Couples' Communication in the Breast Cancer Context

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Statement of Candidate

I certify that I am the student whose name appears below and the work in this thesis titled '*Couples' Communication in the Breast Cancer Context'* has not previously been submitted for a degree nor has it been submitted as part of requirements for a degree to any other university or institution other than Macquarie University.

I also certify that this thesis is an original piece of research and has been conceptualised, implemented, analysed and written by me. Chapter 2 of this thesis lists two authors Yisha Yu and A/Prof Kerry Sherman. Yisha Yu, the student submitting this thesis, is the primary author of this chapter and is responsible for the preparation of the manuscript. A/Prof Kerry Sherman supervised the development of all the studies and the writing of the abovementioned papers. Any other assistance that I have received in my research work and the preparation of the thesis has been appropriately acknowledged. In addition, I certify that all information sources and literature used are indicated in the thesis.

The research presented in this thesis was approved by the Macquarie University Human Research Ethics Committee, reference number: 5201200864 on 6th December 2012.

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Thesis Abstract

Breast cancer is one of the most frequently diagnosed cancers among women in Australia. Whereas the past two decades have seen significant medical advancements and substantially improved diagnostic and intervention practices, the flipside of this progress is that an increasing number of women must contend with the myriad physical and psychological challenges of breast cancer and its treatment. Not surprisingly, a substantial proportion of women diagnosed with breast cancer experience elevated psychological distress in the form of anxiety, depression and post-traumatic stress many years after diagnosis and treatment.

Explanatory research focused on interpersonal dynamics points to the importance of effective communication between spouses in facilitating psychological and relationship outcomes, such as, reduced psychological distress, and the maintenance or enhancement of couple relationship satisfaction. Few studies to date, however, have focused on couples' communication in cancer as a primary outcome, frequently using brief (typically single-item) and imprecise global indices of communication. Many questions, therefore, remain regarding how couples communicate about cancer, how they negotiate and co-ordinate coping, and the associations of specific dimensions of communication behaviours with psychological and relationship outcomes, and the underlying processes of these associations.

Another limitation of the existing literature is that many of the studies have focused on positive dimensions of interpersonal and communication variables, such as social support dynamics and open disclosure of feelings, as compared to negative dimensions of interpersonal and communication behaviours. This is problematic as positive and negative social interactions are distinct constructs and relate to psychosocial adaptation outcomes in

different ways, with some research even suggesting a more detrimental effect of negative social interaction, as compared to the beneficial effects of positive social interactions.

An initial literature review was conducted to conceptualise the associations between major adaptive and non-adaptive communication strategies, and couples' psychological distress and marital satisfaction and to identify areas of knowledge gaps. Major theoretical and methodological frameworks that have guided this research, and directions for future research are then considered. The two empirical studies in this thesis examine negative dimensions of couple communication behaviours and their linkages with key psychological and relationship outcomes in women with breast cancer and underlying processes of these associations. Specifically, the first empirical study examines the associations of patient-reported avoidance of specific cancer-related topics, reports of partner avoidance of these topics, and coping and psychological distress among breast cancer survivors. The results of this study indicated that greater women's and perceived-partner's communication avoidance about cancer topics were associated with poorer mental health outcomes (anxiety, depression, and stress) in the women with breast cancer. This study also provided support for the view that avoiding talk about cancer may influence the woman's emotional distress by impeding her coping ability, consistent with the transactional stress and coping paradigm.

The second empirical study examines the association between perceived partner social constraints, as well as patient's report of their own social constraints, with patient relationship satisfaction. Previous research has only assessed perceived partner constraints, without consideration of the potential adverse effects of the patient's own constraints on partner disclosure and relationship satisfaction. The results of this study indicated that greater women's and perceived-partner social constraints were associated with poorer patient-reported relationship satisfaction. This study also provided support for the view that social

constraint signals may be detrimental to relationship satisfaction by impeding individuals' social processing about cancer, consistent with the social cognitive processing model.

Overall, the literature review and results of the two empirical studies contribute to the understanding of the role of couples' communication in breast cancer adaptation. The results of the two empirical studies indicate that the way in which couples communicate and relate with one another, the frequency of unsupportive responses, and topical focus of their conversations, are all important considerations for whether or not couple talk contributes to couples' psychosocial adaptation to cancer. The results hold important implications for clinical practice and care of women with breast cancer, as they suggest that helping couples navigate and overcome unsupportive partner constraint behaviours, and minimise communication avoidance about specific cancer-related topics between spouses may be important targets for psychosocial interventions.

Chapter 1: Literature Review

Couples' Communication in Breast Cancer: A Literature Review with Theoretical and Methodological Considerations

Breast cancer is a major public health problem throughout the world (Benson & Jatoi, 2012) and is one of the most frequently diagnosed cancers among women in Australia (BCNA, 2016). Whereas the past two decades have seen significant medical advancements and substantially improved diagnostic and intervention practices (McDonald, Clark, Tchou, Zhang & Freedman, 2016), the flipside of this progress is that an increasing number of women must contend with the myriad physical and psychological challenges of breast cancer and its treatment. Surgical interventions are often invasive and painful, resulting in bodily changes that can compromise a woman's self-esteem and identity, and interfere with her sexual functioning (Bartula & Sherman, 2013; Przezdziecki et al., 2013). Established adjuvant treatments, including radiotherapy, chemotherapy, and hormone therapy, are often accompanied by long-lasting side effects, such as fatigue, pain, and nausea (Gho, Steele, Jones, & Munro, 2013). These side effects can significantly impair functioning and disrupt a woman's social and family roles, and challenge her autonomy (Hilton, Crawford & Tarko, 2000). It is common for the woman facing breast cancer to experience intrusive thoughts about disease recurrence or progression, given the considerable uncertainty regarding treatment efficacy and cancer prognosis (Stanton & Revenson, 2011). Not surprisingly, a substantial proportion of women diagnosed with breast cancer experience elevated psychological distress in the form of anxiety, depression and post-traumatic stress many years after diagnosis and treatment (Bower, 2008). A recent meta-analysis of 43 cohort studies involving over 11,000 breast cancer patients, found the prevalence of clinical depression was 11% on the basis of diagnostic interviews, and 20% as measured by self-report interviews (Krebber et al., 2014). Similarly, the prevalence of anxiety disorders among long-term

survivors generally has been estimated at 17.9% (Mitchell, Ferguson, Gill, Paul & Symonds, 2013).

Most women facing breast cancer fortunately do not navigate their illness alone. Women who are married or in a committed relationship at the time of diagnosis, often identify their spouses as their most important source of social support, with many women desiring to talk with their partners about different aspects of their illness to deal with their cancer experience (Mallinger, Griggs, & Shields, 2006; Manne, Ostroff, Winkel, Grana, & Fox, 2005). Research in the general cancer context has consistently demonstrated that being in a partnered relationship confers substantial health benefits to the patient facing cancer (Badr, 2016), and positively impacts on patient psychological adjustment, treatment and survival outcomes (Proulx, Helms & Buehler, 2008). For example, a 2013 analysis of Surveillance, Epidemiology, and End Results (SEER) data (Aizer et al., 2013) for the ten most frequently diagnosed cancers, found that married individuals were 53% more likely to receive definitive treatment, 17% less likely to be diagnosed with metastatic cancer and 20% less likely to die of cancer, even after adjusting for demographics, stage and treatment type, than their unmarried counterparts.

Explanatory research focused on interpersonal dynamics points to the importance of the emotional and practical support that spouses provide their ill partners in facilitating treatment decision making, patient engagement with rehabilitation (Badr, 2016) and adaptive coping efforts (Badr, Carmack, Kashy, Cristofanilli & Revenson, 2010). Some couples report greater closeness (Dorval, Guay, Mondor, Masse & Falardeau et al., 2005), emotional growth (Manne, Ostroff, Winkel, Goldstein & Fox et al., 2004) and intimacy (Manne, Ostroff, Rini, Fox & Goldstein et al., 2004) from navigating breast cancer together. However, even though maintaining good relationship functioning between spouses is a key predictor for patient

adjustment outcomes during and after active cancer treatment (Traa, De Vries, Bodenmann & Den Oudsten, 2015), a cancer diagnosis places significant demands on spouses and couple relationships and introduces many opportunities for conflict that can contribute to marital strain (Hodges, Humphris & Macfarlane, 2005). Some couples experience significant changes to established communication patterns and roles that erodes marital quality over time, and in some cases, precipitates separation and divorce (Badr, Acittelli & Carmack, 2008; Karraker & Latham, 2015). Moreover, many spouses come to assume their caregiving responsibilities with little-to-no orientation or training (Blum & Sherman, 2010; Weingarten, 2013), and experience psychological reactions that parallel patterns observed among cancer patients themselves, such as greater levels of anxiety and depression and poorer physical health than their non-caregiving counterparts (Applebaum & Breitbart, 2013; Lambert, Girgis, Lecathelinais & Stacey, 2013).

Over the past two decades, the growing evidence base in psycho-oncology on the impact of cancer on partners and couple relationships has seen scholars broadening their scope from examining the ill-affected patient experience, to also exploring interpersonal dynamics that uniquely contribute to couples' psychosocial adaptation to cancer. This body of research increasingly points to the importance of effective communication between spouses in facilitating psychological and relationship outcomes, such as, reduced psychological distress, and the maintenance or enhancement of marital satisfaction (Bodenmann, 1995; Badr, 2016; Li & Loke, 2014a). Few studies to date, however, have focused on couples' communication in cancer as a primary outcome, frequently using brief (typically single-item) and imprecise global indices of communication. Although studies on how couples communicate about cancer are emerging, much remains unknown about how they negotiate and co-ordinate coping, and the association of specific communication

behaviours with different psychosocial adaptation outcomes and the underlying processes of these associations.

In writing this narrative review, we sought to facilitate a greater understanding of the role of couples' communication in breast cancer adaptation to inform future descriptive and intervention research. Specifically, this review conceptualises the associations between major adaptive and non-adaptive communication strategies, and couples' psychological distress and relationship satisfaction and identifies areas of knowledge gaps. The review then considers major theoretical and methodological frameworks that have guided this research, and proposes directions for future research.

Understanding Adaptive and non-Adaptive Communication Strategies

Research on healthy couples navigating various life stressors has consistently found couple communication as a strong predictor of relationship satisfaction and psychological adjustment for both partners generally (Holman, Birch, Carroll, Doxey & Larson et al, 2001 – check formatting), such as individuals and partners navigating bereavement (Lepore, Silver, Wortman & Wayment, 1996) and abortion (Major & Gramzow, 1999). Healthy couples who deal with their stressors via open disclosure of feelings and thoughts, proactive perspective taking of one another's views and seek to jointly problem-solve challenges report lower individual psychological distress and greater relationship satisfaction with their spouses (Holman, Birch, Carroll et al, 2001). Couples who deal with their challenges by avoiding talk about their problems, or engage in demand-withdrawal communication (i.e., one partner within a dyad pressures the other to talk about an issue, and the other partner withdraws and responds in either a passive or defensive manner) often report greater individual distress and lower relationship satisfaction with their spouse (Siffert & Schwarz, 2011). This pattern of association has also been found among couples navigating a broad range of health stressors,

such as chronic pain (Hoffman, Meier, & Council, 2002), rheumatoid arthritis (Danoff-Burg, Revenson, Trudeau & Paget, 2003), and prostate cancer (Lepore & Helgeson, 1998).

Emerging literature in the context of breast cancer specifically has identified a number of adaptive and non-adaptive communication processes that are associated with couple's psychosocial adaptation to illness. Specifically, couples who openly and sensitively discuss cancer-related concerns with one another are more likely to view the cancer as a "we-disease" (Kayser, Watson, & Andrade, 2007) and use adaptive couple-based coping efforts to resolve problems, such as joint problem-solving and information seeking (Badr, Carmack, Kashy, Cristofanilli & Revenson, 2010). A longitudinal study of women with early breast cancer and their partners, found that patients and partners who reported high levels of mutual constructive communication (i.e., open discussion of cancer-related topics and expression of feelings) both reported lower psychological distress and greater relationship satisfaction (Manne, Ostroff & Norton et al., 2006). Conversely, demand-withdrawal communication was related in this study to greater psychological distress and poorer relationship satisfaction for both partners. Both these cancer-related communication patterns were found to be stable at follow-up nine months later. Another longitudinal study of couples coping with lung cancer evaluated whether communication about a couple's relationship (e.g., past positive relationship memories, past shared challenges and future plans) as opposed to talk about cancer-related concerns, influenced marital adjustment over time (Badr, Acitelli & Carmack, 2008). In this study, it was found that patients and partners who reported more frequent discussions of their relationship observed greater marital adjustment and less psychological distress over a 6-month period after diagnosis and treatment, regardless of the gender of the affected patient.

Consistent with these prospective studies, mutually constructive communication has been related to lower psychological distress and better relationship satisfaction in cross-sectional studies of women with breast cancer and their partners (Manne, Ostroff & Rini et al, 2004) and other cancer populations (Badr & Taylor, 2009; Hagedoorn, Buunk, Kuijer, Wobbes & Sanderman, 2000; Porter, Keefe, Hurwitz & Faber, 2005). Within a breast cancer context, qualitative research (Fergus & Gray, 2009; Lewis & Deal, 1995) further supports the quantitative findings. Conversely, avoidance of discussing cancer-related concerns and feelings with a partner has been consistently related to negative psychological and marital adjustment outcomes, including diminished relationship satisfaction and exacerbated anxiety and distress (Badr, 2016; Donovan-Kicken & Caughlin, 2010; Figueiredo, Fries & Ingram, 2004; Li & Loke, 2014b).

Despite the potential benefits of effective couple communication on dyadic coping outcomes, individuals facing cancer often report significant difficulty discussing illness concerns and feelings with their spouses (Goldsmith and Miller, 2013; Badr, 2016). One study of women with breast cancer, reported that 35% of the participants did not disclose to any one (including their male support partners) about their primary cancer-related concerns (Kornblith, Regan, Kim, Greer & Parker et al., 2006). There are a number of reasons for couples not talking with each other about cancer (Goldsmith & Miller, 2013). An individual with cancer may try to avoid discussing cancer-related concerns with their spouse due to their anticipation and/or perception that their spouse will respond in a constraining, unsupportive manner. This social constraint can take on various forms and may be overt and coercive, such as a spouse criticising how a woman is coping with her breast cancer or directly undermining the severity of her illness, or diffused and subtle in nature, such as changing the topic when a woman starts talking about a cancer-related concern (Lepore & Revenson 2007). Other reasons for why couples may refrain from talking about cancer with one another include the

desire to protect oneself or one's partner from the discomfort of discussing difficult cancer-related topics, also known as protective buffering (Hagedoorn, Kuijer, Buunk, DeJong & Wobbes et al., 2000). While this relational coping strategy is often enacted with the best of intentions, such as to prevent futile or unproductive discussions, and maintain normality, optimism and patterns of relating (Goldsmith & Miller, 2013), protecting buffering has been found to be associated with lower levels of marital satisfaction (Hagedoorn et al, 2000) and greater psychological distress among cancer patients and caregivers (Langer, Brown & Syrjala, 2009; Manne, Norton, Ostroff, Winkel & Fox., 2007).

To date, the overwhelming majority of existing literature in this area has focused on the study of positive interpersonal and communication variables, such as social support and open disclosure of feelings and concerns, and not on negative interpersonal constructs (Adams, Winger & Mosher, 2015). Studies on negative interpersonal constructs are emerging, with much of the research effort oriented towards the study of protective buffering (Langer, Brown & Syrjala, 2009). More fine-grained analyses of negatively focused couple communications, such as unsupportive social constraints and communication avoidance, and their linkages with specific coping and relationship outcomes are needed to facilitate the development of more sophisticated couple-based interventions that goes beyond prescribing open discussion about concerns and feelings generally (Badr, 2016).

More fine-grained analyses of couple disclosure patterns about specific cancer topics and their linkages with coping and adaptation outcomes are also needed to refine the specificity of couple-based intervention guidelines about which cancer topics couples should be instructed to converse more or less, the frequency and lengths of these conversations, and the circumstances under which it is most appropriate to discuss certain topics, in support of couples' dyadic coping. Conversing about practical cancer-related matters, such as physical

symptom management and experiences with healthcare professionals, may be less difficult for couples than discussing topics that are more emotionally charged, such as fears about disease progression and death, and sexual problems. Previous research has found that oncology health professionals themselves avoid discussing end-of-life and sexuality concerns with women facing breast cancer for reasons such as discomfort with these topics, and general concerns of boundary crossing (Horden & Street, 2007). Most previous research, however, has not considered that couple disclosure patterns may vary by specific cancer topics (Goldsmith & Miller, 2013; Badr, 2016). Critical to this line of research is the development of more sophisticated communication measures that can characterise conceptually distinct dimensions of communication (e.g., openness, avoidance, constraint) across cancer topics and at different time points of cancer experience.

Another limitation of existing literature is the lack of empirical research examining potential mechanisms that give rise to associations between couple communication variables and dyadic coping outcomes. Researchers from diverse fields of social psychology, clinical psychology and health psychology have proposed a large number of intrapersonal, interpersonal and contextual mediating and moderating factors for investigation (Lepore & Revenson, 2007), such as cognitive and social processing (Lepore, Ragan & Jones, 2000; Manne, Myers, Ozga, Kissane & Kashy et al., 2014), coping self-efficacy (Ahmad, Fergus, Shatokhina & Gardner, 2017) and expanded interpersonal resources, such as relational intimacy (Manne & Badr, 2008) and communal coping orientation, that is, appraising cancer as a "we-disease" (Bodenmann & Randall, 2012). Current models of mechanisms, however, are largely underdeveloped due to a general lack of empirical attention to the testing of these proposed factors. The heterogeneity in methodological approaches and disparate theoretical frameworks to investigating couples' communication, coping and adaptation in the cancer context have made it difficult to organise existing literature and move this area of research

forward. Consistent with this, recent systematic reviews of couple-based intervention studies in cancer have found that the majority of studies lack theoretical and conceptual grounding (Badr & Krebs, 2012; Li & Loke, 2014a).

Taken together, current understanding of how couples communicate about cancer, how they negotiate and co-ordinate coping, and the associations of specific communication behaviours with dyadic coping outcomes, and the underlying processes of these associations. The aim of the following section is to review dominant theoretical and methodological approaches that have guided the current state of literature on couples' communication in cancer, and propose directions for future descriptive and intervention research.

Theoretical Frameworks for Studying Couples' Communication in Cancer

Research on couples' communication in cancer over the past decade has been informed by two major theoretical paradigms: "resource theories" and "dyadic-level theories". The range of theoretical models that have been most influential in guiding couples' communication in cancer are now considered.

Resource theories

Resource theories, such as cognitive-social processing theory and social support theories, conceptualise marital relationship as a personal resource from which patients and partners can draw for successful adjustment and adaptation to major life stressors.

Cognitive-social processing theory. The cognitive-social processing theory (Lepore, 2001) has been influential in guiding extant research, and posits that major traumatic or stressful life events, such as cancer diagnosis, negatively influence the psychosocial adjustment of individuals and their immediate family members, as existing schemas individuals have about themselves and their key relationships are challenged. Successful

adaptation can be achieved via use of cognitive and/or social processing strategies. Specifically, cognitive processing involves actively assimilating (e.g., acknowledging that cancer presents as a reason for reconsideration of priorities) and/or accommodating (e.g., accepting that major health events can happen beyond an individual's control) distressing and/or confusing aspects of the cancer experience into more personally meaningful and less threatening terms. Although some cognitive processing is undertaken at an individual level, cognitive-social processing theory posits that social processing which involves talking with key support persons about concerns and feelings about the stressful life event, serves as an equally important means for individuals to achieve aforementioned cognitive processing goals (Clark, 1993).

A central prediction of the cognitive-social processing model is that perceived social constraint signals can inhibit disclosure of concerns and feelings between spouses, thereby limiting opportunities for cognitive and social processing (Lepore & Revenson, 2007; Marin, Holtzman, DeLongis & Robinson, 2007) that could facilitate couples' adaptation to cancer (Pasipanodya, Parrish, Laurenceau & Cohen et al., 2012). Consistent with this, associations have been found between partner social constraints and various indicators of incomplete cognitive processing among women with breast cancer, such as heightened intrusive thinking (Schmidt & Andrykowski, 2004), greater uncertainty and reduced personal control (Cordova, Cunningham, Carlson, Andrykowski & Cordova et al., 2001), and increased use of disengagement coping (i.e., denial, alcohol use; Manne, Ostroff & Winkel et al., 2005). Partner social constraint has been found to moderate the association between intrusive thinking and patient psychological distress (Manne, 1999). Couple-based studies have found that social constraint is associated with less use of couple-based cognitive processing strategies, such as joint problem-solving and information seeking (Badr, Carmack & Kashy et al., 2010).

In contrast to cognitive processing, few studies have adopted the cognitive social processing model to investigate how unsupportive social constraints may influence couples' social processing of cancer and adaptation outcomes. From the cognitive-social processing perspective, socially constraining behaviours from a spouse should inhibit social processing, by increasing the likelihood that the ill individual will avoid talking about cancer-related concerns and feelings (Manne, Myers & Ozga et al., 2014). The only quantitative studies in the breast cancer context to date, however, have yielded inconsistent results (Pasipanodya, Parrish, & Laurenceau et al., 2012; Badr, Pasipanodya & Laurenceau, 2013). The lack of association evident in the study by Badr and colleagues (2013) may be a consequence of methodological issues as only a single-item global question was used to assess partner social constraints which likely did not capture the full range of possible constraining responses (Goldsmith & Miller, 2013), such as negativity, criticism, disinterest and withdrawal (Lepore & Revenson 2007).

Social support theories. Social support theories place emphasis on the importance of effective communication with close others as a way of facilitating identification of unmet needs and support negotiation and co-ordination of adaptive coping strategies, in support of psychosocial adapation to cancer (Manne & Badr, 2008). Most studies based on social support theories to date (e.g., Manne and Glassman 2000; Donovan-Kicken & Caughlin 2011) have been guided by either transactional stress and coping paradigm (Lazarus & Folkman, 1984), or stress-buffering theory (Cohen & Wills, 1985). The transactional stress and coping paradigm proposes that an individual's adapative coping to a stressor will vary according to how one cognitively and behaviourally manages the demands posed by the stressor (Folkman & Moskowitz, 2004). Similarly, stress-buffering theory posits that the emotional and practical support from close social network protects against potential

detrimental effects of stressful life events on physical and psychological health outcomes (Cohen & Wills, 1985).

Sparse but emerging literature focused on couple relationships in the cancer context points to the importance of spousal support in the psychological adjustment of individuals facing cancer (Manne & Badr, 2008). Higher levels of access to supportive spousal responses by the ill individual, such as emotional and practical support, has consistently been associated with lower levels of psychological distress, as reported by individuals navigating breast cancer (Northouse, Laten & Reddy, 1995; Roberts, Cox, Shannon & Wells, 1994), and other cancers such as lung cancer (Quinn, Fontana & Reznikoff, 1986). Findings of cross-sectional (Manne, 1999) and longitudinal studies (e.g., Manne, Norton, Ostroff, Winkel & Fox, et al., 2007) suggest that attempts to avoid discussion about cancer-related topics or concerns between spouses is linked to greater psychological distress for both partners generally (Manne & Badr, 2008). Spousal communication responses that may be perceived by ill individuals as overtly dismissive or avoidant has also significantly associated with higher patient distress (Manne, 1999). The mechanisms underlying these associations remain largely unexplored, although emerging research suggest a mediating role for reduced coping efficacy and greater use of disengagement coping by the individual facing cancer, such as self-blame and denial (Donovan-Kicken & Caughlin, 2011; Manne, Ostroff & Winkel et al., 2005).

Dyadic-level theories

Dyadic-level theories examine the ongoing interaction patterns between spouses that can maintain or enhance couple coping as they navigate the cancer experience (Manne, 2011). A recent review of theoretical frameworks of dyadic coping in the cancer context and examination of evidence base of these concepts (Regan, Lambert, Kelly, Falconier & Kissane et al., 2015) suggests that verbal and non-verbal behaviours within a dyad that deter or inhibit

open discussion between spouses are likely to have a detrimental impact on psychological and relationship outcomes for the ill patient and their partners generally. Major theoretical frameworks of dyadic coping that have informed couple coping in the breast cancer context thus far include the systematic transactional model (Bodenmann, 2005), relationship resilience models (Badr, Acitelli & Carmack Taylor, 2008), and the relationship intimacy model (Manne & Badr, 2008).

Systemic Transactional Model. The systemic transactional model (Bodenmann, 2005) posits that individuals within a dyad first attempt to manage deleterious effects of a stressor using individual coping responses efforts, and in instances of prolonged stress and insufficient individual coping turn to their partners and engage in dyadic coping responses, parallel to ongoing individual coping efforts. Dyadic coping consists of stress signals that may be verbal or non-verbal in nature and may take on various forms. Bodenmann (2005) identified four main dyadic coping strategies: 1) common dyadic coping, which relates to whether couples are engaging in emotion-focused or problem-focused coping together; 2) supportive dyadic coping, which occurs when one partner provides support to assist the other directly with his or her individual coping efforts; 3) delegated dyadic coping, which occurs when one partner explicitly instructs the other to provide support, and, 4) negative dyadic coping, which refers to overtly critical, dismissive or superficially avoidant responses A study of couples coping with metastatic breast cancer found couples that frequently engaged in common dyadic coping reported greater relationship satisfaction with their spouses, whereas use of negative dyadic coping was associated with higher levels of patient and partner distress (Badr, Carmack, Kashy, Cristofanilli & Revenson 2010).

Relationship resilience models. Studies based on relationship resilience models have focused on the influence of engagement in relationship maintenance behaviours to promote

couples' adaptation to cancer over time (Badr, Acitelli & Carmack Taylor, 2008). Stafford and Canary (1991) identified five relationship maintenance strategies: 1) provision of positivity, such as interacting with one's partner in an optimistic, upbeat manner; 2) openness in communication, which relates to discussing and sharing information about the relationship with one's partner; 3) reassurances, which relates to providing one's partner with statements of affirmation that reinforce feelings of commitment and love; 4) social networks, which entail shared time spent with close friends and family; and, 5) shared tasks, which involves spending time together engaging in pleasant everyday activities. No studies have yet used this theory to examine how couples cope with breast cancer specifically. A study of couples coping with lung cancer, however, found couples that engaged in frequent talk with one another about cancer reported increased engagement of relationship maintenance strategies, relationship satisfaction and reduced psychological distress six months later (Badr, Acitelli & Carmack, 2008).

Relationship Intimacy Theory. Manne and Badr (2008) extended this framework and proposed a relationship intimacy model for understanding spousal communication in cancer. The relationship intimacy model focuses on the importance of promoting perceptions of closeness or intimacy between spouses as a way to facilitate couples' psychosocial adaptation to cancer (Manne & Badr, 2008). Specifically, the model encourages relationship-enhancement behaviours that foster intimacy between spouses, such as reciprocal discussion (that is, mutual disclosure of cancer-related concerns and expression of feelings) and partner responsiveness (behaviours that can promote feelings of being heard, understood and cared for). The model discourages relationship interactions that can compromise couple intimacy, such as avoidant communication responses, overt criticism and demand-withdrawal communication patterns, which occur when one partner pressures the other to discuss cancer-related concerns and the responder withdraws from the conversation (Manne & Badr, 2008).

The results of an initial intervention study supports this theoretical framework; a couple-focused intimacy-enhancing intervention was found to increase relationship-enhancement behaviours, reduce relationship-compromising behaviours, increase relationship intimacy and reduce distress in women diagnosed with early-stage breast cancer and their partners (Manne & Badr, 2008). Demand-withdrawal communication (i.e., one partner within a dyad pressures the other to talk about an issue, and the other partner withdraws and responds in either a passive or defensive manner) has been associated with increased psychological distress among couples coping with head, neck or lung cancers (Manne & Badr, 2010). Greater patient and partner past negative communication has been found to predict greater distress over time, largely mediated through the effects of intimacy suggesting that couples' baseline relationship functioning and satisfaction prior to cancer may provide a stress buffering effect (Manne, Badr, Zaider, Nelson & Kissane, 2010; Manne, 2011).

Theoretical considerations and directions for future research

Each of the theoretical models considered above has contributed to current understanding of couples' communication in cancer. Viewed together, the models suggest that the frequency of unsupportive responses, the manner in which couples communicate with one other and topical focus of their talk, are all important considerations for whether or not couple talk is beneficial for patients and partners (Badr, 2016; Goldsmith & Miller, 2013). Resource theories have underscored the importance of conceptualising marital relationship as a personal resource from which patients and partners can draw for successful adjustment and adaptation to cancer. Dyadic-level theories illuminate the important role that ongoing interaction patterns between spouses plays in maintaining or enhancing couple coping in cancer. A notable strength of dyadic-level theories over resource theories is that dyadic-level theories consider the interdependence of communication and coping responses within

couples, and treat the couple and their interactions as the unit of analysis. However, these theories do not include psychological and relationship adaptation in the model (Manne & Badr, 2008). The key strengths of resource theories over dyadic-level theories is that resource theories conceptualise adaptive and maladaptive communication and coping processes, and allow these interpersonal processes to be interrelated with key psychological and relationship adaptation outcomes in their models (Manne & Badr, 2008).

A clear and comprehensive picture of how, for whom, and under what conditions couples' communication may benefit patients and partners is far from being realized. Continued theoretical articulation to integrate current perspectives into one well-defined theoretical framework will be important to help organise existing research and facilitate the development of more targeted interventions to improve couples' psychosocial adaptation outcomes. Empirical testing of mechanisms will also help to elevate this area of research from its current descriptive level. Future research, however, need not be limited to large-scale longitudinal research efforts to advance our understanding of specific aspects of couples' communication processes and the interrelations with dyadic coping outcomes. Cross-sectional studies focusing on in-depth evaluation of specific couple communication behaviours (e.g., adaptive and maladaptive communication strategies, frequency, topical focus) using existing theoretical frameworks that include psychological and marital adaptation in their models, such as resource theories, can reveal important targets for further testing in descriptive and intervention research (Goldsmith & Miller, 2013). Microanalytic, qualitative research (e.g., Donovan-Kicken & Caughlin, 2011; Goldsmith & Miller, 2013) employing observational laboratory (e.g., Manne, Ostroff, & Rini et al., 2004; Manne, Sherman, Ross, Ostroff & Heyman et al., 2004) and process analytic (e.g., Pistrang & Barker, 2005) methods can also offer a rich understanding of couples' cancer experience, help pose new research questions and inform research directions (e.g., Lepore & Revenson, 2007).

Such qualitative research can reveal fine-grained details about the transactional dynamics of communication between spouses and address questions, such as how patients' and partners' appraisals of each other's communication behaviour may shape and influence couple disclosure patterns over time (Lepore & Revenson, 2007).

Methodological Approaches to Studying Couples' Communication in Cancer

There appears to be no clear conceptualisation regarding what constitutes adaptive and non-adaptive couple communication processes about cancer. This has led to the use of diverse methodological approaches and measurement tools in the assessment of couple communication, making evaluations and comparisons of results across studies difficult. Goldsmith and Miller (2013) reviewed how couple communication has been conceptualised and operationalised in research within the cancer context, and identified six main measurement strategies employed by extant research.

The most commonly employed measurement strategy solicits abstract perceptions about the openness of couples' general communication styles, often using global one-item evaluative questions (Goldsmith & Miller, 2013), such as "I take time to express my emotions". Studies using this type of measurement strategy (e.g., Weihs, Enright & Simmens, 2008; Siminoff, Wilson-Genderson & Sherman-Baker, 201) often make use of items and subscales from established and validated measures such as the Marital Communication Inventory (Vess, Moreland & Schwebel, 1985a, 1985b), Social Adjustment Scale (Zemore & Shepel, 1989) and the Family Environment Scale (Giese-Davis, Hermanson, Koopman, Weibel & Spiegel, 2000). A second type of communication measure strategy commonly used in the literature gathers global abstract perceptions about couples' openness in discussing cancer-related concerns specifically (e.g., Lewis, Fletcher et al., 2008; Manne, Badr, Zaider, Nelson & Kissane, 2010). This measurement strategy often employs Likert-type items to

gather frequency of couple communication, such as “I seldom discuss cancer with my spouse”, or general impressions of interest or engagement for example “my partner is interested in knowing about my cancer”.

In contrast to these two measurement strategies which focus on characterising the degree of openness in couples’ communication, a third measurement strategy solicits general impressions of constraint or difficulty in sharing cancer-related matters with one’s spouse (e.g., Eton, Lepore & Helgeson, 2005; Kornblith, Regan & Kim et al., 2006). This measurement strategy uses items such as “I get the sense that my partner doesn't want to hear about my experiences”. Another commonly used measurement strategy evaluates patterns of communication in the context of relational coping (Coyne, Ellard & Smith, 1990). Dyadic coping emphasises the importance of couples adopting a “we” approach in confronting and managing the challenges of a stressor (Badr, Carmack, Kashy, Cristofanilli & Revenson, 2010). Previous studies of breast cancer patients using this type of measure (e.g., Hinnen, Hagedoorn & Ranchor et al., 2008) often asks about couples’ perception of mutuality (i.e., how supported and understood they feel by their spouse), partner responsiveness (e.g., “my partner is sensitive to my needs and talks openly with me about my cancer”).

A less commonly employed measurement strategy evaluates perceived frequency or ease of talk about specific cancer-related topics. Researchers adopting this measurement strategy can specify the dimension of communication (e.g., ease or avoidance of talk, and frequency) they wish to capture related to different cancer topics. Ratings of specific cancer topics can be aggregated to form a composite measure of how couples communicate about cancer, generally (Goldsmith & Miller, 2013). One other type of measurement strategy entails analyses of couple conversations in laboratory and natural contexts. This is the least employed approach for obvious logistical reasons. Previous laboratory based studies have

predominantly used indices of openness based on observed frequency of self-disclosure about cancer-related topics (e.g., Manne, Sherman & Ross et al., 2004).

Methodological considerations and directions for future research

Overall, the frequent use of global, often one-item evaluative questions to assess couples' general patterns of communication in the literature is problematic. This measurement approach lacks specificity and sensitivity and has the disadvantage of eliciting responses more reflective of a woman's general relationship satisfaction with her partner than actual enacted communication behaviours. Indeed, some studies have found conflicting responses from participants who report using open communication with their partners in response to global evaluative questions, but then report engaging in high levels of unsupportive and avoidant responses when discussing specific cancer-related topics (Caughlin, Mikucki-Enyart et al., 2011; Goldsmith & Miller, 2013). The possibility that prior work may have overestimated the influence of couple communication on couple psychosocial adaptation outcomes generally, therefore, cannot be excluded.

Another limitation of past work is that most previous research has not considered that couple communication varies significantly across cancer-topics or between partners (Badr, 2016). Couples can talk about physical health-related matters (e.g., medical treatments, experiences with healthcare providers, prognosis, diagnosis and physical symptoms management), relational concerns (e.g., social/family relationships and support, intimacy and body image concerns, changes in household contribution and responsibilities), and personal emotional disclosures (e.g., expression of difficult concerns and fears such as feelings of burdensome, future plans). Conversing about practical cancer-related matters, such as physical symptom management and experiences with healthcare professionals, may be less

difficult for couples than discussing topics that are more emotionally charged, such as fears about disease progression and death, and sexual problems.

More fine-grained analyses of specific couple communication behaviours and their linkages with coping and adaptation outcomes are needed to develop a more nuanced understanding about which cancer topics couples are to be encouraged to converse more or less, the frequency of these conversations, and the circumstances for when it is most appropriate to discuss specific topics. This work will be important in informing development of more targeted couple-based psychosocial interventions. Critical to such efforts is the development of more sophisticated communication measures that can characterise conceptually distinct dimensions of communication (e.g., openness, avoidance, constraint) across cancer topics and at different time points of cancer experience.

Conclusions and Future Directions

This review sought to facilitate a greater understanding of the role of couples' communication in breast cancer adaptation. Current understanding of how couples communicate about cancer, how they negotiate and co-ordinate coping, and the associations of specific dimensions of communication behaviours with dyadic coping outcomes, and the underlying processes of these associations is limited. Continued theoretical articulation to integrate current theoretical perspectives into one well-defined theoretical framework will be important to help organise existing research and facilitate the development of more targeted interventions to improve couples' psychosocial adaptation outcomes. More fine-grained analyses of specific couple communication behaviours and their linkages with coping and adaptation outcomes are also needed to develop a more nuanced understanding about which cancer topics couples are to be encouraged to converse, the frequency of these conversations, and the circumstances for when it is most appropriate to discuss specific topics. Critical to

such efforts is the development of more sophisticated communication measures that can characterise conceptually distinct dimensions of communication (e.g., openness, avoidance, constraint) across cancer topics and at different time points of cancer experience.

Objectives and Outline of Empirical Studies 1 & 2

Research focused on interpersonal dynamics points to the importance of effective communication between spouses in facilitating psychological and relationship outcomes, such as, reduced psychological distress, and the maintenance or enhancement of couple relationship satisfaction (Bodenmann, 1995; Badr, 2016; Li & Loke, 2014a). Few studies to date, however, have focused on couples' communication in cancer as a primary outcome, frequently using brief (typically single-item) and imprecise global indices of communication.

Another limitation of the existing literature is the limited research on negative dimensions of interpersonal and communication variables, as compared to positive interpersonal and communication constructs (Adams, Winger & Mosher, 2015). Accordingly, the majority of psychosocial interventions designed to facilitate couple coping and adjustment to cancer have broadly prescribed positive social interactions, such as encouraging social and instrumental support, and open disclosure of feelings and concerns generally (Badr, 2016), as opposed to discouraging negative social interactions, such as avoidance of talk, and sending of unsupportive constraint signals (Adam, Winger, & Mosher, 2015). This is problematic as positive and negative social interactions are distinct constructs and relate to psychosocial adaptation outcomes in different ways (Lepore & Revenson, 2007), with some research even suggesting a more detrimental effect of negative social interaction, as compared to the beneficial effects of positive social interactions (Baumeister, Bratslavsky, Finkenauer & Vohs, 2001).

The following two empirical studies focus on the study of negative dimensions of couple communication behaviours and the linkages with key psychological and relationship outcomes in women with breast cancer and the underlying processes of these associations. Specifically, the first empirical study examines the association of patient-reported communication avoidance of specific cancer-related topics, as well as perceived partner avoidance of these topics with women's coping and psychological distress. It was hypothesised that communication avoidance by the woman facing breast cancer and her partner would be associated with her greater depression, anxiety and stress. It was also predicted that both the woman's and her perceived partner's communication avoidance would be associated with her psychological outcomes, with effects mediated by her greater use of disengagement coping strategies and less use of engagement strategies. A further aim of the first empirical study was to evaluate and characterise the degree of communication avoidance of specific cancer-related topics by the women with breast cancer and their spouses.

The second empirical study examines the association between perceived partner social constraints, as well as patient's report of their own social constraints, with patient reported relationship satisfaction. Previous research has only assessed perceived partner constraints, without consideration of the potential adverse effects of the patient's own constraints on partner disclosure and patient relationship satisfaction. It was hypothesised that perceived partner social constraints and women's own social constraint signals would be associated with greater patient- and partner communication avoidance about cancer-related thoughts and concerns, respectively. It was also hypothesised that both women's perceived partner and own social constraints would be related to lower levels of patient relationship satisfaction. A further aim of this study was to delineate the relative importance of constraint behaviours on patient relationship satisfaction, from the effect of the other dyad's own communication avoidance behaviours, using distinct communication measures that assess each construct

separately. Specifically, it was predicted that women's perceived partner social constraints would be associated with poorer patient relationship satisfaction, with effects mediated by less patient social processing about cancer, that is, greater avoidance of talk about cancer-related matters by the women with their spouses. It was also predicted that the women's own social constraints towards their spouses would be associated with poorer patient relationship satisfaction, with effects mediated by less partner social processing about cancer, that is, greater partner communication avoidance about cancer-related matters with the women with breast cancer.

Chapter 2: Empirical Study 1

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Communication avoidance, coping and psychological distress of women with breast cancer

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Abstract This study examined the relationship between communication avoidance of cancer-related topics with psychological distress, and the mediating role of coping strategies, in women with breast cancer. Women diagnosed with breast cancer (N = 338) completed an online survey including measures of self- and perceived-partner communication avoidance, psychological distress (depression, anxiety and stress), and coping strategies. Linear regression analyses indicated that women's and perceived-partner's communication avoidance was associated with anxiety, depression, and stress in the cancer-affected women. Bootstrapping analyses showed significant mediation effects of self- and perceived-partner communication avoidance on all distress outcomes through greater disengagement coping, and on anxiety through lower engagement coping. Emotionally valenced topics (i.e., disease progression and sexuality) were most avoided and practical issues were least avoided. Enhancing couple communication about cancer and women's adaptive coping skills (i.e., discourage use of disengagement coping strategies and promote use of engagement coping strategies) may be important targets for psychosocial intervention.

Keywords Breast cancer · Communication · Couples · Adjustment · Coping

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Introduction

Breast cancer is a heterogeneous disease with a highly variable clinical course (Stanton & Revenson, 2011) presenting affected women with myriad physical and psychosocial stressors (Goldsmith et al., 2008; Manne & Badr, 2008). Surgery interventions are often invasive and painful and can result in bodily changes that compromise a woman's self-esteem and identity and interfere with her sexual functioning (Bartula & Sherman, 2013; Przezdziecki et al., 2013). Established adjuvant treatments such as radiotherapy, chemotherapy, and hormone therapy are often accompanied by long-lasting side effects, such as fatigue, pain, and nausea (Gho et al., 2013). These treatments can significantly impair functioning and disrupt a woman's social and family roles, challenging her autonomy (Hilton et al., 2000). Intrusive thoughts about disease recurrence or progression are also common, given the considerable uncertainty regarding treatment efficacy and cancer prognosis (Stanton & Revenson, 2011). Not surprisingly, a substantial proportion of women diagnosed with breast cancer experience elevated psychological distress in the form of anxiety, depression, and stress many years after diagnosis and treatment (Bower, 2008). A recent meta-analysis of 43 cohort studies involving over 11,000 breast cancer patients, found the prevalence of clinical depression was 11 % on the basis of diagnostic interviews, and 20 % as measured by self-report interviews (Krebber et al., 2014). Similarly, the prevalence of anxiety disorders among long-term cancer survivors generally has been estimated at 17.9 % (Mitchell et al., 2013).

Research focused on interpersonal dynamics points to the importance of couple communication in women's psychological adjustment to breast cancer (for review, see Goldsmith et al., 2008). Women dealing with this serious

Chapter 3: Empirical Study 2

This manuscript has been prepared ready for submission to Journal of Behavioural Medicine.

Social Constraints, Communication Avoidance, and Relationship Satisfaction of Women with Breast Cancer'

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Abstract

This study examined the relationship between social constraints and patient relationship satisfaction, and the indirect effect of avoidance of talk about cancer, in women with breast cancer and their spouses. Women diagnosed with breast cancer identified through a nationwide breast cancer organisation (N = 338) completed an online survey including measures of self- and perceived-partner social constraints and communication avoidance about cancer, and relationship satisfaction. Linear regression analyses indicated that women's own and perceived-partner social constraints were associated with poorer relationship satisfaction, as reported by the women facing breast cancer. Bootstrapping analyses showed significant indirect effects of self- and perceived-partner social constraints on patient relationship satisfaction through greater partner- and women's own communication avoidance about cancer, respectively. Couple-based interventions that aim to reduce partner and women's own constraint behaviours, and promote couple communication about cancer may be important targets for psychosocial intervention.

Keywords: Breast cancer. Social constraints. Communication. Couples. Relationship satisfaction. Social cognitive processing model.

'Social Constraints, Communication Avoidance, and Relationship Satisfaction of Women with Breast Cancer'

The diagnosis and treatment of breast cancer presents women with significant physical and psychosocial challenges that demand psychological adjustment (Goldsmith & Miller, 2013). Treatment for breast cancer which includes surgery, radiation and chemotherapy is often invasive and painful and can result in undesirable and long-lasting side effects such as fatigue, pain, nausea (Gho, Steele, Jones & Munro, 2013), and impaired sexual functioning (Bartula & Sherman, 2013). These treatments can significantly impair functioning and disrupt a woman's social and family roles, challenging her autonomy (Hilton, Crawford & Tarko, 2000). Not surprisingly, the majority of women diagnosed with breast cancer experience some level of elevated distress, with cross-sectional and longitudinal studies reporting that thirty percent of women experience clinically significant levels of anxiety, depression and/or post-traumatic stress symptoms when undergoing breast cancer treatment (Gallagher, Parle & Cairns, 2002; Palesh, Shaffer, Larson, Edsall & Chen et al., 2006). Prior research has also reported other negative outcomes, such as marital distress, body image concerns, intrusive thoughts about cancer recurrence and/or progression, disrupted family roles and responsibilities, and finances (Badr, 2016; Bartula & Sherman, 2013; Burman, Margolin, 1992).

One way many women deal with this serious illness is to share their cancer-related thoughts, feelings and concerns with close others to make sense of their illness and accept the reality of their experience (Lepore & Revenson, 2007; Stanton & Revenson, 2011). Women who are married or in a committed relationship at the time of diagnosis, typically rely on this spousal relationship to help them cope with their breast cancer (Manne & Badr, 2008; Traa, De vries, Bodenmann & Den Oudsten, 2014). Consistent with this, a recent systematic review focused on female breast cancer identified marital functioning and satisfaction as a key

determinant of psychological adaptation for both the women and their partners (Brandao, Pedro, Nunes, Martins & Costa et al., 2017). Among women with breast cancer, higher levels of marital satisfaction have been associated with greater sexual functioning, body image, psychological wellbeing and quality of life (Manne, Ostroff, Rini, Fox, Goldstein & Grana, 2004; Zimmermann, Scott, & Heinrichs, 2009), whereas lower levels of marital satisfaction have been associated with poorer physical outcomes, recovery trajectories and mental health outcomes, such as anxiety and depression (Northouse, Templin & Mood, 2001; Segrin, Badger, Sieger, Meek & Lopez, 2006).

Spouses often become the women's primary source of emotional and practical support, and participate jointly with the women on treatment decision making, recovery and coping processes (Badr, Carmack, Kashy, Cristofanilli & Revenson, 2010). Although many couples report greater intimacy, closeness and emotional growth from navigating the challenges of breast cancer experience together (Dorval, Guay, Mondor et al., 2005; Manne, Ostroff, Rini, Fox, Goldstein & Grana, 2004), cancer can also bring significant challenges to established roles and responsibilities, and communication patterns that contribute to marital conflict, which in some cases, leads to relationship dissolution (Badr, Acittelli & Carmack, 2008; Karraker & Latham, 2015). In recognition of this variability in response to breast cancer, there is a need for researchers to better understand the interpersonal and communication factors that can contribute to differences in marital functioning and satisfaction after a breast cancer diagnosis.

Research in this area has identified a number of adaptive and non-adaptive communication behaviours that influence women's relationship satisfaction in cancer. Couples who openly and sensitively discuss cancer-related concerns and feelings with one another are more likely to view the cancer as a "we-disease" (Kayser, Watson & Andrade, 2007) and use adaptive couple-based coping efforts, such as joint problem-solving and

information seeking (Badr, Carmack, Kashy, Cristofanilli & Revenson, 2010). A longitudinal study of women with early breast cancer and their partners, found that patients and partners who reported high levels of mutual constructive communication (i.e., open discussion of cancer-related topics and expression of feelings) reported greater relationship satisfaction (Manne, Ostroff & Norton, Fox, Goldstein & Grana, 2006). Conversely, demand-withdrawal communication (i.e., one partner within a dyad pressures the other to talk about an issue, and the other partner withdraws and responds in either a passive or defensive manner) was related in this study to poorer relationship satisfaction. These cancer-related communication patterns were also found to be stable at follow-up nine months later. Another longitudinal study of couples coping with lung cancer evaluated whether communication about a couple's relationship specifically, as opposed to talk about cancer-related concerns, influenced relationship satisfaction over time (Badr, Acitelli & Carmack, 2008). In this study, it was found that patients and partners who reported more frequent discussions of their relationship observed greater relationship satisfaction over a 6-month period after diagnosis and treatment, regardless of the gender of the affected patient. Consistent with these prospective studies, the association between mutually constructive communication and relationship satisfaction is supported by cross-sectional studies of women with breast cancer and their partners (Manne, Ostroff, Rini, Fox, Goldstein & Grana, 2004); other cancer populations (Badr & Taylor, 2009; Hagedoorn, Buunk, Kuijer, Wobbes & Sanderman, 2000; Porter, Keefe, Hurwitz & Faber, 2005), and qualitative research (Fergus & Gray, 2009; Lewis & Deal, 1995). Conversely, avoidance of discussing cancer-related concerns and feelings with a partner has been linked to lower relationship satisfaction in breast cancer survivors (Donovan-Kicken & Caughlin, 2010), and among individuals coping with other cancers (Badr, 2016).

Despite the potential benefits of constructive communication on couples' relationship satisfaction during the cancer experience, individuals facing cancer often report significant difficulty discussing illness concerns and feelings with their spouses (Badr, 2016Goldsmith & Miller, 2013). One study of women with breast cancer, reported that 35% of the participants did not disclose to any one (including their male support partners) about their primary cancer-related concerns (Kornblith, Regan, Kim, Greer, Oarker, Bennet & Erick, 2006). One likely reason why an individual with cancer may try to avoid discussing cancer-related concerns with their spouse is their anticipation and/or perception that their spouse will respond in a constraining, unsupportive manner. This social constraint can take on various forms and may be overt and coercive, such as a spouse criticising how a woman is coping with her breast cancer or directly undermining the severity of her illness, or diffused and subtle in nature, such as changing the topic when a woman starts talking about a cancer-related concern (Lepore & Revenson, 2007) . Recent conceptualisations of social constraints define the construct to include both objective signs of constraining behaviours from one's social context, as well as subjective construal of these social conditions, that may reduce an individual's willingness and/or ability to disclose cancer-related thoughts, feelings or concerns (Lepore & Revenson, 2007).

The concept of social constraints remains relatively under-researched in psycho-oncology (Lepore & Revenson, 2007), with most prior work focusing on the study of positive social variables such as social support, and not negative interaction constructs (Adams, Winger & Mosher, 2015). Psychosocial interventions designed to facilitate patient coping and adjustment to cancer have primarily reinforced the importance of positive social interactions, such as encouraging social and instrumental support between spouses, as opposed to discouraging negative social interactions, such as unsupportive constraint signals (e.g., Baumeister, Bratslavsky, Finkenauer & Vohs, 2001). This is surprising given that positive

and negative social interactions are distinct constructs and relate to psychosocial adaptation outcomes in different ways (Lepore & Revenson, 2007), with some research even suggesting a more detrimental effect of negative social interaction as compared to the beneficial effects of positive social interactions (Baumeister, Bratslavsky, Finkenauer & Vohs, 2001).

Constraint behaviours may compromise relationship functioning because they violate individuals' expectations about the nature of their marital relationship, and possibly undermine feelings of trust, safety, belonging and commitment at a time of heightened emotional vulnerability. Emerging research points to a negative relationship between partner social constraints and relationship satisfaction in qualitative research (Gray, Fitch, Phillips, Labrecque & Fergus, 2000; Kayser, Watson & Andrade, 2007), and cross-sectional studies of women with breast cancer and their partners (Fergus & Gray, 2009; Donovan-Kicken & Caughlin, 2010; Picard, Dumont, Gagnon & Lessard, 2005) and individuals coping with other cancers (Hagedoorn et al, 2011). A 7-day quantitative diary study of women with breast cancer patients and their partners (Pasipanodya, Parrish & Laurenceau et al., 2012) found that greater patient- and spouse-reported partner social constraints within a dyadic couple were related to lower perceived relationship quality and daily intimacy for each individual. Similarly, a longitudinal study of couples coping with colorectal cancer, found marital satisfaction can be maintained in the short-term, even if the spouse is currently unsupportive and unresponsive to the ill patient's needs, but with the caveat that before the couple faced cancer that the non-affected spouse was highly supportive. However, by 9-month follow-up past spousal supportiveness no longer buffered this negative association between unsupportive partner social constraints and marital satisfaction (Hagedoorn et al, 2011).

A useful framework for understanding the negative association between social constraints and poor relationship satisfaction to cancer is the Social Cognitive Processing Model (SCPM; Lepore, 2001; Lepore & Revenson, 2007). In this model major stressful life

events, such as cancer, negatively influence the psychosocial adjustment of individuals and their immediate family members, as existing schemas individuals have about themselves and their key relationships are challenged. Successful adaptation can be achieved via use of cognitive and/or social processing strategies. Specifically, cognitive processing involves actively assimilating (e.g., acknowledging that cancer presents as a reason for reconsideration of priorities) and/or accommodating (e.g., accepting that major health events can happen beyond an individual's control) distressing and/or confusing aspects of the cancer experience into more personally meaningful and less threatening terms. Although some cognitive processing is undertaken at an individual level, SCPM posits that social processing which involves talking with key support persons about concerns and feelings about the stressful life event, serves as an equally important means for individuals to achieve aforementioned cognitive processing goals (Clark, 1993).

A central prediction of the SCPM is that perceived social constraint signals can inhibit disclosure of concerns and feelings between spouses, thereby limiting opportunities for cognitive and social processing (Marin, Holtzman, DeLongis & Robinson, 2007; Lepore & Revenson, 2007) that could facilitate couple relationship satisfaction and adjustment to cancer (Pasipanodya, Parrish, Laurenceau & Cohen, 2012). Consistent with this, associations have been found between social constraints and various indicators of incomplete cognitive processing among women with breast cancer, such as heightened intrusive thinking (Schmidt & Andrykowski, 2004), greater uncertainty and reduced personal control (Cordova, Cunningham, Carlson & Andrykowski, 2001), and increased use of disengagement coping (i.e., denial, alcohol use; Manne, Ostorff, Winkel, Grana & Fox, 2005). Couple-based studies have also found that social constraint is associated with less use of engagement-oriented couple coping strategies, such as joint problem-solving and information seeking (Badr, Carmack, Kashy, Cristofanilli & Revenson, 2010). Unlike cognitive processing, our

understanding of the negative effects of partner social constraints on couples' subsequent social processing is limited and not well understood (Manne, Kashy & Siegel et al., 2014). From the SCPM perspective, socially constraining behaviours from a spouse should inhibit social processing, by increasing the likelihood that the ill individual will avoid talking about cancer-related concerns and feelings (Manne, Kashy, Siegel, Myers, Heckman & Ryan, 2014). A microanalytic qualitative study of breast cancer patients and their partners (Pistrang & Barker, 2005) using a tape-assisted recall technique suggests that constraining responses from partners may deter subsequent patient disclosure about cancer, and contribute to individual and marital distress. One woman with breast cancer, for example, reflected on her spouse's blanket optimism and minimisation of her cancer concerns during an interaction task and noted her increased reluctance to disclose cancer-related concerns and feelings with her partner and heightened emotional distress and dissatisfaction with her spouse. Interestingly, her male support partner explained his communication behaviour was positively intentioned to help maintain the woman's positive outlook, and protect her from his own negative emotions. In a study of couples coping with gastrointestinal cancers (Porter, Keefe, Hurwitz & Faber, 2005), which assessed patient- and partner- perceptions of each other's social constraints, positive associations were found with patient communication avoidance about cancer, but not with partner communication avoidance. The only quantitative diary studies in the breast cancer context to date have yielded inconsistent results. One study of early-stage breast cancer patients reported that greater patient-perceived partner social constraints was associated with greater patient avoidance of sharing cancer-related concerns and other important daily events with their spouse (Pasipanodya, Parrish, & Laurenceau et al., 2012); yet, no such link was evident in a study of women with metastatic breast cancer and their partners (Badr, Pasipanodya & Laurenceau, 2013). However, the lack of association evident in the study by Badr and colleagues (2013) may be a consequence of methodological issues

as only a single-item global question was used to assess partner social constraints which likely did not capture the full range of possible constraining responses (Goldsmith & Miller, 2013), such as negativity, criticism, disinterest and withdrawal (Lepore & Revenson, 2007). Moreover, the use of one-item abstract evaluative questions have the disadvantage of eliciting responses more reflective of a couple's general relationship satisfaction than actual enacted constraining behaviours between spouses (Goldsmith & Miller, 2013).

Past research has identified the link between social constraints and couple relationship outcomes generally, but there has been a lack of attention to clarifying the mechanisms by which social constraints hinder relationship satisfaction. Understanding these mechanisms is important to help inform the development of psychosocial interventions designed to help preserve or enhance couple's relationship satisfaction and facilitate couple coping to managing cancer. Moreover, past research in this area generally has not delineated the relative importance of partner constraint behaviours from the effect of the patient's own communication avoidance behaviours as all-in-one measures have been used that together assess levels of partner social constraint, perceived motivations for these constraint signals, patient- and partner- communication avoidance about cancer and motivation for holding back cancer talk (Manne, Myers & Ozga et al., 2014). The possibility that prior work may have overestimated the influence of partner constraining responses on dyadic coping outcomes generally, therefore, cannot be excluded.

Drawing from the SCPM, the present study aimed to extend prior work among couples coping with breast cancer in several ways. First, the study examined the association between perceived partner social constraints, as well as patient's report of their own social constraints, with the patient relationship satisfaction. Previous research has only assessed perceived partner constraints, without consideration of the potential adverse effects of the patient's own constraints on partner disclosure and patient relationship satisfaction. A

woman's own social constraint signals towards her spouse is important as couple communication is a transactional process and both the woman and her partner's unsupportive responses can reciprocally influence each other's support interactions and subsequent relationship functioning and satisfaction (Lepore & Revenson, 2007). We hypothesized that perceived partner social constraints and women's own social constraint signals would be associated with greater patient- and partner communication avoidance about cancer-related thoughts and concerns, respectively. We also hypothesised that both women's perceived partner and own social constraints would be related to lower levels of patient relationship satisfaction. The second aim of the study was to delineate the relative importance of constraint behaviours on patient relationship satisfaction, from the effect of the other dyad's own communication avoidance behaviours, using distinct communication measures that assess each construct separately. Specifically, it was predicted that women's perceived partner social constraints would be associated with poorer patient relationship satisfaction, with effects mediated by less patient social processing about cancer, that is, greater avoidance of talk about cancer-related matters by the women with their spouses. It was also predicted that the women's own social constraints towards their spouses would be associated with poorer patient relationship satisfaction, with effects mediated by less partner social processing about cancer, that is, greater partner communication avoidance about cancer-related matters with the women with breast cancer.

Method

Sample and Procedures

Participants were drawn from a project examining the relationship between communication avoidance of cancer-related topics with psychological distress in the breast cancer context (Yu and Sherman, 2015). Women previously diagnosed with breast cancer or ductal carcinoma in situ (DCIS) were approached for study participation through an

Australian community-based breast cancer consumer organisation, the Breast Cancer Network of Australia (BCNA). An email invitation was sent by a contact person within the BCNA to 885 members who had previously agreed to receive notifications about research studies. Eligibility criteria included: 1) female; 2) over 18 years of age; 3) previously diagnosed with Ductal Carcinoma in Situ (DCIS), or primary Stage I, II or III breast cancer within the past five years; 4) in a committed relationship with a partner before the breast cancer diagnosis; 6) currently in a relationship and/or cohabiting with the same partner; and, 7) fluent in English. Participants completed the study questionnaire online. It was the responsibility of the women who received the email to determine their eligibility for the study. A total of 338 women agreed to participate. Following online consent, participants anonymously completed the questionnaire which took less than 20 minutes to complete. The conduct of this research was approved by the Macquarie University Human Research Ethics Committee.

Measures

Participants completed the following self-report measures:

Social Constraints. Patient- and perceived partner social constraints was assessed using an existing scale of eight items designed to measure the feeling that one ought to constrain open expression (Lepore & Helgeson, 1998). Items assessed overtly coercive responses such as “my partner minimizes my feelings and concerns”, and more subtle unsupportive responses such as “my partner gets uncomfortable when I try to discuss cancer-related matters with him”. The women rated on a 7-point Likert-type scale the extent to which they agreed with each statement (1=”strongly disagree” to 7 “strong agree”), answering first with regard to constraint signals they perceive to receive from their male support partners, and then with regard to their own sending of constraint signals towards their spouses. Item scores were aggregated and averaged within patient- and perceived partner

social constraint subscales, with higher scores reflecting greater levels of social constraints. Prior research indicates excellent reliability in breast cancer populations (e.g., Donovan-Kicken & Caughlin, 2010). In the present study, internal consistency for these scales was .94 (self) and .94 (partner), respectively.

Communication Avoidance. Patient- and perceived partner communication avoidance about cancer was assessed using a seven-subscale measure reflecting different cancer-related topics (Donovan-Kicken & Caughlin, 2011) that have been identified as important concerns for women with breast cancer (Figueiredo et al., 2004; Goldsmith et al., 2008). The measure has been validated on a sample of breast cancer patients (Donovan-Kicken, 2008; Donovan-Kicken & Caughlin, 2011) and recommended as a general measure of couple communication avoidance about cancer in a recent methodological review of couple communication measures (Goldsmith & Miller, 2013). The measure instructed the breast cancer affected woman to report separately on perceptions of own and partner communication avoidance about cancer, related to the following cancer-related topics (Donovan-Kicken, 2008). The *Death* subscale focuses on end of life matters, such as possibility of disease recurrence and future plans (eight items; e.g., "the possibility of the cancer coming back after treatment"; $\alpha = .93$ for women and $\alpha = .94$). *Treatment* includes items about aspects of medical treatments (five items; e.g., ''side effects from medical treatments''; $\alpha = .91$ for women and $\alpha = .93$ for partners). *Sexuality* addresses intimacy and body image concerns (four items; e.g., ''physical intimacy''; $\alpha = .93$ for women and $\alpha = .95$ for partners). *Being a burden* includes items about added stressors related to finances, household contribution, and care-taking responsibilities (eight items, e.g., ''ability to do household chores''; $\alpha = .90$ for women and $\alpha = .93$ for partners). *Feeling* includes items about expression of concerns and fears related to breast cancer (ten items; e.g., ''aspects of cancer and treatment that makes me nervous''; $\alpha = .94$ for women and $\alpha = .96$ for partners).

Relating includes questions about relationship satisfaction and communication (five items, e.g., ‘‘how well we are getting along’’; α = .91 for women and α = .95 for partners) and *Healthcare* addresses experiences with health care providers (four items, e.g., ‘‘interactions with my physicians’’; α = .96 for women and α = .98 for partners). The women rated on a 5-point Likert-type scale (1 = “strongly disagree” to 5 = “strongly agree”) the degree to which they and their male support partner avoided discussing various cancer-related topics within the dyad (e.g., I avoid talking to my partner about plans for the future”). Item scores were aggregated and averaged to create topic subscale scores. Composite measures of general self- and perceived-partner communication avoidance were created by averaging the respective subscale scores (Goldsmith & Miller, 2013). Scores for the subscales and the general measure both range from 1 to 5, with higher scores reflecting greater inhibition of disclosure about cancer. Prior research indicates evidence for the reliability of this measure between parent-child, romantic and friendship dyads (Caughlin & Afifi, 2004; Donovan-Kicken & Caughlin, 2010). In the present study, internal consistency for these scales was .98 (self) and .98 (partner), respectively.

Relationship Satisfaction. The seven-item, short form of the Dyadic Adjustment Scale (DAS-7; Hunsley, Best, Lefebvre & Vito, 2001) was used to assess the women’s perceptions of their relationship functioning and satisfaction with their spouses. Scores can range from 0 to 36, with higher scores indicating greater relationship functioning and scores less than 21 indicating marital distress. The DAS-7 has demonstrated good construct-related and criterion validity, and found to preserve the pattern of relations found between the longer, 32-item version of the scale. Internal consistency for the scale was high (α =.91).

Physical Functioning. The respondents in the present study varied considerably in terms of their primary breast cancer diagnosis and type of treatment received. In order to control for the potential effect of women’s physical symptomatology associated with disease

variables on patient relationship satisfaction, physical symptom distress was assessed using the seven-item Physical Wellbeing Subscale of the Functional Assessment of Cancer Therapy self-report questionnaire (FACT-B; Cella, Tulsky, Gray, Sarafian & Linn et al., 1993). The scale measured physical symptomatology specific to the breast cancer experience over the previous week, and included items such as "I have nausea" and "I have pain". All items were rated using a 5-point Likert-type scale from 0 ("not at all") to 4 ("very much"). Item scores were averaged with higher subscale scores indicating greater physical functioning wellbeing. Internal consistency for the scale was high (α = .82).

Medical and Demographic Characteristics. Information was gathered on the woman's demographic and disease-related characteristics: age, educational level, country of birth, marital status, relationship length, time since her primary breast cancer diagnosis, and information about cancer treatments that she had received.

Statistical Analyses

Data were analysed using SPSS (version 21; IBM Corp., 2012). Descriptive analyses were used to provide a general description of sample characteristics, and tabulated using frequencies and percentages. Initially, Pearson's correlations were used to identify any socio-demographic disease and treatment variables that were significantly associated with patient relationship satisfaction. All subsequent analyses were adjusted for any covariates that were found predictive of patient relationship satisfaction. Separated simple mediation analyses were conducted to test the indirect effects of patient/partner communication avoidance on the relationship between partner social constraints and patient relationship satisfaction. The significant of the indirect effects were tested using the bootstrapping methodology developed by Hayes (2013), using the SPSS macro called PROCESS (Process Macro, 2015), model 4. This approach was used as opposed to other classical tests of indirect effects (e.g., Baron & Kenny, 1986) due to its greater sensitivity, and robustness against violations of assumptions

of normality (MacKinnon, Lockwood, Hoffman, West & Sheets, 2002; Preacher & Hayes, 2008), especially for smaller and moderate sample sizes (MacKinnon, Lockwood & Williams, 2004). In this study, significance of indirect effect was considered achieved when the 95% confidence interval (CI) generated by the 5000 bootstrap distributions did not include zero. An additional paired samples t-test was used to examine differences in levels of women's own and perceived partner social constraints.

Results

Sample description

Participants were 338 Australian women who had previously been diagnosed with breast cancer. Sample characteristics are shown in Table 1. The average age of the women was 53.5 years (*SD* = 9.22, range 28 to 81). In terms of patient relationship satisfaction, 23% of participants scores below the DAS-7 cut-off for marital distress, with the mean patient relationship satisfaction score falling within the normal range *(M* = 24.51; *SD* = 5.94). Overall, women with breast cancer reported moderately low levels of social constraints with their spouses (*M* = 2.07; *SD* = 1.02, range 1 to 7) and social constraints from their partner (*M* = 2.76, *SD* = 1.59, range 1 to 7). Self- and perceived-partner social constraints was significantly correlated, $r = .50$, $p < .001$. Paired samples *t* tests indicated that women reported significantly higher levels of partner social constraints than their own levels of social constraints; $t(337) = 9.089$, $p < .0001$.

Correlations and Regression Analyses

Zero-order correlations and summary statistics of main study variables are presented in Table 2. Overall, the pattern of associations was consistent with predictions. Patient- and perceived partner social constraints were significantly and positively associated with levels of patient and partner communication avoidance about cancer, and negatively associated with patient relationship satisfaction. Women's communication avoidance and perceived partner

communication avoidance scores were also both negatively correlated with levels of patient relationship satisfaction. Of the potential demographic and medical covariates, only physical wellbeing and relationship length were significantly associated with the study outcomes. Independent *t* tests indicated no significant differences in main study outcomes by cancer treatment status, that is, completed vs. not completed treatment (all *p's* > .15).

Mediation Analyses of Communication Avoidance

The results of the bootstrapping analyses are presented in Table 3, and illustrated in Figures 1 and 2. There was a significant indirect effect of patient communication avoidance (95% BCI -.67, -.04) on the relationship between perceived partner social constraints and patient relationship satisfaction, and a significant indirect effect of partner communication avoidance (95% BCI -1.66, -.74) between patient social constraints and patient relationship satisfaction. In view of the significant correlation between physical symptoms and partner social constraints, patient relationship satisfaction and communication avoidance, we tested whether the magnitude and direction of any of these indirect effects were moderated by physical wellbeing, using the moderated mediation model 7 of PROCESS (Preacher & Hayes, 2008). Physical symptoms were not found to moderate any of the relationships between social constraints and patient relationship satisfaction outcome.

Table 1

Sample demographic characteristics (N = 338)

	%	***N***
Country of birth		
Australia and New Zealand	79.3	268
Great Britain/Ireland	13.9	47
Asia	0.6	2
Europe	2.6	9
America (North and South)	1.8	6
Africa	1.8	6
Education		
Less than 12 years	16.5	56
12 years	9.8	33
Vocational training	28.4	96
University Bachelor's Degree	30.8	104
Masters/Doctoral Degree	14.5	49
Stage of Disease		
DCIS	17.5	59
Grade 1	17.2	58
Grade 2	30.2	102
Grade 3	28.7	97
Don't know	6.6	22
Treatment		
Mastectomy	54.8	185
Chemotherapy	74.2	251
Radiation Therapy	73.6	249

Table 2

Means, standard deviations, and zero-order correlations between main study variables (N = 338)

Variables	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
1. Age (years)	-									
2. Education (years)	-.12*	-								
3. Time Since Diagnosis (months)	.22**	-.12*	-							
4. Relationship Length (years)	.58*	-.16**	.12*	-						
5. Physical Wellbeing	.10	-.04	.07	.13*	-					
6. Partner Social Constraints	.01	.10	.02	-.09	-.13*	-				
7. Women's Own Social Constraints	.03	-.01	.04	-.04	-.10	.50**	-			
8. Communication Avoidance by Women	-.02	.02	.01	-.13*	-.20**	.67**	.44**	-		
9. Partner Communication Avoidance	.04	.04	.03	-.09	-.17**	.76**	.44**	.83**	-	
10. Patient Relationship Satisfaction	-.09	.01	-.07	.01	.13*	-.52**	-.34**	-.42**	-.52**	-
M	53.50	15.17	35.90	25.90	3.25	2.76	2.07	2.31	2.55	24.51
SD	9.20	4.02	24.24	13.12	.67	1.59	1.02	.84	.95	5.93

N = 338

**Correlation is significant at the 0.01 level (two-tailed).

*Correlation is significant at the 0.05 level (two-tailed).

Table 3

Tests of the indirect effect of communication avoidance on the relationship between partner- and patient social constraints, and patient relationship satisfaction

Antecedent	Consequent							
	M (Patient Communication Avoidance)					Y (Patient Relationship Satisfaction)		
		β	SE	*p*		β	SE	*p*
Partner Social Constraints	α	.34	.02	<.0001	c'	-1.53	.24	<.0001
M (Patient Communication Avoidance)	-	-	-	-	*b*	-.91	.45	<.05
C_1 (Relationship Length)	f_1	-.01	.01	>.05	g_1	-.01	.01	>.05
C_2 (Physical Wellbeing)	f_2	-.12	.05	<.05	g_2	.39	.43	>.05
Constant	i_2	-.12	.05	<.05	i_2	30.25	1.81	<.0001
	R^2 = .45					R^2 = .26		
	F (3, 326) = 88.29					*F* (4, 325) = 28.37		
	p < .0001					*p* < .0001		
	M (Partner Communication Avoidance)					Y (Patient Relationship Satisfaction)		
		β	SE	*p*		β	SE	*p*
Patient Social Constraints	α	.41	.05	<.0001	c'	-.78	.31	<.05
M (Partner Communication Avoidance)	-	-	-	-	*b*	-2.78	.34	<.0001
C_1 (Relationship Length)	f_1	-.01	.01	>.05	g_1	-.01	.01	>.05
C_2 (Physical Wellbeing)	f_2	-.14	.07	<.05	g_2	.30	.42	>.05
Constant	i_2	2.28	.26	<.0001	i_2	30.25	1.78	<.0001
	R^2 = .22					R^2 = .27		
	F (3, 326) = 30.42					*F* (4, 325) = 30.20		
	p < .0001					*p* < .0001		

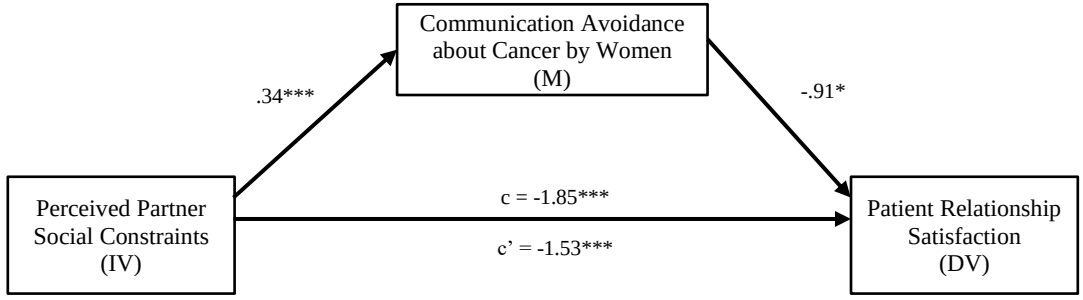

Figure 1. Simple mediation model in $N = 338$ women with breast cancer. *Note.* ***$p < .0001$. The associations between perceived partner social constraints and patient relationship satisfaction via women's own communication avoidance about cancer. Standardised regression coefficients shown. Control variables were relationship length and women's physical wellbeing.

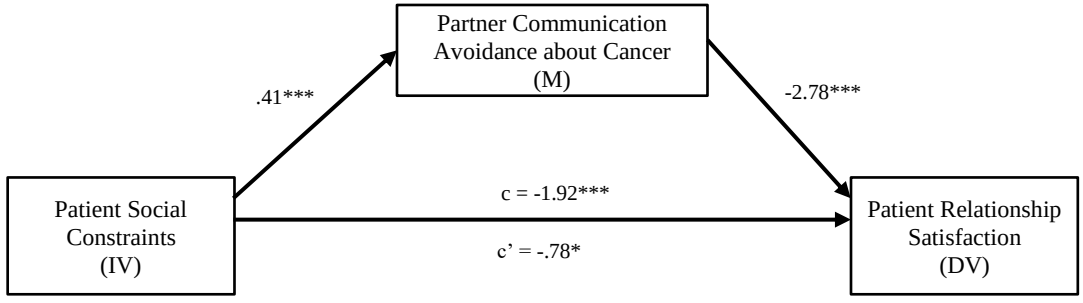

Figure 2. Simple mediation model in $N = 338$ women with breast cancer. *Note.* ***$p < .0001$. The associations between women's social constraints and patient relationship satisfaction via partner communication avoidance about cancer. Standardised regression coefficients shown. Control variables were relationship length and women's physical wellbeing.

Discussion

Current understanding of how social constraint signals between spouses influence relationship satisfaction and couple disclosure about cancer is limited. The present study examined the association of self- and perceived partner social constraints and communication avoidance about cancer, and patient-reported relationship satisfaction among breast cancer survivors. Utilising a measure of social constraints that assessed a broad range of potential couple constraint signals (Lepore & Helgeson, 1998), the results indicated moderately low levels of social constraints between spouses but considerable variability in how much women with breast cancer and their spouses constrained each other from discussing cancer-related topics with one another. The women reported significantly higher levels of perceived partner social constraints than their own sending of social constraint signals, raising the possibility that spouses may be more uncomfortable discussing cancer-related concerns than the women themselves.

Consistent with previous research of community-based breast cancer populations (e.g., Badr, Carmack, Kashy, Cristofanilli & Revenson, 2010), the present study confirmed the presence of poor patient-reported relationship satisfaction in some breast cancer patients and their spouses, with clinically significant levels of marital distress reported in 21% of participants. A diversity of factors can contribute to poor relationship satisfaction among women with breast cancer (Stanton & Revenson, 2011); however, in the present study, greater self- and perceived partner social constraints were associated with poorer relationship satisfaction as reported by the women with breast cancer, consistent with similar results observed in prior research (e.g., Fergus & Gray, 2009; Donovan-Kicken & Caughlin, 2010; Pasipanodya, Parrish, Laurenceau & Cohen, 2012; Picard, Dumont, Gagnon & Lessard, 2005). The study findings are consistent with the predictions of the Social Cognitive Processing Model (SCPM; Lepore, 2001) and provide support for the view that social

constraint signals may be detrimental to relationship satisfaction by impeding individuals' social processing about cancer. The woman's perceived partner social constraints was associated with her greater communication avoidance about cancer-related thoughts and concerns with her partner. The women's report of her own social constraints was associated with greater partner communication avoidance about cancer with the woman. The woman's and her perceived partner communication avoidance were also both associated with lower relationship satisfaction as reported by the woman. These results suggest that the more an individual within a dyad perceives spousal constraint signals, the more avoidant they become talking with their spouse about cancer-related matters, thereby limiting and interfering with necessary social and cognitive processing of threatening aspects of cancer in support of relationship satisfaction and dyadic coping to cancer. Couples who socially process cancer via shared discussions about the illness are more likely to view cancer as a "we-disease" (Kayset et al., 2007) and gain helpful perspectives that can encourage use of adaptive joint coping strategies, such as couple-based problem-solving and information seeking (Badr et al., 2010). Consistent with this interpretation, the results of our mediation analyses showed significant indirect effects of self- and perceived partner social constraints on relationship satisfaction through greater partner- and patient- communication avoidance about cancer, respectively. Thus, reducing social constraints between spouses may facilitate patient relationship satisfaction, and enable couples to more effectively navigate the challenges of cancer experience.

These findings extend the literature in several important ways. To our knowledge, this is the first study to delineate the relative importance of spousal constraint behaviours on patient relationship satisfaction, from the effect of the other dyad's own communication avoidance behaviours, using distinct communication measures that assess each construct separately. Previous research has also only assessed perceived partner constraints, without

consideration of the potential adverse effects of the patient's own constraints on patient relationship satisfaction and communication about cancer. A woman's own social constraint signals towards her spouse is important as couple communication is a transactional process and both the woman and her partner's unsupportive responses can reciprocally influence each other's support interactions and subsequent appraisal of relationship satisfaction (Lepore & Revenson, 2007).

Overall, these findings have implications for clinical practice and care of women with breast cancer and suggest that minimising constraining behaviours and reducing communication avoidance of cancer-related matters between spouses may be important targets for psychosocial interventions. Fostering a woman's and her partner's awareness of what unsupportive constraining behaviours can look like, and their likely negative impact on the couple's subsequent disclosure and relationship satisfaction may be an important first step. Psychosocial interventions that include assertiveness communication training component (Baucom et a., 2009; Hinnen, Hagedoorn, Ranchor & Sanderman, 2008) that explicitly aim to help couples problem-solve each other's constraint behaviours and maintain dialogue between couples about specific cancer-related matters may be more beneficial than interventions that promote only positive social interactions (Yang, Brothers & Anderson, 2008), such as social support and open talk about feelings and concern generally. Tailored psychoeducation about characteristics of adaptive and non-adaptive communication styles, and targeted communication skills training that teach couples on how to make effective assertive requests (i.e., using 'I' statements'), statements of refusal (i.e., saying no) and provide validating responses to difficult disclosures, may be more effective than provision of generic psychoeducational information about symptom management and communication (Keefe et al., 2005). Oncology nurses, counsellors, psychiatrists, psychologists, and social workers who have received training to address couples' communication processes would be

suited to deliver the skills training and psychoeducation. Our finding of the strong associations between a woman's social constraint behaviours and those of her partner, as well as a woman's communication avoidance behaviours about cancer and those of her partner, also suggest that involving partners spouses in the psychosocial interventions provided to women with breast cancer may be beneficial. Although our cross-sectional data do not permit causal interpretation, the high concordance corresponds to communication theories and prior research that emphasise the bidirectional and interdependent influence of unsupportive behaviours between spouses (Lepore & Revenson, 2007).

In the interpretation of these findings, some limitations need to be considered. First, the study employed a cross-sectional design, precluding determination of causality. It is unclear if social constraints between spouses contribute to poorer relationship satisfaction or whether poor relationship satisfaction influences individuals to elicit and/or perceive more frequent spousal constraint signals. It is plausible that poor patient relationship satisfaction may influence spousal social constraints in a bidirectional manner such to create a self-perpetuating cycle of eliciting greater spousal social constraints and reduced social and cognitive processing that further sustains and worsens patient relationship satisfaction and psychosocial adaptation to cancer. The possibility that social constraints may mediate communication avoidance, rather than the reverse, and that relationship satisfaction affect both these processes should also be evaluated. Future work on social constraints, communication avoidance and relationship satisfaction over time will help clarify the precise directionality of these processes and their underlying mechanisms. Findings of intervention studies that successfully reduce communication avoidance about cancer and poor relationship satisfaction through targeting constraint signals between spouses would, however, lend support to the causal interpretation.

Future work should also evaluate social constraints related to different cancer-related topics with relationship satisfaction, within and across days. This is especially important because qualitative research suggests that perceptions of constraints can change over time among couples and that some cancer-related topics may be more emotionally charged and difficult for couples to discuss than others (Badr, Carmack & Taylor, 2006). Future work that differentiates constraint signals on disclosure of cancer-specific and other non-cancer related topics would also help to clarify the extent to which interventions should focus on improving the way couples overcome constraint signals on disclosure about cancer-related matters specifically or broadly improve the way couples communicate and relate to each other.

The third limitation to our study is that couple social constraints, communication avoidance and relationship satisfaction were assessed using self-report measures as completed by the women with breast cancer, without independent verification. It is possible that some of the obtained responses on social constraints and communication avoidance were not reflective of actual enacted behaviours by the women themselves and their partners, and were distorted in socially desirable ways. Moreover, some of the women's perceptions of their partners' communications may have been shaped by the woman's own emotional state and cognitive biases. Future work should supplement self-report methodology with longitudinal and experimental analyses of couple interactions in laboratory or natural contexts.

Fourth, study participants were all fluent in English, had access to computers and were mostly white, and well-educated. The relative ethnic, educational and socio-demographic homogeneity of the participants may have led to sample-specific patterns in the data, limiting the generalisability of our findings beyond our sample. Differences in socio-economic status, culture and family structure can all influence the ways in which couples adapt to stressful life event, such as breast cancer. Nevertheless, the present study sample

aligns with the general demographic picture of women diagnosed with breast cancer in Australia (AIHW, 2012) and previous research of similar community-based breast cancer populations (Przezdziecki et al., 2013; Sheehan, Sherman, Lam & Boyages, 2007).

Another limitation of the study is that the study did not examine the underlying motivations of social constraint behaviours. An individual within a dyad may constrain the other person from discussing cancer-related concerns for various reasons not limited to unsupportive motivations, such as to protect oneself or support partner from unnecessary discomfort of discussing difficult cancer topics, to maintain normality and optimism, to prevent futile or unproductive discussions, and/or to not impose unnecessary burden on spouse (Goldsmith, Miller & Caughlin, 2008). The study also had no way of assessing couples' marital functioning prior to the woman's cancer diagnosis. Future work on relationship satisfaction over time, prior and during cancer will be important to better understand the directionality of the social constraints-relationship satisfaction relationship.

In summary, the present study examined the associations of self- and perceived partner social constraints and communication avoidance about cancer, and patient-reported relationship satisfaction among breast cancer survivors. The results indicate that spousal social constraints is not only directly associated with lower relationship satisfaction, but may also contribute to poor marital functioning by impeding individuals' social processing about cancer. Minimising unsupportive constraining behaviours and reducing communication avoidance about cancer between spouses may be important targets for psychosocial interventions. Future work should clarify the directionality of the social constraints-relationship satisfaction link, and the potential mediating role of communication avoidance, as well as the specific cognitive and emotional pathways that relate spousal social constraints to compromised social processing and relationship satisfaction.

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Chapter 4: General discussion

The diagnosis and treatment of breast cancer present many physical and psychosocial challenges, and can have significant negative impact on a woman's mental health and her relationships. Most women navigating breast cancer fortunately do not navigate cancer alone. The past two decades have seen scholars expand their scope from examining the ill-affected patient experience to also exploring the transactional dynamics of communication between spouses that uniquely contribute to couple's psychosocial adaptation to cancer. Couple communication has consistently emerged as a strong predictor of psychosocial adaptation outcomes in individuals with cancer and their partners (Badr, 2016; Li & Loke, 2014). Few studies to date, however, have focused on couples' communication in cancer as a primary outcome, frequently using brief (typically single-item) and imprecise global indices of communication. Current understanding of how couples communicate about cancer, how they negotiate and co-ordinate coping, and the association of specific dimensions of communication behaviours with different psychosocial adaptation outcomes and the underlying processes of these associations.

This thesis aimed to facilitate a greater understanding of the role of couples' communication in breast cancer adaptation to inform future descriptive and intervention research. Specifically, the literature review conceptualised the associations between major adaptive and non-adaptive communication strategies, and key psychosocial adaptation outcomes, as well as identified areas of knowledge gaps. Major theoretical and methodological frameworks that have guided this research were considered, and directions for future research also posited.

The two empirical studies examined negative dimensions of couple communication behaviours and their linkages with psychological distress and relationship satisfaction and underlying processes of these associations. Specifically, the first empirical study assessed the associations of patient-reported avoidance of specific cancer-related topics, reports of partner

avoidance of these topics, and coping and psychological distress among breast cancer survivors. The results of this study indicated that greater women's and perceived-partner's communication avoidance about cancer topics were associated with poorer mental health outcomes (anxiety, depression, and stress) in the women facing breast cancer. This study also provided support for the view that avoiding talk about cancer may influence the woman's emotional distress by impeding her coping ability, consistent with the transactional stress and coping paradigm. The second empirical study examined the relationship between social constraints and patient relationship satisfaction, and the indirect effect of avoidance of talk about cancer, in women with breast cancer and their spouses. The results of this study indicated that greater women's and perceived-partner social constraints were associated with poorer relationship satisfaction as reported by the women with cancer. This study also provided support for the view that social constraint signals may be detrimental to patient relationship satisfaction by impeding individuals' social processing about cancer, consistent with the social cognitive processing model.

The results of the two empirical studies need to be considered in view of the following limitations. First, both empirical studies employed a cross-sectional design and the data were correlational, precluding determination of causality between any of the study variables. Second, all study data on couple communication, relationship satisfaction and psychological distress was obtained using self-report measures completed by a self-selected group of women who were previously diagnosed with breast cancer. It is possible that women who were experiencing communication difficulties with their partners and marital distress were also more likely to participate in the study. The self-report and retrospective methodology may also have elicited responses that are confounded by the woman's own emotional state, cognitive biases and degree of general relationship satisfaction with her partner. No data from spouses were gathered. The study findings therefore do not provide a

true dyadic perspective on couple communication and are missing half the picture on partner's own psychosocial adjustment, and partner perception of enacted and spousal-perceived patient communication behaviours. Future research that assesses both patient and partner perspectives, using longitudinal and experimental dyadic designs in laboratory or natural contexts will be important. This work will not only allow future researchers to better delineate whether actual enacted communication behaviours or perceived communication behaviours are more important determinants of patient and partner psychosocial adaptation, but also inform the development of models of couple communication and support processes that are more reciprocal and relational in its conceptualisation.

Another limitation is that study participants were all English speaking, had access to computers and were predominantly Australian born of Caucasian background, limiting the generalisability of our findings beyond our sample. Nevertheless, the study sample is similar in composition to previous research of similar community-based breast cancer populations (Przezdziecki et al., 2013) and aligns with previous Australian research of similar community-based breast cancer populations (Sheehan, Sherman, Lam & Boyages, 2007).

Despite these limitations, the two empirical studies contribute to the literature in several important ways. While distilling clinical interventions from the studies' correlational retrospective data is premature, the findings raise questions for further study and suggest implications for clinical practice and care of women with breast cancer. Specifically, the findings indicate that helping couples navigate and overcome unsupportive partner constraint behaviours, and minimise communication avoidance about specific cancer-related topics between spouses may be beneficial targets for psychosocial interventions.

A key finding that may inform intervention practices is the likely differential mediating effects of engagement and disengagement coping on the communication-distress

relationship observed in the first study. Psychosocial interventions for cancer patients typically reinforce the importance of engagement coping strategies, such as seeking social and instrumental support, and problem-solving, and not the adverse effects of using disengagement coping strategies, such as denial and self-blame. Clinically, these findings suggest that delivering support interventions that explicitly aim to both discourage the use of disengagement coping, and promote engagement coping may be most beneficial for women with breast cancer in supporting their psychological adjustment. While not directly tested, in a similar vein, psychosocial interventions that explicitly aim to both discourage negatively oriented dimensions of communication behaviours, such as communication avoidance and unsupportive social constraint behaviours, and promote constructive communication behaviours may be most beneficial to promoting woman's psychological and relationship outcomes.

Additional to communication skills training, individualised psychoeducation about characteristics of supportive and unsupportive communication behaviours, and targeted communication skills training by oncology nurses and psychologists that can help couples overcome and repair communications difficulties and challenges, may be more impactful than psychosocial interventions that simplistically encourage open communication between spouses about all cancer topics at all times. More fine-grained analyses of couples' disclosure patterns about specific cancer topics and their linkages with coping and adaptation outcomes are needed to refine the specificity of couple-based intervention guidelines about which cancer topics couples should be instructed to converse more or less, the frequency and lengths of these conversations, and the circumstances for when it is most appropriate to discuss some topics and not others, in support of couples' coping.

The study findings also inform screening guidelines and practices. Our finding of the negative correlation between relationship length and women's level of communication

avoidance suggests that women in less established relationships may have more difficulty talking about cancer with their spouse and require more careful screening by oncology health professionals. A greater awareness by oncology health professionals of the broad range of social constraint signals that couples can send each other, and commonly avoided cancer topics between spouses may also assist these professionals to more sensitively recognise and address couples' conversational and support needs in clinical practice. More targeted screening of couple's communication avoidance of specific cancer-topics and sending of constraint signals between spouses may also help identify couples at risk of poor individual and relationship adjustment to cancer, and facilitate more timely referral and access to psychosocial services. It may be good clinical practice for oncology health care providers to routinely question the basis of a woman's psychological and marital distress, and normalise the conflict and strain that breast cancer can impose on couple relationships, and the difficulty of talking about particular cancer-related concerns. Conversing about practical cancer-related matters, such as physical symptom management and experiences with healthcare professionals may be less difficult than discussing topics that are more emotionally charged, such as fears about disease progression and death, and sexual problems (Yu & Sherman, 2015).

The finding of the strong associations between a woman's social constraint behaviours and those of her partner, as well as a woman's communication avoidance about cancer and those of her partner, also suggest that inclusion of spouses in psychosocial interventions or offering of additional support to the spouses of women with breast cancer, may be beneficial for improving patient psychological and relationship outcomes. Although recent reviews in the cancer context have found no compelling evidence on the benefit of psychosocial interventions that involve both patient and their spouses as compared to patient-only or partner-only interventions (Brandao, Schulz & Matos, 2014; Regan et al., 2012),

continued couple-based intervention research is important in context of the paucity of quality intervention studies that have used dyadic methodology with data collected from both patients and their partners. Moreover, the majority of couple-based intervention studies in cancer lack theoretical and conceptual grounding (Badr & Krebs, 2012; Li & Loke, 2014). A major contributing factor is that current existing dyadic-level theories do not yet include psychological adaptation in its models (Manne & Badr, 2008). Continued theoretical articulation to integrate current theoretical perspectives into one well-defined theoretical framework will be important to help organise existing research and facilitate the development of more targeted psychosocial interventions to improve couples' psychosocial adaptation outcomes.

Future work should also evaluate other equally important dimensions of communication behaviour, such as communication openness, constraint or frequency of talk related to specific cancer-related topics, with indices of coping and couple coping outcomes. Critical to such efforts is the development of more sophisticated communication measures that can characterise conceptually distinct dimensions of communication across cancer topics and at different time points of cancer experience. Future research that differentiates cancer-specific and general compromised communication processes would also help to clarify the extent to which interventions should focus on broadly improving the way couples communicate and relate to each other or target how they communicate about cancer specifically. Seeking a better understanding of the evaluative process that individuals within a dyad undertakes and the factors that shapes when an individual engages in compromised communication behaviours, and to what extent and what manner, will also be important to informing the development of psychosocial interventions that facilitate couple coping and adjustment to cancer.

It is hoped that this dissertation will facilitate a greater understanding of the role of couples' communication in breast cancer adaptation. Our studies indicate that the manner in which couples communicate with one another, the frequency of unsupportive responses, and topical focus of their talk, are all important considerations for whether or not couple talk contributes to couples' psychosocial adaptation to cancer. The study results, while based solely on patient perspectives, suggest that inclusion of spouses in psychosocial communication interventions provided to women navigating breast cancer may be beneficial for improving psychological and relationship outcomes of women navigating breast cancer. Many questions remain regarding how couples communicate about cancer, how they negotiate and co-ordinate coping, and the associations of specific dimensions of communication behaviours with patient and partner psychosocial adaptation outcomes, and the underlying processes of these associations. Future research that assesses both patient and partner perspectives using longitudinal and experimental dyadic designs in laboratory or natural contexts will help clarify this in the future. In order to move this area of research forward, communication measures need to be refined so that researchers can characterise conceptually distinct dimensions of communication (e.g., openness, avoidance, constraint) across cancer topics and at different time points of cancer experience. This will allow for more fine-grained analyses of specific couple communication behaviours and their linkages with coping and adaptation outcomes, and increase the specificity of couple-based intervention guidelines about which cancer topics couples should be instructed to converse more or less, the frequency and lengths of these conversations, and the circumstances under which it is most appropriate to discuss certain topics. Continued theoretical articulation to integrate current theoretical perspectives into one well-defined theoretical framework will also be important to help organise existing research and facilitate the development of more

targeted couple-based interventions that goes beyond broadly prescribing open disclosure of feelings and concerns.

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6. Appendices

6.1 Appendix I: Conference Presentation 'Communication avoidance, coping and psychological distress of women with breast cancer'

Presented by A/Prof Kerry Sherman at the 31st International Congress of Psychology in Japan, July 24 – 29, 2016

MACQUARIE University

Communication avoidance, coping and psychological distress of women with breast cancer

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Journal of Behavioural Medicine (2015) Communication avoidance, coping and psychological distress of women with breast cancer, 38, 565-577.

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Background

- Breast cancer is a heterogeneous disease with a highly variable clinical course (Stanton & Revenson, 2011) presenting affected women with myriad physical and psychosocial stressors.
- Research focused on interpersonal dynamics points to the importance of couple communication in women's psychological adjustment to breast cancer (for review, see Goldsmith et al., 2008).
- Prior research (e.g., Lewis et al., 2008; Weihs et al., 2008) has tended to use global abstract evaluative questions, such as "*have you been able to talk about your feelings and problems with your partner in the last 2 weeks*" or "*do you frequently discuss your illness with your spouse?*", to assess communication between couples.
- Another limitation of past work is the lack of empirical research examining potential mechanisms that may explain the association between avoidant spousal communication and women's psychological distress (Donovan-Kicken & Caughlin, 2011; Manne et al., 2010).

Study Aims and Hypotheses

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- The current study examined in the breast cancer context the association of patient-reported communication avoidance of specific cancer-related topics, as well as perceived partner avoidance of these topics, with women's coping and psychological distress.
- A further aim was to evaluate and characterise the degree of communication avoidance of specific cancer-related topics by the cancer-affected women and their spouses.
- Research Hypotheses:
  - Communication avoidance by the cancer-affected woman and her partner would be associated with her greater depression, anxiety and stress.
  - Both the woman's and her perceived partner's communication avoidance would be associated with her psychological outcomes, with effects mediated by her greater use of disengagement coping strategies and less use of engagement strategies.

Method

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- Participants
  - 338 women diagnosed with breast cancer
  - Age: 53.50 years (*SD* = 9.22, range 28 to 81)
  - The women on average were diagnosed 35.9 months prior to study entry (*SD* = 24.24, range = 6-213).
  - Average relationship length: 25.9 years (*SD* = 13.12, range 1.8-63 years).
- Procedure
  - Participants completed an online survey including measures of self- and perceived-partner communication avoidance, psychological distress (depression, anxiety and stress), coping strategies and demographic characteristics.

Measures

Communication Avoidance

- Communication avoidance was assessed using a seven-subscale measure reflecting different cancer-related topics (Donovan-Kicken & Caughlin, 2010) that have been identified as important concerns for women with breast cancer.
- Cancer Topic Subscales
  - **Death**, focuses on end of life matters (α = .93 for women and α = .94 for partners)
  - **Treatment** includes items about aspects of medical treatments (α = .91 for women and α = .93 for partners)
  - **Sexuality** addresses intimacy and body image concerns (α = .93 for women and α = .95 for partners)
  - **Being a burden** includes items about added stressors related to finances, household contribution, and care-taking responsibilities (α = .90 for women and α = .93 for partners)
  - **Feeling** includes items about expression of concerns and fears related to breast cancer (α = .94 for women and α = .96 for partners)
  - **Relating** includes questions about relationship satisfaction and communication (α = .91 for women and α = .95 for partners)
  - **Healthcare** addresses experiences with health care providers (α = .96 for women and α = .98 for partners)

Measures

Psychological Distress

- 21-item short form of the Depression, Anxiety and Stress Scale (DASS-21; Lovibond & Lovibond, 1996)
- α = .88 Depression; α = .81 Anxiety; α = .89 Stress

Coping

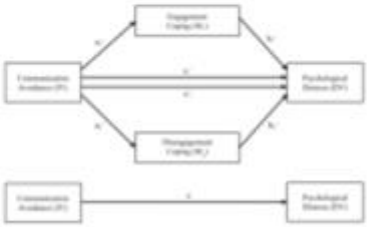
- The Brief COPE (Carver, 1997)
- A two-factor structure was supported when exploratory factor analysis was conducted
  - Engagement coping α = .84
  - Disengagement coping α = .77

Physical functioning

- 8-item Physical Wellbeing Subscale of Functional Assessment of Cancer Therapy self-report questionnaire (FACT-B; Cella et al., 1993)
- α = .82

Results

- Linear regression analyses indicated that women's and perceived-partner's communication avoidance was associated with poorer anxiety, depression, and stress in the cancer-affected women.
- Bootstrapping analyses showed significant mediation effects of self- and perceived-partner communication avoidance on all distress outcomes through greater disengagement coping, and on anxiety through lower engagement coping.



Results

Degree of communication avoidance of specific cancer-topic avoidance

- Most to least avoided topic subscales by **women**
  - Expression of cancer related feelings *M*=2.65
  - Concerns about sexuality *M*=2.62
  - Concerns about disease progression and death *M*=2.50
  - Experiences with health care providers *M*=1.84
  - Cancer treatment *M*=1.95

- Similar pattern found for perceived partner communication avoidance as rated by cancer-affected women

Discussion

- Couples coping with cancer have more difficulties discussing emotionally valenced topics related to disease progression and death, sexuality, and feelings than more practical concerns such as cancer treatment and relationship with health professionals
- The study findings are consistent with the transactional stress and coping paradigm and provide support for the view that avoiding talk about cancer may influence the woman's emotional distress by impeding her coping ability.

Implications for Clinical Practice and Care

- Minimising communication avoidance of cancer-related matters between spouses and enhancing a woman's coping capacity (i.e., discourage use of disengagement coping strategies and promote use of engagement coping strategies) may be important targets for psychosocial intervention.

Clinical Implications

- Tailored psycho- education about each woman's personal vicious cycle of maladaptive communication and coping processes may be more effective than provision of generic psycho-educational information.
- A greater awareness by oncology health professionals of commonly avoided cancer topics between spouses may assist these professionals to more sensitively recognise and address couples' conversational needs in clinical practice. More targeted screening of women's communication of specific cancer topics and coping styles may help identify women at risk of developing psychopathology and facilitate more timely referral and access to psychosocial services. It may be good clinical practice for oncology health care providers to routinely question the basis of a woman's psychological distress and normalise the difficulty of talking about particular cancer- related concerns.
- Delivering support interventions that explicitly aim to both discourage the use of disengagement coping, and promote engagement coping, may be most beneficial for women with breast cancer, in view of the differential mediating effect of engagement and disengagement coping on the communication-distress relationship.

Study Limitations

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- Methodological
  - Cross-sectional design
  - Mediation analyses can only be suggestive of a true mediating effect
  - Couple communication data were obtained using the woman's self-report of her and partner's communication, without independent verification. It is possible that some of the women distorted their responses in social desirable ways, confounding research findings.
  - Future work should supplement self report methodology with experimental analyses of couple interactions in laboratory or natural contexts.
  - Only one dimension of communication behaviour: communication avoidance. Future work should evaluate other equally important dimensions of communication behaviour, such as communication openness, constraint or frequency of talk related to specific cancer-related topics, with indices of coping and distress outcomes

Conclusion

MACQUARIE University

- This study utilised a multi-topic communication measure to assess the associations of patient-reported avoidance of specific cancer-related topics, reports of partner avoidance of these topics, and indices of coping and psychological distress among breast cancer survivors.
- The results indicate that couples coping with cancer have more difficulties discussing emotionally valenced topics than more practical concerns, holding important clinical implications for screening guidelines and clinical practice.
- The results also indicate that communication avoidance about cancer between spouses is not only directly associated with more negative psychological consequences for the woman, but may also influence her psychological distress by impeding her coping ability.
- Enhancing couple communication about cancer and women's adaptive coping skills (i.e., discourage use of disengagement coping strategies such as self-blame and denial, and promote use of engagement coping strategies such as positive reframing and acceptance) may be important targets for psychosocial intervention.
- Further research is needed to ascertain the directionality of the communication-distress relationship and the potential mediating role of coping, and to determine the most appropriate psycho-intervention approaches for this situation.

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6.2 Appendix II: Ethics Approval Letter for Empirical Studies 1 and 2

Appendix II of this thesis has been removed as it may contain sensitive/confidential content

6.3 Appendix III: Measures used in Empirical Studies 1 and 2

6.3.1 Information Sheet and Informed Consent Form

PROTOCOL NO: 5201200864

INVESTIGATORS: Yisha Yu & Kerry Sherman, PhD, Macquarie University Sydney

Before you decide whether or not you wish to participate in this study, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish.

What is this study about?

You are invited to take part in a research study examining women's experience coping with breast cancer, specifically in relation to communicating about various cancer-related topics with partners, family and friends .

Why have I been invited to participate in this study?

You are being invited to participate in this study as you have voluntarily supplied your name and details to be listed as part of the Breast Cancer Network Australia Registry, so that you could be contacted to take part in psychological research.

This is a research study and your participation is completely voluntary. Please read this form carefully. If there is anything in this consent form that you do not understand please contact Dr Kerry Sherman (details below).

Once you understand what the study is about and if you agree to take part, you will be asked to provide your consent by clicking 'I agree to participate'.

Who Can Participate?

To be eligible for the study, you need to self-identify as:

- A woman over 18 years of age
- Diagnosed with breast cancer for the first time (any stage, including DCIS and metastatic disease) within the last 5 years Was in a committed relationship with a partner before your breast cancer diagnosis and is currently in a relationship and cohabiting with the same partner.
- Have a fluent understanding of English as the questionnaire measures are not currently produced in other languages.

Who is conducting the research study?

This research is being conducted by Ms Yisha Yu (yisha.yu@mq.edu.au), a student at Macquarie University, Sydney, to meet the requirements for the degree of Master of Philosophy in Psychology under the supervision of Senior Lecturer Dr Kerry Sherman (Ph. 9850 6874, email: kerry.sherman@mq.edu.au) of the Department of Psychology, Faculty of Human Sciences.

What does participation involve?

If you agree to participate, you will be asked to complete an online questionnaire, which takes approximately 30 minutes to complete. During that time, you will be asked about your opinions, feelings, and experiences related to your breast cancer experience, in particular how and why you and your partner have avoided talking with each other about cancer-related topics.

Will I benefit from the study?

Participating in this study may or may not help you feel more comfortable with your breast cancer experience. We hope, however, that the information from this study will help us improve the services and resources offered to women and their families coping with breast cancer.

What if I don't want to take part in this study or if I want to withdraw later??

Participation in this study is completely voluntary and your decision to participate or not will have no effect on your current or future relations with Macquarie University, the School of Psychology, or any relations you share with BCNA. If you decide to participate, you are free to withdraw at any time during the questionnaire without affecting those relationships. It is not possible to withdraw your data after they have been submitted due to the anonymous nature of the questionnaire.

What happens with the results?

If you are willing to participate, you can be confident that your identity will be protected and that your responses will be valued and respected. The records of this study, including all questionnaires, will be kept confidential. In any sort of professional report we might publish (for example, in a psychology journal), we will not include any information that will make it possible to identify a participant. Research records will be stored on a password protected computer file or kept in a locked cabinet in a locked room and only the researchers will have access to them. Five years after publication, all data will be destroyed.

Are their risks to me in taking part in this study?

There are no known risks associated with this study. However, it is possible that you may feel some degree of emotional discomfort when answering some questions about your breast cancer experience. You can choose to not answer those questions. If you do feel upset or distressed in any way while filling in this questionnaire, please stop answering questions and contact Lifeline (phone: 13 11 14; http://www.lifeline.org.au/), and/or Relationships Australia (phone: 1300 364 277; http://www.relationships.org.au) . Lifeline provides 24 hour crisis telephone and online counselling. Relationships Australia offers family and relationship counselling as well as a range of specialist counselling services. You are also encouraged to inform the Principle Investigator for this study, who can refer you to a counsellor as required. The questions in the survey do not require you to identify yourself. All participants however are given the option to leave their contact details at the end of the survey to go into a draw to win a $50 gift voucher. Women who make their contact details available to study research staff and score high on psychological distress on their survey response will be contacted by research staff to be provided with appropriate referrals to a counsellor if desired, or to other resources as required.

Who do I contact if I have questions or need further information?

If you have any information about the study, or if you have any problems while you are participating in this study, you may contact Dr Kerry Sherman at Macquarie University either by phone on 02 9850 6874 or by email (Kerry.Sherman@mq.edu.au).

Who should I contact if I have concerns about the conduct of this study?

The ethical aspects of this study have been approved by the Macquarie University Human Research Ethics Committee. If you have any complaints or reservations about any ethical aspect of your participation in this research, you may contact the Committee through the Director, Research Ethics (telephone (02) 9850 7854, fax (02) 9850 8799, email: ethics@mq.edu.au). Any complaint you make will be treated in confidence and investigated, and you will be informed of the outcome.

Thank you for taking the time to consider this study.

CONSENT FORM

Title: Women's communication experiences when coping with breast cancer

Investigators: Yisha Yu and Dr Kerry Sherman

I have read and understood the Participant Information Sheet. The nature and purpose of the research study is clear to me. I understand that I may not directly benefit from taking part in the study.

I understand that, while information gained during the study may be published, I will not be identified and my personal results will remain confidential.

I understand that any refusal to participate in the research will not prejudice my future care in any way. I understand that I am free to leave this study at any time during the questionnaire.

I have contact information of mental health support services in case I want to talk to someone about my concerns. I have the names and telephone numbers of the research team in case I have any queries about the study.

I freely agree to be a participant in this study.

If you are willing to participate in the following study, please indicate your consent by clicking the **"I agree to participate"** button below.

Please note: by clicking this link you will be taken to the online questionnaire.

If you do not wish to participate in this study, please click on the **"I do not wish to participate"** button below and you will be returned to the BCNA home page.

Please click 'print' if you would like to keep a copy of study information for future reference.

- o I agree to participate
- o I do not wish to participate

6.3.2 Demographic Information

What is your age (in years)?

What is your country of birth?

Australia	New Zealand	United Kingdom/Ireland	Asia	Middle East	Western Europe	Eastern Europe	Pacific Islander	Other
1	2	3	4	5	6	7	8	9

What is the highest level of education you have completed?

Less than Grade 10	Grade 10 (School Certificate)	Grade 12 (Higher School Certificate)	Vocation/Tafe	University Bachelor's degree	Master's degree	Doctoral degree
1	2	3	4	5	6	7

What is your current marital status?

Single, never married	Married, or living with partner	Divorced, or separated	Widowed
1	2	3	4

How long have you been with your current partner in years (including dating and marriage, if applicable)?

In what month and year were you diagnosed with breast cancer?

Please indicate what grade of breast cancer you were diagnosed with

DCIS	Grade 1	Grade 2	Grade 3	Don't know as yet
1	2	3	4	5

Are you about to have a mastectomy?

Yes; single mastectomy	Yes; double mastectomy	No, I am not	No I have already had a mastectomy
1	2	3	4

Are you currently undergoing radiation therapy for your breast cancer?

Yes	No, I have yet to start radiation therapy	No, I have completed all my breast cancer treatments
1	2	3

How long have you been undergoing radiation therapy?

Year(s) _____

Month(s) _____

Are you currently undergoing chemotherapy for your breast cancer?

Yes	No
1	2

How long have you been undergoing chemotherapy?

Year(s) _____

Month(s) _____

6.3.3 Topic Avoidance Scale

When couples are dealing with breast cancer, there might be cancer-related topics that they avoid discussing. The following list contains topics that people might avoid talking to their partners about. Please consider how strongly you agree that YOU AVOID talking to your partner about these topics

I avoid talking to my partner about…

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
my cancer	1	2	3	4	5
plans for the future	1	2	3	4	5
questions I have about the future	1	2	3	4	5
end of life	1	2	3	4	5
the possibility that I might not recover	1	2	3	4	5
the chance that I might die	1	2	3	4	5
the possibility of my cancer coming back after treatment	1	2	3	4	5
the chance that my cancer might not be cured	1	2	3	4	5
certain aspects of my treatment(s)	1	2	3	4	5
all aspects of my treatment(s)	1	2	3	4	5
reconstructive surgery	1	2	3	4	5
side effects from my treatment(s)	1	2	3	4	5
decisions about possible treatment regimens	1	2	3	4	5
my body	1	2	3	4	5
my appearance	1	2	3	4	5
our sexual relationship	1	2	3	4	5
physical intimacy	1	2	3	4	5
my ability to do household chores	1	2	3	4	5
how much I seem like myself	1	2	3	4	5
my physical discomfort	1	2	3	4	5
whether I am a burden on my partner	1	2	3	4	5
who will take care of me if I become extremely ill	1	2	3	4	5

I avoid talking to my partner about…

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
work and other responsibilities I have	1	2	3	4	5
finances	1	2	3	4	5
insurance and medical expenses	1	2	3	4	5
some or all of my concerns	1	2	3	4	5
some or all of my emotions	1	2	3	4	5
negative feelings that I have	1	2	3	4	5
things that I'm worried about	1	2	3	4	5

aspects of my cancer and treatment that make me nervous	1	2	3	4	5
upsetting information that I get from physicians	1	2	3	4	5
distressing information about cancer that I hear in the news	1	2	3	4	5
my anger	1	2	3	4	5
my partner's anger	1	2	3	4	5
our marriage/our relationship	1	2	3	4	5
how well we are getting along	1	2	3	4	5
our communication	1	2	3	4	5
how satisfied I am with our relationship	1	2	3	4	5
talking to our children or other loved ones about my illness	1	2	3	4	5
interactions with my physicians	1	2	3	4	5
experiences with health care providers	1	2	3	4	5
doctor visits	1	2	3	4	5
hospital stays	1	2	3	4	5

Next, please think about the topics that your partner avoids talking to you about. In your opinion, how strongly do you agree that YOUR PARTNER AVOIDS discussing the following things with you?

My partner avoids talking with me about…

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
my breast cancer	1	2	3	4	5
plans for the future	1	2	3	4	5
questions I have about the future	1	2	3	4	5
end of life	1	2	3	4	5
the possibility that I might not recover	1	2	3	4	5
the chance that I might die	1	2	3	4	5
the possibility of my cancer coming back after treatment	1	2	3	4	5
the chance that my cancer might not be cured	1	2	3	4	5
certain aspects of my treatment(s)	1	2	3	4	5
all aspects of my treatment(s)	1	2	3	4	5
reconstructive surgery	1	2	3	4	5
side effects from my treatment(s)	1	2	3	4	5
decisions about possible treatment regimens	1	2	3	4	5
my body	1	2	3	4	5
my appearance	1	2	3	4	5
our sexual relationship	1	2	3	4	5
physical intimacy	1	2	3	4	5
my ability to do household chores	1	2	3	4	5
how much I seem like myself	1	2	3	4	5

my physical discomfort	1	2	3	4	5
whether I am a burden on my partner	1	2	3	4	5
who will take care of me if I become extremely ill	1	2	3	4	5

My partner avoids talking with me about…

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
work and other responsibilities I have	1	2	3	4	5
finances	1	2	3	4	5
insurance and medical expenses	1	2	3	4	5
some or all of my concerns	1	2	3	4	5
some or all of my emotions	1	2	3	4	5
negative feelings that I have	1	2	3	4	5
things that I'm worried about	1	2	3	4	5
aspects of my cancer and treatment that make me nervous	1	2	3	4	5
upsetting information that I get from physicians	1	2	3	4	5
distressing information about cancer that I hear in the news	1	2	3	4	5
my anger	1	2	3	4	5
my partner's anger	1	2	3	4	5
our marriage/our relationship	1	2	3	4	5
how well we are getting along	1	2	3	4	5
our communication	1	2	3	4	5
how satisfied I am with our relationship	1	2	3	4	5
talking to our children or other loved ones about my illness	1	2	3	4	5
interactions with my physicians	1	2	3	4	5
experiences with health care providers	1	2	3	4	5
doctor visits	1	2	3	4	5
hospital stays	1	2	3	4	5

6.3.4 Depression, Anxiety and Stress Scale (DASS-21)

Please read each statement and indicate how much the statement applied to you over the past week. There are no right or wrong answers. Please do not spend too much time on any statement.

	Not at all	Some of the time	A good part of the time	Most of the time
I found it hard to wind down	0	1	2	3
I was aware of dryness of my mouth	0	1	2	3
I couldn't seem to experience any positive	0	1	2	3
I experienced breathing difficulty (e.g., excessive rapid breathing, breathlessness in the absence of physical exertion)	0	1	2	3
I found it difficult to work up the initiative to do things	0	1	2	3
I tended to over-react to situations	0	1	2	3
I experienced trembling (e.g., in the hands)	0	1	2	3
I felt that I was using a lot of nervous energy	0	1	2	3
I was worried about situations in which I might panic and make a fool of myself	0	1	2	3
I felt that I had nothing to look forward to	0	1	2	3
I found myself getting agitated	0	1	2	3
I found it difficult to relax	0	1	2	3
I felt down-hearted and blue	0	1	2	3
I was intolerant of anything that kept me from getting on with what I was doing	0	1	2	3
I felt I was close to panic	0	1	2	3
I was unable to become enthusiastic about anything	0	1	2	3
I felt I wasn't worth much as a person	0	1	2	3
I felt that I was rather touchy	0	1	2	3
I was aware of the action of my heart in the absence of physical exertion (e.g., sense of heart rate increase, heart missing a beat)	0	1	2	3
I felt scared without any good reason	0	1	2	3
I felt that life was meaningless	0	1	2	3

6.3.5 The Brief COPE

The following statements deal with ways you've been coping with the stress in your life since you found out that you have breast cancer. There are many ways to try to deal with problems. These items ask what you've been doing to cope with this one. Obviously, different people deal with things in different ways, but I'm interested in how you've tried to deal with it. Each item says something about a particular way of coping. I want to know to what extent you've been doing what the item says. How much or how frequently. Don't answer on the basis of whether it seems to be working or not — just whether or not you're doing it. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can

	I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot
I've been turning to work or other activities to take my mind off things.	1	2	3	4
I've been concentrating my efforts on doing something about the situation I'm in.	1	2	3	4
I've been saying to myself "this isn't real".	1	2	3	4
I've been using alcohol or other drugs to make myself feel better.	1	2	3	4
I've been getting emotional support from others.	1	2	3	4
I've been giving up trying to deal with it.	1	2	3	4
I've been taking action to try to make the situation better.	1	2	3	4
I've been refusing to believe that it has happened.	1	2	3	4
I've been saying things to let my unpleasant feelings escape.	1	2	3	4
I've been getting help and advice from other people.	1	2	3	4
I've been using alcohol or other drugs to help me get through it.	1	2	3	4
I've been trying to see it in a different light, to make it seem more positive.	1	2	3	4
I've been criticizing myself.	1	2	3	4
I've been trying to come up with a strategy about what to do.	1	2	3	4
I've been getting comfort and understanding from someone.	1	2	3	4
I've been giving up the attempt to cope.	1	2	3	4
I've been looking for something good in what is happening.	1	2	3	4
I've been making jokes about it.	1	2	3	4

I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.	1	2	3	4
I've been accepting the reality of the fact that it has happened.	1	2	3	4
I've been expressing my negative feelings.	1	2	3	4
I've been trying to find comfort in my religion or spiritual beliefs.	1	2	3	4
I've been trying to get advice or help from other people about what to do.	1	2	3	4
I've been learning to live with it.	1	2	3	4
I've been thinking hard about what steps to take.	1	2	3	4
I've been blaming myself for things that happened.	1	2	3	4
I've been praying or meditating.	1	2	3	4
I've been making fun of the situations.	1	2	3	4

6.3.6 Physical Well-Being Subscale of Functional Assessment of Cancer Therapy self-report questionnaire (FACT-B)

Below is a list of statements that other people with breast cancer have said are important. Please read each statement and indicate how much the statement applied to you OVER THE PAST WEEK.

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I have a lack of energy	0	1	2	3	4
I have nausea	0	1	2	3	4
Because of my physical condition, I have trouble meeting the needs of my family	0	1	2	3	4
I have pain	0	1	2	3	4
I am bothered by side effects of treatment	0	1	2	3	4
I feel ill	0	1	2	3	4
I am forced to spend time in bed	0	1	2	3	4

6.3.7 Social Constraints Measure

People have lots of different reasons for why they might avoid talking about something. The next section of the questionnaire asks you to think about reasons why you and your partner may avoid talking about topics related to your breast cancer. First, please consider the extent to which you agree that these are the reasons WHY YOU AVOID talking to your partner.

	Strongly disagree	Disagree	Somewhat disagree	Agree	Somewhat agree	Agree	Strongly agree
My partner discourages me from talking about certain cancer-related things.	1	2	3	4	5	6	7
My partner doesn't like to talk about negative cancer-related topics.	1	2	3	4	5	6	7
I think my partner gets uncomfortable when I try to discuss cancer-related matters with him.	1	2	3	4	5	6	7
My partner avoids me when I try to discuss things with him.	1	2	3	4	5	6	7
I get the sense that my partner doesn't want to hear about my feelings and concerns.	1	2	3	4	5	6	7
My partner minimises my feelings and concerns.	1	2	3	4	5	6	7
I have been instructed not to talk openly about cancer-related matters.	1	2	3	4	5	6	7
I can tell that my partner doesn't want to talk about cancer-related concerns.	1	2	3	4	5	6	7

Now, please think about the reasons WHY YOUR PARTNER AVOIDS talking to you about topics related to your breast cancer. In your opinion, how much do you agree that these are the reasons why that happens?

	Strongly disagree	Disagree	Somewhat disagree	Agree	Somewhat agree	Agree	Strongly agree
I discourage my partner from talking about certain cancer-related topics.	1	2	3	4	5	6	7
My partner knows that I don't like to talk about negative cancer-related topics.	1	2	3	4	5	6	7

I get uncomfortable when my partner tries to discuss cancer-related concerns with me.	1	2	3	4	5	6	7
I avoid my partner when he tries to discuss cancer-related matters with me.	1	2	3	4	5	6	7
My partner gets the sense that I don't want to hear about his feelings and concerns related to my breast cancer.	1	2	3	4	5	6	7
I minimise my partner's feelings and concerns.	1	2	3	4	5	6	7
My partner has been instructed not to talk openly about cancer-related matters.	1	2	3	4	5	6	7
My partner can tell that I don't want to talk about cancer-related matters.	1	2	3	4	5	6	7

6.3.8 Dyadic Adjustment Scale (DAS-7)

Most persons have disagreements in their relationships. Please indicate below the approximate extent of agreement or disagreement between you and your partner for each item on the following list.

	Always disagree	Almost always disagree	Frequently disagree	Occasionally disagree	Almost always agree	Always agree
Philosophy of life	5	4	3	2	1	0
Aims, goals and things believed important	5	4	3	2	1	0
Amount of time spent together	5	4	3	2	1	0

How often would you say the following events occur between you and your partner?

	Never	Less than once a month	Once or twice a month	Once or twice a week	Once a day	More often
Have a stimulating exchange of ideas	0	1	2	3	4	5
Calmly discuss something	0	1	2	3	4	5
Work together on a project	0	1	2	3	4	5

The circles on the following line represent different degrees of happiness in your relationship with him. The middle point “happy” represents the degree of happiness of most relationships. Indicate below the degree of happiness all things considered of your relationship.

Extremely unhappy	Fairly unhappy	A little unhappy	Happy	Very happy	Extremely happy	Perfect
0	1	2	3	4	5	6