

**WE-NESS: COUPLE IDENTITY AS SHARED BY MALE PARTNERS OF BREAST
CANCER PATIENTS**

by

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ABSTRACT

Research on partners of those facing cancer has tended to define the relationship in a coping context. Though cancer is acknowledged as a crisis for both partners and patients and as a life altering experience, the voices of male partners' have often been overlooked. The present study explored the wider relational context of partners of women facing cancer. Seven male partners of breast cancer patients under the age of forty-five shared their experience of being a partner to a woman going through cancer in a single open-ended interview. Dialogical phenomenology allowed for clarification of the landscape of these partners' experience by providing opportunity to formulate their experience and also to unfold meanings attributed to this experience. Seven core themes were identified in the accounts shared by these men: crisis and aftermath; children, parenting, and fertility; personal impact; breast cancer as a shared experience; honouring voices and voice; relational choreography; and relational outlook. These men revealed different ways that being a partner of a woman with cancer is a shared experience. One pattern that emerged describes how a "you and me" couple identity framework can shift into a "we" perspective. Another facet of the results revealed how couple identity emerged in relational patterns of engagement during conversational interviewing, a distinctive feature that fits well with previous findings. As partners, these men are and need to be acknowledged as involved and affected.

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First and foremost, thank you to the men who shared their stories and their journeys with me. You let us in to the often-unknown understanding of relationships through illness. It was an honour to have sat with you and heard your stories.

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CHAPTER 1: INTRODUCTION AND LITERATURE REVIEW

Context

Humans exist in relationship. Engaging in a romantic relationship allows for an I-Thou connection to occur when individuals engage with one another in a mutually open and present way (Halling, 2008). A cognitive distinction of separating self from the other can be challenging when in an intimate relationship (Aron, Aron, Tudor, & Nelson, 1991). In an intimate long-term relationship, there is this blurring of self and other that is hard to quantify. Where one partner ends, and the other begins, becomes grey. When one individual falls ill, or is in an accident, there is a social system around them that also is shaken and shifts with perhaps the most fundamental relationship being an intimate partnership. “Coping with a stressful life circumstance is a social process” (Lyons, Mickelson, Sullivan, & Coyne, 1998, p. 582) as it happens within a social context. Intimate relationships have been widely studied and are well known to mitigate the amount of stress an individual experiences (Northouse, Templin, Mood, & Oberst, 1998; Pistrang & Barker, 1995). Being in a romantic relationship gives some of the best support possible when facing an illness. In one study, 80% of the female respondents considered their partner to be their greatest source of support (Préau et al., 2011). Though these relationships can be a great source of strength, the very nature of being in a romantic relationship also increases one’s vulnerability to facing stressful situations such as illness.

When facing a new and stressful situation, an individual’s reaction may be different than ever before. Being in a relationship with that person can bring a sense of seeing them in a new light; as if seeing them for the first time (Halling, 2008). There is the opportunity to be surprised by their reactions, and to enter into their experience.

Within the literature on stress and coping, models have historically been interested in the relational dynamic and have developed relational frameworks to the coping process (Ben-Zur, Gilbar, & Lev, 2001; Bodenmann, 2005; Bodenmann, Meuwly, & Kayser, 2011; Lyons et al., 1998). Various topics have been pursued in regards to couples including coping, relationship satisfaction, dyadic adjustment, predictors of distress, and transference of distress.

Tedeschi and Calhoun (2004) use an earthquake metaphor to describe the seismic event a cancer diagnosis is in one's life. It has the capabilities to "severely shake, threaten, or reduce to rubble many of the schematic structures that have guided understanding, decision making, and meaningfulness" (p. 5). Fundamental assumptions of the world in regards to predictability, controllability, identity, and safety are challenged (Janoff-Bulman, 1992; Tedeschi & Calhoun, 2004). Many studies have identified the distress that patients and partners experience and some have identified the experience as a trauma (Brosseau, McDonald, & Stephen, 2011).

In Canada, breast cancer is the most commonly diagnosed cancer among women (23,800 expected new cases this year) with 18% of cases occurring in females under the age of 50 (Canadian Cancer Society's Advisory Committee on Cancer Statistics. (2013). Cancer has been referred to as an interpersonal disease (Ey, Compas, Epping-Jordan, & Worsham, 1998; Thornton & Perez, 2007) based on the effects it has on those closest to the cancer patient. Partners of breast cancer patients present higher levels of distress and poorer quality of life than those partners of healthy women (Moreira & Canavarro, 2013). Many partners have been observed to exhibit similar responses as the cancer patient to the stress of cancer. Research has been focused on what to call this stress, as well as the patterns of distress among couples. Many studies have quantitatively observed the effect of cancer on those closest to the patient through dyadic coping models, level of distress, importance of age, and predictors of transference of

stress at an individual level. Though there have been advances in including the partners in empirical research, and recognition that they have important stories to tell, there is a paucity of studies giving voice to these men's experience in a holistic sense.

Relational self. Some investigators recognize that relationships are just as real as the people themselves. One way in which this is seen is through some version of a relational self. Relational self has been referred to as interdependent self, holistic, collective, contextual, and connected self (see Markus & Kitayama, 1991). Authors exploring relational self principles, suggest that the non-relational self is a fraction of the whole, and that it experiences the most meaning when in the right social relationships. This interdependence is most notably seen in non-individualistic cultures and is associated with many levels of relational embeddedness including family, friends, and broader society. The relational self is an influential source of individuals' "interpersonal patterns – and hence [also of] the self and personality" (Andersen & Chen, 2002, p. 621). The influence of significant others on our motivations and emotional lives shows up in links to our personality, identity, and in how we react, talk, and live our lives. The relational self is "composed of people's stored knowledge about the self in the context of their relationships with significant others that is distinct from, but linked in memory to people's stored knowledge about their significant others" (Chen, Boucher, & Kraus, 2011, p. 150). Integrative conceptualizations of the relational self emphasize combinations of shared social activities, along with human agency, allowing for self-determination and adaptations of social practices (e.g. Martin, 2005). In relationships, such integrative models emphasize a two-way influence of the relationship on the person and vice-versa. Though there is room for multiple levels of the relational self, the focus of investigation in the present study is that of the relational self in an intimate committed relationship.

Couples, Coping, and Identity

In exploring what we know about couples facing cancer, the following is a review of the literature on dyadic coping and couple identity, in regards to the impact of cancer on the couple and their relationship. A distinction between the conceptualizations of a *you and me* perspective of couples and a *we* perspective is identified.

Taking a family systems approach, when one member of the family is ill, it influences the entire family. The past two decades have seen an influx in the literature in regards to partners' psychological response to cancer. The focus has been on coping processes (Fagundes, Berg, & Wiebe, 2012; Kraemer et al., 2000), and psychological distress (Bishop et al., 2007; Hodges, Humphris, & Macfarlane, 2005; Northouse et al., 1998; Northouse, Mood, Templin, Mellon, & George, 2000). Relational coping processes are a starting point in giving voice to the partners' experience.

Dyadic coping. Many conceptualizations of dyadic coping have emerged over the past two decades with two identified similarities. The first similarity across dyadic coping conceptualizations is that dyadic coping is a response to a dyadic stress. A dyadic stress is defined as "a specific stressful encounter that affects both partners either directly or indirectly and triggers the coping efforts of both partners within a defined time frame and defined geographic location" (Bodenmann, 2005, p. 33). The second similarity is that dyadic coping "refers to the way partners deal with individual and dyadic stressors" (Bodenmann et al., 2011, p. 254). With these similarities as a basis, there are two prongs of dyadic coping that stem forth. The first concept identifies and compares the individual coping of both partners in relation the others' individual coping to identify similarities and differences (see Barbarin, Hughes, & Chesler, 1985). The second prong, and the one setting the backdrop for the present study, is the

systemic approach put forth by Bodenmann where dyadic coping is described as an addition to individual coping.

Bodenman (2005) proposes dyadic coping, not as a replacement for individual coping but rather, as a model adding to the coping efforts of the couple. The systemic-transactional dyadic coping model put forth by Bodenmann, followed Lazarus and Folkman's transactional model of stress and coping (see Lazarus & Folkman, 1987). Bodenmann's model builds upon the transactional model of stress, highlighting a systems perspective, holding to the tenant that we do not experience stressors alone. Dyadic coping contends that a single stressful encounter can affect both partners "either directly or indirectly and trigger the coping efforts of both partners" (Bodenmann, 2005, p. 33). Dyadic coping therefore, is a stress communicating process where "one partner's appraisal of a stress is communicated to the other partner, who perceives, interprets, and decodes these signals and responds with some form of dyadic coping" (Bodenmann, 2005, p. 36). An illness such as cancer is a dyadic stressor; it can affect people both on an individual level and couple level (Badr, Carmack, Kashy, Cristofanilli, & Revenson, 2010). Researchers have used Bodenmann's model to observe the impact of cancer on the couple and their relationship. Dyadic coping has been identified as a significant predictor of relationship quality (Bodenmann et al., 2011). Within psycho-oncology, dyadic coping acknowledges that the illness affects both individuals in a relationship and identifies the responses as a couple to the illness.

Though the process of couples coping may be similar to Lazarus and Folkman's stress and coping theory, within the literature some relational characteristics have been identified as facilitative to dyadic coping. Studies have shown that open communication and greater relationship satisfaction are most characteristic of couples that adjust to cancer (Acitelli & Badr,

2005; Badr & Carmack Taylor, 2008; Banthia et al., 2003; Pistrang & Barker, 1995). Couples who view cancer as a relationship issue rather than an individual issue report higher relationship satisfaction than couples that do not (Acitelli & Badr, 2005). Badr et al. (2010) conducted a study to understand in what ways common dyadic coping was associated with less cancer distress and greater dyadic adjustment. In a sample of 191 couples coping with metastatic breast cancer, they reported patient and partner's cancer related distress scores being significantly correlated. The results indicate that positive dyadic coping was associated with better dyadic adjustment, and negative dyadic coping was associated with greater cancer related distress. These findings are consistent with Bodenmann's model of dyadic coping.

An identified important piece in couple communication is the role of self-disclosure. Self-disclosure in a relationship relates to communication processes and intimacy (Manne & Badr, 2008). Although open communication is important, Hagedoorn et al. (2011) reported that the level of self-disclosure is imperative. In a study of 64 newly diagnosed patients and their partners, if partners of cancer patients disclosed more than the patient, both patient and partner reported high levels of depressive symptoms. Other studies have illustrated a demand-withdrawal pattern among distressed couples (Manne et al., 2006). When one partner discloses and the other feels pressured to disclose, sometimes they will withdraw. When one partner withdraws, higher levels of distress are experienced between both partners (Hagedoorn et al., 2011; Manne et al., 2006; Pistrang & Barker, 1995). This highlights the importance of communication being open, but also reciprocal.

Facing cancer is stressful, for both patient and partner (Badr et al., 2010; Hagedoorn et al., 2011; Kangas, Henry, & Bryant, 2002; Thorton & Perez, 2007). It comes as no surprise that individuals naturally want to shield their partner from unpleasant thoughts or feelings. Many

times partners in relationship may engage in protective buffering as an “effort to protect one’s partner from upset and burden by concealing worries, hiding concerns, and yielding to the partner to avoid disagreements” (Manne et al., 2007, p. 381). Just as negative events and distress may be experienced at similar levels between patient and partner, positive effects can be shared in the same way (Moore et al., 2011; Weiss, 2004; Zwahlen, Hagenbuch, Carley, Jenewein, & Buchi, 2010). Though dyadic coping addresses the couple’s coping processes, it is still primarily individualistic in that it is the interplay between the two individuals rather than the shared couple process.

Kayser, Watson, and Andrade (2007) conducted a mixed-methods randomized control trial where both breast cancer patient and their partner completed questionnaires of dyadic coping, mutuality, awareness, and quality of life. Couples in the intervention arm were then interviewed. Through analysis using the “Listening Guide”, the ten interviews identified three relational qualities facilitating the coping process: relationship awareness, authenticity and mutuality. Relationship awareness was defined as “thinking about one’s relationship in the context of the illness” (p. 415). In their study, it was from the men that they noticed this awareness in their dialogue. Authenticity was seen as facilitating coping by bringing awareness among the partners to the others feelings and needs, which allowed them to respond to the other more appropriately. Mutuality was defined as a way of relating to one another as fully as possible in this shared experience with empathy being at the core of the interaction. Kayser et al. (2007) identified cancer as a “we-disease” where there was more interdependence seen among the couples than there was independence and identified the shift that needs to be made within the coping literature on couples.

In these dyadic models, most couples have been conceptualized and understood as two individuals sharing something, which will be referred to as a *you and me* conceptualization. The focus is individualistic in that it is two individuals coming together, two separate entities. The identification with the relationship stays at a you and me individualistic level. A small body of literature has focused on those around the cancer patient's experience from a phenomenological method. Of these, the majority identify this you and me conceptualization of coupleness versus a *we-ness*. One study reported the relationship between being a significant other to someone facing cancer in light of the construct of suffering, as a suffering "at second place" (Lindholm, Rehnsfeldt, Arman, & Hamrin, 2002). Another study with spouses of oral cancer patients, described the essence of their experience as being one of "living in a state of suspension" as seen in four different aspects of the experience: body, human relations, space, and time (Röing, Hirsch, & Holmström, 2008). It is systemic by including the family members and observing their interactions however, it still is a focus at the individual level of the interaction; a focus on how you and me cope together and communicate about this coping.

A you and me couple conceptualization is important as it informs and gives understanding to communication, appraisals, and transactional proceedings. However, some studies within the dyadic coping literature have hinted at an addition to the process from a relational standpoint. In scanning the literature, only one study stood out from a mixed methods phenomenological stance of identifying the couple from a *we* standpoint in their experience versus a you and me conceptualization (Street, Couper, Love, Bloch, Kissan, & Street, 2010).

Couple identity. Although we have individual identities, when in a romantic relationship there is a couple identity that is constructed socially. The best fitting definition of couple identity for the present study refers to couple identity as "the partners' sense of who they are as a

unit” (Miller & Caughlin, 2013, p. 64). Couple identity can be defined by the cognitive shift that occurs in an individual’s perception of themselves “from that of an individual person to that of part of a couple” (Badr, Acitelli, & Carmack Taylor, 2007, p. 213). At any given point, an individual is “at once both an experiencing agent and socially constituted and constructed” (Fergus & Reid, 2001, p. 386). This dyadic relationship is dynamic and interweaves both identities of the individuals that compose the dyad.

There are multiple contexts by which we exist as individuals in this world. What is experienced as real can be defined by our interactions with the natural world around us in its physical sense (*umwelt*), the everyday relations we have with those around us (*mitwelt*), and the intimate relations we have with ourselves and the significant others in our life (*eigenwelt*) (Pervin, 1960; Spinelli, 2006). The nature of being in each of these dimensions is an intricate dance between the inner and the outer world. Specifically the *eigenwelt* dimension informs couple identity based on the immediacy of the couple in relationship at a given point in time. The “us” dimension is hard to quantify because it is best known between the couple. There is this mutual identity that forms between two intimate individuals as they do life with “a common history of relating, a coherent, relational patterning, or dance unfolds which forms the basis for a couple’s mutual identity or experience of we-ness” (Fergus & Reid, 2001, p. 387).

Within the literature in psycho-oncology, couple identity has been found to partially mediate stressors partners experience due to caregiving. Badr, Acitelli, and Carmack Taylor (2007) conducted a study where they measured 92 healthy spouses who were caregivers for a partner with a chronic physical illness across couple identity, caregiver stress, primary stressors (role overload, relational deprivation) and secondary stressors (role captivity, loss of self, self-esteem, competence). Caregivers reported couple identity partially mediating the effects of

negative primary and secondary role stressors, and fully mediating positive primary and secondary role stressors, between caregiver stress and caregiver mental health. Identifying with the “we” in relationship seems to change the partner’s experience of stress and cancer. Though there have been investigations into couple identity, the focus has been identifying the degree of couple identity rather than understanding the meaning attributed to thinking of oneself as a unit (Miller & Caughlin, 2013).

Age. Most of the studies published with a focus on understanding the relational nature of cancer have a reported mean length of relationship between 24 and 31 years (Fergus, 2011; Fergus & Gray, 2009; Moreira & Canavarro, 2013; Song et al., 2012), with ages therefore being mid to late adulthood. It is possible that many of these individuals have an established sense of we-ness, that may be more apparent simply due to the length of their relationship. However, younger women face different psychosocial issues than older women. Developmentally, most women under 50 “are in a committed relationship, many have children at home, and many continue to contemplate childbearing... many are at the peak of their careers professionally” (Beaucom, Porter, Kirby, Gremore, & Keefe, 2005/2006).

According to Erickson’s life-span stages, at the psychosocial level, individuals in early adulthood (20s and 30s) are at a stage of intimacy versus isolation (Prochaska & Norcross, 2010). To engage in intimacy, individuals need to possess the ability to be supportive and provide affection without losing their own sense of self. An inability to do this may result in social isolation. At this stage of life, according to Levinson’s (1986) model of adult development, they are in a life structure of shifting between novice and the mid-era phases. Life structures encompass the different roles, relationships, conflicts and balancing an individual does

at certain points in life. In early adulthood, it is a time of transition with the era spanning from 17 to forty-five years of age (Boyd, Bee, & Johnson, 2009).

In comparing older and younger adults, significant differences in emotional stability can be seen based on the life context of the individual. Older adults experience fewer stressors overall and report that stressors had less of an impact on their daily routines (Brose, Scheibe, & Schmiedek, 2013). With a cancer diagnosis, these individuals are facing secondary aging versus primary aging where the changes are due to disease versus age-based physical changes that are shared by the wider age population (Boyd et al., 2009). Participants' age is an important factor as there is a gap in the literature to the experience of younger partners facing cancer.

We-ness. Skerrett (2003) reported that in regards to breast cancer, couples who were able to identify the cancer as “our problem”, were better able to have a direction for their coping efforts and establish a meaning structure for their experience both individually and together. Karen Fergus has built off Skerrett's findings in her work with couples facing breast and prostate cancer (Fergus, 2011; Fergus & Gray, 2009). An experience that emerged out of Fergus' work with prostate cancer couples was the experience of a communal body. The purpose of the study was to understand “how the experience of prostate cancer affected the couple's intersubjective identity and unique dyadic culture and how, in turn, the couple's identity and relationship culture influenced their adjustment to cancer” (Fergus, 2011, p. 97). Couples described being a couple through this experience as an interwoven self (Fergus, 2011). One wife experienced such empathy that she had a dream that she underwent the surgery that her husband was to have. She described it as if she had gone through the experience and came out of it thinking that she had a feeling for what her partner was feeling. This is described as the intersubjectivity of the couple and the depth of connection that is present. Fergus (2011) suggests that not only is viewing the

illness as a “we” enhances couple adaptation to the illness but that identifying as a couple with a strong sense of “we” can act as a protective buffer in responding adaptively to the illness.

Fergus’ suggestion is similar to Acitelli and Badr (2005) who suggest the partners’ relationship awareness and appraisal of the chronic illness as “our illness” positively influences the wellbeing of the relationship. They describe four forms of relationship awareness: explicit thinking, implicit thinking, explicit talking, and implicit talking. It is at the implicit thinking dimension where the individual takes on a couple orientation and thinks of themselves as a *we*. “When the relationship becomes part of one’s identity, the increased identification will be accompanied by greater investment in the relationship because it reflects upon the self” (Dalton, 2005, p. 5). In light of the partner’s sense of who they are as a unit, the definition of we-ness put forth by Fergus and Reid (2001) is adopted for the present study as “partners’ often nonconscious participation in a highly implicit, collective reality that is both shaped by, and integral to the personal identity of each member of the couple” (p. 387; see also Reid, Dalton, Laderoute, Doell, & Nguyen, 2006; Reid, Doell, Dalton, & Ahmad, 2008; Sayre, Lambo, & Navarre, 2006).

The dominant model in psycho-oncology in regards to couples is a dyadic model. Identifying the couple as the unit of study, and examining the interplay between the individuals in the relationship as they cope together with a cancer illness, are the main tenants of dyadic coping in psycho-oncology (Manne & Badr, 2008). However, some of the literature is beginning to explore an additional component of the dyadic model of identifying the couple-ness as “we” (Acitelli & Badr, 2005; Dalton, 2005; Fergus, 2011; Fergus & Gray, 2009; Lewis et al., 2005; Lyons et al., 1998; Reid et al., 2006; Reid et al., 2008; Street et al., 2010). In this conceptualization, it is a focus on the implicit, underlying, unifying togetherness conceptualization of the couple (see also Sayre et al., 2006). Psycho-oncology is one area of the

literature where this distinction between individual and dyadic conceptualizations of the couple and their coping has been identified.

Purpose of Current Study

The current study adds to research on couple identity by exploring the *you and me* and *we* experiences while a couple has faced breast cancer. The central hope of this project is to clarify and add depth to the current understandings of the experience of romantic partners of cancer patients, recognizing they have important stories to tell.

Research on partners of people going through cancer has tended to define the relationship in various concepts but most commonly identified as coping. This study seeks to explore wider relational contexts of male partners of women facing breast cancer. Phenomenology is particularly effective in exploring alternatives to conventional formulations of constructs. Thus the research question for this study is “what is the relational experience of men as partners of women facing breast cancer?” In gathering partners' stories, this study helps clarify and enrich our understanding of couple identities in the context of a health crisis.

CHAPTER 2: METHODS

Design

This study is an investigation nested in two ongoing randomized control trials of online treatment programs for cancer patients and their partners. These studies examine support to female breast cancer patients (Moving Forward with Breast Cancer; J. Stephen, personal communication, October, 2012) and couples (Couplelinks; K. Fergus, personal communication, October 2012) through an online medium. The Moving Forward with Breast Cancer (MFBC) study compared and tested the efficacy of two forms of internet-delivered support groups for enhancing the adjustment process after the women have undergone primary treatment for breast cancer. The Couplelinks study examines a treatment designed to strengthen couple relationships and coping, focusing on young couples and the unique challenges they face. The present study has recruited participants from each of these studies. A subsample of the MFBC participants had male partners who were recruited for the follow-up investigation. The male partners from the Couplelinks study were invited to participate in a follow-up investigation. The current qualitative study is nested within these two studies to the degree that these men were not completely naïve to the psychosocial matters of cancer as research. The purpose of this study is to understand the lived experience of male partners of women facing breast cancer. In emphasizing “the things in themselves”, the research team adapted the principles of dialogal phenomenology to inform the method used for present study (e.g., Halling, 2008).

The phenomenological method is appropriate for the research question “what is the relational experience of men as partners of women facing breast cancer?” As stated in the literature review, male partners of breast cancer patients have not been researched in as much detail as the patients themselves. The phenomenological approach emphasizes “returning to the

psychological subject matter with an open attitude and evoking fresh, detailed descriptions that capture the richness and complexity of psychological life as it is concretely lived” (Wertz, 2005, p. 176). The focus of this research study is to go back to the men’s experience, being encouraged by research on dyadic coping, communal coping, post-traumatic growth, and so on. The aim is to hover “low” over their experience to revisit the depths, richness, and meaning behind what they are saying, rather than trying merely to apply different constructs to their experience a priori. The emphasis is on giving voice to the man’s experience of being a partner. The relational context for this project is the experience of partners of women who have received psychosocial treatments in their cancer recovery. Couples can share joint experiences in everyday life in the same fashion that individuals can experience aspects of their lives as separate or unique (Halling, 2008; Wertz, 2005; but cf. Sayre et al., 2006). Although some psychological theories assume all human experience is exclusively individual, thereby requiring that experience of relationships must be built upon individual experience, phenomenological models allow for the possibility of shared experiences.

Dialogal phenomenology emphasizes dialogue among researchers as an important strategy towards engaging understanding and gaining insight into participants’ meanings. Birthed out of an observation in psychological research of the gap between the objective and subjective data, dialogal phenomenology seeks to merge research and clinical practice by building a sense of community and connection (Halling, Kunz, & Rowe, 1994). This merging of knowledge from the subjective and objective is done through reflective conversation that both creates community and is grounded in community. The focus of the dialogue goes beyond the content of what is said, to what is meant by what is said in an attitude of openness. This process oriented dialogal strategy focuses on emergent processes rather than steps identified a priori. A

dialogue, is “a focused conversation, whether with one person or with several people, that leads to a deeper personal understanding of, or insight into, an important aspect of our lives” (Halling, 2008, p. 165). The analysis is a process of fostering dialogue whereby the research team is constantly in dialogue in regards to the phenomenon. This dialogue has been present from the inception of the study through to the writing up process. The dialogue has three levels by which researchers engage and through which they move during the conduct of dialogal phenomenology: preliminary, transitional and fundamental dialogue (Halling, Kunz, & Rowe, 1994; Halling & Leifer, 1991). For the purposes of clarity, the dialogues are presented sequentially, however it should be noted the circular and fluid nature that these conversations embody that are neither sequential nor hierarchical in practice.

The research team starts in preliminary dialogue with the focus of discussions on the individuals’ perspective of the phenomenon under investigation. This discussion involved writing out and dialoguing about our own preconceptions of couples, relationships, and the impact of illness as it pertains to the phenomenon at hand of being a partner to someone facing cancer. Please see APPENDIX A for a summary of the researcher perspectives taken from this initial dialogue. This type of dialogue is broad and encompasses preconceptions, theories, and personal stances. Drawing on preliminary level reflections, transitional dialogue emerged as team members take on a more direct and immediate approach with the phenomenon. This dialogue took shape throughout the research project and appeared strongly in the formulation of the interview protocol and in the carrying out of interviews. Initial impressions were discussed among the core research team (supervisor and principal investigator) following each interview. Transitional dialogue was also present in the conceptualization of meaning units and interaction units where themes drawn from these men’s experiences took concrete shape. A third level of

dialogue, fundamental dialogue, arises as personal accounts of the phenomenon interweave together in the research process. The themes brought forth in transitional dialogue are built upon in this phase, continuously informed by the data. This level of analysis occurs in the formulation of the within-case themes and the shared themes.

When working in dialogue, it has been found that the multiple perspectives brought forth can aid in moving past obstacles or impasses, disagreements can be used constructively, and it can be easier to find words to describe what has come to be the understanding of the phenomenon (Halling, 2008). In addition to these, examining the relational focus of being a partner of a woman facing cancer, the dialogal strategy is particularly apt in clarifying the relational nuances. Much of what is shared by the partners can be taken multiple ways, and to get to the heart of what they are sharing, requires cycles of dialogue, being challenged by another's perspective as an aid to bracketing preconceptions and immersing ourselves in the data.

Researchers unfamiliar with phenomenological research sometimes perceive the methodological processes described above as unclear based on the openness needed for the principles to be flexibly applied across different research settings. APPENDIX B is supplied to systematically illustrate after the fact how the principles presented above were applied over the course of this particular project. The procedures described in the schedule could only be described after they emerged during the course of the project. It should be noted the procedures outlined in APPENDIX B are not intended to be offered as a reified set of procedures to be employed in future research.

Recruitment

The recruitment process itself embodied the core principles of dialogal phenomenology.

Working collaboratively as a team, with an attitude of openness, thorough discussion of the kind of people to approach to obtain descriptions began the process. Purposive sampling was conducted in recruiting male partners from the two studies. For the Moving Forward with Breast Cancer (MFBC) study, a subgroup of female participants who had identified being in a committed romantic relationship at time of participation, were mailed an initial letter of contact inviting their partners to participate in this study (see APPENDIX C). An initial letter of contact was mailed out to 11 male participants who had completed the Couplelinks study from the Ontario team (see APPENDIX D). The principal investigator conducted a follow-up phone call for the MFBC participants; to answer any questions they may have and invite their partner to participate in the current study. A research assistant with the Couplelinks team in Ontario made the follow-up phone call to those from their study. Two participants from the Couplelinks study and eight male partners from the MFBC study took the invitation to participate. At the time of interest, an interview date and time was established. For those in the Greater Vancouver Area, options of an interview over the phone or in person were given. In total, three of the 10 interviews were conducted in person and the rest were conducted over the telephone.

The inclusion criterion is the same as the Couplelinks and MFBC studies. Participants are male partners of women who at the time of participation in MFBC or Couplelinks investigations had received a diagnosis of invasive breast carcinoma in the last 36 months (e.g. non-metastatic), or ductal carcinoma in-situ, at or before the age of 40, and who had completed or are nearing the end of active treatment.

Participants must have been at least 18 years of age, been able to speak English, and been able to provide informed consent. Participant selection included openness to all levels of socioeconomic status, ethnicity, race, and religious affiliation. Exclusions from the current

research were those who had been diagnosed by a professional of a mental illness that may have interfered with their capacity to benefit from the program (e.g. suicidality, psychotic disorders, substance abuse, spousal abuse, etc.) A committed intimate relationship is the phenomenon in which the current research is most interested and therefore, couples were selected to be in a committed, heterosexual relationship (e.g. married, cohabitating, engaged, or steadily dating for at least six months at the time of participation).

With recruitment from two ongoing studies, we set a target of 10 interviews to be conducted. Once recruitment started, there was strong motivation coming from individuals desiring to participate in the study. A robust sense that this population had not been heard arose during the recruitment process, and that sense seemed to kindle a desire for them to participate. There were more volunteers than the 10 interviews scheduled; with some prospective participants asking to be put on a list should one of the 10 interviews we had scheduled fall through. As the relational experience was the focus of the study, we desired to have a broad scope of participants to understand this phenomenon of being a male partner to a female going through breast cancer. Sequencing of the 10 interviews was conducted based on the primary principle of purposive sampling and purposive sequencing. Since everyone was motivated, we wanted the broadest scope of individual experiences as possible to capture the range of experience. Focus was on contextual richness, paying attention to tone and fluency of the interview as well as some background information. For a contextual life story of each of the seven participants, please see APPENDIX E.

Procedure

The process of dialogal phenomenology cannot be put into specific steps a priori. Guidelines for the rigorous conduct of dialogal phenomenology are referenced in Halling et al.

(2006, p. 264-265). These questions provide the essence and principles of dialogal phenomenology the research team embodied. The following procedures are described in the ways in which dialogal phenomenology was implemented in this specific project.

Before the scheduled interviews, the participants were e-mailed the informed consent (APPENDIX F), and a demographic questionnaire (APPENDIX G) to be completed and returned via e-mail before the time of their interview. For those whose interview was in person, the forms were handed in to the primary investigator prior to the interview commencing. At that time, a preparing for the interview paragraph (APPENDIX H) was sent to participants to help them start thinking about what they would like to say based on their experience. This was done to support reflective practice, in approximating the gold standard of multiple interviews (Polkinghorne, 2005). One interview is still considered sufficient and therefore to aid in maximizing the time spent in the interview, a priming sheet was provided to participants pre-interview. For those from the MFBC study, many of them had not had the opportunity to share their story in depth and this was the first time they were given space to share how they were impacted.

The interviews were conducted between March and May 2013. As a thank-you for participating, a \$75 gift certificate to a restaurant in their area was provided as a date night for the couple. This gift certificate was mailed out the week of the interview for those interviews via phone and handed to the participant at the end of the interview in person.

The interviews were carried out by the principal investigator and ranged in times from 35 minutes to one and a half hours. An open-ended question started the conversation with follow up probes and questions to help get a better understanding of the partners' experience (APPENDIX I). Directly after the interview, participants were debriefed (APPENDIX I), and consent towards forwarding them an online component to the debriefing process via e-mail was obtained.

Recording and storage of interviews. Interviews were audio recorded and stored according to the standard of at least two layers of protection, including encryption and physical barriers.

Data Analysis

Though the studies from which this project recruited participants are yet to be completed, based on the nature of the question posed, it stands alone and analysis proceeded without reference to results from the first phases of the project, which have yet to be written. The analysis framework for dialogal phenomenology was summarized above in the description of project design. The interviews were conducted in a safe environment for the participants. The interview process being open-ended (APPENDIX I) allowed participants to focus on personal individual experience and/or shared experience. The following descriptions illustrate strategies employed in support of the research team dialogue (cf. Giorgi & Giorgi, 2003).

Meaning units and interaction units. Once interviews were transcribed, the transcriptions were coded using meaning units and interaction units. Meaning units were considered complete thoughts within the interview (e.g. “the fear of losing her”, “your love life taking a pounding”, “gotten pretty good at being able to carry on”). Throughout the research process, it became clear that *the way* in which the men shared their experience of being a partner was impactful over and above *what* they were explicitly saying about their experience. Based on this observation, interaction units were identified in the transcripts. An interaction unit was thus identified when the interaction was central to their experience over and above the content of their statements (e.g. the choice to conduct the interview in a separate part of the house than where his partner was and could not overhear us, emotional intensity expressed at specific times in the interview, etc.). Interaction units were present throughout the interviews of the men.

Thematic analysis. Primary themes (within-case themes) were formulated out of the meaning and interaction units for each transcript. The research team sorted the meaning and interaction units based on what “hung together” in regards to the content and process that was captured in the meaning and interaction units. This process was conducted for each of the interviews separately. A primary process theme was formulated in one interview, as the interactive units were imperative to the understanding of the man’s experience. Once all the primary themes were framed, shared themes (across-case themes) were then formulated from review and reflective integration of all primary themes. The sorting of primary themes to shared themes resembled the same process as the sorting of meaning units into primary themes. One process theme (formulated from interaction units) arose from among the primary themes.

In the final shared theme formulation, there were both concrete themes based on verbal content from the interviews, and a process theme, based on the importance in the process of the way in which these men shared their experience. After formulation of the themes themselves, we then clarified the relationships among the themes (post-structural analysis). Quotes were selected from the transcripts to add thick descriptions to the theme formulations.

The essence of the analytic process was dialogue among researchers. As analysis of the data started, the thesis supervisor’s role changed from coaching to dialoguing. Simply stated, coaches do not perform but support the performance that the athlete then performs. This was true of the process up until this point. In dialogue, the conversation becomes the performance itself and therefore requires active participation among members of the research team. The principles of trust, commitment to understanding the stance of one another, acknowledging our own biases and having them pointed out by one another, are core principles set out by Halling (2008) for dialogal analysis. These principles were already established and inherent in our conversations as

student and supervisor (please refer to Halling, Leifer, & Rowe, 2006, pp. 264-265, for 15 questions as guidelines).

Descriptive scope. The ten interviews were sequenced in order of interviews that contributed to the broadest scope in regards to experience (refer to APPENDIX B). Then, decisions of how many interviews were needed to be included in analysis, to undergird the descriptive scope that was achieved by the shared themes, followed. Criterion for satisfying the inclusion within analysis was conducted in consultation with another graduate student who read through the candidate interview. The question asked was whether the eighth interview broadened the descriptive scope or deepened the grounding for the shared themes derived in the first seven interviews analyzed. Based on our previous conversations, we had to ask the question of whether or not the eighth interview needed to be in the descriptive scope or not. At this point we brought in another partner with a fresh perspective to clarify this decision. After sorting meaning units of the eighth interview into the themes formulated, it was concluded that this eighth interview (and sequenced ninth and tenth) did not add to the scope already formulated, and thus were not included.

Rigour

Halling et al. (2006) identify 15 questions to guide researchers in conducting research from a dialogal phenomenological stance (see p. 264-265 for a full description of the openness required by the research team). Although we did not rely on the formulation of these 15 questions, as a research team in reviewing them, they adequately characterized the process employed in the current project.

As stated above, there were more volunteers than were needed to address the research question. There was a strong response from male participants in motivation for their voice to be heard. There were some men who came forward after we had completed our interviews asking to

be put on a list should one of the ten interviews we had scheduled not taken place. This contributed to the broadness of descriptive scope achieved.

Purposive recruitment allowed for diversity in context and allowed for broad contextual richness to emerge. For example, there was one case where his wife's reoccurrence of breast cancer had just been made known before the phone call, yet he desired to share their experience. With participants being given the option of where they would like the interview to be conducted, they were given the opportunity to choose the best location for them to participate in an environment with the greatest degree of openness and clarity. For example, in one of the three interviews conducted in person, the participant chose to have the interview conducted in a separate area of the house away from his partner. Whereas in another case, the participant chose to have the interview conducted in his home where his partner sat in on the interview, and participated. Though at first, unsure of how this would affect the data, once the interview was conducted, it was clear richness of the data was gained in having them both participating in the interview.

Relational phenomenology. The quality of relationship between the participant and the interviewer was established to provide safety and sensitivity to the experiences of the participant. The interviewer was trained in counselling and psychotherapy, providing her with skills for setting up interviewing relationships of this nature.

For the integrity of theme formulation and post-structural analysis (Giorgi & Giorgi, 2003), a strategy of triadic reflexivity was employed to help maintain the breadth of perspective on the research team (Klaassen, McDonald, & Graham, 2004). To clarify the *we* distinction as it is at the heart of this project, a sororal graduate student was recruited as an analysis partner. Her role as analysis partner was to act as an individual identity contrapuntal voice (see Gilligan et al., 2003). After reading and becoming familiar with two transcripts, as partner, she helped clarify

and emphasize the you and me elements of the analysis by drafting individual versions of the primary themes based on some aspects of those participants' experience. As the counterpunal voice to the we framework, she highlighted the individual level thematic patterns aiding the clarification of personal and relational aspects of participants' experience.

Once a draft of the shared themes was formulated (as a result of dialogue among the core research team), the same analysis partner was brought in during the discussion of the shared themes. A focus at this point was clarification of the formulations of we-ness in the shared themes. The reviewing of the formulations of the shared themes was informed by the theme descriptions, but also from her familiarity with two of the seven transcripts.

After the themes had been formulated, an additional graduate student was brought in as interrater to check the sorting of meaning unit to the final thematic constellation. This included sorting of meaning units into the final theme formulation. Comparison of his sorting to the principal investigator informed the final theme formulations.

CHAPTER 3: RESULTS

Narrative of the Experience

Across the interviews, there was a strong coherent narrative of the male partners' experience. Breast cancer's emergence in their lives occurred in an unexpected way especially due to age and stage of life. The process typically started with diagnosis, surgery, chemotherapy, and then subsequent treatments whether that was radiation, hormone therapy, and/or reconstruction surgery. Although in Canada we have access to some of the leading treatments and care for cancer, many of the men still expressed the overwhelming tone taken by the entire experience throughout treatment. The efficiency of the process can be overwhelming for the family as there is not a lot of time for them to process what is occurring. After the initial shock, many focused on the practicalities that needed to be taken on in their families and described doing what *had to be done*. Moving forward, many expressed difficulties in certain areas that continue to date. However many expressed feeling closer as a couple as a result of the experience. Cancer continues to impact their daily living and can be seen as a separate entity within their relationship. It should be noted, what came alive in their interviews was the interactive intensity of this shared experience. It became helpful to communicate the interactive intensity through the following themes.

Within case themes were compared and condensed into seven shared themes: crisis and aftermath; children, parenting and fertility; personal impact; breast cancer as a shared experience; honouring our voices and voice; relational choreography; and the coexistence of positivity and fear nested within relational outlook (see Table 1). Of the seven themes identified, relationship choreography and the relational outlook are two themes in which four and three subthemes fit respectively. This does not mean their importance supersedes the other themes but rather speaks

Table 1.

Themes and Subthemes

Crisis and Aftermath

Children, Parenting and Fertility

Personal Impact

Breast Cancer as a Shared Experience

Honouring our voices and voice

Relationship Choreography

 Roles

 Practicality

 Support

 Intimacy

Coexistence of Positivity and Fear Nested with a Relational Outlook

 Outlook

 Fear

 Positivity

to the patterns of interconnections among themes despite their intrinsic differences. The following are descriptions of the themes that emerged in asking these men about their experience of being a partner through an encounter with breast cancer. These themes reflect the interactive intensity and meaning dimensions of their shared experience. Personal distinctives and typicality patterns complement and enrich these shared patterns. It should be noted the metaphorical language used in the themes is particularly appropriate for conceptualizing these men's experience as it aids in the integration of experience near (descriptive, low-hovering) and experience far (broader theoretical conceptualizations) (see Halling, 2008, Chapter Seven). A concerted effort in proactively maintaining both near and far dimensions of their experience was employed in the use of metaphor.

Themes

Crisis and aftermath. As an experiential anchor, the "crisis" takes shape as both a single overwhelming moment like diagnosis, and also unexpected continuing overwhelming moments of when the reality of what was occurring hit him and the subsequent realizations. For some, when sharing about the diagnosis, emotion was expressed with tears resurfacing, slowing speech, and some halts and hesitations in recounting that time indicating the gravity of the impact the diagnosis had on them. Others were concretely able to describe what they experienced. "When I got the phone call my world just came crashing down because we were not expecting to hear that" (Matt).

Out of the blue she called me at work, I mean she had found a lump previously, but given the fact she was only twenty seven and had gone to her GP and said the odds are so ridiculously small... and then she got the test results back and it was just like everything changed... left work the next day and the year was completely focused on that... When you first get diagnosed and you find out about you know potential side effects of

treatment, it's all kind of a big whirlwind at the start... It's strange I try and look back on things and I don't really have a lot of firm crystalized memories. (Tom)

Other participants described the initial period as shocking, horrible and the worst part of the whole process. Initial thoughts and reactions were of fear and questions:

The first thing was, 'How am I going to raise the kids by myself?' Second... Then you start to think, 'Oh my god, I'm going to lose my wife.' And then it all gets... Then it starts to... Like, those are actually clean clear thoughts because those are your own thoughts and then the other people start putting input into your head and that's where it gets confusing. (Jay)

This crisis continued to unfold based on the uncertain nature of cancer. Despite positivity and taking a proactive stance, there was still a lot that the couple did not have control over. "It just changes you in minor ways because the MS did to a degree, but I think the cancer pushed I even more so. Or I think it has" (Terry).

Aftermath is the decisions and "immediate" changes to be made as a result of the diagnosis. This immediacy is more felt immediacy not always temporal. Decisions also included surgery and treatment options and what the next course of action was for them as a family. This theme carries with it uncertainty and the ongoing nature of the crisis. One partner described cancer as being a third entity within their relationship daily impacting future decisions. For Jack and their family, it was practical decisions of whether or not to move back to the country they came from. For MJ, who was dating his partner at the time, he had to ask of himself whether or not he was going to stay in the relationship:

You need to figure out basically if you're going to be in with that person for the battle or pack your sh** and get out. Not in a sense of a hatred thing but you need to figure out what you're going to do.

As the starting place in the cancer narrative, crisis and aftermath are anchors to these men's experience. Crisis and aftermath set up the rest of these men's experience and the themes derived from those experiences. The rest of these men's experience, and the rest of the themes are built upon the pivotal point of the crisis experienced by these men.

Children, parenting and fertility. As younger couples, and in the childbearing years, most of the interviews made reference to children either present or future. Based on the age and stage of these individuals, children and parenting were salient to the experience of these men. Many found breaking the news to the children hard, and desired to do it in a way that would not cause panic. Maintaining normalcy around the house became an important goal for many of the participants with children.

The hard thing with the kids though was trying to explain to them in a way that you're not going to panic them or anything.... it was important to keep things as normal as possible for them. Also, to let them know so much more about what's going on and what they can expect. (John)

When my wife got diagnosed, the children were 9 and 5 um and she wanted to explain to the kids that she would be going through some changes so as... not to concern them. I suppose our relationship with the kids has changed a bit. We support each other if that makes sense... I don't know how much a 5 year old can support a dad but... (Jack)

Another partner mentioned issues that have arisen in their co-parenting as a result his wife's personal change due to the cancer and thus disciplining the children has shifted.

She doesn't want to discipline because life's short. But they've still got to have that – in my opinion – they still... They didn't go through the cancer but they still have to have that upbringing of discipline.... And she's getting that, so she's coming over onto my page a bit and I'm coming onto her page a bit. (Jay)

Fertility came up in two cases, one where the couple already had one child, and the other where there is the unknown towards the possibility of children. Decisions have to be made quickly after diagnosis if measures are to be pursued to preserve the options of biological children in the future:

That was one of the hardest non-cancer decisions we had to make is, ok, we envisioned a big family: multiple kids, a big home. And we had to all of a sudden change our outlook on how the family is. (Matt)

Heaven forbid that we can't have kids, that's going to be a tough road to go down. I think everything is going to be ok, but there's definitely some larger issues looming. (Tom)

The breast cancer narrative for male partners is grounded in family. Family means different things to different couples as described by these men. No matter their situation, whether parenting, family planning, or fertility concerns, family is intrinsic to the breast cancer narrative.

Personal impact. Many of the men recounted their reactions to and the ways in which the event of cancer impacted them and their partner. "Impact" is also taking a step back and observing the ways they pulled things together even while things are unfolding. Impact included both change and continuity. For some the process meant personal transformation in one way or another. One partner gained a greater awareness of his emotions and became able to express them more freely now than previously. Others described regrets about way they handled the situation, for example, in not being as involved or in recognizing that their coping was "busying themselves" instead of facing what was happening directly. For others, their perspective shifted:

I used to see these women with the head-covering scarf and think, 'Oh that woman – she's fighting cancer right now. Oh it's too bad.' But now I look at it and I think, Hey here's a person who's in for a hell of a fight here and she's putting herself out there and

saying, 'Hey look at me, I'm not... This is something that happened to me but I don't have to sit here in a corner and hug my knees about it. I can be out... I can still be doing all this stuff. It's not going to affect me-take that away from me'. (John)

Working as a paramedic, going to people who are going through similar circumstances, I can empathize with the partner and I can certainly relate to the patient. The whole process has made me a little- it's made me a little more emotional. (Jack)

Some men told about maintaining positive outlooks or hope. For others, continuity appeared to take the shape of "stubbornness," rigidity, or tensions in the couple relationship. The men commented on this continuity as not always being helpful for their relationship or for the emotional wellbeing of either of them. "I don't think I was ever scared or any of those things really... I know she resents some of my attitudes cause I guess I was always a lot less stressed about the whole thing than she was" (Tom).

Personal impact informs the cancer narrative as it is not just reactions to the event of cancer, but it's the shift experienced through the struggle these men experience in working with the reality of cancer in their life. Personal impact is a process unfolding over time, both welcomed transformation and grieved loss; both rigidity and healthy stability.

Relationship choreography. This theme highlights the way a couple lives with "the cards they are dealt". As a couple, a dance is created between them regarding how they live with cancer. Within their relationship changes occurred and new steps needed to be created to adjust and accommodate the presence of cancer. As co-creators, the couples shape and inform one another's next moves. Within the overall dance, roles are dynamic, practicality is grounding, support is contextual and intimacy learns a new move.

Roles. With roles being dynamic, many of the men found themselves taking on differing roles than they normally carry out. The male partners commented on their own role within the

relationship as being one of supporters. For some that meant doing research, being her communications liaison, caregiving, and accompanying their partners to treatments, tests, and doctor's appointments. They expressed feelings of powerlessness and helplessness. For some this was related to practicality in actively taking over tasks that was apart of their partner's role before cancer. For most of them a sense of responsibility kicked in and they did what needed to be done at the moment:

It's my job to support. That's it. What else can I physically be? I can't give her a kidney.

I can't give her a thing. I can do nothing except let her know that I'm there for her. (MJ)

When she was going through her chemotherapy, I felt it didn't matter what I was going through that I was there, she was the focus, and I was to support her. (Jack)

If I think back on it, it was more a sense of responsibility kicked in and you just do what you got to do... honestly I think my role was more one of just kind of being more steady and supportive. (Tom)

With the dynamic nature, sometimes the partners perceived that they took missteps in their role either overstepping in their caring and not giving their partner what they really needed at that moment. For some that meant taking a step back from doing everything for their partner, and for others that meant taking time to just sit and be and continue to be in relationship with their partner.

Practicality. In doing what needed to be done, the partners expressed practicality as being grounding. It was orienting to be able to do something where they felt like they were helping out. For many of them, their roles shifted to include tasks that the women usually had done:

I'll come home from work and then, 'Ok, I've got to get dinner ready, got to clean up from that, got to get lunches ready for tomorrow and got to get the kids off the bed'. And then anything else that didn't get done – you know, keep laundry moving through and

then whatever else and time there might be. You know, that's usually 8:30, 9:00 so I'm like, 'I'm kind of done in now!' (John)

Sometimes the practicality was carried out in response to emotional turmoil. The men often kept their own emotions from their partners, as they did not want to cause the women more distress. Most of them acknowledged that the women usually did find out, and did not appreciate their choice.

There's only one occasion where I've kept something to myself so not to upset the wife- not to concern her cause I know she would get all emotional. But she found out anyway so it doesn't matter. (Jack)

I kept my emotions from her for a long time and it turned into a bit of a battle too because she wants to know... she wants to be there for me. And I'm kind of the guy that wants to keep it away from her. (Jay)

Support. In all the interviews, the men spoke of support as crucial to their experience. For most of them this involved family members, either immediate family being there to support one another, or extended family. Other support came from friends who would bring over meals or take care of children; from the medical system being open to requests and answering questions; from support groups, individuals with whom they can be open; and having from their own space to escape and process. Each partners' support reflected their life contexts. There were some mismatches in the support offered and the support needed. For some that was mismatches in familial support. For one couple, to facilitate the healing process after chemo, they shut down their house from outsiders. For them, that was needed at the moment to support the wife's healing process. It even meant, that when her cousin showed up (trying to support), they turned her away because it was not the support they were needing or asking for at the time. Both Terry

and John spoke of the mismatches in his desire to support by trying and fixing things and the support his wife was desiring:

I'd be doing so much and then she would get upset about it and say *I can do things still for myself. I'm not an invalid.* So then, I'd take a step back but it was at the wrong time. So I stepped back thinking- fine then, you can do that. But that was the time where she needed me. It was one of those things. It was adjusting. (Terry)

It's hard because when you see any sort of glimmer of anything, like her being up and about to fix herself a bit of a snack, it's like, "Oh hey! Well do this, do this, do this", I was totally misreading it and she would get mad at me saying "I can barely do this and you expect too much of me". It's not, I'm just trying to understand if you can be up and around. There was a series of missteps on my part. (John)

Intimacy. Intimacy within their relationship was often impacted especially as the wife went through treatment. Intimacy appeared as a different move in their dance as a couple. Some men described finding different ways of expressing and engaging in intimacy, for example by pursuing emotional intimacy.

I think [intimacy has] been impacted but we get around that. We realize that it's important in a relationship but it's not everything. I think we remind ourselves of that every day. And as often as we do talk about it, it's important because I think for any young couple that's going through it, it's never going to be the same after you've gone... after the female goes through treatment. (Matt)

I'd like to say I'm not superficial to that [partner losing part of her breast] but I think that would be a lie. But now, it really doesn't bother me. I look at it as I'm the luckiest person on the planet, because she didn't lose a whole breast for her, and to me it makes no

difference. I'm good with it. I'm totally fine with that and I think she knows that which helps. (MJ)

The metaphoric dance of the cancer narrative is the couple's relational choreography of the way they handle the journey of cancer. Some are clumsy some are graceful, others are in sync and others are off beat.

Breast cancer as a shared experience. It was evident after a few interviews and it was confirmed once all were conducted that these men desired for us to hear them saying that breast cancer was a shared experience for them as a couple. It impacted her physically and them mentally and emotionally. Cancer intruded the men's life to a similar extent as the women in accompanying them to treatments and appointments as well as the shifts that were made at home. He says, "I'm in this with her." "You've got to be ready for the road shifts, because that's not just her, that's for both of us" (MJ).

"Fortunately I had a really understanding employer who let me take off as much time as I needed to go to doctor's appointments and go to all 12 of her chemo treatments and all of her radiation treatments and all of the oncologist appointments, and all the surgeon appointments" (Tom).

A couple of the men hinted that breast cancer could bring a couple closer together:

We're always there for each other and I think we never turned our backs on each other and I think, if anything, in some interesting... In some weird way, it might've brought us closer together because we were both going through a challenge together. And I think that's the way we looked at it – is we're doing this together. (Matt)

We were there for each other and when I would start to feel a little bit down, it was starting to get overwhelming, you couldn't be depressed around her. She was always so positive and so upbeat that that gave me the strength to give that back to her when she'd

get that way. So we kind of fed off of each other but neither one of us said a word to each other that we were worried even. (Terry)

They were clear that they knew of couples who separated as a result of the cancer. These couples' shared experience is significant especially in contrast of knowing that other couples fell apart over the course of cancer. Their voice shares the meaning of being a couple in the journey of cancer. For most of these men they saw the possibility that cancer *can* bring couples closer together. Many of them describe this possibility not just as who I am but also, what I do with what we are facing and also, who we are as a couple.

When we stay close and listen descriptively to what these men are saying while sharing their experience, we-ness emerges. The relational context for some is more adequately described as a you and me relationship, and for others it is a we . For a subset of these men, their unfolding experience highlights a shift from a you and me identity to a we. A continuum of the way in which these men share about their experience emerges. In the cancer narrative, the theme of shared experience, can be characterized as we, notwithstanding the fact, that some of them are describing a primarily you and me relationship.

The shared aspects of the experience sometimes focused on the couple but in other cases included larger family connections. For Jack, for instance, the relational shifts included their children participating in the family as a unit, including supporting one another and participation in shared activities as a priority. Their couple identity was, in Jack's account, deeply intertwined with their sense of themselves as a family unit.

Honouring voice and voices. In addition to saying they shared experiences as a couple, these men also showed what it is like to be a couple in the ways they talked about their relationship. This theme was drawn mostly from interaction units and rather less from meaning units (see meaning units and interaction units under data analysis in the methods section above).

For instance, when the men talked about their partners' strength as a woman in facing the cancer, they clearly showed a key quality of their relationship as a couple. For these men, their awareness of their partners' strength showed their openness to their partner and thus provides a glimpse into an honouring quality in their relationship. Also some of the men made it clear in the interview how important it was to understand their partners' voice. For example, in describing his partner's desires, one man respectively clarified her desire to bear a child even though children were not that important to him. This theme was also seen in the ways the we-voice was honoured in the interview. For the couple interviewed together, the husband gave an example of their togetherness by explaining the gifts they gave one another for one of their anniversaries.

He starts his story by checking with her to confirm they were on the same wavelength: you know what I'm thinking...I bought half the set [of Japanese dishware], she bought the other half. We built the whole set without either one of us talking to the other" [they were attuned to pleasing one another with the same gift and happened to purchase complementary parts of the gift, showing their connection as a couple]. (Terry)

The simple activities of scheduling and conducting interviews also displayed important features of couple relationships that honoured his voice, her voice, and/or their voice. For instance, MJ decided to have the interview conducted in his space in their home, a converted garage. This location was physically separate from his wife who was also home. On the other hand, Terry requested that his wife be present during the interview as the most appropriate way of interviewing him, as shown by the following interaction unit.

[given the physical layout of their home, their joint involvements and interests, and their 'take' on the invitation for the interview, they decided to include her in the interview while agreeing that the interview was focused on him. Their overall interactions during the interview as a whole confirmed their indication that her participation in his interview

was a natural choice for them that did not detract from his voice in the interview and in fact strengthened and clarified his statements and perspectives]. (Terry)

The processing of honouring voice and voices was just as strongly evident in the way their accounts were shared, i.e. in interaction, as it was in specific comments.

The coexistence of positivity and fear nested within relational outlook. Outlook, fear and positivity arose as themes mutually informing one another. The relational outlook these men embraced was one of looking forward and drawing upon where they have come from. The formation of this outlook is deeply influenced by the role of positivity and the presence of fear in an intense dynamic of interconnections.

Relational outlook. These men described the future outlook for themselves as slowing down, taking a step back, “stopping and smelling the roses”, and enjoying the moments they can with their partner and their family. For many of them, the outlook they assume is one where they live for the moments because of the threat to those moments been taken away by cancer. “We don’t know what tomorrow’s going to bring so we’re going to make today special and that’s how we basically go through life” (Terry). There was a shift in focus for some from material things to the importance and priority to be put on family.

We want to do as much as a family as possible. And I said that I wanted to do that pre-cancer but I wasn’t. I was more working, just trying to get enough money so that we can have that excellent vacation every year. So, I was away from home a lot. And now I try to be home as much as possible – more than I work... Yeah it [cancer] was a really big reset button... I want all the good things that came out of it but I don’t want all the stress that was involved in it. (Jay)

Positivity. It seemed throughout the interviews that the men held onto this positivity, which posed the question of what was informing this positivity. For some it seemed there was a

confidence in their relationship that informed this sense of strength and positivity. This positivity seemed to arise from three different sources providing him with strength: confidence in himself and his abilities, watching her face this bravely, or drawing on the strength of them as a couple. For the partner who reported the recurrence of cancer, he still maintained a positive outlook drawing strength from the previous round, and feeling oriented in how he was to change for the future round. For others we sensed this hope that had no logical reasoning behind it. This hope and positivity was without a specific reason yet still present. Finally there was a layer of the man's personality that this is just who he was – the essence of him and how he views the world is through a positive outlook.

I always tell her that everything is going to work out and we'll deal with it- I mean that's always been our mantra for the whole thing you know, doesn't matter what happens, what happens is going to happen, we'll just find a way to manage it. And that's what we've done up until now and it's been great. Um, and I really have no reason to think that that won't continue to be the case. (Tom)

Fear. The presence of fear was expressed for all men at varying points of their experience. This fear arose out of the unknown of what was going to happen present at diagnosis and continuing now as they were sharing their experience. Questions arose in their minds about what would they do without her and how were they to raise children as a single parent. Experiences shared were of worrying, facing the potential of her not being there, and realizing how lost he would be without her. There were “a few nights of tears because nothing mattered to me more in my own life than my wife” (Terry). There was internal tension with “the fear of losing her... but supporting her through it” (Jack). “Yeah that fear is just always there. It's just always there” (MJ). This fear does not end once they are given a clean bill of health. For all of

these men, based on the time of interview and inclusion criteria for phase one of the research, none of them had reached the five-year survival milestone.

I have to come to terms with knowing that it's a fear that I wake up and I probably think about once a day is, 'What's going to happen if it comes back?' ... It's just a daily reminder that it's a battle you live with every day. For me, it's the fear of the cancer coming back and the fear of... I've got to admit to myself and my wife that I have that fear of losing her because what will it be like as a single parent with a child... I have to remind myself of that. But at the same time I've got to be mindful of the fear my wife lives with day to day. (Matt)

The cancer narrative continues for these couples and they go forward with an outlook informed by their experience, a reflection of the fear that comes with cancer, and the positivity and hope they have going forward with their partner.

Integrative Summary

The overall pattern of themes is first and foremost an expression of the cancer narrative. This narrative is to be taken as a whole with equal attention given to each of the themes. Themes are presented at a descriptive level, with theoretical integration to be expounded upon in the discussion. The themes identified were integral to these men's experience as they are what they chose to share with us as researchers. The cancer narrative cannot be characterized as having separate chapters; there are associations between and across the different themes, though each theme is distinctive and coherent on its own. The way these themes relate to one another can be likened to a six-sided cube. When looking at any one side of the cube, there are three or four sides that can be seen at the same time. When looking at one of the seven themes identified above, there are other themes that come to the forefront. For example, when focusing on

children, parenting, and fertility, themes of relationship choreography, fear, and breast cancer as a shared experience are highlighted as well.

Through dialogue, a conceptual integration of these themes emerged in the metaphoric image of a tornado. Characteristics of a tornado highlight and clarify features of these men's experiences and illustrate how the themes hang together. A tornado is a whirlwind and its sudden, intense nature captures what these men told us about the unexpected nature and crisis experienced at the onset of cancer. The following highlights the convergence of these men's experience to some descriptors of a tornado that emerged out of dialogal analysis. The shape of a tornado has a tight and smaller base with a larger mouth at the top (see Figure 1). At the base of the tornado is the theme of crisis and aftermath – a “source” for the whirlwind. This is a concrete theme emerging clearly as a focused, shared feature across these men's experiences. It highlights a pivotal point for the accounts of these men, fitting the way the research question guided the focus of investigation. Many of their accounts were similar in description of the crisis and their experiences also took on similar patterns in the way medical treatment proceeded. It is from this focused point, that the rest of the themes emerge as they “flow out of” the experience of crisis and aftermath.

As the funnel moves upward, the themes of children, parenting, and fertility; personal impact; and relationship choreography all float and flow within the funnel. Like the motion of a tornado circling, these themes may be mutually present and informative to the process, shaping and informing one another (like the 6-sided cube analogy above). At the very top of the whirlwind, the coexistence of positivity and fear, are nested within the relational outlook shared by these partners. As described above, the outlook these men expressed is directly informed by the fear they experience and the positivity they adopt, despite their circumstances. These

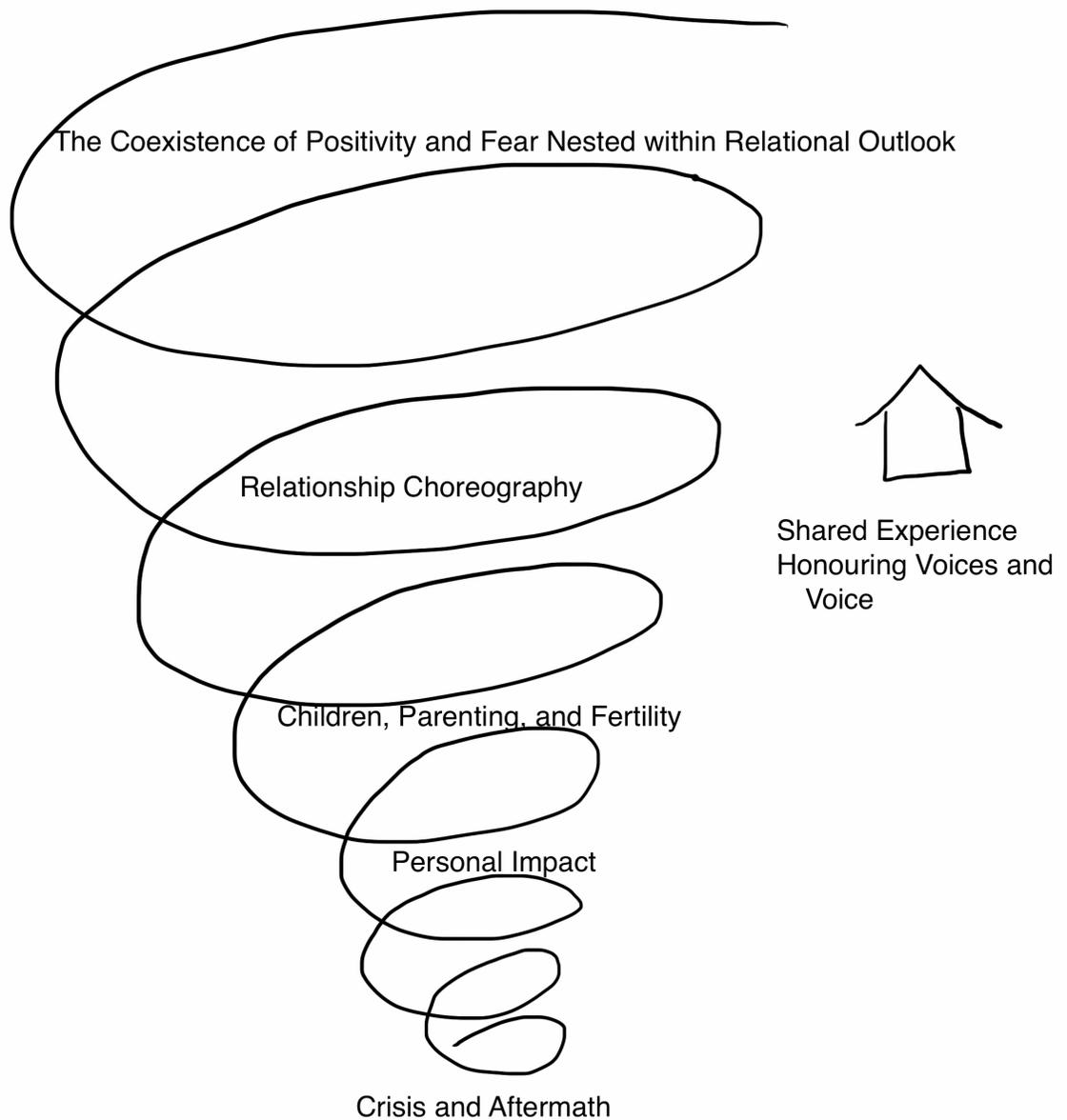


Figure 1. Facing Cancer Together. The picture of men's experience of living through their partner's encounter with breast cancer takes the shape of a chaotic but powerful story. Instability is the source of energy and power for the tornado. It is the colliding of the uncertainties and threats with their resources and strength as a couple.

outlooks are varied and are changing based on the individual, but also on what is to come in the future.

On the side of the diagram, a house represents the relational aspects of the narrative. The two themes characterized by the house are honouring voice and voices and breast cancer as a shared experience. Just as when a house is seen in a tornado flying around all over the funnel, these themes can show up at different “places” and at different “times” in the unfolding process of living through cancer and its treatment. When sharing of the initial stages of the cancer process, the way these men spoke was informed by their desire to let us know that cancer is a shared experience. The way in which they talked about the crisis, or the challenges in children, parenting, and fertility included honouring either their voice as a couple, or his or her voice separately. These themes represented by the house speak to the way in which the content of the other themes within the tornado were shared. These themes of shared experience and honouring voices appeared throughout the different themes and in the participants’ shared experience.

The image of a tornado captures some important features of the powerful, dangerous crisis emerging when couples face the challenges of living with breast cancer. As noted in the diagram, the uncertainties, threats, and resources come together in a whirlwind of activities and experiences that take shape in coherent yet unpredictable ways. The overall tornado is based on the cancer narrative. Though there are novel concepts to be expanded upon in regards to a continuum of couple identity and the shared experience and typicality structure of we-ness, the importance of the cancer narrative should not be overlooked.

CHAPTER 4: DISCUSSION

This present study explored the relational identity of couples facing breast cancer together from the perspective of the male partner. Interviews with male partners of intact couples come together in an overarching cancer narrative of impact on couples and families, while the men experience their place as being unheard. Findings from this project confirm and strengthen results from previous investigations of couple identity when faced with a health crisis like cancer.

We-ness as a Shape of Couple Identity: A Thread in Cancer Narratives of Partners

In line with current literature, these men shared the deep impact of cancer on their lives as partners. The post-structural analysis brings forth an image of a tornado as a metaphoric image, highlighting the interplay of the impact of cancer on many aspects of the men's lives of being a partner during a health crisis. The unifying aspect of their experience was set in the tone of crisis and aftermath from which other themes emerged. The narrative moved through the most salient areas of life that were impacted due to illness as a partner. The cancer narrative continues in their everyday life as they live with an outlook that is mutually informed by their positivity and fear of the future. In addition to a broad fit with research on partners of cancer patients, the results of this project show additional features of ways the couple relationship is entangled with a crisis of health.

As noted previously, a major concept for framing couple relationships, in the context of cancer, is coping and more specifically dyadic coping. Features of coping activities emerged in the stories these men shared. However, a key finding in the present research is the central importance of couple identity in their cancer narrative. In particular, a distinctive presence of *we-ness* and *you and me* forms of couple identity emerged across these men's experiences. For the present purposes, a working definition of couple identity can draw upon Miller and Caughlin's (2013) definition: "the partners' sense of who they are as a unit" (p. 64). The men expressed a

strong sense of who they and their partners are as units. In listening to their stories, what came alive in discussion from their experience was a continuum of couple identities embedded in the broader narrative of the cancer experience. This pattern of results fits in fruitful ways with principles emerging from previous research.

On one end of the continuum there was a distinct *you and me* couple identity quite concretely and explicitly stated that mirrored much of what is stated in the literature: couples are made up of two people. *You and me* is based on an interaction between two people whether mutual, reciprocal, or mediated. Though being in a relationship may be significant to their identity, the sense of who they are as a unit is based on interaction and shared experience and is less based on a shared identity. An example of the *you and me* identity was evident in one interview where the man constantly identified her needs and his needs, and their journey was one based on interaction. He spoke of a conversation once between them where he said to her,

“when all this is done, I’m going to need a break for a little bit and just need to go off and do something.” And it helped me to at least feel that, you know grind away, do what you need to do here and you’ll get a bit of a break and you can condense into a few days and be done. That felt wonderful. I went to Vegas, I went to one or two casinos, I could drink a beer on the street, just wander around and sort of see stuff without any responsibility.

(John)

John’s perspective of his wife’s cancer affected him as well, yet the way he spoke of it, was less of an identification with the relationship, and more of an interaction mediated by the fact that they are married, and both his and her needs could be met.

On the other end of the continuum is a *we-ness* couple identity, a relational version. *We-ness* is understood as two people interacting within a framework of we-ness. They still can interact separately and together with other contexts, yet their sense of who they are as a unit is

less based on interactions, and more on a mutual stance and an identification with the relationship itself (Reid, Doell, Dalton, & Ahmad, 2008). This latter version was explicitly seen through the details of Terry's account and interactions with his partner. Since they chose to have her present during the interview, they were able to participate as a couple (even though they accepted the primary focus on Terry), showing their we-ness in their actions. We-ness emerged just as concretely as did statements about togetherness, closeness, and being "one". One couple identified the strong identification with the relationship from the start of the man's account. When his wife was asked about when she would like to do surgery, he responded by saying "yeah they asked us if we wanted to wait until after Christmas Eve. We said, no just do it" (Jay). In this account, Jay explicitly is identifying their relationship right from the start in the way he spoke of their experience.

With *you and me* and *we* as anchors on different ends of the continuum, there is space in the middle capturing a shift from a *you and me* conceptualization to a *we*. Through immersion in their accounts, this shift was seen in these men's experience as they shared the changing of who they are as a unit in light of this experience. It is a process of coming together, not enmeshment, but a stance in their experience and the way in which they talk about the experience. The shift from a *you and me* identity to a *we* identity was most noticeably seen through both what they were saying and the way in which they were saying it. The way in which these men spoke of their relationships, the attention they paid to making sure that their partner's voice was heard, and the salient features of their experience, all confirm the presence of a shift towards we-ness in their relationship. What was important in their expression of we-ness or the shift to we-ness was grounded in their identity as a partner (Fergus & Reid, 2001; Reid, Dalton, Laderoute, Doell, & Nguyen, 2006), in full harmony with their personal identity. Confirmation of the nature of illness as "our illness" was apparent in their shared accounts. This continuum pattern is not merely a

matter of degree or variation, but it also captures a process of moving from a *you and me* couple identity to a *we*. The reverse direction of process did not fit with the experience of these men. We-ness is not always implicit, and neither is *you and me* forms of couple identity always explicit. These descriptions open up features of being a couple in health crisis that go far beyond notions of coping or managing stressors. These men had not been heard and their stories emphasized the impoverished understanding of these men's experience. In addition to evoking coping processes, the crisis of cancer provoked identity concerns and core aspects of outlook on life. Couple identity was a clear feature of those broader developments.

An interesting aspect of the we-ness identity that emerged from these results was the range of meanings that we-ness embodied. In one account, the meaning of we-ness was family togetherness. His we-ness was expressed as "family" to a much stronger degree than simple marital we-ness. This account broadened our pre-conception of we-ness since we tended to perceive we-ness as being focused as a couple identity per se. Rather we-ness can also take the shape of family togetherness that fully embeds the couple. In asking about their experience, these men shared not only their own story, but their partners' story and their story as a couple as it was embedded in his experience. The interactive theme of honouring voices and voice highlighted these similar aspects of we-ness as seen in Fergus (2011) through the communal body. The experience of we-ness is not just shared experience, or doing things together as a couple, but an interweaving of family identity and personal identity in a pattern of dynamic mutuality.

These results converge in helpful ways with another dialogal phenomenological study that focused on what it means to be a couple (Sayre et al., 2006). Three major themes of coupleness emerging in that project were: relational commitment, transformation of interactions and of the relationship, and connection that transcends a paradox of joining the personal and coupleness. The last theme offers a particularly salient connection with the experience of we-ness as it

emerged for the men in this study. For instance, the results of the present project strongly suggest that this paradoxical feature of we-ness emerges more clearly for some men accompanying their partners through cancer than it does for others. This contrasting set of experiences for different men converges with the Sayre et al. (2006) description of the phenomenon of being a couple. They spoke of being a couple as a process of “becoming”. The couples were on a journey with some being further along that journey than others. The same pattern is seen in the continuum emerging in the results of this study. The continuum captures a process that includes clear identification of some men with the couple, and also includes other men whose identification is more individualistic. Moreover, the continuum describes a directional process with growth and deepening that is oriented towards the we-ness.

In addition, the way these couples expressed their experience was pivotal in understanding their shared experience. The importance of the para-verbal communication, and the meaning behind what is being said were important in regards to what it means to be a couple and the study of intimacy (cf. Halling, 2008; Sayre et al., 2006). Sayre et al.’s study helps to trace horizons of understanding in couple identity that will, of course, need to be further deepened. The findings of the present study continue in the same direction of deepening our understandings of we-ness.

Another key finding these male partners sometimes reported is how surprising or weird it was to realize that they had grown closer with their partner as a result of facing cancer together. Though not all of the men expressed this, it is interesting in understanding more about this experience for those that did. There have been reports of this phenomenon in the literature especially within the context of cancer. Posttraumatic growth (PTG) is the term given to “positive psychological change experienced as a result of the struggle with highly challenging

life circumstances” (Tedeschi & Calhoun, 2004, p. 1). Prevalence of PTG has been reported as high as 42% within cancer couples (Dorval et al., 2005).

Though coming closer as a result of cancer may have been surprising to some men, the literature falls in line with these men’s experience. In looking at intact couples, the literature points out that overall social support and depth of commitment in the relationship, and a presence of the women’s PTG are significantly associated with the male partner’s personal growth (Weiss, 2004). These characteristics are reflective of most of these men’s experience as well. All the men’s partners in this study had previously been involved in phase one research, and so had been exposed to an intervention cultivating support and well being. It is plausible that the PTG of some women contributed to the PTG of some men.

Within the last decade psycho-oncology literature has stressed the importance of the couple facing cancer. Findings in this project contribute to the growing number of qualitative investigations of the cancer experience especially to studies of shared experience when faced with an illness as life altering as cancer.

Clinical Implications

These men told us, and through the motivation of them coming forward, and the great response to the research question, that they feel unheard and left out. When given the opportunity, these men desire to share their story. These men show there is openness to psychosocial questions, interventions, and research. The principles and guidelines in cancer care highlight the importance of caring for the partners in addition to the patients (Canadian Association of Psychosocial Oncology, 2010). These men have been through our system within the past few years and it is evident that in practice, these principles of support are not there for these men. What these men are communicating is seen through the thematic interconnections of this study. First and foremost these men need to be heard. It involves paying attention to, and

including partners into conversations surrounding the patients' care as well as their own emotional needs. As seen above, these men try through practicality to do things to help, however many of them have expressed the reality that they need to learn how to just *be*. Though many studies have suggested educational support groups for couples or for partners of cancer patients, (Bultz, Speca, Brasher, Geggie, & Page, 2000; Manne, Babb, Pinover, Horwitz, & Ebbert, 2004), this is not being put into practice. A goal to strive towards is priming individuals before even a crisis such as cancer hits, so that when it does occur, they may be in a position where they reach out for help. As clinicians by paying attention to their story, their coping, and their perspective will help in aiding the process for these men.

Limitations and Future Directions

The conceptualization of we-ness identified in the present study enhances our understanding of dyadic coping going forward for intact couples. Some of the couples in this study shared how they had seen others leave their partners during the diagnosis and journey of cancer. Our study is focused on intact couples, and although it may well be possible to understand why partners may leave after a cancer diagnosis, there is limited evidence available (e.g., Dorval, Maunsell, Taylor-Brown, & Kilpatrick, 1999) for expanding the contexts of the current project to include couples whose relationships deteriorate and break off. Similarly, expanding contexts for couple identity research should include couples counselling (Reid et al., 2006) and diverse family environments (e.g., Sayre et al., 2006).

Phenomenological research is an important program of research emphasizing a bottom-up process drawing on participants' experiences as crucial data. A stance of openness is a major contribution of phenomenological research, seeking to understand depths of lived experience and breath of horizons with less emphasis on trying to apply constructs to participants' experience. Phenomenological research helps in navigating continued programs of inquiry into the

phenomena under study. This study, in a fashion similar to the report of Sayre et al. (2006), provides only a preliminary, in-depth examination of what it means to be a couple living through an illness such as cancer. What is needed to further these research programs is, in the first instance, a metasynthesis of multiple phenomenological studies to further deepen and expand understandings of these phenomena, and continue to shed light on the continuum of couple processes embracing you and me and we.

The experience near dimension of the results and interpretation (descriptive, low-hovering) are omitted from the theoretical formulations of many non-phenomenological models. From that point of view, the experience near features of the descriptions and results offered here need to be reframed in experience far theoretical models. Since the results and discussion have been formulated true to phenomenology, this experience near aspect of conceptualization is a limitation for those from different schools of thought who desire theoretical models to be exclusively formulated in ways that stay the same in all different situations and contexts. This criterion for theory development is contrary to the core of phenomenology and thus constitutes a constant and ongoing tension in the academic community and in broader literature.

Methodological limitations of the current project included conducting only one interview with each partner instead of conducting multiple at different time points, and conducting interviews with one partner without systematically gathering account from both partners. Further research would benefit from broadening the descriptive scope to include same-sex couples, different cultures, and different types of cancer or illness, etc. Due to the richness present in the couple interview conducted in the current project, and the strength of their couple identity, future research on we-ness and its presence within a relationship may well be expanded in couple-based interview procedures (see Sayre et al., 2006). For future research, giving partners an option of whether to do an initial interview individually or with their partner may be an important

consideration. In this way they are given a choice and those choices may well reflect features of couple identity. Building upon this research, future research could also be done with the action-project method. One development in this project was the strong importance of patterns of interaction and tacit meaning. This set of concerns is highlighted in the action-project method (see Young, Valach, & Domene, 2005). The action project method addresses the “manifest behaviour, internal emotional and cognitive processing, and the meanings that people construct around their experience when describing it to others” (Young, Valach & Domene, 2005, p. 55) through focused conversation and video confrontation. The reflexivity cultivated within the action-project method as well as the sensitivities that may be gained to the other’s perspective would be of value to the future directions of research. Allowing a couple to engage a video confrontation focused on their interaction units promises to be quite productive. This kind of research strategy could focus directly on experiences of we-ness and couple reflexivity.

As part of a broader program of research, further studies addressing theoretical and methodological integration of multiple research questions on couple identity will be required. Given the availability of several relevant programs of quantitative research, continued development of qualitative investigations may well benefit from combinations with mixed-methods designs.

Conclusion

Cancer as an experience is life-altering for many younger couples. Younger couples are in a phase of life that typically includes many responsibilities such as children and career. In exploring the wider relational context of partners of women facing breast cancer, there was a concrete shared experience among them. Phenomenological design and analysis allowed for clarification of the landscape of these partners’ experience. These results descriptively span the range from experience near to experience far. Both experience near and experience far

formulations are needed in the further understanding of humans in relationship. These men told us that being a partner of a woman facing breast cancer is a shared experience. Though this journey is viewed as a crisis that unfolds over time, there is potential for couples to draw closer together as a result. They showed us that a “you and me” relationship framework can shift into a “we” perspective through the process of confronting life-changing health challenges. Some couples reflect a we-ness identity even before facing cancer together, perhaps reflecting previous challenges and growth as a couple. As partners, these men hope to be acknowledged as involved in and affected by their partners’ care and journey with cancer.

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APPENDIX A – RESEARCHER PERSPECTIVES

Perspectives of the core research team. As a relational phenomenology project, this study draws upon resources of a core research team: a female principle investigator and a male supervisor. The perspectives of core team members were formulated and refined during design and conduct of the study both to strengthen team sensitivity to participants' experiences and to acknowledge our engagement in the development of understandings (e.g., Fischer, 2006, 2009). As principal investigator, although I do not have a direct relationship to the topic at hand of being a partner of a cancer patient, my relationship to the topic is informed by my own relationship as a wife, as well as observing couples facing cancer both personally and professionally. I was introduced to the topic of stress and dyadic coping through serving as a research assistant on a master's thesis, and this guided my interests into the phenomena of relationships and stress arising when facing life-threatening illness. I bring clinical experience that contributes to my approach to the interview process. In light of the literature and personal experience I lean toward there being both a *you and me* in relationships as well as an essence of *we*. Facing the mortality of a partner, as well as the changes in the relationship, roles, and all that the illness brings, can be stressful or challenging. Just as all relationships are different, my expectation is that data from interviews are varied and partners' experiences are directly informed by the strength and nature of the couple's relationship.

As a research team, we adopted a relational stance in this project, engaging ourselves, others, and people's accounts of their lives as shaped by relationships with others in crucial ways. We are both clinically trained, helping to shape our sensitivity to tacit aspects of human experience. We are both in committed couple relationships but of different generations, with decades difference in the length of our respective couple relationships. We found our differing developmental life contexts to shape team interaction in complementary ways. We also shared

commitments to advocacy in research, with strong interests in promoting voice among research participants, expanding research in neglected areas, and prioritizing clarity of personal uniqueness even while highlighting shared patterns of meanings.

As supervisor, I am shaped by experience as a husband, father, son, and family member of many strands. My interests in this topic are shaped by varied experiences in health care systems, research settings, clinical practice, and personal life. My research approaches are shaped by engagement in dozens of projects drawing upon quantitative and qualitative paradigms that highlight hermeneutic dimensions of inquiry with critical attention to social justice priorities. In light of literature and personal experience, I approached this project anticipating the emergence of a range of versions of couple identity, including *you and me* and *we*. I am also acutely aware of great diversity in contexts, forms, and understandings of close couple relationships.

APPENDIX B

Overview of dialogal method as it emerged from the first interview through to post-structural analysis

The core of dialogal phenomenology is descriptive rigour as embodied in key principles: stay focused on the phenomenon, listen carefully to what others have to say, and learn to trust your own experience and the group process (e.g., Halling, 2008, p. 168). These guidelines direct an emergent research process through a continual dialectic of experience near formulation and experience-far reflective formulation. The core research team of principle investigator and supervisor jointly and reflexively engaged interview data (recordings and transcripts) and contextual features of each participant's personal background with "the phenomenon as partner in the dialogue" (p. 169). Throughout the process of inquiry, the principal investigator and the supervisor each maintained a research journal. This dual journal was drawn on through the process and aided in the process of enhancing reflexivity as well as sustaining a process of continual bracketing and cultivating engaged, reflective understanding of the phenomenon. The following overview summarizes team activities in concert with guidelines developed by dialogal phenomenology researchers (Halling, 2008; Halling et al., 2006). As noted by Halling and his colleagues, the processes of phenomenological engagement with others cannot be reified into steps, discrete criteria, or externalist accounts grounded in abstractions. The following list is offered, instead, as descriptions of a set of dynamic, multifocal processes grounded in immersion and reflexive engagement.

Step one: Ten interviews established as a target

At the start of recruitment, the research team established ten interviews to be conducted by the principal investigator, recruiting from men whose partners had finished their participation in the study *Moving Forward with Breast Cancer* or men who had participated in *Couplelinks*

with their partner. This decision was made in consultation with a project committee member, Joanne Stephen, drawing on her familiarity with these projects.

Step two: Debriefing of each interview

Conversations of debriefing were conducted by the core research team as preliminary familiarization and conceptualization for each interview. The principal investigator's research journal was also brought in to inform reflections on each interview as they were conducted. Questions asked at this time started the process of sequencing of the interviews to be transcribed: What would it mean for something new to emerge? What's surprising or unusual in this interview? Is there any novelty to this interview? What is the expressive style of this interview?

Step three: Sequencing interviews for transcription

A sequencing of interviews to be transcribed was determined based on the contextual richness and emergent differences among interviews. The first interview conducted was transcribed and the next interview for transcription was chosen on the criterion of selecting an interview with the greatest difference in context from the previous interview. See APPENDIX D for life context of each participant. These conversations started the comparison and understanding of preliminary descriptive scope. Transcription started with the principal investigator transcribing the first two interviews, one being transcribed by the supervisor, and the rest being transcribed by a transcriptionist outside of the research team.

Step four: Identifying meaning units and interaction units in the transcripts

Meaning units were identified as complete thoughts within the transcripts. Members of the research team immersed themselves in the interviews with repeatedly listening to the interviews. Interaction units were a fruit of the emergent process as it became apparent that the way in which these men were sharing their stories was just as important as what they were

saying. Meaning units and interaction units were coded (M- meaning, I-interaction) for each interview.

Step five: Identifying primary themes (within-case themes)

Once meaning and interaction units had been coded for the interview, the research team took the transcript/interview as a whole and asked questions, what is it these men were trying to tell us? What is salient to their experience? Condensing meaning units into primary themes involved a process of asking the question “how do the meaning units hang together?” Units that addressed similar topics or ideas were gathered together into a primary theme.

Step six: Identifying shared themes (across-case themes)

Starting by taking three interviews with their within-case themes, the following questions were asked: How do their themes fit together? Which aspects overlap? What is distinctive? How do they condense? Conversations among the core research team over a period of weeks brought together the beginning of shared themes. Once a list of shared themes emerged, primary themes were brought in from subsequent interviews, comparing and contrasting their themes to the shared themes with further shared themes emerging when needed based on the addition of interviews.

Step seven: Adjudication process: analysis partner as devil’s advocate

As our residential “individualist,” a sororal graduate student was brought in once shared themes emerged to formulate individualist theme counterparts to initial formulations of shared themes. This triadic reflexivity strategy (Klaassen, McDonald, & Graham, 2004) enriched and clarified relational horizons being described by participants. Dialogue among the core research team and this partner helped refine formulations of shared themes.

Step eight: Establishing the descriptive scope of the interviews for analysis

The same sequencing order used for transcription was used for analysis. As the landscape of experience for these men was taking shape, the core team discussed the descriptive scope of the experience being described and whether or not all ten interviews were needed for tracing the breadth traced by these interviews. At the seventh interview, the core research team decided that we had satisfied the criterion for adequate descriptive scope. The eighth interview was then selected as a candidate interview by a fellow graduate student to sort meaning units into the draft formulation of shared themes. (See APPENDIX D for life context of each participant.) The fellow graduate student and the principal investigator discussed his sorting and their understanding of the shared themes, helping to inform the final theme formulations and constellation. The core research team concluded that the eighth, ninth, and tenth interviews did not add to the descriptive scope of the analysis.

Step nine: Post-structural analysis

Once shared themes were formulated, the research deliberated for weeks on how themes were related in the men's experiences of accompanying their partners through breast cancer diagnosis and treatment. Orienting questions asked in this process included: How do these themes hang together? What is the relationship among them? What role did positivity play in their story? From where did this positivity emerge? What role did intimacy play in their story? What is the most connecting aspect of all for these men? Where were the relational aspects emerging in their journeys? The descriptive image of a tornado emerged that encompassed the story of their encounters with cancer as a couple.

Step ten: Analytic partner for we-ness

The same sororal graduate was brought in again as analysis partner in the refinement of descriptive organization captured by the image of a tornado. Dialogue among research team

members at this level informed the understanding through vivid description of we-ness in the context of these men's experience of accompanying their partners through diagnosis and treatment of breast cancer.

Step eleven: Integrative synthesis for process integrity

The drafting of the discussion invoked a process of integration and reflectively synthesizing analysis, formulation, and reporting. This encompassed joint team reflection guided by the fifteen questions outlined in Halling et al. (2006), discussed near the end of the research process as a check of the adherence of our work to dialogal phenomenology. Feedback from committee members was brought into the writing process, based largely on discussion and review of drafts of the thesis document. This reflexive practice also included the preparation and reporting accomplished by the thesis oral presentation. These different pieces came together in a cumulative step of review, integration, and a synthesis of what had been accomplished in this project.

**APPENDIX C – INITIAL LETTER OF CONTACT (MOVING FORWARD WITH
BREAST CANCER)**



BC Cancer Agency

CARE & RESEARCH

An agency of the Provincial Health Services Authority



Dear [Name],

I wanted to thank you again for your participation in the Moving Forward with Breast Cancer study. I appreciate the time and effort that you dedicated to this project.

I would like to take this time to let you know of a research opportunity from our lab that may be of interest to your partner called The Other Half: the lived experience of partners of cancer patients.

Partners of cancer patients have an important story to tell, and we want to hear it. Researchers at BCCA and TWU want to hear from your partner about their experience of being a partner to someone who has been diagnosed and treated for breast cancer.

What does participating entail?

If your partner were to take part in this study, their time commitment would involve participating in a 40 to 60 minute audiotaped interview with a research team member. Their participation will help fill the apparent gap in knowledge regarding the psychological, emotional, and social implications that breast cancer has on male partners and their relationship.

We would appreciate you passing on this information to your partner to see if they would like to participate.

We will be following-up with a phone call within two weeks to tell you more about the study, and to see if your partner is interested in participating. However, please feel free to contact our research team member Jillian through email: jillian.forsyth@mytwu.ca or you can call us directly toll free [1.800.663.3333](tel:18006633333) ext. 4955 or 4965 should you not wish to be contacted.

Thank you for considering this additional opportunity.

Kind Regards,

Dr. Joanne Stephen
Principal Investigator
Patient and Family Counselling
BC Cancer Agency
13750 96th Avenue
Surrey, B.C. Canada V3V 1Z2

APPENDIX D – INITIAL LETTER OF CONTACT (COUPLELINKS)

Dear: [name of male Couplelinks participant]

We wanted to thank you again for you and your partner's participation in the Couplelinks study. We very much appreciate all the time and effort that both of you dedicated to this project.

We are writing to you now, to see if you would be interested in participating in another study that is looking at how breast cancer impacts a couple's relationship from the partner's perspective.

If you were to take part in this study, your time commitment would involve participating in a 1-hour audio-taped telephone interview with a researcher from Trinity Western University, Jillian Hart. This study has been approved by Trinity Western University and the BC Cancer Agency in Vancouver. Dr. Joanne Stephen of CancerChatCanada is supervising this study.

Your participation will help to fill the apparent gap in knowledge regarding the psychological, emotional, and social implications that breast cancer has on male partners like you, and your relationship.

A member of the Couplelinks team will call in the next two weeks to follow-up and see if you are interested in participating. However, please feel free to email or contact me should you not wish to be contacted.

Thank you for considering this additional opportunity.

Warm regards,

Amanda Pereira
Couplelinks Project Coordinator
amandagp@yorku.ca

APPENDIX E – PARTICIPANT’S LIFE CONTEXTS

Participant Backgrounds

The following summarizes a brief life context for each participant. As a part of the background questionnaire, the men were asked to choose a pseudonym to go by in the research. Some chose to keep their own name whereas others provided a pseudonym. All participants ranged in age from 34 to 48, and were together an average of 13 years.

Jack. Jack and his wife have been married for 16 years. Their family includes two children who are both under the age of 10 currently. Jack and his family had recently moved from overseas to Canada for a job opportunity for his wife. Three months after moving here, his wife was diagnosed with breast cancer. After diagnosis they chose to stay here to receive treatment rather than moving back to their homeland. At the time of our interview Jack was completing further training for his job.

Tom. Tom and his wife married two years ago but have been together for 10 years. They were in a committed relationship before her cancer diagnosis, and through the process of her cancer treatment, they were engaged. When she was well enough they were married. At the present time they have no children.

John. John and his wife have been together for 18 years. They have two children. They live in a remote area and had to travel some distance to get to a treatment centre.

Jay. Jay and his wife have been together for 14 years. They have two children. They found out about her breast cancer while she was breast-feeding their second son. Throughout the process they have moved to a different province, and are currently business partners.

MJ. MJ’s interview was one of two conducted in the participant’s home. MJ’s partner discovered she had cancer after they were dating for two years. MJ has had a lot of loss due to cancer in his family and described taking what he had learned by watching other family members go through it to how he approached his partner’s cancer.

Terry. Terry and his wife met through college where she was his tutor. They stressed the importance of their friendship even going as far to say that they have an agreement that if marriage gets in the way of their friendship, the marriage has to go. About one year into their marriage she found out that she had multiple sclerosis. Over the course of her cancer treatment, Terry was let go from his work, and then was in the process of looking for a job while taking care of her.

Matt. Matt and his wife have been together for 10 years. He originally is from the United States and he and his wife met through work. Since then, he has moved to Ontario and they have one son who was born right after Matt’s mother died from a recurrence of breast cancer. Within that year, Matt’s wife was also diagnosed with breast cancer. Matt participated in the Couplelinks study.

APPENDIX F – INFORMED CONSENT

The Other Half: The lived experience of partners of cancer patients Participant Consent Form

I. Who is conducting this study?

Principal Investigator

Joanne Stephen, PhD
Patient and Family Counselling Clinician
BC Cancer Agency
604-707-5900 ext 4960

Co-Investigator

Jillian Hart, M.A. (student)
Counselling Psychology, Trinity Western University
e-mail: jillian.forsyth@mytwu.ca
604-616-1462

Thesis Supervisor: Dr. Marvin McDonald, 604-513-2121 ext. 3223

II. Why are we doing this study?

The purpose of this research is to understand the lived experience of couples facing cancer. We have learned that partners of cancer patients also have important stories to tell. This current research sets out to gather partners' stories to help clarify ways they can be supported through challenges and joys as they accompany partners who face cancer. We are looking for partners of cancer patients who have been in a committed romantic relationship for at least one year, and your partner's cancer diagnosis has happened while you have been together.

III. What happens if you say "Yes, I want to be in the study"?

If you choose to participate, an initial selection process will be conducted so as to ensure that you meet the inclusion criteria for this project. The criteria includes being a male in a committed, heterosexual relationship (e.g., married, cohabitating, engaged, or steadily dating for at least six months at the time of participation). Your partner has received a diagnosis of invasive breast carcinoma (i.e., non-metastatic), in the last 36 months or ductal carcinoma in-situ, at or before the age of 40, and has completed or nearing the end of active treatment. You also must be fluent in English. If you meet the research criteria, you will be contacted by telephone to set up a time and date for an interview that is convenient for you. If you are not selected for the study, no further information will be required from you and all information that you have provided up until the will be destroyed.

The interview that you will be participating in will last between 40 and 60 minutes. The interview will take place either by telephone if you live outside of the Greater Vancouver Region, at Fraser River Counselling Center, or at a location that is convenient to you. This interview is an opportunity for you to share your experience of being a couple. The interview will be centered on the question "can you describe your experience of your relationship due to your/your partner's cancer diagnosis?" Audio recordings will be made of all interviews. After the interview we will debrief the interview. Any further follow-ups thereafter may be conducted via phone or e-mail.

IV. Study Results

The results of this study will be reported in a graduate thesis and may also be published in journal articles.

V. Is there any way being in this study could be harmful for you?

Due to the nature of the topic we are discussing, as participants, you may experience an emotional reaction based on what you share. Sharing about a relationship that has been threatened by cancer may be distressing. However, the aim of the conversation is not to ask you to answer questions or share stories that you are not comfortable in sharing. At any point during the process if you wish to discontinue participation, you may do so freely. What you choose to share in the interview is up to your discretion. If you find you are experiencing distress, please bring this up with your interviewer as they have identified support services in your area should you want to continue to talk about your experience or seek support.

VI. What are the benefits of participating in the study?

Research has shown the benefit of sharing ones story in a research study. The aim of the interview is to provide a safe place for you to share your experience and help contribute to research in the area of couples and cancer. Your stories will be published for others to be able to understand what it is like firsthand to experience cancer in a relationship.

VII. Measures to maintain confidentiality

Your confidentiality will be respected. Information that discloses your identity will not be released without your consent unless required by law. Your rights to privacy are legally protected by federal and provincial laws that require safeguards to insure that your privacy is respected and also give you the right of access to the information about you that has been provided to the researcher. If needed, you also have the opportunity to correct any errors in this information.

Once selected for the study, you will decide on a pseudonym of how you would like to be identified for the study. In all documents and final reports, your pseudonym will be used as an identifier therefore your identity will not be known in the transcripts, in the final thesis document, presentations, and any further publications. Computers containing transcripts and audio recordings will be kept secured with password protection and encryption.

All audio recordings, transcripts, and notes taken during the process will be kept in a password-protected, encrypted folder. When thesis requirements have been met, all audio recordings will be permanently deleted. Transcripts will be saved in a password-protected document and stored in a locked filing cabinet in the offices of the Counselling Psychology Department of Trinity Western University.

VIII. Remuneration for your Participation

As a small token of my appreciation, participants who complete the project as explained above will receive a 75\$ gift certificate. This will be mailed to you once an interview time has

been scheduled. Participants may withdraw from the project at any time without consequence. Should this happen, all recordings, transcripts, and notes collected to date will be immediately disposed of.

IX. Contact for Information about the Study

If you have any questions or desire further information with respect to this study, you may contact Jillian Hart at 604-616-1462 or e-mail jillian.forsyth@mytwu.ca

X. Contact for Complaints

If you have any concerns about your rights as a research subject and/or your experience while participating in this study, you may contact the Research Subject Information Line in the UBC Office of Research Services at 604-822-8598 or if long distance e-mail RSIL@ors.ubc.ca or call toll free 1-877-822-8598. In addition please contact Ms. Sue Funk in the Office of Research, Trinity Western University at 604-513-2142 or sue.funk@twu.ca

Consent

Taking part in this study is entirely up to you. You have the right to refuse to participate in this study. If you decide to take part, you may choose to pull out of the study at any time without giving a reason without consequence to the remuneration.

- Your signature below indicates that you have received a copy of this consent form for your own records.
- Your signature indicates that you consent to participate in this study.
- Your signature indicates that have read and understood the risks and benefits to participating in this study

Signature

_____ Phone: _____

Print Name

Date: _____ E-mail _____

APPENDIX G – DEMOGRAPHIC QUESTIONNAIRE

Demographic Questionnaire

The following questions provide us with factual background information about yourself. Please answer by circling the answer that fits you best or writing in the space provided. You may choose not to answer any questions that you are not comfortable answering.

Your Name: _____

1. Age: _____ years old
2. Status of your current romantic relationship:
Dating
Married
Cohabiting
Common-Law
Other (*please specify*) _____
3. How long have you and your romantic partner been in a committed relationship? _____ year(s)
4. Do you currently live with your romantic partner?
Yes
No
5. What is the highest level of education you have completed? _____
6. Do you have any children?
Yes If yes, how many children currently live with you? _____
No
7. Please select all members of your family that were born in Canada (*check all that apply*):
Yourself
Your mother
Your father
8. What is your religious affiliation, if any?
Catholic
Protestant
Jewish
Hindu
Muslim
Sikh
Buddhist
No Religious Affiliation

- Other (*please specify*) _____
9. What is your ethnicity?
- White
 - Chinese
 - South Asian (*e.g., East Indian, Pakistani, Sri Lankan, etc.*)
 - Black
 - Aboriginal (*e.g., North American Indian, Métis or Inuit [Eskimo]*)
 - Filipino
 - Latin American
 - Southeast Asian (*e.g., Vietnamese, Cambodian, Malaysian, Laotian, etc.*)
 - Arab
 - West Asian (*e.g., Iranian, Afghan, etc.*)
 - Korean
 - Japanese
 - Other (*please specify*) _____
10. Is there anything else about you or your relationship with your spouse/partner that you feel is important for us to know? (*please describe*) _____
- _____
11. Date of Diagnosis
- _____/_____/_____
 Month Year
12. Please indicate the type of treatment your partner has received: (*check all that apply*)
- Chemotherapy
 - Radiation Therapy
 - Surgery
 - Hormonal Therapy
13. Do you currently have any physical or mental health concerns?
- Yes If yes, please describe: _____
- No

Your preferred Pseudonym: _____

APPENDIX H – PREPARING FOR THE INTERVIEW

Before the Interview...

We appreciate your participation in this study. We have learned that partners of cancer patients have an important story to tell. Researchers need to gather partners' stories as well as those of significant others. In this project we are interested in your story. We are hoping to be able to offer others like yourself more effective support care services and therefore it is important to hear from you about your experience during this time in life. During this project we are aiming to provide a "safe space" for you to pause and share your experience of being in a romantic relationship with someone who is facing cancer.

We acknowledge that some people find day-to-day living to be a mix of joys and sorrows – often without moments to pause for reflection, or even to sort out many uncertainties or confusing things that happen. Others sometimes find that the care and support available is quite helpful. The hope of this interview is to provide that space to pause and reflect on your experience. As an expert in your life, what is important for us as researchers and as professionals working with families of those facing cancer to know or acknowledge? What is important in your relationship? Have there been shifts in your relationship due to cancer (roles, expectations etc.)? What has been helpful for you as a couple in facing cancer? What has not been helpful? What thoughts, feelings, or emotions come up for you as you look towards the future?

APPENDIX I - INTERVIEW PROTOCOL AND DEBRIEFING

Interview Protocol

These questions illustrate possible versions and sequences of questions. Phrasing and pacing will be adjusted to fit the language and situation of the person being interviewed. Additional adjustments may be made to accommodate background or outlooks of participants who are recruited from different sources.

- 1) Can you tell me a bit about your life together (relationship) before your partner was diagnosed with cancer?

The following are possible probes that may be asked to help those who may have had little opportunity to pause and reflect about their relationship

- a) What was your daily life like? Work life, home life?
- b) How would you describe your relationship?
- c) What would you say was important in your lives as a couple?

- 2) Can you tell me how cancer came into your life?

The following are possible probes that may be asked to help those who may have had little opportunity to pause or to tell their story

- a) Some people experience shifts, surprises, or different kinds of experiences when life events happen. Can you describe what happened when your partner was diagnosed with cancer? (ask about personal reactions if they weren't described)
- b) Were there shifts in your relationship? In what areas? (roles, expectations, day-to-day activities, etc.)
- c) What were/are your feelings surrounding your partner's illness? About how things have happened?
- d)

- 3) Current life: What is life like now? What is life like with your partner?

The following are possible probes that may be asked to help those who may have had little opportunity to pause and reflect

- a) What have been important moments or things that have happened?
- b) What aspects of your relationship have been most shaped by the presence of cancer? In what ways?
- c) Has what matters most to you in your relationship changed? In what way?
- d) Sometimes couples keep things to themselves in order to protect their partner. Has this been your experience? In what ways?

- 4) Where are things going? If we take a moment to look ahead, how do you see things/life going now (from this point forward)?

The following are possible probes that may be asked to help those who may have had little opportunity to pause and reflect

- a) What emotions, thoughts, or feelings come up for you as you look ahead?
 - b) What is your outlook on life now? Has your partners' cancer shaped your outlook?
- 5) Debriefing of interview process
 - a) [interviewer: reflecting the degree of ease or difficulty, etc., with the discussion during the interview, select among & adjust the following questions]
 - b) How comfortable did you find our discussion today? Where there surprises for you in the things that came up? Would you like to hear about the stories of other partners? How much do you as a couple focus on your relationship? Would you like us to contact you once a summary of the project is available?
 - c) [offer the opportunity to add to their comments after the interview is completed or anytime in the future]