonna be like a weepy mess halfway through. This is a safer method” (35p).

The thematic presentation for time constraints reveals several important insights. First, though providers cited time constraints as major challenge for themselves, they did not report an awareness of the ways in which it presents a challenge for women. In this study, women reported an awareness of time constraints and suggested they labored to access care working within the established parameters of the appointment. Providers’ accounts that encouraging women to talk about sexual health issues is equivalent to “wandering into the weeds,” “opening a Pandora’s Box,” or creating a situation in which they will be “a weepy mess” suggests they may believe women are not aware of this ever-present clinical challenge. The tone providers take was sometimes oppositional, communicating that providers have to work against two enemies – time constraints and patients’ inability to appreciate the realities of those restrictions. Survivors’ accounts
revealed that they are aware of the time restrictions providers face and want to work together to meet this challenge and find a way to address their concerns in a comprehensive way. It may be beneficial to help providers reframe the time constraints challenge from that of an individual barrier to an issue, which requires collaborative problem solving. Providers also reported that sometimes set priorities for the visit without soliciting patients’ priorities in an in-depth way. Patient-centered medical care includes this kind of collaborative work.

**Feeling ill-equipped to address survivors’ needs.** Time constraints exacerbate the challenges of the next theme providers reported. Providers in this study reported that feeling ill-equipped to address patients sexual health concerns is an obstacle for them when attempting to deliver medical care. They said this inability stems from factors such as medical evidence is unclear, not having adequate training, and the belief there is nothing that can be done to alleviate patient suffering ($n = 14$).

Conflicting medical evidence is a major challenge reported by some providers. One gynecologist summed up the predicament facing providers this way: “The reason they’re confused is because there’s no textbook and there are very few conclusive studies about how to manage sexual function. Again, breast cancer or not, the science is not very mature” (12p). They suggested this is a difficult reality to communicate to patients. Sometimes providers reported this regularly influences whether they bring up the topic and the depth they go into about possible treatments. One provider lamented this, saying, “The medical evidence is unclear and that’s really hard because you don’t know how to translate that to patients” (13p).
Providers reported the awareness that cancer research and research regarding women’s sexual health are in their infancy. They also said clinical guidelines change quickly and sexual health issues are difficult to talk about. Due to these reasons they cited lack of training as a personal barrier to engaging in these discussions. One family medicine physician talked about how his lack of training in sexual health influences his current approach to care: “Sexual health - I don’t think would be at the forefront of my thought process when a patient comes in because we’re just not taught to think about that issue, but it is certainly something that is worth addressing” (21p). Another internal medicine physician spoke how his lack of familiarity with the issue affects his behavior in the clinic:

I’ll be honest, as a physician, those types of things I may not pursue and I think part of it may be a knowledge deficit, or what do I do if I open up that Pandora’s Box. So if I do open it up I feel as a physician [that’s dangerous] – usually we go for things we know how to treat. (17p)

Nurses also reported a deficit in training. One registered nurse in the women’s health department said:

I would say that it was a bit challenging for me just because it wasn’t something that I had been doing. You know, I mean we went through that with school but since I don’t do it on a regular basis it was a little bit challenging for me just remembering the medical side of things. (3p)

The belief that nothing can be done to address sexual health changes was the final challenge providers in this study reported. Many of these themes reflect that sexual health is a complex topic with few certain answers. This is difficult for many providers who don’t want to deliver another piece of bad news to patients if it is not necessary.
Therefore, if patients don’t bring it up they reported that it is unlikely for them to venture into that territory on their own. One oncologist explained it this way:

Maybe knowing there are no foolproof solutions keeps some of us from bringing it up. I’ve definitely heard that from other doctors. Just afraid to get the conversation started because they know they don’t have an answer that will satisfy. And as doctors, that’s hard because they want to help people. I mean, that’s why we’re here. (33p)

Sexual health concerns in breast cancer survivorship are varied, complex, and potentially highly emotional. The medical science is unclear and both survivors and providers reported difficulty navigating these delicate issues in a medical system that puts limits on their time.

Table 12

*The Provider’s Perspective of Barriers to Providers Addressing Sexual Health*

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<th>This percentage of providers</th>
<th>described these communication barriers, which are characterized by the following dimension(s).</th>
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<tr>
<td>(n = 10, or 25%)</td>
<td>Coping with Patient Reluctance Based on Patient-Provider Demographic Differences</td>
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<td></td>
<td>Male Biological Sex Age differences</td>
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<tr>
<td>(n = 31, or 78%)</td>
<td>Struggling to Operate within Time Constraints that affect the Delivery Care</td>
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<td></td>
<td>Faced-paced clinic prevents them from review patient history</td>
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<tr>
<td></td>
<td>Only enough time to discuss primary biomedical complaints</td>
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<tr>
<td></td>
<td>Insufficient time to build necessary rapport</td>
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<tr>
<td>(n = 20, or 50%)</td>
<td>Feeling Ill-Equipped to Address Survivors’ Needs</td>
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<td></td>
<td>Medical evidence is not clear</td>
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<td></td>
<td>Lack of training</td>
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<td></td>
<td>Belief they cannot alleviate patient suffering</td>
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RQ6: Closer Comparisons of Survivor, Partner, and Provider Perspectives.

Survivors, partners, and providers reported many of the same broad categories of barriers to addressing sexual health issues in a medical setting. However, there were important distinctions (see Table 13). Viewing survivor and partner narratives side-by-side revealed both parties reported that patient-provider demographic are difficult to navigate and that the system sometimes makes it tough for women to build relationships with providers and to access timely care for their sexual health concerns.

As noted earlier, while partners may perceive these issues as obstacles created by the medical system – obstacles their wives or girlfriends have experienced – partners did not report the belief these issues stand in the way of their wives/girlfriends accessing care and openly discussing concerns. For the most part, partners reported survivors feel up to the task of doing everything possible to receive the care they need. If they experience issues getting care for their sexual health issues it’s largely due to the fact that science has not caught up with the problem. Of the men who participated in this study only one reported the difficulty his wife has discussing sexual health actually prevents her from receiving medical care. However, he added the caveat that this difficulty would greatly diminish if she had the chance to get to know and trust one provider (they had recently moved and she still had not developed a bond with anyone yet). The remainder of the partners reported that survivors could assert themselves in the pursuit of sexual health care.
On man said, “She would be more comfortable talking to the doctor than I would, I can tell you that” (10b). Another partner reported, “I think she is very outspoken . . . so I wouldn’t think she’d have any problem bring up the topic whoever the person was” (5b). According to this partner, “I think she would be comfortable sitting there with the doctor to hear of any options that might help with the decreased libido. I don’t think there is much that would deter her from talking to him” (11b).

Partners discussed the challenges women faced, however, they often qualified those challenges by emphasizing survivors’ straightforward and resourceful nature. One man reiterated, “She is on top of everything and if she has a sexual health issue or health concern and if she has anything that bothers her she talks to her PCP and gets on top of it right away” (11b). Another partner described his wife this way: “She’s a pretty strong individual. So she’s learned how to become her own advocate and learned to take a stand for what she wants or needs or questions she had so I don’t believe that [talking about sexuality] would be an issue for her” (3b).

In general, although partners identified a few of the same barriers cited by survivors, many of them did not seem to appreciate the level of difficulty survivors have navigating this terrain. Some of this discrepancy may be due to the fact that several of the partners suggested they were uncomfortable with the topic of sexual health and let their wives/girlfriends take the lead in researching these issues and talking to providers. Given the difficulty survivors and partners expressed about communicating with each other, it seems likely that women may not have discussed the full extent of their hesitation, fear, or frustration with their partners. Further, as sexual health is such a complex and sensitive
subject to openly discuss, a self-selection bias and observer effect may be influencing the nature and depth of partner responses within the interviews.

When survivor and provider accounts were compared, similar themes were found in each participant group. For instance, women reported inhibition due to the taboo nature of sexual health and providers reported a heightened awareness of survivors’ reluctance. Providers suggested this embarrassment often prevents survivors from making an appointment or bringing up the topic in a medical visit. There were also parallel findings with regard to the feeling that sexual health issues have no easy solutions. Women reported hesitation to bring up the topic because they know there is nothing the provider can do to help them and providers reported their own frustration with the absence of readymade treatment options. Providers’ concerns about their lack of training in sexual health and the conflicting medical literature make it less likely they will broach the topic. Thus, for these reason, communication about sexual health is stalled from both perspectives.

While providers did not cite time constraints as a challenge for women trying to address their sexual health issues, it was the most frequently mentioned barrier for providers. They discussed a number of ways time restrictions negatively impact patient care. The predominant time-related concerns were that they don’t believe they have the ability to address anything beyond the primary biomedical complaint (long life vs., quality of life) especially when “secondary” issues have psychosocial implications. Many reported these time restrictions prompted providers to make it their policy to wait for the patient to bring up the topic of sexual health, fearing wandering “into the weeds” will
throw off their clinic schedule and negatively impact patient care for the rest of the day.

As a result, even though many medical professionals reported the provider should broach the topic, for the reasons outlined above, many do not. As one gynecologist alluded to in earlier analysis:

I think if you’re really looking at what’s best for the patient? Yeah it’s probably best that the provider bring it up... in an ideal world it’s gonna be the provider you know, in my reality I usually am not having the conversation unless it’s a patient so I prefer it being the patient (who brings it up). (11p)

During the course of this analysis several other provider motives for not bringing up the topic of sexual health with survivors were uncovered. These motives have particular import because they reflect some of the biases survivors reported experiencing and have implications for patient care. Sometimes providers reported not bringing up the subject with survivors because they did not believe the issue was relevant to them. Previous analysis revealed reasons why providers don’t think sexual health concerns are relevant to certain groups of women (see comparison discussion for research question 5). However, this set of themes represents beliefs that providers reported directly influences their decision to broach the topic in the clinic. Providers reported that older women are not as concerned with sex, long-term survivors don’t experience symptoms, if sex is an issue survivors will bring it up themselves, and other providers are taking care of women’s sexual health care needs.

One family medicine physician explained how age and survivorship length influence his decision to bring up the topic of sexual health:

Maybe depression from getting older [would concern me] but not that [sexual health]. It was a long time ago so those effects are likely gone and I know this is bad, but being older maybe they just aren’t concerned about that anymore. (31p)
He went on to say, “I know that and so I know I don’t need to say anything about it.”

This belief is potentially dangerous as phase 1 of this study indicated that women of all ages and survivorship lengths reported sexual health-related quality of life significantly lower than that of healthy control populations previously studied. In addition, older women in phase 2 of this study reported feeling discriminated against or dismissed because of their age.

Other providers reported that because they have high quality relationships with patients, patients would bring up the topic if sexual health changes occurred. One internal medicine nurse practitioner reported, “I don’t automatically bring it up . . . usually if it's a concern for women they bring it up. They may not bring it up with every provider but they will with me, we have a good relationship” (34p). Further, a psychiatrist, who treats several cancer survivors explained her philosophy of care and how it influences the extent to which she asks her current patients about sexual health:

Most of my patients are very comfortable with me because they’ve been seeing me a long time and we’ve developed this trusting relationship. I think the person they’re gonna talk to is gonna be the person who gives them the sense that they are gonna listen and empathize and care and not trivialize. My patients will talk with me about these issues. They would just feel comfortable and so I wouldn’t have to go digging around. (22p)

However, even when a provider develops a trusting relationship with patients, expresses empathy, and validates patient concerns, that does not necessarily equate to patients bringing up their sexual health problems. Survivors reported challenges with the topic of sexual health that are not rooted in anything the provider does or does not do. As such, it is important for providers to be aware that sexual health concerns are associated
with breast cancer and its treatments and that survivors may be experiencing them, even if they do not proactively offer that information.
Table 13

Variations across Perspectives: Barriers to Addressing Sexual Health

<table>
<thead>
<tr>
<th>Survivors reported these barriers,</th>
<th>partners reported these communication barriers,</th>
<th>and provider reported these barriers,</th>
<th>which interact in the following ways,</th>
<th>and suggest these actions points to enhance survivors’ quality of life.</th>
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</thead>
<tbody>
<tr>
<td>Feeling Inhibited by the Taboo Nature of Sexuality</td>
<td>Feeling Inhibited – noticeably absent</td>
<td>--</td>
<td>Partners did not report spouses/girlfriend experienced enough discomfort or embarrassment with the topic to prevent them from discussing sexual health. While they did report obstacles created by the medical system, they did not suggest these issues stand in the way of survivors accessing care.</td>
<td>This suggests survivors may not be discussing how the challenges they face are impacting their ability to address their sexual health issues. Future research should explore the degree to which this communication is happening. Increased communication may facilitate partner understanding and enable couples to work together to meet challenges.</td>
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<tr>
<td>Discomfort with psychological and physiological aspects</td>
<td>Inability to Access Timely or Coordinated Care</td>
<td>Trust needed to discuss sexuality does not develop</td>
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<tr>
<td>Inability to Access Timely or Coordinated Medical Care</td>
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<tr>
<td>Provider-provider communication</td>
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<tr>
<td>Continual referrals</td>
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<tr>
<td>Inability to access providers</td>
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<td>Time constraints doing appointments</td>
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<tr>
<td>Believing Providers Cannot Help Them</td>
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<tr>
<td>No solutions to sexual health problems</td>
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<tr>
<td>Providers’ knowledge gap</td>
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<tr>
<td>Feeling Ill-Equipped to Address Survivors’ Needs</td>
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<td>Medical evidence is not clear</td>
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<td>Lack of training</td>
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<td>Belief that they cannot alleviate patient</td>
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<tr>
<td>Provider barrier:</td>
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<tr>
<td>Women and providers perceive barriers in terms of providers’ expertise and availability of effective and safe treatments. According to both groups, this causes reticence to fully engage the topic.</td>
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<td>Patient and provider education efforts should be supported. Resources should be created to increase providers’ self-efficacy and offer sensitive communication strategies to discuss conflicting evidence. To prevent patients from giving up, efficient coordination of care efforts should be aimed at helping patients</td>
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<tr>
<td>Feeling Inhibited by the Taboo Nature of Sexuality</td>
<td>--</td>
<td>Provider Barrier: Coping with Patient Reluctance Based on Demographic Differences. Male Biological Sex Age differences. Struggling to Operate within Time Constraints that Affect the Delivery of Care. Insufficient time to build necessary rapport. Provider reported awareness of patients’ discomfort discussing sexual health with providers of different demographics. They suggested overcoming this barrier is a challenge because it requires time to build patient-provider rapport—time they do not have.</td>
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<td>Provider education efforts should be aimed at helping providers broach the topic in sensitive ways and offering them strategies to continue the conversation if time becomes an issue. For instance, they could engage in collaborative agenda setting by asking the question at the beginning of the interaction and then work together to set their priorities for their time together that day. This strategy ensures patients have a voice. They may decide to discuss it briefly or at length, to make a follow-up appointment, or to set up an appropriate referral.</td>
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| Feeling Inhibited by the Taboo Nature of Sexuality | Feeling Inhibited by the Taboo Nature of Sexuality Discussing sexual health during the medical visit Coping with Provider Behavior which makes it Difficult to Address Issues Medical providers do not bring up the topic Providers report they know how difficult it is for patients to discuss sexual health. They suggest when providers fail to bring up the topic it presents a barrier for survivors. However, further analysis revealed assumptions about certain groups of survivors that are linked directly to providers’ decision not to bring up the topic: older women are not as concerned with sex, long-term survivors don’t experience symptoms, if sex is an issue survivors will bring it up themselves, and other providers are taking care of women’s sexual health care needs. Assumptions about when and why particular groups of women are not affected by changes create health care disparities because, in this case, they are connected to whether or not the provider broaches the topic. Education efforts should be aimed at addressing these beliefs. |

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Research Question 7: Helpful and Unhelpful Provider Communication Behavior

Survivors’ perspectives. All parties reported that barriers exist to accessing and delivering quality sexual health care. This intensifies the need to understand what survivors, partners, and providers view as helpful and unhelpful provider communication behavior. The following analysis explored what survivors reported providers did and said to make an interaction about sexual health easier or more helpful and what kinds of behaviors made those interactions more problematic. Five themes emerged that characterized helpful or unhelpful provider communication behavior and two emerged, which functioned differently depending on a number of contextual factors. Helpful provider communication behavior was identified as: *telling survivors about sexual health effects earlier in the cancer continuum, facilitating an in-depth conversation, and communicating in sensitive and responsive ways.* Unhelpful provider behaviors included *communicating in ways that are perceived as dismissive and signaling discomfort with the topic of sexual health.* Emergent themes found to be both helpful and unhelpful included: *incorporating the partner into the appointment and providing referrals* (see Table 14).

Themes are presented in a way intended to clearly demonstrate the nature and function of different kinds of behaviors. Themes illustrating helpful provider communication are presented first. These are followed by unhelpful behaviors and behaviors that were framed as both helpful and unhelpful. Within these categories the presentation order was first organized chronologically (information content of messages to be conveyed earlier in the cancer continuum or earlier in the conversation to later).
After which, the emotional aspects of communicating messages were presented (sensitive communication or dismissive communication behaviors).

**Helpful – Telling survivors about sexual health effects earlier in the cancer continuum.** Survivors widely reported they wished their providers had initiated the sexual health conversation within them sooner. This theme emerged in the following forms: discuss breast reconstruction complications, talk about the effect of chemotherapy and adjuvant treatments on sexual health, and if hesitant to have the discussion at least verbally broach the topic and provide patients with additional learning resources ($n=29$).

Women reported they wished their providers had informed them about the sexual health changes during the initial diagnosis and treatment phases of their cancer experience. Some women said they wanted to know specifics regarding the kinds of sexual health issues they could experience, their causes, and possible treatments. Others said that if the provider had simply given an indication these issues were on the horizon they would not have been so confused or afraid when those symptoms emerged. One woman said, “He [the provider] never brought that up. Two years ago, if he said, ‘if you have sexual effects don’t be shy, let’s discuss it’ I think that maybe it would have been a more normal experience” (16).

Survivors said they understand why some providers may not think it is appropriate to discuss sexual health issues during diagnosis and primary treatment. They hypothesized providers may not want to overwhelm them at that stage in their disease process. However, this perceived concern for patients had unintended consequences. This survivor noted:
They look at my clinical history and physical and they say “Oh my god. Oh my god. How can I give her one more burden?” I know that’s what’s going through their mind . . . but how is that better? So I find out the worst, when I find out its worst? So don’t protect me? (5a)

Reflecting back on that time in their lives, women reported they would have liked to know about the potential for these issues and suggested if the conversation was handled in a supportive way it would have helped them in the long run. For instance, according to this woman:

I think that in my initial consultations with the oncologist, it would have been nice if he had looked at me and said, “You may not want to hear this right now because I know you’re in shock, but this is gonna impact your sex life drastically and you know although that’s not my forte, I want you to know that I’ve got your back on this and I will get you in touch with the right people to work on that when the time comes.” That would have been nice. (30)

Women also indicated they want providers to verbally state the issues instead of handling the matter through the sole use of questionnaires and pamphlets. This survivor described why she believes it is helpful to tell patients the truth at an earlier stage:

I think they need to be honest and tell the patients, “These are some of the changes that you may see happening with your body and if we notice them soon enough and start treating them soon enough then you’ll have better outcomes.” Even if you’re uncomfortable just at least say these words out loud. Don’t give people a written questionnaire or pamphlet without saying those words out loud. That’s the coward’s way out because people are just gonna check off the boxes that they think the doctors are gonna want to see or they’re too embarrassed to talk about it. They’re not going to read what you’ve given them with everything else they have to read. The doctors need to just come right out and say, “You may have some problems and if it’s important to you we’re gonna talk about it and we’re gonna try to find solutions.” If they say it out loud and then went to go through a pamphlet with me to take home that’s fine, but it doesn’t replace hearing the words. (31)

Some women reported that none of their providers mentioned the possibility of sexual health issues. Others said there may have been “a pamphlet about it in the pile of
things they gave me to read” (31). However, they suggested one of the reasons the reality of these issues didn’t register with them was because the providers didn’t engage that conversation verbally.

**Helpful - facilitating an in-depth conversations.** Despite this, survivors reported that it’s not enough to merely have that conversation. They indicated that when those conversations take place in survivorship it is helpful for providers to facilitate an in-depth discussion about sexual health. When these sexual health discussions take place survivors suggested they should not be viewed like “one item on a check list” (39). They outlined several behaviors providers can enact to ensure they’re facilitating an in-depth discussion with patients: provide specific information about what is happening to the body, listen and allow patients to feel heard, asking specific, open-ended questions, and go beyond general replies and provide concrete strategies to address issues ($n = 30$).

Women reported several things providers can do to make the conversation more helpful. First, they reported a need for more specific information. One woman spoke about this desire: “Please go into detail. For me, I’m one of those people who needs to know the ins and outs of everything. I like more detail” (39). Women cited a lack of specific information as a cause for much of their distress. This survivor described how giving more information can increase a woman’s ability to cope with changes: “Knowledge is power. Do empower us . . . explain exactly what could happen and why. I want to understand. Tell me what to expect and then empower me to deal with it. Don’t avoid it” (5a).

Sometimes women thought they were being given specific information about
symptoms only to find out that the nature of those symptoms was not accurately portrayed. For instance, one survivor who was post-menopausal at diagnosis talked about how her provider prepared her for the treatment-related hot flashes: “I remember some gynecologist saying, ‘You may have some hot flashes.’ Well, ‘You may have some hot flashes’ was a big understatement. It changes your body over night” (18). Women reported a preference for more detailed information about the symptoms they were experiencing. Knowing more about the cause and nature of their sexual health issues may prevent survivors from suffering the shock, confusion, and powerlessness presented in results from research question 5.

Survivors also reported that it is very helpful for providers to demonstrate they’re listening to patients’ concerns. It can be difficult for survivors to openly discuss sexuality so they appreciate it when providers allow them to express their concerns without interruption. One woman discussed the importance of listening: “listening, and for me, I was emotional bringing it up, so being just courteous about it, and allowing it to be an emotional situation when a patient brings it up” (25). It is critical for providers to listen to patients’ concerns. If survivors do not feel they’re being listened they were more likely to stop their attempts to have those concerns addressed.

Another element of facilitating an in-depth conversation is the use of specific, questions. Survivors suggested it is helpful for providers to ask a series of specific, open-ended questions from the beginning to the end of the interaction. One woman reported it is very important that survivors don’t feel like providers are not simply rattling off a checklist when they ask patients questions. She said, “Ask about it, every person. If
they’re going to quickly ask me, ‘yes or no,’ kind of looking down, I’m going to say, ‘No.’ Don’t just check it off but follow up and be thorough. Make it priority” (17).

Survivors reported that it was helpful when providers ask specific open-ended questions as opposed to broad inquiries with yes or no answers. According to one survivor providers should:

Ask about it and then pursue the answer. If they just say “Are you happy with your sex life?” That’s not specific enough. I’m more likely to say, “yah, fine.” You need to ask - you need to ask about it with a leading question that requires an answer and not just a yes or a no. (37)

Another survivor expressed her frustration with the fact that most providers only asked general questions:

I did not like everybody asking me if I was okay. Because no you’re not okay. But you can’t always express that to people. Everybody would say ‘Are you okay?’ “No” . . . I’d [say for providers to] say something more specific. Come out and say how is your sex life? How is your libido? Is it higher than it was last time, is it less? (29)

She indicated that if providers had asked her more specific questions it would have (a) alerted her to the fact that some of the issues she was experiencing were in fact due to her breast cancer treatments and (b) made it easier for her to talk about specific issues. For instance, she suggested if the provider said the word “libido” or “orgasm” it would have made her feel more comfortable replying because she wouldn’t have had to be the one to say those embarrassing terms first.

Survivors reported that providers can also help by delivering concrete strategies to attempt to address their issues. They said provider responses regarding possible solutions are sometimes too general. One woman expressed her frustration with this lack of specificity: “I tried to get help to fix the problem, and her response was very general . . .
like she wasn’t really trying to help me find something to help. So more specific
information would have been good” (13). Women said providing a strategy doesn’t only
mean providing a medication strategy. They would like a range of recommendations.
This survivor said she thinks this would be a good approach to take:

If you want to know more about it, here’s some resources for you. Read this. Go
to this website. Join this group of people. Try this, try that. Giving it at least five
minutes of serious conversation would have made it feel less like a toss off, and
maybe given me some ideas. (11a)

Patients reported they appreciate providers who invest time and thought into exploring
different avenues for addressing patient concerns because it communicates to them that
the provider cares – that (s)he wants to help the patient improve their quality of life.

**Helpful - communicating in sensitive and responsive ways.** Patients reported a
desire to have an in-depth conversation with providers. Yet, they also suggested it is
helpful when the provider adopts sensitive and thoughtful communication practices
during those conversations. Specifically, survivors indicated they would like providers to
be sensitive when talking about implications for patients’ relationships, use sympathetic
and supportive nonverbal communication behaviors, look for and respond to patient
signals, and provide developmentally sensitive/appropriate material ($n = 14$).

Survivors reported it is very helpful (to women in relationships) when providers
acknowledge and respect the implications cancer and its treatments can have for their
partnerships. Women reported providers have not always handled this task appropriately.
This woman discussed an instance in which she tried to discuss sexual health with her
oncologist. She said, “He was very cavalier. He said ‘I’m gonna save your life but I
might not save your marriage’” (24). Patients reported that when providers ask about the
partner and vocalize their investment in helping the couple find ways to manage sexual health challenges they feel more confident about remaining in that provider’s care.

Women also reported they find it encouraging when providers use nonverbal behaviors that communicate engagement and emotional investment. This survivor talked about a physician who made her feel more comfortable: “He actually held my hand and looked in my eyes and that meant so much to me” (21). Women reported noticing providers’ body language. This woman talked about the importance of that kind of communication:

I think first of all, body language. The doctor that sits up really straight and his arms crossed or her arms across like “Now what do you want to tell me?” you obviously don’t want to tell too much. Whereas my family practitioner, she sits back in the chair, like she’s got all day, when you know she doesn’t really. And goes, “Okay let’s talk about what's going on with you.” She shakes her head and looks at me and sits closer to me if I’m upset. (27)

Lastly, part of provider sensitivity is demonstrating an awareness of concerns that may be the most relevant to the patient. For the women in this study, this took the form of providing developmentally appropriate material. One woman reported being very distressed when her provider gave her materials that she felt didn’t align with her experience:

She gave me a book, not like a book, but like a little pamphlet. I felt like, “okay, this pamphlet is obviously designed for somebody in their 70s.” Just because the way it was worded, and what they were talking about . . . it wasn’t really designed for women in their 20s. (39)

This woman said she was looking for materials that would give her information about things she felt the pamphlet was not addressing, “how do I feel sexy, and how do I get my boyfriend to accept the fact that I don’t have hair. Like just real things.” When her
provider gave her a pamphlet with photos of women in their 70s and sections that included “phases of a marriage” she felt her individuality was not being recognized. Survivors suggested it is helpful for providers to offer supplementary material depicting women and issues that women can relate to. This further supports the need for providers to become aware of the patient’s priorities in order to deliver comprehensive, patient-centered care.

**Unhelpful - communicating in ways that are perceived as dismissive.** While women reported that discussing the topic earlier, in-depth, and in sensitive ways is helpful, they also reported provider communication behaviors they found particularly unhelpful. Women said that communicating in ways that do not recognize and honor women’s individual experiences is unhelpful because it is perceived as dismissive. Survivors identified several provider behaviors they feel communicate a dismissal of their concerns: rushing the patient, providing what survivors believe to be empty assurances, not providing next steps, telling the patient her concerns are unrealistic or invalid, voicing providers’ assumptions that sexual health is not important to particular types of survivors, and treating women like medical objects/specimens ($n = 24$).

As noted, time constraints are a huge challenge for providers. However, women reported feeling rushed by providers’ hurried or distracted demeanor. One woman talked about behaviors she finds particularly dismissive: “Don’t be distracted on your computer. Don’t let people knock on the door, make it a protocol in my office, when I’m with a patient don’t come in there” (21). When providers make patients feel rushed it can prevent them from asking their questions. This survivor expressed her frustration with her
provider’s rushed attitude:

She does not have it on her mental checklist of what she needs to do. She needs to examine my breast. She needs to ask me her three questions, whatever they are, whatever the number is, and she’s out of there, and I feel like I have to practically hold her hand to keep her in there with me, and because I feel such pressure I forget stuff to ask. I’ll think, “Okay I have three questions. I want to remember to ask her these three things.” And because she’s in and out so fast I’ll forget them. I feel like I don’t even have time. They’re just in such a hurry to get to the next one.

Survivors reported that, especially when they cannot get an appointment for a long time, they may have several issues they want to discuss. Often when a provider looks rushed in these appointments sexual health concerns are left unaddressed.

Another provider behavior, which patients found dismissive is the use of blanket assurances without accompanying questions and solutions. Survivors reported that providers have offered a variety of assurances that can ring hollow. For instance, one survivor said she once expressed concern over changes to her body and asked her provider about options for addressing her sexual health issues. She said to the provider, “I can’t deal with all this change in my body” and she [the provider] said, ‘but change is good for you.’ I'm thinking ‘Not this kind of change.’ And Dr. Jones said, ‘You're doing everything right’ and I just said ‘okay’” (24). In this case, the provider’s assurances frustrated the survivor so much that months passed before she decided to try to talk to another provider about her concerns.

Women expressed similar frustration when they attempted to discuss their body image issues with providers and providers responded by trying to bolster their self-esteem. This woman told the story of one such interaction with a provider:
If the survivor says “I think I’m just not - I don’t feel good about the way I look. I’m not happy with the way I look.” I don’t think it’s a good thing for the provider to say “Oh you look fine.” Because now you have shut down an open dialogue. You have closed that door because now this person goes, “You’re not listening to me. . . I know how I look. I know how I feel.” So you telling me that I look wonderful is not helping me. If anything I feel at this point that I really can’t trust what you say because I don’t believe you now. (15)

Even though medical professionals are most certainly trying to help when they provide affirmations about a survivor’s appearance it can be interpreted as dismissive and affect the patient’s trust in the provider, particularly if that is their only response to the patient’s concerns. Survivors also reported the sole use of the assurance that things will get back to normal is not helpful. This woman said her oncologist told her:

“It will change, it will go back to normal,” that's what I heard from my oncologist . . . “It'll come back, you're young, it'll come back” . . . and I'm just like whatever, I just wanted to get through it and I honestly stopped asking questions to my doctor. I stopped telling them my side effects. (32)

What makes these providers’ behavior so upsetting for women is that they are often viewed as a replacement for possible solutions. Women reported providers did not give patients next steps. The same woman continued:

I was just kind of like, “Oh! There is really nothing you can do . . . This is it.” He just told me “to find creative ways to deal with it and this is it”. . . after that meeting I just felt hopeless. I had no idea what to do next. You mean there are no next steps? Alright, well maybe this is it, and there is nothing I can do about it. (32)

Survivors cited additional concerns about the way providers in he past had dismissed their concerns by suggesting their expectations regarding sex were unrealistic or their concerns were invalid. For instance, one survivor reported that when she asked a doctor for help and he replied, “’You can’t expect to have sex forever.’ Kind of in a way telling me that that I was asking too much, and I was even younger then and I just
thought ‘oh my gosh’” (35). This provider’s response caused the survivor to question herself. She continued: “It made me feel like ‘Wait a minute’ kind of doubting myself. I was like ‘maybe I’m asking for too much. Maybe because I’m in my 50’s I shouldn’t be thinking that way’. . . I just couldn’t believe he said that” (35). This is an example of the kind of behavior, which may increase older women’s perceptions that providers don’t recognize them as sexual beings. As a result, some of these older patients may remain silent about their problems.

Other women reported that providers directly told them their concerns were not important. One woman told the story of two separate interactions in which providers invalidated her suffering: “I was talking with my oncologist about my feelings about losing my breast and he responded, ‘Well it’s just a breast. I mean it’s not like an arm or a leg or a different part of the body.’” After reconstruction she spoke with another provider about nipple sensation: “I said do you think there will ever be a way to regain sensation in her breast? And he was like ‘Well you know in the list of things that’s important that’s not very important on the list’” (7a).

Survivors reported that in addition to invalidating their concerns, sometimes providers communicated their assumptions that sexuality was not important to women. This hampers survivors’ efforts to have their concerns addressed. One survivor talked about an instance in which a provider suggested sex wasn't a concern for her due to her age:

I think the medical profession looks at you and sees a senior citizen and goes “Well that’s not gonna be a big concern of yours.” I was actually told that once, like “yah, this can be an issue, but I know you’re probably not worried about that
anymore.” Well not as much as we were at 40 but . . . but do we both miss it? Yeah we do. (27)

Survivors reported sometimes providers assumed the only reason women brought up sexual health concerns was because their partners were encouraging them to do so.

This survivor shared the story of when talked to a provider about low libido. The provider assumed she was asking for her husband:

I mentioned it to my gynecologist at my regular yearly appointment. I said, “I seem to have like absolutely no desire to have sex. I have no sex drive.” And his response blew me out of the water and I was stunned. He said, “Doesn’t your husband know you’ve been through enough?” I really had nothing to say to that. I didn’t say anything about my husband. I wasn’t saying, “Oh he wants to have sex and I don’t” I said, “I have no sex drive.” That was what I said and that was his response. They didn’t even go together . . . It was a giant leap and I said, “Well, you were not the person to have this discussion with.” Obviously nothing helpful is coming from here . . . I am not going to now sit here and explain that’s not what I meant and this had nothing to do with my husband. This isn’t him saying to me, “What’s the problem?” (37)

Women suggested that when providers communicated their assumptions about the nature of women’s sexual health, their satisfaction with care suffered. Survivors also reported that they found it unhelpful when providers objectified them – treated them like “specimens” or “like cancer” instead of like people. Several survivors talked about occasions when providers made them feel like objects. This woman told a story about visiting her gynecologist:

When I was at a gynecologist looking for some options he [the provider] asked if I was okay having a resident in that appointment and I said that was fine but when he started, he started pointing out “this is this, that is that, this is vaginal atrophy” and he got into this really clinical conversation with the resident right in front of me and then it was like oh . . . he was having a conversation with the resident and not with me . . . I think I was only 47 then I really felt odd and really broken and . . . it was hard and I cried when I left the appointment. (12a)
Gynecological exams can make many women feel uncomfortable. This provider’s behavior disregarded the patient’s humanity when she was already in a vulnerable situation. Another woman recounted her story about visiting her oncologist after the removal of her breasts:

He said when he first saw me after surgery “Let me take a look at you. What did they do to you? Let’s see what they did to you?” and I felt so horrible, and I felt so exposed and I felt, “Oh my god, why did you have to say that like that? . . . You’re not treating me like a person. You’re making me feel horrible . . .” I wanted to scream at him. I wanted to say, “I can’t believe you’re even saying this. Don’t look at me. I’m leaving now.” I felt horrible. I felt ashamed. I felt exposed. (35).

As discussed earlier breast cancer surgeries can be very traumatic for women. They may cause them to struggle with who they are as women. In a time when this survivor was already grappling with her loss, this provider made her feel like an object of curiosity. Women’s accounts reveal that when navigating the uncertain terrain of survivorship providers must be very careful not to dismiss a woman’s sense of self, as many aspects of that self are already threatened in the aftermath of cancer.

_**Unhelpful - signaling discomfort with the topic of sexual health.**_ While women reported that dismissive provider communication caused them emotional distress and thwarted the possibility of having a productive medical interaction, they also suggested that providers shut down a conversation about sexual health by signaling their discomfort with the topic. Survivors recalled specific interactions where they could tell the provider was uncomfortable talking about sex. This perception upset them because sex was not a particularly easy topic for survivors to discuss either. However, they viewed it as part of the provider’s role and found it unhelpful when they were put in a position of sacrificing
or delaying their medical care due provider comfort level. Survivors reported several ways they discerned provider discomfort: providers directly tell the patient they are uncomfortable, they nonverbally signal discomfort, and they shift the topic away from sexual health ($n = 11$).

Women reported providers directly told them they were uncomfortable with the topic. One survivor said that when she finally broached the topic with her provider she replied, “I'm not comfortable talking about this’ . . . and I was like, “Oh! How can you not talk about that?’ I don't understand” (32).

Providers indirectly signaled their discomfort through nonverbal behavior. This woman reported, “They [providers] need to learn how to talk about these things without turning red, which is what my internist does. He does. He turns bright red and then you’re like, ‘Oh I better drop this’” (23)? This behavior can shut down the interaction before it begins.

Patients also suggested they sensed a provider’s discomfort when the provider changed the topic. This woman said she had “a couple appointments where I tried to bring it up with our oncologist, but he would steer the conversation away from sex and to something else like, ‘we talked about your headaches last appointment . . . ’” (12a). After failed interactions women sometimes felt at a loss for whom to turn to. They suggested they didn’t know whom to visit next and this sometimes delayed or marked the end of their efforts to address their concerns with medical professionals.

**Helpful/Unhelpful - providing referrals.** The issue of provider discomfort was strongly related to the provision of referrals. Providing referrals emerged in almost half
the interviews with survivors. It was a provider behavior that women found helpful and
unhelpful in different situations. Whether or not women found referrals helpful depended
upon the context in which they were given. Referrals were helpful when patients were
referred to providers who were comfortable with topic or when referrals were given to
providers who can address special elements of a survivor’s concerns. Providing referrals
was unhelpful when the subsequent medical professionals were not equipped to address
women’s issues and women ended up being passed back and forth between providers (n =
19)

Survivors suggested they understand that providers may be uncomfortable
discussing sexuality. In those cases, while survivors may be temporarily upset, they
reported that referrals could be helpful in those situations. For instance, this woman said,
“If they are not comfortable talking about that then get someone in the room who is
comfortable . . . like my doctor - that may not be her thing, but she must have a colleague
or someone” (8a). Referrals were also seen as helpful when connecting a patient with
another provider would help the survivor access specialized care for her particular needs.
This woman talked about the need for appropriate referrals:

To have access to another physician or specialist or nurse practitioner or
psychologist, or whatever their issues specifically warrant, if they are about the
couple, or an individual psychological thing, if they are having sexual health
problems they can call this person, this person, this person . . . I’m gonna set you
up with our psychologist or counselor for a one session. (36)

Often referrals to psychological services were viewed as particularly helpful. One
woman reported: If her provider said, “‘As part of our protocol we invite you to see a sex
therapist as a couple.’ I would welcome that. It could be a safe place for my husband and
me to talk to enhance our sex life” (5a).

There are times, however, when the provision of referrals was viewed as obstructive. Women reported that navigating continual referrals was a barrier to addressing sexual health so it is no surprise that when providers offer a referral it was sometimes unhelpful. Providing referrals was unhelpful when survivors were referred to medical professionals who didn’t know how to address issues and women ended up being passed from one provider to another.

One woman talked about her dissatisfaction with a referral given to her by her primary care provider. The provider referred her to a therapist: “She was like 21, and he didn’t have a clue to what I am going through” (26). This survivor spoke of her experience of being bounced back and forth between providers: “My oncologist doesn’t want to [talk about sexual health]. I talked to my primary [care provider] and my oncologist about it and they’re just referring it to the gynecologist [who subsequently referred her back to her oncologist]” (35). As coordination of care was a barrier cited by survivors in research question 6 it is expected that women find this practice can negatively impact the quality of their health care.

*Helpful/Unhelpful – normalizing sexual health issues.* Efforts to coordinate care with other providers were problematic at times. However, women also reported varying outcomes associated with provider communication behaviors confined to the primary interaction. Survivors suggested that provider attempts to normalize sexual health issues have complex implications. Survivors suggested it is helpful when providers normalize sexual health issues by letting patients know other patients experience symptoms too.
However, when providers relied on the linguistic trope the “the new normal” patients reacted negatively ($n = 13$).

Survivors reported that normalizing sexual health distress would be beneficial. Women are sometimes unaware that sexual health issues are a widespread problem. As a result, they may assume something is wrong with them particularly and may engage in self-blame. When providers let survivors know other women suffer these symptoms during the process of addressing their concerns, women find it comforting. One survivor said normalizing her concerns would have been helpful because, “just to know I’m not alone. That would be huge because I thought I was odd or wrong in some way” (8a).

However, survivors reported that normalizing their concerns is not always helpful. According to survivors, some providers rely on the linguistic trope the “the new normal.” Many survivors said this phrase represents a narrative they reject. Multiple participants expressed their dislike for this expression. One woman said, “this oncologist standing in a corner with his body language, with his arms crossed and his feet crossed, standing there, leaning against the wall, saying now this is a new normal, I just react so poorly to that” (21). Survivors also sensed when the phrase was in the past it was used when providers just didn’t know what to say to the patient and wanted to find a way to move the conversation along. One survivor talked about her experience with “the new normal”:

I would talk to my oncologist and I’d just get the sense of he had no idea what to tell me and so when I feel like a doctor is just completely lost and I feel completely lost . . . he pulled out a few lame things from his repertoire. The stuff that everybody says about “it's the new normal.” Well, I don’t want it to be my new normal. I reject that reality, you know? I want to make things better. I don’t want to just accept what is without even fighting for it. (34)

Phrases like the new normal are prevalent in popular culture. However, survivors
reported that “the new normal” does not carry the same meaning for everyone and can be harmful to women.

*Helpful/Unhelpful - incorporating the partner into the appointment.* Another communication practice providers may adopt, which has varying results is including a woman’s significant other in the medical interaction. Survivors found it helpful when providers included their partners in the sexual health discussion when the following conditions were met: the partner can act as a memory aid for the survivor, the partner’s presence helps the survivor to get more information from the provider, the provider is able to validate women’s experiences and facilitate partner understanding, and the provider acts as a mediator – helping to get the conversation started and diffuse tension. Survivors reported that integrating the partner into the appointment is unhelpful when and if the survivor is concerned about her privacy and preserving her partner’s pre-cancer view of her, when including the partner would put him on the defensive or make him feel like the issues they are experiencing are his fault, when the survivors feels like including him will needlessly burden him, and when the provider talks to the partner instead of to the survivor \( n = 32 \).

The women in this study suggested that when a provider includes the husband in a medical interaction about sexual health the partner can help her remember important elements of what was discussed. This woman suggested, “Even if I walked out of an appointment and write stuff down right away, I don’t always remember everything. So two sets of ears is good for that reason” (2a). They also reported partners can help them ask all of their questions. According to this survivor, if her husband was in her last sexual
health medical interaction “he would have also been able to probably ask more questions, and at least try to get more information, because it was emotional for me to bring up” (25).

Sexual health is an emotional topic for many couples. Some survivors said if the provider includes the partner he would have an opportunity to hear the provider validate women’s experiences and facilitate the partner’s understanding of the challenges they are facing. Some women suggested partners think they are exaggerating their symptoms or complaining. For instance, one woman said, “It could be good if every once in a while he heard it wasn’t just me. I’m complaining - that kind of thing. To hear it from the doctor . . . I think that would be beneficial” (35). Other survivors said it would help their partners understand there are medical reasons for the problems – that the issues do not have anything to do with the partner. According to one survivor, “I think it would be helpful because I think the doctor could then kind of relay that it’s because of the cancer, not anything he’s doing or relating to him, which might put him at ease” (29).

Lastly, survivors reported it is useful for provider to include the partner because it allows the provider to facilitate communication and ease tension that may arise. Women reported this could be especially helpful when the couple has difficulty communicating about these issues at home. One survivor viewed it as an opportunity:

[It’s an] opportunity to start the dialogue knowing that there’s somebody there that will see what I see and maybe tell me, you could have worded this a little differently to make it less threatening . . . I think for us, we need a mediator. We really need someone to assist us in opening a dialogue with each other and teach us how to properly dialogue with each other. (21)

Including the partner is not always viewed as helpful. When women are
embarrassed or concerned about preserving their partner’s pre-cancer view of them they reported being more reluctant to participate in this kind of interaction. This woman talked about her feeling regarding including her partner: “I would feel embarrassed. I feel like I am inadequate. I would not have brought it up [with him there], there is no way. If she [the provider] would have asked me, I would say everything’s good” (8a). Another woman echoed these sentiments:

I probably want him to protect him from hearing it, hearing any of it, because I don’t want him to think of me different . . . all you want is your husband to not see you differently even though you know he does, but you want him not to. (16)

Survivors also reported that including partners in the discussion would be unhelpful due to their concerns for them: they don’t want to put them on the defensive or to further burden them. Several women suggested if their partners were part of the discussion they would not be able to accept they are not the cause of the sexual health issues. This woman talked about how she would change her behavior in order to protect her husband: “I would probably censor what I would say because I wouldn’t want to, not necessarily offend my husband, but just I guess put him on the defensive” (29). Another survivor suggested her husband “would not see it as a hormonal thing, he would see it as something about his performance is wrong” (4a).

One woman said she had concerns about saddling her boyfriend with more cancer-related problems. She reported, “If I am having a problem with my ovaries, or not being able to become naturally lubricated that’s not his problem. I feel like he has enough to worry about. I would prefer to take care of on my own” (39). This inclination may contribute to partners’ lack of awareness regarding the severity of the barriers women
experience when trying to access care for their sexual health issues (see research question 6). Women may be intentionally sheltering them from selected pieces of information.

Lastly, survivors reported that it would be unhelpful to include the partner if providers start speaking to the partner instead of to the patients. This woman shared her thoughts about this: “When a doctor directs all of his comments to your husband it’s a clear indication he’s not interested in you” (24). When survivors sensed the provider was not interested in her perspective they withdrew from the conversation. They suggested the tendency among providers to focus most of their attention on their partners was demoralizing and made them reluctant to discuss issues with those particular providers in the future.

Phase 1 of this study hinted at the complexity involved in including survivors’ partners in a medical interaction regarding sexual health. Phase 2 of this study explored that complexity and extended our knowledge of the factors influencing its utility. According to survivors, including the partner in the clinical appointment must be carefully considered and handled delicately.

Variations by age and survivorship length. Important lessons can also be learned by examining how age and survivorship length influence what women find helpful and unhelpful from medical providers in an interaction about sexual health. Instead of uncovering differences according to age and survivorship length, however, this analysis uncovered the added salience of one theme reported by multiple groups of women. Women in older adulthood and those who have been survivors for more than five years recounted why it’s so crucial that providers facilitate an in-depth conversation, and in
particular, do so by asking specific questions about survivors’ sexual health status.

Variations in age were reported in that women emphasized the importance of providers asking older adults about their sexual health concerns. They suggested this is especially important for older women. They said their generation may be less apt to bring it up themselves because discussing sexuality was not the norm in decades past and they don’t want to complain or “bother” the provider with those issues. One woman expressed how grateful she was when her provider asked her about her sexual health concerns:

I’m a good old Presbyterian girl and that, to me that [sexual health] was a kind of a vanity thing, and uncomfortable for me to bring up because you wouldn’t have done that in my day. You be thankful you’re here. Who cares what you look like? So I was very thankful that he brought it up and asked me are you having pain with intercourse? (10a)

This 62-year-old woman suggested it is common for women of her generation to keep their concerns to themselves. She said, “You keep that stiff upper lip. That’s all there is to it” (24).

Survivorship length played into women’s desire for providers to directly ask them about their sexual health concerns. Women five years post treatment discussed how the challenges of treatment and adjusting to survivorship in general can prevent women from prioritizing sexual health concerns. This is a challenge to addressing their concerns, which was referenced in research question 6. They suggested that as time goes by it gets harder address those issues. As this woman reported:

I used to laugh and say, “Look, its not that I don’t want to [have sex], I’m just too damn tired.” Nobody can understand that type of exhaustion and that feeling you have unless you’ve gone through it. I worked all through treatment and adjusting to life and work and family in the years after that. It got too far out for us and it
just didn’t happen. And no one asked me, is this a problem? Can I help? I just gave up. (21)

While a lot of attention is focused on early survivorship, and rightly so, according to these survivors, providers must expand their definitions of who is appropriate for this conversation as women in older adulthood and long-term survivors are suffering.

Table 14

<table>
<thead>
<tr>
<th>This percentage of survivors</th>
<th>described these behaviors,</th>
<th>which are characterized by the following dimension(s).</th>
</tr>
</thead>
<tbody>
<tr>
<td>(n = 29, or 73%)</td>
<td>Telling Survivors about Sexual Health Effects Earlier in the Cancer Continuum</td>
<td>Breast reconstruction complications</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Effect of chemotherapy and adjuvant treatments</td>
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<tr>
<td></td>
<td></td>
<td>Verbally broach the topic and provide additional learning resources</td>
</tr>
<tr>
<td>(n = 30, or 75%)</td>
<td>Facilitate an In-Depth Conversation</td>
<td>Provide specific information about what is happening to the body</td>
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<tr>
<td></td>
<td></td>
<td>Listen</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Ask specific, open-ended questions</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Provide concrete strategies</td>
</tr>
<tr>
<td>(n = 14, or 35%)</td>
<td>Communicate in Sensitive and Responsive Ways</td>
<td>Respect implications for relationships</td>
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<td></td>
<td></td>
<td>Supportive nonverbal behaviors</td>
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<tr>
<td></td>
<td></td>
<td>Look for and respond to patient signals</td>
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<tr>
<td></td>
<td></td>
<td>Provide developmentally sensitive/appropriate material</td>
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</table>

Unhelpful
<table>
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<tr>
<th>(n = 24, or 60%)</th>
<th>Communicate in Ways That are Perceived as Dismissive</th>
<th>Rushing the patient Empty assurances No next steps Telling patient their concerns are unrealistic or invalid Acting on assumptions about the insignificance of sexual health Treating women like medical objects</th>
</tr>
</thead>
<tbody>
<tr>
<td>(n = 11, or 28%)</td>
<td>Signal Discomfort with the Topic of Sexual Health</td>
<td>Directly disclosing discomfort Nonverbally signaling discomfort Topic shift</td>
</tr>
<tr>
<td><strong>Helpful or Unhelpful</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(n = 19, or 48%)</td>
<td>Provide Referrals</td>
<td>Referred to provider who is comfortable Referred to providers who can address special concerns vs. Subsequent medical professionals are not equipped to address women’s issues Being passed from one provider to next</td>
</tr>
<tr>
<td>(n = 13, or 33%)</td>
<td>Normalize Sexual Health Issues</td>
<td>Letting patients know they are not alone vs. “The new normal”</td>
</tr>
<tr>
<td>(n = 32, or 80%)</td>
<td>Incorporate Partner in the Appointment</td>
<td>Memory aid Acquire more information, Validate women’s experiences Facilitate partner understanding Provider as a communication facilitator vs. Privacy concerns Preserving pre-cancer view of survivor Put partner on the defensive Make partner uncomfortable Burden the partner Provider talks to the partner, not survivor</td>
</tr>
</tbody>
</table>

**Partners’ perspectives.** When partners were asked about survivors’ perspectives regarding helpful and unhelpful provider communication, they reiterated several themes
mentioned by the survivor group. Four themes emerged that illustrate helpful or unhelpful provider communication behavior and one emerged, which operated as helpful or unhelpful in different situations. Partners suggested survivors would say that helpful provider behavior is behavior that: *enhance patient satisfaction through direct communication*, *tell patients their future questions will be answered*, and *normalize survivors’ sexual health issues*. They suggested that unhelpful communication is *communicating in ways that survivors perceive as dismissive*. Similarly to survivor interviews, providers’ *efforts to include partners in the medical interaction* were perceived as helpful or unhelpful for various reasons (see Table 15).

_Helpful – Enhance patient satisfaction through direct communication._ Partners emphasized the importance of direct communication when discussing sexual health. Partners reported that survivors would prefer communication behaviors that are straightforward and fact-based. They said survivors find direct communication helpful in a variety of ways: broaching the topic by asking specific and direct questions, provide direct communication about what and why symptoms will/are being experienced, directly communicate specific strategies to address issues, and use data to support patient understanding and to bolster their confidence in the provider (*n* = 7).

Partners reported a desire for communication to be “direct” when bringing up the topic, explaining what is happening, and providing strategies to address sexual health issues. One partner reported his wife would prefer a provider to bring the topic up by asking her a direct question: “Just being direct, point blank. Not just how is your health, but how is your sexual health” (6b)? Partners also indicated survivors have a need for
more specific information about what is happening to their bodies. According to one partner:

She and I are both so direct – I think you have to be very honest and upfront and say exactly what the situation is and what the implications are for the physical changes that a person will go through and what that might mean. (3b)

After providers explain what the sexual changes are why they are happening partners said survivors would benefit from being given strategies to address the issues. One man explained, “When people go in they want direct answers and they want to know what to do” (2b).

Partners repeatedly used the word “direct” to describe the kind of communication they think women would find helpful. They indicated they understand sexual health is a sensitive topic and may be difficult to discuss, but they feel women are frustrated by the lack of straightforward engagement by health care providers. They reported one way providers could maintain an upfront demeanor and deliver facts is to use data to support their claims and enhance patient understanding. This husband said his wife would find the following helpful:

Some information based on surveys of how other people have dealt with sexual health issues and breast cancer. But just keep it factual. It would be good to say “these are the physical things and these are the results of the experience we know from surveys from talking to people.” (4b)

One partner suggested an emphasis on directness would dictate whether his wife remained in the care of a provider. He said, “I think she would read that as a sign of weakness [if the provider did not address the issue head on]. She would wonder if she was at the right provider” (6b). While survivors’ accounts focused on the specificity of
information gathered and distributed. Partner accounts emphasized the importance of communicating that information in a direct manner.

**Helpful – Telling patients future questions will be answered.** Partners felt that survivors are not only concerned about getting the facts in the most clear-cut way possible, but they also want to know they will be able to get their questions answered in the future. Partners outlined one primary approach for doing this. Specifically, partners reported women find it helpful if providers take the step to tell survivors they will be there for them whenever they have questions about sexual health issues ($n = 3$).

Partners suggested it is helpful to tell survivors they are here for them when and if patients are ready without pushing the conversation on the women. This partner indicated the most helpful thing a provider can do is to “let you know they are available to discuss if you want and if not, end of conversation” (10b). He was the only partner in the current study that suggested his wife may feel embarrassment significant enough to prevent her from bringing up her sexual health concerns with a provider. While he emphasized he believed his wife would find this strategy helpful, he was also the partner who was the most resistant to talking about sexual health issues himself (for more see subsequent theme including partner perspectives about their inclusion in the medical interaction section).

Partners suggested another way to let survivors know they will be able to find answers to their sexual health concerns in the future is by making them aware of the possibility of referrals. One partner suggested his wife would find it helpful if the provider had said, “Some things may require follow-up . . . think about this. If you have
any questions at a later stage you can meet with me or another provider. We have specialists to answer your questions” (4b). While survivors indicated they want specific information about the ways in which reconstruction and treatment can cause sexual health distress earlier in the cancer continuum, partners reported survivors’ preferences in a slightly different way. They said that mentioning sexual health issues may emerge and can be followed up on at a later time would suffice. Largely, they did not report that survivors required more in-depth information about sexual health symptoms before they emerged.

**Helpful - Normalize sexual health issues.** Another feature of provider communication that partners suggested would be helpful is the normalization of sexual health changes. They reported that provider communication efforts should aim to normalize sexual health issues for survivors. Partners reported normalizing sexual dysfunction would let patients know they are not alone ($n = 3$).

Partners reported that sometimes women believe their symptoms are their fault. According to partners, women would appreciate hearing these issues have a medical basis and that many survivors experience them. One man described how helpful his wife would have found it if her provider normalized the experience by letting her know she was not alone:

> I think a lot of it is just knowing that other people have the same feelings you do. When it happened she felt like she was the only one in the world that’s ever felt that. To have the doctor say, “Well a lot of our patients go through issues.” Just saying that would bring some comfort, like “Okay, well I’m not the only one.” (1b)

Like survivors, partners reported that not knowing the origin of the symptoms can
be traumatic for women. This is why they reported in the previous theme that they prefer providers to mention the possibility of these issues to women before they experience them. However, unlike survivors, partners did not report that other forms of normalization might be unhelpful.

Unhelpful - Communicating in ways that survivors perceive as dismissive.

While survivors perceived “the new normal” to be a form of normalization that is unhelpful because it feels dismissive, partners did not report this to be an element of dismissive behavior. However, partners did describe several ways providers communicate, which are perceived as dismissive. In particular, partners said survivors find it unhelpful when providers rush them, treat them like a medical object/specimen, or tell them they understand where they are coming from ($n = 5$).

Similar to survivor accounts, partners also reported that women find it difficult to have a successful medical interaction when the provider sends signals that time is limited. One man said he wife believes providers sometimes send messages they are not fully engaged in their interaction: “They look at their watch and cue ‘I have to go.’ Somebody looking at a watch tells you . . . we don’t really want to talk about this. I know she hates that” (7b). This partner also suggested his wife disliked it when she felt providers were rushing her: “One thing she tells me is that doctor was always in a hurry. They were always looking at the door or at their phone . . . they didn’t have time to have conversations to listen what you feel” (8b). Partners reported when survivors feel rushed they are dissatisfied with the care they receive.

Another provider behavior that partners reported is objectification. They spoke
about instances in which survivors were upset because providers treated them like a medical object/specimen. This man recounted his story:

I remember when we went to a doctor for reconstruction. He did not make eye contact with her at all. He stared at her chest during the entire evaluation. That really bugged us. He did not make any eye contact and we walked out of his office and that really bothered us. (2b)

Partners suggested women find this kind of behavior dehumanizing because they are being reduced to their individual parts instead of being treated as a whole person. Finally, partners indicated women find it dismissive when providers respond to their requests for help with declarations of understanding. This husband discusses his wife’s point of view:

They [providers] are trying to say “I know, I understand” . . . She is like “they don’t.” They say they do, they don’t. I know they mean well, but they don’t understand these issues. The medical degree doesn't help them know what she’s feeling. So, they say that and nothing else and she’s just like – forget it. (6b)

Again, while providers’ motivation for expressing empathy may be well intentioned, the act may be perceived as dismissive and unhelpful. As evidenced through survivor accounts these behaviors can have devastating effects on patient trust, their willingness to continue sexual health discussions with providers, and their sexual health outcomes.

**Helpful/Unhelpful - Including partners in the medical interaction.** Like survivors, partners recognized that including the partner in the medical interaction can have a positive and negative impact on the already complex interpersonal communication challenges women experience during clinical visits. Partners reported survivors would find their presence helpful because: the partner can act as a memory aid, his presence can
help facilitate subsequent communication about sexual health, by being there he she sees the partner supports her, and it increases his understanding of what she is going through. Partners said survivors would find provider efforts to include them unhelpful when specific information about sexuality and the body is discussed and when she knows her partner does not want to be there \((n = 11)\).

Partners suggested that survivors find their inclusion in the interaction helpful when they can serve as a memory aid for women. One man noted, 

Well I think as human beings we only hear maybe sixty or seventy percent of what our doctor is telling us and we don’t retain everything that was said, that was said by the doctor in appointment and with another set of ears. (11b)

Partners also indicated when providers include them their wives or girlfriends believe it will facilitate more open communication within the couple. This partner said, “She thinks I might be more apt to talk about it . . . [she thinks] there would be a better chance - she would think that” (10b). However, while this partner indicated he thinks he wife believes it would be helpful for this reason, he suggests it would not. He said, “I would not talk.”

Another man reported his wife believes his inclusion in the clinical visit would facilitate communication (and in his case, he reported it would) (1b). He also suggested that being included would be a benefit because, from her perspective, it would show he is invested in improving her health: “I think she would appreciate it . . . I’m taking the interest – that I care and I’m and opening up lines of communication and hearing from the doctors and I think she would be in favor of that” (1b). Even when partners reported being included in the visit doesn't necessary open up communication during or after the visit they still reported survivors would find it helpful because it helps partners
understand women’s experiences. This man talked about a time he visited a provider with his wife: “It was fine. It was good for me to be there. I think she thought I could understand what she’s going through but it didn’t really spur any post appointment conversation between the two of us” (3b).

Partners also identified instances in which survivors would find it unhelpful for a provider to take steps to include them in the interaction. Partners reported women would find it unhelpful when specific details about sex and women’s bodies were discussed. This would be unhelpful according to partners, because women believe these kinds of details would make partners uncomfortable. This man said:

If the conversation went to trying different sexual positions or different types of sex I think I might be uncomfortable being there. She would probably think that's a bit much too so, yeah, probably not that. Also specifics about her body parts, she wouldn't like that either and I wouldn't want to be there. I wouldn't want to talk. (10b)

Men indicated when survivors know the partner does not want to be there it would make his inclusion more problematic for her. One partner explained it this way:

I would be very uncomfortable discussing with a doctor. I would be the problem there. I admit it. I have no interest in discussing it with a doctor and she’s knows that. I think she probably doesn’t want to hear what I might say if she thinks about it. (10b)

This partner openly discussed the fact his wife knows he doesn't want to be there: he would be uncomfortable and resistant and his replies to provider inquiries would likely trouble her further:

I don’t know what the doctor is going to act on to improve the situation and I frankly, I don’t want him to put me in a position where I have to say things I’m uncomfortable saying in front of him or that would upset her. I just don’t see a point in getting into the weeds over this. She knows how I feel and she wouldn't find it helpful for me to be there. (10b)
Partners suggested there are many reasons women believe including the partner in the interaction would be helpful. However, from the partner’s perspective, this hypothetical belief would not be substantiated in practice.

Table 15

*The Partner’s Perspective of Helpful and Unhelpful Provider Communication*

<table>
<thead>
<tr>
<th>This percentage of partners</th>
<th>described these behaviors, which are characterized by the following dimension(s).</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Helpful</strong></td>
<td></td>
</tr>
<tr>
<td>(n = 7, or 54%) Enhance Patient Satisfaction Through Direct Communication</td>
<td>Broach the topic by asking direct questions</td>
</tr>
<tr>
<td></td>
<td>Provide direct explanations about what is happening and why</td>
</tr>
<tr>
<td></td>
<td>Directly communicate specific strategies</td>
</tr>
<tr>
<td></td>
<td>Use data to support claims</td>
</tr>
<tr>
<td>(n = 3, or 23%) Tell Patients their Future questions will be Answered</td>
<td>Tell survivors they are open for questions</td>
</tr>
<tr>
<td></td>
<td>Provide referrals</td>
</tr>
<tr>
<td>(n = 3, or 23%) Normalize Sexual Health Issues</td>
<td>Let survivor know she is not alone</td>
</tr>
<tr>
<td><strong>Unhelpful</strong></td>
<td></td>
</tr>
<tr>
<td>(n = 5, or 38%) Communicate in Ways Survivors Perceive as Dismissive</td>
<td>Rush the patient</td>
</tr>
<tr>
<td></td>
<td>Treat patient like a medical object/specimen</td>
</tr>
<tr>
<td></td>
<td>Say “I understand where you are coming from</td>
</tr>
<tr>
<td><strong>Helpful or Unhelpful</strong></td>
<td></td>
</tr>
<tr>
<td>(n = 11, or 48%) Incorporate Partner in the Appointment</td>
<td>Memory aid</td>
</tr>
<tr>
<td></td>
<td>Facilitate communication a</td>
</tr>
<tr>
<td></td>
<td>Social support</td>
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<td></td>
<td>Support understanding of patient experience</td>
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**Providers’ perspectives.** Six themes emerged from the data that characterize providers’ views of the kinds of communication behaviors survivors think are helpful and unhelpful in a medical interaction about sexual health. The following themes illustrate behavior that is either helpful or unhelpful. One theme surfaced that be helpful or unhelpful in different conditions.

Providers suggested survivors find it helpful when they give patients a chance to voice their concerns, facilitate an in-depth conversation, communicate in sensitive and responsive ways, and provide referrals to other medical professionals. They reported patients find it unhelpful when they communicate in ways survivors view as dismissive or they signal their discomfort with the topic. Providers also noted their efforts to include partners in the medical interaction can be beneficial or harmful to survivors for various reasons (see Table 16).

**Helpful - Give patients a chance to voice their concerns.** Providers reported that sexual health problems are a significant byproduct of breast cancer and its treatments. As such, they indicated it is important to give survivors the chance to voice sexual health concerns. They described two primary mechanisms for doing that: bring up the topic and ask general questions to prompt patient responses ($n = 16$).
Some providers suggested it is important to bring up the topic by asking the patient if they are experiencing any sexual health changes. An oncology nurse practitioner said in her mind this is an unspoken mandate: “We’re giving them AIs [aromatase inhibitors] and hormone therapy. We’re essentially making people that weren’t in menopause in menopause. I mean we’re doing these things to these people. I think it’s our job to ask” (38p). Other providers reiterated the significance of asking and reported they received training, which emphasized the willingness to do so. A family medicine physician explained: “There was a urogynecology fellowship where I was and it was part of our training to be proactive about asking some of these questions” (39p).

Providers reported several reasons why it is helpful for a medical professional to broach the topic. For instance, one gynecologist said he understands some women may be uncomfortable with the topic and it can be helpful if providers start the conversation: “I think if the physician opened the door with a question, it would make it easier rather than the patient having to bring it up” (6p). An oncologist even said she incorporates asking specific sexual health questions into her routine of care for certain cancer survivors:

Every time I see a patient on tamoxifen or arimidex, which are our pills, one of the first questions we ask is “Are you having any side effects?” Even if they say no “Are you having hot flashes?” “Are you having pain during sex?” because I want to document in every patient are they having hot flashes? How bad are they? So we do go down that list of side effects with every patient as part of their routine “I’m on tamoxifen” visit. (33p)

However, according to providers, another way to allow patients the chance to voice their concerns is to ask broad questions about survivors’ quality of life. A family medicine physician, who also completed an obstetrics fellowship, described his strategy:
I’ve done a lot of women’s health and so I don’t ask things like “How’s your sex life?” I usually ask things more like “Since treatment is there anything that’s impacting you” . . . then usually it kind of elicits itself out from there. (35p)

Several providers suggested asking broad questions is the most helpful approach. They reported that asking about a survivor’s “home life” or “family life” gives patients the leeway to focus on the aspect of sexual health that is significant to them (pain during sex, reconstruction issues, body image issues, relationship problems, etc.) They reported this also allows women who are embarrassed, or who may not be ready to discuss their problems, to save that concern for another time.

Since providers work under continual time constraints, they often reported considering how their communication decisions impact the efficiency of their clinic schedule. One family medicine physician talked about the belief that asking general questions balances the patient’s needs and timing constraints. He said he asks:

“How are things . . . how’s family in general?” I think you just want to take an overall wellness approach . . . “How are things going in your life?” Because you don’t always open that Pandora’s box with the patient. So general questions are better and if it doesn’t pop maybe the patient isn’t ready. I mean you just don’t because you don’t have time to do it – to chase it down a rabbit hole. (41p)

While this strategy may have benefits, there are significant drawbacks. Survivors reported a preference for providers to ask specific questions about sexual health instead of using general inquiries. A discussion regarding how this practice compares to survivor and partner preferences in included at the end of this section.

**Helpful - Facilitate an in-depth conversation.** In addition to letting the conversation emerge by giving patients a chance to voice sexual health concerns, providers reported it is also important to facilitate in-depth conversations about those
sexual health issues. Four behaviors emerged from provider accounts that support this overall directive. Providers indicated survivors find it helpful when providers listen, ask open-ended follow-up questions, summarize what they think they heard and ask for confirmation, and provide strategies and resources to address issues ($n = 27$).

Providers recognized that listening is an integral component of their job. According to this family medicine physician, asking the question is only the first step in the process. Providers must then pause and fully engage while the patient answers. She indicated that a provider must “allow time for the patient to answer versus just going through a review of systems like ‘Any chest pain, shortness of breath, any problems with sex?’ Give the patient time to answer the question” (7p).

After the provider has listened to the survivors’ concerns they indicated (s)he now needs to ask follow-up open-ended question to explore the issue further. A family medicine registered nurse said providers should ask the following questions: “‘Any sexual issues we need to talk about?’ We’ll even get into ‘when was your last sexual encounter?’ ‘Oh it was last week. Ok so how often? Is it once a month? Is it twice a month?’ We’ll delve into that.” (23p). Providers reported the use of open-ended questions is also helpful because they allow providers to draw out issues that survivors may want to talk about but cannot directly disclose without assistance. According to this family medicine physician:

You’ll pick up on something subtle that’s thrown out there by the patient. For example, talking about age related conditions, and they’ll throw out something a little bit vague, “Hey doc, I want to see if you’re gonna bite on this.” They’ll say things like, “You know it’s so hard to -- or as you’re getting older and it’s not like it used to be, if you know what I mean.” And “Well what do you mean? Are
you having problems with.”? I usually say with intercourse. “Are you finding things less enjoyable, less pleasurable? Is it uncomfortable?” (2p)

After patients tell their stories one provider said it’s critical to stop, summarize what they heard and ask the patient to confirm or help clarify the provider’s interpretation. One gynecologist talked about how to do this and explains why he thinks it is helpful for patients:

Summarize what you’ve heard the client say. Say, “Ma'am, this is what I think you’ve said that you’re here for today.” Repeat it back to them and say “did I miss anything?” and if you’re able to more or less summarize what they’re here for to their satisfaction, they know that we’re already starting off on the right foot in terms of “he understands that this is what is bothering me and these are the issues that we’re gonna address today.” I think that when you start with those initial things it makes the rest of the visits more rewarding and more beneficial. (14p)

Finally, providers suggested in order to complete the conversation survivors want strategies and resources to address issues. This family medicine physician emphasized this, suggesting providers should “have some idea of possible solutions – the patient’s gonna be like ‘Well why did you bring this up if you can’t even help me with it’” (7p). Possible solutions can be different things for different patients with different kinds of sexual health problems. Several providers discussed how medical professionals should have an open mind when delivering their advice. A nurse practitioner from the women’s health department suggested this means thinking beyond traditional medication. She talked about some specific strategies she has suggested to patients:

You know one of the practitioners says, “It’s porn and corn.” You know, you can get your popcorn, you watch porn, and then usually we get a laugh out of that. And sometimes it’s having conversations about different positions. Some positions, depending on your anatomy, might be more comfortable than others, and sometimes you might need to be in a more female dominated position that might be a little bit more comfortable, and again the different lubricants and things like that they can try. (3p)
This is especially apt in the case of breast cancer survivors as many of the hormone-based medications historically used to treat low desire and pain during intercourse are contraindicated for them. Another provider reported it helps to give survivors a variety of options and resources:

I’m both a visual and an auditory learner, and so I use both techniques kind of together when I work with patients. I think giving them literature, giving them some online references – online can be dangerous but – but you navigate it and you engage in a partnership with the patient. I also say, “Let's try this. Let’s work together on this” and eventually we will find something that hopefully is able to – maybe not completely relieve your symptoms but at least improve them to a point where your lifestyle has improved. (19p)

These suggestions overlap with many of the behaviors survivors reported to be helpful. However, survivors reported they are not seeing these behaviors from their providers in the clinic. This could be because, in this study, survivors and providers were not matched. However, there could be other factors contributing to this discrepancy. Those factors are discussed when perspectives are further explored at the end of this section.

Helpful - Communicate in sensitive and responsive ways. Like survivors, providers reported that facilitating an in-depth discussion should be accomplished through the use of sensitive and responsive communication practices. They indicated it is important to be sympathetic to patient concerns and to respond to patient emotions. Providers suggested survivors demonstrate this sensitivity through the use of nonverbal behaviors that indicate investment, the validation patient concerns, expressions of empathy, providing assurances, and the normalization of sexual health concerns \((n = 12)\).

One family medicine physician talked about how to express investment in patient
concerns using nonverbal behaviors that indicate engagement. She said, “When people are talking about sexuality don’t type on the computer, don’t fiddle with stuff, turning away and say ‘Really? That’s a problem for you?’ Be inviting in your posture, leaning forward, not sitting back in the chair” (16p). Providers suggested nonverbal expressions are an effective way of communicating that you care about the patient’s concerns. They also reported there are several other things providers can do to increase survivors’ trust in the provider and their satisfaction with the interaction. First, they reported patients want providers to validate their concerns. This psychiatrist talked about what she does for patients when they talk about intimacy problems:

I empathize and validate. So really try to figure out where your patient is coming from emotionally and what this means to her and validate that you know these are important concerns and that you’re pleased that your patient brought them up and absolutely you’re willing to talk about these things. (22p)

In addition to validation, providers suggested it is important to express empathy and concern. One family medicine physician said it’s helpful to “Let them know that you understand and that this is a difficult thing for them but that you want to help them” (31p). Another behavior providers said their patients appreciate is when providers give assurances. This oncologist reported: “I try to be very optimistic. I try to [tell them] . . . that with time it will get better and though they will have some lifestyle changes they’ll be able to accept them and thrive, if you will” (1p).

Providers reported that normalizing survivors’ sexual health concerns is also helpful. They indicated two dimensions of normalizing patient experiences may ease some patients’ minds. First, they suggested they normalize sexual health distress because
patients want to know they are not alone. One oncologist said she tries to normalize during her initial questions to survivors. She reported that she usually says:

“Most women in your setting have hot flashes. Do you have those? . . . These menopausal side effects can be distressing. Most women have vaginal dryness and waking and difficulty sleeping. Has that happened to you?” I think that’s a way a patient might be more comfortable. (33p)

A gynecologist talked about how she asks questions in a way “that conveys some of these things are normal for a breast cancer survivor. Like body image issues in the bedroom” (39p).

Providers suggested any behavior that helps patients feel less alone or insecure about the changes to their body is helpful. One family medicine physician described how he believes normalizing can help women feel more comfortable after breast cancer surgery: “Do normalize. Say ‘that seems pretty normal to me.’ Like if somebody disfigured my body – let’s assume there’s a mastectomy or something – I would be comforted by that” (27p).

Another way providers reported normalizing is helpful is by using “the new normal.” Providers said this phrase is universally understood and helps survivors conceptualize and accept their “new reality.” They suggested this phrase assists them in seeing that “all is not lost” however, their sexual lives will likely never be the way they were pre-cancer. One gynecologist said he tells patients, “It will be a new normal but a normal not so different from what they had. I just tell them, give it time” (1p). This oncologist reiterated his belief in the explanatory power of “the new normal.” He said, “It’s best to be straightforward but sensitive. I usually tell patients things won’t be
exactly the way they used to be and they need to get used to a new normal for this phase of life. They appreciate that (4p).

Two discrepancies emerge from this theme. While women report giving assurances and normalizing health issues can be unhelpful, providers did not report an awareness of this. Normalization in particular is an issue that has been reported in various ways throughout survivor, partner, and provider interviews. This is yet another area in which intentions may be honorable but an inability to view communication issues from different perspectives can negatively impact patient outcomes. A more detailed accounting of this will be offered at the end of this section.

**Helpful - Provide referrals to other medical professionals.** In addition to participating in-depth, sensitive interpersonal communication within the interaction, providers said providing referrals to other medical professionals is helpful to survivors. Providers reported that patients find this helpful for two reasons: because doing so ensures they will have their questions answered if you (the original provider) do not have time to have an in-depth conversation or when another provider is better qualified to address patient concerns ($n = 8$).

One family medicine physician talked about how the issue of time can make referrals the most helpful approach for the patient. He reported his policy is to let the patient bring it up. He says in a fast-paced clinic environment women may be less likely to do that and if they do it usually occurs in the last 5 minutes of the encounter. He suggested in these cases it is better for the patient is he refers them to another provider. He said, “I think the best approach is to refer . . . I just think when providers see nine or
ten [patients] in a half day the likelihood of that coming up unless the patient is willing to bring it up earlier [is slim]” (26p). Another family medicine physician said referral is a necessary part of his function given time constraints. He said, “We have to identify the problem and that’s kind of our job in the constraints that we practice in, and then allow the specialist to have the time to do it” (25p).

Providers suggested it’s important to know when another provider is better suited to patient needs. Sometimes providers may sense a cultural divide and believe someone else will be better able to speak to that patient’s concerns in a sensitive way. One family medicine physician said:

We do have providers from all different backgrounds and let’s say you’re from a particular religious or cultural background where you don’t feel comfortable . . . To just be like “Hey I don’t know exactly how to address this problem but I know the people that can” and then just refer immediately to other people that can help out. (24p)

Providers also said referring is helpful when survivors prefer to talk to a woman. This family medicine physician talked about why, in this instance, referring means the best care for the patient.

I used to be a little insulted by the women who just wouldn’t see me because I’m a guy. But now I’m just like, “Makes a lot of sense.” I just accommodate them and so I think that’s kind of big thing too. So if you’re gonna get the best care from a woman provider – if that’s gonna work for you then that’s what’s gonna work for you, and so it’s giving every possible opportunity to see the right provider and the right situation that might help the patient get all the care that they need. (35p)

Finally, some providers said a different type of medical professional may have the expertise to help women with certain kinds of sexual health issues. In this case, the most
helpful thing for the patient is to receive a referral. One gynecologist described why he believes referral is the best action he can take for some of his breast cancer survivors:

I try to do the best I can for every patient. I will answer their questions and get as involved as they want and as I can. Sometimes if I feel that there’s something there that I know I can’t answer or can’t be truthful about I will refer them to someone who can. I frequently refer patients to female doctors, to reproductive endocrinologists and fertility doctors, to psychiatrists, psychologists. That’s the best thing to do. I frequently do that on a lot of these things because I, in all honesty, have no interest in getting into it because I don’t read about it, I don’t get into the literature on that subject. (1p)

While providers reported the benefits of referrals, they did not suggest that there may be unintended consequences of referrals that impact patient care. Survivors reported that continual referrals without coordination among providers lead to feelings of powerlessness and can cause them to terminate their efforts at receiving medical care. Survivor and provider accounts suggest that cultivating an awareness of the various ways referrals can function in this context could prevent patients from experiencing further distress as they attempt to cope with sexual health changes after cancer treatment.

*Unhelpful – Communicate in ways survivors view as dismissive.* While there is some discrepancy between survivor and provider accounts regarding what is helpful interpersonal communication within the medical visit, providers reported several broad themes that align with patient perspectives. Namely, they suggested using communication techniques survivors view as dismissive is unhelpful to patients. Providers outlined several behaviors they believe survivors would find unhelpful. They reported the following behaviors are likely to make survivors feel as they their concerns are being dismissed: questioning the severity or importance of their concerns, telling patients they should be thankful they survived cancer, and telling survivors there is nothing they can
do \( n = 12 \).

One family medicine physician spoke about how providers can sometimes adopt an attitude that quality of life issues like sexual health are not pressing concerns. He said, “[It] is definitely something that I think can happen. People can kind of be like, ‘Oh well that’s less important.’ So if there’s any sort of dismissive attitude then it pfft” (31p).

This attitude can be very damaging to the patient especially given how challenging it is for some women to discuss changes with providers. This psychiatrist noted:

Don’t say like “Oh well that’s not really all that important or well too bad. You’re just gonna have to live with that.” If a patient brings up sex it’s got to be pretty important to them because it’s not a comfortable topic in our culture. So if somebody cares enough to bring it up, you should care enough to take it seriously. (22p)

Providers may say things because they earnestly think they are helpful. However, when those words communicate to patients that their concerns, which they take very seriously, are minimally important they feel dismissed. This family medicine physician identified another common phrase he believes would be particularly unhelpful. He suggested, “Don’t’ play that card ‘Oh it’s what’s on the inside that counts’” (27p). Telling patients they should be thankful they survived cancer is another response providers recognized as unhelpful. One internal medicine physician said he thinks patients, “don’t feel comfortable especially if there’s already that fear they [providers] may just blow me off because you know ‘Hey look. Why are you talking about this? You survived cancer’” (17p).

In addition to insinuating there is nothing that should be done about survivors sexual health concerns, providers indicated it’s unhelpful when providers outright tell
patients there is nothing that can be done. One oncologist said when providers say they don't think there is a solution or don’t offer strategies to treat sexual health issues it’s as if they are saying, “’No way. We’re not even talking about it.’ I think that’s a problem” (4p). Providers in family medicine and gynecology also reported that saying, “‘Oh we can’t do anything about it’” (35p) or “‘I don’t know what I can do for that problem’” (6p) is troubling to patients. They said it indicates to women that providers are not willing to search for possible solutions. These accounts reflect survivors’ self-reported frustrations with providers who suggested their concerns were not important or who provided no next steps, effectively stating “there is nothing I can do.”

Unhelpful - Signal discomfort with the topic of sexual health. Mishandling body language is one way providers suggested they could be unhelpful in the interaction. Nonverbal communication is a tool that can signal engagement and caring. It can also signal discomfort. Providers suggested when they demonstrate they are uneasy by blushing it can end the conversation immediately (n = 9).

Providers said when they express discomfort, most notably by blushing, women typically don’t pursue answers to their questions. One gynecologist noted that when providers send these kinds of signals survivors realize the conversation will not be productive. She said, “You can tell when someone’s uncomfortable with something. So if your provider is visibly uncomfortable and shutting off, blushing, then that’s going to send the message that ‘Ok, this isn’t a good person to talk to this about’” (11p). As noted earlier, this can be problematic because survivors might not know who to go to next.
Another gynecologist said behaviors like blushing can also make survivors feel that, in bringing up the topic, they have done something wrong:

And if you are red in the face and extremely uncomfortable discussing it, you know patients are not gonna receive that information well. Most of them are gonna be like “Wow. Not only was that an uncomfortable – that was a mistake. I shouldn’t have even brought it up. I should just deal with it on my own.” (19p)

Women cited blushing as a nonverbal indicator they used to assess providers’ comfort levels. Understanding why these responses happen and learning to control them is important as women suggested it can impact whether or not they continue to address their sexual health issues with providers.

**Helpful/Unhelpful - Include partners in the medical interaction.** Feeling comfortable enough with the topic of sexual health to have a conversation with survivors is important because sometimes providers may have to manage even larger interpersonal challenges, namely, including the significant other in the interaction. Providers reported that including the partner in the patient-provider interaction can be both helpful and unhelpful depending on a variety of factors. Providers suggested including partners is helpful when it allows partners to provider social support during the interaction, when it creates a situation where both people have the information to work to together to enact the management plan, and when it helps partners understand what the survivor is going through. They said including partners is unhelpful when: the patient doesn’t want to hurt or embarrass her partner; it may exacerbate survivors’ existing insecurity; the patient has privacy concerns, or the partner takes over the interaction \((n = 32)\).
Overall, providers reported the usefulness of including the partner depends on the overall relationship dynamic. One gynecologist explained in a way that represents several dimensions of this theme:

It depends on the couple. The dynamic between the patient and the provider change . . . with some people it’s very helpful because if it’s a healthy relationship it bolsters them or supports them versus sometimes you’re subjected to having a show put on because they want to show something to their spouse through the provider. Like “Look how much pain I’m undergoing.” You know there’s an exhibition going on and it’s clearly apparent to us. (32p)

When the relationship dynamic is healthy some providers reported the partners presence is helpful because it allows partners to provide social support to the survivor. One gynecologist suggested the partner’s presence indicates solidarity. She said, “In terms of emotional support it really shows solidarity. This is an “us” problem and we’re coming for help about it” (13p). When partners come to the visit it may communicate to patients and providers that the partner wants to share ownership of the problem and responsibility for addressing it.

Providers noted including the partner is helpful to the patients because it increases the odds the provider’s instructions will be adhered to. Providers said if both people are given all the information they need at the same time by the same source they can more effectively work together to enact the provider’s management plan. One oncologist reported he likes to have partners present in the interaction, “especially during the counseling part of their visit because it reinforces my management plan. It makes us all a team, be on the same page in terms of what realistic expectations . . . it’s very beneficial” (14p).

When the partners are present to receive information is also helps them
understand what the survivor is going through. This family medicine physician said he encourages partners to come into the clinic room if the survivor is comfortable. He described the benefit for the survivor this way:

It’s an opportunity because this is what I bring to the table as a family medicine doctor – education, what’s normal. What’s normal in terms of how they’re feeling, of the anxiety, or the difficulty that they’re going through right now, and so it’s very helpful for me to tell the husband as well as the wife so that the husband understands that it’s common for all women to feel less healthy, less sexy while they’re going through this, and very concerned. (24p)

In addition, if survivors have some troubling feelings it can help partners to hear the depth and nature of those concerns. This family medicine physician said, “If she did have some false beliefs or guilt or is feeling bad about herself, it may be beneficial for the partner to hear that cause in some relationships that talking and communication doesn’t go on at home” (16p).

Patients are not always ready to open up. Providers reported that incorporating the partner can be unhelpful too. One instance is when the patient has concerns about including him because she doesn’t want to hurt or embarrass her partner. This nurse practitioner from the women’s health department noted that sometimes women are worried about the effect their words will have on their partners. She suggested sometimes survivors might be uncomfortable having that conversation with their partners there “because they might be afraid they might say something that offensive to them or hurt their feelings, ‘No, I’m not enjoying it but I’m like forcing myself to or faking it’” (3p).

One family medicine physician said he fears survivors may have that concern: “Patients don’t want to say things that might hurt the other person or make them feel as if somehow he’s done something wrong” (31p). Providers reported if the partner is
embarrassed it is harder to have a productive visit. One gynecologist put it this way: “[When] the husband’s horrified that she’s talking about these problems . . . He’s mortified embarrassed and that makes it harder to get things accomplished” (13p).

The patient may have other concerns about including the partner that make his inclusion difficult. Providers reported that survivors often are suffering from a lack of self-confidence and including the partner threatens to exacerbate that insecurity. According to one gynecologist, “If they’re [survivors] already feeling reticent or self-conscious or they’re not meeting their partner’s needs, then having the partner there can make them even more reticent to talk about it” (39p).

Patients may not always be ready to discuss issues with their partner present. This doesn't always stem from concerns about his comfort level. Providers said challenges can also stem from patient privacy concerns. One internal medicine physician talked about the importance of maintaining confidence in the patient-provider relationship:

For my initial discussion with patients I like the partner not to be there. I think it’s fine in a situation once you’ve gotten to know the patient and you know – you sort of know what their goals are. When you’re doing your initial intake it’s very helpful to have the patient by themselves only because patient’s – I’ve been told things by patients they won’t even tell their partner and I think it’s helpful to kind of create that honesty and start fostering a good discussion between the patient and the physician (37p).

A final concern providers noted regarding including the partner is the power balance within the interaction. Providers suggested is it unhelpful for the partner to be there when (s)he takes over the interaction. This family medicine physician stated his concern for the survivor in that dynamic: “I’ve seen patients be pushed into addressing things maybe they’re not ready to” (35p). Some providers said that when a partner is
present that person’s priorities for the visit become dominant. One oncologist described her hesitance surrounding including the partner in delicate conversations like those pertaining to sexual health:

I hate having the spouses present. I hate it. I’m actually shy so I feel like I’m under a microscope when I’ve got somebody sitting there staring at me. I also don’t like it because although sometimes spouses think they’re being helpful, they’ll interject and sometimes they’ll overpower the patient and they won’t let the patient answer. And sometimes I’ve had to say “Well let me let your wife answer.” I would prefer the patient to be solo because they’re gonna be more truthful. (11p)

When thinking about the benefits and challenges of including the partner, several providers expressed concern for patients – especially when the relationship might be abusive. This family medicine provider talked about his worry for women in that scenario:

I just I don’t like that dynamic when there are two adults and the person that’s not the patient owns the conversation. It makes me feel that the patient may be – I mean, are they being abused in some way or neglected in some way, shape or form? And that’ll be difficult to erase from my consciousness. (41p)

These results may point to another miscommunication between survivors and partners. Survivors reported finding it unhelpful when providers included the partner in the interaction when they felt like the provider began to speak to the partner and not to them. They suggested this made them feel the provider didn't truly care about their concerns. However, providers reported an awareness that sometimes including the partner is unhelpful for patients because the partner takes over the medical interaction. Providers reported difficulty dealing with partners in the medical interaction when they are “squeaky wheels.” It seems providers’ increased attention to partners may stem from a
struggle to reclaim control of the interaction and not from a shift in the provider’s priorities (from survivor to partner).

Table 16

**The Provider’s Perspective of Helpful and Unhelpful Provider Communication**

<table>
<thead>
<tr>
<th>This percentage of providers</th>
<th>described these behaviors, which are characterized by the following dimension(s).</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Helpful</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>$(n = 16, \text{ or } 40%)$</td>
<td>Give Patients a Chance to Voice Concerns</td>
</tr>
<tr>
<td></td>
<td>Bring up the topic</td>
</tr>
<tr>
<td></td>
<td>Ask general/broad questions</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>$(n = 27, \text{ or } 68%)$</td>
<td>Facilitate an In-Depth Conversation</td>
</tr>
<tr>
<td></td>
<td>Listen</td>
</tr>
<tr>
<td></td>
<td>Ask open-ended follow-up questions</td>
</tr>
<tr>
<td></td>
<td>Summarize and ask for confirmation</td>
</tr>
<tr>
<td></td>
<td>Provide strategies and resources to address issues</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>$(n = 12, \text{ or } 30%)$</td>
<td>Communicate in Sensitive and Responsive Ways</td>
</tr>
<tr>
<td></td>
<td>Nonverbal behaviors that communicate investment</td>
</tr>
<tr>
<td></td>
<td>Validate patient concerns</td>
</tr>
<tr>
<td></td>
<td>Express sympathy</td>
</tr>
<tr>
<td></td>
<td>Give assurances</td>
</tr>
<tr>
<td></td>
<td>Normalize sexual health concerns</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>$(n = 10, \text{ or } 25%)$</td>
<td>Provide Referrals</td>
</tr>
<tr>
<td></td>
<td>Helpful due to limited time</td>
</tr>
<tr>
<td></td>
<td>When another provider is better qualified</td>
</tr>
<tr>
<td><strong>Unhelpful</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>$(n = 12, \text{ or } 30%)$</td>
<td>Communicate in Ways Survivors View as Dismissive</td>
</tr>
<tr>
<td></td>
<td>Questioning the severity/importance of concerns</td>
</tr>
<tr>
<td></td>
<td>Survivors should be thankful to be alive</td>
</tr>
<tr>
<td></td>
<td>Saying there is nothing I can do</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>$(n = 9, \text{ or } 23%)$</td>
<td>Signal Discomfort with the Topic</td>
</tr>
<tr>
<td></td>
<td>Blush</td>
</tr>
<tr>
<td><strong>Helpful or Unhelpful</strong></td>
<td></td>
</tr>
</tbody>
</table>
| (n = 32, or 80%) | Incorporate Partner in the Appointment | Social support  
Partner understanding of survivor experience  
Survivor doesn’t want to hurt/embarrass partner, Survivors’ existing insecurity exacerbated  
Patient privacy concerns  
Partner takes over the interaction |

**RQ7: Closer Comparisons of Survivor, Partner, and Provider Perspectives.**

Survivors, partners, and providers reported many of the same broad categories of helpful provider behavior. Each group suggested helpful provider communication gives patients an opportunity to voice their concerns, offers specific information about causes of issues and treatment options, and attends survivors’ emotional challenges. They also reported certain provider communication behaviors are unhelpful because they may be perceived as dismissive. However, there were important variations among these themes. Perspectives differed regarding the timing and the best method of executing helpful communication behaviors. Further, there was some discrepancy with respect to what dismissive behavior entailed. Some of the behaviors providers cited as helpful were perceived by some patients to be dismissive (See Table 17). The following discussion details discrepancies that inform our understanding of deficiencies in sexual health care.

First, each group described variations in the preferred communication approach. When comparing survivor and partners accounts of helpful provider communication approaches both groups of participants discussed their desire for providers to facilitate an in-depth conversation by providing more information, however, each group emphasized
different tactics of facilitation. Survivors reported a need to be asked “specific questions” and to be supplied with “specific information.” Partners described the process in terms of its “directness.” Partners’ view of survivors’ preferences seemed to be driven by frustration based on perceptions that providers were uncomfortable or evasive.

Another area of distinction emerged from examining survivor and provider perspectives about bringing up the topic with women. Women reported a strong preference for providers to ask patients if they are experiencing sexual health distress. However, the majority of survivors and partners indicated that their medical providers have not done this. This necessitated further exploration of the discrepancy. Providers who thought it was important to ask survivors about sexual health did not always actually enact that behavior for the following reasons: providers don’t think about mentioning sexual health, they assume the patient will bring it up, they are focused on cancer monitoring, and they do not see patients behaviors that “trigger” the discussion (n = 19).

One reason, (they assume the patient will bring it up), was cited by providers as a reason they do not think sexual health is relevant to patients (see research question 6 comparison section). However, this group of providers viewed bringing up the topic as helpful, but for the following reasons did not initiate the discussion. These providers described sexual health as something that is not “on my radar” with survivors. As a result they did not think to bring it up. One family medicine physician talked about this: “I don’t actually do that but I think it would be helpful. Certainly, not saying anything is not helping those patients who are too nervous to bring it up. I just don’t think about it” (31p). Providers who thought they should bring up sexual health but did not do so also
said they assumed other providers were addressing the topic. This internal medicine physician said it’s important to screen survivors for sexual health distress but admitted, “No. I don’t [ask survivors] but I should. I guess I historically made the assumption they would bring it up or it’s being taken care of elsewhere” (30p). Other providers reported they typically don’t bring it up because they are concentrating on other aspects of cancer care. This oncologist said: “I’m probably not as good about asking as I should be I’m focused so much on their breast cancer care. I forget to ask – part of survivorship is still sexual history but I don’t get to it sometimes” (8p).

Lastly, providers didn’t always ask about sexual health even when they reported looking for patient behaviors that “trigger” their awareness sexual health could be a problem. If they were not triggered they did not broach the topic. This gynecologist said, “If they don’t give me any of those triggers, like I’m having pelvic pain, and I just sort of glaze over it, you know what I mean, I certainly could be missing it – absolutely” (13p). If this is accurate more broadly, it could indicate that patients and providers are both waiting for signals from each other that may never be sent.

Another layer of variation between survivor and provider accounts surrounding broaching the topic of sexual health is how the question is asked. Providers reported it is important to give patients a chance to voice their concerns. Many providers suggested the most helpful and “safest method” is to do this without opening a “Pandora’s Box” is through the use of broad quality of life inquiries. One family medicine physician previously recounted, he takes an overall wellness approach and asks questions like “How are things going in your life?” instead of asking the patients specific questions.
This is problematic because survivors reported a desire for providers to ask a series of specific, direct, open-ended questions from the beginning to the end of the interaction. One woman said earlier, “Come out and say how is your sex life? How is your libido” (29p)? Multiple survivors indicated that if providers asked specific questions it would help women feel more comfortable and alleviate a lot of stress and worry. This may be the most helpful way providers can normalize sexual health.

Discrepancies between survivor and provider were also seen when examining the ways providers talk about the issues women experience. First, providers’ accounts suggested giving assurances is an element of communicating in sensitive and responsive ways. They said reassuring women, “You look great” is helpful emotional support. Due to self-reported knowledge gaps, assurances were often the only thing they felt equipped to do. While providers thought they were delivering emotional support, survivors reported that assurances were viewed as “empty” or “hollow.” When providers used this strategy, particularly when assurances were not followed up by additional questions and concrete resources or solutions, women thought their concerns were not being taken seriously.

Another provider communication behavior reported in different lights was normalization. Providers suggested it was helpful to use the trope “the new normal” to assist patients in conceptualizing their emerging reality in a way that honors their loss but also emphasizes they will adapt and possibly reclaim aspects of their functioning. Providers viewed it as a good balance between “caution and optimism.”
However, survivors often reported a strong negative reaction to normalization when it was presented in the form of “the new normal.” Women reported this term was dismissive and upsetting. Often they viewed it as a method providers used to change the topic. It was particularly upsetting because survivors felt the provider was simultaneously communicating (s)he was not interested in doing the research needed to help them find a strategy to address the issue and that the survivor should simply accept the changes.

In addition to normalization, giving referrals was a behavior that was perceived differently among survivors and providers. Survivors indicated the referrals were helpful in certain contexts and unhelpful in others while referrals appeared as only positive within the provider data. Women viewed referrals as helpful when the original provider was not comfortable with the topic of sexual health or when the referral is being made to a specialist whose expertise would address needs specific to their case. Women reported referrals were unhelpful when the subsequent provider was not equipped (due to comfort level of expertise) to address patient concerns or when being referred represents another step in a repetitive process of being bounced back and forth between providers.

Providers reported no unhelpful aspects of referrals. Part of the disconnect may be that, as medical scientists, providers’ cognitive reference point is what happens at the population level. Applying science to delivering patient care at the individual level is more complex. While medical professionals are trained to understand that behaviors like the provision of social support and providing referrals are helpful to patients in general, they may not always be taught to reflect on how those strategies intersect with individual patients. Humanizing medical care by comparing perspectives within these narratives
helps highlight that. Humanizing medical care is imperative because the consequences for patients are real. Many patients reported they “stop talking” about their symptoms, “withdraw” or “give up” after multiple interactions in which physicians may be making good faith efforts to help them. As such, illuminating this disconnect is critical for patient care.

Partners did not report the negative effect of referrals either. In fact, partners relayed less nuanced accounts of potential barriers to medical care and less helpful and unhelpful provider behavior. In some respects, this is to be expected as they are not primary players in the interaction and the sample size is smaller. However, there may be additional explanatory factors. Women reported they did not want to disclose their issues for fear of burdening partners, hurting their feelings, or worrying it would change their relationship. They also reported difficulty communicating with partners when attempts were made. Survivors may not be disclosing many of the realities they face. This may contribute to partners’ lower awareness of patient concerns, barriers, and helpful and unhelpful medical provider communication behaviors. It could also make communication within the couple more problematic because the partners are not working with all the requisite information.

When comparing perspectives regarding the inclusion of the partner in the interaction it was discovered that some partners suggested survivors want them there because they believed it would facilitate communication during the interaction or open up a conversation they could continue in a private setting. This was especially relevant when the couple had trouble communicating at home. However, some partners suggested this
was not the case: they would not talk even if asked to. This does not align with many survivor narratives as they believed partners would discuss these issues if included. In many ways, the communication problems were accumulating in different spheres of survivors’ lives, making it difficult for them to manage their sexual health concerns. It is important for survivors, partners, and providers to understand the potential for miscommunication in order to improve medical care and relational coping.
| Telling Survivors about Sexual Health Effects Earlier in the Cancer Continuum | -- | Give Patients a Chance to Voice Concerns | Providers suggested the most helpful and “safest method” to let patients be heard is through the use of broad quality of life inquiries. “How are things going in your life?” “How are things since treatment?” “Is there anything you’d like to talk about?” instead of asking if the patient is experiencing sexual health problems. | Provider education efforts should be aimed at encouraging them to screen for sexual health issues using sexual health-specific questions. |
| Effect of chemotherapy and adjuvant treatments | Verbally broach the topic and provide additional learning resources | Ask general/broad questions | Survivors reported a preference for a more direct approach with the use of follow up questions to gather unique information about their cases. They indicated specific sexual health questions help survivors understand their symptoms are due to breast cancer treatment. Often survivors report they don’t want to say words like “orgasm” to providers. When providers use those words first in can help remove the taboo surrounding them. |
| Facilitate an In-Depth Conversation | Ask specific, open-ended questions | | |
| Normalize Sexual Health Issues Helpful/unhelpful: | | Communicate in Sensitive and Responsive Ways Helpful: Normalize sexual health | Survivors reported normalizing their sexual health concerns is helpful when it lets them know they are not alone (population level normalization). However, when providers use “the new normal” to normalize sexual health concerns for the individual woman’s extended future (individual level | Providers should work to cultivate an awareness of the unintended consequences of linguistic devices they use. Symbols such as “the new normal” have entered the public consciousness, but that doesn’t mean their sue is advisable. Symbols carry different |

Table 17

Variations across Perspectives: Communication Behavior Survivors find Helpful and Unhelpful

<table>
<thead>
<tr>
<th>Survivors reported these behaviors,</th>
<th>partners reported these behaviors,</th>
<th>and provider reported these behaviors,</th>
<th>which interact in the following ways, and suggests these actions points to enhance survivors’ quality of life.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Telling Survivors about Sexual Health Effects Earlier in the Cancer Continuum</td>
<td>--</td>
<td>Give Patients a Chance to Voice Concerns Ask general/broad questions</td>
<td>Providers suggested the most helpful and “safest method” to let patients be heard is through the use of broad quality of life inquiries. “How are things going in your life?” “How are things since treatment?” “Is there anything you’d like to talk about?” instead of asking if the patient is experiencing sexual health problems. Provider education efforts should be aimed at encouraging them to screen for sexual health issues using sexual health-specific questions.</td>
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<tr>
<td>Effect of chemotherapy and adjuvant treatments Verbally broach the topic and provide additional learning resources</td>
<td></td>
<td></td>
<td>Survivors reported a preference for a more direct approach with the use of follow up questions to gather unique information about their cases. They indicated specific sexual health questions help survivors understand their symptoms are due to breast cancer treatment. Often survivors report they don’t want to say words like “orgasm” to providers. When providers use those words first in can help remove the taboo surrounding them.</td>
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<tr>
<td>Facilitate an In-Depth Conversation Ask specific, open-ended questions</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Normalize Sexual Health Issues Helpful/unhelpful:</td>
<td></td>
<td>Communicate in Sensitive and Responsive Ways Helpful: Normalize sexual health</td>
<td>Survivors reported normalizing their sexual health concerns is helpful when it lets them know they are not alone (population level normalization). However, when providers use “the new normal” to normalize sexual health concerns for the individual woman’s extended future (individual level</td>
</tr>
<tr>
<td>Letting patients know they’re not alone vs.</td>
<td></td>
<td></td>
<td>Providers should work to cultivate an awareness of the unintended consequences of linguistic devices they use. Symbols such as “the new normal” have entered the public consciousness, but that doesn’t mean their sue is advisable. Symbols carry different</td>
</tr>
<tr>
<td>&quot;the new normal&quot;</td>
<td>concerns</td>
<td>normalization</td>
<td>meanings for different people.</td>
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<td>---------------------------------</td>
</tr>
<tr>
<td>Communicate in Ways That are Perceived as Dismissive</td>
<td>Communicate in Sensitive and Responsive Ways</td>
<td>Provider education efforts should aim to help them contextualize their use of social support.</td>
<td></td>
</tr>
<tr>
<td>Empty assurances</td>
<td>Give assurances</td>
<td>Providers reported saying things like “you look fine” “give it time” “you’re doing everything right” are viewed as empty assurances and dismissive of survivors’ concerns – especially when not coupled with specific strategies and resources that can be used to address sexual health issues. Providers reported that assurances are an integral part of communicating in sensitive ways and may not always appreciate they function differently for some survivors.</td>
<td></td>
</tr>
<tr>
<td>Provide Referrals Helpful/unhelpful</td>
<td>Tell Patients their Future questions will be Answered Helpful</td>
<td>Women reported that referrals are unhelpful when the subsequent provider is not equipped (due to comfort level or expertise) to address patient concerns or when being referred represents another step in a repetitive process of being bounced back and forth between providers. Partners and providers (except 1) did not report negative implications of referrals. Partners viewed referrals as helping survivors answer their questions. Providers reported only benefits related to enhancing care.</td>
<td></td>
</tr>
<tr>
<td>Subsequent medical professionals are not equipped to address women’s issues Being passed from one provider to next</td>
<td>Due to limited time Another provider is better equipped</td>
<td>Open communication regarding the challenges of navigating the medical system may increase the likelihood couples can work together to access the right provider. Provider education efforts should aim to enhance interpersonal communication within the interaction. Providers should ask about patients’ previous attempts to treat issues and together come up with a plan about who to see next and what they should do if they still feel like their concerns are not being addressed.</td>
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<tr>
<td>Provide Referrals Helpful</td>
<td>Provide referrals</td>
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<tr>
<td>Incorporate Partner in the Appointment Provider as a communication facilitator</td>
<td>Incorporate Partner in the Appointment Facilitate communication</td>
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<tr>
<td>Patients and partners reported survivors like the partner to be included in the interaction because it facilitates communication when the couple has trouble talking at home. However, some partners report even though their spouses/girlfriends may think it will help, they would be unwilling to talk.</td>
<td></td>
<td>Future research should explore what would help partners more openly communicate about survivors’ sexual health issues. Less threatening means for providing partners with information should be developed.</td>
<td></td>
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</table>
CHAPTER 6

Discussion

This study aimed to produce a more comprehensive understanding of the biopsychosocial nature of breast cancer survivors’ sexual health concerns and how their interactions with medical professionals could enhance sexual health-related care. Phase 1 examined the interconnected nature of various factors (e.g., age, provider preference) critical to survivors’ sexual health and willingness to communicate about it as well as the prevalence of sexual health dysfunction across the life span and survivorship trajectory. Phase 2 expanded this knowledge by capturing survivor, partner, and provider narratives about sexual health concerns, challenges/barriers, and helpful and unhelpful clinical communication approaches to addressing sexual health. Comparing narratives of each group revealed how convergence and divergence in survivors, partners, and providers’ perspectives ultimately influenced the quality of survivorship care.

The following in-depth discussion of results begins with an exploration of how this work contributes theoretical and methodological insights. In particular, I focus on how the theoretical and methodological frames used allow for researchers to capture the psychosocial nature of health and, at the same time, demonstrate how the method used is critical to ensuring a more open dialogue about a topic that is typically stigmatized or silenced in nature. Thus, I also discuss how these theoretical and methodological insights
extend the research more broadly with regard to other challenging, taboo, or sensitive health contexts. I then explore how this research might be translated to practice by enhancing patients’ quality of life and medical care. This is followed by a presentation of best practices for each voice (survivor, partner, and provider). Finally, possible avenues for future research and study limitations are discussed.

**Capturing Psychosocial Aspects of Health**

This research demonstrates the theoretical importance of using narratives as well as the FSGI model in highlighting aspects of health care that are psychosocial (i.e., relational and communicative) in nature (and not necessarily attended to in health care). Given sexual health is a challenging topic, this study further suggests the important of this theoretical frame in other challenging or sensitive communication scenarios.

The FSGI model suggests that health experiences are best understood by considering the physical, psychological, and social/relational aspects of a patient and her environment across time and taking into account a wide range of developmental issues. The results reinforce the importance of considering multiple domains of health. Women experienced interwoven physical, psychological, and social/relational sexual health issues. By gathering narratives that included these domains it was possible to understand how they interacted to shape women’s sexual health concerns and also to suggest avenues for addressing those concerns. It further revealed how excluding the knowledge generated from one aspect of the picture (e.g., psychological or social/relational) diminishes our understanding of the other aspects of sexual health. For example, understanding that panic (psychological) as a result of previous experiences with painful intercourse
(physical) and the fear that women will disappoint their partners (relational), can contribute to decreased intimacy and the inability to become aroused may help providers administer medical advice and treatments targeted to the multiple sources of distress.

The results also demonstrate that contrary to providers’ assumptions, sexual health is prominent concern for women of all ages across the entire survivorship spectrum. The effect on women’s sexual health may be long-lasting and not something that dissipates within a few years post-treatment. Therefore, Rolland’s emphasis on viewing health issues through a developmental or life span lens is warranted. Moreover, this further suggests that survivorship care needs to be more psychosocial in nature (rather than just biological as many providers indicated).

Tied to this notion is the importance of a patient’s relational experiences, both at home and in the clinic. Rolland describes the interaction of the health care provider, the individual, the illness phase, and the family as the therapeutic quadrangle (1988). As such, they all collectively play a role in sexual health care. The results of this study support this and demonstrate the need to ensure we are hearing from multiple voices involved in survivorship care. Providers and partners may not be aware of the full extent of survivors’ sexual health concerns or the barriers to receiving care. Further, while partner and provider behaviors were intended to support and assist survivors, those efforts often resulted in unforeseen consequences. While a relational approach that captures multiple viewpoints is certainly more time-intensive and challenging in research, the collection of narratives from multiple voices was key to uncovering areas in which sexual health-related survivorship care can be enhanced or modified. In doing so, it also
became evident that although health care has been moving from a biomedical approach to a more biopsychosocial approach, that in practice, this does not always occur.

**Using Methods That Cultivate Openness**

While both FGSI and narrative demonstrate a strong approach theoretically to understanding sexual health in survivorship, the methods were also helpful in breaking down barriers to talking about the issue. In other words, it is important to utilize methods that allow insiders to have a voice (and feel comfortable using that voice) when they are addressing an issue that they typically have been silenced on (like sexual issues) and further ensure openness is cultivated in practice (at home and the clinic).

Research on other silenced, challenging or other taboo topics shows the importance of facilitating more openness in patients’ health. Scholarship on posttraumatic stress disorder, palliative care, and HIV/AIDS all demonstrate that although the people closest to individuals and their medical providers influence patients’ wellbeing, open communication is often difficult. Silence and miscommunication are common problems, which perpetuate suffering for individuals with these sensitive health issues (Fallowfield, Jenkins, & Beveridge, 2002; Hendriksen, et al. 2009; Urlić, 2010). To understand how communication in those relationships functions, in-depth stories need to be captured. Replicating the current approach of gathering narratives of multiple parties critical to patients’ health can shed light on communication impasses that impact quality of life for people struggling with various stigmatized conditions.

Narrative served as an invaluable approach to uncover the often-stigmatized issue of sexual dysfunction and likely allowed for participants to feel more comfortable to
disclose their experiences to me. For instance, by gathering written narratives before in-depth interviews it allowed survivors and partners to direct the investigation to areas of significance for them. It also allowed them time and space to make sense of their experiences and become more comfortable opening up about those experiences before interacting with me. Following up on written narratives within the structure of the interview enabled me to capture multidimensional stories regarding a highly sensitive topic in a less threatening way. As such it may be a suitable approach to exploring other challenging, taboo, or sensitive topics.

In addition, this approach could have health benefits. Although I did not measure whether writing was therapeutic for my participants, the health benefits of narrative have been documented (see Pennebaker’s extensive body of research). Writing narratives improves emotional regulation in patients with posttraumatic stress disorder (Gidron, Peri, Connolly, & Shalev, 1996). Narratives may also decrease knowledge deficits that negatively impact palliative care (Wittenberg-Lyles, Goldsmith, Ragan and Sanchez-Reilly, 2010) and have elucidated the realities of living with the stigma of HIV/AIDS (Black, 2013). Thus, the narrative approach can have a many benefits to both research and patients or participants.

This study also demonstrates the utility of mixed method research with narratives and a communication scale, the (WTCSH), in particular. This scale had yet to be used in health research. The insights from the data collected via the scale illustrate its utility not only in the health domain (and potentially intervention development) but also in investigating challenging communication scenarios. Results of phase 1 connected
women’s willingness to communicate about sexual health to sexual health outcomes. The scale is particularly useful in challenging conversations because questions are designed to assess hesitancy in specific and varied communication scenarios. For instance, in this research it alerted me to variation in women’s responses related to discussing sexual health with a provider while the partner is present. As a result, phase 2 was able to capture different elements of women’s willingness and hesitancy to discuss sexual health concerns in that context. Such findings could be utilized in interventions in which health practitioners/researchers are trying to identify those patients who are less willing to talk (and thus, need immediate attending to). Health interventions might also want to include Pennebaker’s approach as writing narratives could be an optimal tool for facilitating health improvements (and then such narratives could be used in medical education in line with Charon’s narrative medicine approach).

The theoretical and methodological lessons learned from this exploration of sexual health may be particularly informative as sexuality is one of the most difficult topics for patients to discuss (Goldsmith & Miller, 2014). As such it is important to consider how these findings could be utilized to improve the lives of survivors and their partners as well as survivorship care. Sexual health seems to be an especially complicated aspect of care that survivors, their partners, and their various providers view as physical albeit wrapped within a web of emotion, relational concerns, and ultimately a mixture of physical, social, and psychological outcomes. It can be confusing to both survivors and providers who should be attending to this aspect of care and how this can be done most effectively. Is it emotionally focused care or is it physical care or is it both? Given this, it
is important to identify how these results can be translated to enhance practice.

**Translational Insights for Sexual Health and Survivorship Care**

Health communication inquiry is firmly grounded in the goal of facilitating the improvement of health care and health outcomes (Kreps & Maibach, 2008). This discussion centers on how the lessons learned through this study can be applied to strengthen patient care and quality of life.

**Age and survivorship length are important factors in survivorship care.** The combination of quantitative data and the thematic representation of qualitative findings highlight the complexity of sexual health issues survivors face. First, phase 1 of this study demonstrated that women of all ages and survivorship lengths experience sexual health issues that impact their quality of life. While previous studies have indicated that younger women are more likely to suffer compromised quality of life as compared to their older peers (Howard-Anderson, Ganz, Bower, & Stanton, 2012; Korenke et al. 2004) or that the negative effects of cancer resolve with time, this study revealed no significant relationship between age, survivorship length, and sexual health-related quality of life. Rather, regardless of age and survivorship lengths all women reported SQOL that was significantly lower than previously studied “healthy” control groups.

Narratives in Phase 2 extended this revelation by uncovering specific variations in women’s experiences according to age and survivorship duration. These findings could inform providers’ understanding of how to better attend to survivors’ unique needs. For instance, both women in older adulthood and long-term survivors discussed how socio-historical generational norms (you should not talk openly about sex) and increased length
of survivorship (the longer I have the problem the less I believe it is solvable) both inhibit their willingness to address their sexual health concerns. Ageing stereotypes prevalent in their care further complicate this communication impasse. Older women described how their sexual health concerns were dismissed because of their age and providers admitted to having assumptions about sex no longer being a concern later in life. In addition, the intergenerational nature of the provider-patient dynamic can be challenging for older women. They illustrated difficulty talking with younger providers because of the parent-child dynamic this creates and providers’ inability to view them as sexual beings.

Interviews with providers confirmed this. Providers cited a variety of reasons for not bringing up sexual health in the interaction, among them, age, and survivorship length.

These findings generate several translational contributions. Medical education efforts for providers should address these stereotypes and highlight the relevance of sexual health distress for women of all ages as well as long-term survivors. Special attention in terms of how to talk to older generations seems especially warranted. Providers need to become more aware of the generational factors that may silence women. While awareness is key to improving sexual health care, so too is communication competence. Thus, these related medical education efforts should aim to offer providers communication strategies that can enhance a woman’s comfort level in disclosing her concerns. This seems particularly important when providers and patients are less “matched” demographically (race, age, sex).

For instance, women reported that in demographically discordant patient-provider interactions, providers can use several communication strategies that help bridge this gap
and increase patient trust. They suggested that avoiding dismissive statements, acknowledging the differences (in the case of gender) but emphasizing their desire to help, asking specific questions, listening carefully, and validating women’s experiences eased otherwise tense or uncomfortable patient-provider dynamics.

The varying experiences reported by survivors of different generations also suggest the need to create resources tailored to developmentally diverse women. A growing number of hospitals, cancer centers, and cancer-related non-profit corporations now offer resources for women experiencing sexual health issues. However, this work can be used to inform and improve those resources. Pamphlets, online materials, and written or video narratives should represent women of different ages and include obstacles those women may face as well as their strategies for communicating with partners and providers. Women in this study reported that while they may have seen a pamphlet or section of a website dedicated to sexual health, they quickly dismissed them because they could not see themselves in the stories and issues presented. Designing materials that represent various survivor experiences may increase their willingness to investigate sexual health issues further as well as their self-efficacy for approaching providers.

This can be done both in virtual and print form as recent researchers have demonstrated. For instance Fisher (2014) compiled her findings into a book presenting narratives from the voices of breast cancer patients across the life span (so by age group) to better illustrate the coping behaviors and concerns of women of varying developmental phases of life. She also wrote the book for multiple audiences (clinicians, researchers, and
families) in order to allow for it to be a teaching tool for clinicians and researchers but also something families could use to learn and model healthy behaviors by seeing themselves in more authentic narratives. Fisher also puts her research on the internet on her web site (www.motherdaughterbreastcancer.com) to make it more accessible to the public. Similarly Davis (2013) published her ethnography of pediatric mental health care to provide a more comprehensive, rich narrative depicted with multiple voices. She uses the collected stories to show the role of the practitioner or and social service workers are central to helping children in families in difficult environments. Other communication researchers have further demonstrated how such narrative research might be implemented into curriculums to teach healthy behavior whether it is preventive in nature (e.g., Hecht and Miller-Day’s DRUG Resistance curriculum for youth) or for provider training (e.g., Wittenberg-Lyles’ COMFORT curriculum in palliative care). These scholars provide some models for how the narratives collected in this study can be used in far-reaching, important ways for both medical education and intervention-making.

**Multiple types of providers are critical to survivorship care.** The results from Phase 1 demonstrate that survivorship care, as it pertains to sexual health in particular, is not tied to just one type of provider. Rather, multiple provider types have the opportunity to help patients address sexual health issues. Although gynecologists might be the most likely recipients of women’s sexual health concerns, women also reported going to family medicine physicians, oncologists, and general internal medicine physicians for their primary health care. Yet, over 70% of women also reported that they were hesitant to make an appointment for a sexual health issue. Previous research by Sporn and
colleagues (2014) supports the notion that women may address sexual health concerns with different types of providers. Their study showed that women wanted both primary care providers and oncologists to broach the topic. Collectively, this research suggests that multiple provider specialties are important to ensure survivors’ sexual health needs are addressed. All provider specialties need to be trained to broach the topic and let patients know they are available to discuss those concerns should they arise. As the women in this study reiterated, providers may not be introducing the topic. Both the women and their partners reported that it’s not only important for providers to initiate the discussion but that they should do so directly, frequently (across the survivorship spectrum), and be willing to listen or provide resources if they are ill-equipped to address all of their concerns.

**Sexual health should be addressed early in the cancer continuum and across survivorship.** The findings from all perspectives clearly demonstrate that sexual health is an important and complex issue for survivors and an aspect of care that cuts across multiple medical specialties. Yet, the women in particular indicated that their sexual health concerns and needs during survivorship could be better attended to if they had some foresight that complications would occur. Addressing sexual health earlier in the cancer continuum seems critical to improving sexual health care during survivorship.

Phase 2 uncovered several troubling consequences stemming from the fact that providers neglected to warn women about probable sexual health dysfunction. Women were not only surprised by issues but were also not sure how to address them. Women may then suffer in silence – believing they are the only ones experiencing these issues or,
possibly worse, fearing their symptoms indicate the presence of another underlying health
condition or that the cancer has metastasized to their reproductive organs. As these
women illustrated, their uncertainty about this issue led to the exacerbation of fears about
their own survival. Setting appropriate expectations for survivors before problems
emerge is important to their care and quality of life (Akechi et al., 2014; Bolte, 2012).
Providers should bring up the topic of sexual health and address them early in the cancer
continuum to prepare survivors. In particular, women reported they wanted more
information regarding the possibility of potential breast reconstruction complications, as
well as the effects of chemotherapy and adjuvant treatments on their sexual dysfunction.

As was noted in the Phase 1 results, women with poorer sexual health outcomes
were also less willing to communicate about the issue with their provider. This finding
contrasts previous research that showed lower sexual satisfaction was related to a higher
probability that patients will ask providers for help (Flynn et al., 2012). The current study
instead suggests that women with sexual health dysfunction may not be bringing up the
topic. Thus, it is especially important that providers initiate talk about sexual health early
on, listen to survivors’ individual preferences concerning those conversations, and
continue to engage the discussion across survivorship care. Women in phase 2 of the
study consistently reported a desire for the provider to ask patients about their sexual
health in survivorship. They discussed their difficulty bringing up multiple dimensions of
sexual health with providers, including feeling inhibited due to embarrassment “talking
about body parts” or saying words like “orgasm.” Other women found it difficult to
discuss the psychological or relational aspects of sexual health. They reported feeling
ashamed and being worried their providers will think they are another “crazy woman.”

Broaching the topic across the cancer trajectory is important but so too is the manner in which providers do so. Survivors reported a desire for the provider to ask specific questions about patients’ sexual health as opposed to making general quality of life inquiries. Patients reported general questions do not facilitate a communication about sexual health as well as specific questions do. When providers say potentially embarrassing terms it helps combat the taboo nature of sexuality and helps women feel more comfortable disclosing their concerns. Asking specific questions may also communicate to women that sexual health changes are experienced by other survivors (something the women, partners, and providers all deemed as important). This may encourage women to open up about issues they were afraid to talk about or assumed would go away on their own. This suggests two things: (1) it cannot be assumed patients will be motivated to bring up the topic of sexual health based on severe sexual health distress and (2) women believe specific questions are the most helpful means of engaging in sexual health discussions. This is especially true when providers ask specific sexual health questions in tandem with telling patients sexuality can be affected by breast cancer treatments. As this woman noted earlier:

It’s important to say, “A lot of breast cancer survivors will have vaginal dryness or pain during intercourse. They may also have other symptoms like hot flashes. Do you have any of these symptoms or are you experiencing anything else that is affecting your sex life because I’m here to help.” (28)

Many providers in phase 2 of this study espoused an opposite view. They suggested if survivors are experiencing sexual health concerns they will bring it up – that it is not necessary, therefore, for the provider to do so. Some providers acknowledged
that women may have difficulty bringing up the topic, however, they also suggested patients usually send other signals which “trigger” the provider’s awareness that sexual health might be a concern (e.g., mentioning pelvic pain or screening positive for depression). By capturing both the provider and survivors’ viewpoints the findings of this study reveal that this may not actually be true. This assumption by providers is problematic given that some patients indicate they generally await a signal from their physician before bringing some of sexual health issues (Ong, Visser, Lammes, & de Haes, 2000). Furthermore, many providers reported a reliance on general questions such as “How are things going since treatment?” or “How is everything at home?” in order to broach the topic. While well intentioned this approach is not always helpful to women. Comparing these perspectives reveals a fundamental disconnect regarding how to initiate a conversation about sexual health.

The discrepancies offer several translational contributions. Providers need to be aware of The National Comprehensive Cancer Network, (NCCN) new Guidelines for Survivorship Care (2013). These guidelines include the recommendation that sexual dysfunction be assessed at regular intervals for all survivors. It supplies specific, direct questions that should be asked of survivors including, “Do you have any concerns regarding sexual function or sexual activity?” The findings of this study provider further support that not only is this not being done in practice (and across medical specialties), but that doing so in a sensitive and responsive manner is critical to ensure survivors’ sexual health needs are met. Doing so will improve patient outcomes – particularly for those who may be hesitant to bring up the topic on their own.
These insights also provide other avenues to support women experiencing sexual health distress. More emphasis should be placed on raising awareness about the emergence of sexual health issues. Hospitals, cancer centers, and non-profit corporations could provide more information about the consequences of breast cancer and its treatments for sexual health via their websites, paper resources, or support groups. Doing so may prevent the shock and confusion that distressed survivors in this study. Further, materials that help women cope with inhibition and embarrassment surrounding difficult or taboo words or phrases should be created. Developing materials that offer suggestions for ways to broach the topic and remain engaged in the conversation may enhance women’s confidence and their ability to receive care.

**The coordination of care is critical to sexual health survivorship care.**

Communication at a larger level in the health care system is also of concern in survivorship care. While coordinated care is often the model for excellent care, the modern-day healthcare system is not structured in a way that facilitates that in cancer survivorship (American Society of Clinical Oncology, 2013; National Coalition for Cancer Survivorship, 2012). Women reported barriers that providers were not aware of that pertained to patients’ inability to access timely coordinated care. For instance, patients reported difficulty acquiring appointments and being referred from one provider to another in an endless loop. Women were ultimately left to feel like providers were “passing the buck” leaving their concerns/needs unaddressed. The coordination of care when providers are with different practices, healthcare systems, and locations is quite challenging. Still, it might be helpful to at least include this in the medical interaction.
Providers might ask about patients’ previous attempts to treat issues with medical professionals or devise a plan regarding whom they should see if they still feel like their concerns are not being addressed.

Problems with coordination of care also indicate the need to pursue the translational goal of creating and successfully implementing survivorship care plans. The Institute of Medicine (IOM), a nonprofit organization created under the charter of the National Academy of Sciences to provide notational recommendation on science and medicine, developed the term “survivorship care plan,” a tool that may be especially critical to improving the coordination of care or communication among the multiple providers and practices involved in survivors’ care. These plans contain a written record cancer treatment history and contact information for specialists and primary care physicians (Peairs et al., 2011). They also include plans for surveillance of recurrence; treatment of long-term and late effects of cancer treatment (including sexual health); screening and prevention for additional cancers; evaluation of psychosocial issues; treatment of comorbid conditions; preventative health such as immunizations, diet, and exercise; and a plan for coordination between care providers (Peairs et al.).

The survivorship plan is created by the patient and the oncologist in partnership with her primary care providers and gives her the information she needs to promote her health as well as clarifying which physician should take responsibility for different components of cancer care (Earle, 2006). Although a complex undertaking, if survivorship care plans were more widely and routinely used several of the organizational and communication barriers women and providers report experiencing would be
minimized. Cancer navigators can also take a more active role in connecting women with the appropriate providers. That being said, it is important to note that there are systematic barriers and variability across medical organizations that cannot necessarily be changed. For instance, the time it takes to procure and appointment or how many channels patients must navigate to make an appointment may be fixed. When designing resources to help providers and patients to seek and deliver health care those constraints need to be considered. Where survivorship plans and cancer navigators are not accessible it is important to support women in taking an active role in navigating their particular corner of the health care system. Women would benefit from the creation of sexual health resources that describe provider specialties and what kind of care they deliver as well as information about wait times and referral processes.

**Sexual health includes relational issues.** In line with the FSGI model, the women, partners, and providers all illustrated that sexual health is also a relational issue that greatly impacts their overall quality of life. Providers were aware that sexual health problems can result in the dissolution of a marriage or committed relationship. At the same time, because this physical issue could also be deemed a social issue, it seemed to blur the boundaries for survivors and providers as to who should address sexual health concerns when they included relational considerations.

By comparing women and partner narratives it became clear that couples need help navigating the challenges sexual health dysfunction brings to their relationship. Such situations are ripe for miscommunication between romantic partners. The need for more open communication also became evident. For example, several concerns women cited
(e.g. fear their partners do not find them attractive) could be perpetuated by partner behaviors (e.g., looking away), which partners reported using in order to minimize survivor distress. Thus, while husbands thought they were buffering or protecting survivors from distress they were instead adding to it. Previous research on relational well-being further suggests the importance of couples talking openly about their feelings, concerns, and challenges. Not talking (or avoidance) has not only been linked with sexual dysfunction but also relationship distress (Badr & Taylor, 2009). This miscommunication represents an actionable education point. Survivors and partners need to be aware that their interpretation of the other person’s behaviors/needs is not always accurate.

Simply informing women and partners that these discrepancies exist may create a platform from which to facilitate more open communication about their sexual experiences. However, direct verbal communication can be challenging (given the context) so it may be helpful to find less threatening means of communicating sensitive information within partnerships. Reflective writing is one tool that could accomplish this. Several women and partners in this study reported they shared their narrative reflections with one another after participating in the study. They indicated that doing so actually helped them understand each other’s point of view and provided them with time to process potentially upsetting information before talking with one another.

Writing has often been supported as a therapeutic tool when coping with traumatic experiences, including breast cancer (Pennebaker’s work) but these reports also suggest that it can enhance relational health. Sharing experiences, feelings, and concerns by writing about them (and then exchanging them) might be an especially helpful, less-
threatening way in which couples can work together to cope with the many sexual health challenges they are faced with across survivorship. The narratives from this study could also be used to create psychosocial resources to provide husbands and wives with each other’s perspectives. The women and men in this study both reported a desire to see more resources created to help couples cope with sexual health changes together. While some cancer centers like the Sexual Health Clinic at MD Anderson Cancer Center are starting to explore this, it is more commonly rare to find such resources. It is even more important for providers to be aware of sexual health issues, seek out existing resources for survivors, and be ready to disseminate information crated to patients’ needs that will empower women and their partners.

**Sexual health for survivors is a time-intensive, multi-dimensional, biopsychosocial issue.** The findings highlight how complex sexual health is in survivorship care. It is a challenging multi-dimensional issue and needs to be attended to as such in medical care. More modern-day models of sexuality should be incorporated into medical education. Earlier models of sexual health viewed a woman’s sexuality as linear (e.g., Kaplan; 1979) and identified three phases of sexual response: desire, excitement, and orgasm. More recent approaches recognize the emotional and relational dimensions of physical sexual dysfunction are as problematic as the physical problem itself (Basson, 2001).

Still, often providers treated these realms of sexuality as distinct. And while some providers recognized the biopsychosocial nature of sexual health in a theoretical sense, many seemed to be separating sexual health as either a physical issue or a socioemotional
one in practice. Providers in this study admitted being reticent about delving into psychosocial aspects of sexual health, suggesting it takes too much time to build the rapport they feel is needed. They were uncomfortable managing anything but the biomedical aspects, particularly given the time constraints of medical appointments.

Some providers said, “I am not a counselor” and suggested that addressing the psychosocial implications of sexual health is not something they are not equipped to do or that it is outside of their role. Several providers reported that they need to operate in accordance with divides between biomedical and psychosocial aspects of health. If they are having a conversation about depression they “stick to depression” and if it’s about “prescribing blood pressure medication” they stay “in that realm” (1). It is not surprising then that providers could be unsure of their role in sexual health care or that survivors may not know who to address such concerns with.

This issue, as it was uncovered in this study, presents several translational imperatives. A prime avenue for improving patient care is through the use of narrative. The transportation-imagery model (Green and Brock, 2000, 2002) suggests that being “transported into a narrative world” mediates between reading a story and the acceptance of beliefs or events within the story. The more the reader is transported into a story the more will influence the reader’s beliefs and actions. The exploration of patient narratives offers providers the opportunity to gain a sense of how dimensions of sexual health are interconnected in various ways for different patients (Charon, 2006) and to experience and accept the medical validity of those concerns.

Narrative medicine trainings using the narratives reported herein could be helpful
to providers involved in sexual health care. If trainings include narrative presentations followed by discussions, reflective writing, or simulated patient interactions providers may become more comfortable addressing multiple aspects of a patient’s case. In addition, patient narratives may help providers understand how some well-intentioned linguistic devices and expressions of social support (e.g., referencing the “new normal”) are not always helpful.

Nonetheless, it is important to recognize how much time constraints are a real concern for providers. Medical professionals in this study described an earnest desire to deliver multidimensional care that attended to survivors’ concerns, especially their sexual health issues. However, they often cited time constraints as the reason that prevented them from doing so. They also stressed the difficulty of time constraints in that they didn’t allow the providers the time needed to let patients share their concerns—to tell their story. Rita Charon proposes that identifying, understanding, and knowing what to do with stories can improve patient-provider communication and enhance quality of care (Charon, 2001). Further, she suggests it can improve efficiency of care. Providers here were hesitant to learn about the ways patients’ psychosocial sexual health concerns impact their overall sexual functioning particularly because of the time constraints. They reported that it was the equivalent of “wandering into the weeds,” “opening a Pandora’s Box,” or creating a situation in which survivors will be “a weepy mess.” As such, providers viewed patients’ psychosocial concerns and time constraints as barriers to the provision of patient care.
While the current healthcare system presents extraordinary challenges to providers and there is a need for shift in policy that would allow them more space to address patient concerns, those changes are unlikely to take place in the near future. As such, there is a need help providers reframe their conceptualization of psychosocial dimensions of care. Knowledge of patients’ psychosocial concerns is a tool, which if appreciated and appropriately used can increase providers’ ability to deliver care in a timely, comprehensive fashion. However, providers need help becoming comfortable listening to patient stories and identifying how those stories can be used to address health problems and conduct collaborative agenda setting. More frequent and targeted exposure to complex biopsychosocial narratives in medical training may assist providers in feeling comfortable eliciting their own patients’ stories.

Lessons Learned and Best Practices for Survivors, Partners, and Providers

As the previous discussion demonstrated, this research suggests several avenues for enhancing provider educational protocols and improving resources for patients and partners. Based on the insights of providers, survivors, and partners it is also possible to delineate several “best practices” or communication strategies for each perspective represented here. The following outlines these practices for providers, survivors, and partners.

Providers’ best practices. Providers would benefit from training to help them manage time constraints, increase their understanding of patient concerns, and bolster their self-efficacy in the area of sexual health. However, there are several strategies that providers can implement which may improve patient care in the immediate term.
According to the women and partners in this study providers should ask specific questions when screening for sexual health concerns with patients of all ages and survivorship lengths. They should gather the patient’s history of attempts to address sexual health issues so that if need be they can coordinate meaningful referrals.

Reflecting on the use of certain linguistic devices such as “the new normal” is also advisable. Finally, where demographic differences and knowledge gaps exist providers should express their investment in the patient’s quality of life and their commitment to addressing their concerns. These insights may extend to other sensitive health contexts in which the evidence for certain medical treatments is conflicting or unclear.

**Survivors’ best practices.** Overall, survivors need to be empowered to bring up the topic of sexual health and to navigate communication problems with providers and the medical system. Women’s discussion of their concerns and barriers also contributes to our understanding of the specific behaviors we need to help patients enact. Based on this research, women’s ability to access care may be improved if they can reflect on their hesitation to voice their sexual health concerns. Reflection may help them identify the root of their hesitation and work towards disclosing their issues to trusted providers. First, where possible, making an appointment specifically to discuss sexual health increases the likelihood those concerns will be addressed. If women know they will be more comfortable talking to a woman they should communicate that preference when making appointments. If this is feasible, for many women it will remove one barrier to the discussion.
Women had trouble saying certain words or where not exactly sure how to phrase their inquiries. Women should be encouraged to write down their concerns prior to the appointment and practice reading them out loud. If it proves too difficult to ask the provider their questions they can hand the provider a sheet of paper to read as a way to begin the discussion. Women suggested that often their sexual health goals for a given medical appointment fell to the wayside due to other concerns or because of discomfort. Reflecting on their goals for the appointment and writing them down may also be a helpful way to assist their provider in agenda-setting for the interaction.

**Partners’ best practices.** Based on this research partners need help to support survivors and care for themselves. This is especially important as partners and women’s ability to cope with sexual health distress is linked (Meyerowitz et al., 1999). This study provides several insights, which partners can use to communicate with survivors and potentially improve relational health. Partners should be aware that women could be misinterpreting the motivations for their actions and communication strategies (e.g. averting their eyes from women’s chest and their use of assurances). Where possible, partners should seek safe spaces (such as professional counseling) to communicate the intentions behind their behaviors and voice potentially upsetting information. Further, partners demonstrated a lack of awareness about the severity of the barriers women face when attempting to access medical care. According to the women in this study, it would be helpful for partners to ask survivors about their attempts to address sexual health issues. If survivor and partner have a shared understanding of the obstacles they may be bettered equipped to support one another and to cope with the challenges they encounter.
Directions for Future Research and Limitations

This research offers many translational insights that can be applied to enhance care. However, future research could deepen our understanding of the knowledge generated through this work as well as evaluate its applicability. Further, additional studies could address limitations of the study related to the sample and methodology.

The FSGI model and narrative theory allowed this research to capture the biopsychosocial nature of sexual health issues and communication impasses for women across the life span. The nature of the issues, which emerged suggests that other theoretical lenses could be used to narrow in on specific aspects of women’s experiences that hinder their quality of life. For instance, communication privacy management (CPM) (Petronio, 2002) examines the dialectic between a need to disclose personal information and the desire for privacy (Petronio) and has been used to explore sensitive issues (Petronio, Flores, & Hecht, 2007) as well as patient-provider relationships (Petronio, DiCorcia, & Duggan, 2012). CPM might help us develop a more nuanced understanding of women’s motivation for disclosing sexual health concerns in various health care environments. It may also uncover theoretically grounded strategies for women attempting to disclose sexual health concerns and strategies for providers seeking to help patients voice personal information.

The insights generated through this study also point to the utility of Kreps’ (1988) Relational Health Communication Competence Model (RHCCM) for heightening our understanding of sexual health issues. The RHCCM uses the image of the wheel to represent health care delivery. It posits that higher relational health communication
competency helps move the wheel forward as it results in higher levels of social support, information exchange, and cooperation. Lower competency is associated with lack of social support, information barriers, and decreased cooperation (Kreps). Certain communication contexts represent “steeper terrain,” which require highly developed relational communication competence. The sexual health issues presented here illustrate that steep terrain.

In the future, the RHCCM may be used jointly with narrative theory/narrative medicine to create medical education interventions for providers. Narratives may be used as a teaching tool, which increases the relational communication competence that leads to more productive clinical interactions about sexual health. Narratives are increasingly being used in medical school curriculum and future work should seek to maximize this momentum. Several narrative-based projects have received funding in recent years (see Vardhana, Lang, Sobol, & Krishnan 2007; Ragan, Wittenberg-Lyles, Goldsmith, & Sanchez-Reilly, 2008; Wittenberg-Lyles, Goldsmith, Ragan and Sanchez-Reilly, 2010). As noted in earlier sections of this discussion, narrative training may help humanize sexual health concerns for providers. However, more specifically, designing narrative interventions that evaluate provider communication competency through cross sectional or pre-post experimental designs is a lofty, yet worthy goal for future study. Such studies will build the case for the narrative approach as evidenced-based care. Taken together, insights from these theories could inform the development of new models for investigating how we can more competently communicate about sexual health issues in survivorship.
The WTCSH scale offers additional opportunities for future research. As previously noted, in this study the scale was used to establish the connection between sexual health outcomes and communication and focused my attention on certain aspects of variation with respect to willingness to communicate (i.e., willingness to have the romantic partner present in the interaction). This indicates the potential for the scale to be used in other sensitive communication contexts in which researchers and practitioners would benefit from understanding what elements of communication are the most problematic for patients. Future studies should be conducted to refine the scale and use it to inform intervention-making by identifying patient needs and specific areas of concern.

The new NCNN guidelines for survivorship care stipulate that survivors should be asked about their sexual health concerns in a direct manner at regular intervals. Yet, the results of this study imply this is not occurring. Future studies should explore the diffusion of these guidelines to provider populations. Are various specialties of providers aware of the new recommendations? How are they informed or how might they be better informed? If they are informed, are they integrating the guidelines into their clinical practice and how? Are patient outcomes linked to the adoption of these guidelines? There is a clear need to understand how care recommendations are disseminated, whether they are integrated into practice, and how they can be evaluated to assess if they have improved care.

Similarly, the adoption and execution of the IOM’s mandate for survivorship care planning needs to be investigated. The survivorship care plan is intended to prevent many of the coordination of care problems cited by women in this study. However, none of the
women in this study suggested that they had a survivorship care plan. The cancer community has endorsed the potential utility of these plans, yet, the way these plans function in the everyday clinical environment has been questioned (Kantsiper et al., 2009). Which provider should be initiating this? Should the patient feel more empowered to initiate the plan? Future studies should explore the feasibility of implementing these plans in various clinical settings and later determine if and how the tool is successful in facilitating survivors’ continued care.

The biopsychosocial nature of women’s sexual health is a predominant theme in this work. This study suggests the important role partners play in women’s sexual health concerns. Open and sensitive communication within couples may improve outcomes for patients struggling with sexual health concerns. To fully attend to the potential of the CIT the interviews with survivors and partners also captured positive incidents. Though not the focus of the current analysis, a study that explores those positive moments or events is planned for the future and could lead to the identification of helpful communication strategies that improve overall quality of life for partnered women. Studies should also explore to what extent helpful communication within couples influences post-traumatic growth. Posttraumatic growth (PTG) is positive psychological change experienced after a life-altering struggle and has been linked with patient outcomes (Danhauer et al., 2013). Exploring how relational communication encourages or hinders PTC will further our understanding of the ways relational, psychological, and physical components of women’s sexual health are linked.
This work identified another area of significance for partners, namely, their function within the medical interaction. The presence of a partner in an appointment in which sexuality was discussed was viewed as both positive and negative by patients, partners, and providers. Future research should investigate this phenomenon in depth and identify strategies to overcome challenges faced by each party.

Lastly, survivors and partners reported that feeling like the provider cannot help them poses a significant barrier for women. Providers indicated they feel like they don’t have the (interpersonal or medical) knowledge to engage the conversation when medical evidence is unclear. Ussher and colleagues’ (2013) study also discovered absence of provider knowledge and confidence as a significant barrier to sexual health care. As such, future research should create and evaluate provider education interventions. These education efforts should aim to increase medical professionals’ self-efficacy and provide them with sensitive communication strategies to discuss conflicting evidence.

There are several limitations of the current study that create specific opportunities for future work. First, in phase two of this research it is possible to link data between partners and survivors. However, survivors and partners were recruited through separate efforts and therefore, most of the patients in this study do not receive care where participating providers practice medicine. Recruiting matched patients and providers might capture a more thorough comparison of the issues.

Second, these narratives are self-reported reflections on different memorable moments, interactions, and events. In order to gain a deeper understanding of what is being said and done in medical interactions it would be beneficial to record real medical
visits. Interviews could be conducted with patients afterwards to investigate how their perception of the interaction aligns with their expectations and the behaviors that occurred within the clinic room.

The third limitation is the lack of diversity in the sample. The majority of participants in this study for both phases were White and highly educated. Therefore, the study does not capture the multiplicity of perspectives that may be revealed through the inclusion of participants of various cultures, socioeconomic status, and education levels. For instance, preliminary analysis reveals African American women report difference in communication preferences with provider as well as additional challenges in broaching the topic. Future work should explore these variations in order to create interventions that can be tailored to a diverse survivor population.

Another limitation of this study is the small sample size for partners. Although saturation of themes was accomplished, a larger sample may be able to draw out further areas of significance. As suggested above future research could deepen our understanding of the challenges couples face when coping with sexual health distress and interacting with the medical system.

Overall, this study offers theoretical, methodological, and translational contributions to psycho-oncology family communication, life span communication, health communication, and medical education scholarship. It suggests a comprehensive approach to addressing sexual health issues among breast cancer survivors is needed. This approach should include resources and support for women and couples; the coordination of existing resources and care providers; physician and patient education
efforts to increase self-efficacy and coping; and the development of narrative interventions to humanize sexual health problems and enhance providers’ ability to provide sensitive, timely, and effective care.
APPENDIX A

Informed Consent Form: Phase 1

INFORMED CONSENT FORM
SEXUAL HEALTH AFTER ONCOLOGY

RESEARCH PROCEDURES

This research is being conducted to increase understanding of sexual health issues in breast cancer survivorship. You are being asked to complete a short questionnaire. It should take you no longer than approximately 20-30 minutes to finish.

RISKS

There are no foreseeable risks for participating in this research. There are no physical, social, legal or economic risks to participating in the study. However, you may find that some of the questions on survey feel quite personal. If you think it will be too upsetting to think about sexual health experiences in survivorship, you are free to choose not to participate or to discontinue participation at any time. You are encouraged to find a comfortable private space to complete this survey.

BENEFITS

There are no benefits to you as a participant other than to further research regarding how breast cancer survivors experience sexual health issues. It is our hope that the knowledge gained through this project will improve medical care and support services for breast cancer survivors.

CONFIDENTIALITY

While it is understood that no computer transmission can be perfectly secure, reasonable efforts will be made to protect the confidentiality of your transmission. The survey database is password-protected. The researcher is the only person who will see your survey answers. You are not required to supply your name and contact information to complete the survey. However, if you choose to supply that information at the end of the survey so I may contact you with other study-related materials, it will be collected on a separate webpage so that I will not view your survey answers and contact information together when retrieving the data. This means I will not personally view your name connected to your survey answers. To further protect your confidentiality, I will then
manually remove your name and contact information from the secure online database and store it in a separate password-protected file on my private computer. The researcher will be the only person who will have access to the contact information file. At no time will your survey answers be connected back to you.

**PARTICIPATION**

Your participation is voluntary, and you may withdraw from the study at any time and for any reason. If you decide not to participate or if you withdraw from the study, there is no penalty or loss of benefits to which you are otherwise entitled. There are no costs to you or any other party.

**COMPENSATION**

Each participant that completes and submits the questionnaire will be entered into two drawings for a $20.00 Visa gift card as compensation for your time.

**CONTACT**

Mollie Rose Canzona, doctoral candidate with the Department of Communication at George Mason University, is conducting this research. She may be reached at 336.414.8989 or mcanzona@gmu.edu for questions or to report a research-related problem. The faculty advisor’s name is Dr. Carla L. Fisher. You may contact the George Mason University Office of Research Integrity & Assurance at 703-993-4121 if you have questions or comments regarding your rights as a participant in the research. This research has been reviewed according to George Mason University procedures governing your participation in this research. Please feel free to retain this document for your records. You may also use the researcher’s contact information to receive updates on research progress and findings.

**CONSENT**

By checking this box I am indicating I have read this form and I agree to participate in this study.

If you do not wish to take the survey you may exit this screen. Version date: 13 January 2014

Office of Research Integrity & Assurance Project Number: 557134-1 Date Approved: 1/15/14 Approval Expiration Date: 1/14/15 IRB: For Official Use Only

**Informed Consent Form: Phase 2**
INFORMED CONSENT FORM
SEXUAL HEALTH AFTER ONCOLOGY

RESEARCH PROCEDURES

This research is being conducted to increase understanding of sexual health issues in breast cancer survivorship. You are being asked to write a short reflection on a critical moment regarding sexual health in breast cancer survivorship and to participate in an individual telephone interview with the researcher. In order to complete the written reflection and the interview it is estimated you will contribute approximately one hour of your time. When choosing times and dates the researcher may contact you for an interview please choose times that you feel you will have adequate privacy to comfortably discuss sexual health matters.

RISKS

There are no foreseeable risks for participating in this research. There are no physical, social, legal or economic risks to participating in the study. However, you may find that some of the questions in the interview feel quite personal. If you think it will be too upsetting to think about sexual health experiences in survivorship, you are free to choose not to participate or to discontinue participation at any time.

BENEFITS

There are no benefits to you as a participant other than to further research regarding how breast cancer survivors experience sexual health issues. It is our hope that the knowledge gained through this project will improve medical care and support services for breast cancer survivors.

CONFIDENTIALITY

While it is understood that no computer transmission can be perfectly secure, reasonable efforts will be made to protect the confidentiality of your transmission. The researcher is the only person who will know your name or contact information. This information will only be retained in order to send and receive your critical event narrative reflection and to set up and conduct the interview. After you have completed the reflection and interview your name and other identifying information will be removed from the data. The researcher will transcribe the audio recordings of the interview and remove your name and other identifying information. Your name will be replaced with a unique number that serves as an identification key. The researcher will be the only person who will have access to the identification key. The identification key will be located in a password protected digital file on the researcher’s computer. Your name and other identifying information will not be seen by anyone other than the researcher and will not be reported in research presentations or publications.
PARTICIPATION

Your participation is voluntary, and you may withdraw from the study at any time and for any reason. If you decide not to participate or if you withdraw from the study, there is no penalty or loss of benefits to which you are otherwise entitled. There are no costs to you or any other party.

COMPENSATION

Each participant will be entered into two drawings for a $20.00 Visa gift card as compensation for your time.

CONTACT

Mollie Rose Canzona, doctoral candidate with the Department of Communication at George Mason University, is conducting this research. She may be reached at 336.414.8989 or mcanzona@gmu.edu for questions or to report a research-related problem. The faculty advisor’s name is Dr. Carla L. Fisher. You may contact the George Mason University Office of Research Integrity & Assurance at 703-993-4121 if you have questions or comments regarding your rights as a participant in the research. This research has been reviewed according to George Mason University procedures governing your participation in this research. Please feel free to retain this document for your records. You may also use the researcher’s contact information to receive updates on research progress and findings.

CONSENT

I have read this form and agree to participate in this study.

________________________________________ Name __________________________ Date of Signature

Version date: 13 January 2014

Office of Research Integrity & Assurance Project Number: 557134-1 Date Approved: 1/15/14 Approval Expiration Date: 1/14/15 IRB: For Official Use Only
APPENDIX B

Sociodemographic and Medical Information Questionnaire

Please answer the following 20 questions.

1. Your gender:
   Male
   Female
   Transgender

2. Your age ________

3. Diagnosis date __________

4. Stage Breast Cancer you were diagnosed with ________________

5. How would you classify yourself?
   Black
   Asian/Pacific Islander
   White
   Hispanic
   Multiracial
   Other __________________

6. What is the highest level of education you have completed?
   Grammar school
   High School or equivalent
   Vocational or Technical School (2 year)
   Some College
   Bachelors Degree
   Masters Degree
   Doctoral Degree
   Other __________________

7. Work Status:
   Don't work
Work fulltime (40+ hours/week)
Full-time student/Work part-time (20 hours/week)
Full-time student/Work part-time (40+hours/week)
Work part-time (20hrs/week)
Fulltime student/don't work
Volunteer (under 20 hrs/week)
Volunteer (20+hrs/week)

8. Total household income:

$0-20,000
$21-30,000
$31-40,000
$41-50,000
$51-60,000
$61-70,000
$71-80,000
$81-90,000
$91-100,000
$100,000+

9. Relationship status (check all that apply)

Single
Dating
Long-term partnership
Married
Divorced/separated
Widowed

10. Sexual orientation?

Homosexual
Heterosexual
Bisexual
Asexual
Prefer not to say

11.Type of treatment you received (check all that apply)

Chemotherapy
Radiation
Surgery
Hormone Therapy
12. If you received surgery for breast cancer, what kind of surgery did you undergo? (check all that apply)

Lumpectomy
Quadrantectomy
Mastectomy
Double mastectomy
Reconstruction

13. For each treatment received please indicate the number of treatment cycles you received?

Chemotherapy ______
Radiation ________
Surgery ________
Bone marrow transplant ______
Hormone Therapy ______

14. Please indicate the last date you received the following treatments:

Chemotherapy ______
Radiation ________
Surgery ________
Bone marrow transplant ______

15. Have you ever taken hormonal therapy such as tamoxifen?

No
Yes
Don't know
Not applicable

16. Are you still being treated with hormonal therapy? If not, what was the last date you had hormonal therapy?

No _________
Yes _________
Don't know _________
Not applicable _________

17. Were you put into an early menopausal state or premature ovarian failure due to the treatments you received?
18. Did breast cancer treatment you received result in lasting physical changes (visible scars, current hair loss, or weight changes)?

No
Yes
Don’t know
Not applicable

19. Who do you consider your general health primary care provider?

General Internal Medicine Physician
Family Medicine Physician
Nurse (Nurse Practitioner, NP or General Registered Nurse, RN)
Obstetrician-Gynecologist (OB/GYN)
I do not have a provider I consider my general health primary care provider.

20. If you had a sexual health concern in survivorship which provider would you visit to discuss it?

General Internal Medicine Physician
Family Medicine Physician
Nurse (Nurse Practitioner, NP or General Registered Nurse, RN)
Obstetrician-Gynecologist (OB/GYN)
I don’t know
APPENDIX C

Sexual Quality of Life – Female (SQOL – F)

This questionnaire consists of a set of statements, each asking about your thoughts and feelings that you may have about your sex life. The statement may be positive or negative.

You are asked to rate each one according to how much you agree or disagree with the statement by marking on of the six responses choices.

In answering these items think about the following definitions:

**Sex life**: is both the physical sexual activities and the emotional sexual relationship you have with your partner.

**Sexual activity**: includes any activity, which may result in sexual stimulation or sexual pleasure such as intercourse, caressing, foreplay, masturbation, or oral sex.

1. When I think about my sex life, it is an enjoyable part of my life overall.

   Completely agree
   Moderately agree
   Slightly agree
   Slightly disagree
   Moderately disagree
   Completely disagree

2. When I think about my sex life, I feel good about myself.

   Completely agree
   Moderately agree
   Slightly agree
   Slightly disagree
   Moderately disagree
   Completely disagree

3. When I think about my sex life, I feel frustrated.
4. When I think about my sex life, I feel depressed.

5. When I think about my sex life, I feel like less of a woman.

6. I have lost confidence in myself as a sexual partner.

7. When I think about my sex life, I feel anxious.

8. When I think about my sex life, I feel close to my partner.
9. When I think about my sex life, I feel that I can talk to my partner about sexual matters.

10. When I think about my sex life, I feel angry.

11. I worry about the future of my sexual life.

12. I have lost pleasure in sexual activity.
13. When I think about my sex life, I am embarrassed.

Completely agree
Moderately agree
Slightly agree
Slightly disagree
Moderately disagree
Completely disagree

14. I try to avoid sexual activity.

Completely agree
Moderately agree
Slightly agree
Slightly disagree
Moderately disagree
Completely disagree

15. When I think about my sex life, I feel guilty.

Completely agree
Moderately agree
Slightly agree
Slightly disagree
Moderately disagree
Completely disagree

16. When I think about my sex life, I worry that my partner feels hurt or rejected.

Completely agree
Moderately agree
Slightly agree
Slightly disagree
Moderately disagree
Completely disagree

17. When I think about my sex life, I feel I have lost something.

Completely agree
Moderately agree
Slightly agree
Slightly disagree
Moderately disagree
18. When I think about my sex life, I am satisfied with the frequency of sexual activity.

Completely agree
Moderately agree
Slightly agree
Slightly disagree
Moderately disagree
Completely disagree
APPENDIX D

Willingness to Communicate about Sexual Health Scale (WTCSH)

Indicate how strongly you agree or disagree with the following statements:

1. I’m comfortable talking about my sexual health issues with people other than providers in survivorship:
   
   Strongly agree
   Agree
   Neither agree or disagree
   Disagree
   Strongly disagree

2. I’m quick to make an appointment to talk with physician when experiencing sexual health issues in survivorship:

   Strongly agree
   Agree
   Neither agree or disagree
   Disagree
   Strongly disagree

3. I’m comfortable talking about sexual health issues with health care providers in survivorship:

   Strongly agree
   Agree
   Neither agree or disagree
   Disagree
   Strongly disagree

4. I experience difficulties communicating successfully with health care providers about sexual health in survivorship:

   Strongly agree
   Agree
   Neither agree or disagree
5. I am a competent communicator when talking about sexual health issues in survivorship:

Strongly agree
Agree
Neither agree or disagree
Disagree
Strongly disagree

6. I’m comfortable having my spouse/partner present when communicating with health care providers about my sexual health in survivorship.

Strongly agree
Agree
Neither agree or disagree
Disagree
Strongly disagree
Semi-Structured Interview Scripts: Survivors

1. Introductory questions: Confirm age relationship status, survivorship length, last treatment, type of treatment received.

2. Think about sexual health before diagnosis, during treatment period, and after treatment. Tell me a bit about what it meant to you at each time period? How has it changed?

3. Thank you for writing the reflection about your sexual health after cancer. I’m going to draw your attention to several aspects of what you wrote.

First, you said that…. *(fill in with details from participant’s reflection)*

Possible Follow up questions:
What do you remember about that experience? Was your husband there?
What did you say? What did your partner say and what were you thinking and feeling?
How is this impacting your relationship (if it is)?

3. What do you remember about a positive moment or event in your sexual life after treatment?

4. Can describe any sexual health issues you may have experienced directly after treatment, and then tell me a bit about how those issues may have changed (or not changed) over time?
   Follow up: What issues remain now?

5. Have you discussed the sexual issues with any type of provider after primary treatment? If so, which ones?

6. If you have not discussed these issues with a provider, what type do you think you would go to if you wanted to talk about it and why?
   Follow up: Why did you select these providers?

7. If the answer to 5 is YES:
• What do you remember about that experience? What did you say? What did they say? What were you thinking and feeling?
• Which aspects of your sexual health did you bring up?
• Where there sexual health issues that where easier to discuss and others you were nervous to talk about or that you didn’t bring up for any other reason?

7. If the answer to 5 is NO:
   • Why?
   • Tell me about a time you were considering/attempting to discuss sexual health with your provider. What were you thinking and feeling?
   • Which aspects of your sexual health would you want to bring up?
   • What aspects of your sexual health (topics) do you think would be easier to bring up and which topics would you be hesitant to bring up when you imagine this conversation and why?
   • If you do not talk to providers, do you talk to people? Who are they? What do you discuss?

8. Added question based on participant responses: Have you ever had a discussion with a provider about the use of hormone replacement therapy to address sexual health issues?

9. If the answer to 5 is YES: Reflecting more on that interaction can you think of anything else about trying to get medical care for your sexual health concern that was challenging?

10. If the answer to 5 is NO: Is there anything else you imagine would be challenging when attempting to get medical care for your sexual health concern?

11. Tell me everything a provider can do to make a conversation about sexual health more helpful or easier for you. Then I’d like to hear everything a provider can do to make those interactions particularly unhelpful or make things harder for you.

12. Has your partner ever accompanied you to a doctor appointment in which sexual health issues were discussed?

   If NO:
   • Would you want your spouse/partner to accompany you to a visit where you discussed sexual health and why?
   • How would it change things for you to have him there?
   • What would be helpful and unhelpful about having him there?
   • What do you think he would feel about being present for that conversation?

   If YES:
Semi-Structured Interview Script: Partners

1. Introductory questions: Confirm survivor’s age (and partner’s age), relationship status, survivorship length, last treatment, type of treatment received.

2. Think about sexual health before diagnosis, during treatment period, and after treatment. Tell me a bit about what it meant to you at each time period? How has it changed?

3. Thank you for writing the reflection about your wife/girlfriend’s sexual health after cancer. I’m going to draw your attention to several aspects of what you wrote.

First, you said that . . . (fill in with details from participant’s reflection)

   Possible Follow up questions:
   What do you remember about that experience? Was your husband there?
   What did you say? What did your partner say and what were you thinking and feeling?
   How is this impacting your relationship (if it is)?

3. Can you tell me about a positive moment or event in your sexual life that you think would stand out to your wife/girlfriend after her cancer treatment?

4. Could describe any issues that your wife/girlfriend may have had right after treatment, and then tell me a bit about how those issues may have changed (or not changed) over time?

   Follow up: What issues remain now?

5. Has your wife/girlfriend discussed sexual issues with any type of provider after primary treatment? If so, which ones?

   Follow up: Why do you think she selected these providers?

6. If she has not discussed these issues with a provider, what type do you think she would go to if you wanted to talk about it and why?

7. If the answer to 5 is YES:
• What do you remember her saying about that experience? What did she say? What did the provider say? What was she thinking and feeling?
• Which aspects of her sexual health did she bring up?
• Which issues do you think were easier for her to discuss and were there other issues you think she was particularly nervous to talk about or that she didn’t bring up for any other reason?

7. If the answer to 5 is NO:
• Why do you think that is?
• Can you tell me about a time she was considering/attempting to discuss sexual health with her provider. What do you think she was thinking and feeling?
• Which aspects of her sexual health do you think she would want to bring up?
• What aspects of her sexual health (topics) do you think would be easier for her to bring up and which topics would she be hesitant to bring up in that conversation and why?
• If you she not talk to providers. Does she talk to other people? who are they? What does she discuss?

8. Added question based on participant responses: Has she ever had a discussion with a provider about the use of hormone replacement therapy to address sexual health issues?

9. If the answer to 5 is YES: Can think of anything else about situation that was challenging for her?

10. If the answer to 5 is NO: Is there anything else you imagine she would find challenging when attempting to get medical care for her sexual health concern?

11. Tell me everything a provider can do to make a conversation about sexual health more helpful or easier for her. Then I’d like to hear everything a provider can do to make those interactions particularly unhelpful or make things harder for her?
   Follow up: What do providers do that are helpful and unhelpful from your perspective?

12. Can you tell me about a time you accompanied her to a doctor appointment in which sexual health issues were discussed?

If yes:
• What was that experience like?
• Did you want to be there?
• How do you think your wife/partner felt about having you there?
• Did it change things for her to have you there?
• Do you think there are things about having you there that made her worry/difficult and do you think there were things that were helpful/eased her mind.
If no:
• Did you want to be there?
• How do you think your wife/partner would feel about having you there?
• Do you think it would change things for her to have you there?
• Do you think there are things about having you there that would make her worry/difficult and do you think there were things that would be helpful/ eased her mind.

**Semi-Structured Interview Script: Providers**

1. Job title or current specialty? Years of practice?

2. What kinds of sexual health challenges can survivors experience after diagnosis and primary treatment? (Follow up if not captured: physical, emotional, and relational challenges)

3. Have you ever had a breast cancer survivor as a patient?

   IF YES: Can you tell me about a time you discussed sexual health with a breast cancer survivor? What do you remember about that experience?

   IF YES and not had that conversation: Why do you think you that topic didn’t come up?

   IF NO: If you were to have a breast cancer survivor as a patient, do you think that conversation would happen? When? Why or why not?

4. IF YES: What aspects of sexual health did you discuss with the patient(s)?

   Follow up: Have you ever had a discussion about hormone replacement therapy to treat sexual health issues?

   IF NO: What aspects of sexual health do you think are generally discussed?

5. IF YES: How do you think that conversation went? Was anything challenging about that interaction? If no, why? If yes, what?

   IF NO: Was anything challenging about attempting to have that conversation or do you think anything would be challenging about that conversation?

6. Do you think it’s best for the patient to bring the topic up or for you to?

7. Patient’s view: Can you think of anything that patients would find challenging about getting medical care for sexual health concerns?
8. What do you think a patient would find helpful and unhelpful from a provider in a conversation about sexual health (in terms of what you say or do)?

9. Has a partner/spouse ever accompanied a patient to a visit where you talked about sexual health with a BC survivor?

IF YES: What was that experience like? How does it change things for you to have the spouse/partner there? Is it helpful?

How do you think it changed things for the patient to have her spouse/partner there? Do you think it was helpful?

IF NO: What do you think that experience would be like? How do you think it would change things for you to have the spouse/partner there? Would it be it helpful?

How do you think it would change things for the patient to have her spouse/partner there? Do you think it would be helpful?

10. Breast cancer survivors have the potential to visit many different types of providers to discuss their sexual health.

Do you think they have any ideas about which provider type is more appropriate to discuss this with or do you think they may prefer a specific type of provider when it comes to sexual health matters?

Why do you think they think/feel that?

11. What do you see as your role in sexual health care for survivors and which type of provider do you see as most appropriate for these discussions?


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BIOGRAPHY

Mollie Rose Canzona earned her Bachelor of Arts in English from Salem College in Winston-Salem, North Carolina. She received her Master of Arts in print and multimedia journalism from Emerson College in Boston, Massachusetts where she focused on health and science writing. Her thesis investigated identity revision among chronic disease patients online. Her research centers on family coping during health transitions and patient-provider communication and training. She is particularly interested in how illness uncertainty and communication about sensitive or stigmatized topics are tied to health outcomes across the life span.