Dyadic coping in cancer and couple-based interventions

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Statement of Originality

The thesis contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. I give consent to the final version of my thesis being made available worldwide when deposited in the University’s Digital Repository**, subject to the provisions of the Copyright Act 1968.

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I hereby certify that this thesis is in the form of a series of published papers of which I am a joint author. I have included as part of the thesis a written statement from each co-author, endorsed by the Faculty Assistant Dean (Research Training), attesting to my contribution to the joint publications.

02/06/2014

Candidate Signature

Date
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Synopsis

This thesis by publication is composed of an introduction, seven papers, and a final chapter that includes discussion of the overall body of work undertaken and its implications for future research. The research described in this thesis was undertaken concurrently with the development and initial testing of a novel, self-directed, couple-based intervention for patients with prostate cancer and their partners called Coping-Together. All papers relate to couple-based interventions for patients with cancer and their partners, and the role dyadic coping (i.e., how couples cope with cancer together) plays in couples’ adjustment to cancer. At the time of submission, four of seven papers have been accepted for publication, which meets the requirements set out by the University of Newcastle for submitting a thesis by publication.

The Introduction presents an overview of the psychological impact of cancer on couples and the role dyadic coping plays in their adjustment to the disease. It provides a discussion on the prevalence of psychological distress among patients and partners, a summary of how coping with cancer has evolved from an individual concept to a dyadic concept, and a rationale for why in some cases it may be beneficial to intervene with distressed patients and partners together, rather than separately.

Paper One, “Couples coping with cancer: Exploration of theoretical frameworks from dyadic studies”, presents a review of the various theories of dyadic coping that have been used to explore how couples adjust following a diagnosis of cancer. This is an important first step in outlining the current state of dyadic coping in the context of cancer. This narrative review identified seven theoretical perspectives of coping and interpersonal relationships that have been applied in the cancer context, including the Systemic Transactional Model of dyadic coping (STM), and provides a summary of the findings, and compared and contrasted the specific characteristics of
each theoretical perspective. This paper is currently under review with *Psycho-Oncology*.

**Paper Two**, “*Cross-sectional relationships between dyadic coping and anxiety, depression, and relationship satisfaction for patients with prostate cancer and their spouses*”, explores empirical data collected from a baseline survey of a pilot study of a couple-based intervention called *Coping-Together*. This paper adds to the growing empirical evidence that patients’ and partners’ dyadic coping behaviour influence their own psychosocial outcomes and that of their spouse. The results suggested that positive forms of dyadic coping were associated with increased relationship satisfaction, whereas negative forms of dyadic coping were associated with decreased relationship satisfaction and increased anxiety and depression. The results also indicated that spouses’ use of dyadic coping influenced one another’s outcomes on anxiety, depression, and relationship satisfaction. This paper has been accepted for publication in *Patient Education and Counseling*.

**Paper Three**, “*Do Couple-Based Interventions Make a Difference for Couples Affected by Cancer?: A Systematic Review*”, presents the results of a systematic review of couple-based interventions for patients with cancer and their partners. Given the growing evidence that suggests couples’ react to cancer as an interdependent system, interventions designed for couples are becoming increasingly popular in psycho-oncology. This paper summarises the current evidence regarding the efficacy, feasibility, and acceptability of couple-based interventions in the context of cancer. The review indicated that couple-based interventions have a moderate impact on quality of life, psychological and relationship outcomes for couples affected that is comparable to individual-based interventions for patients and partners. However, the uptake of these interventions by couples, coupled with the rates of attrition from them, is an issue that
requires further exploration. This paper has been accepted for publication in *BMC Cancer*.

**Paper Four**, “*Uptake and attrition in couple-based interventions for cancer: Perspectives from the literature*”, presents a review of the uptake and attrition rates of patients and partners approached to participate in randomised controlled trials of couple-based interventions. Paper Three indicated that couple-based interventions were efficacious, however their applicability and feasibility needs to be explored in greater detail. This descriptive review explores the variation in uptake and attrition by cancer type and stage, and by intervention type, content, and delivery. The results suggested that uptake did differ between patients and partners, and was not affected by cancer type. In terms of attrition, partners of patients with late-stage cancer were more likely to drop out of a trial compared to patients. This paper has been accepted for publication in *Psycho-Oncology*.

**Paper Five**, “*A Qualitative Investigation of Health Care Professionals’, Patients’ and Partners’ Views on Psychosocial Issues and Related Interventions for Couples Coping with Cancer*” is a qualitative paper that compares and contrasts the perspectives of health care professionals (HCPs) involved in cancer care and couples facing cancer on how best to provide psychosocial support for couples. This paper provides a more in-depth exploration of the factors that influence the dissemination of couple-focused care. A range of HCPs, including oncologists, nurses, and psychologists, and couples facing various cancer diagnoses (e.g., breast prostate, head and neck) were interviewed. Results showed that HCPs and couples have different views regarding couple-focused care in cancer. For example, whereas most HCPs discussed the importance of referring couples to specialist psychosocial care, most couples felt they were coping well enough without specialist couple-focused psychosocial care and that
their primary health care professionals could provide sufficient psychosocial support. This paper is currently under review with *BMC Cancer*.

**Paper Six**, “‘You need something like this to give you guidelines on what to do’: Patients' and partners' use and perceptions of a self-directed coping skills training resource” is a qualitative paper exploring the feasibility of a self-directed, couple-based intervention called *Coping-Together* for patients with cancer and their partners. The results showed that couples enjoyed the self-directed format, and the intervention’s focus on practical strategies made it a welcome addition to other resources. Despite this, couples felt that the intervention included too many exercises, and felt that it was not feasible to expect both spouses to use the resource simultaneously as was intended. This paper has been accepted for publication in *Supportive Care in Cancer*.

**Paper Seven**, “A pilot, multisite, randomized controlled trial of a self-directed coping skills training intervention for couples facing prostate cancer: Accrual, retention, and data collection issues” reports on the implementation and two month follow-up from the *Coping-Together* pilot study. *Coping-Together* was found to be a feasible and acceptable intervention for couples that is well placed to be adapted in to routine cancer care. A lack of statistical power makes inferences regarding the efficacy of *Coping-Together* difficult, although the majority of non-significant trends that emerged suggest that the intervention has potential. This paper is currently under review with the *British Journal of Cancer*.

**In conclusion**, this body of work examined the current evidence and theoretical frameworks relevant to dyadic coping in couples facing cancer; examined the empirical basis for dyadic coping and couple-based interventions in couples; explored the barriers and facilitators of couple-based interventions and psychosocial care in routine practice; explored the feasibility, acceptability and efficacy of the first self-directed couple-based
intervention for couples coping with prostate cancer. The findings for this thesis fill important research gaps in psycho-oncology, specifically relating to the role of dyadic coping, the variation in HCPs and couples’ views on couple-focused care, and the potential of self-directed interventions for couples.
List of citations for papers included in this thesis

**Paper One:** Regan T., Lambert, S., et al. (2014). Couples coping with cancer: Exploration of theoretical frameworks from dyadic studies. *under review with Anxiety, Stress, and Coping.* [Appendix 1.1].


**Paper Four:** Regan, T., Lambert, S., et al. (2013). "Uptake and attrition in couple-based interventions for cancer: Perspectives from the literature." *Psycho-Oncology, 22(12).* [Appendix 4.1].


**Paper Six:** Lambert, S. D., Girgis, A., Turner, J., Regan, T., et al. (2013). “You need something like this to give you guidelines on what to do”: Patients' and partners' use and perceptions of a self-directed coping skills training resource. *Supportive Care in Cancer, 12(21).* [Appendix 6.1].

**Paper Seven:** Lambert, S. D., McElduff, P., Girgis, A., Levesque, J., Regan, T., et al. (2013). A pilot, multisite, randomized controlled trial of a self-directed coping skills
INTRODUCTION

Dyadic coping in cancer and couple-based interventions
In 1946, the World Health Organization (WHO) defined health as “a state of complete physical, social and mental well-being, and not merely the absence of disease or infirmity” [1]. This definition has served to promote an all-inclusive perspective of health, and research regarding the relationship between physical and mental health has been particularly prominent over the last 60 years [2-5]. There is growing evidence that people suffering from chronic illnesses including cancer, cardiovascular disease, stroke, and diabetes mellitus, tend to report poorer mental health than those not suffering from chronic illnesses [6]. Moreover, there is evidence to suggest that poorer mental health may also be associated with mortality [7]. Thus, understanding how best to support the psychological needs of patients and their families who are dealing with a chronic illness is an essential part of holistic health care.

**Global Cancer Prevalence, Incidence, Mortality**

Estimates of global cancer prevalence, incidence, and mortality have been compiled by the GLOBOCAN 2008 project, in conjunction with the International Agency for Research on Cancer (IARC) and the WHO [8, 9]. At the end of 2008, the global five-year prevalence of all cancer types (except non-melanoma skin cancer) was estimated at 28.8 million cases [8]. In that same period, 12.6 million new cases of cancer were diagnosed, and 7.5 million people died as a result of the disease [9].

Among women only, breast (33.9% of all cancer types), cervical (10.2%) and colorectal (9.8%) were the most prevalent in the five year period to 2008 [8]. The most frequent new diagnoses were breast (22.9% of new diagnoses), colorectal (9.4%), cervical (8.8%), lung (8.5%), and stomach (5.8%) cancers. In terms of mortality breast (13.7% of cancer deaths), lung (12.8%), colorectal (8.6%), cervical (8.2%), and stomach (8.2%)

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1 Caution must be taken when interpreting global cancer statistics, given differences in population characteristics, screening and detection practices, treatment practices, and diagnosis reporting procedures.
cancers had the highest rates of mortality [9]. Among men, prostate (23.7% of all cancer types), and colorectal cancer (13.1%) were the most prevalent in the five year period to 2008 [8]. The most frequent new cancers were lung (16.5% of new diagnoses), prostate (13.6%), and colorectal (10.0%) cancer. Lung (22.5%), liver (11.3%) and stomach (11.0%) cancer had the highest rates of mortality for men [9].

**Australian Cancer Prevalence, Incidence, and Mortality**

For the five-year period up to the end of 2007, 339,077 people were living with cancer in Australia [10]. Prostate cancer (39% of all cancer cases) was the most prevalent cancer among Australian men, followed by melanoma (14%) and bowel cancer (14%) [10]. For women, breast cancer (36%) was most prevalent, followed by melanoma (13%) and bowel cancer (13%) [10]. Moreover, prostate, breast, bowel and melanoma were also the most frequent new diagnoses among Australians diagnosed with cancer [9]. In 2008, Australia had the highest standardised incidence rate of cancer in the world, with 314 per 100,000 individuals being diagnosed with the disease, compared to a global standardised incidence rate of 180 per 100,000 individuals [9, 10]. Australia also had the highest rates of melanoma and prostate cancer, and the fourth-highest rate of breast cancer [9, 10]. These rates of prostate and breast cancer have increased since the early 1990’s, a trend most likely attributable to increases in screening practices such as prostate-specific antigen (PSA) testing and the BreastScreen program during this period [11-13]. There were 42,844 deaths as a result of cancer in 2010, with the majority (57%) of these being male [10]. Lung, bowel, prostate, breast, and pancreatic cancer accounted for almost half of all cancer deaths for both sexes, with lung cancer accounting for almost 20% of all cancer deaths [10]. Prostate cancer accounted for 13.3% of male deaths, breast cancer accounted for 15.3% of female deaths [10]. Bowel cancer accounted for 9% of deaths in males, and 9.5% of deaths in females [10].
Although cancer is prevalent in Australia, survival rates are amongst the highest in the world [10, 14]. For the period between 2006 and 2010, the five-year survival rate for both sexes across all cancers was 66.1%, with females (67.4%) having a marginally higher rate than males (65.1%). Breast cancer survival rates in Australia for this period were 90%, and prostate cancer survival rates for this period were 92% [10], comparable to reported rates of survival in North America, Japan and Western Europe [15]. However, mortality-to-incidence ratio (MIR) estimates indicate that survival from cancer diagnosis is more likely in Australia compared to all other countries [9, 10].

The prevalence, incidence, and mortality rates of cancer in Australia emphasise that the disease remains a significant health issue. However, given Australia's excellent cancer survival rate, patients and those close to them are living longer with both the physical and psychological consequences of cancer. Understanding how the person diagnosed is affected psychologically by cancer and its treatment, as well as how their loved ones manage cancer-related challenges is an integral part of providing quality supportive care [16].

**The Psychological Impact of Cancer**

Despite improvements in cancer detection and treatments leading to increased survival, a cancer diagnosis generates significant fear and distress for patients, their partners, and their families [17, 18]. Depending on cancer type, stage, and the criteria used to define distress, it has been estimated that between 4% and 47% of patients diagnosed with cancer will experience significant psychological distress as a consequence of the disease and its treatment [19-23]. This can impact on patient’s quality of life [24, 25] and treatment satisfaction [26-28]. Zabora and colleagues [23] conducted one of the largest studies of psychological distress among patients with cancer, and reported a prevalence rate of 35.1% across all cancer types. Patients
diagnosed with lung (43.4%) and brain (42.7%) cancers reported the highest rates of distress, whereas patients with prostate (30.5%) and gynecological (29.6%) cancers reported the lowest.

A cancer diagnosis reverberates throughout an individual’s family and broader social network, of which couples make up just one smaller support network. The news that someone has cancer is often distressing to their partners [29], their children [30, 31], and elderly parents and other relatives and friends [32]. Fearful reactions to cancer are common, but in many cases are a temporary response to the diagnosis, key illness-related events, or other transitions during the cancer trajectory [33]. Fluctuations in psychological distress are common as patients, their partners, and families cope with the news of the diagnosis and the effects of treatment, through to coping with issues in survivorship and palliative care [34]. Each of these stages presents various challenges, although it is important to acknowledge that the research presented in this thesis typically focuses on the time period around diagnosis and treatment. Increasingly, the impact of a diagnosis of cancer on partners or spouses is being recognised in the literature [35, 36]. Aside from having to take on new caregiving tasks, often with little advance warning, partners are also faced with the threat of being separated from their spouse, and the loss of the future they had envisioned spending together. The prevalence of psychological distress among partners has been estimated to be between 20% and 50% [29, 37]. Partners report similar emotional reactions to a cancer diagnosis as patients (e.g., fear, shock, anxiety) [18], and some studies have suggested that partners may experience these feelings to a greater degree than patients [38, 39]. Given the significant role partners play in the management of patients’ cancer and their adjustment to disease [40], it is important to examine how couples respond to a cancer diagnosis together.
The emotional toll of cancer has also been shown to remain over significant periods of time for patients and partners, although for many it does appear to decline with time [20, 41-44]. At six months post-diagnosis, it has been estimated that between 20-40% of patients experience depression and/or anxiety [20, 41-43]. At 12-months post-diagnosis, Burgess and colleagues [41] reported prevalence rates of depression and anxiety (including borderline and clinical cases) were as high as 48%, declining to 15% by five-year follow-up. Mitchell and colleagues [44] found similar outcomes reporting the long-term psychological impact of cancer, reporting that the relative risk for depression was lower among patients that were 2-10 years or more than 10 years post-diagnosis compared to those diagnosed within the last two years. However, the relative risk for anxiety was higher for those diagnosed more than 10 years ago than those diagnosed within the last two years or 2-10 years. This suggests that a large proportion of patients experience distress for a significant period post diagnosis and treatment, and that having experienced cancer may actually increase the risk of developing additional psychological distress many years after an initial diagnosis.

In a similar fashion, there is evidence to suggest that psychological distress among partners or carers also declines over time [45-47]. Lambert and colleagues reported the prevalence of borderline or clinical anxiety or depression at 6-8 months post-diagnosis has been estimated at 35.8% and 15.1%, respectively [47]. Although the proportion of partners reporting issues with anxiety has been shown to decline to 30.5% at 12-months post-diagnosis, a slight, non-significant increase to 15.8% was reported for depression [47]. However, whereas patients might be at an increased risk of anxiety and depression compared to population norms [44], a study by Turner and colleagues [48] found that the rates of anxiety and depression among partners measured at least five years since the patient’s diagnosis were not significantly different to population norms. Taken together, what these cross-sectional studies highlight is that although the
immediate and shorter-term psychological impacts reported by patients and partners are similar, it appears as though patients might be at greater risk of psychological distress in the long-term.

**Patient-Partner Interdependence and Dyadic Coping**

There is a growing body of research that suggests intimate couples respond to stressors as an integrated system [49, 50]. That is, one spouse’s distress will influence the other spouse’s distress. This is often described as a ‘cross-over effect’ or ‘emotional contagion’ [51, 52], and is particularly relevant to the study of couples facing cancer as they move from the acute post-diagnosis phase, through treatment, and into survivorship. The relationship between patient and partner psychological distress has been estimated to be moderately correlated ($r_{35-49}$) [52-55]. Some variations have been noted by cancer type, patient/partner gender, cancer phase, and various socio-demographic factors [54], including whether or not the couple has young children [56]. In a meta-analysis of couples’ responses to cancer, Hodges and colleagues [53] found that male patient-female partner couples reported similar levels of distress, whereas among female patient-male partner couples, females reported more distress. Differences in distress were also reported according to role and varied at different time periods. Partners reported more distress than patients during treatment, whereas patients reported more distress than partners in the months between one to two months following treatment. However, gender and cancer-type differences over time were not reported given the heterogeneity of the samples included in the analysis [53]. A review by Kim and Given [54] found that from the acute phase of cancer treatment (i.e., up to 2 years post-diagnosis) through to the long-term survivorship, the most commonly occurring factors that predicted distress among caregivers were being a spouse, and being female. From long-term survivorship to end-of-life care, being a caregiver to a breast cancer
patient predicted as much if not more psychosocial issues, greater fear of recurrence, and less social support compared to caregivers of patients with other types of cancer. Ernst and colleagues [56] found that women with cancer who have young children report more anxiety than men with cancer who have young children. However, men with cancer who have young children report more anxiety than men with cancer who do not have young children, whereas women with and without young children did not differ in the amount of anxiety reported.

Two studies by Segrin and colleagues [52, 55] have demonstrated the interdependence of psychological distress and quality of life between patients and their partners. Among a sample of women with breast cancer and their partners [52], moderate correlations between one another’s levels of anxiety and depression existed from baseline to the third (and final) follow-up point ten weeks later. Partner’s perceptions of relationship quality were related to their own anxiety and to the patients anxiety. Partner’s anxiety at the second follow-up predicted patients anxiety at the final follow-up point. In contrast, patient’s perceptions of relationship quality were only related to the partner’s anxiety, and patients’ anxiety did not predict partners’ anxiety at any point.

In a separate study, Segrin and colleagues [55] found that there was interdependence between patients’ and partners’ psychological distress and quality of life (QoL). Partner’s depression, anxiety, and fatigue at the second follow-up point (8 weeks post-baseline) predicted the patients depression, anxiety, and fatigue at the third and final follow-up point (16 weeks post-baseline). Interestingly, patients’ anxiety and fatigue at baseline predicted their partners’ anxiety at the second follow-up point. Patient’s physical QoL was associated with their partner’s psychological distress, even when controlling for patient’s psychological distress. Given Hodges and colleagues [53]
indicated that male/female patient/partner combinations vary in terms of when they experience more or less distress, this finding further highlighted that different time points of the cancer experience impact differentially on patients and partners. This suggests that patients’ and partners’ psychological distress are not the only outcomes of a cancer diagnosis that can impact on one another’s well-being.

**Coping with Stress: Emergence of Dyadic Coping Theories**

Couples’ adjustment to cancer stressors are based on improvements in communication, developing a shared understanding of one another’s experiences, and improving each member of the couples’ ability to cope with stress [57-59]. These behaviours can be categorised as improvements in dyadic coping [49, 60]. Dyadic coping refers to how patients and partners cope with stress together, rather than on their own. Stress has typically been defined as either a reaction to a stimulus (e.g., Selye’s General Adaptation System [GAS]) [61], or as a process between an individual and their environment (e.g., Lazarus & Folkman’s transactional model of stress and coping) [62]. The GAS aims to explain the physiological response to stressful situations, and suggests individuals experiencing a prolonged stressor will go through three phases: an alarm phase (increases in blood pressure, breathing), a resistance phase (increased output of stress hormones), and once the stressor is removed, an exhaustion phase, where coping becomes most difficult. In contrast, Lazarus and Folkman suggested that the impact of a stressor is determined by how it is appraised by the individual [62], and how well an individual is equipped to cope with a stressor. That is, rather than simply reacting to a stressor, Lazarus and Folkman suggest a series of transactions between the individual and their environment occur (e.g., is the stressor a threat to safety, are ones’ coping resources adequate) that determine whether or not a stressor will have a negative impact on the individual. According to Lazarus and Folkman, coping with stress involves the
“constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (p.141) [63]. This framework has heuristic value to guide descriptive studies and inform the design of interventions, as it defines a pathway from a stressful event (such as cancer), to how that stressful event is appraised by the individual, and how that individual’s coping style affects their adjustment to the event. The inclusion of significant others’ in the stress-coping model has been limited. Stress-coping theorists have typically operationalised the concept of ‘social support’ as including an intimate partner, rather than specifically identifying partners as a key resource that can be drawn upon by individuals to deal with stress [64, 65]. In the context of cancer, this is a significant shortcoming given the evidence that couples respond to cancer as an interdependent system [52, 55, 66]. Thus, in recent years psycho-oncology researchers have increasingly expanded their scope to consider how couples cope together, rather than as individuals.

Research regarding how couples cope with stress has existed since the early part of the 20th century [67-69]; however, interest in this concept has grown significantly within the last 20 years [60, 66, 70]. Until recently, few theories have made clear distinctions between individual-stress and couple-stress. Typically, stress has assumed to occur within the individual’s specific social circumstance, and thus have an influence on their broader social support network [62, 71, 72]. “Dyadic stress” is the term often used to describe the stress that both partners in a couple experience when faced with a common challenge or threat, or when there is a ‘cross-over’ or transfer of stress from one partner to the other [51, 73]. According to Bodenmann [73], dyadic stress “affects both partners either directly or indirectly and triggers the coping efforts of both partners within a defined time frame and a defined geographic location” (p.33), and occurs in addition to individual-stress. Couples’ experiences of dyadic stress often result in them
engaging in dyadic coping, with the goal of recovering from the stressors and maintaining a healthy relationship with each other. It is only relatively recently that theories of how couples cope with stress in the context of cancer have started to emerge [49, 74-78]. Theoretical frameworks including the Systemic Transactional Model (STM) of Dyadic Coping [49], Relationship-Focused Coping [77], Collaborative Coping [74], and Coping Congruence [79] have been applied to explore how patients’ and partners’ coping strategies influences each other’s coping and psychosocial outcomes [79-82]. These frameworks share many overlapping constructs that have been shown to have positive and negative influences on adjustment to cancer, such as mutual constructive communication [82], sharing feelings between spouses [80], hiding worries or concerns from spouses [81], and engaging in joint problem-solving [79]. However, Bodenmann’s STM of dyadic coping is the most complete framework [49, 60].

Bodenmann described dyadic coping as a systemic process, wherein the well-being of the individual is dependent on the well-being of their partner [49, 60]. The STM builds on Lazarus and Folkman’s framework, as it outlines how couples appraise, cope and ultimately adjust to stressors as a system. How an individual appraises and copes with stress influences how the other member of the dyad appraises and copes with stress. Similarly, an individual’s appraisal and coping is influenced by how their partner appraises and copes with the stressor [49, 60]. In summary, this model proposes that when partner A communicates stress, coping strategies are initiated by partner B. These coping efforts are interpreted by partner A, who responds in turn. STM differs from other models of dyadic coping in that it conceptualises couples as a reciprocal system of appraisal, response, and mutual coping, whereas other models of dyadic coping tend to focus on efforts from one partner to assist the other [73]. From a STM perspective, couples’ coping responses may take a positive or negative form. Positive dyadic coping includes a) supportive dyadic coping, where one partner provides support (either
emotion- or problem-focused) to assist the other partner with their coping (e.g., listening empathetically to patient’s fears); b) delegated dyadic coping, where one partner takes over certain roles to reduce burden on the other (e.g., doing household chores); and c) common dyadic coping, where couples engage in emotion- or problem-focused coping together (e.g., seeking information together on ways to alleviate chemotherapy side-effects). Negative dyadic coping refers to a partner’s coping response that is ambivalent (e.g., partner provides support unwillingly), hostile (e.g., partner is sarcastic about or minimises partner’s concerns), or superficial (e.g., the supportive behaviour actually lacks emotional input). The process of dyadic coping as described by Bodenmann and Berg and Upchurch [83] is illustrated in Figure 1. Given the potential for dyadic coping to predict elements of couples’ adjustment to cancer, it is timely to 1) examine more closely how theories of dyadic coping have been applied within the cancer literature, and 2) explore the empirical evidence regarding the influence of dyadic coping strategies on psychosocial outcomes among couples coping with cancer.

**Interventions for Patients and Partners Affected by Cancer**

The prevalence of psychological distress among patients and their partners highlights the need for interventions that improve adjustment for individuals and couples following a cancer diagnosis. Aside from the benefits to patients’ and partners’ psychological and physical well-being [57, 84, 85], there are also significant health care cost-benefits for intervening with distressed individuals [86, 87]. There have been several meta-analyses and reviews of psychosocial interventions designed for patients diagnosed with cancer and their partners [84, 85, 88-100]. By and large these interventions show low to moderate efficacy across various psychosocial outcomes, including QoL [97], anxiety [90, 96, 98, 99], depression [93, 96, 98], problem solving [93], and the ability to provide direct patient care [89, 93]. Despite some promising
results regarding the outcomes for patients and partners, these reviews and meta-analyses must be interpreted with caution [94]. These reviews vary with respect to their assessment of the methodological quality of the studies included in analyses. For example, the inclusion of non-randomised studies, or studies with small sample sizes could potentially result in an overestimation of the efficacy of patient-based interventions. A review by Newell and colleagues [95], although applying a particularly conservative methodological inclusion criteria, concluded that the evidence available at the time (1999) was inconclusive, given the risk of bias that was present among a large proportion of available studies. Similarly, two reviews of caregiver interventions [91, 92] have highlighted that despite some success, a lack of methodological rigour, and the heterogeneity of research design, theoretical frameworks and outcome measures limits the generalisability of caregiver-only interventions. Thus, although the evidence suggests that individual psychosocial interventions can have significant benefits, careful consideration should be given to the context of how psychosocial interventions are provided. Given the interdependence of patient and partner distress, it is appropriate to examine the efficacy of interventions specifically designed for couples. A systematic review of couple-based interventions is needed that 1) encompasses the broad range of outcome measures used in couples research, 2) explores the content of couple-based interventions and how they are delivered to couples, and 3) identifies the mechanisms of couple-based interventions that appear to drive improvements in adjustment to cancer for couples.

**Issues in Providing Couple-based Psychosocial Cancer Care**

Although couple-based interventions show promise, little is known about clinician and/or patient and partner perspectives on the psychosocial support needs of couples in cancer care [101, 102]. Evertsen and Wolkenstein [101] found that partners often felt physicians and urologists did not provide them with enough psychosocial support or...
validation during consultations, and assumed they were adequately equipped to take on caregiving responsibilities during and after treatment. This is concerning, given partners often take on the majority of caregiving responsibilities [40] and report greater unmet needs [40, 103]. Traa and colleagues [102] explored health care professionals (HCPs) and couples views on the sexuality needs following colorectal cancer. They reported several barriers to discussions of sexuality between HCPs and couples, including a lack of appropriate knowledge, a view that sexuality was an inappropriate topic to discuss during consultations, and a lack of appropriate referral systems. Taken together, this suggests that HCPs and couples facing cancer differ with regard to their main concerns and priorities. Areas of divergence and consensus between HCPs and couples should be explored in greater detail and from a dyadic perspective. A better understanding of the various factors that influence a couple’s decision to seek additional psychosocial support, and the role HCPs involved in their care play in these decisions, is needed to ensure these services are delivered appropriately.

**The Coping-Together Intervention: A Self-directed Coping Skills Intervention for Couples Facing Cancer**

Despite the growing body of evidence supporting the efficacy of psychosocial interventions for people affected by cancer [88, 90, 95], the implementation of these interventions into routine care is limited [104]. Reasons for the lack of dissemination of interventions are likely due to a number of factors. These include the costs associated with having highly trained psychosocial professionals delivering interventions and support [58], practical issues such as a lack of time or living too far from the intervention [105, 106], as well as issues relating to health care professionals’ and couples’ views on psychosocial needs and psychosocial interventions [107, 108]. One potential solution to overcoming these issues is the development of self-directed
psychosocial interventions that accompany and complement existing psychosocial support services in oncology settings. Self-directed interventions can overcome some of these barriers and have been shown to be acceptable alternatives for people affected by cancer [105, 109], and efficacious in reducing psychological distress [105].

With these issues in mind, Lambert and colleagues developed *Coping-Together*, a self-directed coping skills intervention for couples facing cancer. *Coping-Together* was developed on the basis of three well-known theoretical frameworks: Lazarus and Folkman’s stress and coping framework [62], Bodenmann’s Systemic Transactional model (STM) of dyadic coping [49], and Bandura’s theory of self-efficacy [110]. The content of *Coping-Together* was provided to couples via four booklets, each addressing a key aspect couples face when dealing with cancer: 1) symptom management, 2) communicating with health care professionals, 3) supporting each other, and 4) managing worries and emotions. A relaxation CD and “Communicating effectively with Health Care Professionals” DVD accompanied these booklets. Each booklet presented coping tips for individuals and couples, and participants used the resources as they wished. A two-arm, randomised controlled trial pilot study was undertaken with men diagnosed with prostate cancer and their partners. The intervention group received *Coping-Together*, and the control group (Minimal Ethical Care [MEC]) received Cancer Council NSW information booklets. All participants completed baseline and two month follow-up surveys. It was hypothesised that at the two month follow-up couples in the *Coping-Together* group would report less anxiety, depression, and cancer-related distress, and more positive illness/caregiving appraisal, relationship satisfaction, individual and dyadic coping. The role of dyadic coping is the primary focus of this thesis.
Research Aims

The evidence-base for the efficacy of psychosocial interventions for couples as a means of enhancing coping and improving adjustment to cancer is growing [57, 111]. Moreover, there are calls from peak psycho-oncology services and research groups for greater implementation of psychosocial services for patients and partners [112-114]. Thus, there is a need to explore dyadic coping in greater detail, as well as the factors that influence the efficacy, uptake, and implementation of couple-based interventions.

First, given the various theoretical frameworks used to describe dyadic coping, it is pertinent to explore how these have been applied within the context of cancer. Moreover, as dyadic coping is one of the potential mechanisms that influences how couples adjust to a cancer diagnosis, it is relevant to examine how this construct influences couples’ adjustment. In particular, the STM of dyadic coping [80], which is the most comprehensive and parsimonious theory of dyadic coping, and was a central theoretical construct in the development of Coping-Together, will be explored as it relates to couples coping with prostate cancer. Second, a thorough and comprehensive systematic review is needed to explore the variation in intervention efficacy, content, and delivery, and the variation in uptake and attrition from couple-based interventions. Third, a number of barriers to the uptake and implementation of couple-based interventions have been highlighted. Given that feasible patient access and HCPs’ attitudes are just two of the issues potentially inhibiting dissemination of couple-based interventions [106, 107], it is pertinent to explore novel methods of delivering psychosocial interventions to couples that address these barriers. Thus, the feasibility and efficacy of delivering a self-directed intervention to couples should be explored.

Each chapter in this thesis aims to address one or more of these issues by exploring outcomes associated with the delivery of Coping-Together, and exploring various
factors associated with the feasibility and dissemination of psychosocial cancer care for couples. This work aims to:

1) examine current evidence and theoretical frameworks relevant to dyadic coping in couples facing cancer (Paper One);

2) examine the empirical basis for dyadic coping in couples and couple-based interventions (Papers Two and Three);

3) explore the barriers and facilitators of couple-based interventions and couple-focused psychosocial support in routine practice (Papers Four and Five);

4) explore the feasibility of the first self-directed couple-based intervention for couples coping with cancer (Papers Six and Seven).
Table 0.1.

What each paper in this thesis addresses.

<table>
<thead>
<tr>
<th>Paper Number</th>
<th>Research Focus</th>
<th>Purpose of paper</th>
<th>Design</th>
</tr>
</thead>
<tbody>
<tr>
<td>One</td>
<td>Evidence of benefit (dyadic coping)</td>
<td>To review the various theoretical frameworks used to explore dyadic coping among couples facing cancer</td>
<td>Narrative review</td>
</tr>
<tr>
<td>Two</td>
<td>Evidence of benefit (STM of dyadic coping)</td>
<td>To explore the relationships between patients’ and partners’ use of dyadic coping strategies and psychosocial outcomes</td>
<td>Cross-sectional survey</td>
</tr>
<tr>
<td>Three</td>
<td>Evidence of benefit (couple-based interventions)</td>
<td>To examine in depth the efficacy, content, and delivery of couple-based interventions for couples facing cancer</td>
<td>Systematic Review</td>
</tr>
<tr>
<td>Four</td>
<td>Barriers &amp; facilitators</td>
<td>To review and synthesise uptake and attrition rates for couple-based interventions by cancer type and stage, and intervention type, content and delivery.</td>
<td>Systematic Review</td>
</tr>
<tr>
<td>Five</td>
<td>Perspectives on dissemination</td>
<td>To explore the views of HCPs and couples on the provision of psychosocial care of couples</td>
<td>Qualitative interview study</td>
</tr>
<tr>
<td>Six</td>
<td>Feasibility and acceptability</td>
<td>To explore the feasibility of providing a self-directed, couple-based intervention to couples facing cancer</td>
<td>Qualitative interview study</td>
</tr>
<tr>
<td>Seven</td>
<td>Feasibility and efficacy</td>
<td>To explore the feasibility of a self-directed, couple-based coping skills intervention, and to begin to examine the efficacy for reducing psychosocial distress.</td>
<td>Pilot randomised controlled trial</td>
</tr>
</tbody>
</table>
Figure 0.1. Bodenmann’s (1995; 1997; 2005) Systemic Transactional Model of dyadic coping

**Dyadic Appraisal**
- Patient Appraisal
- Partner Appraisal

**Dyadic Coping**
- Common Dyadic Coping
- Supportive Dyadic Coping
- Negative Dyadic Coping
- Delegated Dyadic Coping

**Dyadic Adjustment**
- Patient Adjustment
- Partner Adjustment
References


Introduction to Paper One

Couples coping with cancer: Exploration of theoretical frameworks from dyadic studies

**Aims and purpose**

This paper describes the various theoretical models that have been used to explore how couples cope following a diagnosis of cancer (often referred to as dyadic coping), with specific attention paid to the interdependence of patients’ and partners’ coping strategies and how they influence their own and one another’s psychosocial outcomes. To date, reviews of dyadic coping models in the context of chronic disease have taken a broad approach, and have been limited in their exploration of the interdependence of dyadic coping and psychosocial outcomes among couples coping with cancer, and the relative strengths and weaknesses of these dyadic coping models. The main findings from this paper are: 1) overlap exists in regard to how the different theories conceptualise positive and negative dyadic coping strategies and the outcomes they influence, 2) variation exists between theories regarding what individuals do to help each other cope, and 3) Bodenmann’s Systemic Transactional Model appears to present the most comprehensive model of dyadic coping for couples coping with cancer.

This is the first paper in this thesis and is currently under review with Psycho-Oncology. The citation is Couples coping with cancer: Exploration of theoretical frameworks from dyadic studies. *under review with Anxiety, Stress, and Coping*. [Appendix 1.2].
Paper One

Couples coping with cancer: Exploration of theoretical frameworks from dyadic studies

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Abstract

Background
A diagnosis of cancer and the subsequent treatment journey are distressing not only for the person directly affected, but also for their intimate partner. Several theories have been proposed to guide the study and description of the strategies used by individuals and couples to manage this distress. This paper explored the theoretical frameworks used in the literature that address the patterns of coping among couples affected by cancer.

Methods
A literature search was undertaken to identify descriptive studies of how couples cope following a cancer diagnosis published between 1990 and 2013. To be considered for this paper, studies had to be published in English or French, examined the interdependence of patients’ and partners’ coping on their own and the others’ psychosocial outcomes. Data were extracted using a standardised form and reviewed by two of the authors.

Results
Twenty-three peer-reviewed manuscripts were identified, from which eight theoretical perspectives were derived: Relationship-Focused Coping, Stress-coping, Systemic-Transactional Model (STM) of dyadic coping, Collaborative Coping, Relationship Intimacy model, Communication models, and Coping Congruence. Most of the manuscripts used one of the coping perspectives. Although these theoretical perspectives tended to give emphasis to different aspects of couples coping with cancer, a number of conceptual commonalities were noted, including the proposition that behaviours such as protective buffering, overprotection, and demand-withdraw will have a negative impact for individuals and couples.

Discussion
The STM was found to be the most comprehensive perspective, although it is used sparingly in the cancer literature. Proposals for future research are discussed.
Background

Having a supportive spouse can help to buffer the stressful impact of cancer [1, 2]. However, the psychological reactions of patients’ partners has been found to parallel the patterns observed among patients themselves [3, 4] and may, in some contexts, be more intense [5]. Whereas traditional models of stress and coping such as Lazarus and Folkman’s transactional model [6] have focused on the individual’s ability to appraise and manage competing demands, over the last two decades more attention has been given to how partners’ coping is related to patients’ coping and outcomes during stress [7]. “Dyadic stress” is the term often used to describe the stress that both partners in a couple experience when faced with a common challenge or threat (such as cancer might present) to their relationship, or when there is a ‘cross-over’ or transfer of stress from one partner to the other [8, 9]. “Dyadic coping” refers to the responses by the couple generally reflecting the goal of recovering from the stressor and maintaining a healthy relationship [8, 10, 11]. As evidence grows regarding the impact of cancer on couples and families, psycho-oncology research has been expanding its scope from examining the individual experience, to exploring that of both the patient and their partner together [12, 13].

Taking a dyadic approach to exploring how couples cope with cancer entails exploring the interdependence of patients’ and partners’ psychological distress and coping strategies [14]. Many theories of dyadic coping have been proposed, with some focusing on the match or fit between individual coping strategies in a couple relationship [15], some focusing on how one spouse helps the other cope (specifically on the how one responds to the needs of the other) [16], and others focusing on shared or mutual patterns of coping [17]. However, the strengths and limitations of each of these models as applied to people with cancer requires further examination. Two
reviews by Berg and Upchurch [18] and Revenson and DeLongis [14] have explored dyadic coping within couples facing a range of chronic illnesses, including cancer. Although both reviews highlighted key theoretical frameworks, to the best of the authors’ knowledge, no article has examined the different models of dyadic coping and the variations in coping processes used by couples specifically in the context of cancer. Given the growing interest in couple-focused psychosocial care [19] and the evidence indicating that patients and partners influence each other’s’ responses to cancer [20], it is pertinent to examine dyadic coping models more closely. Consequently, this paper aimed to:

1) Describe the various theoretical perspectives of dyadic coping that have guided research in this area;

2) Describe studies and related findings that explore the relationships between dyadic coping and psychosocial outcomes;

3) Identify the similarities and differences between these theoretical perspectives

Describing and comparing the conceptual models that have guided the research to date, and exploring the relationships between these models and other psychosocial outcomes, will improve the understanding of these concepts for both psycho-oncology researchers and clinicians. A more thorough understanding of how the particular behaviours associated with these perspectives influence adjustment to cancer, and the conditions under which these behaviours are more or less prevalent, will aid the development of future couple-focused psychosocial care.

**Methods**

**Inclusion/exclusion Criteria**
A search was conducted to identify the theoretical perspectives used to describe the coping processes used by couples when one member has cancer, and the interdependence of coping strategies on psychosocial outcomes. In their review, Revenson and DeLongis [14] defined a theory of dyadic coping as “requiring data from both members of the couple, acknowledging it’s interdependence, and using it in analyses” (p.110). In this paper, we only included papers that analysed the interdependence of patients’ and partners’ coping on their own psychosocial outcomes and the others’ psychosocial outcomes. The inclusion criteria were:

- Descriptive studies published in English or French (languages spoken by authors) in a peer-reviewed journal or book chapter.

- Published between January 1990 and December 2013.

- Measured the coping strategies used by both the patient and the partner, regardless of cancer type or stage, and the influence of coping strategies used by one member of the couple on the other’s psychosocial adjustment and/or psychological symptoms (including relationship satisfaction health related quality of life [QoL]) as a primary outcome.

Couple-based intervention research was considered to be beyond the scope of the present paper, particularly as a number of recent reviews have addressed this literature [e.g., 21, 22].

**Search Strategy**

The key search terms were: [cancer] (title) AND [coping] (abstract) AND [couple OR dyadic OR spouse OR partner OR caregiver] (abstract). The literature search was conducted online by accessing PsycINFO, ISI Web of Knowledge, Medline, PubMed,
and CINAHL databases. The reference list of each article was also examined to identify any additional literature not already identified.

**Study Selection**

The search strategy identified 1375 papers in total. After removing duplicates, the abstracts of 727 papers were assessed for relevance by the first author. The second author reviewed 10% of all abstracts and a Kappa score of 0.78 was calculated, indicating an acceptable level of inter-rater agreement [23]. Thus, it was considered that additional double coding was not required. Fifty full-text studies were assessed for eligibility by the first and third author. Where there was disagreement between reviewers, consensus was reached through discussion between the first, second, and third author. The final sample included 23 papers. The main reason for excluding papers was that they did not analyse the interdependence of patients’ and partners’ coping strategies and psychosocial outcomes, instead focusing on how the partners’ coping style affects the patient [e.g., 24, 25-28]. Table 1 presents more specific detail about each paper. Table 2 describes how the various behaviours of each theoretical perspective relate to each other [29].

**Data Collection**

Data that were extracted from each paper included: sample details, study design, coping and psychosocial outcome measures used, moderating and mediating variables reported in the paper (see Table 1).

**Synthesis of Results**

The results were synthesised using a narrative summary approach [30]. The aim of this approach in this context was to collate primary evidence of how patients’ and partners’ coping strategies influence with cancer along the theoretical frameworks used.
Synthesis of the results included categorisation of papers according to explicitly stated theoretical frameworks where appropriate (e.g., the Systemic Transactional Model of Dyadic Coping [17]). If no specific theoretical model was stated, papers were categorised based on how constructs of coping were measured or analysed. For example, papers that focused on the interdependence of communication behaviours between patients and partners and psychosocial outcomes were categorised as “Communication Models of Coping”; papers that examined how patients’ and partners’ individual coping strategies “fit” or complemented the others’ coping strategy were categorised as “Coping Congruence”.

Results

Theoretical Perspectives Used To Study Couples Coping With Cancer

Seven theoretical perspectives pertaining to how couples cope with and adapt to cancer were identified: a) Relationship-Focused Coping [RFC; e.g., 10, 16, 31, 32], b) Lazarus and Folkman’s Transactional Model of Stress and Coping [33], c) Systemic Transactional Model of dyadic coping [34], d) Collaborative Coping Model [35], e) Relationship Intimacy Model [e.g., 36, 37], f) Communication Models of Coping [e.g., 38, 39], g) Coping Congruence [e.g., 15].

Study Characteristics

Of the 23 included papers, 12 used a longitudinal design, 8 used a cross-sectional design, and three used a daily-diary design (Table 1). Seven papers included patients with breast cancer, six included patients with prostate cancer, three included patients with colorectal cancer, two included patients with lung cancer, and five included patients with various cancer types.

Relationship-Focused Coping
Three studies explored Relationship-Focused Coping (RFC) [16, 31, 32]. RFC shares similarities with Lazarus and Folkman’s model in that it acknowledges the importance of individuals’ response to their own distress and desire to overcome the challenging practicalities of a cancer diagnosis, as well as the importance of responding and adapting to their partner’s emotional needs [6, 10]. Three types of relationship-focused coping have been outlined: a) active engagement, which refers to how individuals engage their partners in joint problem-solving and emotion sharing, including strategies to optimise their communication; b) protective buffering, which refers to how individuals deny their own worries, hide concerns, or are reluctant to disclose emotions in order avoid conflict; and c) overprotection, referring to individuals’ tendency to underestimate their partner’s ability to manage tasks, which can lead to excessive or unwanted help, thus undermining the individual’s self-efficacy [10, 16]. Active engagement has generally been associated with positive outcomes for patients and partners within the context of cancer, including being positively associated with greater self-efficacy, psychological distress, and perceptions of patients’ coping by partners [16], as well as patients’ and partners’ perceptions of relationship functioning [16, 31]. In contrast to active engagement, protective buffering and overprotection have often been associated with negative psychosocial and relationship outcomes. Protective buffering has been associated with less self-efficacy and poorer perceptions of spousal coping [16], increased psychological distress [32], and poorer relationship functioning [31]. Collectively, these studies highlight the use of protective buffering can be associated with poorer psychosocial outcomes, although the conditions under which negative effects occur are unclear. Past supportive behaviour may impact on satisfaction with the relationship, which in turn may predict whether using protective buffering will have a negative impact on patients and partners.

**Lazarus and Folkman’s Transactional Model of Stress and Coping**
Only one study was identified that explored Lazarus and Folkman’s model in the context of couples coping with cancer [33]. Lazarus and Folkman’s model of stress and coping [6] is based on the assumption that individuals’ use both cognitive and emotional appraisals of a stressor to evaluate how they will cope with the stressor, and that the type of coping used is determined by personal resources and environmental context. The inclusion of significant others in the stress-coping model has been limited, despite social support being considered a key resource among stress-coping theorists that can be drawn upon by individuals to deal with stress [40, 41]. Kershaw and colleagues [33] found that for patients with prostate cancer, greater communication by their partner at baseline predicted greater hopelessness appraisal at four month follow-up, which predicted lower mental QoL at eight month follow-up. For partners, greater patient uncertainty appraisal at four months predicted greater active coping at eight months. However, partners did not typically engage in active coping, and there was no relationship between partners’ use of active coping and their own mental or physical QoL.

**The Systemic-Transactional Model**

Only one study was identified that applied Bodenmann’s Systemic Transactional Model (STM) of dyadic coping [8, 17] to both patients and partners [34]. The STM expanded on Lazarus and Folkman’s model to include shared appraisal of threat, open communication, and mutual or reciprocal efforts to help one another (see Table 1). In summary, this model states that when stress is communicated by partner A, coping strategies are initiated by partner B to restore balance within the dyad. These coping efforts are then interpreted by the partner A, who responds in turn. STM differs from RFC in that STM conceptualises couples as a reciprocal system of appraisal, response, and mutual coping, whereas RFC identifies efforts from one partner to assist the other,
without the reciprocity of the STM [8]. From a STM perspective, couples’ coping involves partners’ communication of stress and coping responses, which coping responses may take a positive or negative form. Positive dyadic coping includes a) supportive dyadic coping, where one partner provides support (either emotion- or problem-focused) to assist the other partner with their coping (e.g., listening empathetically to patient’s fears); b) delegated dyadic coping, where one partner takes over certain roles to reduce burden on the other (e.g., doing household chores); and c) common dyadic coping, where couples engage in emotion- or problem-focused coping together (e.g., seeking information together on ways to alleviate chemotherapy side-effects). Negative dyadic coping refers to a partner’s coping response that is ambivalent (e.g., partner provides support unwillingly), hostile (e.g., partner is sarcastic about or minimises partner’s concerns), or superficial (e.g., the supportive behaviour actually lacks emotional input).

Badr and colleagues [34] found that greater use of common dyadic coping was significantly associated with greater relationship satisfaction for patients and partners, whereas negative dyadic coping had the opposite effect. Negative dyadic coping was found to be associated with higher patient and partner distress, whereas common dyadic coping was associated with less cancer-related distress for partners, but with an increase in patient distress. The effect of negative dyadic coping was found to be stronger among patients and partners who perceived their spouse as being more ambivalent about their coping efforts. This suggests that although withdrawing from one another when under stress might be harmful to the relationship and ones’ own distress, the perception that ones’ spouse might withdraw and does not seem to care about providing support might be even more detrimental for the couple.

**Collaborative Coping Model**
Collaborative coping is a concept based on mutual problem-solving [35] and refers to the manner in which couples actively discuss and combine their resources to solve problems. One study was identified that applied this model [35]. It shares similarities with common dyadic coping, although it expands on this to define four types of collaborative coping strategies (Table 2), two positive and two negative: a) collaborative strategies, where partners assume an active and equal part in decisions regarding the patient’s treatment, and in devising strategies to manage stressors; b) supportive strategies, which involve the establishment of emotional and practical support; c) uninvolved strategies, where individuals do not engage with their partners and do not offer support; and d) control strategies, where one partner dominates the other to manage the situation. Berg and colleagues [35] found that greater use of collaborative strategies was associated with greater positive mood for patients with prostate cancer, and less negative mood for their partners compared to other strategies. In both cases, this effect was found to be mediated by patients’ and partners’ perceptions of the effectiveness of collaborative coping. This suggests that a desire to engage in behaviours that will benefit the relationship, and the perception that doing so will be of substantial benefit to the relationship, may be as important as engaging in the behaviours themselves.

**Relationship Intimacy Model**

Five studies were identified that applied the Relationship Intimacy Model [11, 37, 42-44]. Manne and Badr [11, 36] developed a model of couples’ adaptation to cancer that explored the level of intimacy within the couple, based on Reis and Shaver’s interpersonal process model of intimacy [45]. In particular, the Relationship Intimacy Model focuses on the quality of intimacy and closeness experienced within the couple, and in turn addressing this element of the relationship as a means of improving
psychological outcomes. Manne and Badr [11, 36] identified several intimacy-enhancing behaviours, which emphasise a willingness to discuss and manage challenges that the relationship might endure and ensuring that important relationship elements are continued throughout the cancer experience. These behaviours include mutual constructive communication (the way in which couples discuss cancer-related stressors); reciprocal self-disclosure (disclosure of thoughts and feelings); partner responsiveness (extent to which an individual feels their partner has understood their thoughts and feelings); relationship engagement (manner in which couples’ view the cancer has affected them, individually and as a dyad). Self-disclosure and partner-responsiveness are similar to active engagement (Coyne & Smith, 1991) and stress communication (Bodenmann, 1995; Table 2).

Manne and colleagues have undertaken several cross-sectional examinations of relationship intimacy among couples facing a range of cancer diagnoses [11, 42, 44]. For women diagnosed with breast cancer, their own emotional disclosures did not enhance their feelings of relationship intimacy, whereas emotional disclosures by their partners did, whereas for partners their own emotional disclosure or that of the patient enhanced relationship intimacy [11]. Among a sample of couples facing head and neck or lung cancer, Manne and Badr [42] found that patients and partners who reported more self-disclosure reported less distress and greater cancer-specific intimacy. For couples coping with prostate cancer, Manne and colleagues [44] found that patients and partners who reported greater use of mutual constructive communication reported less psychological distress and greater levels of relationship intimacy. Moreover, greater perceived spousal disclosures were also associated with less distress, and greater cancer-specific intimacy and relationship intimacy. Belcher et al. [37] found that greater relationship intimacy among patients and partners was related to receiving support from ones’ spouse, thus provision of support was also related to greater relationship intimacy.
As well as outlining relationship enhancing behaviours, Manne et al. [11, 36] identified three relationship compromising behaviours: a) avoidance or reluctance to discuss issues or feelings; b) criticism, referring to purposefully unsupportive behaviours (e.g., being critical of a partner’s coping strategies); and c) demand (or pressure)-withdraw communication, which refers to putting pressure on someone to discuss issues they are not ready or willing to, to the extent that the pressured person then withdraws from communication. Manne et al. [44] found that the relationship between patient-demand and partner-withdraw communication was associated with increased psychological distress. In a subsequent study with a similar sample, Manne, Badr, & Kashy [43] reported that an individual’s past positive communication predicted their current relationship intimacy, but their partner’s past positive communication did not. An individual’s and their partner’s past negative communication predicted their current level of distress, although this was mediated by current relationship intimacy.

**Communication Models of Dyadic Coping**

Six studies [2, 38, 39, 46-48] specifically explored communication and how it influenced coping and psychosocial distress. Badr and Taylor [38] reported that patients and partners who described their relationship more positively, made greater use of supportive social networks, and worked together more often on common tasks reported less psychological distress and greater relationship satisfaction. Providing support for ones’ spouse, when at the same time spouses’ reported an increased reliance on external social networks, resulted in increased distress for patients but decreased distress for partners. In a subsequent study, Badr and Taylor [39] found that patients with prostate cancer who experienced erectile dysfunction reported better relationship satisfaction and sexual satisfaction when they used more mutual constructive communication (i.e., open expression of concerns and feelings, efforts made to
empathise with partner regarding cancer) compared to patients who used less mutual constructive communication. This moderating effect of mutual constructive communication was not found on other patient outcomes.

However, among partners, greater mutual constructive communication was associated with greater levels of marital satisfaction, regardless of sexual satisfaction. Manne et al. [48] found that patients and partners who used more mutual constructive communication, less mutual avoidance and less demand-withdraw communication at baseline experienced less distress and greater relationship satisfaction nine months later. Another study by Manne et al. [2] found that for couples coping with breast cancer, unsupportive behaviour by the partner was related to patient distress and avoidant coping. However, partner unsupportive behaviour was mediated by the patient’s perception of their partner’s behaviour, and did not have a negative impact for the patient unless the patient actually perceived the behaviours as being unsupportive. Dagan and colleagues [46] reported that over time, patients and partners who received support from their spouse reported less distress. However, this effect was moderated by each individual’s personal control (i.e., the extent to which one feels they have control over what will happen to them). Patients and partners who reported low personal control reported high distress when they perceived their spouse as being unsupportive.

In contrast to Badr and Taylor (2009) and Manne et al. (2006), Hagedoorn et al. (2011b) found that disclosure of thoughts and feelings between patients with colorectal cancer and their partners was harmful in some instances. Emotional disclosures to a spouse were not associated with changes in depressive symptoms for patients or partners. Moreover, patients and partners reported increased depression at follow-up when partners were high disclosures but patients were low disclosures. This suggests a
mismatch in the way patients and partners discuss their concerns could be harmful for some couples.

**Coping Congruence Model**

Six studies were identified that applied the coping congruence approach to dyadic coping [15, 49-53]. Coping congruence can be distinguished from other types of dyadic coping in that it focuses on a match or mismatch in the coping responses of the couple, rather than how one partner helps the other cope (e.g., relationship-focused coping), or the coping response of the couple as a unit (e.g., STM, collaborative coping).

Revenson, Abraido-Lanza, Majerovitzm and Jordan [54] defined coping congruence as attempts to maintain a sense of control and stability for the couple when dealing with a stressful event. It relies on individuals understanding the coping behaviours used by their partner, and how best they can adjust their own behaviour to ensure a workable ‘fit’ between the two strategies (Table 2). Congruence in coping styles might mean using a similar coping style (e.g., both partners use emotion-focused coping) so as not to interfere with the other’s coping effort, or using a complementary coping style (e.g., one partner uses emotion-focused and the other problem-focused coping) so as to expand the coping options that are available to the couple [54]. The coping strategies described are generally emotion-focused (i.e., changing ones emotional response to stress), problem-focused (i.e., trying to remove or manage the cause of the stress), approach-based (i.e., actively addressing stressful issues), or avoidance-based (i.e., a reluctance to discuss issues), or combinations of these.

Generally, studies have found that using similar or complementary coping is associated with greater patient and partner illness adjustment and marital satisfaction [52]. For instance, Fagundes, Berg, and Wiebe [51] examined couples’ negative affect over 14 days, and found that patients with prostate cancer who experienced high levels
of intrusive thoughts experienced less negative affect when their wives also experienced high levels of intrusive thoughts. This was also true for partners, suggesting that congruence on high levels of intrusive thoughts moderated feelings of negative affect. This suggests that couples are more open to discussing intrusive thoughts, if they perceive that their spouse understands their concerns.

In contrast to the role of congruent or complementary coping strategies, Ben-Zur, Gilbar, and Lev [15] found that a discrepancy in the use of emotion-focused coping strategies by both patients and partners was related to increased psychological distress and decreased psychological adjustment for patients. Barnoy and colleagues [50] found evidence that a lack of congruence in information-coping styles was also related to increased distress and decreased well-being. For male patients, increased distress was related to low congruence with their partner on blunting information-coping. For partners, increased distress high and decreased well-being were related to high congruence on blunting.

Some studies identified variables that moderated the influence of the individual coping strategies used by patients and partners [49, 53]. For instance, Banthia et al. [49] found that among couples facing prostate cancer, those who reported greater dyadic adjustment were less likely to report use of maladaptive coping strategies. Moreover, individual’s maladaptive coping strategies (avoidance of stressful situations and reluctance to discuss intrusive thoughts about cancer) significantly predicted their spouse’s psychological distress. Taylor and colleagues [53] found that behavioural disengagement by patients and partners predicted their own levels of psychosocial distress. Patients’ disengagement also predicted partner distress, whereas partners’ use of humour buffered patient distress.
Discussion

Comparative Analysis of Theoretical Perspectives

The theoretical perspectives reviewed emphasized different aspects of couples coping with cancer, though there are a number of conceptual commonalities among them. The first commonality relates to what one partner does to help the other cope (Table 2). In this paper, these behaviours included active engagement (relationship-focused coping) [10], congruent or complementary coping [54], and self-disclosure (relationship intimacy model) [36]. These behaviours are all characterised by increased communication, emotional openness, and problem solving, and were associated with improvements in relationship satisfaction [31], relationship intimacy [37, 42], and psychological distress [42, 46]. These behaviours all involve one partner being proactive in initiating a coping strategy that their spouse can potentially respond to and engage with. However, they differ in terms of which aspect of coping they emphasise. Active engagement highlights one spouse’s willingness to initiate discussion of concerns or development of strategies to overcome particular issues, whereas self-disclosure privileges discussion of feelings surrounding particular cancer issues. Coping congruence relies on one spouse being able to adapt their own coping strategy to complement the coping strategy of the other. How and when each particular strategy can be applied, and the likelihood of a strategy producing a favourable outcome is as yet unclear based on the manuscripts reviewed.

The second commonality to emerge among the theoretical perspectives is the proposition that behaviours such as protective buffering and overprotection [relationship-focused coping; 16], avoidance, criticism, and demand-withdraw [36], and negative dyadic coping [in this instance avoidant coping; 8, 34] will have a negative impact for individuals and couples. These behaviours are largely characterised by a
lack of emotional disclosure, a propensity to withdraw and avoid discussion and/or confrontation, and a lack of appropriate emotional insight and/or empathy. They were associated with increased psychological distress [16, 34, 42], decreased relationship satisfaction [31, 34], decreased relationship intimacy [42], and decreased feelings of control and self-efficacy [16]. Despite typically being associated with negative outcomes, it could be argued that protective buffering and overprotection begin as a well-intentioned behaviour to ensure ones’ spouse receives enough support, though they may also mask a reluctance to truly engage with ones’ spouse and confront issues that may lead their partner and themselves to feel distress. Demand-withdraw communication is somewhat similar, in that one spouse initiates conversation with the positive intention of developing an open dialogue, though if their partner is not open to discussion, or the initiating spouse demands too much from their partner, this causes them to remove themselves from the conversation. This is consistent with previous work regarding highlighting that positive and negative communication may occur concurrently. For example, Cohan and Bradbury [55] reported that whereas wives’ negative communication predicted increased relationship satisfaction 18 months later, husbands use of humour predicted increased in the likelihood of couples divorcing. What this suggests is that communication that may be initially negative (or positive) in nature may incite behavioural change over time that is beneficial (or not) for the couple [56, 57].

The third commonality across these models includes what couples do to cope together. Common dyadic coping (STM) [8, 34], collaborative coping [35], and relationship engagement (relationship intimacy model) [36] overlap in terms of how they conceptualise the need for spouses to engage with each other. However, each of these approaches emphasised different coping aspects. Relationship engagement tended to be more emotion-focused, and aimed to reconcile the view that a significant stressor
typically affects the couple, not just the individual, and thus aimed to develop a sense of engagement between spouses to enhance relationship intimacy. Collaborative coping is more problem-focused, and focused on strategies to overcome specific issues that couples might face together. Common dyadic coping conceptualised emotion- and problem-focused approach as being equally important to the dyadic coping process.

Given these commonalities, two comments are noteworthy in terms of expanding our understanding of couples coping with cancer. First, it appears that Bodenmann’s STM provided the most complete picture of how couples cope, as it outlines positive and negative coping strategies used by individuals and by couples in response to a stressor. However, the STM does not describe why couples may engage in specific coping behaviours. Attachment theory might provide some scope to explore this further. Whereas theoretical perspectives on dyadic coping highlight how couples cope with a cancer diagnosis (e.g., specific behaviours, interactions with partner), attachment theory attempts to understand emotional processes underpinning coping behaviours within relationships. Two studies have explored attachment among patients and partners coping with cancer [58, 59]. Porter and colleagues [58] found that patients from couples where both members were securely attached reported significantly less psychological distress and significantly greater marital quality compared to couples where one or both members were insecurely attached. Shields and colleagues [59] found that for husbands of patients with cancer, secure and anxious attachments of either themselves or the patient was related to greater marital satisfaction compared to either spouse having an avoidant attachment. For wives, greater marital satisfaction was related to their own secure attachment, whereas husbands’ anxious attachment was related to greater marital satisfaction and avoidant attachment was related to lower marital satisfaction. The limited available evidence suggests that positive dyadic coping is related to secure attachments [60], and could possibly influence associations between
attachment security and psychosocial outcomes, including relationship satisfaction. Future studies should consider the role attachment plays in couples’ adjustment to cancer.

Second, just as individuals’ adjustment to cancer is rarely confined to just themselves, couples’ adjustment to cancer is rarely confined to the patient and the partner, and will typically occur within a broader social context. Social support and social exchange (e.g., from family, friends, health care professionals) has been shown to promote adaptive coping [61], and has been associated with improved quality of life outcomes for patients with cancer [62]. There are similarities between concepts from within the social support literature and those reviewed here. For example, concepts such as social control [63] and invisible support [64] share similar characteristics overprotection and protective buffering respectively. Thus, it may be of benefit to examine social context of couples coping with cancer [65]. Pietromonaco, Uchino, and Dunkel-Shetter [66] recently proposed a model integrating theories of social support, attachment theory, and dyadic coping in the context of health. This provides an excellent framework to explore how broad social constructs influence the exchange of support within couples’ social networks, the attachments that couples develop with each other and with these networks, and the impact this has on the specific coping behaviours couples facing cancer engage in.

Limitations

Our focus was also on descriptive and theorizing studies rather than interventional trials. The latter may incorporate conceptual models but lay outside the scope of this paper. Moreover, the cross-sectional design of studies reviewed limits our understanding of the true causal effects dyadic coping behaviours have on psychosocial outcomes. This paper did not include studies published in languages other than English or French, conference
abstracts, or dissertations. Although only peer-reviewed studies were included, the possibility of publication bias remains.

**Clinical Implications and Future Directions**

Couples coping with cancer are often faced with a multitude of stressors that can place significant strain on their relationship. The identification of several common processes and behaviours across dyadic coping models and attachment theory should enhance understanding of how adult relationships can be used to optimise positive adjustment. Understanding what drives individuals to engage with or retreat from their partners when they need each other most is fundamental to enhancing clinical outcomes and psycho-oncology research. The moderate impact of couple-based interventions within cancer has been well-documented [21, 22] and based on this review, several recommendations emerge regarding future interventions.

First, couple-based interventions should be tailored to address a couple’s particular needs. For example, physical distress was identified as a moderator of the positive impact communication has on relationship satisfaction. Regardless of the theoretical framework that is adopted in the development of couple-based interventions, understanding what is actually generating distress within the relationship should be understood and thus support should be tailored to develop more effective coping strategies. Second, it may be necessary to reconceptualise what aspect of individual and couple behaviour clinicians aim to improve. Typically, interventions primarily aim to decrease psychological distress. As discussed by Badr and Krebs [21], levels of distress among participants in published couple-based intervention studies can vary significantly. A focus on reducing distress is thus hampered by floor effects. Targeting other relational processes and skills, such as communication, self-efficacy, and intimacy, as a means of decreasing avoidance and encouraging greater dyadic coping
within couples, may have a broader impact on distress or relationship satisfaction. Third, potential moderator and mediators of dyadic coping processes should be explored in more detail (see Table 1). For example, low past spousal support was found to moderate the relationship between active engagement and relationship satisfaction [31], suggesting that both prior and current relationship patterns may play equally influential roles in determining how efficacious particular coping strategies are for couples. Manne and colleagues [2] found that cancer-specific intimacy mediated the negative relationship between self-disclosure and psychological distress, as well as perceptions of partner self-disclosure and psychological distress. This suggests that engaging in the coping behaviour may not by itself be enough, because it is also important that individuals believe in what they are trying to achieve, and that they view their partners in a similar fashion.

This paper has also identified a number of promising avenues for future research. In particular, more research is needed to explore under what conditions the theoretical frameworks reviewed may best be harnessed to improve understanding of relational processes and couple-based interventions. A greater understanding of the moderating and mediating variables that affect those coping with cancer is another avenue for future research. In addition, no studies reviewed considered couples from minority cultures, low socio-economic background, or same sex relationships, or the wider family influence on couples (e.g., children), and the complexities of couple relationships (e.g., previous marriages). These issues sit at the heart of a couple’s relationship history, and may well be incredibly influential in the development of coping styles.

Dyadic coping research has developed rapidly within the last two decades, and has been influential in developing many couple-based interventions for couples facing
cancer [1, 44, 67]. This paper identified key commonalities across theoretical frameworks and models typically used to examine the role of dyadic coping in enhancing adjustment.
References


Figure 1.1. Flowchart of literature search

- # records identified through database searching = 1375
- # duplicates removed = 648
- # records screened (titles and abstracts) = 727
- # full-text articles reviewed = 50
- # studies included in review = 23
- # Records excluded = 677
  - Did not analyse interdependence of data = 16
  - Correlational data only = 8
  - Did not assess coping = 3
- # Records excluded = 27
Table 1.1. Papers included in review.

<table>
<thead>
<tr>
<th>Author</th>
<th>Sample</th>
<th>Design</th>
<th>Coping/Relational Process Measure</th>
<th>Outcome measures</th>
<th>Theoretical Framework</th>
<th>Moderators</th>
<th>Mediators</th>
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<td>Kuijer et al.</td>
<td>106 patients and their partners (various cancer types)</td>
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<td>Ways of giving support (Buunk et al., 1996)</td>
<td>CES-D (Radloff, 1977); 7-item &quot;mastery&quot; scale (Pearlin &amp; Schooler, 1978); Relationship Improvement According to Patients, Partners' Evaluation of Patient's Coping with the Disease, Partners' Self-Efficacy in Providing Support (created by authors)</td>
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<td>Manne et al.</td>
<td>235 women with breast cancer and their partners</td>
<td>Longitudinal</td>
<td>Protective buffering 10-item scale developed for cancer patients and their partners (Manne et al., 1999)</td>
<td>Dyadic Adjustment Scale (DAS; Spanier, 1976); Psychological Distress Scale of the Mental Health Inventory (Veit &amp; Ware, 1983)</td>
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<td>Relationship satisfaction</td>
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<td>Relationship-focused coping</td>
<td>Past spousal support</td>
<td>moderated active engagement &gt; relationship satisfaction</td>
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<td>DAS (Spanier, 1976); Brief Symptom Inventory (BSI; Derogatis, 1993); Personal Assessment of Intimacy in Relationships (PAIR; Schaefer &amp; Olson, 1981)</td>
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<td>Relationship Intimacy mediated relationship between past communication and current distress – less relationship intimacy predicted more distress</td>
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<td>What partners do together to cope with stress (often common stressors)</td>
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Introduction to Paper Two

Cross-sectional relationships between dyadic coping and anxiety, depression, and relationship satisfaction for patients with prostate cancer and their spouses

Aims and purpose

Paper One included a narrative review of seven dyadic coping theoretical frameworks, and concluded that Systemic Transactional Model (STM) was the most comprehensive model applied in the context of cancer. However, to date, the STM has been underutilised in the context of cancer. Paper Two applies the STM in an empirical design and explores the relationship between dyadic coping and anxiety, depression, and relationship satisfaction among couples coping with prostate cancer. The data for this paper are taken from the baseline survey of the Coping-Together pilot study on which this thesis is based, and was analysed using the Actor-Partner Interdependence Model (APIM). The APIM provides a framework for multilevel linear modelling of dyadic data. Although both positive and negative dyadic coping were associated with couples’ psychosocial outcomes, the findings from this paper suggest that interventions for couples might be strengthened by focusing on reducing negative dyadic coping behaviour, as opposed to focusing on positive dyadic coping behaviour.

This is the second paper in this thesis and has been accepted for publication Patient Education and Counseling. Regan, T., Lambert, S., et al. (2014). Cross-sectional relationships between dyadic coping and anxiety, depression, and relationship satisfaction for patients with prostate cancer and their spouses. Accepted for publication (11/04/2014) with Patient Education and Counseling. [Appendix 2.2].
Paper Two

Cross-sectional relationships between dyadic coping and anxiety, depression, and relationship satisfaction for patients with prostate cancer and their spouses

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Abstract

Introduction

Dyadic coping has an impact on couples’ adjustment to breast cancer; however, there is limited evidence regarding whether dyadic coping influences couples’ adjustment to other types of cancer. The objective of this analysis was to further our knowledge of the relationships between dyadic coping, anxiety, depression, and relationship satisfaction among couples facing prostate cancer.

Methods

Forty-two men recently diagnosed with prostate cancer recruited from urology clinics and their spouses completed measures of dyadic coping, anxiety, depression, and relationship satisfaction. The Actor-Partner Interdependence Model was used to examine the relationships among these concepts.

Results

Relationship satisfaction was significantly associated with patients’ and wives’ use of positive and negative dyadic coping, and their partners’ use of these strategies. Although patients’ and wives’ use of supportive dyadic coping was not associated with their anxiety and depression, their partner’s use of this strategy was associated with anxiety and depression. Only husbands’ and wives’ perceptions of their partner’s negative dyadic coping was associated with anxiety and depression.

Discussion

Couples respond to a prostate cancer diagnosis as an interactional system. Future research should focus on tailoring couple-based interventions such that patients and spouses are equipped to provide the specific support their partners need.
Introduction

Prostate cancer is among the most common cancer diagnoses among Australian men, with an estimated 18,560 new cases diagnosed in 2012 [1]. Approximately 92% of newly diagnosed patients will now survive five years or more [1]. As a result, more men are living longer with both the physical and psychological consequences of the disease [2-4]. The prevalence of psychological distress among patients with prostate cancer ranges from 8% to 55% [5-7], and there is growing attention being given to the consequences of a cancer diagnosis on patients’ spouses. A recent study by Lambert and colleagues [8] found that 28.4% of partners and caregivers of men with prostate cancer were anxious. Moreover, there is evidence to suggest that women, regardless of whether they are the patient or the partner, typically report more psychological distress than men [9, 10]. The negative consequences of elevated psychological distress are well-documented for both patients and their partners, and include difficulties in making decisions about treatment [11], lower treatment adherence [11, 12], lower quality of life [13], higher health risk behaviours [11], and higher severity and incidence of treatment side effects [12].

Although stress and coping have traditionally been examined at the individual-level [14], over the last 20 years there has been growing attention given to the relational context of coping with cancer, often referred to as dyadic coping. A recent review by Regan et al. [15] has found that the Systemic Transactional Model (STM; [16]) of dyadic coping offers the most comprehensive model to explain the behaviours couples engage in when coping with stress. The STM conceptualizes dyadic coping as a reciprocal system involving couples’ shared appraisals of stress and coping [16, 17]. In the STM, stress is communicated by one spouse to the other, who then initiates a positive or negative dyadic coping response. This response is then appraised by the first spouse, who responds in turn, and so on. Responses to a partner’s stress are categorised
as positive or negative dyadic coping. “Positive dyadic coping” includes a) supportive responses, where one spouse initiates emotion- or problem-focused strategies to support the other spouse; b) delegated coping, where one spouse takes over certain tasks from the other spouse; and c) common or shared coping, where spouses engage in joint emotion- or problem-focused coping. “Negative dyadic coping” refers to responses that are ambivalent, hostile or superficial, lacking in emotional warmth or empathy. A meta-analysis by Bodenmann [18] suggested there was a strong relationship between positive dyadic coping and relationship satisfaction among couples receiving marital therapy.

**The Systemic Transactional Model Applied to Cancer-related Stress**

Despite recognition that cancer is a distressing experience for both patients and spouses, few studies have used the STM of dyadic coping in the cancer context [19, 20]. Badr and colleagues [19] found common dyadic coping was associated with greater relationship satisfaction for both patients and spouses and less cancer-related distress for spouses (but not patients). This suggests that common dyadic coping might differentially impact patients and spouses. Negative dyadic coping was associated with less relationship satisfaction and greater cancer-related distress for patients and spouses. Kayser [20] used the STM of dyadic coping in studying the efficacy of a couple-based intervention, the *Partners In Coping Program* (PICP), for spouses dealing with early-stage breast cancer. Common dyadic coping and stress communication were enhanced for patients who participated in PICP compared to a control group. Also, husbands in the intervention group were less likely to use negative dyadic coping than the comparison group.

Despite increasing interest in dyadic coping among couples facing prostate cancer [21-25], no study has applied the STM of dyadic coping to this population. Previous studies of couples coping with prostate cancer have focused on the congruence
between patients’ and spouses’ coping responses [22, 24], the importance of open communication to relationship intimacy [21, 25], and the role of collaborative problem solving [23]. Thus, the reciprocal influence of positive and negative dyadic coping behaviours among patients with prostate cancer and their spouses is unclear. In addition, the studies to date that have used the STM of dyadic coping were conducted with women with breast cancer, and given potential variations based on gender and cancer type, this evidence-base might not generalize to couples facing prostate cancer. Thus, the present study directly expands our understanding of the role of dyadic coping in adjusting to cancer by examining the relationship between dyadic coping and psychological and relationship outcomes among men with prostate cancer and their spouses.

Given the beneficial impact positive dyadic coping has had for individuals and couples in previous studies [18-20], it was first hypothesized that common dyadic coping and supportive dyadic coping (by oneself or by a partner) would be associated with lower levels of anxiety and depression and greater relationship satisfaction for patients and their spouses. Second, it was hypothesized that negative dyadic coping (by oneself or by the partner) would be associated with higher levels of anxiety and depression and lower relationship satisfaction for patients and spouses. Third, based on evidence that women report more distress than men regardless of coping used [9, 19], it was hypothesized that dyadic coping would differentially affect patients and wives, with wives’ anxiety, depression and relationship satisfaction more likely than patients’ to be influenced by their own and their partner’s dyadic coping.

**Methods**

This research was a secondary exploratory analysis of the *Coping-Together* pilot study, a randomised-controlled trial of a novel, self-directed, booklet-based intervention
for patients with prostate cancer and their spouses (for a detailed description see Lambert et al. [26, 27]. Ethical approval was obtained from the relevant University and Local Area Health ethics committees.

**Procedures**

Participants were recruited from urologists in New South Wales and South Australia, Australia. Eligibility criteria were a) being diagnosed with primary, localised prostate cancer within the previous 4 months; b) receiving or planning to receive treatment; c) patient’s or spouse’s score of 4 or higher on the Distress Thermometer (DT); d) a spouse (male or female) who is willing to participate; and e) patient and spouse being sufficiently fluent in English and cognitively able to use study materials and complete surveys. Urologists referred patients to the study who met the medical inclusion criteria, gave interested patients a study pamphlet, and obtained verbal consent for a member of the team to meet with them at their next clinic appointment, or to phone them. A research assistant then contacted or met consenting patients to confirm their eligibility criteria. Eligible patients and spouses were then given a study pack.

**Data Collection**

Data collection occurred between February 2012 and August 2013. Patients who agreed to participate were provided with an initial study pack containing the baseline survey and a reply paid envelope, and a similar envelope to pass on to their spouse. Once patients and spouses returned their baseline survey they were randomized to the *Coping-Together* or control group, and sent a follow-up survey two months later. This analysis will focus only on baseline (i.e., pre-randomisation) measures of dyadic coping, anxiety, depression and dyadic adjustment, and combines the intervention and control groups.
Independent variables.

**Dyadic Coping Inventory (DCI).**

Five of the nine subscales from the Dyadic Coping Inventory [DCI; 28] were included in this analysis:

1) **Supportive Dyadic Coping by Oneself (SDCO; 5 items, e.g., “I show empathy and understanding to my partner”).**

2) **Negative Dyadic Coping by Oneself (NDCO; 4 items, e.g., “I do not take my partner’s stress seriously”).**

3) **Supportive Dyadic Coping by Partner (SDCP; 5 items, “My partner expresses that he/she is on my side”).**

4) **Negative Dyadic Coping by Partner (NDCP; 4 items, “My partner provides support, but does so unwillingly and is unmotivated”).**

5) **Common Dyadic Coping (GDC; 5 items, e.g., “We engage in a serious discussion about the problem and think through what has to be done”).**

As our focus was the specific positive and negative dyadic coping behaviours patients and partners used, and behaviours that patients and partners engaged in together, four subscales were omitted: Stress Communication by Oneself, Stress Communication by Partner, Delegated Dyadic Coping by Oneself, Delegated Dyadic Coping by Partner. The Stress Communication subscales focus on discussing and describing the stress they experience, and in this sense do not specifically capture positive or negative aspects of the coping experience. The Delegated Dyadic Coping subscales were excluded given they focus more on problem-oriented stressors than emotional-oriented stressors [29].
Items were scored on a five-point Likert scale from 1 (‘Very Rarely’) to 5 (‘Very Often’). Cronbach’s alpha ranges from $\alpha=0.63-0.93$ [28].

**Dependent variables.**

**Relationship satisfaction.**

The satisfaction subscale of the Revised-Dyadic Adjustment Scale [R-DAS; 30, 31] was used to explore the relationship between dyadic coping and relationship satisfaction. Items from the R-DAS satisfaction subscale are scored on a six-point scale, ranging from 0 (“All the Time”) to 5 (“Never”). Scores below 14 on this subscale are used to identify individuals who might be dissatisfied with their relationship [32]. Cronbach’s alpha has been reported as $\alpha=0.90$ [30].

**Anxiety and depression.**

The Hospital Anxiety and Depression Scale [HADS; 33, 34] is a 14-item self-report scale designed to measure anxiety and depression symptoms and has been used widely within the cancer literature [35]. The HADS contains separate 7-item subscales for anxiety and depression, with item scores ranging from 0 to 3. The HADS has been widely used in studies of patients with cancer and their caregivers, though it has come under scrutiny in recent times [36-38]. Despite concerns regarding its psychometrics properties, the HADS is the recommended measure to assess anxiety among patients with cancer [35]. Cronbach’s alpha has been reported as $\alpha=0.68-0.93$ [34].

**Demographic information.**

Patients’ and partners’ date of birth, marital status, relationship length, birth country, primary language, education, employment status, weekly income were collected during an initial phone call to orient patients and their partners to the study. Information on date of diagnosis and treatment was collected as part of the main survey.
Data Analysis

Dyadic data were analysed using the Actor-Partner Interdependence Model (APIM) [39], with data from each member of the couple viewed as nested scores within the same group. The APIM suggests that an individual’s score on an independent variable will influence their own score on a dependent variable (actor effect; Figure 1), as well as their partner’s score on a dependent variable (partner effect; Figure 1). Thus, an actor/partner effect can be demonstrated by either the patient or the spouse. In an effort to avoid confusion, we purposefully used the terms ‘spouse’ or ‘wife’ when referring to the patient’s partner, and ‘partner’ when referring to the APIM. For example, an actor effect may occur if a patient’s level of Supportive Dyadic Coping (SDCO) is associated with their own anxiety (denoted in Figure 2 by the solid line), and a partner effect may occur if the SDCO used by a patient is associated with his wife’s level of anxiety (denoted in Figure 2 by the dotted line). The variable P-SDCO (Partner-Supportive Dyadic Coping) indicates that from the wife’s perspective it is the supportive dyadic coping of their ‘partner’ (i.e., the patient) that is impacting on their anxiety, and vice versa from the patient’s perspective.

A hierarchical linear modeling (HLM) approach suggested by Campbell and Kashy [39] and implemented using PROC MIXED in SAS [40], was used to fit the APIM to the data. HLM was chosen in view of its ability to handle missing data under the missing at random assumption [41, 42]. Five models were defined to explore the relationships between dyadic coping and anxiety, depression, and relationship satisfaction: a) supportive dyadic coping by oneself (SDCO; hypothesis 1), b) supportive dyadic coping by ones’ partner (SDCP; hypothesis 1), c) common dyadic coping (GDC; hypothesis 1), d) negative dyadic coping by oneself (NDCO; hypothesis 2), and e) negative dyadic coping by ones’ partner (NDCP; hypothesis 2). Each model
was adjusted for the actor’s dyadic coping score and their partner’s dyadic coping score. Relationship length was also adjusted for within each model, as previous research suggest couples in longer relationships report more positive adjustment to cancer [43].

Results

Sample Characteristics

One hundred and seventy patients were referred to the study. Of these, 57 did not meet the eligibility criteria, 51 declined participation, and 20 did not respond to follow-up attempts to contact them. Thus, 42 couples were enrolled in the study and returned baseline data, reflecting an uptake rate of 37.2% of eligible participants. Although male partners were eligible, none were recruited. Reasons for ineligibility included spouse not agreeing to participate (n = 16), cancer not localized (n = 2), no treatment planned (n = 7), more than four months since diagnosis (n = 11), DT score less than four (n = 11) and ‘other reasons’ (n = 10). Reasons for refusal included lack of interest (n = 31), being too busy (n = 9), too ill (n = 1), uncomfortable with the study (n = 1), and ‘other’ reasons (n = 9). Table 1 shows the demographic information of the sample.

Dyadic Coping, Anxiety, Depression, and Relationship Satisfaction

Table 2 shows the correlations between the dyadic coping and outcome variables. Correlations for patients are below the diagonal, spouses are above the diagonal. Of note, patients’ depression and relationship satisfaction scores were significantly correlated with supportive dyadic coping by oneself (SDCO), negative dyadic coping by the partner (NDCP), and common dyadic coping (GDC) variables, whereas anxiety was not significantly correlated with any dyadic coping variables. For spouses, anxiety was significantly correlated with negative dyadic coping scores
(NDCO and NDCP), relationship satisfaction was significantly correlated with supportive dyadic coping by oneself (SDCO) and negative dyadic coping by oneself (NDCO), whereas depression was not significantly correlated with any dyadic coping variables. As shown in Table 3, compared to patients, spouses had significantly higher anxiety, perceived significantly less supportive dyadic coping by their partner, and perceived significantly more negative dyadic coping by their partner.

**Model One: Supportive dyadic coping by oneself (SDCO) and anxiety, depression and relationship satisfaction.**

As shown in Table 4, Partner-supportive dyadic coping (P-SDCO) was found to have a main effect on anxiety ($z = 2.05$, $SE = .13$, $p = .04$; partner effect) and depression ($z = 2.43$, $SE = .10$, $p = .02$; partner effect), partially supporting our first hypothesis. This means that patients’ anxiety and depression were associated with their wives’ use of supportive dyadic coping strategies (P-SDCO), and that wives’ anxiety and depression was associated with their husband’s use of supportive dyadic coping (P-SDCO). P-SDCO was not significantly associated with relationship satisfaction. This means that for patients and wives, relationship satisfaction was not associated with their partners’ use of supportive dyadic coping. However, for both patients and wives, their anxiety and depression were not associated with their own use of supportive dyadic coping (SDCO). Patients’ and wives’ own use of SDCO was associated with relationship satisfaction ($z = 3.42$, $SE = .05$, $p = .001$), suggesting an actor effect.

**Model Two: Supportive dyadic coping by partner (SDCP) and anxiety, depression and relationship satisfaction.**

As shown in Table 4, supportive dyadic coping by partner (SDCP; $z = 2.10$, $SE = .05$, $p = .04$; actor effect), and Partner-supportive dyadic coping by partner (P-SDCP; $z = 2.01$, $SE = .05$, $p = .04$; partner effect) were both significantly associated with
relationship satisfaction, but not anxiety nor depression, again partially supporting our first hypothesis. This suggests that how patients and wives perceived the supportive coping efforts (SDCP) of the other had an impact not only on their own relationship satisfaction, but also on the other’s relationship satisfaction (P-SDCP).

**Model Three: Common dyadic coping (GDC) and anxiety, depression and relationship satisfaction.**

Common dyadic coping (GDC; $z = 2.15, \ SE = .04, p = .03; \ actor \ effect$) and Partner-common dyadic coping (P-GDC; $z = 3.02, \ SE = .04, p = .003; \ partner \ effect$) were significantly associated with relationship satisfaction, but not anxiety nor depression, still partially supporting our first hypothesis (Table 4). This suggests that how husbands’ and wives’ view the manner in which they engage with each other to cope with stress relationship satisfaction, but not anxiety nor depression.

**Model Four: Negative dyadic coping by oneself (NDCO) and anxiety, depression and relationship satisfaction.**

Negative dyadic coping by oneself (NDCO; $z = -4.23, \ SE = .07, p < .001; \ actor \ effect$) and Partner-negative dyadic coping by oneself (P-NDCO; $z = -4.51, \ SE = .07, p < .001; \ partner \ effect$) were significantly associated with relationship satisfaction, but not anxiety nor depression, providing partial support for our second hypothesis (Table 4). This suggests that patients’ and wives’ negative dyadic coping efforts had an impact on their own relationship satisfaction (NDCO) and on the other’s relationship satisfaction (P-NDCO).

**Model Five: Negative dyadic coping by partner (NDCP) and anxiety, depression and relationship satisfaction.**
In contrast to NDCO, negative dyadic coping by partner (NDCP) was significantly associated with anxiety ($z = 3.14$, $SE = .16$, $p = .002$; actor effect), depression ($z = 2.45$, $SE = .13$, $p = .01$; actor effect), and relationship satisfaction ($z = -2.32$, $SE = .07$, $p = .02$; actor effect), supporting our second hypothesis (Table 4). This suggests that husbands’ and wives’ perceptions of their partner’s negative dyadic coping is associated with their anxiety, depression, and relationship satisfaction. However, as no partner effect was noted, how husbands’ and wives’ perceived their other’s negative dyadic coping was not associated with the other’s anxiety, depression, and relationship satisfaction. Of note, NDCP is the only form of dyadic coping associated with all three outcomes.

**Differential influence of dyadic coping between patients and wives**

The differential influence of dyadic coping between patients and wives was also examined. After controlling for outliers, no significant interactions were found thus our third hypothesis was not supported. However, some interesting trends emerged. When wives reported more negative dyadic coping by oneself (NDCO), they tended to report less relationship satisfaction than when patients reported more NDCO ($z = -1.9$, $\chi^2 = 22.3$, $p = .06$). When wives perceived more supportive dyadic coping by partner (SDCP) they tended to report less anxiety, an effect which was not evident for patients ($z = -1.7$, $\chi^2 = 8.3$, $p = .09$). When patients reported using more supportive dyadic coping by oneself (SDCO) they also tended to report less depression, an effect which was not evident for wives ($z = 1.4$, $\chi^2 = 7.5$, $p = .17$). These trends suggest that patients and their wives may respond differently to dyadic coping.

**Discussion**

Dyadic coping is emerging as a key aspect in understanding patients’ and spouses’ adjustment to cancer [15]. This study is the first to explore the STM of dyadic
coping among patients with prostate cancer and their spouses. It is also one of only a few studies [23, 25, 44] within the context of cancer to collect data for both patients and spouses and analyse it in a dyadic manner, thus providing a much broader understanding of the reciprocal influence patients’ and spouses’ coping has on the other.

Findings from this study partially supported our first hypothesis, as supportive dyadic coping by oneself (SDCO), supportive dyadic coping by partner (SDCP), and common dyadic coping (GDC) were significantly associated with greater patient and wife relationship satisfaction. This is consistent with previous studies of the STM of dyadic coping in cancer [19, 45], and with other studies exploring the influence of similar types of dyadic coping among couples facing cancer [46-48]. Partners’ supportive dyadic coping (P-SDCO) was associated with anxiety and depression, for patients and wives (i.e., a partner effect emerged), but SDCO was not. GDC was not significantly associated with anxiety or depression. The association between P-SDCO and increased anxiety and depression might suggest one of two things: 1) it might reflect an individual’s high anxiety in eliciting more support from the partner, or 2) as an individual’s partner uses more supportive dyadic coping (e.g., “I express to my partner that I am on his/her side”), that individual is more likely to report increased anxiety and depression. Two previous longitudinal studies have shown the potentially negative impact that an individual’s attempts to be supportive may have on the other [19, 49]. Badr and colleagues [19] reported that engaging in common dyadic coping (GDC) was associated with increased distress at follow-up points for patients with breast cancer, but not their partners. Lafaye and colleagues [49] found that partners’ use of social-support seeking (from the patient or externally) at baseline predicted more anxiety and less QoL at follow-up points. Taken together, this suggests that providing support for another while also under significant stress might increase anxiety and depression for oneself. Expend additional cognitive and physical energy to support
someone else might divert time and personal resources away from one’s own issues, and is an important consideration for future couple-based interventions.

Our second hypothesis regarding negative dyadic coping was also partially supported, as negative dyadic coping by oneself (NDCO), and negative dyadic coping by the partner (NDCP) were significantly associated with decreased relationship satisfaction. Contrary to our hypothesis, only NDCP was significantly associated with increased anxiety or increased depression; NDCO was not. The relationship between NDCP and increased anxiety and depression is consistent with previous research [50-52]. For instance, among a sample of patients receiving treatment for clinical depression Bodenmann and colleagues [50, 51] found that patients and spouses who reported more psychological distress also perceived the support from their partner as being more negative in nature. Meier and colleagues [52] found a similar result among a sample of patients with chronic obstructive pulmonary disease and their spouses. Moreover, Manne and colleagues [53] found that patients’ perceptions of partner’s unsupportive behaviour mediated the relationship between partner-reports of their behaviour and patient’s psychological distress. This suggests that how behaviour is perceived by the individual determines whether or not it as a negative impact on the individual, and thus perception might be as important as the dyadic coping behaviour itself [53, 54].

Our third hypothesis regarding the differential impact of dyadic coping strategies for patients and wives was not supported. However, the trends that did emerge suggested that patients and spouses might respond differently to supportive and negative dyadic coping, which is in line with other studies [19]. For instance, Badr et al. [19] noted that negative dyadic coping was more detrimental to male spouses’ reported relationship satisfaction than for patients. Our data suggested that for wives, anxiety was negatively associated with SDCP, and NDCO was negatively associated with
relationship satisfaction. This might indicate that when wives perceived more supportive dyadic coping by the patient, they reported less anxiety, and when they used more negative dyadic coping they also reported less relationship satisfaction. For patients, depression was negatively associated with SDCO, suggesting that when patients use more supportive dyadic coping, they report less depression. This is consistent with previous dyadic coping studies that have suggested women might be more likely to report that their partner’s dyadic coping predicted marital quality, whereas men were more likely to report that their own dyadic coping predicted marital quality [55-57].

**Limitations**

This study had several limitations. Foremost is the size of the sample that renders generalisation of findings to other groups difficult. Also, a more appropriately powered sample is needed to investigate the differential impact of dyadic coping among patients and partners. Notwithstanding the size of the sample, and the exploratory nature of this pilot study, results from this study lay some groundwork to further explore the impact of dyadic coping among couples facing prostate cancer. Although participation was limited to couples where one member scored four or more on the DT, the prevalence of anxiety and depression among patients’ and partners’ were comparable to those across other studies that did not screen for distress [25, 53]. Thus, it is not clear if our findings would generalize to more distressed couples. Also, given that patients and partners typically report less distress over time [58, 59], the delay between recruitment of participants (i.e., when participants completed the DT) and the completion of the baseline survey might have been too long. Alternatively, participants, and particularly men (i.e., patients), might be more likely to buffer or hide emotional distress when completing the baseline survey compared to women [9]. Additionally, a potential bias
relating to participants who declined, because their partner was not interested in the study should be acknowledged. It may be the case that these couples simply did not feel they needed an intervention, or possibly the opposite, in that these couples might have been too distressed or unsupportive of one another.

Another limitation is that the present cross-sectional analysis limits our understanding of dyadic coping to a very short period in the cancer trajectory, and we cannot conclude whether a particular style of dyadic coping causes more or less psychological distress or relationship satisfaction. In addition, the sample was largely homogenous (elderly, white, educated, middle-class, heterosexual couples), limiting our ability to generalize the findings to other age, racial, and socio-economic groups, and same-gender couples. Similarly, given all patients were male, and all spouses were female, it was not possible to tease out whether differences were due to sex or social role (i.e., being the patient or being the partner). Couples also reported being in a relationship for a significant length of time (M = 33 years) and the vast majority reported being satisfied in their relationship. Thus, we are unable to generalize the findings to couples in short-term or unsatisfactory relationships.

**Conclusion and Practice Implications**

In conclusion, this study has highlighted the influence that dyadic coping strategies have on the way patients and their partners adjust following a prostate cancer diagnosis. Findings particularly highlighted that it is not partners’ supportive dyadic coping strategies that might be most strongly associated with less anxiety and depression within couples, but rather perceptions of their use of negative dyadic coping strategies being associated with more anxiety and depression. The implication is that improving couples’ ability to identify negative dyadic coping behaviours and to modify their interactions accordingly, as a means of increasing adjustment, rather than
specifically targeting supportive and common dyadic coping strategies might be more beneficial for couples. Health care professionals’ ability to identify potentially maladaptive coping efforts early in their interactions with couples might ensure that couples at risk of distress are referred to receive appropriate support in a more timely fashion. Additional longitudinal studies are needed to explore the causal mechanisms that underlying the relationship between anxiety, distress, and partners’ dyadic coping. Furthermore, additional studies are needed to examine the impact of broader family relationships (e.g., adult children, siblings, parents), and past relationships (e.g., deceased spouses, previous marriages) on the relationships between dyadic coping and outcomes.
References


35. Luckett, T., et al., A review and recommendations for optimal outcome measures of anxiety, depression and general distress in studies evaluating psychosocial...
interventions for English-speaking adults with heterogeneous cancer diagnoses.


Figure 2.1

Actor-Partner Interdependence Model (Kenny, Kashy, & Cook, 2002).
Figure 2.2

Actor-Partner Interdependence Model of dyadic coping and anxiety, depression and relationship satisfaction.

*Note that Actor's and Partner's Dyadic Coping refers to all of the five types of dyadic coping included in this analysis: Supportive Dyadic Coping by One's Self (SDCO-P-SDCO), Supportive Dyadic Coping by the Partner (SDCP/P-SDCP), Negative Dyadic Coping by One's Self (NDCO/P-NDCO), Negative Dyadic Coping by Partner (NDCP/P-NDCP), Common Dyadic Coping (GDCP-GDC).
Table 2.1. Sample characteristics

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<tr>
<td>Employment</td>
<td>Full time/self employed</td>
<td>44%</td>
<td>18%</td>
</tr>
<tr>
<td></td>
<td>Part time</td>
<td>10%</td>
<td>11%</td>
</tr>
<tr>
<td></td>
<td>Pensioner</td>
<td>44%</td>
<td>42%</td>
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<tr>
<td></td>
<td>Volunteer/household duties/unemployed</td>
<td>2.6%</td>
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</tr>
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<tr>
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<td>$500-$799 pw</td>
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<td>19%</td>
</tr>
<tr>
<td></td>
<td>$800-$1000 pw</td>
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<td>14%</td>
</tr>
<tr>
<td></td>
<td>&gt; $1000 pw</td>
<td>51%</td>
<td>57%</td>
</tr>
<tr>
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<td>Prefer not to answer</td>
<td>10%</td>
<td>11%</td>
</tr>
<tr>
<td>Relationship status</td>
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<td>97%</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Other</td>
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<td></td>
</tr>
<tr>
<td>Surgery</td>
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<td>68%</td>
<td></td>
</tr>
<tr>
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<td>32%</td>
<td></td>
</tr>
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<td>100%</td>
<td></td>
</tr>
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<td>Variable</td>
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</tr>
<tr>
<td>------------------</td>
<td>----------</td>
<td>---------</td>
<td>---------</td>
</tr>
<tr>
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<td></td>
</tr>
<tr>
<td></td>
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<td></td>
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<td>95%</td>
<td></td>
</tr>
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<td></td>
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<td>4.9%</td>
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<tr>
<td>Watch and wait</td>
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<td>88%</td>
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<tr>
<td></td>
<td>Yes</td>
<td>12%</td>
<td></td>
</tr>
<tr>
<td></td>
<td>SDCO</td>
<td>SDCP</td>
<td>NDCO</td>
</tr>
<tr>
<td>--------</td>
<td>------</td>
<td>------</td>
<td>------</td>
</tr>
<tr>
<td>SDCO</td>
<td>-</td>
<td>0.10</td>
<td>-0.41</td>
</tr>
<tr>
<td>SDCP</td>
<td>0.42</td>
<td>-</td>
<td>-0.10</td>
</tr>
<tr>
<td>NDCO</td>
<td>-0.25</td>
<td>-0.29</td>
<td>-</td>
</tr>
<tr>
<td>NDCP</td>
<td>-0.13</td>
<td>-0.45</td>
<td>0.63</td>
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<tr>
<td>GDC</td>
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<td>0.54</td>
<td>-0.44</td>
</tr>
<tr>
<td>HADSA</td>
<td>-0.15</td>
<td>0.14</td>
<td>0.04</td>
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<tr>
<td>HADSD</td>
<td>-0.35</td>
<td>0.10</td>
<td>0.23</td>
</tr>
<tr>
<td>DASSAT</td>
<td>0.28</td>
<td>0.36</td>
<td>-0.54</td>
</tr>
<tr>
<td>P-SDCO</td>
<td>0.25</td>
<td>0.26</td>
<td>-0.45</td>
</tr>
<tr>
<td>P-SDCP</td>
<td>0.31</td>
<td>0.35</td>
<td>-0.19</td>
</tr>
<tr>
<td>P-NDCO</td>
<td>0.08</td>
<td>-0.17</td>
<td>0.04</td>
</tr>
<tr>
<td>P-NDCP</td>
<td>-0.11</td>
<td>-0.23</td>
<td>0.05</td>
</tr>
<tr>
<td>P-GDC</td>
<td>0.35</td>
<td>0.39</td>
<td>-0.39</td>
</tr>
<tr>
<td>P-HADSA</td>
<td>0.05</td>
<td>-0.24</td>
<td>0.26</td>
</tr>
<tr>
<td>P-HADSD</td>
<td>0.24</td>
<td>0.05</td>
<td>0.04</td>
</tr>
<tr>
<td>P-DASSAT</td>
<td>0.22</td>
<td>0.31</td>
<td>-0.56</td>
</tr>
</tbody>
</table>

*Correlations in bold indicate significance at the .05 level. Patient correlations are below the diagonal, spouses are above the diagonal. Variable abbreviations: Supportive Dyadic Coping by Oneself (SDCO), Supportive Dyadic Coping by Partner (SDCP), Negative Dyadic Coping by Oneself (NDCO), Negative Dyadic Coping by Partner (NDCP), Common Dyadic Coping (GDC), Anxiety (HADSA), Depression (HADSD), Relationship satisfaction (DASSAT), Partner-Supportive Dyadic Coping by Oneself (P-SDCO), Partner-Supportive Dyadic Coping by Partner (P-SDCP), Partner-Negative Dyadic Coping by Oneself (P-NDCO), Partner-Negative Dyadic Coping by Partner (P-NDCP), Partner-Common Dyadic Coping (P-GDC), Partner-Anxiety (P-HADSA), Partner-Depression (P-HADSD), Partner-Relationship satisfaction (P-DASSAT).
Table 2.3.

Descriptive results for patients and spouses.

<table>
<thead>
<tr>
<th>Variable Abbreviations</th>
<th>Patients</th>
<th></th>
<th>Spouses</th>
<th></th>
<th>p-value*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Range</td>
<td>Mean (SD)</td>
<td>Range</td>
<td></td>
</tr>
<tr>
<td>HADSA</td>
<td>4.91 (3.64)</td>
<td>0-13</td>
<td>6.77 (4.40)</td>
<td>0-20</td>
<td><strong>.04</strong></td>
</tr>
<tr>
<td>HADSD</td>
<td>2.13 (2.61)</td>
<td>0-9</td>
<td>3.15 (3.62)</td>
<td>0-17</td>
<td>.15</td>
</tr>
<tr>
<td>DASSAT</td>
<td>16.97 (1.66)</td>
<td>13-20</td>
<td>16.31 (2.04)</td>
<td>11-19</td>
<td>.12</td>
</tr>
<tr>
<td>SDCO</td>
<td>18.34 (3.33)</td>
<td>10-25</td>
<td>18.23 (3.53)</td>
<td>7-24</td>
<td>.89</td>
</tr>
<tr>
<td>SDCP</td>
<td>20.08 (3.48)</td>
<td>12-25</td>
<td>18.16 (4.01)</td>
<td>7-25</td>
<td><strong>.02</strong></td>
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<tr>
<td>NDCO</td>
<td>6.80 (2.88)</td>
<td>3-12</td>
<td>5.95 (2.24)</td>
<td>4-11</td>
<td>.14</td>
</tr>
<tr>
<td>NDCP</td>
<td>6.23 (2.45)</td>
<td>4-12</td>
<td>7.53 (3.05)</td>
<td>4-14</td>
<td><strong>.04</strong></td>
</tr>
<tr>
<td>GDC</td>
<td>17.05 (4.21)</td>
<td>7-25</td>
<td>18.13 (4.12)</td>
<td>9-25</td>
<td>.25</td>
</tr>
</tbody>
</table>

* p-values in bold indicate significance at .05 level.

Variable abbreviations: Supportive Dyadic Coping by Oneself (SDCO), Supportive Dyadic Coping by Partner (SDCP), Negative Dyadic Coping by Oneself (NDCO), Negative Dyadic Coping by Partner (NDCS), Common Dyadic Coping (GDC), Anxiety (HADSA), Depression (HADSD), Relationship satisfaction (DASSAT).
Table 2.4.

Effects of Supportive Dyadic Coping (SDCO/SDCP), Negative Dyadic Coping (NDCO/NDCP), and Common Dyadic Coping (GDC) on patients’ and spouses’ anxiety, depression, and relationship satisfaction.

<table>
<thead>
<tr>
<th></th>
<th>Anxiety (HADSA)</th>
<th>Depression (HADSD)</th>
<th>Relationship Satisfaction (R-DAS satisfaction subscale)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>z</td>
<td>SE</td>
<td>p&gt;</td>
</tr>
<tr>
<td><strong>Model 1</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SDCO</td>
<td>-.58</td>
<td>.13</td>
<td>.56</td>
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<tr>
<td>P-SDCO</td>
<td><strong>2.05</strong></td>
<td><strong>.13</strong></td>
<td><strong>.04</strong></td>
</tr>
<tr>
<td>Relationship Length</td>
<td>.66</td>
<td>.04</td>
<td>.51</td>
</tr>
<tr>
<td><strong>Model 2</strong></td>
<td></td>
<td></td>
<td></td>
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<td>SDCP</td>
<td>-.69</td>
<td>.12</td>
<td>.49</td>
</tr>
<tr>
<td>P-SDCP</td>
<td>-.84</td>
<td>.12</td>
<td>.40</td>
</tr>
<tr>
<td>Relationship Length</td>
<td>.64</td>
<td>.04</td>
<td>.52</td>
</tr>
<tr>
<td><strong>Model 3</strong></td>
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<td>GDC</td>
<td>.72</td>
<td>.12</td>
<td>.48</td>
</tr>
<tr>
<td>P-GDC</td>
<td>-.56</td>
<td>.12</td>
<td>.58</td>
</tr>
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<td>Relationship Length</td>
<td>.61</td>
<td>.04</td>
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</tr>
<tr>
<td><strong>Model 4</strong></td>
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<td>.13</td>
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<tr>
<td>P-NDCO</td>
<td>1.60</td>
<td>.18</td>
<td>.11</td>
</tr>
<tr>
<td>Relationship Length</td>
<td>.53</td>
<td>.04</td>
<td>.60</td>
</tr>
<tr>
<td><strong>Model 5</strong></td>
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<td></td>
<td></td>
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<tr>
<td>NDCP</td>
<td><strong>3.14</strong></td>
<td><strong>.16</strong></td>
<td><strong>.002</strong></td>
</tr>
<tr>
<td>P-NDCP</td>
<td>1.68</td>
<td>.16</td>
<td>.09</td>
</tr>
<tr>
<td>Relationship Length</td>
<td>.36</td>
<td>.04</td>
<td>.72</td>
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</tbody>
</table>
Introduction to Paper Three

Do Couple-Based Interventions Make a Difference for Couples Affected by Cancer?: A Systematic Review

Aims and purpose
The results presented in Paper Two add to the growing evidence that couples react to cancer as an interdependent system. This lends support to the view that both patients and their partners might benefit most from the synergistic change that might result from dyadic interventions, given that reducing distress in one member of the dyadic might indirectly result in better outcomes in the other. Traditionally, psychosocial interventions for people affected by cancer have been delivered separately to patients and partners. Recent systematic reviews and meta-analyses have suggested that the effective management of psychological distress can improve quality of life for patients and for their partners. To date, few reviews or meta-analyses have sufficiently explored the role of couple-based interventions, by not including details regarding effect sizes, including studies that did not examine outcomes for partners as well as patients, or including studies that focused on just one outcome (e.g., quality of life or sexuality). None of these reviews have examined in detail the variation in aspects including intervention content, intervention delivery mode, and who delivers the intervention. This information is important for improving couple-based interventions in the future. Paper Three is a systematic review that aims to explore the content, mode of delivery, and efficacy of previous couple-based interventions for patients and partners facing cancer.

This is the third paper in this thesis and has been published in BMC Cancer. The citation is Regan, T., Lambert, S., et al. (2012). "Do Couple-based Interventions Make a Difference for Couples affected by Cancer? A Systematic Review." BMC Cancer, 12. [Appendix 3.2].
Paper Three

Do Couple-Based Interventions Make a Difference for Couples Affected by Cancer?: A Systematic Review

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Aaf Girgis,
The University of New South Wales, Sydney, Australia

Brian Kelly,
The University of Newcastle, Newcastle, Australia

Karen Kayser,
The University of Louisville, Louisville, USA

Jane Turner,
The University of Queensland, Brisbane, Australia
Abstract

Background:

With the growing recognition that patients and partners react to a cancer diagnosis as an interdependent system and increasing evidence that psychosocial interventions can be beneficial to both patients and partners, there has been a recent increase in the attention given to interventions that target couples. The aim of this systematic review was to identify existing couple-based interventions for patients with cancer and their partners and explore the efficacy of these interventions (including whether there is added value to target the couple versus individuals), the content and delivery of couple-based interventions, and to identify the key elements of couple-based interventions that promote improvement in adjustment to cancer diagnosis.

Method:

A systematic review of the cancer literature was performed to identify experimental and quasi-experimental couple-based interventions published between 1990 and 2011. To be considered for this review, studies had to test the efficacy of a psychosocial intervention for couples affected by cancer. Studies were excluded if they were published in a language other than English or French, focused on pharmacological, exercise, or dietary components combined with psychosocial components, or did not assess the impact of the intervention on psychological distress (e.g., depression, anxiety) or quality of life. Data were extracted using a standardised data collection form, and were analysed independently by three reviewers.

Results:

Of the 709 articles screened, 23 were included in this review. Couple-based interventions were most efficacious in improving couple communication, psychological distress, and relationship functioning. Interventions had a limited impact on physical distress and social adjustment. Most interventions focused on improving
communication and increasing understanding of the cancer diagnosis within couples. Interventions were most often delivered by masters-level nurses or clinical psychologists. Although most were delivered in person, few were telephone-based. No difference in efficacy was noted based on mode of delivery. Factors associated with uptake and completion included symptom severity, available time and willingness to travel.

**Discussion:**

Given effect sizes of couple-based interventions are similar to those reported in recent meta-analyses of patient-only and caregiver-only interventions (~d=.35-.45), it appears couple-based interventions for patients with cancer and their partners may be at least as efficacious as patient-only and caregiver-only interventions. Despite evidence that couple-based interventions enhance psychosocial adjustment for both patients and partners, these interventions have not yet been widely adopted. Although more work is needed to facilitate translation to routine practice, evidence reviewed is promising in reducing distress and improving coping and adjustment to a cancer diagnosis or to cancer symptoms.
Background

Cancer is the leading cause of disease-related burden in Australia and accounts for nearly one-fifth of the total disease burden [1]. In 2010, approximately 115,000 Australians were diagnosed with cancer, with 1 in 2 men and 1 in 3 women diagnosed before the age of 85 [1]. As the number of people living beyond initial diagnosis is increasing, so is the time during which the disease sequelae and psychosocial consequences must be managed. The ability of patients and their partners\(^2\) to manage cancer challenges has been shown to impact on their short and long-term adjustment to the disease [2]. Therefore, reducing psychological distress, increasing coping ability, and improving the quality of life (QoL) of individuals with cancer and their partners or caregivers are priorities for researchers and clinicians [3, 4].

Conceptualisations of Adjustment to Cancer

One of the most popular frameworks for understanding adjustment to life stressors, such as cancer, was described by Lazarus & Folkman in their seminal book “Stress, Appraisal, and Coping” [5]. Lazarus & Folkman described coping with stressful events as an active process, placing emphasis on the context in which stressors are presented and must be dealt with. It follows that how individuals cope with a cancer diagnosis is partially determined by their ongoing appraisal of new and unfamiliar challenges that arise during the course of their illness. Findings from a recent meta-analysis of appraisal and coping styles [6] found that when cancer is appraised as a threat, individuals tend to engage more in problem-focused coping, whereas when cancer is appraised as a threat, individuals tend to engage more in problem-focused coping, whereas when cancer is appraised as a threat, individuals tend to engage more in problem-focused coping, whereas when cancer is appraised as a threat, individuals tend to engage more in problem-focused coping, whereas when cancer is appraised as a threat, individuals tend to engage more in problem-focused coping, whereas when cancer is appraised as a threat, individuals tend to engage more in problem-focused coping, whereas when cancer is appraised as a threat, individuals tend to engage more in problem-focused coping, whereas when cancer is appraised as a threat, individuals tend to engage more in problem-focused coping, whereas when cancer is appraised as a threat, individuals tend to engage more in problem-focused coping, whereas when cancer is appraised as a threat, individuals tend to engage more in problem-focused coping, whereas when cancer is appraised as a threat, individuals tend to engage more in problem-focused coping, whereas when cancer is appraised as a threat, individuals tend to engage more in problem-focused coping, whereas when cancer is appraised as a threat, individuals tend to engage more in problem-focused coping, whereas when cancer is appraised as a threat, individuals tend to engage more in problem-focused coping, whereas when cancer is appraised as a threat, individuals tend to engage more in problem-focused coping, whereas when cancer is appraised as a threat, individuals tend to engage more in problem-focused coping, whereas when cancer is appraised as a threat, individuals tend to engage more in problem-focused coping, whereas when cancer is appraised as a threat, individuals tend to engage more in problem-focused coping, whereas when cancer is appraised as a threat, individuals tend to engage more in problem-focused coping, whereas when cancer is appraised as a threat, individuals tend to engage more in problem-focused coping, whereas when cancer is appraised as a threat, individuals tend to engage more in problem-focused coping, whereas when cancer is appraised as a threat, individuals tend to engage more in problem-focused coping, whereas when cancer is appraised as a threat, individuals tend to engage more in problem-focused coping, whereas when cancer is appraised as a threat, individuals tend to engage more in problem-focused coping, whereas when cancer is appraised as a threat, individuals tend to engage more in problem-focused coping, whereas when cancer is appraised as a threat, individuals tend to engage more in problem-focused coping, whereas when cancer is appraised as a threat, individuals tend to engage more in problem-focused coping, whereas when cancer is appraised as a threat, individuals tend to engage more in problem-focused coping, whereas when cancer is appraised as a threat, individuals tend to engage more in problem-focused coping, whereas when cancer is appraised as a threat, individuals tend to engage more in problem-focused coping, whereas when cancer is appraised as a threat, individuals tend to engage more in problem-focused coping, whereas when cancer is appraised as a threat, individuals tend to engage more in problem-focused coping, whereas when cancer is appraised as a threat, individuals tend to engage more in problem-focused coping, whereas when cancer is appraised as a threat, individuals tend to engage more in problem-focused coping, whereas when cancer is appraised as a threat, individuals tend to engage more in problem-focused coping, whereas when cancer is appraised as a

\(^2\) For the purpose of this review, ‘partners’ refers to spousal partners, rather than non-spousal caregivers. This is consistent with the majority of interventions reviewed here, and with widely accepted definitions of dyadic coping.
harm/loss or as a challenge, emotion-based coping is more likely to be used. Meaning-making coping was later added to the framework as a means of reconciling an appraisal of a stressor that is incongruent with one’s personal beliefs and goals [7]. There is an intuitive clarity within Lazarus and Folkman’s approach to coping, but translation into clinical practice has not been so straightforward. Coyne and Racioppo [8] highlighted that understanding coping and coping styles has not necessarily improved researchers’ understanding of the efficacy of psychosocial interventions aimed at increasing coping. They suggested that despite numerous reviews and meta-analyses of coping interventions, the lack of consistency in intervention types, experimental designs, outcome measures, and a lack of methodological rigour make it difficult to enunciate the key elements of these interventions that can produce improvements in individuals’ and partners’ psychological distress.

**Current Evidence about Interventions to Promote Adjustment**

Several meta-analyses have been conducted in recent years to better understand the impact of psychosocial interventions for people with cancer [9-14]. For instance, Meyer and Mark [9] conducted a meta-analysis of controlled studies that implemented various psychosocial interventions for individuals with different cancer types and found these to have small effects on outcomes measured such as emotional adjustment, functional adjustment, treatment and disease symptoms (d=.17 - .28). However, when controlling for intervention type, non-behavioural interventions (e.g., interventions that focus on increasing social support and allow for expression of emotion) showed stronger effects on emotional adjustment measures (d=.39) in comparison to cognitive-behavioural or psycho-education interventions. Another meta-analysis by Sheard and Maguire (1999) attempted to minimise heterogeneity of outcome measures by focusing on psychological interventions for anxiety and depression, conducting separate analyses for each of these
outcomes. Overall, a moderate effect of psychological interventions on anxiety (d=.42) was found. Larger effects on anxiety and depression were found for studies where treatments included more than eight hours of therapy, and were conducted with a more experienced therapist [12]. Longer-term interventions (minimum 12 weeks) had a greater impact on QoL than short-term interventions (d=1.19, d=.47) [11]. This suggests that at least some of the effects of these psychosocial interventions may be attributed to the relationships formed between individuals and their therapist or therapeutic group.

**Psycho-educational Interventions**

Group psycho-education interventions (i.e., interventions where the primary aim was to educate patients on the management of psychological symptoms) were found to have significantly stronger effects on anxiety (d=1.59, p<.01) than group therapy that excluded psycho-education (d=.27) [12]. A similar trend was found on depression outcomes, as group psycho-education was more efficacious (d=.94) than group therapy that excluded psycho-education (d=.42) [12]. Consistent with this, individual format interventions were less efficacious than group format therapies (relaxation only d=.03; individual therapy; d=.30). This strong, positive effect of psycho-education was also found on measures of QoL in a separate meta-analysis conducted by Rehse and Pukrop [11].

**Cognitive Behavioural Therapy-based Interventions**

A meta-analysis by Osborne, Demoncada, and Feuerstein [10] compared psycho-education interventions with Cognitive Behavioural Therapy (CBT) interventions on measures of anxiety and depression. No evidence was found to support the efficacy of psycho-education interventions, due largely to the small number of studies included. CBT interventions, on the other hand, were shown to have strong effects on both anxiety and depression (g=1.99, g=1.21, respectively). Further, Osborne et al. found
evidence to suggest that individual-based CBT interventions were more efficacious than group-based CBT interventions. A similar result was found in Tatrow and Montgomery’s [13] meta-analysis of CBT techniques for improving distress in individuals with cancer. CBT delivered in an individual format (d=0.48) produced larger effect sizes than therapy delivered in a group format (d=-0.06). A meta-analysis of the moderators of effects in psychosocial interventions for breast cancer patients found that individual interventions may result in greater effect sizes than group-based interventions; however, this difference was eliminated when controlling for interventions that included homogenous cancer types versus interventions that included heterogeneous cancer types [14].

**Interventions Directed Towards Partners**

Research has traditionally focused on the impact of cancer on patients, and only recently has significant attention been paid to the impact of a diagnosis on partners [15]. Patients and partners often describe similar reactions to a cancer diagnosis, including shock [16-18], distress [19-21], anxiety [16, 17, 21], depression [16, 17, 21], fear and uncertainty [17, 18, 22], and denial [17]. Moreover, there is evidence to suggest that partner or caregiver anxiety may be associated with patient anxiety, and may influence other illness adjustment outcomes including depression, fatigue, and symptom management [23]. Thus, interventions that address the concerns of partners are essential. Recent reviews and meta-analyses suggest that interventions targeting caregivers (who are often the partners of patients with cancer) can significantly improve coping ability, QoL, communication, sexual functioning, and self-efficacy, and can significantly reduce caregiver burden [24-29]. More specifically, a meta-analysis by Northouse et al. [28] found that caregiver interventions were superior to usual care in reducing anxiety (g=0.20) and improving physical functioning (g=0.22 - 0.26) and family and marriage
relationships ($g=.20$). Moderator analysis revealed that a greater number of intervention sessions ($M=5.2$ sessions) and a greater number of intervention hours ($M=7$ h) had a positive influence on coping ability. This is similar to the findings from the aforementioned meta-analysis by Sheard and Maguire and Rehse and Pukrop [11, 12]. Harding and Higginson [26] presented evidence to suggest that the mode of delivery for caregiver interventions is also an important consideration. Although caregivers in these studies found both individual and group formats acceptable, some formats were preferred for selected content. For instance, the content of individual format interventions targeted problem solving skills, emotional expression, and pain management education [26]. The content of group-based, caregiver-only interventions was generally similar to group-based patient-only interventions, with a focus on information exchange, shared experiences, and the promotion of self-help [26]. Somewhat surprisingly, few interventions have focused on improving the partners ability to provide physical assistance to patients, beyond the management of pain [24]. Two reviews [25, 27] have highlighted that despite some success, a lack of methodological rigour, and the heterogeneity of research design, theoretical frameworks and outcome measures limits the generalisability of caregiver-only interventions.

Despite evidence of the substantial impact of a cancer diagnosis on both patients and partners [15] and interventions targeting patients and partners separately having at least a moderate impact on coping and adjustment to the disease, there have been few studies investigating the efficacy of couple-based coping interventions [30]. McLean and Jones found some evidence to support the use of a couple-based intervention for palliative care patients, though cited a lack of studies to make concrete recommendations [31]. A review of couple-based interventions by Baik and Adams included 14 studies, and concluded that couple-based interventions can lead to improvements in dyadic-level adjustment [32]. Although they provided an overview of
the results of each intervention, this review did not provide particular depth with regard to intervention efficacy. Moreover, the authors also included studies that did not report partner outcomes [33], and one case study [34]. Although these can still be considered couple-based interventions, the lack of partner outcomes limits interpretations of the differential effects of a couple-based intervention for patients and partners. Hopkinson and colleagues undertook a review of couple-based interventions and their impact on symptom management and other health behaviours [35]. They concluded that couple-based interventions can improve adjustment to cancer, and provided a concise overview of the studies that relieved symptoms psychosocial distress. However, the authors provided little detail with regard to the size of the differences between intervention and control couples, or the specific measures used to assess the various psychosocial domains. Hopkinson and colleagues also included studies that did not report partner outcomes, and in some cases did not require a partner to be involved in the intervention [36, 37]. Finally, Scott and Kayser recently undertook a re-view of couple-based interventions to improve sexuality and body image for women with cancer [38]. They found that some interventions that included partners produced greater effect sizes than interventions that focused on patients only. Moreover, intervention effects tended to be maintained for longer following a couple-based intervention compared to a patient-only intervention. These improvements and their maintenance are hypothesized to be based on improvements in dyadic coping and increased knowledge of the patient’s diagnosis and treatments.

There is growing evidence demonstrating the efficacy of patient-only and caregiver/partner-only interventions in reducing psychological distress and improving QoL, and longer-term improvements in sexual functioning and body image when partners actively participate in interventions [9-13, 25-28, 38]. This review will complement existing reviews by examining 1) the efficacy of couple-based
interventions across a wide range of outcome measures, 2) how the content of specific couple-based interventions is tailored and delivered to couples and 3) which elements of couple-based interventions seem most promising in reducing psychological distress and improving adjustment among patients and partners.

**Method**

A systematic review was undertaken to explore the efficacy, content, and delivery of couple-based interventions. The heterogeneity of intervention content, intervention delivery, cancer type, outcome measures, intervention length, and follow-up length made the implementation of a meta-analysis unfeasible [39, 40]. To maximise methodological quality, this review was conducted in accordance with the guidelines suggested by the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) [41].

**Inclusion Criteria**

Studies were included if they:

- Evaluated a psychosocial intervention (psychological, behavioural, or educational) for people with cancer AND their partners.

- Used an experimental or quasi-experimental design; were published between January 1990 and May 2010. [NB: This period was chosen as the majority of couple-based interventions began to emerge around this time.]

- Targeted individuals diagnosed with cancer (any type and any stage along the illness trajectory).

- Were published in English or French [languages spoken by the authors].

- Included depression, anxiety, distress, or QoL as an outcome measure.
Studies were excluded if:

- They compared interventions that were relatively similar in their focus.

- Pharmacological, exercise, or dietary elements were the central component of
the intervention, with psychosocial elements being secondary (in order to delineate the
efficacy of the psychosocial component).

- They focused specifically on sexuality and sexual functioning as outcome
measures. While related to psychological distress, these were deemed to be a separate
consideration worthy of more specific attention.

- They did not report patient and partner outcomes separately.

**Literature Search**

CINAHL, PSYCINFO, MEDLINE, EMBASE, and ISI Web of Science were searched
for relevant articles. The key search terms were (couple* OR partner* OR support* OR
caregiver* OR carer* OR family OR spouse* OR husband* OR wife OR wives OR
close relative(s), OR next of kin(s), significant other(s), OR couple(s), OR family, OR
families, OR relative(s) AND (cancer OR neoplasm*).

The NOT command was used to exclude the following terms: Nutrition OR physical
activity OR diet OR child* OR youth OR adolescent*. Reference lists of recent
literature reviews, unpublished articles, doctoral theses, and of all individual articles
retrieved were also searched.

In addition, individual researchers known to do work in this area were contacted by e-
mail and asked if they had studies currently under review or in-press that may be
eligible for inclusion in the review.

**Data Extraction**
The titles and abstracts for all identified papers were assessed for relevance by the first author and were rejected if the study did not meet the inclusion criteria. The abstracts of the remaining studies were then assessed against the inclusion and exclusion criteria by two reviewers and those that met the criteria were retained for full review. Where there was disagreement between reviewers, consensus was reached through discussion. Two reviewers independently extracted data using a standard data collection form, which included authors, country, aims, sample size, cancer type, intervention components, intervention duration, and method of delivery of the intervention.

**Methodological Criteria**

The methodological quality of the studies included in this review was assessed using the criteria described by the Effective Public Health Practice Project (EPHPP) [42] and the National Health and Medical Research Centre (NHMRC) guidelines for hierarchically assessing levels of evidence [43]. The EPHPP is a reliable, valid and comprehensive tool for use in detecting bias within intervention studies, and is considered suitable to be used in systematic reviews of the effectiveness of interventions [44, 45]. Six domains from each study were given a rating from 1- ‘strong’ to 3 - ‘weak’. These domains were: selection bias, study design, confounders, blinding, data collection methods, and withdrawals and dropouts. Each study was then given a global rating from 1- ‘strong’ to 3 - ‘weak’. Studies were rated as strong if they: 1) included participants likely to represent the target population, 2) used an randomised controlled trial or controlled clinical trial (CCT) design, 3) controlled for confounders, 4) blinded participants to the research question, and blinded outcomes assessors to participant status, 5) reported reliability and validity of the measures used, or used outcomes measures with known reliability and validity, and 6) reported an attrition rate of 20% or less. The methodological quality of each study was assessed by three authors. Uncertainty
regarding the quality of any studies was resolved through discussion among three of the authors. Using the guidelines described in the EPHPP [42], eight studies had a global rating of ‘strong’ [23, 46-52], whereas the remaining 15 studies were rated as ‘moderate’. The most common reason for a study not receiving a rating of ‘strong’ was due to a low response rate from eligible participants, which led to otherwise ‘strong’ articles being rated as ‘moderate’.

The National Health and Medical Research Centre (NHMRC) has published guidelines for hierarchically assessing levels of evidence to indicate the degree to which bias has been minimised [53]. A level of II reflects evidence obtained from an appropriately designed randomised controlled trial, level III-1 reflects evidence from a pseudo-randomised controlled trial, and level III-2 reflects evidence obtained from comparative non-randomised studies with concurrent controls (e.g., cohort studies). Six studies in this review had an evidence level of II [12, 46, 47, 49, 50, 52, 54], twelve had an evidence level of III-1 [4, 23, 48, 51, 52, 55-61], and five had an evidence level of III-2 [62-67].

Results

Twenty-three couple-based intervention studies were included in this review. Initially 1279 articles were identified across the electronic databases: 237 articles identified from the CINAHL database, 144 from PSYCINFO, 406 from MEDLINE and 492 from ISI Web of Science. Of these, 570 duplicates were removed. The titles and abstracts of the remaining 709 studies were screened, and 27 studies were retained for full-text review. Details of the excluded studies and entire literature search are presented in Figure 1. Of the 27 studies kept for full review, 10 were subsequently excluded: seven described a planned couple-based intervention (no efficacy data available) or described a peer support intervention (e.g., support from a cancer survivor, not necessarily known to the
patient); and three because the primary focus was not relevant to this review (e.g., were not specifically psychosocial interventions). Six additional studies were identified after making contact with researchers in the field.

Table 3.1 outlines the key information for each of the studies included in this review. This includes the author, design, methodological quality rating [42], evidence level rating [43], description of the intervention and control conditions, including length of intervention and delivery format, sample, the outcomes measured in each study, and significant outcomes with effect sizes (Cohen’s [68]). Along with the content of each intervention, each intervention was classified as either a dyadic intervention (where both patient and partner engage in the intervention simultaneously and with similar roles), a coaching intervention (where the partner takes on more of a ‘proxy’ therapist role), or an individual intervention (where patients and partner receive the same or similar intervention separately). Effect size was calculated using the difference in mean scores between the intervention and control group (for patients and partners separately) at specified time-points, divided by the pooled sample standard deviation [69]. All effect sizes are shown as positive values, regardless of the measure used, to indicate improvement for the experimental group compared to the particular comparison group.

**Characteristics of Couple-Based Interventions**

**Classification of interventions.**

The couple-based interventions reviewed here can be classified under three broad categories. Thirteen studies [23, 46, 47, 49, 50, 58, 60, 61, 63-67] had a primary focus on improving communication between partners. Eight [4, 51, 52, 54, 56, 59, 70, 71] studies had a primary focus on developing specific skills to enhance coping ability (e.g., relaxation techniques, stress management, obtaining information). Two studies [48, 55]
had a primary focus on educating patients and partners on specific elements of cancer and cancer care (e.g., symptom management, potential treatment side-effects).

**Delivery of interventions.**

Table 3.1 outlines the details of the delivery of these couple-based interventions. Fifteen interventions were delivered to couples face-to-face [4, 47, 49-52, 54, 58, 60, 61, 64-67, 71], four were delivered by telephone [23, 46, 56, 63], three were delivered face-to-face and over the telephone [48, 57, 59, 72], and one was delivered using face-to-face, over the telephone and through educational videos [55]. Twenty of the interventions were delivered to both patients and partners at the same time [4, 47-52, 54, 56-61, 63-67, 71]. Three of these interventions were classified as ‘coaching’ interventions [48, 50, 59], as they tended to utilise the partner as a proxy therapist, whose role in the intervention was to assist the patient. The remaining 17 interventions were classified as ‘dyadic’ interventions, as they addressed the couple as unit. Three interventions were delivered to couples separately (via telephone, though with related content) [23, 46, 55]. Seven interventions were delivered by psychologists or clinical psychology doctoral students [4, 47, 49, 56, 58, 63, 65], one was delivered by PhD level psychologists and licensed clinical social workers [66], three were delivered by masters-level therapists from psychology or social work backgrounds [54, 60, 66], six were delivered by masters-level nurses [23, 48, 51, 52, 57, 71], one was delivered by a psychiatric nurse counsellor [23], two were delivered by nurses (experience and qualifications not otherwise described) [55, 59], and three were delivered by health care professionals described as therapists or counsellors (experience or professional background not provided) [61, 64, 67]. Seven of the interventions required those delivering them to undergo specific training of intervention protocols, ranging in length from six-hours to a four-day seminar [50, 51, 54-56, 63, 71]. All studies followed a specific intervention protocol,
and all but seven studies [48, 49, 58, 61, 64, 65, 67] outlined their plans to maintain treatment fidelity.

** Characteristics of participants in couples-based interventions **

Table 3.2 presents a summary of participant characteristics. The majority of patients was Caucasian, highly educated, diagnosed with breast or prostate cancer, and aged in their early 50s. There was an even proportion of patients across disease stages.

** Participant uptake and attrition. **

Based on 17 studies that provided clear eligibility and randomisation data, 2315 out of 4631 (49.99%) eligible couples were randomised into a couple-based intervention (M=136.18, SD=119.07). Across all studies, 84.49% of patients (N=1956, M=115.06, SD=100.60) and 82.55% of partners (N=1911, M=112.41, SD=100.64) who were randomised into an intervention provided data at the first follow-up point. At the final follow-up point, 73.19% of patients (N=1678, M=111.87, SD=76.16) and 71.30% of partners (N=1607, M=107.13, SD=74.72) provided data. The most common reasons for withdrawal were the distance to the intervention being too far, burden of illness too great, or participants felt that the intervention did not meet their needs. Furthermore, some studies suggested participants were more likely to drop out if they had late-stage cancer, lung cancer, poor physical functioning at baseline, or poor emotional connection or warmth to their partner at baseline [4, 58, 59], though none of the studies reported any pattern of systematic attrition.

** Outcomes **

Outcome measures used for patients and partners are shown in Table 3.1.

** Quality of Life (QoL). **
QoL was conceptualised as the couples’ perceptions of how cancer has impacted everyday aspects of their physical and emotional functioning and activities. Among the five studies that assessed global QoL, four used self-report measures [51, 52, 54, 71] and one used clinician ratings [71]. One study reported weak to moderate improvements in QoL for patients immediately following the intervention [71] whereas the remaining four studies reported no significant change immediately following the intervention. Four studies assessed change between six and 12 months post-intervention and only one of these reported improvements at follow-up compared to the control group [54]. Four assessed partners’ QoL [51, 52, 54, 71], and two studies [52, 71] reported weak to moderate improvements immediately following the intervention, and also at six, and 12 month follow-ups.

**Psychological distress.**

Across studies psychological distress was conceptualised as emotional distress, anxiety, depression, worry, negative thoughts, and/or negative mood. Of the 18 studies that assessed psychological distress [4, 23, 46-50, 52, 55, 58-61, 63-65, 67], nine reported greater improvements for intervention patients than control patients [4, 23, 46-48, 50, 55, 58, 59] at the first follow-up point, and three studies reported improvements compared to baseline scores at the first follow-up point [64-66]. Six studies reported greater improvements for intervention patients than control patients at the final follow-up [4, 46-48, 51, 58], and one study [65] reported greater scores compared to baseline at the final follow-up point. For partners, two studies reported significant improvements for intervention groups compared to control groups immediately following the intervention [46, 47], and three studies reported within-group improvements compared to baseline scores [64-66]. Four studies reported improvements for intervention partners compared to control group partners at the final follow-up point [46-48, 58], and one
study reported within-group improvement at the final follow-up point compared to baseline [65].

Physical distress.

Physical distress was conceptualised as the impact cancer and treatments (including side effects) had on individuals’ physical functioning, pain, and fatigue. Of the eight studies that assessed physical distress specifically (i.e., separate to global QoL measures) [46, 47, 51, 56, 59, 61, 71], three reported greater improvements for intervention patients than control patients immediately following the intervention [46, 56, 59]. Three studies reported greater improvements for intervention patients than control patients at the final follow-up point [46, 55, 59]. Two studies assessed partners’ ratings of their own physical distress [46, 59], and one study assessed partner’s ratings of how much they were affected by the patient’s physical distress [71]. In one study, intervention partners also reported less physical symptoms (of their own) compared to control partners immediately following the intervention [55]. Another study reported that intervention partners reported being significantly less affected by the patient’s physical distress compared to control partners immediately following the intervention [71].

Sexuality.

Sexuality was conceptualised as the sexual functioning and satisfaction of patients and partners since their diagnosis. Of the five studies that assessed sexuality [4, 47, 48, 56, 71], one study reported greater improvements for intervention patients than control immediately following the intervention [4]. Two studies reported greater improvements for intervention patients than control patients at the final follow-up point [4, 48]. For partners, one study reported improvements immediately following the intervention and at the final follow-up [48].
Social adjustment.

Social adjustment was conceptualised as the ability of patients and partners to maintain family, vocational, and social roles. Six studies assessed social adjustment for both patients and partners [46, 54, 55, 59, 66]. Three studies found greater improvements for intervention patients compared to control patients immediately following the intervention [46, 54, 59]. Two studies found greater improvements for intervention patients compared to control patients at the final follow-up point [46, 54]. Two studies reported greater improvements for intervention partners compared to control partners immediately following the intervention [46, 59], and one study found greater improvements for intervention partners than control partners at the final follow-up point [46].

Relationship functioning.

Relationship functioning was conceptualised as the quality of the relationship between patients and partners and their satisfaction with the relationship. Of the nine studies that assessed relationship functioning [47-49, 58, 60, 61, 64, 65, 67], five reported greater improvements for intervention patients compared to control patients immediately following the intervention [47-49, 58, 60, 64]. Four studies greater improvements for intervention patients compared to control patients at the final follow-up point [47, 48, 58, 65]. Four studies reported greater improvements for intervention partners compared to control partners immediately following the intervention [47-49, 58], and four studies greater improvements for intervention partners compared to control partners at the final follow-up point [47, 48, 58, 65].

Appraisal variables.
Appraisal was conceptualised as how patients and partners perceived and understand their abilities and their emotional status. Three studies assessed illness appraisal, caregiving appraisal, hopelessness appraisal, and uncertainty appraisal [51, 52, 71]. One study [51] reported that intervention patients had less negative illness appraisal than control patients at the final follow-up point, whereas partners had less negative illness appraisal immediately following the intervention. The same study [51] also reported less hopelessness appraisal for intervention patients than control patients immediately following the intervention, and at the final follow-up point. Another study by the same team [71] reported an improvement in hopelessness appraisal for partners, and less uncertainty appraisal for both patients and partners, immediately following the intervention.

Coping strategies.

Coping strategies were conceptualised as changes in the way patients and partners attempted to cope with the disease as a result of skills learned via the intervention. Of the five studies that assessed coping strategies [4, 49, 51, 52, 71], two reported greater improvements (i.e., increased coping efforts [4]; more active engagement with partner [49]) for intervention patients compared to control patients immediately following the intervention. Two studies reported greater improvements for intervention partners compared to control partners immediately following the intervention (i.e., increased coping effort [4, 52]). Two studies reported greater improvements for intervention patients compared to control patients, and intervention partners compared to control partners at the final follow-up point (i.e., increased coping effort [4, 52]).

Self-efficacy.

Self-efficacy was conceptualised as patients’ and partners’ perceived competence and confidence in managing stress and assisting with disease related issues (e.g., patient’s
symptoms). Of the four studies that assessed self-efficacy [52, 56, 59, 71], one study reported greater improvements for intervention patients compared to control patients immediately following the intervention and at the final follow-up point [52], and another study reported greater improvements for intervention partners compared to control partners immediately following the intervention and at the final follow-up point [59].

**Couple communication.**

Couple communication was conceptualised as how couples communicate and discuss thoughts, feelings, and practical issues surrounding the cancer between each other. Of the two studies that assessed communication [4, 71], both reported greater improvements for intervention patients and partners than control patients and partners immediately following the intervention with one of these reporting sustained improvements for intervention partners compared to control partners at the final follow-up point [71].

**Problem solving.**

Problem solving was conceptualised as how patients and partners approach and manage particular issues and stressors. One study assessed problem-solving and reported greater improvements for intervention patients than control patients immediately following the intervention and at the final follow-up point [50].

**Discussion**

The aim of this review was to examine the efficacy, content and delivery of couple-based interventions, and the elements of these interventions that seem most promising in improving adjustment in patients and partners. Most of the couple-based interventions included in this review demonstrated significant improvements for intervention couples...
compared to control couples, albeit with small to medium effect sizes (d~.35-.45), on a range of psychosocial outcomes. The effect sizes reported are similar to those reported in meta-analyses of patient-only and partner/caregiver-only interventions [10, 12, 13, 28]. Couple-based interventions tended to have the greatest impact on improving outcomes such as couple communication, psychological distress, relationship functioning; and in some instances they maintained intervention effects longer than patient-only interventions [4, 50]. Two separate meta-analyses have indicated than an important moderator of intervention effects in patient-only interventions is the total time spent with the therapist delivering the intervention [11, 12]. Considering the findings of this review and those of these two meta-analyses, it could be suggested that the strengthening of supportive relationships (whether it be the strengthening of the therapeutic relationship or the couple relationship) is key to achieving positive outcomes following psychosocial interventions. Only two studies [4, 50] included in this review that compared the efficacy of the couple-based intervention with a comparable patient-only intervention found stronger outcomes for the couple-based intervention at six and 12-month follow-ups compared to the patient-only intervention. Improving support, shared learning, and practicing learned skills may allow easier transfer from the clinical setting to the couple’s natural environment, increasing the likelihood that improvements will be maintained at the conclusion of the intervention [50]. Addressing these skills are even more important when considering population subgroups that may be more at risk for distress. Some patterns in outcomes emerged when comparing the target population and timing of the intervention, mode of delivery, who delivered the intervention, and specific content of the intervention.

**Target Population and Timing**
Interventions targeting early-stage cancers appeared to result in greater improvements when compared to interventions targeting late-stage or advanced cancers. For instance, improvements in immediate anxiety and QoL were more likely to occur for those with an early-stage diagnosis than for those with a late-stage diagnosis [23, 71]. For a late-stage diagnosis, there was evidence to suggest that intervention improved patients’ appraisal of their cancer and feelings of hopelessness, and partners’ appraisal of their caregiving [51, 65]. These types of communications perhaps reflect a change in patients’ and partners’ existential position following an arduous cancer journey. Despite couples making improvements in hopelessness and negative illness appraisal from baseline to follow-up, they may still require continued professional support, as the burden of cancer may exceed their resources during these stressful times. It has also been noted that the measurement of mental and physical functioning among such seriously ill populations needs to be more realistic. Rather than measuring at, for example, bi-monthly intervals, the measurement of QoL at more regular intervals (e.g., weekly) and focusing on improving patients’ and partners’ present functioning may be more appropriate than attempting long-term gains [51]. Other interventions targeting self-care and symptom management discussion were found to be efficacious in improving physical distress and both patients’ and partners’ ability to manage symptoms regardless of their diagnosis [48, 59].

One study included in this review [54], and a study by Manne and colleagues [3] have concluded that intervention effects were greater for patients with unsupportive partners [3], patients with higher levels of physical distress [3], couples in shorter relationships [54], and patients receiving chemotherapy compared to patients not receiving chemotherapy [54]. This suggests that patients with less supportive partners and couples in shorter relationships may still be developing skills in how to cope with major life stressors together. Similarly, patients that report great physical distress, or are
receiving chemotherapy, are potentially facing increased stressors and burdens from their disease. Thus, it may be more appropriate to target particular interventions, or elements of interventions, to specific patient characteristics, to increase the likelihood of a positive outcome for the couple.

**Mode of Delivery**

No significant differences emerged when comparing face-to-face and telephone delivery of interventions, suggesting that either modality is appropriate for these types of interventions. However, among the studies that included telephone interventions, the majority of participants felt there were benefits being able to talk to a counsellor without leaving their home, though they felt that a degree of face-to-face interaction was still necessary [56].

**Health Care Professionals Delivering the Intervention.**

The vast majority of interventions reviewed were delivered face to face by highly trained health care professionals, including employed psychologists, social workers, or nurses. Most had a masters-level degree, at least, and lengthy experience in the field. Additionally, all studies devised and followed specific intervention protocols and endeavoured to maintain high standards of treatment fidelity through regular reviews of their intervention sessions. However, only 50% of the studies implemented specific training in their interventions, ranging between six and 40 hours.

**Focus of the Intervention**

Whereas the specific interventions presented in each study were varied in terms of their theoretical framework and delivery, the majority focused on increasing communication between the patient and partner as a means of improving coping and adjustment to cancer. These interventions typically had two broad aims: enhance participants’ ability
to express emotion (i.e., uninhibited communication of cancer concerns, and overcoming the propensity of patients and partners to ‘hold back’ concerns) and to communicate needs for managing cancer symptoms (targeting self-care and self-efficacy).

Limitations of Studies Reviewed

The positive outcomes of the couple-based interventions reviewed should be tempered by acknowledgement of some methodological limitations. The methodological strength of the included studies was affected most heavily by a failure to adequately describe attrition rates, randomisation techniques, blinding procedures, as well as limited use of intention-to-treat analyses. There are limitations relating to the cultural generalisability of these findings, given the vast majority of patients participating in these interventions were middle-aged Caucasian women in heterosexual relationships. None of the interventions reviewed here specifically recruited same-sex couples, and only one [56] specifically recruited from a minority population. Campbell et al. [56] recruited African-American prostate cancer patients (a significantly under-represented population) using African-American psychologists, with some success.

Uptake of couple-based interventions.

The utilisation of psychosocial services by patients following a cancer diagnosis is low, with evidence suggesting that less than 20% of patients actively engage with cancer support services [73, 74]. Among the couple-based interventions included in this review, approximately 50% of eligible couples agreed to be participate, and were subsequently randomised. Moreover, 74.45% of patients and 71.30% of partners who were randomised provided data at the final follow-up point. Despite these encouraging figures, improving uptake of psychosocial interventions for couples should remain a high priority. The most common reasons for refusal of a couple-based intervention were
being too busy to participate [54, 58-60, 71], the intervention not meeting expectations or refusal of group assignment [51, 58, 60, 71], being too ill to participate [23, 55, 59, 60], and living too far away from intervention facilities [47, 54, 60]. These barriers to the uptake of psychosocial interventions point to the need for greater flexibility in content and delivery. Although telephone interventions were generally well-accepted by participants, some participants indicated they would prefer at least some face-to-face contact; however, face-to-face contact does not appear to be critical for positive outcomes to be achieved with a couple-based intervention. The content of an intervention should vary depending on participants needs when they are invited into the study. Patients, partners, and families often highlight the period immediately following diagnosis as being the most emotionally taxing [75]. Coping-focused interventions may be more beneficial than information-focused interventions during this period. As patients and partners adjust to the shock of a cancer diagnosis, information and symptom-management based interventions may be a simpler and more efficient means of providing support [46]. This is consistent with evidence from a larger study of the utilisation psychosocial services following a cancer diagnosis [73]. Curry and colleagues reported that the most common reasons for refusal of psychosocial services by patients with cancer include services not being suitable at the time they are offered; a preference for self-management; a preference for informal support; and not requiring/wanting any help [73]. Greater flexibility in the way interventions are delivered and greater flexibility in the content of the intervention should lead to improvements in the uptake of psycho-social interventions for couples.

‘Usual care’ conditions.

Fourteen studies compared a couple-based intervention to a ‘usual care’ condition [47, 58, 59, 61]. Across these 14 studies, little (if any) detail was provided regarding what
the provision of usual care involved. This is similar to the findings of a recent systematic review of best supportive palliative care studies [76]. No reference is made to the clinical guidelines for psychosocial care of patients with cancer as described by the National Comprehensive Cancer Network (NCCN) [77] or the National Health and Medical Research Council (NHMRC) [21], particularly with regard to ongoing screening and follow-up assessment of distressed participants. This lack of methodological rigor may serve to exaggerate the efficacy of couple-based interventions by introducing systematic bias, particularly at larger sites where usual care conditions may vary (e.g., referral to social work team vs. referral to psychologist) [49]. Moreover, comparing couple-based interventions to a usual care conditions does not allow the potential strengths of a couple-based intervention in comparison to patient-only or partner-only intervention to be investigated. Only two studies adequately compared the efficacy of an intervention delivered to an individual (patient-only) compared to the same intervention delivered to a couple, and a usual care group [4, 50]. From these studies, the advantages of a couple-based intervention compared to patient or partner-only interventions are much clearer. While both the experimental groups showed greater improvements compared to the usual care group, intervention effects tended to maintain longer among couples than individuals.

**Limitations of the Review**

This review did not include studies published in languages other than English or French, conference abstracts, dissertations, or book chapters. Although this ensures that only peer-reviewed studies were included, a publication bias is possible (e.g., ‘file drawer’ problem).

**Future Directions**
This review has clarified the current state of the literature on couple-based interventions for patients with cancer and their partners. However, much is still needed in this area. There is a need for large, multi-site, longitudinal RCTs of couple-based interventions. In particular, given the differences in the level of psychological distress reported by men and women [2], more studies are needed to identify what each gender wants or needs from a couple-based intervention. In the context of a couple-based intervention, there is enormous scope to develop content that addresses the needs of the patient and the partner, but also to further develop content that increases understanding of each other’s needs. More intervention studies across a variety of cancer types, particularly among males (e.g., melanoma, testicular cancer), are needed. Available studies for males have primarily focused on men with prostate cancer, which invariably comes with an older sample. More couple-based interventions for younger couples are needed, as it is likely that a much different set of concerns exist for younger couples compared to older couples (e.g., raising a young family, less financial stability, impact on career). Future RCTs should also endeavour to compare target interventions with the same intervention provided to individuals only, and with usual care conditions.

Moreover, whilst delivery of interventions either face-to-face or over the telephone is acceptable, more studies are needed to ascertain couples’ preferences for psycho-social interventions. Recent advancements in technology, in particular the emergence of Smartphone technology and the increase use of online social networking may provide new and exciting opportunities for the delivery of couple-based interventions.

There is also a need for studies that evaluate the relative cost-effectiveness of face-to-face, telephone, computer-based and print-based self-directed (e.g., workbook based interventions [78]) interventions for couples. Of the studies reviewed here, none
addressed the costs involved in providing these types of interventions. The related healthcare burden and strain on those delivering interventions must also be investigated. If a couple-based intervention is as efficacious as a patient or partner-only intervention, and the effects are maintained longer, then there may be potential to alleviate some burden on healthcare clinics and professionals.

**Conclusions**

In summary, the findings from this review suggest that there are clear benefits to be gained following the implementation of a couple-based intervention. Although more work is needed, there is enough evidence to be confident that these interventions show promising results in reducing distress and improving coping and adjustment to a cancer diagnosis or to cancer symptoms. Collaboration between researchers and clinicians is crucial to ensuring future research builds on this evidence and the development of efficacious, effective, and accessible interventions continues.
References


43. National Health and Medical Research Council (NHMRC), A guide to the development, implementation and evaluation of clinical practice guidelines, National Health and Medical Research Council (NHMRC), Editor. 1999: Canberra, Commonwealth of Australia.


# relevant records identified through database searching = 1279

# additional records identified through other sources = 6

# records after duplicates removed = 709

# records excluded = 693

# records screened (titles and abstracts) = 709

Focused on Biomed Factors = 71

Focused on Chemo/Drug Therapy = 180

Focused on non-Psychosocial Therapy (e.g. art/music therapy) = 39

Focused on Screening Information = 41

Focused on Cancer Predictors = 47

Focused on Community Engagement = 14

Broad Cancer Information/Discussion = 34

Focused on Caregiver interventions = 39

Focused on Family Interventions = 36

Focused on Patient-only Interventions = 159

Focused on couples, but not interventions = 21

Primarily focused on couple-based intervention, not published in English or French = 3 (2 German, 1 Chinese)

# full-text articles assessed for eligibility = 27

# full-text articles excluded, with reasons = 10

Focused on couples, describes proposed peer-support intervention

Focused on couples, but not outcomes of interest (e.g. sexual functioning) = 3

# eligible studies identified after contacting authors

# studies included in review = 23
<table>
<thead>
<tr>
<th>Author / Design/Methodological Quality</th>
<th>Description of intervention</th>
<th>No. Couples</th>
<th>Outcome measures at baseline (* indicates patient only; # indicates partner only)</th>
<th>Significant outcomes: * &lt; .05; ** &lt; .01 Cohen’s d (between group comparisons)</th>
</tr>
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</table>
| Badger et al. (2007)/CCT/Strong/III-1/Individual | Three-arm intervention trial  
Arm 1: Six, weekly Telephone Interpersonal Counselling intervention (TIP-C) ($M = 34$ minutes) delivered by a psychiatric nurse counsellor (with oncology expertise). No study-specific training.  
Arm 2: self-managed, telephone-based exercise intervention ($M = 11$ minutes) not clear who delivered. No study-specific training.  
Arm 3: Attention Control (AC) group who received printed information on breast cancer, received follow-up calls ($M = 7$ minutes). No study-specific training. | TIP-C = 38  
Exercise = 23  
Attention Control = 37 | Depression: CES-D; Anxiety: PANAS, SF-12, Index of Clinical Stress | Comparisons between TIP-C and AC  
6 weeks: Patients Anxiety** $d = 1.31$ |
| Badger et al. (2010)/RCT/Strong/II/Individual | Two-arm intervention trial:  
Arm 1: Telephone Interpersonal Counselling intervention (TIP-C). 8 weekly phone calls to patient, 4 bi-weekly phone calls to partners ($M = 31$ minutes). Intervention delivered by Masters-level nurse, social worker with psychiatric and oncology expertise. No study-specific training.  
Arm 2: Health Education Attention Condition (HEAC). 8 weekly phone calls to patient, 4 bi-weekly phone calls to partners ($M = 28$ minutes). Intervention delivered by research assistants. No study-specific training. | TIP-C = 36  
HEAC = 35 | Depression: CES-D, Anxiety: PANAS; SF-12; Index of Clinical Stress; Spiritual well-being: subscale of Quality of Life-Breast Cancer; Physical distress: UCLA PCI; MFI; Social well-being scale: PSS-FA | 8 weeks: Patients Depression* $d = .24$, Fatigue* $d = .14$, Perceived social support* $d = .38$, Spiritual well-being* $d = .28$; Partners Depression $d = .13$, Social well-being* $d = .43$, Perceived social support $d = .32$, Spiritual well-being = .21  
16 weeks: Patients Depression $d = .20$, Fatigue $d = .29$, Perceived social support $d = .38$, Spiritual well-being = .31; Partners Depression $d = .20$, Social well-being $d = .45$, Perceived social support *$d = .48$, Spiritual well-being = .25 |
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<tr>
<th>Author / Design/Methodological Quality[1]/Evidence Level[2]/Intervention Type</th>
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</tr>
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</table>
| **Baucom et al. (2009)** / RCT/Strong/II/Dyadic | Two-arm intervention trial:  
Arm 1: Six, face-to-face, 75-minute biweekly Relationship Enhancement (RE) sessions, emphasis on problem-solving skills & emotional expressiveness. Intervention delivered by advanced doctoral students in clinical psychology, trained in couples therapy  
Arm 2: Usual care (control condition) | RE = 8  
Control = 6 | Psychological distress: BSI, PGI; QoL*: Fact-B; SIS; Physical distress: BFI; BPI; RSS; Sexual functioning: DISF; Relationship Functioning: QMI | 12 weeks: **Patients**: BSI d = .32; PGI d = .23; Relationship Functioning d = .65; QoL d = .38; **Partners**: BSI d = .16; PGI d = .63; Relationship Functioning d = .20  
12 months: **Patients**: BSI d = .59; PGI d = .12; Relationship Functioning d = .11; QoL d = .48; **Partners**: BSI d = .16; PGI d = .49; Relationship Functioning d = .25; |
| **Budin et al. (2008)** / CCT/Moderate/III-1/Individual | Four-arm intervention trial:  
Arm 1: Disease Management (DM; TAU control condition)  
Arm 2: DM and standardised psychoeducation (SE); SE delivered by four, disease phase-specific videos  
Arm 3: DM and telephone counselling (TC); TC delivered in four disease phase-specific videos by nurses trained in TC methods.  
Arm 4: Disease management and standardised psychoeducation and telephone counselling (SE + TC). | SE = 66  
TC = 66  
SE + TC = 58  
Control = 59 | Psychological distress: PAIS-SR; PAL-C; Physical distress: SRHS; PAL-C, BCTRI*; Social Adjustment: PAIS | *Means and SDs not available to compute Cohen’s d  
T3 (adjuvant therapy)-T4 (ongoing recovery **Patients**: Psychological distress** (TC vs. other groups)  
**Partners**: Physical distress* (SE+ TC vs. other groups) |
| **Campbell et al. (2006)** / CCT/Moderate/III-1/Dyadic | Two-arm intervention trial:  
Arm 1: Six, weekly 60-minute, Coping Skills Training (CST), focused on problem-solving skills, training in cognitive & behavioural coping skills. The session were delivered by a trained, African-American, doctoral level medical psychologist  
Arm 2: Usual care (control condition) | CST = 20  
Control = 20 | QoL*, SF-36; Physical Distress: EPIC, POMS-SF#, CSI# Sexuality: EPIC; Self-efficacy (symptom control): SESCI | 6 weeks: **Patients** Physical Distress* (bowel bother) d = .47 |
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<tbody>
<tr>
<td>Donnelly et al. (2000)/CCT/Moderate/III-2/Dyadic</td>
<td>Single-arm, pre-post pilot intervention: Weekly, telephone-based interpersonal psychotherapy (IPT) sessions during chemotherapy delivered by a trained clinical psychologist, undertaking post-doctoral fellowship in psycho-oncology.</td>
<td>N = 13</td>
<td>Psychological Distress: IES; MHI</td>
<td>n/a</td>
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<tr>
<td>Kayser, Feldman, Borstelmann, &amp; Daniels (2010)/RCT/Moderate/II/Dyadic</td>
<td>Two-arm intervention trial: Arm 1: Partners in Coping Program (PICP) improve coping ability, supportive communication, assessing couples’ social support, and caring for children, nine 60-minute biweekly face-to-face sessions over an average of 5 months, delivered by a masters-level clinical social worker whom received specific intervention training</td>
<td>PICP = 36</td>
<td>QoL: FACT-B*, QL-SP#, IIRS#</td>
<td>6 months: <strong>Patients</strong> Physical well-being (d = .34); Emotional well-being (d = .33); Social well-being (d = .32); Functional well-being (d = .40); Total FACT-B (d = .38); <strong>Partners</strong> Emotional well-being (d = .54); Illness intrusiveness (d = .38)</td>
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<td></td>
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<td>Control = 27</td>
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<td>12 months: <strong>Patients</strong> Physical well-being (d = .47); Emotional well-being (d = .55); Social well-being (d = .27); Functional well-being (d = .34); Total FACT-B (d = .44); <strong>Partners</strong> Emotional well-being (d = .38); Illness intrusiveness (d = .26)</td>
</tr>
<tr>
<td>Kozachik et al. (2001)/CCT/Moderate/III-1/Dyadic</td>
<td>Two-arm intervention trial: Arm 1: Cancer Care Intervention (CCI), focus on symptom management, emotional support, and caregiver preparedness, coordinating community &amp; family resources; nine contacts (five face-to-face &amp; four via telephone) every two weeks over a course of 16 weeks, delivered by masters-trained oncology nurses.</td>
<td>Exp = 61</td>
<td>Depression: CES-D</td>
<td>n/a</td>
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<td>Arm 2: Usual care (control condition)</td>
<td>Control = 59</td>
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### Description of intervention

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</table>
| Kuijers et al. (2004)/CCT/Moderate/III-1/Dyadic | Two-arm intervention trial:  
  Arm 1: Focus on improving relationship equity, five 90-minute biweekly face-to-face sessions with a psychologist, no intervention-specific training undertaken.  
  Arm 2: Wait-list control group | Relationship Equity = 32, Control = 27 | Depression: CES-D; Relationship Functioning: 0-10 Ladder | 10 weeks: **Patients** Depression d = 1.1; Relationship Functioning d = .63; **Partners** Depression d = .02; Relationship Functioning d = 1.09  
  3 months: *Patients** Depression d = .45; Relationship Functioning d = .19; *Partners** Depression d = .10; Relationship Functioning d = .18 |
| Kurtz et al. (2005)/CCT/Moderate/III-1/Coaching | Two-arm intervention trial:  
  Arm 1: Symptom management intervention, 10 contacts (5 face-to-face, 5 telephone) over 20 weeks with nurse, no intervention specific training undertaken  
  Arm 2: Treatment as usual (control condition) | Symptom management = 118, Control = 119 | Depression: CES-D; Symptom Severity*/Symptom Assistance#: authors own symptom severity index; Physical/Social Functioning: MOS, SF-36; Self-efficacy#: authors own mastery index | 10 weeks: **Patients** Depression d = .23; Symptom Severity: d = .28; Physical Functioning: d = .18; **Partners** Depression d = .25; Self-efficacy d = .13; Symptom Assistance = .12; Social Functioning d = .18  
  20 weeks: Patients** Depression d = .39; Symptom Severity: d = .32; Physical Functioning: d = .38; **Partners** Depression d = .04; Self-efficacy d = .12; Symptom Assistance = .11; Social Functioning d = .22 |
| Manne & Badr (2008)/Cohort/Moderate/III-2/Dyadic | Single-arm intervention trial:  
  Intimacy-Enhancing Couples’ Therapy (IECT), focus on relationship-enhancing behaviours by improving reciprocal disclosure and responsiveness, viewing the illness in relationship terms; five 1-hour weekly face-to-face sessions with an unspecified therapist trained in specific intervention content | N = 16 | Psychological Distress: MHI, IES, Relationship functioning: PAIR | ^ Pre-post within group comparison  
  6 Weeks: **Patients** MHI (Distress)* d = .71; IES (Intrusiveness)* d = .37; IES (Avoidance)* d = .25; PAIR (perceived partner responsiveness)* d = .36; PAIR (cancer-specific closeness) d = .15; **Partner** MHI (Distress)* d = .79; IES (Intrusiveness)* d = .96; IES (Avoidance)* d = .84 |
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</table>
| McCorkle et al. (2007)/CCT/Strong/III-1/Coaching | Two-arm intervention trial:  
Arm 1: Standardised Nursing Intervention Protocol (SNIP) for patients and partners following a radical prostatectomy. Focus on monitoring/managing symptoms, teaching self-care, counselling patients and family members;  
Arm 2: Usual care (control condition), 16 contacts (8 in-home, 8 telephone) over 8 weeks, delivered by Advanced Practice Nurses and board certified nurse practitioners trained in specific intervention content | SNIP = 62  
Control = 64 | Depression: CES-D, Sexuality, Relationship Functioning: CARES | 3 months: **Patients Depression d = .23; Relationship Functioning d = .10;  
**Partners Depression d = .11; Relationship Functioning d = .41; Sexual Functioning d = .27 |
| McLean et al. (2008)/Cohort/Moderate/III-2/Dyadic | Single-arm intervention trial:  
Adaptation of Emotionally Focused Couple Therapy (EFT) emphasises the sharing of emotions, normalizing feelings of separation, 8-20 face-to-face sessions with doctoral-level psychologists with some training in EFT | N = 16 | Depression: BDI-II, BHS; Relationship Functioning: RDAS | *Comparisons to baseline scores  
After eight sessions:  
**Patients BDI-II d = .33; BHS d = .23; RDAS d = 1.07;  
**Partners BHS d = .16; RDAS d = .67  
3 months:  
**Patients BDI-II d = .54; BHS d = .17; Relationship Functioning d = .84;  
**Partners BDI-II d = .29; BHS d = .18; Relationship Functioning d = .76 |
| McLean et al. (2011)/RCT/Strong/II/Dyadic | Two-arm intervention trial:  
Arm 1: Adaptation of Emotionally Focused Couple Therapy (EFT) emphasises the sharing of emotions, normalizing feelings of separation; eight, one-hour weekly face-to-face sessions with psychologist trained in EFT  
Arm 2: Usual care (control group) | EFT = 22  
Control = 20 | Depression: BDI-II, BHS; Relationship Functioning: RDAS, Coping: RFCS* | 8 weeks:  
**Patients Relationship Functioning** d = 1.65; Coping** d = .36;  
**Partners Relationship Functioning** d = 2.03 |
|                                      |                              |             |                                                                                   | 12 weeks:  
**Patients Relationship Functioning** d = 1.32; Coping** d = .37;  
**Partners Relationship Functioning** d = 1.22 |
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<tbody>
<tr>
<td>Mohr et al. (2003)/Cohort/Moderate/III-2/Dyadic</td>
<td>Single-arm intervention trial: Focus on facilitating shifts in beliefs, goals and values, facilitating conversations about death and dying, increasing intimacy and emotional support; eight one-hour weekly face-to-face sessions with PhD-level psychologist or clinical social worker, no intervention-specific training undertaken</td>
<td>( N = 6 )</td>
<td>Anxiety: authors own measure (distress &amp; worry about dying); Depression: BD-I; QoL: SF-36; Relationship Functioning: authors own positive/negative scale; Social Support: PSSS* (positive &amp; negative); ZCBZ#</td>
<td>Eight weeks: \textbf{Patients} Anxiety (distress about dying) ( d = .54 ); Relationship functioning (positive) ( d = .74 ); \textbf{Partner} Anxiety (worry about dying) ( d = .38 )</td>
</tr>
<tr>
<td>Nezu et al. (2003)/RCT/Strong/II/Coaching</td>
<td>Three-arm intervention trial: Arm 1: Problem-solving therapy for patients and a supportive other (PST-SO), focus on enhancing problem-solving skills, ten 90-minute weekly face-to-face sessions, masters level psychologists, social workers, and nurses, 115 hours training in intervention-specific content Arm 2: Problem-solving therapy for patients only (PST) Arm 3: Wait-list control group.</td>
<td>( PST-SO = 50 ) ( PST = 50 ) ( Control = 50 )</td>
<td>QoL*: CR, CARES; Psychological Distress*: CR(HRSD), POMS, BSI; KAS-R#: Problem Solving: SPSI-R</td>
<td>(^\text{Comparisons between PST-SO and PST} ) 10 weeks: \textbf{Patients} POMS ( d = .18 ); BSI ( d = .33 ); CARES ( d = .26 ); Problem Solving ( d = .08 ); \textbf{Partners} KAS-R- (Psychiatric) ( d = .13 ); KAS-R-(Social) ( d = .16 ) 12 months: \textbf{Patients} POMS ( d = .44 ); BSI ( d = .84 ); CARES ( d = .67 ); Problem Solving ( d = .57 ); \textbf{Partners} KAS-R- (Psychiatric) ( d = .99 ); KAS (Social) ( d = .31 )</td>
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<tr>
<td>Northouse et al. (2005)/CCT/Strong/III-1/Dyadic</td>
<td>Two-arm intervention: Arm 1: FOCUS program (interventions: family involvement, optimistic attitude, coping effectiveness, uncertainty reduction and symptom management; initial intervention phase: three 90-minute home visits spaced one-month apart/Booster phase: Two phone calls to both patient and caregiver (~30 minutes/call) provided after 3-month follow-up, delivered by masters-level nurse, trained in the FOCUS program Arm 2: Usual care (control condition)</td>
<td>( N = 182 )</td>
<td>QoL &amp; Physical Distress: FACT-B, FACT-G, SF-36; Appraisal: AIS, MUIS, BHS; Coping: BriefCOPE</td>
<td>3 months: \textbf{Patients} AIS ( d = .04 ); BHS ( d = .10 ); \textbf{Partners} AIS* ( d = .19 ) 6 months: \textbf{Patients} AIS* ( d = .13 ); BHS ( d = .17 ); \textbf{Partners} AIS ( d = .05 )</td>
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<td>Author / Design/Methodological Quality [1]/Evidence Level [2]/Intervention Type</td>
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<tr>
<td>Northouse et al. (2007)/CCT/Strong/III-1/Dyadic</td>
<td>Two-arm intervention: Arm 1: FOCUS program (intervention): family involvement, optimistic attitude, coping effectiveness, uncertainty reduction and symptom management; three 90-minute home visits spaced and two phone calls to both patient and caregiver (~30 minutes/call) spaced two-weeks apart, between baseline and 4-month follow-up, delivered by masters-level nurse, trained in the FOCUS program</td>
<td>Focus = 129</td>
<td>QoL &amp; Physical Distress: FACT-G, SF-36, EPIC; Sexuality: EPIC; Appraisal: MUIS, BHS, AIS; Coping: BriefCOPE; Self-Efficacy*: LCSES; Communication: LMISS</td>
<td>4-months: Patients MUIS = .22; LMISS = .22; Partners SF-36M/FACT-G = .25, .26; Appraisal (all) = .27/.32; LCSES = .26; LMISS = .31, EPIC (urinary, symptom distress) = .30, .34</td>
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<td>Control = 134</td>
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<tr>
<td>Northouse et al. (2011)/RCT/Moderate/II/Dyadic</td>
<td>Three-arm intervention: Arm 1: Brief FOCUS program, family involvement, optimistic attitude, coping effectiveness, uncertainty reduction and symptom management; 2 x 90-minute home visits, one 30 minute phone call, delivered by masters-level nurse trained in the FOCUS program</td>
<td>Brief = 159</td>
<td>QoL: FACT-G, SF-36; Psychological Distress: RFD; Appraisal: AIS, MUIS, BHS; Coping: BriefCOPE; Healthy Lifestyle: author’s scale; Self-efficacy: author’s scale; Dyadic support: SSQ</td>
<td>3 months: Patients Self-efficacy* d = .15; Partners Coping (Avoidant)* d = .41; Dyadic support* d = .27; QoL* d = .25</td>
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<td></td>
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<td>Extensive = 162</td>
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<td>Control = 163</td>
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<td>Arm 2: Usual care (control condition)</td>
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<td>Arm 2: Extensive FOCUS program, family involvement, optimistic attitude, coping effectiveness, uncertainty reduction and symptom management; 4 x 90-minute home visits; two 30 minute phone calls, delivered by masters-level nurse trained in the FOCUS program</td>
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<td>Arm 3: Usual care (control condition)</td>
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| Porter et al. (2009)/ CCT/Moderate/III-1/Dyadic | Two-arm intervention:  
Arm 1: Partner-assisted emotional disclosure (PAED) focused on decreasing the ‘holding back’ of cancer-related disclosures to partners, increasing relationship quality and intimacy, decreasing psychological distress; 4 face-to-face sessions with masters-level social worker or psychologist  
Arm 2: Partner-assisted educational (EDU) intervention received general cancer information only | PAED = 65  
EDU = 65 | Psychological Distress: POMS-SF; Relationship Functioning: QMI; MSIS | *Means and SDs not available to compute Cohen’s d  
Post-intervention Patients: QMI**; MSIS* |
| Scott, Halford, & Ward (2004)/ CCT/Moderate/III-1/Dyadic | Three-arm intervention:  
Arm 1: MI intervention: educational materials regarding patients’ particular cancer and associated treatments, no specific psychological intervention provided, five 15-minute phone calls, medical information booklets  
Arm 2: PC intervention: combined MI intervention with supportive counselling and education in coping skills, four 2-hour sessions: pre & post-surgery, 1 week & 6-months after; two 30-minute phone calls 1 & 3-months post-surgery delivered face-to-face by three female psychologists, with 3-15 years experience.  
Arm 3: CanCOPE: same as PC intervention, but undertaken with couples focus on teaching of supportive communication skills | N = 94 | Psychological Distress: IES; Sexuality: PAIS-SR SSS, BISF; Coping: WOC-CA; Communication: qualitative interviews | ^ Comparisons between CanCOPE and PC  
Post-intervention Patients Coping** d = .25; IES (Avoidance)* d = .36; SSS d = .56; BISF (Desire) d = .50; Partners Coping* d = .36  
12 months Patients Coping* d = .82; IES (Avoidance)* d = .55; SSS d = .39; BISF (desire) d = .08; Partners Coping* d = .61 |
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<td>Shields &amp; Rousseau (2004)/Cohort/Moderate/III-2/Dyadic</td>
<td>Three-arm intervention trial: Arm 1: 2-session workshop intervention, focus on comparing, contrasting patient/partner experiences of cancer, increasing communication, helping couples find meaning; delivered face-to-face by unspecified therapist</td>
<td>2-sessions = 12</td>
<td>Psychological distress: SF-12; IES; Relationship Functioning: RDAS</td>
<td>n/a</td>
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<td>Arm 2: 1-session workshop intervention (as above)</td>
<td>1-sessions = 21</td>
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<td>Arm 3: No treatment control group.</td>
<td>Control = 15</td>
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<tr>
<td>Thornton, Perez, &amp; Meyerowitz (2004)/CCT/Moderate/III-1/Dyadic</td>
<td>Two-arm intervention: Arm 1: Brief (45 minute) one-off supportive intervention pre-surgery focusing on improving communication within couple and between couple and medical team, delivered face-to-face by unspecified counsellor</td>
<td>N=65</td>
<td>QoL: MOS, FACT-P; Physical Distress: UIS; Psychological Distress: PANAS, IES, PSS-FA; Relationship Functioning: RDAS</td>
<td>3 weeks: Patients FACT-P (social/family well-being)* d = .58; Partners PSS-F<em>A d = .29; 12 months: Partners PSS-F</em>A d = .54</td>
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<td>Arm 2: Usual care (control group)</td>
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Centre for Epidemiological Studies - Depression Scale (CES-D); Positive and Negative Affect Schedule (PANAS); SF-12 (anxiety measure); Caregiver Strain Index (CSI); Index of Clinical Stress; UCLA Prostate Cancer Index (UCLA PCT); Multidimensional Fatigue Inventory (MFI); Perceived Social Support-Family scale (PSS-FA); Brief Symptom Inventory (BSI; psychological distress measure); Posttraumatic Growth Inventory (PGI); Functional Assessment of Cancer Therapy-Breast (FACT-B-QoL measure); Functional Assessment of Cancer Therapy-General (FACT-G, QoL measure); Self-image scale (SIS – qol measure); Brief Fatigue Inventory (BFI); Brief Pain Inventory (BPI); Quality of Life Questionnaire for Spouses (QL-SP); Illness intrusiveness Rating Scale (IIRS); Rotterdam Symptom Scale (RSS; physical distress); Derogatis Inventory of Sexual Functioning (DISF); Psychosocial Adjustment to Illness Scale - Self Report (PAIS-SR); Profile of Adaptation to Life Clinical Scale -Psychological Well-being subscale (PAL-C); Self-rated Health Subscale (SRHS; physical distress); PAL-C - physical symptoms subscale; Breast Cancer Treatment Response Inventory (BCTRI); BCTRI Side Effects Severity subscale; PAIS- Vocational, Domestic, Social subscale (social adjustment measure); Short-Form Health Survey (SF-36; QoL measure); Expanded Prostate Cancer Index Composite (EPIC; physical distress and sexuality measure); Self-Efficacy for Symptom Control Inventory (SSECI); Impact of Event Scale (IES); Mental Health Inventory (MHI); Medical Outcomes Study (MOS); Cancer Rehabilitation Evaluation System (CARES); Partner Unsupportive Behaviours Scale (PUBS, from Partner Responses to Cancer Inventory); Beck Depression Inventory (BDI-II); Beck Hopelessness Inventory (BHI); Revised Dyadic Adjustment Scale (RDAS); CR – Clinician Rated; Hamilton Rating Scale for Depression; Profile of Mood States (POMS); Katz Adjustment Scale-Relative’s Form (KAS-R; partner rated); Relationship-Focused Coping Scale (RFCS); Mishel Uncertainty in Illness Scale (MUIS); Appraisal of Illness Scale (AIS); Brief Coping Orientations to Problems Experienced (Brief-COPE); Lewis Cancer Self-Efficacy Scale (LCSES); Lewis Mutuality and Interpersonal Sensitivity Scale (LMISS); Risk of Distress Scale (RFD); Quality of Marriage Index (QMI) ; Miller Social Intimacy Scale (MSIS); Profile of Mood States- Short Form (POMS-SF); Sexual Self Schema (SSS) for Women; Brief Index of Sexual Functioning (BIFS); Revised Ways of Coping Questionnaire - Cancer Version (WOC-CA); Caregiver Burden Scale (Time subscale); Caregiver Burden Subscale (Difficulty subscale); Dyadic support; Social Support Questionnaire; Personal Assessment of Intimacy in Relationships inventory (PAIR); Functional Assessment of Cancer (Prostate), Urinary Incontinence Scale (UIS)
Table 3.2. Description of Patients and Partners

<table>
<thead>
<tr>
<th></th>
<th>Patients</th>
<th>Partners</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Mean, SD, Age (years)</strong></td>
<td>54.48 (6.12)</td>
<td>53.37 (4.34)</td>
</tr>
<tr>
<td><strong>Gender, % female</strong></td>
<td>73.71</td>
<td>55.77</td>
</tr>
<tr>
<td><strong>Ethnicity, %</strong></td>
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<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>81.90</td>
<td>84.98</td>
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<tr>
<td>African-American</td>
<td>10.15</td>
<td>5.34</td>
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<tr>
<td>Hispanic</td>
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<td>2.79</td>
</tr>
<tr>
<td>Asian</td>
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<td>1.40</td>
</tr>
<tr>
<td>Other</td>
<td>3.71</td>
<td>5.25</td>
</tr>
<tr>
<td><strong>Cancer Site, %</strong></td>
<td></td>
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</tr>
<tr>
<td>Breast</td>
<td>48.67</td>
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</tr>
<tr>
<td>Prostate</td>
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<tr>
<td>Gynaecological</td>
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<tr>
<td>Lung</td>
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<tr>
<td>Head &amp; Neck</td>
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<td>Leukaemia</td>
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<td>Non-Hodgkins</td>
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<tr>
<td>Hodgkins</td>
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<td>Gastrointestinal</td>
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<tr>
<td>Other</td>
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<tr>
<td><strong>Cancer Stage, %</strong></td>
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<tr>
<td>Stage I</td>
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<tr>
<td>Stage II</td>
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<tr>
<td>Stage III</td>
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<tr>
<td>Stage IV</td>
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</tr>
<tr>
<td><strong>Partner Relationship, %</strong></td>
<td></td>
<td></td>
</tr>
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<td></td>
<td></td>
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<tr>
<td>------------------</td>
<td>-------</td>
<td>-------</td>
</tr>
<tr>
<td>Spouse</td>
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<tr>
<td>Family Member</td>
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<tr>
<td>Friend</td>
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**Education, %**

<table>
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<td>36.43</td>
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</table>

<table>
<thead>
<tr>
<th>Some university/University graduate</th>
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<th></th>
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<tbody>
<tr>
<td></td>
<td>68.77</td>
<td>63.57</td>
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</table>
Introduction to Paper Four

Uptake and attrition in couple-based interventions for cancer: Perspectives from the literature

Aims and purpose

Paper Three provided an in-depth overview of the current literature regarding couple-based interventions in cancer, and concluded that these types of interventions are moderately efficacious in reducing psychological distress and improving quality of life and communication. Despite this, uptake of interventions by couples in the studies included in Paper Three varied considerably. To improve dissemination of couple-based interventions it is necessary to develop a stronger understanding of the specific factors that might affect uptake and attrition. Paper Four presents a descriptive synthesis of the variation in uptake and attrition rates of couple-based interventions that were included in the systematic review presented in Paper Three. Variation in rates of uptake and attrition are described by cancer type and stage, and by intervention type, content, and delivery.

This is the fourth paper in this thesis and has been published in Psycho-Oncology. The citation is Regan, T., Lambert, S., et al. (2013). "Uptake and attrition in couple-based interventions for cancer: Perspectives from the literature." Psycho-Oncology, 22(12). [Appendix 4.2].
Paper Four

Uptake and attrition in couple-based interventions for cancer: perspectives from
the literature

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Sylvie D. Lambert
McGill University, Montreal, Canada

Brian Kelly
The University of Newcastle, Newcastle, Australia
Abstract

Introduction: Recognition that patients and partners are both affected by a cancer diagnosis has led to increased interest in couple-based interventions. Although these interventions show promise for enhancing both patients’ and partners’ illness adjustment, couples’ acceptance of these interventions is not well documented. This review explores these issues as reflected in uptake and attrition rates in published trials.

Methods: A literature search identified 17 manuscripts reporting the uptake and attrition rates of couple-based interventions for couples facing cancer. The uptake (percentage of eligible couples randomised into a trial) and the attrition (percentage of couples who dropped out of a trial) rates were extracted by cancer type, cancer stage, intervention type, intervention focus and intervention delivery method.

Results: Uptake and attrition rates ranged from 13.6% to 94.2% and 0% to 49.4%, respectively. Low uptake rates were noted for communication-focused interventions and those requiring both the patient and the partner to participate in the intervention simultaneously. Attrition was also high in the latter group. Uptake rates appeared slightly lower than individual-based interventions (58%–76%), as were attrition rates, although only for late stage cancer (~30% couple-based vs. ~69% individual-based). Common barriers to uptake included accessibility, competing priorities and illness severity.

Conclusions: The couple-based interventions had slightly lower uptake rates than what has been previously reported for individual-based interventions; however, lower attrition suggests patients and partners may be more inclined to complete an intervention when they participate together. The findings support the need to develop...
strategies to improve the delivery and acceptability of couple-based interventions in clinical practice.
Introduction

In recent years it has become increasingly recognised that how patients and partners cope with a cancer diagnosis influences how well they adjust to the illness, and that patients’ and partners’ responses to cancer tend to be heavily entwined [1–3]. Consequently, clinicians and researchers have begun to explore more closely the efficacy of couple-based interventions and the role of these in providing couples with the necessary support to deal with cancer [4–7]. Several reviews [8–10] and a meta-analysis [11] have been published recently supporting the efficacy of couple-based interventions in reducing anxiety and depression and improving quality of life. Despite the promise of couple-based interventions, there has been little exploration of the factors associated with the uptake and attrition of couple-based interventions. Among individual-based interventions, the uptake rate for patients with early stage cancer has been reported at approximately 76% [12, 13], and attrition rate has been reported to be as high as 54% [14]. For patients with advanced cancer, uptake rates ranging from 4% to 62% and attrition rates of up to 66% have also been reported [15]. For partners, uptake of psychosocial interventions ranges between 31% [16] and 76% [17] and attrition rates between 19.5% [18] and 69% [19]. This review set out to identify some of the influential factors that may be unique to couple-based interventions.

In their review of couple-based interventions, Baik and Adams [8] suggested that there was no systematic pattern of intervention refusal or attrition based on the demographic or baseline measures. Badr and Krebs [11] and Regan et al. [9] further highlighted the paucity of detail regarding uptake and attrition rates reported in existing couple-based interventions and suggested that to improve the applicability of couple-based interventions, there needs to be a better understanding of how these interventions

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3 For the purpose of this review, ‘partners’ refers to spousal partners, rather than non-spousal caregivers. This is consistent with the majority of interventions reviewed here; however, some did include non-spousal caregivers, although these participants are a small minority.
have been designed and delivered to couples, and whether intervention designs and/or delivery modes influences couples’ participation. A closer examination of whether there are patterns in uptake and attrition rates according to factors such as cancer type and stage, intervention focus and type and delivery method will provide some insight into why couples do or do not engage with interventions and what may influence their continued participation and ultimately the efficacy of these interventions. This may assist the future design and implementation of couple-based interventions among psycho-oncology researchers and clinicians.

**Method**

This analysis used the search results from a recent review by Regan et al. [9] that reported on the efficacy of couple-based interventions and provides an in-depth examination of the issues surrounding uptake and attrition. The search undertaken in the context of this review is summarised later in the text and further detailed in Regan et al. [9]. Key search terms included (couple* OR partner* OR support* OR caregiver* OR carer* OR family OR spouse* OR husband* OR wife OR wives) AND (cancer OR neoplasm). A search of Cumulative Index to Nursing and Allied Health, PsycINFO, Medical Literature Analysis and Retrieval System Online and Web of Knowledge for couple-based interventions for couples facing cancer identified 709 unique articles, and of these, 23 were retained for review.

Studies included in the original review were included if they:

- evaluated a psychological intervention designed for both people with cancer and their partners.
- used experimental or quasi-experimental design.
- were published between January 1990 and June 2012 (emergence of couple-based interventions in cancer).
- included depression, anxiety, distress and/or quality of life as an outcome.
• reported on patients and partners outcomes separately (to allow the different effects of the intervention on patient and partner to be identified).

Studies were excluded if they:

• included pharmacological, exercise, or dietary elements as the central component of the intervention.

• focused specifically on sexuality and sexual functioning as outcome measures (it was felt that these require more specific attention).

An additional inclusion criterion for this subsequent review were:

• included data relating to the number of couples approached and randomised into a couple-based intervention, and recorded the number of patients and partners that were still present at follow-up points.

Data Extraction and Analysis

As uptake and attrition rates were not systematically reported across manuscripts reviewed, all rates were manually calculated on the basis of raw data provided on the number of participants referred to the study, eligible and withdrawn. Complete data to calculate the uptake and attrition rates were available for 17 of the 23 studies identified in the Regan et al. [9] review (see Tables 1 and 2 for each studies’ uptake rate, attrition rate and other study details). Attempts to obtain missing data from the authors of the remaining six studies were unsuccessful. Uptake of an intervention was defined as the percentage of eligible participants (i.e. the number of participants that were referred to the study and met the study inclusion criteria) randomised into the intervention trial.

Attrition rates, defined as the percentage of randomised participants that dropped out of an intervention, were calculated for the first and final follow-ups. Three studies [4, 20, 21] used a pre–post design, and therefore, their rates were included at the first follow-up point only.

Uptake and attrition rates are reported by cancer type and stage, and intervention
type, focus and mode of delivery. For cancer type, seven studies [5, 22–26] were conducted with couples facing breast cancer, five with couples facing prostate cancer [20, 27–30] and five with other diagnoses (four studies with mixed diagnoses and one with gastrointestinal cancer) [4, 21, 31–33]. For cancer stage, eight studies were conducted with patients with early stage cancer (i.e. stages 1–2) [5, 22–24, 27–30] and nine studies with patients with late stage cancer (i.e. stages 3–4) [4, 7, 20, 21, 25, 26, 31–33]. For intervention focus (i.e. the primary focus of the therapeutic principles applied), eight studies focused on improving communication within couples [4, 5, 7, 21, 22, 25, 27, 30], seven studies focused on developing specific skills to enhance coping ability (e.g. mutual relaxation techniques) [20, 24, 26, 29, 31–33] and two studies focused on educating patients and partners on cancer care (e.g. symptom management) [23, 28]. These categories were determined by reviewing the descriptions of intervention content provided in each study and discussion among authors. For intervention type, 11 interventions were dyadic (patient and partner engage in all components of the intervention equally and simultaneously) [4, 5, 7, 20, 21, 24, 26, 29–31, 33], three were coaching interventions (partner takes on a ‘coaching’ role, assists patient application of newly learnt strategies) [25, 28, 32] and three were individual-based interventions (patients and partner receive the same intervention separately) [22, 23, 27]. For intervention delivery, rates were compared across 13 interventions delivered face-to-face [4, 5, 7, 21, 24–26, 28–33] and four delivered by phone [20, 22, 23, 27].

**Methodological Criteria**

The Effective Public Health Practice Project [34] and the National Health and Medical Research Centre (NHMRC) guidelines for assessing levels of evidence [35] were used to evaluate the methodological quality of the included studies. The details of this evaluation are included in the Regan et al. review [9]. In summary, seven studies had a global rating of ‘strong’ [4, 5, 22, 25, 27–29] according to the Effective Public Health
Practice Project, and the remaining 10 studies were rated as ‘moderate’ [7,20,21,23,24,26,30–33]. Six studies in this review had an evidence level of II according to the NHMRC guidelines [5,7,24,25,27,33], 10 had an evidence level of III-1 [20–23,26,28–32] and one had an evidence level of III-2 [4].

Results

Characteristics of Patients and Partners

Women made up 67% of patients and 62% of partners. Most patients and partners were Caucasian (patients = 81.9%; partners = 85%), had some university education (patients = 68.8%; partner = 63.6%) and were aged in their mid-50s (patients M = 54.5; partners M = 53.4). Only one study [20] included a target sample from a minority population (African American).

1. Uptake of Couple-based Interventions

Table 3 summarises the uptake rates (including standard errors and confidence intervals) of couple-based interventions across cancer type and stage, and intervention focus, type and delivery method. Across the 17 studies included in this review, 48.8% of eligible couples agreed to be randomised to a couple-based intervention trial. Uptake rates ranged from 13% to 94.1%; lower rates were noted among studies by Baucom et al. [5], Kayser et al. [24], Porter et al. [21] and Campbell et al. [20], whereas the highest uptake rates were found in the studies by McLean et al. [4,7], McCorkle et al. [28] and Nezu et al. [25].

Cancer type and cancer stage: The uptake rate among couples facing prostate cancer was 58.2%, 45.3% for couples affected by breast cancer and 47% for other cancer diagnoses. By cancer stage, the uptake rates for early stage cancer were 45.6% and 51.4% for late stage cancer. It is important to note that the uptake rate for breast cancer and the uptake rate for early stage cancer may have been influenced by two studies with particularly low uptake rates, Kayser et al. (13.6%) [24] and Baucom et al.
When these studies were removed, the uptake rate for breast cancer was 61.2% (702 of 1148, SE = 1.4, CI = 58.3%–64%), and for early stage, the uptake was 57.2% (912 of 1595, SE = 1.2, CI = 54.7%–60%). The uptake rate for men with early stage prostate cancer was almost twice (63.4%) the one noted for women with early stage breast cancer (33.2%). Only one late stage prostate cancer study [20] was included, and the uptake rate was 28.7%, whereas the uptake of late stage breast cancer was 80%. All studies involving other cancer types involved patients with late stage cancers.

**Intervention focus, type and delivery method.**

The overall uptake rate for communication interventions was 43.1%; for coping interventions, it was 51% and for education interventions 51.8%. Dyadic interventions reported an uptake rate of 46.3%, individual-based interventions an uptake rate of 48% and coaching interventions reported a rate of 59.2%. Face-to-face interventions reported an uptake rate of 49.8%, whereas phone interventions reported a rate of 45%.

**2. Attrition Rates from Couple-based Interventions**

Table 4 summarises the attrition rates (including standard errors and confidence intervals) for couple-based interventions by patients and partners separately (at first follow-up and at the final follow-up) across cancer type and stage, and intervention focus, type and delivery method. Although the studies did not explicitly identify whether couples’ participation was contingent on both the patient and the partner remaining in the study, differential attrition rates were noted for patients and partners. Overall, 18.5% of patients and 17.6% of partners did not provide data at the first reported follow-up point (M = 11 weeks post-baseline). From baseline to the last reported follow-up point (M = 33 weeks post-baseline), 25.7% of patients and 27.7% of partners did not provide data.

**Cancer type and stage.**
At the first reported follow-up point, 14.8% of breast cancer patients, 24.8% of patients with ‘other’ cancer diagnoses and 12.6% of prostate cancer patients did not provide data. Among partners, 24.8% in other cancer studies, 17.8% in prostate cancer studies and 16.9% in breast cancer studies did not provide data at the first follow-up point. At the last reported follow-up point, 37% of patients with other cancer types, 19.4% of breast cancer patients and 17.8% of prostate cancer patients did not provide data. For partners, attrition was 35.3% in other cancer studies, 26.7% in breast cancer studies and 19.6% in prostate cancer studies.

At the first follow-up point, 22.3% of patients with a late stage diagnosis and 13.1% of patients with an early stage diagnosis did not provide data. Among the partners of patients with an early stage diagnosis, 17.7% did not provide data. The proportion of partners of patients with late stage cancer who did not provide data was the same as the number of patients who did not provide data. By the final reported follow-up point, 30.7% of patients with a late stage diagnosis and 19.8% of patients with an early stage diagnosis did not provide data. Among partners, 29.5% of late stage partners and 27.1% of early stage partners did not provide data.

**Intervention focus, type and delivery method.** At the first follow-up point, 18.9% of patients in education-focused trials, 22.7% of patients in coping skills-focused trials and 8.6% of patients communication-focused trials did not provide data. Among partners, 22.4% in education-based trials, 22.7% in coping skills-focused trials and 13.8% in communication-focused trials did not provide data. By the final follow-up point, 31.4% of patients in coping skills-focused trials, 24.3% of patients in education-focused trials and 10.4% of patients in communication-focused trials did not provide data. Among partners, 37.9% in education-based trials, 30.4% in coping skills-focused trials and

---

4 Studies did not consistently differentiate between confirmed study withdrawals, participants lost to follow-up, and return of incomplete data. The term ‘did not provide’ data refers to the number of participants whose data were not included at follow-up.
14.9% in communication-focused trial did not provide data.

In terms of intervention type, at the first follow-up point, 15.8% of patients in a coaching intervention, 20.6% of patients in a dyadic intervention and 15.3% of patients in an individual-based intervention did not provide data. Among partners, 18.5% in an individual-based intervention, 22.5% in a dyadic intervention and 15.8% in a coaching intervention did not provide data. By the final follow-up point, 27.4% of patients in a dyadic intervention, 24% in a coaching intervention and 20.1% in an individual-based intervention did not provide data. Among partners, 33.8% in an individual-based intervention, 27.5% in a dyadic intervention and 24% in a coaching intervention did not provide data.

Among patients, comparable attrition rates were noted across intervention delivery methods – 16.2% for a phone intervention and 19.1% for face-to-face intervention. Among partners, 19.9% in interventions delivered by phone and 16.7% in interventions delivered face-to-face did not provide data. By the final follow-up point, 27.1% of patients in a face-to-face intervention and 19.6% of patients in a phone intervention did not provide data. Among partners, 33.8% in a phone intervention and 26.7% in a face-to-face intervention did not provide data.

Discussion

The aim of this review was to describe the patterns of uptake and attrition in couple-based interventions by cancer type and stage, and intervention type, focus and delivery. The authors acknowledge that presenting proportions across multiple categories (e.g. cancer type and cancer stage) may limit generalizability of the findings.

Although this review was not able to conclude the statistical significance of comparisons of uptake and attrition rates across disease or intervention groups, some observations are noteworthy. First, when accounting for outliers [5,24], the uptake rate among couples facing breast cancer appeared similar to those facing prostate cancer,
which is somewhat surprising, given the evidence that women are often more likely to accept psychosocial services in an oncology outpatient clinic than men [36]. Taken together with the growing evidence that partners experience as much, if not more, psychological distress following a cancer diagnosis as patients [22,37,38], it is possible that the uptake rates for prostate cancer was partially influenced by female partners encouraging prostate cancer patients to participate in the intervention. On the other hand, given that sexual functioning is often impacted, men with prostate cancer may be more open to accepting an intervention they feel will help them within a relational context.

The second noteworthy pattern was that uptake rates varied across intervention types. Uptake rates slightly favoured coaching interventions (59.2%, CI=55.8%–62.6%) than individual-based interventions (48%, CI = 44.6%–51.2%) and dyadic interventions (46.3%, CI = 44.5%–48%). This is somewhat surprising and may reflect a logistical issue for couples who are unable to commit to an intervention simultaneously or feel they do not require the same level of psychosocial support. This is consistent with a study by Lambert et al. [39] regarding the feasibility of a self-directed, couple-based intervention, where common barriers included finding the time to use the intervention materials together, and having different levels of readiness to address certain issues.

The third noteworthy pattern that emerged from this review was that at the final reported follow-up point, patients with a late stage diagnosis and their partners reported similar attrition (patients = 30.7%, 95% CI = 28.1%–33.3%; partners = 29.5%, 95% CI = 26.9%–32.2%), whereas attrition among partners of patients with early stage cancer was somewhat higher than the patients themselves (patients = 19.8%, 95% CI = 17.4%–22.4%; partners = 27.1%, 95% CI = 24.3%–30%; Table 4). Previous studies of attrition have found that late withdrawal from interventions was more likely to occur among
employed participants [40], and thus this might suggest that towards the conclusion of studies partners of early stage cancer patients may perceive the intervention as interfering with family or work commitments and wish to move on from it.

The fourth notable uptake/attrition pattern that emerged from the findings was the variation in uptake and attrition that existed among communication-focused, coping-focused and education-focused interventions. Communication-focused interventions seemed to have slightly lower uptake (43.1%, 95% CI = 40.5%–45.7%) than coping-focused (51%, 95% CI = 49.1%–52.9%) and education-focused interventions (51.8%, 95% CI = 48.1%–55.5%). Communication-focused interventions also seemed to have more favourable attrition rates than coping and education-focused interventions, particularly at the final follow-up. This might highlight that these types of interventions might not be appealing to couples initially, but once they are enrolled, the benefits of these might become more apparent and encourage couples to continue with the intervention. Conversely, and although based on just two studies (one delivered to individuals separately [23] and one delivered as a coaching intervention [28]), education-focused interventions appear to have high initial face validity, but the high attrition noted (at the first follow-up) might highlight issues pertaining to their relevance as participants progress through the cancer trajectory and actual usefulness of these interventions.

**Barriers to Intervention Uptake and Completion**

Two studies had notably lower uptake rates than the others [5,24]. Whereas Baucom et al. provided little information about why their interventions were not as readily accepted as others, Kayser et al. reported 42.3% declined because of the distance to the intervention being too great, and 13.2% said they were too busy to participate. Across all interventions, travel distance was most often cited as a major barrier for couples, followed by illness severity, being too busy/not having the time and the intervention not
meeting couples’ expectations. Few studies provided details regarding the differences (i.e. variations in demographic information or medical history) between eligible couples that accepted an intervention and those who did not.

Two studies reported notable differences in terms of the rate of attrition between patients and partners [26,30]. Thornton and colleagues [30] reported that patients who did not complete the study were more likely to be employed than patients who completed the study and that partners who dropped out reported lower relationship quality and less positive affect than partners that completed the study. Northouse et al. [26] found that in patients with shorter disease-free intervals, more disease symptoms and more uncertainty about their illness were more likely to drop out of the study. Taken together, this suggests that a subsample of participants who may benefit most from a psychosocial intervention were less likely to see the trial through.

**Limitations**

Given the wide variation in samples, interventions and outcomes, it was deemed inappropriate to conduct a meta-analysis. This limits the generalizability of some of the patterns described here, particularly across multiple categories (e.g. cancer stage and type, and intervention type). As such, the results are intended to be interpreted as being descriptive only. A limitation of this review and of the literature of couple-based interventions for cancer in general, particularly for studies with patients with advanced cancer, is that mortality was not consistently reported, making it difficult to tease out the reasons for attrition.

**Future Research**

This review has identified some of the patterns that might be associated with couples’ willingness to participate in and complete couple-based interventions following a cancer diagnosis and identified a number of promising avenues for future research. First, additional research with homogenous subsamples is needed to determine
the cumulative influence of the factors explored in this review on uptake and attrition rates. Second, research to date has given relatively little attention to how the advances in evidence regarding efficacy of couple-based interventions in cancer settings can be translated into clinical practice. Hence, effectiveness studies are needed in diverse clinical settings. In addition, to promote the translation of the evidence on couple-based interventions, studies are needed to explore the views and attitudes of health care professionals about the needs of couples. In particular, a focus on strategies to integrate couple-based interventions into routine clinical care and strategies to reduce stigma that can sometimes accompany psychosocial interventions in cancer care are required [41]. Third, few studies have investigated the characteristics of couple-based interventions that are likely to increase uptake and reduce attrition (e.g. the therapeutic focus and simultaneous participation by patients and partners). Further investigation of the views held by couples regarding the influence (including risks and benefits) of a focus on couple or relationship issues would be beneficial [33]. Fourth, the barriers to uptake and the reasons for attrition identified by the manuscripts reviewed, including employment and level of satisfaction with relationship, suggest the content and mode of delivery of couple-based interventions need to be tailored to the couples’ needs to improve accessibility and acceptability. This is particularly pertinent for couples, as finding the time to engage in an intervention together as well as managing the demands of treatment visits, family and work commitments might be an unrealistic expectation [30]. Tailoring of the content of couple-based interventions was suggested by couples participating in a study by Lambert et al. [39] as a means of increasing the relevance and acceptability of the intervention. Last, few studies reviewed considered the influence of specific relationship factors (e.g. cultural or religious influences and sexual orientation) on the uptake and attrition of couple-based interventions, an area in urgent need of more attention. The application of couple-based interventions for same-sex couples is yet to
be comprehensively addressed in the cancer literature, although important findings from fields such as HIV care may be informative and relevant [42]. A greater understanding of these issues from both clinicians and researchers may help to improve the uptake and delivery of couple-based interventions, and ultimately improving the care provided to patients and partners.
References


psychotherapy to advanced breast cancer patients. Supportive Care in Cancer 2010, 18:1605-1613.


Table 4.1. Uptake of couple-based interventions by eligible participants

<table>
<thead>
<tr>
<th>Author</th>
<th>No. Eligible Couples</th>
<th>% Eligible Couples Randomised</th>
<th>Primary Cancer Type</th>
<th>Delivery</th>
<th>Most common cancer stage</th>
<th>Intervention Focus</th>
<th>Intervention Type</th>
</tr>
</thead>
<tbody>
<tr>
<td>Badger et al. (2007)</td>
<td>115</td>
<td>84.35%</td>
<td>Breast</td>
<td>Phone</td>
<td>Early</td>
<td>Communication</td>
<td>Individual</td>
</tr>
<tr>
<td>Badger et al. (2010)</td>
<td>166</td>
<td>42.77%</td>
<td>Prostate</td>
<td>Phone</td>
<td>Early</td>
<td>Communication</td>
<td>Individual</td>
</tr>
<tr>
<td>Baucom et al. (2009)</td>
<td>108</td>
<td>12.96%</td>
<td>Breast</td>
<td>Face-to-face</td>
<td>Early</td>
<td>Communication</td>
<td>Dyadic</td>
</tr>
<tr>
<td>Budin et al. (2008)</td>
<td>588</td>
<td>42.35%</td>
<td>Breast</td>
<td>Mixed</td>
<td>Early</td>
<td>Education</td>
<td>Individual</td>
</tr>
<tr>
<td>Campbell et al. (2007)</td>
<td>157</td>
<td>28.66%</td>
<td>Prostate</td>
<td>Phone</td>
<td>Late</td>
<td>Coping Skills</td>
<td>Dyadic</td>
</tr>
<tr>
<td>Kayser et al. (2010)</td>
<td>464</td>
<td>13.58%</td>
<td>Breast</td>
<td>Face-to-face</td>
<td>Early</td>
<td>Coping Skills</td>
<td>Dyadic</td>
</tr>
<tr>
<td>Kozachik et al. (2001)</td>
<td>225</td>
<td>53.33%</td>
<td>Other</td>
<td>Face-to-face</td>
<td>Late</td>
<td>Coping Skills</td>
<td>Dyadic</td>
</tr>
<tr>
<td>Kurtz et al. (2005)</td>
<td>550</td>
<td>43.09%</td>
<td>Other</td>
<td>Face-to-face</td>
<td>Late</td>
<td>Coping Skills</td>
<td>Coaching</td>
</tr>
<tr>
<td>McCorkle et al. (2007)</td>
<td>136</td>
<td>92.65%</td>
<td>Prostate</td>
<td>Face-to-face</td>
<td>Early</td>
<td>Education</td>
<td>Coaching</td>
</tr>
<tr>
<td>McLean et al. (2008)</td>
<td>17</td>
<td>94.12%</td>
<td>Other</td>
<td>Face-to-face</td>
<td>Late</td>
<td>Communication</td>
<td>Dyadic</td>
</tr>
<tr>
<td>McLean et al. (2011)</td>
<td>45</td>
<td>93.33%</td>
<td>Breast</td>
<td>Face-to-face</td>
<td>Late</td>
<td>Communication</td>
<td>Dyadic</td>
</tr>
<tr>
<td>Nezu et al. (2003)</td>
<td>150</td>
<td>88.00%</td>
<td>Breast</td>
<td>Face</td>
<td>Late</td>
<td>Communication</td>
<td>Coaching</td>
</tr>
<tr>
<td>Northouse et al. (2005)</td>
<td>250</td>
<td>72.80%</td>
<td>Breast</td>
<td>Face-to-face</td>
<td>Late</td>
<td>Coping Skills</td>
<td>Dyadic</td>
</tr>
<tr>
<td>Northouse et al. (2007)</td>
<td>383</td>
<td>68.67%</td>
<td>Prostate</td>
<td>Face-to-face</td>
<td>Early</td>
<td>Coping Skills</td>
<td>Dyadic</td>
</tr>
<tr>
<td>Northouse et al. (2011)</td>
<td>706</td>
<td>68.56%</td>
<td>Other</td>
<td>Face-to-face</td>
<td>Late</td>
<td>Coping Skills</td>
<td>Dyadic</td>
</tr>
<tr>
<td>Porter et al. (2009)</td>
<td>603</td>
<td>21.56%</td>
<td>Other</td>
<td>Face-to-face</td>
<td>Late</td>
<td>Communication</td>
<td>Dyadic</td>
</tr>
<tr>
<td>Thornton et al. (2004)</td>
<td>207</td>
<td>51.21%</td>
<td>Prostate</td>
<td>Face-to-face</td>
<td>Early</td>
<td>Communication</td>
<td>Dyadic</td>
</tr>
</tbody>
</table>

1 Individual-based (patients & partner receive same intervention separately); dyadic (patient & partner receive same intervention simultaneously); coaching (partner assists patient learn/apply strategies)
<table>
<thead>
<tr>
<th>Author</th>
<th>No. couples randomised</th>
<th>% Patients Lost First F/up</th>
<th>% Patients Lost Last F/up</th>
<th>% Partners Lost First F/up</th>
<th>% Partners Lost Last F/up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Badger et al. (2007)</td>
<td>97</td>
<td>3.09%</td>
<td>4.17%</td>
<td>7.22%</td>
<td>11.34%</td>
</tr>
<tr>
<td>Badger et al. (2010)</td>
<td>71</td>
<td>7.04%</td>
<td>9.86%</td>
<td>7.04%</td>
<td>9.86%</td>
</tr>
<tr>
<td>Baucom et al. (2009)</td>
<td>14</td>
<td>7.14%</td>
<td>14.29%</td>
<td>7.14%</td>
<td>14.29%</td>
</tr>
<tr>
<td>Budin et al. (2008)</td>
<td>249</td>
<td>20.88%</td>
<td>28.92%</td>
<td>26.10%</td>
<td>49.40%</td>
</tr>
<tr>
<td>Campbell et al. (2007)</td>
<td>45</td>
<td>33.33%</td>
<td>n/a</td>
<td>33.33%</td>
<td>n/a</td>
</tr>
<tr>
<td>Kayser et al. (2010)</td>
<td>63</td>
<td>14.29%</td>
<td>25.40%</td>
<td>14.29%</td>
<td>25.40%</td>
</tr>
<tr>
<td>Kozachik et al. (2001)</td>
<td>120</td>
<td>14.17%</td>
<td>25.83%</td>
<td>14.17%</td>
<td>25.83%</td>
</tr>
<tr>
<td>Kurtz et al. (2005)</td>
<td>237</td>
<td>24.89%</td>
<td>41.35%</td>
<td>24.89%</td>
<td>41.35%</td>
</tr>
<tr>
<td>McCorkle et al. (2007)</td>
<td>126</td>
<td>15.08%</td>
<td>15.08%</td>
<td>15.08%</td>
<td>15.08%</td>
</tr>
<tr>
<td>McLean et al. (2008)</td>
<td>16</td>
<td>6.25%</td>
<td>n/a</td>
<td>6.25%</td>
<td>n/a</td>
</tr>
<tr>
<td>McLean et al. (2011)</td>
<td>42</td>
<td>4.76%</td>
<td>14.29%</td>
<td>4.76%</td>
<td>14.29%</td>
</tr>
<tr>
<td>Nezu et al. (2003)</td>
<td>132</td>
<td>0.00%</td>
<td>1.52%</td>
<td>0.00%</td>
<td>1.52%</td>
</tr>
<tr>
<td>Northouse et al. (2007)</td>
<td>263</td>
<td>10.65%</td>
<td>18.63%</td>
<td>10.65%</td>
<td>18.63%</td>
</tr>
<tr>
<td>Northouse et al. (2011)</td>
<td>484</td>
<td>29.13%</td>
<td>37.60%</td>
<td>29.13%</td>
<td>37.60%</td>
</tr>
<tr>
<td>Porter et al. (2009)</td>
<td>130</td>
<td>20.77%</td>
<td>n/a</td>
<td>20.77%</td>
<td>n/a</td>
</tr>
<tr>
<td>Thornton et al. (2004)</td>
<td>106</td>
<td>12.26%</td>
<td>24.53%</td>
<td>38.68%</td>
<td>38.68%</td>
</tr>
</tbody>
</table>
Table 4.3. Uptake rates from couple-based interventions by patients and partners, by cancer type, stage, and intervention type, stage, delivery

<table>
<thead>
<tr>
<th>Category</th>
<th>Uptake rate % (N)</th>
<th>Standard Error (SE)</th>
<th>95% Confidence Interval</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Overall</strong></td>
<td>48.8% (2377/4870)</td>
<td>0.7</td>
<td>47.4% - 50.2%</td>
</tr>
<tr>
<td><strong>Cancer type</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><em>Prostate</em></td>
<td>58.2% (611/1049)</td>
<td>1.5</td>
<td>55.2% – 61.2%</td>
</tr>
<tr>
<td><em>Breast</em></td>
<td>45.3% (779/1720)</td>
<td>1.2</td>
<td>42.9% - 47.7%</td>
</tr>
<tr>
<td><em>Other</em></td>
<td>47% (987/2101)</td>
<td>1.1</td>
<td>44.8% - 49.1%</td>
</tr>
<tr>
<td><strong>Cancer stage</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><em>Early</em></td>
<td>45.6% (989/2167)</td>
<td>1.1</td>
<td>43.5% - 47.8%</td>
</tr>
<tr>
<td><em>Late</em></td>
<td>51.4% (1388/2703)</td>
<td>1.0</td>
<td>49.4% - 53.3%</td>
</tr>
<tr>
<td><strong>Cancer stage &amp; type</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><em>Early-Breast</em></td>
<td>33.2% (423/1275)</td>
<td>1.3</td>
<td>30.6% - 35.8%</td>
</tr>
<tr>
<td><em>Late-Breast</em></td>
<td>80% (356/445)</td>
<td>1.9</td>
<td>75.9% - 83.6%</td>
</tr>
<tr>
<td><em>Early-Prostate</em></td>
<td>63.4% (566/892)</td>
<td>1.6</td>
<td>60.2% - 66.6%</td>
</tr>
<tr>
<td><em>Late-Prostate</em></td>
<td>28.7% (45/157)</td>
<td>3.6</td>
<td>21.7% - 36.4%</td>
</tr>
<tr>
<td><strong>Intervention focus</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><em>Communication</em></td>
<td>43.1% (608/1411)</td>
<td>1.3</td>
<td>40.5% - 45.7%</td>
</tr>
<tr>
<td><em>Coping</em></td>
<td>51% (1394/2735)</td>
<td>0.9</td>
<td>49.1% - 52.9%</td>
</tr>
<tr>
<td><em>Education</em></td>
<td>51.8% (375/724)</td>
<td>1.9</td>
<td>48.1% - 55.5%</td>
</tr>
<tr>
<td><strong>Intervention type</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><em>Dyadic</em></td>
<td>46.3% (1465/3165)</td>
<td>0.8</td>
<td>44.5% - 48%</td>
</tr>
<tr>
<td><em>Individual-based</em></td>
<td>48% (417/869)</td>
<td>1.7</td>
<td>44.6% - 51.2%</td>
</tr>
<tr>
<td><em>Coaching</em></td>
<td>59.2% (495/836)</td>
<td>1.7</td>
<td>55.8% - 62.6%</td>
</tr>
<tr>
<td><strong>Intervention delivery</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><em>Face-to-face</em></td>
<td>49.8% (1915/3844)</td>
<td>0.8</td>
<td>48.2% - 51.4%</td>
</tr>
<tr>
<td><em>Telephone</em></td>
<td>45% (462/1026)</td>
<td>1.6</td>
<td>42% - 48.1%</td>
</tr>
</tbody>
</table>
Table 4.4. Attrition rates from couple-based interventions by patients and partners, at first follow-up and final follow-up

<table>
<thead>
<tr>
<th>Category</th>
<th>First follow-up attrition rate % (N)</th>
<th>Standard Error (SE)</th>
<th>95% Confidence Interval</th>
<th>Final follow-up attrition rate % (N)</th>
<th>Standard Error (SE)</th>
<th>95% Confidence Interval</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Overall</strong></td>
<td>18.5% (440/2377)</td>
<td>0.8</td>
<td>17% - 20.1%</td>
<td>25.7% (562/2185)</td>
<td>0.9</td>
<td>23.9% - 27.6%</td>
</tr>
<tr>
<td><strong>Cancer type</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prostate</td>
<td>12.6% (80/611)</td>
<td>1.4</td>
<td>10.5% - 16%</td>
<td>17.8% (101/566)</td>
<td>1.6</td>
<td>14.8% - 21.3%</td>
</tr>
<tr>
<td>Breast</td>
<td>14.8% (115/779)</td>
<td>1.3</td>
<td>12.3% - 17.5%</td>
<td>19.4% (151/779)</td>
<td>1.4</td>
<td>16.7% - 22.3%</td>
</tr>
<tr>
<td>Other</td>
<td>24.8% (245/987)</td>
<td>1.4</td>
<td>22.2% - 27.6%</td>
<td>37% (311/841)</td>
<td>1.7</td>
<td>33.7% - 40.3%</td>
</tr>
<tr>
<td><strong>Cancer stage</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Early</td>
<td>13.1% (130/989)</td>
<td>1.1</td>
<td>11.1% - 15.4%</td>
<td>19.8% (196/989)</td>
<td>1.3</td>
<td>17.4% - 22.4%</td>
</tr>
<tr>
<td>Late</td>
<td>22.3% (310/1388)</td>
<td>1.1</td>
<td>20.2% - 24.6%</td>
<td>30.7% (367/1197)</td>
<td>1.3</td>
<td>28.1% - 33.3%</td>
</tr>
<tr>
<td><strong>Intervention focus</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Communication</td>
<td>8.6% (52/608)</td>
<td>1.1</td>
<td>6.4% - 11.1%</td>
<td>10.4% (48/462)</td>
<td>1.4</td>
<td>7.8% - 13.5%</td>
</tr>
<tr>
<td>Coping</td>
<td>22.7% (317/1394)</td>
<td>1.1</td>
<td>20.6% - 25%</td>
<td>31.4% (424/1349)</td>
<td>1.3</td>
<td>29% - 34%</td>
</tr>
<tr>
<td>Education</td>
<td>18.9% (71/375)</td>
<td>2</td>
<td>15.1% - 23.3%</td>
<td>24.3% (91/375)</td>
<td>2.2</td>
<td>20.1% - 29%</td>
</tr>
<tr>
<td><strong>Intervention type</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dyadic</td>
<td>20.6% (302/1465)</td>
<td>1.1</td>
<td>18.6% - 22.8%</td>
<td>27.4% (360/1274)</td>
<td>1.3</td>
<td>25.8% - 30.8%</td>
</tr>
<tr>
<td>Individual-based</td>
<td>15.3% (64/417)</td>
<td>1.8</td>
<td>12% - 19.2%</td>
<td>20.1% (84/417)</td>
<td>1.9</td>
<td>16.4% - 24.3%</td>
</tr>
<tr>
<td>Coaching</td>
<td>15.8% (78/495)</td>
<td>1.6</td>
<td>12.7% - 19.3%</td>
<td>24% (119/495)</td>
<td>1.9</td>
<td>20.3% - 28.1%</td>
</tr>
<tr>
<td><strong>Intervention delivery</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Face-to-face</td>
<td>19.1% (365/1915)</td>
<td>0.9</td>
<td>17.3% - 20.9%</td>
<td>27.1% (479/1769)</td>
<td>1.1</td>
<td>25% - 29.2%</td>
</tr>
<tr>
<td>Telephone</td>
<td>16.2% (75/462)</td>
<td>1.7</td>
<td>13% - 19.9%</td>
<td>19.6% (84/417)</td>
<td>2.0</td>
<td>16.4% - 24.3%</td>
</tr>
</tbody>
</table>
Introduction to Paper Five

A Qualitative Investigation of Health Care Professionals’, Patients’ and Partners’ Views on Psychosocial Issues and Related Interventions for Couples Coping with Cancer

**Aims and purpose**

Paper Four explored the variation in uptake and attrition for couple-based interventions in cancer, focusing on the rates reported in each study and how they varied by cancer type and stage, and by intervention type and content. Although the results in Paper Four highlighted some of the potential barriers to couple-based interventions, the issues surrounding barriers and facilitators to couple-focused psychosocial care in general (including interventions), require more in-depth exploration. Paper Five includes a qualitative analysis of some of these issues, and explores health care professionals’ (HCPs) and couples’ perspectives on the delivery of psychosocial care to couples affected by cancer via a series of semi-structured interviews. The results suggest that HCPs and couples may have contrasting views on the need for specific, couple-focused psychosocial care during cancer. Whereas HCPs preferred to refer couples to specialised psychological services, most couples felt this was unnecessary, and that their primary carers were able provide adequate support for them.

This is the fifth paper in this thesis and is currently under review with BMC Cancer. The citation is Regan, T., Lambert, S., et al. (2014). "A Qualitative Investigation of Health Care Professionals’, Patients’ and Partners’ Views on Psychosocial Issues and Related Interventions for Couples Coping with Cancer. Under review with BMC Cancer [Appendix 5.2].
Paper Five

A Qualitative Investigation of Health Care Professionals’, Patients’ and Partners’ Views on Psychosocial Issues and Related Interventions for Couples Coping With Cancer

Tim Regan
The University of Newcastle, New South Wales, Australia

Janelle V. Levesque
The University of New South Wales, New South Wales, Australia

Sylvie D. Lambert
McGill University, Montreal, Canada

Brian Kelly
The University of Newcastle, New South Wales, Australia
Abstract

Introduction

There is growing evidence that cancer affects couples as an interdependent system and that couple-based psychosocial interventions are efficacious in reducing distress and improving coping skills. However, adoption of a couples-focused approach into cancer care is limited. Previous research has shown that patients and partners hold differing views from health care professionals (HCPs) regarding their psychosocial needs, and HCPs from different disciplines also hold divergent views regarding couples' psychosocial needs. This study aimed to explore the perspectives of HCPs and couples on the provision of couple-focused psychosocial care in routine cancer services.

Methods

A qualitative study using semi-structured interviews was undertaken with 20 HCPs (medical oncologists, nurses, psycho-oncology professionals) and 20 couples where one member had been diagnosed with cancer (breast, prostate, head/neck, bowel, multiple myeloma). Interviews were analysed using the framework approach.

Results

Three core themes were identified: "How Do Couples Cope with Cancer?" emphasised the positive and negative coping strategies used by couples, and highlighted that partners perceived a lack of engagement by HCPs. "What Is Couple-focused Psychosocial Care for People with Cancer?" described varying perspectives regarding the value of couple-focused psychosocial care and variation in the types of support couples need among HCPs and couples. Whereas most couples did not perceive a need for specialist couple-focused support and interventions, most HCPs felt couple-focused psychosocial intervention was necessary. "How Can Couple-Focused Psychosocial Care be Improved?" described couples' view of a need for better provision of information, and the importance of their relationship with oncology clinicians. HCPs' identified a lack of confidence in responding to the emotional needs of couples, and barriers to providing psychosocial care, including
challenges identifying distress (through screening) and referring distressed individuals/couples for specialist assessment.

Discussion

The three core themes revealed discrepancies about couple-focused psychosocial care between HCPs and couples, and HCPs from different professional backgrounds, and several barriers to the provision of psychosocial care for couples. Despite HCPs and couples acknowledging that a couple-focused approach to psychosocial support was potentially beneficial, the majority of couples did not feel they needed specific couple-focused interventions. These issues and recommendations for future research are discussed.
Introduction

There is a substantial body of evidence to support the efficacy of psychosocial interventions for people with cancer [1], including couple-based interventions [2]. Such interventions can improve a couple’s ability to adapt to the psychosocial consequences of cancer, ameliorate psychological distress, maintain or enhance quality of life (QoL) and improve couple’s communication [2-7]. These studies provide support for the inclusion of couple-based psychosocial interventions within routine cancer care [8, 9]. Nevertheless, despite a strong focus on improving the availability and delivery of these interventions [9-12], progress in translating this evidence to routine care is slow [8].

Both couple and health care professional (HCP) related barriers have been identified to prevent the implementation of couple-based intervention in routine cancer care. From the couples’ perspective, a recent systematic review found overall low uptake (48.8%) of couple-based interventions and high attrition rates (25.7%) [13]. Interventions requiring couples to participate simultaneously or to travel presented considerable difficulty for potential participants. Other known barriers to the uptake of psychosocial interventions by patients and their partners include having negative views regarding psychosocial support [14] and financial concerns regarding utilising these services [15]. Additional studies exploring patients’ and partners’ views of the delivery of psychosocial care have shown that although patients are typically satisfied with their psychosocial care, partners are often less so [16-19]. Often this dissatisfaction stems from the poor provision of information regarding cancer treatment, including physical and emotional side-effects [17-19], a perceived lack of understanding of patients’ and partners’ psychosocial issues [16, 19], and a lack of support for partners and/or family [16-18]. The lack of support to partners and families is of particular concern, given partners of patients with cancer take on the majority of caregiving responsibilities [20], and often report a greater number of unmet needs [20, 21] and anxiety [22, 23] than patients.
A number of studies have broadly explored HCPs’ views on the implementation of psychosocial care [16, 24-29]. However, few studies have specifically explored HCP related barriers to the implementation of couple-based interventions in routine cancer care [13, 30]. Across studies, attitudes among HCPs’ about psychosocial care of patients with cancer seem to be a salient barrier [16, 24-29]. Current clinical practices guidelines encourage HCPs to screen for distress using specific screening questions and tools [10, 31]. However, across disciplines, HCPs have been found to have divergent views in particular about the importance of identifying and addressing psychosocial issues [24, 26, 28] and who should provide psychosocial support [25]. Discrepancies also exist between HCPs and couples [26, 27, 32, 33]. For instance, studies have shown that in comparison to patients and partners, HCPs often underestimate the importance of couples’ psychosocial concerns [26], their communication and spirituality needs [33], and sexuality needs [32], and patients’ ability to cope with the ongoing cancer issues (e.g., symptom management, seeking support) [27]. These conflicting perspectives and attitudes among HCPs might negatively impact on patients’ and caregivers’ experience, and the HCPs providing care in general [34, 35].

Although the attitudes and beliefs of HCPs, patients and their partners impact on the acceptability and dissemination of psychosocial support in routine practice [10], little is known about the barriers that influence implementation of psychosocial support for couples, as opposed to individuals. The current study addressed this research gap by taking a broader view of couple-focused psychosocial support, and explored the couples’ views regarding their psychosocial needs from a dyadic perspective, and the views held by HCPs regarding the role of couples-focused psychosocial support in cancer care. Exploring these issues among patients, partners and HCPs enables investigation of areas of consensus and divergence. The aims of this study were to explore and contrast HCPs’ and couples’ perspectives on the psychosocial issues couples face, the role of psychosocial interventions, and how health services may be improved to facilitate the uptake of evidence-based couple-focused interventions in routine care.
Methods

Design

This was a qualitative study using thematic analysis to identify recurrent themes in the data [36]. The Framework approach was chosen to help guide data analysis [37, 38], as it provides a structured strategy for categorising and contrasting participants' perspectives, and increasingly used within psycho-oncology research [39, 40].

Sample and Procedures

Convenience samples of oncology-based HCPs and couples were recruited between March 2012 and October 2013. The HCPs included medical oncologists, nurses, social workers and psycho-oncology professionals. HCPs were contacted by email and invited to participate in a 30-minute telephone interview. A consent form, information statement, and a demographic survey were then e-mailed to those who responded favourably to this initial invitation. The main inclusion criteria were: fluent in English, experience in providing supportive care to couples facing a cancer diagnosis, and an interest in discussing their views on the psychosocial care of couples. As patterns in the findings emerged, purposeful sampling of HCPs was undertaken [41]. For example, cancer care nurses were often identified by other HCPs as being key to the psychosocial care of couples, and therefore more were recruited to enhance variability and comparability within the sample. Fifty-six health care professionals were contacted, with 22 responding to the study invitation and of these, 20 participated in an interview. Specific reasons for refusal were difficult to obtain as non-responders to email invitations were not followed-up (as per ethics agreement). Non-participation by two HCPs after originally agreeing was due to participants not being able to participate in the scheduled interview, and not responding to follow-up calls. Table 1 summarises the professional characteristics of the participating HCPs.

Couples (i.e., two adults in an intimate relationship) were recruited from support groups, psycho-oncology services, and hospital-based oncological services. Several recruitment strategies were used: 1) Members of the research team attended support group meetings, introduced the study
to the group, and provided interested individuals or couples with a study pack. Verbal consent was obtained at this time to contact interested parties by telephone to schedule an interview; 2) Members of the research team attended multi-disciplinary clinics, and were introduced to potential participants by clinic staff. The study was introduced, study packs were provided to interested parties, and verbal consent was obtained to make contact by phone and arrange an interview; 3) Study packs were provided to clinical staff, who passed them on directly to potential participants. Clinical staff obtained verbal consent from participants for members of the research team to follow-up with couples by phone, answer any questions, and arrange an interview. Four couples were referred through other studies conducted by the authors. The main inclusion criteria were: fluent in English, at least one member had received a cancer diagnosis, and both members of the couple were interested in discussing their experiences. Once participants’ consent forms were returned, a semi-structured phone or face-to-face interview was scheduled. One hundred and seven eligible patients were initially invited to participate in the study. If their partner was also present, they were directly invited as well. If not, with patients’ permission, they were contacted by phone and invited. Twenty-two patients and their partners agreed to be interviewed, and 20 completed the interview, resulting in a consent rate of 20.5%. The two most common reasons for declining study invitation were lack of interest (n = 24) or a lack of time (n = 10). Reasons for refusal could not be obtained for 51 couples, as they were provided study packs by clinic staff and ethics approval precluded follow-up with non-responders. Two couples did not complete the interview after providing consent due to the death of the patient (n = 1), and lack of interest (n = 1). Table 2 summarises the demographic characteristics of the couples interviewed. Approval from the Area Health and University ethics committees was granted prior to commencing the study.

**Data Collection**

**Semi-structured interviews.**

Semi-structured interviews were conducted with all participants. For HCPs, 10 face-to-face interviews were conducted in private rooms at two separate hospital sites in New South Wales,
Australia. The remaining 10 interviews were completed over the phone. The majority of couples were interviewed in their homes (n = 18). Two telephone interviews were conducted with couples. All interviews were conducted by the first author (TR). The interviewer had established relationships with some HCPs prior to commencing the study to the extent that they are part of a common professional network. For couples, only cancer type, treatments, and some basic demographic details were known prior to the interviews. All participants were interviewed once, and interview length ranged from 12 to 40 minutes (M = 27 minutes, SD = 9 minutes) for HCPs, and from 19 to 79 minutes (M = 47 minutes, SD = 18 minutes) for couples. All interviews were audio-recorded and transcribed verbatim with transcripts sent to participants who requested them. Table 3 broadly outlines the interview guide used to focus the discussion. The interview guide was used flexibly with respect to the order of questions and the depth to which some issues were explored.

**Data analysis.**

Transcripts were analysed by hand to highlight initial themes before all interviews were entered into NVivo 10 to further develop the thematic framework. All of the transcripts were coded by one author (TR), one author coded six couple and six HCP transcripts (JL) and one other co-author (BK) coded six HCP transcripts. Interviewer and analytical biases were managed during regular analysis meetings among all authors. The first and second authors (TR, JL) engaged in regular discussion of cases throughout the data analysis phase to ensure rigor. In regards to the themes that were identified, a high degree of similarity was found among the authors and all agreed with the revisions made to the interpretative framework.

The framework approach outlines five stages of data analysis: familiarisation with the data, identification of thematic framework (using a priori aims, and issues that emerge from the data), indexing (using the thematic framework to code the data), charting (grouping the data according to the parts of the thematic framework they correspond with using codes), and mapping and interpretation (providing explanations of the findings, and the relationships between themes as they
relate to the overall aims of the study) [38]. An initial framework was developed based on the study aims and the stages of the interview process (Tables 4 & 5, column 1). The data were then indexed based on this initial framework by assigning codes to sentences and/or paragraphs that reflected the study aims. Codes were single words or short phrases that captured the essence of the excerpts. These codes were then used to revise the initial framework (Tables 4 & 5, column 2). Across interviews the dominant themes and sub-themes were identified (Tables 4 & 5, columns 3 & 4), and then compared across HCPs’ and couples’ interviews.

**Determining sample size.**

Data appeared to become redundant (i.e., thematic saturation) following the 18th interview for HCPs and the 17th interview for couples. As participants had agreed to participate, two more interviews with HCPs and three more with couples were conducted beyond this point and included in the analysis.

**Maintaining research quality.**

The Consolidated Criteria for Reporting Qualitative Research framework was used to guide the reporting of the findings [42]. In addition, criteria of credibility, transferability, and confirmability were used to ensure the rigor of this study [43-48]. Strategies used to address credibility included recording interviews and transcribing them [36], authors frequently discussing findings [43, 49], encouraging participants to pursue their own lines of thinking [36], and searching the data for conflicting patterns [46]. Transferability was addressed by relating our findings to similar findings in the literature [44], clearly describing the sample and setting for this study [44, 50], and using direct quotes [48]. Confirmability was addressed by rigorous review of interview transcripts, the codes used to identify themes, and drafts and revisions of the findings [36].

**Results**

Four themes emerged from the interviews with HCPs, and four from those with couples (see Table 4 & 5, third column). HCPs’ and couples’ themes were then reviewed and similar content between the two groups were integrated resulting in three core themes (see Figure 1):
In figure 1, couple themes are represented with dotted-line boxes, HCP themes by solid-line boxes, combined themes are in grey and bold, and combined subthemes are grey and italicised.

**How Do Couples Cope With Cancer?**

“How Do Couples Cope With Cancer?” is a theme that combines the couples’ themes “The Way We Cope with Cancer”, “Responding to Cancer”, and “Transition to Survivorship”, with the HCPs’ theme “The Partners Place in Cancer Care”. Within the theme of “How Do Couples Cope With Cancer?”, two sub-themes were identified, “Positive Aspects of Coping Together” and “Negative Aspects of Coping Together”.

Although both patients and partners spoke of having to cope with a range of emotions following a cancer diagnosis, including, fear, anger, and shock, a sense of helplessness was particularly evident for partners.

“It’s a feeling of helplessness not being able to do anything for [patient]... just hoping that you put trust in the medical profession and hope they get it right.” (Partner, woman with breast cancer)

HCPs expressed similar views regarding partners’ experiences. Some HCPs suggested that partners are still grappling with their own emotional distress when they become caregivers and have to assist with new caring tasks. Further to that, HCPs also described partners’ struggle in determining how best to support the patient and reconciling their own needs for support as the ‘healthy’ person.

“I think it’s fair to say that partners feel really lost about what support they should give... what’s their role, should [they] be the care co-ordinator, should they be a recipient of care just like the affected person is, should they be the counsellor or should they be the receiver of counselling?” (Oncologist)

Both HCPs and couples described examples of helpful or adaptive ways of coping with cancer together, but only HCPs described detrimental coping responses among couples. The two
aspects of helpful or adaptive partner support that were commonly identified by HCPs and couples, included emotional and practical support.

The partner’s role in provision of emotional support to the patient was most often described in terms of listening to the patient and conveying to the patient an understanding of the diagnosis and treatment. This form of support was re-iterated by couples, although patients often described partner emotional support as simply ‘just being there’. This was typified by the acknowledgement and validation of patients’ distress. In addition, couples described emotional support as providing a sense of unity, and reinforced the notion that they were “in this together”.

“Just being there is a help...that someone understands, appreciates what you’re going through...advice isn’t what you need so much from your partner, it’s just being there and understanding.” (Patient, breast cancer).

Patients, partners, and HCPs described examples of practical support as picking up medication, arranging transport, and being present at appointments to help retain and understand information. In addition to discussing the central role of partners in providing support, HCPs further acknowledged the confidence and ability that partners needed to undertake these roles. Psycho-oncology professionals most often emphasised the communication skills couples needed to acknowledge each other’s distress, and be able to maintain open communication with one another. Oncologists tended to described skills pertaining to health literacy, including finding, retaining, and acting upon cancer information.

“...the spouse or family member being there helps in retaining information, usually more objectively than the patient themselves. And it also provides me an idea of the kind of problems that the patient and the family will face depending on how they interact with one another...” (Oncologist).

Nurses and social workers focused on communication and practical tasks (e.g., managing appointment schedules, getting medication). In contrast, partners did not typically discuss whether they had specific confidence or ability to provide this support, but often mentioned that they just “got on with it”, and did the best they could at the time. HCPs also felt that they themselves needed
to develop skills to manage both patients’ and partners’ needs and expectations, whose needs might be quite different from each other.

In terms of negative behaviours, HCPs emphasised that these were typically demonstrated by the partner rather than the patient. HCPs identified two characteristics of partners believed to impede adjustment by the couple: 1) partners who did not know how to provide support; and 2) partners who were viewed as not wanting to provide support (as perceived by the HCPs). HCPs commented that partners who did not know how to provide support would typically avoid discussions that might upset the patient, in an attempt to protect them from further distress, which in turn seemed to result in a lack of communication within the couple. HCPs described scenarios where couples’ reluctance to speak to each other about particular issues was often misinterpreted by each member of the couple, and as a result created a tension within the relationship.

“[the couples who say] ‘I would talk to my partner about this, but they’re the patient now, they’re sick I can’t lay this on them’... then the other person thinks ‘why are they acting weird?’... it’s basically putting up a wall between you and them and then they just see the wall.” (Psychologist)

Based on their perceptions of partners’ behaviours during medical consultation, HCPs also provided examples of partners who simply did not want to provide support to the patient. HCPs often linked partners’ negative behaviours towards both the patient and the HCP to their level of emotional distress. Moreover, some HCPs expressed the view that such hostility was also indicative of pre-existing relationship problems, accentuated by the stress of cancer.

“[Partners] can be quite angry or off put and just tend to sort of sit there with their arms crossed and they’re only there because they feel that they have to be there. And I guess that’s the sort of thing that stands out to me that they don’t really want to be there...” (Oncologist)

What is Couple-focused Psychosocial Care?

“What is Couple-focused Psychosocial Care?” (Figure 1) is a theme that combines parts of “Psychosocial Care for One or Two?”, a theme identified in HCPs’ interviews as they described how best to support patients and partners, and elements of “Our Experiences with HCPs”, a theme
that emerged from couples’ description of their positive and negative experiences with HCPs. Two sub-themes were identified for “What is Couple-focused Psychosocial Care”: 1) “The Value of Couple-focused Psychosocial Support”, 2) “What support and who should provide it?”.

**The value of couple-focused psychosocial support.**

All HCPs, regardless of their discipline, identified the value of extending psychosocial support to include both patients and their partners as a means of improving patients’ and partners’ quality of life. The perceived level of psychosocial care was a recognised quality of care indicator. However, HCPs differed in terms of the specific value give to this type of care. Psycho-oncologists’ comments were connected to their perceptions of the kind of communication skills couples needed to cope with cancer together, and emphasised that couple-focused psychosocial support can provide an otherwise unavailable platform to facilitate discussions about issues of concern to patients and partners and address communication problems. Communication was identified as having reciprocal value for patients and partners, in that they both benefited from discussing the impact the cancer was having on them, and assisted couples in maintaining a strong relationship in time of crisis.

“One of the things I’ve noticed is that this [cancer] can have a really big impact on the way you relate to each other as partners...giving them that permission to say ‘yes, this is really awful’. (Social worker)

Of note, psycho-oncologists also identified that the other value of couple-focused psychosocial support is an increased understanding among all HCPs regarding the particular needs and concerns of a couple, which in turn can be used to tailor support for patients and partners.

In contrast to psycho-oncology professionals, oncologists, and to a lesser extent nurses, typically felt that the value of couple-focused psychosocial support was in the specific benefits it has for patients and their recovery, and not so much the benefit for the partner. Nevertheless, oncologists often described that partners who had a greater understanding of what the patient was going through
physically and emotionally typically provided better practical support to patients (e.g., adhering to medication; wound dressing).

“I acknowledge that it’s important to manage the couple’s health as much as... not as much as but as an entity for the reason of it being helpful for the patient themselves.”

(Oncologist).

Nurses held similar views to oncologists, insofar as suggesting anything (including psychosocial care) that is of benefit to the patient is potentially worthwhile, though at the same time indicated that it was often difficult to see the value in providing care of partners if it interrupted their already limited time with patients.

**What support do couples need?**

The two particular support needs of couples that HCPs identified were essentially extensions of individual needs: 1) the need for information; and 2) the need for validation of psychological distress. Oncologists in particular stressed the importance of disease and treatment-related information. Oncologists suggested that it often took time for couples to get past immediate thoughts that cancer is synonymous with death, and to develop an understanding of what the specific diagnosis means for the patient moving forward. Most HCPs, and predominantly oncologists, described the difficulty in providing a clear picture of the patient’s situation to couples, and were mindful of how much information they needed to deliver and at what time point.

“...often the partners become quite teary and they’re fretful that this is going to be a life threatening illness, then as they get more and more information, they get more confident in what’s going on.” (Oncologist).

The second dimension of this theme is the validation of distress. This aspect was most clearly articulated by nurses and psycho-oncology professionals. Although nurses and psycho-oncology professionals held similar views on the importance of cancer information to oncologists,
they also stressed the importance of balancing cancer information with an acknowledgment that patients and/or partners might experience anxiety or depression as a result of the cancer diagnosis, and might also encounter relationship issues couples (e.g., sexual functioning) that could increase distress. The role of psychosocial support was described by psycho-oncology professionals in terms of HCPs conveying an understanding of the couples’ distress. Most psycho-oncology professionals viewed validation of couples’ distress as being the first step in developing a support plan that included both patients and partners.

“…patients are looking for lots of normalisation and validation… the fact they are anxious or worried, that it is OK, they're not going crazy … it’s very similar for both of them really because partners are looking for that as well” (Psychologist)

Of note, couples also raised the need for informational support, but instead of focusing on the type and amount of information received, they spoke of how it was delivered, highlighting the importance of trust and confident in their HCPs.

“I think you can have ‘information overload’. As long as I feel comfortable in knowing what's going to happen then I really don't want to know the bad side effects of the drug I'm taking ... I'd rather go there knowing I've got to have it and I'm not scared about having it.” (Patient, Breast cancer).

Couples also overlapped with HCPs in terms of the importance of gauging the “normality” of their distress, particularly in regards to the beneficial role of support groups. Most couples felt that they could manage their stressors on their own or within their social networks (e.g., family, friends), and more intense support, such as counselling, was perceived as unnecessary.

“The attitude that I’ve got, I don’t feel that they could sort of tell me anything I don’t already know or don’t already have…we’re good support for one another and as I said, we’re positive about it, I mean disappointed too [about poor prognosis], but positive, so I really don’t need [psychosocial support]...Maybe later on I don’t know, but if it gets to a stage where they give you a timeframe on [survival], maybe then”. (Patient, head and neck cancer).

Few couples reported seeking additional psychosocial support beyond what was typically offered to them, which most often included cancer support groups, dedicated clinical care nurses,
and cancer specific telephone support (mainly offered through the Cancer Council). Couples often felt that making social comparisons to other support group members helped them to accept their own situation, and that examples of survivorship from within the group helpfully re-frame their outlook as they moved through their treatment.

Who should provide couple-focused psychosocial support?

Differences emerged among HCPs regarding their views on who provides psychosocial care for couples. Psycho-oncology professionals were clear that when appropriate to do so (i.e., the patient wanted the partner to be involved), they preferred to provide psychosocial support to patients and partners together. Oncologists most often felt they lead the care of their patients including ensuring patients were appropriately referred to receive the psychosocial support they needed. A minority of oncologists acknowledged that efforts should be made to include partners in these referrals, but no oncologists discussed the development of a specific care plan that included the partner. Oncologists and nurses, despite recognising the key role of partners, were generally explicit that their immediate focus was the patient. Nurses and oncologists suggested that although they are often faced with distressed couples, they did not believe that providing psychological support was part of their role, and were either reluctant to engage with couples, or simply did not have the ability, time or resources to explore psychosocial issues with couples. Moreover, most oncologists and nurses described that once the need for additional support was identified (based on their own clinical judgement or that of another HCP), their main role with partners was to essentially facilitate access to supportive care services through referrals.

How Can Couple-Focused Psychosocial Care be Improved?

“How Can Couple-Focused Psychosocial Care be Improved? combines elements from the sub-theme “Improving Psychosocial Support During Survivorship” (from the couples’ theme “Transition to Survivorship”) and the sub-theme “Provision of Information” (from the couples’ theme “Our Experiences with HCPs”; table 5) and the themes “The Quest for Adequate
Psychosocial Care” and “Issues in Distress Screening for Couples” (HCPs; table 4); This theme reflected HCPs’ and couples’ perspectives on the two key elements related to couple-focused psychosocial care that could be improved: 1) provision of information and 2) addressing barriers to psychosocial care.

Provision of information.

Provision of information was identified by both HCPs and couples as an area that could be improved. HCPs from all disciplines acknowledged that information was often misunderstood by patients and partners, and that improvements were needed to increase couples’ understanding and confidence when discussing their situation.

“Once the people get into the treatment they sort of realise ‘Well I didn’t necessarily understand what you were saying. I’ve suddenly got these side effects and it was only 2% of the population that gets them. I’m that 2% and it’s bad. What are we going to do about that?’ So there are a lot of issues around understanding what’s been said and the responsibility for that falls both to the health care professional and the patient and their carer” (Nurse).

Most HCPs described the difficult balancing act between tailoring the information they provide, and providing all available information. Provision of information was equally raised by couples as an area for improvement, particularly as it pertained to the prognosis and emotional consequences of the diagnosis and treatment. Most couples preferred HCPs to be completely transparent in the information provided about the disease and likely outcomes, and couples did not mentioned having discussions regarding information preferences with HCPs. Couples’ reports of negative experiences with HCPs typically related to a lack of consistency of information among HCPs, and a lack of clarity about their diagnosis and treatment. For partners, the lack of clarity of information contributed to the perceived burden of new care responsibilities, noting the use of technical language by HCPS and lack of clarity regarding prognosis.

“We’d been seeing [oncologist], but we hadn’t considered that it was incurable. We just assumed that it was curable. We hadn’t asked and maybe they’re the questions you’re afraid to ask...[partner] said “is it going to kill him?” and [oncologist] says “Yes”.. We hadn’t
Couples also identified the need for more information about the often unexpected emotional consequences of cancer and treatment course, particularly referring to experience of anxiety and depression, mood changes, and the sense of helplessness that can accompany prolonged exposure to a stressor such as cancer. Although couples often spoke of being buoyed by the confidence of their HCP (usually oncologists or nurses) in discussing the medical aspects of their cancer, they did not describe having oncologists and nurses having the same level of confidence discussing the psychological aspects.

“There’s a lot of stuff that’s kind of kept in the background. You’re not told, like I said, his personality changed. I didn’t know it would change.” (Partner, man with head and neck cancer).

Improving HCP-perceived barriers to psychosocial care for couples.

HCPs’ described several barriers to psychosocial care for couples that need to be addressed to improve couple-focused psychosocial care: 1) lack of acknowledgement and screening of partners’ distress, and 2) perception that couple-focused care is outside their expertise. Some HCPs felt that a lack of acknowledgment of partners’ distress and their practical concerns had a negative impact on couples facing cancer. In particular, psycho-oncologists described how partners often feel their distress is invalid, which can create additional distress within the couple.

“Whoever is in front of the patient and the partner more often could say ‘And how are you going?’ to the partner… that validation could be the difference between the levels of distress… they’re still going to be very stressed, but one reason is just because they feel it’s invalid.” (Psychologist).

Psycho-oncologists felt that increasing understanding among HCPs of the interdependencies between partners’ and patients’ adjustment can start overcoming some barriers. On the other hand, social workers and nurses described often being patient-focused due to a lack of time, resources,
and training to adequately address the patient’s needs, let alone the needs of both members of the couple.

“If they’re a struggling sort of couple in any way than they should be dealt with by a counsellor as a couple, because as nurses we do our very best, but we’re not counsellors, [...] But apart from that we don’t have the time.” (Nurse)

Despite awareness of patients’ and partners’ distress, HCPs felt that the process of referring couples to receive psychosocial support lacked consistency within and between their respective health services. Views on current strategies for screening for emotional distress were central to this issue. The majority of HCPs believed that all patients and partners should be screened for distress, although given the logistics of implementing standardised screening procedures for patients alone are often very difficult, it was acknowledged that this may not be realistic. Although most HCPs described the development of sensitive standardised screening tools was an important consideration, others felt that screening may bring additional problems to the surface that might create an additional burden for the couple or HCPs. Some preferred to rely on their own experience and the experience of other HCPs, believing that specific screening tools may not necessarily improve the detection of distressed individuals or couples,

“I’m such a practical person…let’s get on with this and get this sorted and if we find a problem we’ll deal with it. Let’s not go delving, looking for problems…let’s not make problems where they may not exist. I think the screening tool is good and ... I would never ignore a problem but... I’ve been a nurse for 45 years, I think I sense people’s emotions” (Nurse).

Moreover, many HCPs felt that commonly used screening practices (e.g., pencil-and-paper measurement tools) were not capable of capturing either the reality of patients’ cancer experiences, or partners’ and couples’ experiences. In particular, the practice of screening at only one time point and thus reducing the likelihood of identifying distressed individuals at the time when they need help the most.
“...The problem with that is that it’s usually done in a cross-sectional way without any sense of context...If it was longitudinal, I think there would be a much higher success rate of intervention, because it wouldn’t be so broad, it would be targeted.” (Oncologist).

Discussion

With the increasing evidence that some couple-based interventions are efficacious in reducing distress and improving QoL [2, 51], there is growing interest in developing models of psychosocial care in cancer that include both patients and their partners [52]. Nevertheless, implementation of couple-based interventions and approaches to psychosocial care for couples vary widely [30]. This study highlighted that whereas HCPs and couples perceived the value of couple-focused psychosocial support, they held very different perspectives as to how it should be implemented, which is consistent with previous studies with patients and HCPs [24, 26]. Specific points of divergence in previous studies mirrored the findings of the current study and included the role of partners [16], the provision of information [17, 19], who should deliver psychosocial care [25], and how distressed patients and partners are identified [28].

This study identified several themes and sub-themes that can be summarised within two categories of potential barriers and facilitators to the psychosocial care of couples: 1) person-level barriers, and 2) organisational-level barriers. Person-based barriers and facilitators have been categorised as the behaviour/s of a person (HCP, patient or partner) that might influence the provision of couple-focused psychosocial care [53]. Organisational-based barriers were categorised as the organisational policies, infrastructures, or behaviours of particular groups of people (e.g., HCPs from different disciplines) that influenced the delivery of psychosocial care for couples [53]. One person-level barrier was related to divergent opinions regarding the perceived need for couple-focused psychosocial care. Most HCPs described couple-focused psychosocial support as being an important element of caring for patients and their partners, and described a preference for referring couples to specialist psychosocial services. On the other hand, most of couples felt that they did not need additional support, despite acknowledging that couple-focused care could be very valuable for
those that required it. Referrals to separate HCPs for psychosocial support were thus seen as
unnecessary by most couples, which suggests a preference for psychosocial care to be built in to
routine care. This lack of perceived need for couple-focused assistance might be due to a limited
awareness of what psychosocial support can encompass. For example, a study by Lambert and
colleagues [30] that explored the feasibility of a self-directed couple-based intervention found that
couples preferred to self-manage psychosocial concerns, but also needed some assistance to do this.
This suggests that some initial discussion about psychosocial need and concerns, and strategies to
manage them, might be beneficial for couples who did not perceive a need for specific psychosocial
care. This speaks to the need to increase communication between HCPs and couples about what
they can expect in terms of the emotional impact of cancer, and to discuss options for seeking
additional support if it is needed.

A second person-level barrier that was identified across HCPs’ and couples’ interviews
pertained to HCPs’ views of the partner’s place in cancer care. Similar to Lindau and colleagues
[54], this study highlighted that oncologists and nurses tended to focus on the patient and described
being hesitant to discuss issues pertaining specifically to partners, let alone couple-level issues. In
interviews with couples, this lack of engagement from HCPs contributed to a sense of hopelessness
among partners. This is an issue that is common among previous studies, as partners and caregivers
often perceive that their concerns are less valid or important, and at times they feel ignored by
HCPs [20, 55-57]. Given most couples suggested that counselling was unnecessary, increasing all
HCPs capacity to engage with patients and partners and to discuss their emotional concerns might
be a more feasible way of introducing couple-focused psychosocial care and ensure it is more
closely aligned with couples’ needs. Some patterns were noted between HCPs from different
disciplines regarding the partner’s role: psycho-oncology professionals emphasised the need to
support and improve partner’s emotional functioning and their ability to be an active participant in
the patient’s cancer experience as being important to maintaining a healthy couple relationship. In
contrast, oncologists and nurses acknowledged that partners are an important source of support for
patients, but did not feel that actively engaging with partners was part of their role. Oncologists and nurses often prioritised more immediate elements of patient care over the psychosocial needs of the partner and the impact this had on the patient and the patient-partner relationship, which is consistent with previous studies [32, 33]. Although some HCPs were not always willing or able to engage with partners regarding their feelings or experiences, they were alert to some of the negative interactions between patients and partners that are consistent with what has been previously described as protective buffering [58] and demand-withdraw communication [59]. Such styles of interaction have been associated with greater psychological distress in patient and partners [60, 61]. It should be noted that although HCPs conceptualised some negative behaviour as being indicative of not wanting to provide support, they could also be considered symptomatic of not knowing how to provide support.

A third person-level barrier that emerged in interviews with couples and HCPs is the lack of consensus between couples and HCPs, and HCPs from different backgrounds, regarding the type of support that would be most beneficial for couples. Although previous studies have highlighted that couple-focused care can improve various supportive behaviours (e.g., coping [62], communication [63]), HCPs in the current study did not highlight specific couple support mechanisms, such as improving couples’ understanding of one another’s emotional experience, or describing techniques to provide more practical support to one another. Rather, oncologists and nurses tended to focus on providing medical and treatment information, whereas psycho-oncology professionals focused on validation of distress. These could be viewed as extensions of individual-level support.

In contrast to what is typically viewed as important for couple-focused care in the psycho-oncology literature (e.g., relationship functioning, sexuality [2]), couples did not focus on increased support per se, rather they were more concerned with the trust and confidence in their HCPs, and felt that improving transparency in information provision could improve this sense of trust. Consistent with previous research [64], couples indicated that having oncologists or surgeons who confidently and clearly presented their medical treatment options typically eased their anxiety and
increased their own confidence about what to expect. Couples reported less confidence in recommendations for psychosocial support from HCPS than other treatment recommendations. This is consistent with previous research suggesting patients receive significantly less advice about psychosocial issues than medical issues [65, 66]. Encouragement from HCPs to seek additional psychosocial support, particularly from oncologists, has been suggested by couples as a potential determinant of their decision to seek counselling or not [67], which in part speaks to the influence of HCPs’ prejudices towards psychosocial care [68]. Previous research suggests HCP-Patient discussions of psychosocial concerns is associated with greater participation in counselling or other additional psychosocial support by patients [69]. Nevertheless, it is interesting to note also that concerns held by HCPS about exacerbating distress can inhibit attempts to explore emotional problems among patients [64]. Thus, improving HCPs confidence and skills in initiating discussion of the psychosocial and emotional impact of cancer, and exploring couples information and support needs is required; however, it may be necessary to address the stigma associated with psychosocial care for both couples and HCPs [70].

In addition to person-level barriers, HCPs identified organisational-level barriers. The most prominent one was lack of appropriate training in the recognition and management of psychosocial distress. Despite acknowledging the priority attached to recognising emotional distress as a “Vital Sign” [71], HCPs felt that typical distress screening practices were at odds with the way in which cancer care is currently provided (e.g., the lack of consultation time available). Although some HCPs described screening for distress in terms of asking patients and partners how they were managing, the majority discussed screening as being instrument-driven (i.e., needing to use a measurement tool). There is evidence that suggests that as much as 90% of eligible patients consent to distress screening when screening is administered by dedicated research staff [72, 73]. On the other hand, clinician-led screening has been shown to vary by discipline, with nurses more likely to use routine screening measures than doctors [28]. Despite studies suggesting that partners are often significantly more distressed than patients [74, 75], screening partners for distress has not been
widely adopted. Given the difficulties raised by HCPs regarding screening programs for patients only, additional studies are needed to further examine how screening for partners and couples can be embedded into clinical practice.

Another organisational barrier identified by HCPs was a lack of appropriate training to manage the psychosocial issues couples face, which is consistent with other studies in this field [53]. Given the high prevalence [76, 77] and interdependence [78, 79] of distress between patients and partners, increasing HCPs’ capacity to engage with couples and validate their concerns earlier in the treatment phase may strengthen couples’ ability to manage cancer in the short- and long-term. Some studies have shown that improving HCPs’ communication skills can improve patients’ satisfaction with care [80] and that such skills can be developed through education [81, 82]. A meta-analysis of communication-based interventions for HCPs in oncology suggested that these types of interventions can have a moderate effect on improving HCPs’ skills [83]; however, translation to everyday practice is limited [84]. A comprehensive model of communication skills training has been developed by Kissane and colleagues [84], and participants have reported significant improvements in communicating effectively with patients and families. Communication skills training may also improve HCPs’ information provision by encouraging if HCPs discuss with couples how they would prefer to receive information [85].

Previous research has highlighted several barriers that limit the provision of psychosocial care to individuals from a patient-only perspective [10, 86, 87]. These barriers include difficulties in HCP-Patient communication, a lack of appropriately trained HCPs, concerns regarding distress screening, issues with obtaining reimbursement for services from health insurance providers, stigma surround the use of psychosocial services, and transportation issues. The current study overlapped on several barriers, namely issues involving HCP-Couple communication and HCPs’ ability to identify and manage couples’ distress. Thus, the barriers identified in the current study are not in themselves unique; however, they highlight a broadening scope in oncology that suggests partners are integral to patients’ care.
Limitations

We recognise that selection bias might have been introduced to the study given the recruitment of some HCPs that were known to researchers, and the inclusion of psycho-oncology professionals. The inclusion of psycho-oncology professionals provides a broader context to the issues couples face across the cancer trajectory, and highlights where implementation issues of psychosocial care for couples might occur. However, every effort was made to ensure methodological rigour was applied to the study. Another limitation is the possibility of social desirability bias. That is, some participants may have responded to questions in a manner they thought was consistent with the research aims.

Conclusions and Implications

This study highlighted some of the issues couples face when one spouse is diagnosed with cancer, and steps that HCPs can undertake to improve the support to such couples. As more people live with the direct and indirect effects of cancer a focus on improving HCPs’ ability to engage with couples to improve their self-management is required. Three key areas are evident that require additional attention. First, improve all HCPs ability to engage with partners, and explore the needs of the couple. Previous research has shown that poor communication with patients and partners is associated with psychosocial distress and satisfaction with care [88, 89]. As couples might not always want specific counselling services, enhancing other HCPs’ self-efficacy in discussing psychosocial issues could be of significant benefit to couples. Second, explore the possibility of a psychosocial care manager. Our results are consistent with previous research suggesting that HCPs are often under-skilled in identifying and managing psychosocial distress in patients and partners [53, 90]. A psychosocial care manager would be well-placed to assist in training other staff in the identifying and providing appropriate support to couples who most need it. Third, there is a need to continue the development of interventions for couples. The current evidence regarding couple-based interventions suggests they have a low to moderate impact on reducing psychological distress [2, 51]. Future couple-based interventions should look to build on the current focus of addressing
psychosocial and relationship issues, and explore the possibilities of interventions that aim to improve communication with health care professionals [91] and enhance couples’ ability to advocate for patient and partner needs [92].
References


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52. Western Australia Department of Health, Psycho-Oncology Model of Care, WA Cancer and Palliative Care Network, Editor. 2008, Department of Health, Western Australia: Perth.


Table 5.1. HCPs’ Professional Experience

<table>
<thead>
<tr>
<th></th>
<th>Participants (n = 20)</th>
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<tbody>
<tr>
<td><strong>Gender, N(%)</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>8 (40)</td>
</tr>
<tr>
<td>Female</td>
<td>12 (60)</td>
</tr>
<tr>
<td><strong>Profession, N(%)</strong></td>
<td></td>
</tr>
<tr>
<td>Oncologist</td>
<td>7 (35)</td>
</tr>
<tr>
<td>Psychologist/psychiatrist</td>
<td>6 (30)</td>
</tr>
<tr>
<td>Nursing</td>
<td>5 (25)</td>
</tr>
<tr>
<td>Social worker</td>
<td>2 (10)</td>
</tr>
<tr>
<td><strong>No. Years Professional Experience, N(%)</strong></td>
<td></td>
</tr>
<tr>
<td>0-5</td>
<td>0</td>
</tr>
<tr>
<td>5-10</td>
<td>4 (20)</td>
</tr>
<tr>
<td>More than 10</td>
<td>16 (80)</td>
</tr>
<tr>
<td><strong>No. Years Cancer Experience, N(%)</strong></td>
<td></td>
</tr>
<tr>
<td>0-5</td>
<td>3 (15)</td>
</tr>
<tr>
<td>5-10</td>
<td>4 (20)</td>
</tr>
<tr>
<td>More than 10</td>
<td>13 (65)</td>
</tr>
<tr>
<td><strong>Health Service Location, N(%)</strong></td>
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</tr>
<tr>
<td>Metropolitan</td>
<td>10 (50)</td>
</tr>
<tr>
<td>Regional</td>
<td>10 (50)</td>
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Table 5.2. Couple Demographics

<table>
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<th>Participants (n = 20)</th>
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<tbody>
<tr>
<td><strong>Patient gender, N (%)</strong></td>
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</tr>
<tr>
<td>Male</td>
<td>13 (65)</td>
</tr>
<tr>
<td>Female</td>
<td>7 (35)</td>
</tr>
<tr>
<td><strong>Age (years), M (SD)</strong></td>
<td></td>
</tr>
<tr>
<td>Patient</td>
<td>64.6 (9)</td>
</tr>
<tr>
<td>Partner</td>
<td>63.5 (9.1)</td>
</tr>
<tr>
<td><strong>Relationship length (years), M (SD)</strong></td>
<td>36.8 (14.9)</td>
</tr>
<tr>
<td><strong>Cancer diagnosis, N (%)</strong></td>
<td></td>
</tr>
<tr>
<td>Prostate</td>
<td>8 (40)</td>
</tr>
<tr>
<td>Breast</td>
<td>6 (30)</td>
</tr>
<tr>
<td>Head &amp; neck</td>
<td>4 (20)</td>
</tr>
<tr>
<td>Multiple myeloma</td>
<td>1 (5)</td>
</tr>
<tr>
<td>Bowel</td>
<td>1 (5)</td>
</tr>
<tr>
<td><strong>Time since diagnosis (months), M (SD)</strong></td>
<td>14.4 (17.6)</td>
</tr>
</tbody>
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Table 5.3. Examples of interview questions and codes

<table>
<thead>
<tr>
<th>Interview stage</th>
<th>Examples of questions</th>
<th>Interview stage</th>
<th>Examples of questions</th>
</tr>
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<tbody>
<tr>
<td><strong>HCPs</strong></td>
<td><strong>Couples</strong></td>
<td><strong>HCPs</strong></td>
<td><strong>Couples</strong></td>
</tr>
<tr>
<td><strong>STAGE 1</strong></td>
<td><strong>STAGE 1</strong></td>
<td><strong>STAGE 1</strong></td>
<td><strong>STAGE 1</strong></td>
</tr>
<tr>
<td>Overall</td>
<td>‘In your experience,</td>
<td>Response to</td>
<td>‘How did you</td>
</tr>
<tr>
<td>impression of</td>
<td>what are some of</td>
<td>cancer diagnosis</td>
<td>respond to the</td>
</tr>
<tr>
<td>challenges faced</td>
<td>the biggest</td>
<td>and treatment</td>
<td>diagnosis?’</td>
</tr>
<tr>
<td>by couples</td>
<td>challenges couples</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>face following a</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>cancer diagnosis?</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>STAGE 2</strong></td>
<td>‘What role do you</td>
<td><strong>STAGE 2</strong></td>
<td>‘Can you describe</td>
</tr>
<tr>
<td>Your role in</td>
<td>play in assisting the</td>
<td>Nature of</td>
<td>how you and your</td>
</tr>
<tr>
<td>facilitating the</td>
<td>couple manage</td>
<td>psychosocial</td>
<td>spouse coped</td>
</tr>
<tr>
<td>needs of patient</td>
<td>distress?’</td>
<td>support received</td>
<td>during the</td>
</tr>
<tr>
<td>as well as the</td>
<td></td>
<td>following</td>
<td>treatment?’</td>
</tr>
<tr>
<td>needs of the</td>
<td></td>
<td>diagnosis</td>
<td></td>
</tr>
<tr>
<td>partner</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>STAGE 3</strong></td>
<td>‘How do you feel</td>
<td><strong>STAGE 3</strong></td>
<td>‘What could have</td>
</tr>
<tr>
<td>Opinions about</td>
<td>our health services</td>
<td>Opinions needs</td>
<td>been improved to</td>
</tr>
<tr>
<td>how health</td>
<td>can better assist</td>
<td>of couples</td>
<td>ensure you had</td>
</tr>
<tr>
<td>services could</td>
<td>couples following</td>
<td>a cancer</td>
<td>all the support you</td>
</tr>
<tr>
<td>be improved to</td>
<td>a cancer diagnosis</td>
<td>diagnosis</td>
<td>needed?’</td>
</tr>
<tr>
<td>better assist</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>couples following</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a cancer</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>diagnosis</td>
<td></td>
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### Table 5.4. Stages of framework analysis for HCPs’ views on psychosocial during cancer

<table>
<thead>
<tr>
<th>Challenges couples face following a cancer diagnosis</th>
<th>Major challenges faced by couples</th>
<th>Themes</th>
<th>Sub-themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional impact</td>
<td>Increased burden on partner</td>
<td>‘The Partner’s Place in Cancer Care’</td>
<td>Adapting to new roles</td>
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<tr>
<td>Change in relationship</td>
<td>Partner as a caregiver</td>
<td></td>
<td>Partner as a negative influence on patient and care</td>
</tr>
<tr>
<td>Financial impact</td>
<td>Change in partner’s role</td>
<td></td>
<td>Partner as ally to HCP and PT</td>
</tr>
<tr>
<td>Career impact</td>
<td>Partner distress</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interruption to future plans</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caring for patients</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Impact on family</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Impact on social life</td>
<td></td>
<td></td>
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</table>

<table>
<thead>
<tr>
<th>HCPs’ role in assisting couples manage distress</th>
<th>HCPs’ role in assisting couples manage distress</th>
<th>‘Psychosocial care for one or two?’</th>
<th>HCPs’ Approach to Supporting Couples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Providing cancer information</td>
<td>Provision of appropriate</td>
<td>Who should receive psychosocial</td>
<td></td>
</tr>
<tr>
<td>Emotional support</td>
<td>psychological support</td>
<td>support?</td>
<td></td>
</tr>
<tr>
<td>Involvement in couples issues</td>
<td>Dealing with issues not trained</td>
<td>What kind of support do people need?</td>
<td></td>
</tr>
<tr>
<td>Providing support to patient</td>
<td>for</td>
<td>The Value of Psychosocial Care</td>
<td></td>
</tr>
<tr>
<td>Providing support to partner</td>
<td>Information provision</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Use of available services and resources</td>
<td></td>
<td></td>
<td></td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Improving health services for couples</th>
<th>Improving health services</th>
<th>‘Issues in Distress Screening for Couples’</th>
<th>Who should be screened</th>
</tr>
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<tbody>
<tr>
<td>Improving referrals</td>
<td>Opportunities for counselling</td>
<td>Who should we use to screen (instrument vs. experience)</td>
<td></td>
</tr>
<tr>
<td>Acknowledging couples’ issues</td>
<td>Identifying distressed couples</td>
<td>When should screen – once vs. multiple time points</td>
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<tr>
<td>Screening for distress</td>
<td>Improving distress screening</td>
<td>Why should we screen at all (e.g. to tailor for interventions)</td>
<td></td>
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<tr>
<td>Providing couple-based psychosocial therapies</td>
<td>practices</td>
<td>‘The quest for adequate psychosocial care’</td>
<td>Barriers to adequate psychosocial care</td>
</tr>
<tr>
<td>Improving all HCPs ability to provide support</td>
<td>Resources in rural areas</td>
<td>Improving psychosocial care</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Acknowledging partner distress</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>HCP communication</td>
<td></td>
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Table 5.5. Stages of framework analysis for couples’ views on their experience with cancer and HCPs

<table>
<thead>
<tr>
<th>Initial framework based on a priori issues</th>
<th>Revised framework based on indexing</th>
<th>Themes</th>
<th>Sub-themes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Response to cancer diagnosis</strong></td>
<td><strong>Emotional response to diagnosis</strong></td>
<td>‘Responding To Cancer’</td>
<td><strong>Patient responses</strong></td>
</tr>
<tr>
<td>• Emotional response</td>
<td>• Discussing cancer with family</td>
<td></td>
<td>• Partner responses</td>
</tr>
<tr>
<td>• Relationship impact</td>
<td>• Impact on relationship</td>
<td></td>
<td>• Discussing with family</td>
</tr>
<tr>
<td>• Change in relationship roles</td>
<td>• Future plans</td>
<td></td>
<td><strong>Individual coping strategies</strong></td>
</tr>
<tr>
<td>• Coping strategies</td>
<td>• Intimacy</td>
<td></td>
<td><strong>Dyadic coping strategies - emotional support</strong></td>
</tr>
<tr>
<td>• Family impact</td>
<td>• Coping</td>
<td></td>
<td><strong>Dyadic coping strategies - practical support</strong></td>
</tr>
<tr>
<td>• Career impact</td>
<td>• Individually</td>
<td></td>
<td><strong>Dyadic coping strategies - communication</strong></td>
</tr>
<tr>
<td>• Interruption to future plans</td>
<td>• With spouse</td>
<td></td>
<td><strong>Confidence in diagnosis and treatment</strong></td>
</tr>
<tr>
<td>• Impact on social life</td>
<td>• Difference in coping strategies</td>
<td></td>
<td><strong>Provision of information</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Role of partner</strong></td>
<td></td>
<td><strong>Support groups</strong></td>
</tr>
<tr>
<td><strong>Support received following diagnosis</strong></td>
<td><strong>Support from HCPs</strong></td>
<td>‘Our experiences with HCPs’</td>
<td><strong>Counselling</strong></td>
</tr>
<tr>
<td>• Support from family</td>
<td>• Encouraged to seek psychosocial support</td>
<td></td>
<td><strong>Confidence in diagnosis and treatment</strong></td>
</tr>
<tr>
<td>• Support from social network</td>
<td>• Counselling</td>
<td></td>
<td><strong>Provision of information</strong></td>
</tr>
<tr>
<td>• Support from HCPs</td>
<td>• Information provision</td>
<td></td>
<td><strong>Support groups</strong></td>
</tr>
<tr>
<td>• Information support</td>
<td>• Confidence in treatment</td>
<td></td>
<td><strong>Counselling</strong></td>
</tr>
<tr>
<td>• Emotional support</td>
<td>• Coordination of care</td>
<td></td>
<td><strong>Confidence in diagnosis and treatment</strong></td>
</tr>
<tr>
<td>• Practical support</td>
<td><strong>Support groups</strong></td>
<td></td>
<td><strong>Provision of information</strong></td>
</tr>
<tr>
<td></td>
<td>• Content: Emotion/Practical</td>
<td></td>
<td><strong>Support groups</strong></td>
</tr>
<tr>
<td></td>
<td>• Shared experience</td>
<td></td>
<td><strong>Counselling</strong></td>
</tr>
<tr>
<td><strong>Views on the needs of couples following diagnosis/treatment</strong></td>
<td><strong>Emotional response to treatment</strong></td>
<td>‘Transition to Survivorship’</td>
<td><strong>Managing on-going effects</strong></td>
</tr>
<tr>
<td>• Support for partner</td>
<td>• Experience of loss</td>
<td></td>
<td><strong>Managing on-going effects</strong></td>
</tr>
<tr>
<td>• Improving information provision</td>
<td>• Body image concerns</td>
<td></td>
<td><strong>Managing on-going effects</strong></td>
</tr>
<tr>
<td>• Access to psychosocial support</td>
<td>• Survivor guilt</td>
<td></td>
<td><strong>Managing on-going effects</strong></td>
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<tr>
<td></td>
<td><strong>Acknowledgment of relationship</strong></td>
<td></td>
<td><strong>Managing on-going effects</strong></td>
</tr>
<tr>
<td></td>
<td>• Impact on partners</td>
<td></td>
<td><strong>Managing on-going effects</strong></td>
</tr>
<tr>
<td></td>
<td>• Support for partners</td>
<td></td>
<td><strong>Managing on-going effects</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Provision of cancer information</strong></td>
<td></td>
<td><strong>Managing on-going effects</strong></td>
</tr>
<tr>
<td></td>
<td>• What do couples understand?</td>
<td></td>
<td><strong>Managing on-going effects</strong></td>
</tr>
<tr>
<td></td>
<td>• Managing disparity in understanding</td>
<td></td>
<td><strong>Managing on-going effects</strong></td>
</tr>
<tr>
<td>Initial framework based on a priori issues</td>
<td>Revised framework based on indexing</td>
<td>Themes</td>
<td>Sub-themes</td>
</tr>
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<td>------------------------------------------</td>
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</tr>
<tr>
<td>Follow-up care</td>
<td>Access to psychosocial services</td>
<td></td>
<td>Improving psychosocial support during survivorship</td>
</tr>
<tr>
<td></td>
<td>Discussing psychosocial impact</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>with HCPs</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Long-term side-effects</td>
<td></td>
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</tr>
</tbody>
</table>
Figure 5.1: Integration of couple and HCP themes (themes from Tables 4 & 5)

### Combined theme #1
- **“The Way We Cope With Cancer”**
- **“Transition to Survivorship”**
- **“How do Couples Cope with Cancer?”**
  - **“Positive Aspects of Coping Together – Emotional & Practical Support”**
  - **“Negative Aspects of Coping Together – knowing and wanting to provide support”**

### Combined theme #2
- **“Responding to cancer”**
- **“The Partner’s Place in Cancer Care”**
- **‘Support groups’** (subtheme “Our Experiences with HCPs”)
- **‘Provision of Information’** (subtheme “Our Experiences with HCPs”)
- **“Psychosocial Care for One or Two?”**
- **“What is Couple-focused Psychosocial Care for people with cancer?”**
  - **“The Value of Dyadic Psychosocial Support”**
  - **“What Support Do Couples Need and who should provide it?”**

### Combined theme #3
- **“Provision of Information”** (subtheme “Our Experiences with HCPs”)
- **“Improving Psychosocial Care During Survivorship”**
- **“How Can Couple-Focused Psychosocial Care be Improved?”**
  - **“Provision of Information”**
  - **“Improving HCP-perceived barriers to psychosocial care for couples”**

#### Legend:
- **Couples Theme**
- **HCPs Theme**
- **Combined Theme**
- **Combined Sub-Theme**
Introduction to Paper Six

“*You need something like this to give you guidelines on what to do*”: Patients’ and partners’ use and perceptions of a self-directed coping skills training resource

### Aims and purpose

Papers Four and Five highlighted some of the barriers to delivering psychosocial care to couples facing cancer. These included a lack of time to access psychosocial services, couples’ preference to receive psychosocial support from their primary care team or to self-manage their psychosocial distress. Self-directed interventions have been suggested as a potential method to overcome these and other barriers to psychosocial care for couples. To explore couples’ views on self-directed psychosocial interventions, Paper Six is a qualitative exploration involving a series of semi-structured interviews (separate to Paper Five) regarding couples’ views on *Coping-Together*, a novel, self-directed intervention for couples coping with cancer. Most couples were very positive about *Coping-Together*, and expressed a willingness to use the resource, and highlighted the benefits of the resource (e.g., new ways of coping). Couples also outlined several ways *Coping-Together* could be improved, such as reducing negative information and including more patient testimonials.

This is the sixth paper in this thesis and has been published in Supportive Care in Cancer. The citation is: Lambert, S. D., Girgis, A., Turner, J., Regan, T., et al. (2013). “You need something like this to give you guidelines on what to do”: Patients' and partners' use and perceptions of a self-directed coping skills training resource. *Supportive Care in Cancer, 12(2)*. [Appendix 6.2].
Paper Six

“*You need something like this to give you guidelines on what to do*”:

**Patients’ and partners’ use and perceptions of a self-directed coping skills training resource**

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Abstract

Background
To report on the acceptability of a self-directed coping skills intervention, called *Coping-Together*, for patients affected by cancer and their partners, including the strengths and limitations of the intervention design.

Methods
This initial version of *Coping-Together* included a series of four booklets, which aimed to provide practical coping strategies for the day-to-day management of common physical and psychosocial challenges. Thirty semi-structured interviews were conducted with 27 patients and/or 14 partners. Interviews were audio-recorded, transcribed verbatim, and analysed for content.

Results
Participants endorsed the self-directed format, and the focus of *Coping-Together* on practical information was a feature that set it apart from other resources. The majority of participants interviewed felt that the proposed coping strategies were “doable”; however, only half of the participants reported learning new coping skills after reading the booklets. Additional benefits of reading the booklets were increasing awareness of challenges to prepare for, giving hope that something can help you “pull through”, providing a sense of normality, connecting patients and partners to people and services, and complementing support received from health professionals. Despite the general acceptability of the intervention, some aspects of its design were criticized, including the workbook-like exercises, expectations about using the resource together, level of guidance provided, and amount of information included. In general, most participants felt that too much negative information was included, whereas more experiential information was desired.

Discussion
Preliminary evaluation of *Coping-Together* supported its practical approach and highlighted improvements to enhance its contribution to patient and partner coping.
Introduction

One-third to almost one-half of patients report significant anxiety following a cancer diagnosis [1], with several studies suggesting that partners experience more distress than patients [2-4]. To date, numerous psychosocial interventions have aimed to optimize patients’ illness adjustment [5, 6], but few have targeted partners [7, 8]. This is despite recent reviews supporting the efficacy of couple-based coping interventions in improving not only patients’ illness adjustment, but partners’ outcomes as well [7, 8]. Although the efficacy of couple-based interventions is promising, these are typically delivered by highly trained health professionals; limiting their long-term sustainability due to the high cost and restricted availability of qualified professionals. Furthermore, cited deterrents to accessing professional help for patients and partners include geographical or mobility barriers [9], stigma associated with psychosocial care [10], and a preference to self-manage cancer challenges [11]. The challenge then is to develop efficacious, cost-effective, non-stigmatizing and easily accessible psychosocial interventions to ensure that all couples have timely access to the information and support they need [12]. One suggestion is to use a self-directed format (also termed self-administered), as it has the potential to overcome many of the aforementioned barriers to pursuing face-to-face interventions [13, 14]. A number of studies have recently supported the acceptability and efficacy of self-directed coping skills training interventions [9, 13], particularly among distressed individuals [15], but there appears to be none including partners. This paper reports on the acceptability of a self-directed coping skills intervention, called Coping-Together, for couples affected by cancer. In particular, we examined patients’ and partners’ willingness to use a self-directed resource to learn new coping skills, the perceived benefits of using the resource, and the strengths and limitations of the intervention design.
Methods

Design

This qualitative study was a thematic survey [16] whereby the goal was to discern patterns in the data (or themes) to better understand the extent to which *Coping-Together* was acceptable to patients and partners.

Sample

Patients diagnosed with cancer, regardless of type and stage, and/or their partners (girl/boyfriend, spouse, de facto) were invited to evaluate *Coping-Together*, if they were sufficiently fluent in English and physically and cognitively able to participate in an interview. There were no exclusions based on illness or socio-demographic variables, as variability in terms of treatment modality, cancer stage, and age was purposefully sought to evaluate the acceptability of *Coping-Together* across different contexts, and to determine whether certain sub-groups should be targeted in subsequent studies.

The *Coping-Together* Booklets (acceptability version)

The *Coping-Together* booklets were designed to provide individuals diagnosed with cancer and their partners with practical coping strategies that can be readily used when confronted with common physical and psychosocial cancer challenges. Theoretical frameworks underpinning the aim of this resource included the Lazarus and Folkman’s stress and coping framework [17], Bodenmann’s framework of dyadic coping [18], and Bandura’s self-efficacy theory [19]. The content of the booklets was initially defined by a review of the literature of the physical, social, and emotional impact of cancer on patients and partners, and the related evidence-based coping strategies to overcome the issues faced. This content was supplemented by materials from existing coping skills and couples-based interventions. Several strategies were used to enhance the appeal and
comprehension of the booklets, including aiming for a grade 5-6 on the Flesch-Kincaid scale, using clear headings and colours to denote sections, inserting concrete examples to illustrate the use of the proposed coping strategies, and using tables/boxes and illustrations to break up the text [20]. The development of the booklets was an iterative process whereby as soon as the booklets were developed, they were reviewed by experienced oncology health professionals, including nurses, psychologists, social workers, and oncologists, and by couples, and their feedback was integrated in the next version of the booklets.

The four *Coping-Together* booklets evaluated in this study were a) Symptom Management, b) Couples Communicating Effectively with Health Care Professionals, c) Supporting Each Other, and d) Managing Worries and Emotions. Each booklet provided an overview of the challenges addressed, including quotes from patients and/or partners; practical coping strategies to address these challenges, including worksheets designed to encourage active learning and application of the suggested strategies; testimonials from patients and partners reporting their success with the proposed strategies; and the empirical evidence supporting the strategies. The worksheets were developed in consultation with expert clinicians and/or were inspired by existing workbooks [9]. Table 6.3 provides an overview of each booklet. A written summary of the *Coping-Together* resources, and instructions on how and when to use the intervention, was also included with the booklets.

**Setting and Procedures**

Ethics approval was obtained from the Hunter New England Human Research Ethics Committee and the Human Research Ethics Committees of the Universities of Newcastle and New South Wales. Participants were recruited from oncology clinics and support groups, as well as through cancer organisations and other studies that were
being conducted by the research team. At the oncology clinics, patients were introduced to the study by a member of their health care team and interested patients were either given a study pack or met with the on-site research assistant (RA) who explained the study and provided a study pack. The research team also distributed study packs at three support groups for patients with breast or prostate cancer. In addition, study packs were sent to patients and partners who responded to a study advertisement in the Cancer Council New South Wales Research Report Newsletter, or who had participated in other studies conducted by the team and expressed interest in being involved in other research. All study packs included an information statement, a consent form, an illness and socio-demographic survey, a reply paid envelope, the draft *Coping-Together* booklets, and an identical study pack for patients to pass on to their partners. Once participants were given a study pack, contact information was recorded and verbal consent obtained to follow-up with non-responders. Patients and/or partners who returned a consent form were then contacted to schedule a semi-structured interview.

**Data Collection**

All participants were involved, either as a couple or individually, in a semi-structured interview (face-to-face or by telephone) to obtain an in-depth understanding of their perceptions and use of *Coping-Together* on average 8-9 weeks (range 1-31 weeks) after receiving the booklets. Throughout the study, four RAs were trained to conduct the interviews, which included listening to an exemplary interview, practising questions, and receiving feedback from the first author. Prior to the interview, the RA only knew participants’ basic illness and demographic information. Time and place of the interview were negotiated between the RA and the patient and/or partner. Although face-to-face interviews were preferred, telephone interviews were an acceptable alternative if it was more convenient for participants, as these have been shown to yield
no difference in data quality [21]. Face-to-face interviews were either conducted in participants’ homes or in a private room at the referring clinic. The interview was a three-stage process (Table 6.4) whereby initial open-ended questions, designed to explore patients’ and partners’ experiences since the diagnosis, were followed by more specific questions pertaining to the overall challenges faced by participants. Answers to these initial questions provided the context within which the booklets’ acceptability could then be explored. An interview guide was used with some flexibility in the sequencing of questions and depth of exploration (see Table 6.4 for examples). All interviews were audio-recorded and transcribed verbatim. Transcripts were sent to participants who requested them.

Data Analysis

Words, statements, and/or paragraphs related to the research questions were extracted from the transcripts by assigning a code (i.e., single words or short phrases). Similar excerpts were identified by using the same code. All codes were then grouped into categories and sub-categories to reflect the main sections of the interview guide. Codes were then compared across interviews to identify similarities and differences, which led to the identification of patterns and themes. Half of the transcripts were coded by two of the authors (SL, TR) and during regular meetings, codes assigned were compared and discrepancies discussed. The remaining transcripts were coded independently by one of the coders.

Sample Size

Recruitment stopped when redundancy in the data collected was noted (i.e., data saturation), an indication that a reasonable exploration of participants’ opinions was achieved [22]. Although redundancy in data was achieved after the 20th interview,
interviews were conducted beyond this point, as some participants had been recruited and agreed to participate.

**Maintaining Research Quality**

The Consolidated Criteria for Reporting Qualitative Research framework was used to guide the reporting of the findings [23]. The methods used to enhance rigour were a) transcribing interviews [24], b) prolonged period of data collection [25], c) letting participants guide the inquiry process [26], d) discussing emerging themes at regular research team meetings [27] and with participants [26], e) using participants' actual words to describe the strengths and weaknesses of *Coping-Together* [24, 26], f) delineating the scope of the research; g) describing how the literature relates to key findings [26], h) using a clear coding procedure [28], i) including quotes in the manuscript [29], and j) keeping many drafts of the findings [25].

**Results**

**Sample**

Twenty seven of the 63 eligible patients approached were interviewed (42.9 %) as well as 14 partners, across 25 face-to-face and five telephone interviews: 11/30 interviews were with both the patient and their partner, 16/30 with the patient only, and 3/30 with partners only. In addition, three patients and two partners were re-interviewed to evaluate the revised booklets. Of the 36 eligible patients who were not interviewed: 38.9 % (n=14) were lost to follow-up, and the rest declined participation (61.1 %, n=22). Reasons given for declining study invitation included too busy (22.8 %, n=5), too ill (18.2 %, n=4), not interested (13.6 %, n=3), wanted to move on (13.6 %, n=3), or did not give a reason (31.8 %, n=7). On average, interviews lasted 60 minutes (range = 18
to 99 minutes). Table 6.1 summarizes participants’ socio-demographic and illness variables.

**Strengths of the Intervention Design and Format**

Most participants endorsed the intervention’s self-directed format, with a few preferring it to attending a support group:

“I’m not really into support groups [...] Because you have seen what I’m like [patient teary during interview] - I don’t like doing this in front of people, so I would probably not go […], [but something like this] where you can do it yourself, yes”. (woman, breast cancer)

Main advantages of the self-directed format included being able to use the material when and where participants wanted, at their own pace.

“This would have been helpful, because you know, it’s 3am and you’re as sick as a dog and you can’t sleep and what can I do – where can I read information?” (woman, breast cancer)

Two aspects of the intervention’s design that particularly set it apart from other resources participants had used were its focus (a) on practical coping strategies and (b) on the patient-partner dyad. A few patients mentioned that their partners needed the materials more than they did, as nothing else had been given to them. Of note, almost all participants reported preferring a print-based resource over an online one. Moreover, the focus of *Coping-Together* on overarching cancer challenges and general illness self-management issues (i.e., not a cancer-specific resource) was also endorsed. Typically,
participants used the resource to complement the cancer-specific information they had received from their treating clinicians or obtained through other means. For most participants, the breadth of the information provided and the language used were appropriate, and generally, new concepts were felt to be introduced in simple terms. The majority of participants found that sufficient detail had been provided to understand the coping strategies suggested and that these were relevant and “doable”. With regard to the ideal time to distribute this resource, the majority of participants agreed that this should be at diagnosis, and given to them by their main treating clinician. Although being overwhelmed by the amount of information received in the early post-diagnosis phase was a theme that emerged from many interviews, this was counter-balanced by the comfort of knowing that the information was on-hand, if needed. In addition, the use of colour-coded sections and boxes/tables to break-up the text helped participants manage the amount of information included in the booklets.

Use of the Coping-Together Booklets to Learn New Coping Skills

Primarily, Coping-Together was designed to help patients and their partners learn the adaptive individual and dyadic coping strategies they need to address common cancer-related challenges. Approximately half of the participants reported using the booklets to better understand the challenges they were facing, and learned new ways to independently manage these. These participants referred to the booklets as their “reference guide” to coping with cancer, as they provided “good advice for day-to-day living”. Typically, these participants perused the booklets, “picking and choosing” the coping strategies that were most relevant to them. One woman with breast cancer said: “I just found it so easy to find what I wanted to know and if I didn’t want to read about something, I didn’t have to read about it.” Most of these patients and partners used the booklets to enhance coping skills pertaining to symptom management, managing
worries and emotions, and communicating with the health care team. Fewer patients and partners expressed interest in the dyadic coping strategies proposed in the Supporting Each Other booklet. Specific examples of coping skills learned are provided in Table 6.2. Although an additional third of the participants found the resource to be acceptable, and had read through some sections, they generally did not report learning new coping skills. Reasons for this included minimal interest, too busy, preference for face-to-face support, already well-equipped to cope with cancer challenges, or already using the proposed strategies. For most of the participants who were already aware of the proposed strategies, the booklets still had the benefit of confirming that they were “on the right track”. The smaller proportion of participants who did not use the resource at all (approximately 20%), commonly said that they preferred face-to-face support, tended to avoid cancer information (regardless of purpose or format), or were too busy or too ill.

Additional Benefits of the Coping-Together Booklets

Regardless of whether coping skills were learned or not, those participants who read the booklets reported a number of secondary benefits (see Table 6.2 for supporting quotes). Mostly these included a) increased awareness of challenges need to prepare for, as the content of the booklets prompted them to think about the potential challenges they might face and how these can be addressed; b) provided a sense of hope that something can be done to “help you pull through” or regain some control of the situation; c) provided a sense of normality, which was mainly achieved through the testimonials or quotes; d) connected patients and partners to people and services, as the majority of participants were unclear about what they could expect from their health care team, or did not know what kind of services were available; and e) complemented the support received from health professionals, mainly because the booklets supplemented the
medical information participants had received from health professionals, and/or provided greater detail about the coping strategies mentioned to them in passing during consultations.

**Aspects of the Resource that were Criticized**

Although for more than three quarters of participants *Coping-Together* was useful and acceptable, some of the main limitations to the intervention design included:

1) *Few participants completed the worksheets* - Although the worksheets helped those who completed them to organize their thoughts and remember information, the vast majority of participants did not complete them. Reasons stated were: not so inclined, the worksheets did not appear relevant, they were too distressing (e.g., completing the Distress Thermometer), or it was not clear what they should do after they completed these (given the self-directed nature of the intervention). A few patients and partners also raised the potential for conflict when completing some of the worksheets, particularly when working through opposing opinions or preferences to manage challenges. Some participants felt that simply reading the worksheets was enough to get them thinking about issues and suggested keeping these in the event that they would appeal to a wider audience.

2) *Patients and partners were not using Coping-Together together* - The booklets were developed with a view that couples would use them together. However, few couples actually worked through the booklets together, as most often they were not free at the same time or had different levels of readiness to learn about coping with cancer challenges.
3) **More guidance was needed on how the content should be used** - Many participants mentioned needing to quickly identify the strategies most relevant to them and suggested including a ‘navigation tool’, such as a brief quiz, to help them identify relevant aspects of the booklets, and/or a timeline outlining typical challenges experienced at each phase of the illness, and where corresponding information could be found in the booklets. There was consensus across a number of participants that an initial, one-off, orientation session would provide the overview they needed to be able to efficiently use the booklets at home, and/or that a DVD should complement the booklets and explain more about how the resource can be used.

4) **“Feels too much like a therapy session”** - A number of participants felt that the resource read too much like an academic book or felt like a therapy session, mainly due to its formal appearance. These participants expressed a preference for information to be presented in point form, with a main focus on the practical information, and the inclusion of cartoons with captions to engage readers.

5) **Too much negative information** - For some participants, the focus on ‘challenges’ exacerbated their emotional overload; adversely affecting their use of the booklets. These participants felt that the resource should communicate that “something can be done to help you pull through”. This is not to undermine the usefulness of normalization; rather, participants felt that normalization could be achieved without too great a focus on negative information. Participants also suggested tailoring the content to their individual concerns, so that they are not confronted with information they do not need.
6) **Not enough experiential information** - Across interviews, participants generally indicated that they would have appreciated more testimonials from patients and partners.

**Discussion**

Although professionally-led coping skills training interventions can improve patients’ and partners’ quality of life [7, 8], sustainability issues have prompted consideration of other delivery formats, including the use of a self-directed format [13, 14]. The present study described the initial evaluation of a self-directed coping skills training intervention for both patients and their partners, and found that *Coping-Together* has the potential to enable patients and partners to learn new coping skills. Overall, the self-directed format was not only acceptable to patients, as documented by others [9, 15, 30], but it was also favoured by partners. As partners are often less likely than patients to access face-to-face support [31], a self-directed format might be particularly appropriate for this group. Despite the increasing popularity of online platforms for self-directed interventions [14], most participants still preferred booklets. This finding is consistent with recent studies suggesting that other than their health care team, books/brochures remain top information sources for patients and partners [32-34].

Participants further emphasised that the novelty of *Coping-Together* was its focus on practical strategies to address common cancer challenges. Although existing resources often address patients’ and partners’ information needs around diagnosis and treatment, those pertaining to coping and illness self-management are often neglected [35, 36]. This is despite reviews [37, 38] reporting that self-care, rehabilitation, and coping are prevalent information needs for both patients and partners.
Many features of *Coping-Together* were based on recommendations to design effective educational material, and were found to contribute to its acceptability, including simple language, using clear headings and colours to denote sections, and using tables and boxes to break up the text [20]. However, findings from this study led to the following five key additional recommendations to consider when designing print-based, self-directed interventions for couples.

1) *Use DVD and a brief orientation session to overcome the main limitations of a print-based format* - Participants suggested that audio-visual information (i.e., videos or a DVD) should complement the booklets to facilitate use. In the context of a self-directed coping skills training intervention, ‘video modelling’ can be particularly useful in increasing knowledge, reducing anxiety, and increasing coping abilities [39, 40]. In addition to videos, our study participants felt that they needed guidance from a health professional or volunteer in helping them navigate through the booklets and retrieve the information most relevant to them; a finding consistent with Diefenbach et al. [41].

2) *Tailor intervention to take advantage of ‘teachable moments’* - Although the time period close to diagnosis might be an opportune ‘teachable-moment’ [42], study participants did stress that consideration needed to be given to how much they can realistically process. Although emotions can motivate learning [43], the content emphasising the stress of the diagnosis often exacerbated participants’ emotional overload, adversely impacting on their ability to process information and use the resource. This finding is consistent with other studies reporting on patients’ and partners’ preference to avoid negative cancer information to protect themselves [44, 45]. In addition to the suggestion to re-focus the content of the booklets on the information that can help them improve their situation, this finding suggests that tailoring resources to match patients’ and partners’ imminent concerns might optimize ‘teachable-
moments’. In general, the process of tailoring eliminates irrelevant information and highlights only what individuals would find most pertinent [46]. To date, the impact of tailoring has been largely overlooked when developing print-based, psycho-educational interventions.

3) Use cartoons and experiential information to increase comprehension and use -
One suggestion made by numerous participants to enhance comprehension and use of the booklets was the inclusion of cartoons with captions. This is consistent with a review by Houts et al. [47] that found that cartoons closely linked to text can, when compared to text alone, increased comprehension of, and attention and adherence to, health education material. In addition, the recommendation to include experiential information is consistent with a number of other studies emphasising the value of testimonials in providing both reassurance and access to a great deal of practical information often omitted by health professionals [48, 49].

4) Be flexible about individual versus couple use of the intervention - Coping-Together was developed based on the emerging evidence that positive dyadic coping can enhance patients’ and partners’ illness adjustment [7, 50]. However, for both patients and partners, the priority was to enhance individual coping skills, with few learning new dyadic coping skills. Regan, Lambert, Girgis et al. [7] identified three approaches to couple-based interventions: a dyadic approach (i.e., focusing on the couple and the relationship), an individual approach (i.e., focusing on the patient and partner separately), or a coaching approach (i.e., focusing on how the partner can assist the patient). Findings from the present study suggest that participants might not have expected or believed that they needed a dyadic intervention and seemed to prefer an individual or coaching approach. Although the Regan et al. [7] review found that
improvements in quality of life were mainly found in dyadic interventions, all three approaches were efficacious in improving psychological distress.

5) **Judicious use of worksheets** – Most participants in this study did not complete the worksheets included throughout the booklets. This finding is inconsistent with Beatty et al. [9] who found that 81% of women with breast cancer in their self-help workbook study had completed 25% or more of the suggestions and worksheets. The sample in the present study was more heterogeneous than the one in the Beatty et al. [9] study, which might call into question the generalizability of these tools in helping patients and their partners learn new illness self-management skills across cancer types.

**Strengths and Limitations**

Several strategies were used to enhance the methodological rigour of this study. Although the use of a qualitative research approach allowed for rich descriptions of individuals’ experiences and opinions of *Coping-Together*, this data collection method assumed that if questions were formulated correctly, participants’ descriptions of their use of the resource reflected what they actually thought or had done [51]. This assumption might be problematic, as some participants might have chosen to withhold certain descriptions—or alternatively, embellish them—if they wanted to impress the interviewer. In anticipation of this issue, interviewers regularly emphasized that it was important to identify both the strengths and weaknesses of the resource. Although variation in treatment modality, stage along the illness trajectory, and age was sought, participants remained similar in having had at least a high school degree and reporting a mid- to high-range household income. Also, some illness information was not collected; primarily cancer stage and treatment information.
Research and Clinical Implications

Although evidence suggests that patients and partners benefit from learning new coping skills, the demands on health professionals’ time might limit the extent to which these can be learned during appointments and consultations. Therefore, self-directed coping skills interventions have the potential to enhance cancer care, self-care, and quality of life. However, their efficacy is dependent on the extent to which these are appealing and used by patients and partners. Hence, more studies are needed to not only assess the efficacy of these interventions, but to also examine what patients and partners want from a print-based, self-directed intervention and how use can be optimised; including the role of worksheets to enhance learning and self-efficacy. Recommendations to improve *Coping-Together* have been integrated in a subsequent version of the intervention and efficacy trials are underway [52, 53].

Conclusion

The objective of this study was to describe the development of *Coping-Together* - a self-directed coping skills intervention for couples affected by cancer, and to report on its acceptability. Preliminary evaluation of *Coping-Together* has suggested that a self-directed format was acceptable to participants, and its practical approach has the potential to enhance patient and partner outcomes. Patients’ and partners’ critique of the intervention has led to key recommendations to guide the further development of print-based, self-directed interventions.
References


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Table 6.1 Participants’ background information

<table>
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<tr>
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<th>Partners*</th>
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<td>(n=12)</td>
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<td>Sex (n, %)</td>
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<td></td>
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<td>M</td>
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<tr>
<td>F</td>
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</tr>
<tr>
<td>12 – 23</td>
<td>7 (29.2)</td>
<td></td>
</tr>
<tr>
<td>&gt; 24 months</td>
<td>6 (25.0)</td>
<td></td>
</tr>
<tr>
<td>Diagnosis (n, %)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Breast</td>
<td>10 (41.7)</td>
<td>--</td>
</tr>
<tr>
<td>Prostate</td>
<td>4 (16.7)</td>
<td></td>
</tr>
<tr>
<td>Colorectal</td>
<td>3 (12.5)</td>
<td></td>
</tr>
<tr>
<td>Gynecological</td>
<td>2 (8.3)</td>
<td></td>
</tr>
<tr>
<td>Skin</td>
<td>2 (8.3)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>3 (12.5)</td>
<td></td>
</tr>
</tbody>
</table>

Note. *For some partners, corresponding patient was not interviewed and/or the patients and partners did not live together. **Three patients and two partners did not return a completed demographic sheet.
Table 6.2 Perceived benefits of using the Coping-Together booklets

<table>
<thead>
<tr>
<th>Benefits</th>
<th>Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Facilitated independent coping</td>
<td>They [health professionals] say you need to relax and you need to communicate with your partner and you need to do this and you need to do that – <strong>but they do not tell you how</strong>. I think if you do have some strategies in there to explain that more, that is very beneficial. (woman, breast cancer)</td>
</tr>
<tr>
<td></td>
<td><em>I think it’s a good thing, because [the other] ones [resources...] didn’t really sort of tell me how to cope</em> with a lot of the things, which these books tended to just give a lot more in depth information and which I think is necessary (partner)</td>
</tr>
</tbody>
</table>
| Example of specific strategies learnt:        | - Question prompt list: *That’s really important having those list of questions and prompts, because like I’ve said there are things that hadn’t even occurred to me.* (woman, gynecological cancer)
- Relaxation: Offering all these suggestions on how to deal with emotions, with the breathing and the exercises and your muscle relaxation, meditation all that kind of stuff. I found, really, really useful. (woman, gynecological cancer)
- Assertiveness: At the time I read this [booklets], I was overwhelmed by people ringing up all the time [...] and I found I couldn’t say no. Then I read the bit about assertiveness and I felt like by reading that I thought ok, it’s ok to tell people no [...]. When I did tell them how I felt and that I didn’t want them visiting all the time, they all said, "we understand". (partner, man with prostate cancer)
- Symptom management: *Incontinence has just crept into our world this last week. So I just saw that there and I thought I will go back to that section and look at that [...]. So and loss of appetite and is creeping into it as well so there are things that I will now have to look at.* (partner, man with prostate cancer)
| Increased awareness of challenges needed to prepare for | OK, I’ve got six months of chemo to get through, what are all the different things that we’re going to have to put into place in order to make sure that everybody in the household is taken care of [...] and having something like some of these questions posed at you from the resource, just jogs things in your head and you go, OK – I didn’t think about that. (woman, breast cancer) |
| Provided a sense of hope                       | There’s a lot of people out there who, as soon as they know they’re diagnosed with cancer, they just drop their bundle straight away and they think that’s the end, and I think something like this to help you pull through or give them a guideline of what to do, that’s what is needed. (woman, ovarian cancer) |
| Provided a sense of normality                  | *It was just seeing that someone else has the same thoughts and has recognized the same issues and it’s not just us trying to fly blind.* (partner, woman breast cancer)
  *I really liked the little quotes, because I think that personalizes it and [you are] able to relate to the story. It’s like ‘oh yeah, I feel like that too.’* Just that validation – even though it’s from a book or from words written on a page, it just helps to make you feel not so alone, because cancer is a really lonely journey. (woman, breast cancer) |
<p>| Connected patients and partners to people and services | <em>I said look I’ve been reading this workbook and here’s a website go in there and have a look because they may be able to sort of offer you some suggestions.</em> (woman, breast cancer) |</p>
<table>
<thead>
<tr>
<th><strong>Benefits</strong></th>
<th><strong>Quotes</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Complemented the support received from</td>
<td>You need something that’s going to help you – practical information, all that stuff that is going to help the situation. You don’t need to understand more about what’s going on – you need more help to feel better. (partner, woman breast cancer)</td>
</tr>
<tr>
<td>health professionals</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Most psychologists would tell you all this stuff, but then actually having it written down that I can go back to it, so when I’m having a really bad day – it’s like OK, what did I do before? I found it easy that I could then go back and look at it again. (woman, breast cancer)</td>
</tr>
</tbody>
</table>
### Table 6.3. *Coping-Together* (acceptability version) content

<table>
<thead>
<tr>
<th>Booklet title</th>
<th>Description</th>
<th>Example challenges</th>
<th>Example coping strategies</th>
<th>Example worksheets</th>
</tr>
</thead>
<tbody>
<tr>
<td>Couples</td>
<td>Working with your medical team, knowing how to ask the right questions, getting and understanding the information you need</td>
<td>We don’t know what questions to ask</td>
<td>Use question checklists.</td>
<td></td>
</tr>
<tr>
<td>Communicating Effectively with Health Care Professionals</td>
<td>We don’t know who to ask</td>
<td>Find out who is your health care team</td>
<td>Prepare for appointments, communicate assertively and use other methods of communication</td>
<td>Prioritizing my needs and expectations</td>
</tr>
<tr>
<td>Symptom Management</td>
<td>Coping with common cancer symptoms and treatment side effects.</td>
<td>Fatigue, Pain</td>
<td>Use a symptom diary, talk to your health care team, and use self-care strategies</td>
<td>Using a to-do list</td>
</tr>
<tr>
<td>Managing Worries and Emotions</td>
<td>Addressing the emotional reactions to diagnosis and treatment</td>
<td>I feel stressed/tense, I feel sad, down and/or isolated, I’m having difficulties sleeping.</td>
<td>Use relaxation techniques, do pleasant activities and connect with others, practice good sleep hygiene throughout the day</td>
<td>Your problem-solving plan, Weekly activity schedule</td>
</tr>
<tr>
<td>Supporting Each Other</td>
<td>Enhancing your communication and connection to your partner, adjusting to changes that may arise in your relationship</td>
<td>I just don’t know how to make my partner feel better, We are finding it hard to get along</td>
<td>Use listening skills, body language and empathy, avoid roadblocks to listening well, Use conflict resolution skills</td>
<td>Set some ground rules for conflict resolution</td>
</tr>
</tbody>
</table>
### Table 6.4: Examples of interview questions

<table>
<thead>
<tr>
<th>Stage of interview</th>
<th>Examples of questions</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>STAGE 1 – Ongoing cancer challenges</strong></td>
<td>Can you tell me more about your experience with cancer since the diagnosis until now?</td>
</tr>
<tr>
<td><strong>STAGE 2 – Approach to coping with cancer challenges</strong></td>
<td>What kind of resources (e.g., books, internet) and/or services have you been using? How likely would it be for you to attend a support group/seminar/workshop or use something at home like the Cancer Council booklets?</td>
</tr>
<tr>
<td><strong>STAGE 3 – Opinions of the booklets</strong></td>
<td>How valuable is this type of resource in helping you develop coping skills to help you manage cancer-related challenges? Overall, what are your impressions of, or thoughts about, the booklets? Is the overall format and organization of the booklets appropriate?</td>
</tr>
</tbody>
</table>
Aims and purpose

Paper Seven is the conclusion to the research presented in this thesis. Paper One identified the STM as strong model of dyadic coping. Paper Two highlighted the relationships between dyadic coping and anxiety, depression, and relationship satisfaction. Paper Three highlighted the benefits of couple-based interventions for both patients and partners, and touched on some of the issues that affect uptake and attrition. Paper Four explored the variation in rates of uptake and attrition in more detail, highlighting potential barriers to psychosocial care for couples. Paper Five explored couples’ and HCPs views on the delivery of psychosocial care for couples. Paper Six explored couples’ views on the acceptability of the Coping-Together intervention. Paper Seven builds on these and includes data from the two month follow-up from a randomised controlled trial of Coping-Together. This pilot study examined the feasibility, acceptability, and efficacy of the Coping-Together intervention for couples facing prostate cancer. The main findings from this study highlighted the challenges of conducting dyadic research and included variations in clinicians’ attitudes towards recruitment, higher than expected refusal and ineligibility rate, and patient-reported survey burden. Overall Coping-Together was a feasible intervention for couples that has the potential to be implemented in routine cancer care.

This is the seventh paper in this thesis and has been published in Psycho-Oncology. The citation is: Lambert, S. D., McElduff, P., Girgis, A., Levesque, J., Regan, T., et al. (2013). A pilot, multisite, randomized controlled trial of a self-directed coping skills training intervention for couples facing prostate cancer: Accrual, retention, and data collection issues. Under Review with British Journal of Cancer. [Appendix 7.2].
Paper Seven

A pilot, multisite, randomized controlled trial of a self-directed coping skills training intervention for couples facing prostate cancer: Accrual, retention, and data collection issues

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Cathrine Mihalopoulos
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Dr Peter Chong
Lake Macquarie Urology, New South Wales, Australia
Abstract

Background

Whilst couple-based interventions are efficacious in enhancing patient and partner outcomes, these are typically not implemented into practice due to their cost. To enhance accessibility, a self-directed format is increasingly advocated. The purpose of this study was to: a) examine the acceptability of the methods to evaluate Coping-Together - a self-directed coping skills intervention for couples facing prostate cancer and b) collect preliminary efficacy and cost data.

Methods

42 couples, randomized to a minimal ethical care (MEC) condition or to Coping-Together, completed a survey at baseline and two months after, a cost diary and a process evaluation phone interview.

Results

170 patients were referred to the study. However, 57 couples did not meet all eligibility criteria, and 51 refused study participation. On average, two to three patients were randomized per month, and each couple enrollment took 26 days. Two couples withdrew from MEC, none from Coping-Together. Only 44% of the cost diaries were completed, and 55% of patients and 60% of partners found the surveys too long. Trends in favour of Coping-Together were noted for both patients and their partners.

Discussion

This pilot study identified specific challenges of conducting dyadic research and recommendations for the design of a larger trial.
Introduction

Despite improvement in survival rates, a cancer diagnosis confronts patients with a wide range of complex physical and psychosocial challenges [1]. Cancer still elicits greater negative reactions than any other medical diagnosis, with approximately 30-50% of patients found to experience high psychological distress [2, 3]. Although research has traditionally focused on the negative impact of cancer on patients, it is now well-recognised that cancer also evokes numerous issues to be confronted, questions to be answered, and emotions to be faced for partners [4]. A number of studies have further reported the significant reciprocal relationship between each person’s response to the illness, with partners often experiencing at least as much anxiety or depression as patients [4-7]. Recent studies by Lambert et al. [8, 9] found that 35.8% of partners and caregivers reported anxiety, with those reporting anxiety at six months post-diagnosis continuing to be anxious up to two years post-diagnosis.

With shorter hospital stays, decreased financial resources, shortage of health professionals, and reliance on outpatient treatments, the responsibility for the day-to-day management of cancer challenges falls principally on patients and their partners or caregivers [10, 11]. As a consequence, much attention has been given to developing coping skills and self-management interventions to: a) address individuals’ main information needs as a means of capitalizing on the benefits derived from receiving the right information at the right time; b) equip them with the adaptive strategies and behaviours needed to curtail the impact of cancer on their daily lives; and c) connect people to other resources and services to increase access to external support [10]. A number of trials have substantiated the efficacy of these interventions in increasing patients’ satisfaction with cancer care, ability to cope, and well-being, and in decreasing symptom severity and health care needs [10]. With the recognition of the burden of
cancer on those close to patients, coping skills and self-management interventions are increasingly targeting the patient-caregiver dyad. A review by Regan et al. [12] concluded that the shared learning that occurs in couple-based interventions means that these can be more efficacious than patient-only interventions.

Although the sizeable benefits of coping skills and self-management interventions are well-documented, these are typically not part of routine cancer care [1, 13, 14]. Most often, coping skills and self-management interventions are delivered by health professionals through one-on-one sessions or workshops, which raises two major barriers. First, costs tend to be high and demand can easily exceed the availability of qualified professionals. Second, patients often do not access these interventions due to the additional demands they impose (e.g., travel) and personal preferences [13, 15]. Hence, for patients and caregivers to reap the benefits of these interventions, more accessible, cost-effective, acceptable, and sustainable modes of delivery are needed.

The recent urgency to find sustainable modes to deliver coping skills and self-management interventions has contributed to an exponential increase in the evidence supporting the efficacy and cost-effectiveness of a self-directed format (also called self-help or self-administered) [13, 14]. Although self-directed coping skills interventions are promising, most of these still do not include patients’ partners. To address this gap in the literature, our team has recently developed Coping-Together, a self-directed coping skills intervention for patients diagnosed with cancer and their partners [16].

**Aims and Hypotheses**

A preliminary, qualitative evaluation of Coping-Together supported it to be a practical approach. This evaluation also showed Coping-Together to have potential to increase awareness of challenges to prepare for, facilitate independent coping, give hope that something can help you “pull through”, provide a sense of normality, connect patients
and partners to people and services, and complement support received from health care professionals [16]. The present pilot study builds on this previous study to further a) examine the feasibility of a trial to evaluate this intervention among couples affected by prostate cancer and b) collect preliminary efficacy and cost data. As this is a pilot study, it is expected that trends (defined as p < 0.30) will be noted whereby Coping-Together couples will tend to experience less anxiety (primary hypothesis), cancer specific distress and depression, and more positive illness or caregiving appraisal, self-efficacy, quality of life (QOL), relationship satisfaction and positive individual and dyadic coping (secondary hypotheses) at 2 months post-baseline compared to couples in the control group.

**Methods**

**Design**

This pilot is a multicentre, stratified, double-blind, two-group, parallel, randomized controlled trial to compare Coping-Together to a minimal ethical care (control) group [17]. The design of this study was guided by the CONSORT statement [18]. The development of Coping-Together, including guiding theoretical frameworks, has been described elsewhere [16, 17].

**Sample**

A convenience sample of men diagnosed with early-stage prostate cancer and their partners were invited to participate in the study by their clinicians. Patient inclusion criteria were: diagnosed in the past 4 months, receiving or planning to receive treatment (including active surveillance), having no previous cancer diagnosis, and having a partner (spouse, boy/girlfriend, or de facto) willing to participate in the study. In addition, to be eligible for this study, the patient or their partner had to score four or
more on the Distress Thermometer (DT) at the time of recruitment and both needed to be sufficiently fluent in English and cognitively able to complete surveys and follow-up phone calls. Patient and partner consent was required for the couple to participate in this trial.

**Procedures**

The majority of the participants were recruited through urologists’ private practices in Australia. Urologists identified patients meeting the medical, English fluency, and cognitive ability inclusion criteria. At their next appointment, interested patients were invited to meet with the on-site research assistant to further discuss study participation and obtain their DT score. If the patient scored less than four on the DT, and their partner was present, the DT was then administered to them. If the partner was not present, consent was obtained from the patient to contact their partner and screen for distress by phone. The research assistant then gave or mailed a study pack to eligible patients and partners. If the on-site research assistant was not present at the clinic at the time of recruitment, the urologists then gave interested patients a study pamphlet and obtained verbal consent for a member of the team to contact them within the following week. For these patients, all additional assessment of eligibility was conducted over the phone. The study was also advertised through a range of media outlets, including radio, print, and online channels. Once patients’ and partners’ consent forms and baseline surveys were returned, the couple was randomized. This study was approved by the University of Newcastle, South Western Sydney Local Health District, and the University of New South Wales Human Research Ethics Committees.

**Randomization of Group Assignment**
A computer-generated randomization schedule with block lengths of variable size (4 and 6) and stratified by recruitment source was accessible to the main research assistants.

**Coping-Together and minimal ethical care conditions.**

Participants were randomized to Coping-Together or the minimal ethical care (MEC) control condition. Coping-Together couples received the intervention material within two weeks of returning their baseline survey. This included the four Coping-Together booklets, which addressed the following challenges: a) symptom management, b) communicating effectively with health care professionals, c) supporting your partner, and d) managing worries and emotions [17]. For each challenge, specific coping strategies were proposed; referred to as ‘suggestions’. ‘Suggestions’ were either specific techniques or skills (e.g., step-by-step guide to mindfulness-based meditation) or general advice on how to cope with the challenges. Suggestions were followed by a rationale for their inclusion in the booklet and testimonials from other patients and partners who reported their success with the suggestions. The Coping-Together booklets were complemented by a relaxation CD and a DVD featuring content from the ‘couples communicating effectively with health care professionals’ booklet. One to two weeks after receiving the Coping-Together materials, a research assistant phoned couples (estimated duration = 20 minutes) to review the material received and explore intended use. Couples were able to use Coping-Together at their own discretion and pace for a 2-month period. Couples also received, fortnightly, a 'Top Tips' newsletter highlighting timely content of the booklets, and a follow-up telephone call (Call 1 mean duration = 29 minutes, SD = 17.11; Call 2 mean duration = 24 minutes, SD = 14.33; Call 3 mean duration = 18 minutes, SD = 14.59) from the research team to monitor the use of Coping-Together and other resources and to answer study-related questions.
As MEC couples also had elevated distress, and to blind participants to group allocation, the study did not employ a ‘no treatment’ control group. MEC couples were mailed the Understanding Prostate Cancer and Caring for Someone with Cancer booklets available from the Cancer Council New South Wales, and a Cancer Council Helpline brochure. They also received initial and follow-up phone calls (Call 1 mean duration = 25 minutes, SD = 12.33; Call 2 mean duration = 17 minutes, SD = 9.84; Call 3 mean duration = 14 minutes, SD = 9.51) comparable in intent and content to the Coping-Together couples. All follow-up phone calls were audio-recorded and reviewed to ensure that counselling was not inadvertently provided.

Data Collection

Data collection occurred between February 2012 and August 2013, and included distress screening at the time of recruitment, a baseline and follow-up survey, a health service-use diary, and a process evaluation interview.

Distress screening at the time of recruitment.

The single-item Distress Thermometer (DT) [19] was used to screen patients’ or partners’ levels of distress. The DT asked individuals to select a number, from 0 = ‘no distress’ to 10 = ‘extreme distress’, that best described their overall distress [19]. The DT has convergent validity with the Hospital Anxiety and Depression Scale (HADS) [20], with a cut-off point of four typically resulting in optimal sensitivity and specificity [21].

Primary and secondary outcomes.

Table 7.1 lists the primary and secondary outcomes captured by the baseline and follow-up surveys and the psychometric properties of each measure used.
Anxiety and depression were measured using the Hospital Anxiety and Depression Scale (HADS) [22]. The HADS contains separate anxiety and depression subscales, each comprised of seven items. Patients’ and partners’ scores on the anxiety and depression subscales were obtained by summing scores of the corresponding items (possible range 0-21).

Cancer-specific distress was measured by the three subscales (intrusion, avoidance, and hyperarousal) of the Revised Impact of Event Scale (IES-R) [23]. Participants were asked to rate how distressing each item had been during the past week.

Patients’ and caregivers’ Quality of Life (QOL) was measured with the Assessment of Quality of Life – 8 dimensions (AQoL-8D); a generic measure of health-related QOL [24] comprised of eight subscales: independent living, senses, pain, mental health, happiness, self-worth, coping, and relationships. These dimensions are then combined into two summary scores: mental and physical health. Caregivers also completed the Caregivers’ QOL Index-Cancer (CQOLC) to assess mental and emotional burden, life disruption, positive adaptation, and financial concerns [25].

Relationship satisfaction for patients and partners was measured using the Revised-Dyadic Adjustment Scale (R-DAS) [26]. The items of the R-DAS are divided among three subscales: consensus, satisfaction, and cohesion.

Illness appraisal was measured by Kessler’s Cognitive Appraisal of Health Scale (CAHS) [27], Mishel’s Uncertainty in Illness Scale (MUIS) [28], and the Appraisal of Caregiving Scale (ACS) [29]. The CAHS score for the threat, benign/irrelevant, harm/loss, and challenge subscales were analyzed for patients and partners. The total MUIS was calculated, after reversing relevant items, by summing all
item scores. Last, partners’ scores on the ACS subscales of threat, general stressfulness, and benefit-finding were analyzed.

*Self-efficacy* was measured by the Lewis Cancer Self-Efficacy Scale (LCSES) [30, 31] and the Communication and Attitudinal Self-Efficacy for cancer (CASE-Cancer) Scale [32]. The overall score on the LCSES was computed by summing all items (range 0 – 170). The CASE-Cancer three subscales: understand and participate in care, maintain a positive attitude, and seek and obtain information, were used in the analysis.

Use of 14 coping strategies were assessed using the Brief COPE [33]. The procedure for combining the 14 subscales to form overarching coping subscales varies in the literature, and generally relies on an initial exploratory factor analysis. As this is not possible in this study due to the small sample size, items were combined according to the structure proposed by Cooper et al. [34].

*Dyadic coping* was measured by the Dyadic Coping Inventory (DCI) [35], which includes nine subscales, an evaluation of dyadic coping scale, four aggregated scales, and a total dyadic coping score. In this pilot, the nine subscales (stress communication by oneself, supportive dyadic coping by oneself, delegated dyadic coping by oneself, negative dyadic coping by oneself, stress communication of the partner, supportive dyadic coping of the partner, delegated dyadic coping by the partner, negative dyadic coping by the partner, common dyadic coping) were examined to begin to identify specific aspects of dyadic coping that might be impacted by Coping-Together

**Economic outcomes.**
In addition to being a quality of life measure, the AQoL-8D is also a multi-attribute utility measure, which means that it has an attached utility algorithm that allows the calculation of a utility weight for each respondent’s score pattern. Utility values will be used in a larger economic analysis to calculate Quality-Adjusted Life-Years (QALYs). A “My Cancer Care Diary” [36] was also given to patients and their partners, separately, to each record their own costs related to: a) care from health care professionals, b) hospital or respite care, c) medication use, d) community services or pastoral care, e) additional costs, and f) time off from usual activities. Diaries were returned to the researchers with the follow-up survey.

**Feasibility and acceptability data.**

Feasibility and acceptability data included response and accrual rates as well attrition. Two additional methods were used to collect the feasibility and acceptability data: main survey and process evaluation interview. At the end of the survey, participants were asked to indicate how much time it took to complete the survey, whether the survey was too long (yes/no), and preferences for completing the survey in the future (online, pen and paper, or over the phone). The process evaluation interview served as an exit interview for those couples who consented, and focused on summarising use of the resources sent throughout the study as well as the acceptability of the methods. Across the Coping-Together and MEC groups, 21 patients and 17 partners participated in the process evaluation interviews.

**Demographic information.**

In addition, demographic information were collected at the time of the orientation phone call, including date of birth, marital status, relationship length, country of birth, primary language, education, employment status, gross weekly income, and previous experience with health conditions.
**Data Analysis**

Data were analyzed using Stata v13 and SAS v9.3. Means, standard deviations, and proportions were calculated to describe the sample and flow of participants. For the primary and secondary outcomes, intention-to-treat analysis was conducted separately for patients and partners. The primary outcome, anxiety at two months post-baseline, was analyzed using ANalysis of COVariance (ANCOVA). The main predictor variable in the ANCOVA model was treatment group, and the participants’ baseline score was included as a covariate. ANCOVA was also used to explore the secondary outcome measures. For the cost data, unit costs associated with the recorded occasions of service use were mostly derived from nationally representative sources such as the Medicare Benefits Schedule, Pharmaceutical Benefits Schedule, the National Hospital Cost Data Collection (for hospitalisations) and the Private Health Insurance Administrative Council (for community based, non-Medicare funded allied health costs). Information from all of these sources is available online. Further details of all sources of unit costs are available directly from the authors (SS and CM). Occasions of service use were multiplied by the unit cost associated with each occasion of service. Total costs and average costs per person are reported.

**Results**

**Sample**

Table 7.2 details participants’ demographic and illness variables by group. The average age of patients was 63.8 years (SD = 6.8 years), and the average age of the partners was 59.9 years (SD = 7.5 years). Forty one percent of patients reported trade qualification as their highest level of education, whereas 51% of partners completed primary/secondary school as the highest level of education. Almost half of the patients and partners (46%)
reported being retired. On average, patients and their partners had been in their relationship for 33.7 years (SD = 13.6 years).

**Referral**

During the recruitment period, 170 patients were referred to the study. Of these, 57 couples did not meet all eligibility criteria, and 51 couples declined study participation. Ineligible dyads mainly had no willing partner (n = 16), the patient was more than four months post-diagnosis (n = 11), the patient or partner scored less than four on the DT (n = 11), or no treatment was planned or received (n=7). Top reasons for refusal included being uninterested (n=31) and too busy (n=9). As a result, 42 couples were randomized.

**Efficiency of Recruitment Methods and Accrual**

Almost 1 in 4 patients referred to the study was successfully enrolled. On average, two to three patients were enrolled and randomized per month across six recruiting sites. In general, each couple enrollment (i.e., from the time baseline survey was sent to randomization) took 26 days (range 6-70 days, SD = 14.80). Two sites were successful in referring the anticipated number of patients; both referring 70 patients to the study. The remaining sites referred between two and 13 patients. Some sites did not refer, because of organizational changes; a preference for using low resource, low success recruitment methods (e.g., pamphlets in the waiting room); and challenges in maintaining site commitment to the study. Successful sites had champion clinicians who highly endorsed the intervention (including participating in its development). Accrual did increase when procedures included obtaining verbal consent from potential participants who received a study pack to follow-up with them within a week.
One recruitment strategy that was particularly unsuccessful was the use of media, including an advertisement in a Saturday newspaper local to four of the recruitment sites, and using social media. Across these sources, only four patients were referred to the study.

**Retention**

Of the 42 couples enrolled, 32 patients and 32 partners returned a follow-up survey. Two couples withdrew from MEC (see Figure 1) and four patients and five partners were considered lost to follow-up. No couples withdrew from Coping-Together; however, four patients and three partners were lost to follow-up.

**Feasibility of Distress Screening**

Completing the DT either in person or over the phone was highly acceptable to participants, with no participants refusing to provide a DT score. Only one clinic had in place distress screening procedures, and having to screen for distress was a deterrent for clinicians to recruit. This led to the decision that the research team would screen once patients were referred to the study. The average score on the HADS at baseline for patients was 4.9 (SD=3.6) and for partners was 6.7 (SD=4.4).

**Feasibility of Data Collection Methods**

**Surveys.**

At baseline, patients took 98.7 minutes (SD = 47.6 min) to complete the survey, and 55% felt that the survey was too long. Similarly, partners took an average 99.2 min to complete the survey (SD = 52.8 min), with 60% feeling that the survey was too long. At follow-up, the survey was five pages shorter (reducing the surveys from 30 pages to 25 pages); however, 60% of patients and 65% of partners still felt the survey was too long. Almost a third of participants in the process evaluation said the survey was the aspect of
the study they liked least (29.7%). In general, both patients and partners preferred to complete the survey using pen and paper (87.8% patients, and 84.2% partners) compared to other means (by phone and online).

**Cost data.**

Of the 84 cost diaries sent, 47 were returned (patients = 23, partners = 24). However, 10 diaries were returned blank (i.e., 44% returned a completed diary). This is despite participants in the process evaluation reporting that the cost diaries were not burdensome to complete (83%). Total health care and out-of-pocket costs paid by the patients and partners are presented in Table 7.3. In total, AUD$101,500 (inclusive of out-of-pocket cost) was reported by patients (average = AUD$4,610/patient). For partners, the total cost was AUD$7,400 (average = AUD$493/partner). Overall, 42% of health care costs were incurred by patients, whereas the remaining 58% of health care costs were paid by the government or by private health insurance. The corresponding numbers for partners were 29% and 71%, respectively. The diary section for change to employment and usual activity had few entries. In total, 147.5 days of productivity loss were reported by seven participants. These include 115 days in paid work, 7.5 days in voluntary work, 6 days in household work (child minding) and 19 days of leisure activities. The overall utility score for patients at baseline was 0.86 (SD = 0.13) and at follow-up 0.88 (SD = 0.14). Partners’ baseline utility score was lower, at 0.76 (SD = 0.20), and at 0.77 (SD = 0.19) at follow-up.

**Orientation and follow-up phone calls.**

Although it was initially estimated that most couples would be interviewed as a couple, across the 164 follow-up calls, only 46 (28%) were conducted as a couple. Main reasons for not conducting these as a couple were participants scheduling different times to receive calls due to work and other commitments, not having a speaker phone,
participants preferring to be interviewed separately, patient and partner living separately, and one member of the dyad being unavailable at the scheduled time. In the process evaluation interviews, the orientation call was felt necessary by 65% of participants. Similarly, the frequency (86%), length (79%), and topics (61%) discussed were generally found to be acceptable. However, almost 11% of participants identified that having to explain what they thought or felt was an aspect of the study they liked the least.

**Primary and Secondary Outcome Data**

A number of differences at baseline between patients and partners on primary and secondary outcomes are noteworthy. As indicated in Table 7.4, partners reported higher anxiety, hyper-arousal, stress communication by oneself, and negative dyadic coping by partner than patients. Partners also reported lower physical and mental health, supportive dyadic coping of partner, and problem-focused coping strategies, than patients. Differences in the extent to which partners and patients appraised cancer as a challenge or benign/irrelevant were also noted. Patients reported higher stress communication by partner than partners did.

Given that this is a pilot, a p < 0.30 was taken to be indicative of a possible trend in the data (Table 7.5). For patients, results suggest that Coping-Together might improve patients’ distress (intrusion and avoidance) and contribute to potentially appraising cancer as less challenging. Although both groups reported a decrease in consensus, Coping-Together couples’ decline was smaller than MEC participants’. Some improvements in the MEC group were also noted in terms of mental quality of life, uncertainty, harm/loss appraisal, and supportive dyadic coping by oneself.

For partners, results suggest that Coping-Together partners might report lower caregiver general stress and financial strain. Changes in illness and caregiving appraisal
potentially in favour of Coping-Together were also noted for the benign/irrelevant and benefit-finding subscales. In addition, Coping-Together might contribute to reducing burden. The Coping-Together partners also appeared to maintain their perceived level of cohesion with their partners, whereas this decreased for MEC partners. A similar pattern of findings is noted for emotion-focused coping strategies. In contrast, trends favouring the MEC partners were noted for appraising the cancer less as a challenge and using fewer dysfunctional coping strategies.

**Discussion**

In the past five years, there has been considerable interest in couple-based interventions, including using a self-directed format to increase reach and accessibility [12]. However, the resources required to conduct dyadic research are often underestimated [37]. The current pilot identified some challenges in evaluating Coping-Together, and each is discussed in turn.

**Clinicians’ Recruitment Activities**

The recruitment process was labour intensive and was longer than anticipated, despite including six sites. There are many advantages to a multisite trial, including having sites that might attract patients of varied socio-demographic status and have different support services in place [38]. However, most referrals for this study came from two sites, despite putting in place a number of strategies to improve recruitment, including regular phone or e-mail contact with clinicians and sending regular newsletters. A recent systematic review [39] found that overall, the evidence of successful strategies to improve the recruitment activity of clinicians is currently limited, and no difference in recruitment rate was found according to type of recruiters and level of communication between the trial coordinator and clinicians. However, the review of qualitative studies [39] reporting clinicians’ attitudes towards recruiting patients revealed that barriers to
target include: lack of understanding of research, difficulty articulating the aims of the trial to patients, increase in workload, conflict in role (clinician versus recruiter), and the relevance to, and effect on, clinical practice being unclear.

**Patient Refusal and Ineligibility**

The refusal rate was slightly higher than expected (expected = 30% [17], actual = 39.9%), but still lower than other trials with men with prostate cancer [range = 46 to 57% [40, 41]]. The uptake rate of 37.2% in this study is lower than what has been reported in a review of couple-based interventions by Regan et al. [15]. The use of a self-directed format was expected to increase reach and acceptability; however, the dyadic focus might have adversely impacted the level of interest. The review by Regan et al. [15] found that among couple-based interventions, uptake rates did vary according to the focus of intervention, whereby coaching and individual-based interventions (patient and partner receive the same intervention separately) had slightly better uptake rates than dyadic interventions. The use of a follow-up procedure with non-responders seemed to increase recruitment, which corroborates findings from a meta-analysis by Treweek et al.[42]. Notwithstanding the potential ethical challenges, this meta-analysis [42] also reported that using opt-out rather than opt-in procedures for contacting participants and financial incentives had the greatest impact on recruitment. Other strategies that might need more evidence and could be considered in future trials is the use of multimedia to present study information and training of lay advocates [42].

The ineligibility rate was estimated at 60%, which was mainly based on the expected prevalence of distress [43, 44]. Although the actual ineligibility rate was lower (44.5%), one of the main reasons for ineligibility was a patient or partner scoring less than 4 on the DT. This raises the question: *Was it necessary to screen for distress?* This inclusion criterion was set because it is now well-recognised that ignoring patients’
baseline distress and the potential for floor effects can undermine the efficacy of psychosocial interventions [45]. Despite screening for distress, baseline patient HADS-Anxiety score in our study might still be too low to overcome any floor effect. A recent meta-analysis found that the efficacy of an intervention was zero for a baseline HADS-Anxiety score of 4.20; however, significantly positive outcomes were predicted for baseline scores of 5.85 or more [46]. Hence, consideration might be given to increasing the DT cut-off score used [44] or to use the HADS at the time of recruitment, similar to a study by Savard et al.[47]. Another suggestion is to consider level of distress in the context of subsequent need for services. It is well-recognised that reporting distress does not equate to the desire for additional services [20, 48]. However, in a study by van Scheppingen et al.[49] including distressed patients who also indicated a need for additional help resulted in halving the pool of eligible patients.

**Survey Burden**

Although the evidence remains equivocal on whether survey length has an impact on response rate [50], the survey was nevertheless the most burdensome aspect of this study. Culling five pages from the follow-up survey did not increase acceptability. No study has been found to document the impact of survey length on response rate among individuals with cancer or their caregivers. Therefore, the question about the optimal survey length remains. However, in other contexts, two studies have suggested that a 13-15 page survey was significantly more acceptable than a 23-24 page survey [51, 52]. Mond et al.[53] found no difference between an 8 and 14 page survey in terms of response; however, delivering the survey by hand increased the response rate. It has also been emphasised that survey length becomes a major factor when it takes more than 20 minutes to complete [54] or exceeds four pages [55].

**Economic Data**
Increasingly, including cost-effectiveness analyzes in psychosocial research is advocated [56]. Common self-report methods for health care data include questionnaires or cost diaries [57]. In this pilot, a health service-use diary was used, as this method is generally reported to reduce recall bias [57], but a high proportion of missing data was noted. Among a sample of patients with rectal cancer, van den Brink et al. [57] found that for the assessment of health-care utilization, a cost questionnaire with structured closed questions may replace a health service-use diary for recall periods up to six months. Thus, in future studies, a cost questionnaire will be considered.

Conceptual and Methodological Questions About the Intervention

As this is a pilot study, it was not powered to examine the efficacy of the Coping-Together intervention. Nevertheless, fewer trends in favour of the intervention were noted for patients than anticipated. However, more trends were in favour of Coping-Together than the MEC materials for partners. This is similar to a study by Northouse et al., [31] which found that partners and caregivers reported more benefits from a dyadic intervention than patients in the outcomes of quality of life, appraisal, self-efficacy, and symptoms. In our study, it might also be that two months post-baseline is too soon to detect the potential efficacy of an intervention that requires patients and partners to identify relevant skills and then learn and apply these to their situation. In other studies, the short-term follow-up is often set at three to four months post-baseline [13, 31]. One outcome that might reflect this limitation is supportive dyadic coping by oneself. Although relationship satisfaction trends were seemingly in favour of Coping-Together, MEC patients reported a slight increase in supportive dyadic coping by oneself. It can be posited that Coping-Together exposed patients to gaps in their supportive behaviours, which in turn might have negatively impacted on their frame of reference. However, with time, if dyadic coping skills are learned and
applied, the intended positive impact of Coping-Together on this outcome might be noted.

Another question raised by this pilot is whether choosing an attention control group was the best decision. Providing the Cancer Council booklets might have been an intervention in and of itself, as few MEC participants received these booklets as part of ‘usual care’. The main difference between the Cancer Council booklets and Coping-Together is the type of information given. The Cancer Council booklets focus on factual information about diagnosis and treatment, and might have fulfilled patients’ and partners’ most proximal information needs [58], which is particularly reflected in the impact of the booklets on patients’ uncertainty. Given the focus of Coping-Together on self-care and coping skills, its potential benefits were noted on cancer-specific distress for patients and burden and caregiving appraisal for partners. Hence, future studies might examine the impact of providing the Cancer Council booklets initially and then tailoring the content of Coping-Together to match patients’ and partners’ individual needs related to coping.

Strengths and Limitations

Notwithstanding the exploratory nature of this pilot study, results from this study lay some groundwork to further develop and test interventions for couples facing prostate cancer. A potential bias relating to participants who declined because their partner was not interested in the study should be acknowledged. It may be the case that these couples simply did not feel they needed an intervention, or conversely that these couples might have been too distressed. In addition, the sample was largely homogenous; limiting generalizability of the findings to other age, racial, and socio-economic groups, and cancer types. Some scales (e.g., CAHS) were adapted for
partners, and due to the small sample size, their psychometric properties cannot be tested.

**Conclusion and Practice Implications**

In conclusion, this study reported on the feasibility of evaluating the first self-directed coping skills intervention for couples facing prostate cancer. This study highlighted a number of challenges, including clinicians’ recruitment activities, patient refusal and ineligibility, and survey burden. Findings contribute to the growing evidence for couple-focus psychosocial interventions and a number of suggestions have been put forward for future studies, including to question whether distress screening is necessary and what kind of control group might be more appropriate. A larger study is currently underway to examine further the efficacy and cost results that were presented in this paper [59].
References


49. van Scheppingen, C., et al., Is implementing screening for distress an efficient means to recruit patients to a psychological intervention trial? Psycho-Oncology, 2013: p. n/a-n/a.


<table>
<thead>
<tr>
<th>Outcomes</th>
<th>Measures and Psychometrics</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><strong>Patients</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Partners</strong></td>
</tr>
<tr>
<td><strong>Primary Outcome</strong></td>
<td></td>
</tr>
<tr>
<td>Anxiety</td>
<td>HADS-Anxiety subscale (Zigmond &amp; Snaith, 1983) ((α = .68-.93)) (Bjelland <em>et al</em>, 2002)</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Secondary Outcomes</strong></td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td>HADS-Depression subscale (Zigmond &amp; Snaith, 1983) ((α = .68-.93)) (Bjelland <em>et al</em>, 2002)</td>
</tr>
<tr>
<td>Distress</td>
<td>Revised Impact of Event Scale ((α = .78-.96)) (Weiss. D. S. &amp; Marmar, 1997)</td>
</tr>
<tr>
<td>Quality of life (QOL)</td>
<td>Assessment of Quality of Life – 8 Dimensions Scale ((overall (α = .91), subscale (α = .64-.87))) (Feldman-Stewart <em>et al</em>, 2003)</td>
</tr>
<tr>
<td></td>
<td>Assessment of Quality of Life – 8 Dimensions Scale ((overall (α = .91), subscale (α = .64-.87))) (Feldman-Stewart <em>et al</em>, 2003)</td>
</tr>
<tr>
<td></td>
<td>Caregiver’s QOL Index-Cancer ((α = .73-.91)) (Weitzner <em>et al</em>, 1999)</td>
</tr>
<tr>
<td>Relationship satisfaction</td>
<td>Revised Dyadic Adjustment scale ((α= .81-.95)) (Busby <em>et al</em>, 1995; Manne <em>et al</em>, 2007)</td>
</tr>
<tr>
<td>Appraisal</td>
<td>Kessler Cognitive Appraisal of Health Scale ((α = .70 -.88)) (Ahmad <em>et al</em>, 2005; Kessler, 1998)</td>
</tr>
<tr>
<td></td>
<td>Mishel’s Uncertainty scale ((patients and partners; (α = .64-.92))) (Mishel, 1981; Northouse <em>et al</em>, 2013; Northouse <em>et al</em>, 2007)</td>
</tr>
<tr>
<td></td>
<td>Mihle’s Uncertainty scale ((α = .64-.92)) (Mishel, 1981; Northouse <em>et al</em>, 2013; Northouse <em>et al</em>, 2007)</td>
</tr>
<tr>
<td></td>
<td>Appraisal of Caregiving Scale ((α&gt;.85)) (Oberst, 1991)</td>
</tr>
<tr>
<td>Self-efficacy</td>
<td>Cancer Self-Efficacy Scale ((patients and partners; (α = .97 = .98)) (Lewis, 1996; Northouse <em>et al</em>, 2007)</td>
</tr>
<tr>
<td></td>
<td>Communication and Attitudinal Self-Efficacy Scale for cancer ((patients and partners [adapted]; (α = .76-.77)) (Wolf <em>et al</em>, 2005)</td>
</tr>
<tr>
<td>Dyadic and individual coping</td>
<td>Dyadic Coping Inventory ((patients and partners; (α = .60-.97)) (Bodenmann, 2008; Feldman &amp; Broussard, 2005; Meier <em>et al</em>, 2011)</td>
</tr>
<tr>
<td></td>
<td>Brief COPE ((α = .60-.90)), which measures 14 coping strategies, including self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioural disengagement, venting, positive reframing, planning, humour, acceptance, religion, and self-blame. ((Carver, 1997))</td>
</tr>
</tbody>
</table>
Table 7.2: Participant characteristics

<table>
<thead>
<tr>
<th></th>
<th>Patients</th>
<th></th>
<th>Partners</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>MEC</td>
<td>CT</td>
<td>MEC</td>
<td>CT</td>
</tr>
<tr>
<td></td>
<td>(n = 19)</td>
<td>(n = 23)</td>
<td>(n = 19)</td>
<td>(n = 23)</td>
</tr>
<tr>
<td>Age: years (SD)</td>
<td>63.1 (5.6)</td>
<td>64.3 (7.7)</td>
<td>59.4 (6.7)</td>
<td>60.3 (8.2)</td>
</tr>
<tr>
<td>Length of relationship: years (SD)</td>
<td>33.6 (14.6)</td>
<td>33.7 (13.1)</td>
<td>59.4 (6.7)</td>
<td>60.3 (8.2)</td>
</tr>
<tr>
<td>Relationship status</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married/defacto</td>
<td>17 (94%)</td>
<td>23 (100%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Boyfriend/girlfriend</td>
<td>1 (6%)</td>
<td>0 (0%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary/Secondary</td>
<td>7 (39%)</td>
<td>3 (13%)</td>
<td>10 (56%)</td>
<td>11 (48%)</td>
</tr>
<tr>
<td>Trade qualification</td>
<td>5 (28%)</td>
<td>12 (52%)</td>
<td>3 (17%)</td>
<td>8 (35%)</td>
</tr>
<tr>
<td>University</td>
<td>6 (33%)</td>
<td>8 (35%)</td>
<td>5 (28%)</td>
<td>4 (17%)</td>
</tr>
<tr>
<td>Employment</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full time/self employed</td>
<td>8 (44%)</td>
<td>9 (39%)</td>
<td>2 (11%)</td>
<td>5 (22%)</td>
</tr>
<tr>
<td>Part time</td>
<td>1 (5.6%)</td>
<td>3 (13%)</td>
<td>1 (5.6%)</td>
<td>3 (13%)</td>
</tr>
<tr>
<td>Pensioner</td>
<td>9 (50%)</td>
<td>10 (43%)</td>
<td>9 (50%)</td>
<td>10 (43%)</td>
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<tr>
<td>Volunteer/household</td>
<td>1 (4.3%)</td>
<td>6 (33%)</td>
<td>5 (22%)</td>
<td></td>
</tr>
<tr>
<td>Weekly income</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>$300-$499</td>
<td>1 (5.6%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>$500-$799</td>
<td>5 (28%)</td>
<td>3 (13%)</td>
<td></td>
<td></td>
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<tr>
<td>$800-$1000</td>
<td>2 (11%)</td>
<td>5 (22%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&gt; $1000</td>
<td>10 (56%)</td>
<td>11 (48%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prefer not to answer</td>
<td>0 (0%)</td>
<td>4 (17%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Treatment</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Surgery</td>
<td>5 (26%)</td>
<td>8 (35%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Radiotherapy</td>
<td>3 (16%)</td>
<td>2 (8.7%)</td>
<td></td>
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<tr>
<td>Hormone treatment</td>
<td>0 (0%)</td>
<td>2 (8.7%)</td>
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</tr>
<tr>
<td>Brachytherapy</td>
<td>1 (5.3%)</td>
<td>1 (4.3%)</td>
<td></td>
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<tr>
<td>Watchful waiting or</td>
<td>3 (16%)</td>
<td>2 (8.7%)</td>
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<tr>
<td>active surveillance</td>
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SD = Standard deviation, MEC = Minimal Ethical Care Condition, CT = Coping-Together
Table 7.3: Total health care costs and out-of-pocket expenses by patient and partner

<table>
<thead>
<tr>
<th>Type of Expense</th>
<th>Patient (n=22)</th>
<th>Partner (n=15)</th>
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</thead>
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<tr>
<td></td>
<td>Total Cost</td>
<td>Out-of-Pocket Cost</td>
</tr>
<tr>
<td>Care from doctors and other health care practitioners</td>
<td>AUD$51,300</td>
<td>AUD$27,900</td>
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<tr>
<td>Hospital admission</td>
<td>AUD$40,200</td>
<td>AUD$11,800</td>
</tr>
<tr>
<td>Medicines (prescription, non-prescription, vitamins and herbs)</td>
<td>AUD$9,200</td>
<td>AUD$1,400</td>
</tr>
<tr>
<td>Community services and pastoral care</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Extra costs</td>
<td>AUD$850</td>
<td>AUD$850</td>
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Table 7.4. Comparison of the primary and secondary outcomes between patients and their partners at baseline

<table>
<thead>
<tr>
<th>Variables</th>
<th>Patient (n=42)</th>
<th>Partner (n=42)</th>
<th>P-value</th>
</tr>
</thead>
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<tr>
<td><strong>Anxiety (HADS-A)</strong></td>
<td>4.9 (3.6)</td>
<td>6.7 (4.4)</td>
<td>0.0450</td>
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<tr>
<td><strong>Depression (HADS-D)</strong></td>
<td>2.1 (2.6)</td>
<td>3.1 (3.6)</td>
<td>0.1425</td>
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<tr>
<td><strong>Self-efficacy</strong></td>
<td></td>
<td></td>
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<tr>
<td>Self-Efficacy (LCSES)</td>
<td>140 (21)</td>
<td>136 (30)</td>
<td>0.4694</td>
</tr>
<tr>
<td>Understand and participate in care (CASE)</td>
<td>14.4 (1.7)</td>
<td>14.2 (2.6)</td>
<td>0.6523</td>
</tr>
<tr>
<td>Maintain a positive attitude (CASE)</td>
<td>14.0 (2.2)</td>
<td>13.2 (2.4)</td>
<td>0.1240</td>
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<tr>
<td>Seek and obtain information (CASE)</td>
<td>14.7 (1.9)</td>
<td>14.2 (2.6)</td>
<td>0.3331</td>
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<tr>
<td><strong>Quality of life (AQuoL)</strong></td>
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<tr>
<td>Mental health</td>
<td>0.6 (0.2)</td>
<td>0.5 (0.2)</td>
<td>0.0183</td>
</tr>
<tr>
<td>Physical health</td>
<td>0.8 (0.1)</td>
<td>0.7 (0.2)</td>
<td>0.0097</td>
</tr>
<tr>
<td><strong>Cancer-specific distress (IES-R)</strong></td>
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<td></td>
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</tr>
<tr>
<td>Intrusion</td>
<td>0.6 (0.6)</td>
<td>0.7 (0.8)</td>
<td>0.3507</td>
</tr>
<tr>
<td>Avoidance</td>
<td>0.6 (0.7)</td>
<td>0.7 (0.8)</td>
<td>0.6195</td>
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<tr>
<td>Hyper-arousal</td>
<td>0.4 (0.4)</td>
<td>0.7 (0.9)</td>
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<td><strong>Relationship satisfaction (DAS)</strong></td>
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<tr>
<td>Consensus</td>
<td>24.6 (3.5)</td>
<td>24.9 (3.8)</td>
<td>0.8015</td>
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<tr>
<td>Satisfaction</td>
<td>17.0 (1.6)</td>
<td>16.3 (2.0)</td>
<td>0.1180</td>
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<tr>
<td>Cohesion</td>
<td>12.2 (3.5)</td>
<td>12.5 (3.3)</td>
<td>0.6205</td>
</tr>
<tr>
<td><strong>Dyadic coping (DCI)</strong></td>
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<td></td>
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</tr>
<tr>
<td>Stress communication by oneself</td>
<td>12.5 (2.9)</td>
<td>14.3 (3.1)</td>
<td>0.0083</td>
</tr>
<tr>
<td>Stress communication by partner</td>
<td>14.0 (2.5)</td>
<td>12.7 (2.8)</td>
<td>0.0231</td>
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<td>Supportive dyadic coping by oneself</td>
<td>18.3 (3.3)</td>
<td>18.2 (3.5)</td>
<td>0.8841</td>
</tr>
<tr>
<td>Supportive dyadic coping of partner</td>
<td>20.0 (3.5)</td>
<td>18.2 (4.0)</td>
<td>0.0319</td>
</tr>
<tr>
<td>Delegated dyadic coping by oneself</td>
<td>3.7 (0.8)</td>
<td>3.6 (0.8)</td>
<td>0.4610</td>
</tr>
<tr>
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Table 7.5. Primary and secondary outcome across groups and time for patients

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<td>Self-efficacy</td>
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<tr>
<td>Self-Efficacy (LCSES)</td>
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<td>13.9 (2.2)</td>
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<td>0.57 (0.20)</td>
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<td>0.83 (0.14)</td>
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<tr>
<td>Intrusion</td>
<td>0.54 (0.65)</td>
<td>0.61 (0.57)</td>
<td>0.54 (0.72)</td>
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<td>0.63 (0.77)</td>
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<td>Consensus</td>
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<td>17.4 (1.3)</td>
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<td>11.2 (3.2)</td>
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<td>12.0 (3.2)</td>
<td>13.1 (1.2)</td>
<td>11.5 (2.7)</td>
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<td>20.2 (2.4)</td>
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<td>3.3 (0.8)</td>
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<td>5.8 (1.5)</td>
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<td>Negative dyadic coping of partner</td>
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<td>6.4 (2.6)</td>
<td>5.5 (1.6)</td>
<td>5.7 (2.4)</td>
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<tr>
<td>Stress communication by partner</td>
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<td>14.1 (2.2)</td>
<td>14.5 (1.7)</td>
<td>13.5 (2.6)</td>
</tr>
<tr>
<td>--------------------------------</td>
<td>------------</td>
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<td>------------</td>
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</tr>
<tr>
<td>Supportive dyadic coping by oneself</td>
<td>18.5 (3.5)</td>
<td>18.2 (3.2)</td>
<td>19.2 (2.9)</td>
<td>17.6 (3.0)</td>
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<tr>
<td>Delegated dyadic coping by oneself</td>
<td>3.8 (0.8)</td>
<td>3.6 (0.7)</td>
<td>7.6 (1.0)</td>
<td>7.4 (1.2)</td>
</tr>
<tr>
<td>Negative dyadic coping by oneself</td>
<td>6.5 (2.6)</td>
<td>7.0 (3.1)</td>
<td>6.4 (2.0)</td>
<td>7.3 (2.6)</td>
</tr>
<tr>
<td>Common dyadic coping</td>
<td>17.3 (4.2)</td>
<td>16.9 (4.2)</td>
<td>17.2 (3.9)</td>
<td>17.0 (3.7)</td>
</tr>
</tbody>
</table>

**Appraisal**

| Threat (CAHS) | 13.0 (3.7) | 11.5 (3.6) | 11.6 (3.9) | 10.2 (4.3) | -2.00 (3.37) | -0.89 (3.38) | 0.52 (-2.12 to 3.15) |
| Challenge (CAHS) | 22.6 (2.7) | 24.2 (3.1) | 23.4 (2.8) | 23.9 (3.2) | 0.62 (2.10) | -0.58 (2.06) | -0.82 (-2.38-0.73)** |
| Harm/Loss (CAHS) | 16.2 (4.6) | 13.9 (4.7) | 16.6 (4.4) | 15.8 (6.5) | -0.23 (4.09) | 2.63 (4.68)  | 2.18 (-1.35-5.71)** |
| Benign/Irrelevant (CAHS) | 11.2 (3.4) | 11.5 (3.0) | 11.6 (2.9) | 11.6 (3.4) | 0.00 (2.58) | 0.11 (2.90)  | 0.05 (-1.85-1.96) |
| Uncertainty (MUIS) | 81 (11) | 78 (16) | 71 (10) | 75 (17) | -8.00 (13.02) | -2.84 (9.65) | 4.60 (-2.93-12.13)** |

**Individual coping (Brief COPE)**

| Emotion-focused | 2.1 (0.4) | 2.1 (0.5) | 2.1 (0.5) | 2.0 (0.5) | 0.03 (0.42) | -0.07 (0.38) | -0.10 (-0.37-0.18) |
| Problem-focused | 2.3 (0.8) | 2.4 (0.8) | 2.0 (0.6) | 1.9 (0.6) | -0.15 (0.50) | -0.40 (0.63) | -0.16 (-0.51-0.20) |
| Dysfunctional | 1.4 (0.4) | 1.3 (0.3) | 1.3 (0.3) | 1.3 (0.3) | 0.01 (0.31) | 0.03 (0.24) | 0.00 (-0.19-0.19) |

SD = Standard deviation, MEC = Minimal Ethical Care Condition, CT = Coping-Together, * = p < 0.05; ** = p ≤ 0.30; no symbol = p > 0.30 – need to insert.
Table 7.6. Primary and secondary outcomes across groups and time for partners

<table>
<thead>
<tr>
<th></th>
<th>Baseline</th>
<th>Follow-up</th>
<th>Mean Change (SD)</th>
<th>Difference (95% CI) in means between groups at follow-up adjusted for baseline values</th>
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<tr>
<td></td>
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<td>CT partner (n=23)</td>
<td>MEC partner (n=12)</td>
<td>CT partner (n=20)</td>
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<tr>
<td><strong>Anxiety (HADS-A)</strong></td>
<td>8.0 (5.0)</td>
<td>5.7 (3.5)</td>
<td>4.3 (3.0)</td>
<td>4.5 (3.5)</td>
</tr>
<tr>
<td><strong>Depression (HADS-D)</strong></td>
<td>4.7 (4.4)</td>
<td>1.8 (2.1)</td>
<td>2.1 (2.3)</td>
<td>2.1 (3.8)</td>
</tr>
<tr>
<td><strong>Self-efficacy</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-Efficacy (LCSES)</td>
<td>127 (39)</td>
<td>143 (19)</td>
<td>141 (26)</td>
<td>146 (20)</td>
</tr>
<tr>
<td>Understand and participate in care (CASE)</td>
<td>13.2 (3.4)</td>
<td>15.0 (1.3)</td>
<td>14.6 (1.6)</td>
<td>14.7 (1.7)</td>
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<tr>
<td>Maintain a positive attitude (CASE)</td>
<td>12.7 (3.1)</td>
<td>13.6 (1.6)</td>
<td>13.8 (2.0)</td>
<td>13.9 (2.2)</td>
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<tr>
<td>Seek and obtain information (CASE)</td>
<td>14.1 (3.0)</td>
<td>14.3 (2.2)</td>
<td>15.3 (1.2)</td>
<td>14.5 (2.1)</td>
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<td><strong>Quality of life</strong></td>
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<td></td>
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</tr>
<tr>
<td>Mental health (AQoL)</td>
<td>0.43 (0.22)</td>
<td>0.48 (0.17)</td>
<td>0.53 (0.17)</td>
<td>0.51 (0.18)</td>
</tr>
<tr>
<td>Physical health(AQoL)</td>
<td>0.74 (0.22)</td>
<td>0.72 (0.22)</td>
<td>0.73 (0.19)</td>
<td>0.61 (0.25)</td>
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<tr>
<td>Burden (CQOLC)</td>
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<td><strong>Cancer-specific distress (IES-R)</strong></td>
<td></td>
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<tr>
<td>Intrusion</td>
<td>0.95 (1.03)</td>
<td>0.54 (0.47)</td>
<td>0.30 (0.28)</td>
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<td>Avoidance</td>
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<td><strong>Relationship satisfaction (DAS)</strong></td>
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<td>Consensus</td>
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<td>16.7 (0.9)</td>
<td>16.5 (2.0)</td>
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<td>11.8 (3.7)</td>
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### Dyadic coping (DCI)

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<tr>
<td>Supporting dyadic coping of partner</td>
<td>18.2 (3.4)</td>
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<tr>
<td>Delegated dyadic coping of partner</td>
<td>3.7 (1.0)</td>
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<tr>
<td>Negative dyadic coping of partner</td>
<td>6.9 (2.4)</td>
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<tr>
<td>Stress communication by partner</td>
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<tr>
<td>Supportive dyadic coping by oneself</td>
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<tr>
<td>Negative dyadic coping by oneself</td>
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<td>Common dyadic coping</td>
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### Illness appraisal

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<td>Challenge (CAHS)</td>
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<td>Harm/Loss (CAHS)</td>
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<td>Benign/Irrelevant (CAHS)</td>
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### Appraisal of caregiving (ACS)

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### Individual coping

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<td>Problem-focused</td>
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<tr>
<td>Dysfunctional</td>
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</tbody>
</table>

---

**SD = Standard deviation, MEC = Minimal Ethical Care Condition, CT = Coping-Together, * = p < 0.05; ** = p < 0.30; no symbol = p > 0.30 – need to insert.**
Figure 7.1: Flow diagram of participant’s involvement in the randomised pilot study of Coping-Together for couples facing prostate cancer.

Patients referred to the study N=170

Consent received=42 (uptake rate= 37.2%)

Patients not enrolled (n=128, 75.3%)
- Ineligible (n=57, 44.5%)
  - No willing partner (n=16, 28.1%)
  - >4 months since diagnosis (n=11, 19.3%)
  - Distress thermometer score <4 (n=11, 19.3%)
  - No treatment received (n=7, 12.3%)
  - Prostate cancer diagnosis not confirmed (n=3, 5.2%)
  - Cancer not localised (n=2, 3.5%)
  - Not fluent in English (n=2, 3.5%)
  - Other (n=5, 8.8%; having alternative treatment (n=1), previous cancer diagnosis (n=3), passed away (n=1))

• Refused (n=51, 39.9%)
  - Not interested (n=31, 60.7%)
  - Too busy (n=9, 17.5%)
  - Did not give reason (n=2, 3.9%)
  - Too ill (n=1, 2.0%)
  - Study too personal (n=1, 2.0%)
  - Survey frustrating/too repetitive/long (n=2, 3.9%)
  - Didn’t want ca info (n = 1, 2.0%)
  - Treatment and action regarding prostate cancer on hold (n = 1, 2.0%)
  - Participating in another trial (n = 1, 2.0%)
  - Study irrelevant due to active surveillance (n = 1, 2.0%)
  - Study not what thought it would be (n = 1, 2.0%)

• Non-response (n = 20, 15.6%)

Couples enrolled and randomised (N=42)

Couples randomised to Coping-Together (n=23)

Orientation Call
Completed (n= 21)
Not conducted (n= 2, both conducted at the same time as follow-up #1 call)

Follow-up phone call #1
Completed (n= 23 patients & 22 partners)
Not conducted (n= 1 partner, away)

Follow-up phone call #2
Completed (n= 23 patients & partners)
Not conducted (n= 0)

Follow-up phone call #3
Completed (n= 23 patients & 21 partners)
Not conducted (n= 2 partners; 1 unable to establish contact and 1 unwell)

Two-month follow-up
Completed (n= 19 patients & 20 partners)
Not completed (n=4 patients and 3 partners unable to establish contact)

Final sample
Patient (n = 32)
Partners (n = 32)

Couples randomised to MEC (n=19)

Orientation Call
Completed (n= 17)
Not conducted (n= 2, one was subsequently conducted at the time of the follow-up 1 call and the other couple withdrew)

Follow-up phone call #1
Completed (n= 16)
Not conducted (n= 2, couples withdrew)

Follow-up phone call #2
Completed (n= 14)
Not conducted (n=3; 1 couple withdrew, 1 couple away, 1 couple unable to establish contact)

Follow-up phone call #3
Completed (n= 15)
Not conducted (n=2; 1 couple facing extreme external circumstances, 1 couple unable to establish contact)

Two-month follow-up
Completed (n= 13 patients & 12 partners)
Not completed (n=4 patients and n= 5 partners; 3 patients/4 partners unable to establish contact, 1 couple facing new cancer diagnosis)
DISCUSSION
Introduction

This thesis comprises a body of work that explored issues surrounding dyadic coping and couple-based interventions for couples facing cancer. The aims of this thesis were to:

1) examine current evidence and theoretical frameworks relevant to dyadic coping in couples facing cancer (Paper One);

2) examine the empirical basis for dyadic coping in couples and couple-based interventions (Papers Two and Three);

3) explore the barriers and facilitators of couple-based interventions and couple-focused psychosocial support in routine practice (Papers Four and Five);

4) explore the feasibility of the first self-directed couple-based intervention for couples coping with cancer (Papers Six and Seven).

This final section will summarise the findings and discuss the implications for future research and clinical practice.

Initially, background literature addressing key research issues was reviewed, including: a narrative synthesis of dyadic coping theories used in psychosocial cancer research (Paper One), a systematic review of couple-based interventions in cancer (Paper Three), and a review of uptake and attritions rates (Paper Four) in couple-based interventions in cancer. Empirical data from the Coping-Together pilot study were used to examine the influence of dyadic coping on couples’ adjustment to prostate cancer (Paper Two), and to explore the feasibility of a self-directed couple-based intervention (Paper Seven).

Two separate qualitative studies were undertaken to further examine patients’, partners’, and HCPs’ perspectives on delivering psychosocial care to patients and partners (Papers Five and Six).
Couple-based interventions have the potential to improve the quality of life of patients and their partners [1, 2]. Additionally, couple-based interventions encourage the development of dyadic coping skills that can improve couples’ ability to manage stress together, potentially increasing relationship satisfaction and quality of life. Despite the potential of couple-based interventions, dissemination into clinical practice has been restricted, with limited exploration of the factors affecting this. Prior to the research presented in this thesis there was: limited understanding of the impact of dyadic coping in cancer (beyond couples facing breast cancer); few studies that explored different modes of delivering couple-based interventions; and, few studies exploring couples’ and health care professionals’ views on the barriers and facilitators of psychosocial care for couples.

Main Findings and Implications

Influence of Dyadic Coping Among Couples Coping with Cancer

Paper One identified seven different theoretical frameworks that have been applied to explore how couples with cancer cope together: a) Relationship-Focused Coping [RFC; 3, 4-6], b) Lazarus and Folkman’s Transactional Model of Stress and Coping [7]; c) Systemic Transactional Model of dyadic coping [1], d) Collaborative Coping model [8], e) Relationship Intimacy model [9, 10], f) communication models of coping [11, 12], and g) Coping Congruence [13]. A comparative analysis of these theoretical perspectives was undertaken and a number of conceptual similarities emerged, including what one partner does to help the other cope, what couples do to cope together (e.g., active engagement, collaborative coping), the behaviours couples engage in that have a negative impact on themselves and others, and how some well-intentioned behaviours (e.g., protective buffering) can actually have detrimental effects on psychosocial functioning. Regardless of the theoretical model, positive or supportive
dyadic coping behaviours were associated with positive psychosocial outcomes, and negative dyadic coping behaviours were associated with negative psychosocial outcomes.

Paper Two built on the results of Paper One and explored the STM among couples coping with prostate cancer. Specifically, associations between dyadic coping and anxiety, depression, and relationship satisfaction were analysed cross-sectionally using baseline data from the *Coping-Together* pilot study [14]. The results indicated that relationship satisfaction was positively associated with the use of supportive dyadic coping and common dyadic coping, and negatively associated with the use of negative dyadic coping. In contrast, anxiety and depression were significantly associated with just two types of dyadic coping: Negative Dyadic Coping by Partner (NDCP) and an individual’s partner’s use of supportive dyadic coping (P-SDCO) were significantly positively associated with that individual’s anxiety and depression. Consistent with previous studies [1], it is clear patients’ and partners’ dyadic coping influences their spouses’ psychosocial functioning. Moreover, these findings suggest that the relationship between positive and negative dyadic coping and positive and negative psychosocial outcomes is not as straightforward as indicated by Paper One. Although the cross-sectional design limits causal inferences, the significant association between NDCP and anxiety and depression, coupled with the lack of an association between supportive dyadic coping behaviours and anxiety and depression, suggests that negative dyadic coping might be more influential than supportive dyadic coping with regard to anxiety and depression.

These results from Papers One and Two have significant implications for interventions that target people affected by cancer. Increasing supportive and positive forms of dyadic coping are cornerstones of coping-oriented couples-interventions [15],
which according to Sprenkle and colleagues [16], are often driven by three key factors: behavioural regulation (i.e., learning new adaptive coping behaviour), cognitive mastery (i.e., clarifying and understanding the reasons for stress in the relationship), and emotional experiencing (i.e., increasing mindfulness of a spouses emotional reactions to a stressful situation). Incorporating these aspects into future interventions for couples coping with cancer might improve the efficacy of interventions in increasing supportive dyadic coping.

**Barriers to the Facilitation of Couple-Focused Psychosocial Care**

In Paper Three, couple-based psychosocial interventions were systematically reviewed and typically showed small to medium effect sizes for most outcomes (\(d\sim .35-.45\)), which is similar to many individual-based interventions [17, 18]. The implications of the results of Paper Three are that couple-based interventions show the potential to improve psychosocial functioning for both the patient and the partner. However, the rates of uptake and attrition for couple-based interventions noted in Paper Three suggested there might be significant barriers that affect patients’ and partners’ participation. In Paper Four, the rates of uptake and attrition from the couple-based psychosocial interventions reviewed in Paper Three were examined more closely. Uptake rates ranged from 13.6% to 94.2% and varied by cancer and intervention type; attrition rates ranged from 0% to 49.4% and varied by cancer-stage and intervention content. Common barriers cited in the studies included in Papers Three and Four were not having enough time to participate [19, 20], living too far away from where the intervention took place [21, 22], or being too ill to participate [23, 24]. In Paper Four, rates of uptake and attrition were calculated as proportions, and although some patterns emerged, only descriptive conclusions can be made. This makes it difficult to ascertain the more subtle aspects that impact on couples’ decisions to engage with psychosocial
A more in-depth analysis of potential barriers to participating in couple-focused psychosocial care were explored in the qualitative studies described in Papers Five and Six.

Couples’ and HCPs’ views on providing couple-focused psychosocial support were explored in Paper Five. In Paper Six, couples’ views on the content and acceptability of the *Coping-Together* intervention were explored. In both of these qualitative papers several barriers to couple-focused psychosocial care emerged. In Paper Five, most couples felt that additional psychosocial care was not required, and that they were satisfied with the level of support they had. Rather than receiving specific couple-focused psychosocial care (e.g., being referred to a psychologist), couples typically spoke of developing more supportive relationships with their oncology HCPs as being their preferred form of psychosocial support. In contrast, HCPs typically indicated a preference to refer patients and partners who expressed distress to specialist services. HCPs were also aware of some of the barriers that they felt limited the implementation of psychosocial care for couples, including a lack of appropriate training to identify and support couples under stress, and a lack of consistency in distress screening practices. The issues raised by HCPs are consistent with recent research regarding the barriers to the implementation of psychosocial care at an individual level [25-27]. In Paper Six, the barriers raised by couples regarding the use of *Coping-Together* were similar to those raised in Papers Three, Four and Five. Couples suggested that the content of *Coping-Together* was appropriate, but also included more information than they needed, and suggested more specific tailoring was required to ensure the couples’ needs were met. Similar to one of the barriers raised in Papers Four, couples also suggested that using *Coping-Together* simultaneously was not always possible. Couples felt that greater flexibility in how they were expected to use *Coping-Together* would have increased the extent they engaged with the material. These
findings are consistent with previous research that the most common reason for refusal of professional psychosocial intervention is the inflexibility of most psychosocial interventions [28].

Taken together, these findings suggest that the barriers to psychosocial support for couples are multi-faceted. On one hand, there is a need to develop flexible, tailored interventions to assist couples in managing stress associated with their cancer. On the other hand, there is a need to increase HCPs’ awareness of partners’ issues, and increase HCPs’ willingness to discuss the emotional impacts of cancer with couples. Researchers [29, 30] and policy-makers [31] are gradually beginning to develop models of psycho-oncology care with a broader scope that includes patients’ spouses and families. The success of these approaches will be contingent on improving all HCPs’ capacity to provide acute support for distressed patients, and on researchers to develop appropriate means of tailoring appropriate interventions that meet not only couples’ content needs, but also delivering it to them in a feasible manner.

**Acceptability and Feasibility of Self-directed Couple-based Interventions**

In Paper Six, the feasibility of *Coping-Together*, a novel, self-directed, multimedia, workbook-based intervention for couples facing cancer, was explored through a qualitative interview study in couples facing a range of cancers. There are many barriers that inhibit the delivery and acceptance of psychosocial interventions, of which some are described in other papers in this thesis. As highlighted in Papers Three and Four, two of the most common barriers for couples are access, either in regards to finding the time to attend, being able to travel the distance to attend the intervention, or being well enough to engage with the intervention. *Coping-Together* was designed with overcoming these barriers in mind. The results presented in Paper Six indicated that a self-directed workbook intervention was endorsed by most couples. The format allowed
participants to work through it at their own pace and with a degree of privacy that is not possible with other common support resources, such as support groups. Couples also felt that the content of the intervention was unique compared to most other cancer resources they had used, in particular the focus on individual and couple coping techniques. *Coping-Together* was also viewed favourably for its focus on increasing couples’ awareness of upcoming challenges, normalised couples’ experiences, and provided information on resources and services they might have otherwise overlooked. Overall, the format and content of *Coping-Together* was very well received by couples, suggesting that it is feasible to provide self-directed interventions to couples facing cancer. Given that the majority of health care professionals have limited time to cover all aspects of couples’ experiences during cancer [32], alternative supportive psychosocial care options should be investigated. As partners are even less likely to seek face-to-face psychosocial support than patients [33], the fact they too preferred a self-directed format is promising.

In Paper Seven, a pilot randomised controlled trial compared *Coping-Together* with a Minimal Ethical Care (MEC) intervention among patients diagnosed with prostate cancer and their partners. The results suggested *Coping-Together* is a feasible and acceptable intervention for couples and stakeholders involved in its implementation. That said, issues did arise that demonstrate the difficulties in delivering these types of interventions, but also highlighted potential solutions for future interventions and research. The uptake rate of 37% is notably less than the uptake rates for couple-based interventions for people facing prostate cancer that was reported in Paper Four (~58%). However, Paper Four also demonstrated that couple-based interventions that were delivered separately to patients had better uptake than interventions delivered to patients and partners simultaneously. This is somewhat consistent with what was reported in Paper Six. One of the main barriers participants in Paper Six felt would impede their use
of *Coping-Together* was finding the time to use the resource together. Consistent with
the views of couples in Paper Five, a lack of interest was the top reason for refusal by
eligible couples in Paper Seven (n=31). However, it is not clear if the lack of interest
stemmed from patients or from partners. This introduced a potential bias, which should
be recognized and improved upon in future studies.

**Strengths and Limitations**

The papers that make up this thesis have various strengths and limitations that should be
acknowledged. These include:

1) the generalisability of the findings (All Papers)
2) the low response rates (Papers Two, Five, Six, & Seven)
3) appropriateness of measures and qualitative methods (Papers Two, Five, Six, &
   Seven)
4) self-directed couple-based interventions for couples coping with cancer are
   feasible alternatives (Papers Six & Seven)

Each of these will now be discussed in turn.

**1) Generalisability of findings**

One of the key limitations of the research presented in this thesis is the ability to
generalise the findings to other contexts. The vast majority of the studies reviewed in
Papers One, Two and Three lacked heterogeneity, with most participants being elderly,
white, well-educated, middle-class, heterosexual couples with an early-stage cancer
diagnosis. This limits the scope to generalize the findings to more patients with more
advanced cancers, as well as other age, racial, and socio-economic groups, and same-
gender couples. Papers Two, Six, and Seven specifically targeted couples affected by
prostate cancer. These papers provide explorative data on the influence of dyadic coping
on couples facing prostate cancer, couples’ views on the feasibility of a self-directed intervention, and the potential efficacy of a self-directed couple-based intervention. However, the generalisability of the findings to other couples affected by prostate cancer, and to couples diagnosed with different types of cancer is limited. Prostate cancer presents unique physical side-challenges resulting from the cancer itself and associated treatments [34], particularly continence and sexuality issues [35] which may not generalise or be as pertinent in other cancer contexts.

Additionally, the majority of participants involved in the studies described in Papers Two and Seven were recruited from private urology clinics in Newcastle (and some surrounding suburbs), New South Wales, Australia. A small number of couples were recruited from private urology practices in the Adelaide region in South Australia. The participants might be representative of other patients with prostate cancer from this region or those attending private urology clinics, but they are not representative of all patients diagnosed with prostate cancer. In contrast, the participants that were involved in the studies described in Papers Five and Six were recruited from a variety of sources (e.g., support groups, oncology clinics, psycho-oncology clinics) and thus might represent a broader cross-section of couples’ experiences with cancer. Moreover, a significant strength of Paper Five is that participating couples were coping with a variety of cancer diagnoses.

2) Low response rates for studies in Papers Two, Five, Six, and Seven

All four studies had low response rates: in Papers Two and Seven, 42 of 113 (37.2%) eligible couples agreed to participate; in Paper Five 20 of 105 patients provided with information packs participated (20.%), and Paper Six, 27 of 63 eligible patients (42.9%) agreed to participate (as did 14 partners). The response rates for Papers Two and Seven is notably lower than what was reported in Paper Four for other couple-based
intervention studies involving couples facing prostate cancer (~58%) and may reflect response bias. One of the main reasons for ineligibility in Paper Seven was a patient or partner scoring < 4 on the DT. Screening for distress is recommended in psychosocial interventions [36] given the potential for a floor effect to reduce the capacity of an intervention to lead to meaningful change in distress outcomes. However there is growing debate regarding the optimal cut-off for the DT [37], and whether it is an appropriately sensitive tool for identifying cases of distress, rather than ruling-out non-distressed individuals [38]. The mean baseline scores of the Hospital Anxiety and Depression Scale-Anxiety (HADS-A) indicated that the vast majority of participants were not anxious at baseline, which may also reflect the fluctuating nature of distress from the time of recruitment until the time of completing the baseline survey [39]. It might be worth investigating the use of the HADS-A in conjunction with the DT at screening. If feasible, it may also be worth including clinician-interview questions at screening, to increase the specificity of screening measures overall [40]. Given previous research suggests that distress does not equate to a need or desire for psychosocial support [41], it may be necessary to reconceptualise the focus of supportive psychosocial care in terms of improving all aspects of functioning (e.g., coping, cancer knowledge, communication).

With regard to the two qualitative studies, Paper Six had a notably better response rate when compared to the response rate of couples in Paper Five (20.5%; 20 of 105). Given some of the recruitment structures used in Papers Five and Six (provision of information packs by clinicians), it was not possible to obtain consistent data relating to study refusal. The difference in response rate between Papers Five and Six might be due to the fact that participating in the study described in Paper Five did not present any specific benefit to the couples, whereas the study described in Paper Six perhaps provided some incentive for couples to participate (i.e., the chance to use the
Another bias relating to participants who declined on the basis of their partner not being interested should be acknowledged. These couples may have felt they did not need an intervention.

3) Appropriateness of Measures and Qualitative Methods Used in Papers Two, Five, Six, & Seven

Appropriateness of the measures used in Papers Two and Seven.

The baseline and follow-up surveys used in Coping-Together were considered by most couples to be the most burdensome aspect of their participation in the study. The survey was reduced from 30 pages at baseline to 25 pages at follow-up but couples’ still felt it was too long. Although there is no clear evidence regarding the impact of survey length on participation, surveys that take more than 20 minutes to complete [42], or are more than four pages long [43], are associated with adversely affecting participants experiences. Overall, the survey used in the pilot study of Coping-Together included 18 separate self-report measures. The most relevant of these to this thesis were the Dyadic Coping Inventory (DCI; [44]), Distress Thermometer (DT; [45]), the primary measure of anxiety and secondary measure of depression (the Hospital Anxiety and Depression Scale [HADS; 46, 47], and secondary outcomes; the Revised-Dyadic Adjustment Scale [R-DAS; 48]).

The Dyadic Coping Inventory (DCI) [44] is a well-known and validated measure of dyadic coping. It has been widely used to explore the relationship between marital stress and dyadic coping among intimate couples [49]. Few studies have used the DCI where the stress experienced by the dyad is the result of a physical ailment, such as cancer, and prior to Coping-Together, the DCI has only been applied in the context of breast cancer [1, 50, 51]. The Coping-Together pilot study was the first time the DCI had been used in the context of prostate cancer, and the first time with male-patient,
female-partner combination. This provides a firm footing for future research to compare and contrast dyadic coping strategies used by cancer type, and to explore how dyadic coping might vary according to gender and role.

The DT is the recommend tool to detect clinically relevant distress in psycho-oncology settings [52]. The English-version has established a cut-off score of 4 which has been validated in several studies [53-55], and has been successfully translated in to several different languages [56]. Along with other short-screening tools, the DT has been shown to be more successful in ‘ruling-out’ clinical cases of anxiety or depression than accurately identifying positive clinical cases [38]. Pairing the DT with additional screening (i.e., clinical interview or additional measures) might have increased the likelihood of capturing clinically distressed participants. However, the practicalities and costs involved add additional burden to participants and research staff [57].

Like the DT, the HADS [46] has been used widely within psycho-oncology research and at the time Coping-Together was developed it was widely considered a reliable and valid measure to indicate the presence of psychological distress within this population [54]. That said, recent reviews have criticized the HADS performance compared to clinical interviews in regards to accurately identifying caseness [58], and highlighted issues regarding its most appropriate factor structure (e.g., unidimensional vs. two dimensions vs. three dimensions) [59]. These are relevant concerns, however the Coping-Together pilot study was not concerned with diagnosing clinical anxiety or depression. Thus the findings from Papers Two and Seven regarding the relationship between dyadic coping and anxiety and depression should be considered with this in mind. Despite these concerns, the HADS remains an appropriate tool for identifying people at risk of anxiety and depression within this population, particularly given its brevity and ease of use.
The Revised-Dyadic Adjustment scale [48] and the scale from which it is based (the Dyadic Adjustment Scale [60]) are widely used and [61] validated measures of relationship satisfaction. Most often they have been used within the martial literature, although are increasingly applied within studies involving couples dealing with cancer [62, 63]. Only the satisfaction subscale was examined in the Coping-Together pilot study, and participant responses were consistent with previous scale validations [61]. More recently there has been a push in the literature to develop cancer-specific measures of relationship satisfaction and intimacy [64]. This is based on previous work suggesting that coping with cancer is a unique stressor to couples relationships [65], however is yet to be appropriately validated within the literature.

**Appropriateness of the qualitative methods used in Papers Five and Six.**

The provision of supportive psychosocial care in cancer is complex. It involves many separate yet interdependent facets that must come together in order to deliver appropriate support and desired outcomes for patients, families, and health care professionals. The addition of partners to psychosocial care programs adds another layer of complexity that researchers and clinicians are increasingly interested in exploring. Qualitative research methodologies allow the exploration of complex interactions in order to build greater depth of understanding of particular behaviours [66].

The two qualitative papers (Papers Five and Six) applied similar data analysis techniques to explore different aspects of providing psychosocial care for couples. Although both papers relied on deep thematic analysis of the data to ascertain important themes [67], in Paper Five the Framework approach [68, 69] was used to help guide the data analysis. The Framework approach provides a systematic and structured process of ordering and categorising data regarding each group’s perspectives and experiences. This process clearly identifies similarities and differences within groups, and allows the
group to be neatly compared and contrasted with the other. In Paper Six, although like Paper Five the interviews were semi-structured, the data analysis process was more exploratory in nature. This is consistent with the aims of Paper Six, which were to highlight the aspects of the Coping-Together intervention that couples liked and disliked, and what could be improved.

There are weaknesses to qualitative methodologies which must be acknowledged. The focus on the depth of detail in certain concepts and ideas comes at the price of limiting transferability to other settings. However, there is scope to suggest that some aspects of the findings from Papers Five and Six might be informative for the development of future research. One important limitation must be considered regarding Paper Five. This paper, and the study it was based on, was largely designed and facilitated by the candidate, under close direction from PhD supervisors. The candidate conducted all recruitment, arranged and conducted all interviews with HCPs and couples, and led the data analysis. This was the first time the candidate had conducted these types of interviews with such a range of participants. On reflection the interview process could have been improved. In particular, a more experienced interviewer may have probed participant’s views about couples’ interventions in more depth. This potential interviewer bias is an important consideration, and on reflection it may have better served the study to use more than one interviewer. On the other hand, bias relating to data analysis were managed by utilising several coders, discussing potential biases each may hold, and reviewing and refining themes as necessary. Additionally, it is important to acknowledge research participants in qualitative studies may also be prone to social desirability bias, in that they knowingly or unknowingly feel they need to provide data they feel is consistent with the aims of the study. Attempts were made to minimise bias by recruiting couples with various cancer types (breast, prostate, head
and neck, bowel, multiple myeloma) from different sites (e.g., support groups, cancer treatment clinics, psycho-oncology services).

4) Self-Directed Couple-Based Interventions for Couples Coping with Cancer are Feasible Alternatives

The delivery of psychosocial care is often constrained by a lack of financial resources and appropriately skilled health care professionals [70]. Moreover, access is often difficult for people currently undergoing treatment, or those that live outside of major metropolitan areas [22]. Self-directed formats are one of the strategies often implemented in order to overcome these barriers [71]. Outside of the cancer context, self-directed psychosocial interventions have shown evidence of efficacy [72, 73]. Previous self-directed interventions in the cancer literature have also shown evidence of efficacy [71, 74]. However, *Coping-Together* was the first self-directed intervention for couples facing cancer to be developed, implemented, and evaluated.

As reported in Paper Six, couples were very positive about using a couple-based intervention to learn new coping skills and complement information provided by their HCPs. This is in contrast to the couples interviewed in Paper Five, the majority of which suggested they did not require specific couple-focused psychosocial support or intervention. This suggests that couples may not be aware of what a psychosocial intervention can entail, and that a self-directed intervention might be appropriate even for couples who feel they are coping well with cancer. Having the flexibility to tailor how much information the consumer receives might be a more attractive prospect than sticking with traditionally more rigid psychosocial intervention schedules. Moreover, the results from Paper Seven further highlighted that self-directed couple-based interventions are feasible alternatives to face-to-face interventions in terms of their implementation, but also demonstrated a trend towards reducing anxiety and improving
appraisal of cancer. Although caution is needed when interpreting the results of an exploratory pilot study with limited power, the potential for these types of interventions is evident. First, self-directed workbook interventions address issues of cost associated with psychosocial interventions, given the relatively low production costs versus capacity to deliver to a large number of couples. Although psychosocial care for patients with cancer is relatively inexpensive and cost-effective in comparison to other supportive cancer care domains [75, 76], they are still expensive and highly dependent on the availability and expertise of highly trained professionals. Second, self-directed interventions address barriers relating to access, allowing couples to learn new skills and learn new information when it best suits them. The rigidity of how psychosocial supportive care is delivered to couples reduces interest and access, thus viable alternatives are needed. Third, a self-directed intervention such as this intervention can be easily implemented with existing cancer care services complementing existing psychosocial support. Larger trials among other cancer types are needed to verify the efficacy of the intervention.

Directions for Future Research

The research contained within this thesis contributes to improving understanding of the influence of dyadic coping among couples facing cancer, and the efficacy, feasibility, and acceptability of couple-based interventions for couples facing cancer. This research highlighted the similarities and differences between different theoretical conceptualisations of dyadic coping, and identified the Systemic Transactional Model as being the strongest and most appropriate to apply in the context of prostate cancer [77]. Based on the STM, this research highlighted that using negative dyadic coping to cope with stress during prostate cancer can have a stronger influence on how ones’ partner responds to stress than supportive dyadic coping strategies. The findings of Papers Two
and Seven indicated that couples facing prostate cancer respond to the disease as an integrated system. In particular, ones’ negative coping responses are significantly associated with their partner’s psychosocial outcomes. However, given the limitations of the sample this research could not adequately address the role of gender, which has been shown to significantly mediate couples’ ratings of distress following cancer [78]. Thus, more research is needed to increase understanding of gender effects and dyadic coping in prostate cancer, and how gender impacts on responses to a self-directed couple-based intervention. Although these findings help to grow the understanding how couples cope with cancer, future research should consider how best to integrate couple-focused approaches into routine psycho-oncology care. This research identified that despite evidence that couple-based interventions can improve psychosocial functioning for patients and partners, there are divergent perspectives between HCPs and couples regarding how couple-based interventions and couple-focused psychosocial support fit into routine oncological care.

Finally, this research found that a self-directed, couple-based, workbook intervention is an acceptable psychosocial resource for couples facing cancer, and potentially broadens the range of intervention options available to couples. When considering the development of future self-directed intervention studies for couples it is important to pay specific attention to how couples will be recruited into the study. Despite a high prevalence of anxiety and depression among people diagnosed with cancer and their partners, evidence of couple-based intervention efficacy, supportive HCPs, and favourable feedback regarding self-directed interventions, Papers Six and Seven highlighted that the recruitment of an appropriately large sample to adequately evaluate the impact of interventions on coping skills and psychosocial functioning is difficult. Part of the reason for this was discussed in Paper Five, where HCPs and couples held contrasting views on the need for couple-focused care. Increased distress
does not equate to a need for psychosocial intervention [41], and thus in order to develop a greater understanding of why couples’ engage in psychosocial care future research should focus on: 1) increasing knowledge about the determinants of couples’ perceived need for a psychosocial intervention, and 2) how best to align HCPs’ capabilities with the needs and expectations of couples. In Paper Five it was suggested by some couples that having an oncologist’s recommendation to seek specific psychosocial intervention or services might have made a significant difference to their attitude towards the need for psychosocial care. Previous research has indicated that perceived need for specific psychosocial support services is difficult to gauge among those with high levels of social support, and that supportive relationships might inhibit support seeking behaviour [79]. Thus, increasing understanding of the circumstances that drive couples to seek or accept additional support would be of great benefit to future research and intervention development. Related to this is the need to increase HCPs’ capability to provide psychosocial support within routine cancer care, and for these HCPs to work with couples in order to identify their specific needs, and align responses and services to the these needs.

There is also a need to acknowledge the broader family and social networks that surround couples during cancer, and the role they play in providing support. Just as an individual’s psychosocial responses and use of coping strategies to cancer typically involves a spouse or close partner, couples’ responses also involve a broader social network. The couple’s relationship exists as a smaller support system entrenched within a larger support network, and it could be suggested that a couple’s response to cancer reverberates throughout the family, and can set the tone for how family members cope. This would suggest that the importance of couple-based interventions could be magnified in the context of their immediate and broader family. Interventions for families, such as Kissane and Bloch’s Family Focused Grief Therapy [80], have
highlighted the complexities of delivering psychosocial care to families. However, there is limited research exploring the specific relationship between couples responses to cancer, and the subsequent impact on families. The dynamics between the couples’ psychosocial responses and coping strategies and their impact on the family should be explored in more detail.

The growing evidence base regarding the genetic contribution of cancer is another area that should be considered for future research among couples. There is evidence to suggest that genetic testing for cancer is not only distressing for those undergoing testing, but also for their partners [81, 82]. Although some dyadic coping behaviours (e.g., team approach to stress) have been shown to be associated with dyadic adjustment in the face of being informed of being at a greater risk of developing cancer [83], more research is needed to explore: 1) the true prevalence of distress among couples undergoing genetic cancer testing, and 2) specific couple-focused psychosocial support for these couples.

The research presented in this thesis focused largely on the impact of cancer around the time of diagnosis and treatment. The exception to this is that almost half of the couple-based interventions included in the systematic review and the review of the rates of uptake and attrition involved patients with a late-stage diagnosis. Regardless, there is a need to more closely explore the influence of dyadic coping, during palliative care. Additionally, it might be beneficial for couples and health care professionals to explore the lessons learned from the Coping-Together pilot study in the context of palliative care. A structured self-directed intervention at this stage might be an appropriate way of complementing professionally-led psychosocial support during this period, or be an appropriate alternative for those who do not wish for additional support at this time.
Conclusion

Couples face extraordinary challenges in the face of a cancer diagnosis, treatment, and recovery. These challenges can place significant burden on individuals and their most valued and intimate relationships. This thesis 1) examined current evidence and theoretical frameworks relevant to dyadic coping in couples facing cancer, 2) examined the empirical basis for dyadic coping in couples and couple-based interventions, 3) explored the barriers and facilitators of couple-based interventions and couple-focused psychosocial support in routine practice, and 4) explored the feasibility of the first self-directed couple-based intervention for couples coping with cancer. Research regarding how couples cope with cancer is growing quickly, and although some questions regarding the impact of couples’ coping on their psychosocial functioning and the role of HCPs in facilitating coping have been explored in more depth in this thesis, there are many questions and avenues for research remaining. Engaging patients, partners, families and HCPs in future research and understanding their specific needs in context of psychosocial care is vital for reducing the burden of cancer.
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