THE FEASIBILITY AND EFFECTS OF A ‘CARING FOR COUPLES COPING WITH CANCER (4CS)’ PROGRAMME TO SUPPORT COUPLES COPING WITH CANCER AS A UNIT

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Ph.D

The Hong Kong Polytechnic University

2015

THE HONG KONG POLYTECHNIC UNIVERSITY

SCHOOL OF NURSING

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LI QIUPING

A THESIS SUBMITTED IN PARTIAL FULFILMENT OF THE
REQUIRMENTS FOR THE DEGREE OF
DOCTOR OF PHILOSOPHY

FEBRUARY 2015

CERTIFICATE OF ORIGINALITY

I hereby declare that this thesis entitled “The feasibility and effects of a ‘Caring for Couples Coping with Cancer (4Cs)’ programme to support couples coping with cancer as a unit” is my own work and that, to the best of my knowledge and belief, it reproduces no material previously published or written, nor material that has been accepted for the award of any other degree of diploma, except where due acknowledgement has been made in the text.

Signed __________________

LI Qiuping

Abstract of dissertation entitled:
“The feasibility and effects of a ‘Caring for Couples Coping with Cancer (4Cs)’ programme to support couples coping with cancer as a unit”
submitted by LI Qiuping
for the degree of Doctor of Philosophy
at The Hong Kong Polytechnic University in February, 2015

Abstract

Title: The feasibility and effects of a ‘Caring for Couples Coping with Cancer (4Cs)’ programme to support couples coping with cancer as a unit

Background: As the primary informal caregiver for cancer patients, spousal caregivers are the population at a high risk of hidden morbidity. The factors impacting couples coping with cancer are complex, and within spousal caregiver-patient dyads the impact is mutual. Taking into account the hidden morbidities and relational dynamics of cancer couples, it is concluded that the factors that have an impact on couples coping with cancer are complex and multi-faceted, and that there is a need for a complex intervention to support cancer dyads.

Aim: To examine the feasibility and effects of a ‘Caring for Couples Coping with Cancer “**4Cs**” Programme’ to support couples coping with cancer as the unit of intervention in China.

Methods: The Medical Research Council’s (MRC) framework in developing and evaluating complex interventions was adopted in developing and piloting this ‘Caring for Couples Coping with Cancer “**4Cs**” Programme’. Of the four phases in the process of developing-evaluating-implementing a complex intervention, this study conducted the first two phases: development and determination of feasibility/piloting.

In phase I of the development of the **4Cs** programme, three steps were conducted: (1) identifying evidence: evidence identified from extensive reviews of the literature and a focus group interview study; (2) identifying or developing a theory: a preliminary Live with Love Conceptual Framework (P-LLCF) was proposed, and the P-LLCF was tested using mixed methods design; and (3) modelling the process and outcomes: the **4Cs** programme was developed based on the P-LLCF.

In phase II of determination of feasibility/piloting: the **4Cs** programme was piloted by a pre-intervention and post-intervention study design. A pre-intervention and post-intervention study design was conducted among cancer patients and their spousal caregivers. Among the 135 couples approached, a total of 117 dyads were successfully recruited at baseline, with 92 dyads successfully followed-up at 6 weeks. An information booklet and six face-to-face group sessions of the **4Cs** program were offered to couples as dyads. Outcome measures, including dyadic mediators (self-efficacy), dyadic appraisal (Cancer Related Communication Problem, CRCP), dyadic coping (Dyadic Coping Inventory, DCI), and dyadic outcomes (physical and mental health, negative and positive emotions, and marital satisfaction), were assessed at T0 (pre-intervention) and T1 (post-intervention). Repeated measures analysis of variance and structural equation modeling (SEM) were applied in testing the outcomes of the **4Cs** program.

Results: The recruitment and retention rates were 86.7% and 78.6%, respectively. Significant improvements were seen in the couples' scores on overall (total) self-efficacy (CBI-B) ($P<0.01$), CRCP ($P<0.05$), DCI ($P<0.05$), the physical component summary (PCS) of SF-12 ($P<0.05$), anxiety ($P<0.01$), and benefit findings ($P<0.05$) from baseline to 6 weeks post-intervention. Patients had a significantly higher level of increase in the mean CBI-B (MD= +5.1, d=0.41) than spousal caregivers (MD= +1.4, d=0.19) ($P<0.05$). Spousal caregivers had a significantly higher level of increase in physical component summary score ($P<0.01$), and much greater level of decrease in anxiety ($P<0.05$) than the patients. No significant effects on time and role of marital satisfaction were identified. The overall effect sizes calculated in this study ranged from medium to small. The SEM of all six models resulted in convergence and showed goodness of fit to the data and variables, supportive of the constructs in the P-LLCF.

Conclusion: This study provides evidence suggesting that the **4Cs** program is acceptable, feasible, and effective in supporting cancer couples coping with the illness as dyads. Although a generally positive effect was identified in the pre- and post-intervention outcome measures, further evaluation of this **4Cs** program in a large, multisite RCT is needed to provide substantial evidence.

Key Words: Cancer; spousal caregivers; caregiver-patient dyads; couple-based intervention; dyadic mediator; dyadic coping; dyadic appraisal; dyadic outcomes

Publications arising from the thesis

Refereed Journal Articles

1. Li, Q., Xu, Y., Zhou, H., & Loke, A. Y. (2015). Testing a Preliminary Live with Love Conceptual Framework for Cancer Couple Dyads: a mixed-methods study. *European Journal of Oncology Nursing,* Article first published online: 29 APR 2015. DOI: 10.1016/j.ejon.2015.03.010.
2. Li, Q., Xu, Y., Zhou, H., & Loke, A. Y. (2015). A couple-based complex intervention for Chinese spousal caregivers and their partners with advanced cancer: an intervention study. *Psycho-oncology,* Article first published online: 23 MAR 2015 DOI: 10.1002/pon.3809.
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Manuscripts under review

1. Li, Q., Xu, Y., Zhou, H., & Loke, A. Y. (2015). The development of a complex intervention program to support couples coping with cancer. *Cancer Nursing (*Submitted on May 13, 2015).

Conference Presentations References

1. Li Q., Loke A.Y., Mak, Y.W., & Shae, W.C. (2015). The introduction of a 'Caring for Couples Coping with Cancer (4Cs)'programme to support couples coping with cancer. *The 18th East Asian Forum of Nursing Scholars (EAFONS),* Taipei, Taiwan, February 5-6, 2015.
2. Li Q., Loke A.Y., Mak, Y.W., & Shae, W.C. (2013). The new research direction: Caregiver-patients dyads-----the spousal caregivers and cancer patients. *The 16th East Asian Forum of Nursing Scholars (EAFONS)*, Bangkok, Thailand, February 21-22, 2013, 339.
3. Li Q., Loke A.Y., Mak, Y.W., & Shae, W.C. (2013). Couple-oriented program for patients with cancer and their spousal caregivers. *Women's Health*, 2013: *The 21st Annual Congress*, March 22-24, Washington, DC.
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5. Loke A.Y., & Li Q. (2013) A vulnerable and hidden patient population: the spousal caregivers for cancer patients. *The ICN Conference*, 2013, May18-23, Melbourne, Australia.

Acknowledgements

I am very grateful to have so many supporters around during my doctoral journey. I would like to express my gratitude to these supporters to whom I am much indebted.

My deepest thanks and sincerest appreciation must go to my supervisors Professor Alice Yuen Loke, Dr. Yim-wah Mak, and Dr. Wan-chaw SHAE for giving me encouraging and constructive feedbacks throughout the entire study period. Special and heartfelt thanks must go to Professor Loke, my chief supervisor. You have been the holistic mentor throughout my doctoral experience and offered stimulation, guidance, encouragement and constructive advices during every step of my doctoral process. I have to admit that you are the person who guided me published the first English paper. I believe that only we can understand how difficult it was, and how preciousness the experience is. This experience of ours and our established relationship will be forever!

I would like to express my sincere gratitude to Dr. Vico Chung Lim CHIANG for his helpful advice in focus group study. I would also like to give thanks to all professional experts from the School of Nursing at the Hong Kong Polytechnic University for their expertise comments and validation to my project. I also appreciate my fellow students in the School of Nursing at the Hong Kong Polytechnic University for their support in many different ways.

I am especially grateful to Wuxi peoples' hospital for offering the access to the hospital for data collection. Special thanks also go to Ms. Xu Xifeng, Ms. Xu

Yinghua, and Ms. Zhou Huiya for their enthusiasm, their concern for cancer care, and their excellent work both in the interviews of cancer couples and the questionnaire data collection. Their persistence was critical to the achievement of the high response and adherence rates of this study. My special appreciation goes to all the participating couples for their valuable time and sharing their experience of coping with cancer as dyads. Their enthusiasm and encouragement reassured me that my efforts to support their coping with cancer together were worthwhile.

I am also deeply grateful to Professor Guy Bodenmann at Universität Zürich for his kind permission for translating and using the instrument of Dyadic Coping Inventory (DCI), and for his offering the related information on psychometrics and scoring.

Special thanks go to Jiangnan University for the support to my study. I would like to thank my family and friends for all their kind help and encouragements in need, particularly for their pushing me forward during my difficult period, which made my study possible.

Last, but not least, very special thanks must go to myself for the learning ability, strong responsibility and collaborative spirit, also for the ability to prioritize, to focus on project, problem-solving skills, and positive attitude, all these facilitated the accomplishment of the project, which bring our original intention to target on couples “to live caring and being cared” to the reality. Thanks for all your hard work. I love all of you! Wish all the best to all!

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PART I INTRODUCTION AND THE ADOPTED MEDICAL RESEARCH COUNCIL (MRC) FRAMEWORK

Chapter 1

Introduction

1.1 Research background

Cancer is a leading cause of death worldwide and accounted for 7.6 million (13%) of all deaths in 2008, where 70% of all cancer deaths occurred in low- and middle-income countries (WHO, 2013). Deaths from cancer worldwide are projected to continue rising, with an estimated 13.1 million deaths in 2030 (WHO, 2013). In China, cancer is projected to account for 1.9 million (20% of all deaths) in 2005, which is about one fourth of total deaths due to chronic disease (7.5 million) (WHO, 2012). World Health Organization (WHO, 2012) also estimated that deaths from chronic disease including cancer in China will increase by 19% over the next ten years in 2015.

It is well-accepted that cancer and its treatment affect not only the patient but also their close family members leading to the description of cancer as a 'we-disease' (Kayser, Watson, & Andrade, 2007). This is evidenced by the high rates of psychological distress reported by family caregivers of cancer patients (Janda et al., 2007), and the fact that the psychological well-being of cancer patients and their informal caregivers is closely related (Hodges, Humphris, & Macfarlane, 2005). It is particularly true when the primary caregiver is the patient's spouse. To varying degrees, cancer affects the couple as a unit, rather than as isolated individuals (Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008).

With new and advanced medical treatment, individuals with cancer have relatively good 5-year survival rates and 68% of adults diagnosed with cancer today can expect to be alive in 5 years (Jemal et al., 2011). This creates burden on their family caregivers, particularly the spouse (Cain, MacLean, & Sellick, 2004; Glajchen, 2004; Pitceathly & Maguire, 2003). Predominantly, the primary family caregiver for cancer patients are their spouses, this is the case in USA (Kurtz, Kurtz, Given, & Given, 1995), as well as in Taiwan and in China (Chen, Chu, & Chen, 2004).

Starting from hearing the news of a diagnosis of cancer, both patients and their spouses must cope together, through the stages of cancer disease progression. The readjustment and adaptation of the couple may include breaking the ‘bad news’ to other family members, managing household and childcare responsibilities, negotiating changes in family and occupational roles, and interference with future life plans (Harden, 2005; Lopez, Copp, & Molassiotis, 2012; Maughan, Heyman, & Matthews, 2002). Spouses also cope with challenges, such as worrying about their ability to provide emotional and practical support to the patient, and the potential loss of their life partner (Maughan et al., 2002; Thomas, Morris, & Harman, 2002).

Spousal caregivers may be especially vulnerable since they are more willing to sacrify themselves for the care of their partner. It is reported that the average number of hours spent in the caregiving role per week by a spouse is substantially greater than an adult child, and spouses are shown to provide this care for a much longer period of time (Montgomery & Kosloski, 1994). Spousal caregivers reported more fatigue, less energy, and more sleep difficulty than non-spousal caregivers (Steele & Fitch, 1996). Studies also showed that spouse caregivers of cancer patients can experience high levels of stress, potential burnout, depressive symptoms, marital distress, poor health, and unmet needs (Braun, Mikulincer, Rydall, Walsh, & Rodin, 2007; Chen et al., 2004; Hagedoorn et al., 2008; Kurtz et al., 1995; Nijboer et al., 1998). However, caregivers receive little support to perform their vital role (Given, Given, & Kozachik, 2001). It is the aim of this study to focus primarily on the spousal caregivers in their caregiving for spouse with cancer, and to support couples coping with cancer as dyads.

1.2 Research aims and objectives

The purpose of this research is to develop, deliver and evaluate a ‘Caring for Couples Coping with Cancer “**4Cs**” Programme’ aims to support couples coping with cancer as dyads.

Objectives

- To explore the experiences of couples coping with cancer, including their concerns and needs regarding their experiences and roles.
- To delineate a framework for caring for couples coping with cancer.
- To develop and deliver a ‘Caring for Couples Coping with Cancer “**4Cs**” Programme’ to support Chinese couples in their journey of coping with cancer as dyads.
- To determine the acceptability and feasibility of the ‘Caring for Couples Coping with Cancer “**4Cs**” Programme’.
- To explore the effects of the ‘Caring for Couples Coping with Cancer “**4Cs**” Programme’ on improving couples’ dyadic mediator (the self-efficacy), dyadic appraisal (couples’ communication), dyadic coping (couples’ coping), and dyadic outcomes (physical and mental health, negative emotions, positive emotions, and marital satisfaction).

1.3 Significance and values

It is the first study in China that focus on supporting couples with cancer, and to examine the effectiveness of a complex intervention of ‘Caring for Couples Coping with Cancer “**4Cs**” Programme’ in supporting couples coping with cancer as dyads using skill training, psycho-educational, and cognitive behaviour therapy approach.

The findings of this study will provide evidence if couples who attend the ‘Caring for Couples Coping with Cancer “**4Cs**” Programme’ will report greater improvements in couples’ dyadic mediator (the self-efficacy), dyadic appraisal (couples’ communication), dyadic coping (couples’ coping), and dyadic outcomes (physical and mental health, negative emotions, positive emotions, and marital satisfaction). Consequently, the findings of this study will benefit not only the couples coping with cancer, but also the development of the related support programme for couples coping with different chronic disease in China.

1.4 The adopted Medical Research Council (MRC) framework

The Medical Research Council (MRC) framework provides guidance on the development, evaluation and implementation of complex interventions to improve health (Medical Research Council, 2008). A complex intervention is an intervention that consists of various components that act independently or inter-dependently (Campbell et al., 2000; Craig et al., 2008), and whose function and process are standardised (Hawe, Shiell, & Riley, 2004).

1.4.1 The process from development through to implementation of a complex intervention

As showed in Figure 1-1, there are four phases in the process of developing-evaluating-implementing a complex intervention: development, determination of feasibility/piloting, evaluation, and implementation (Medical Research Council, 2008).

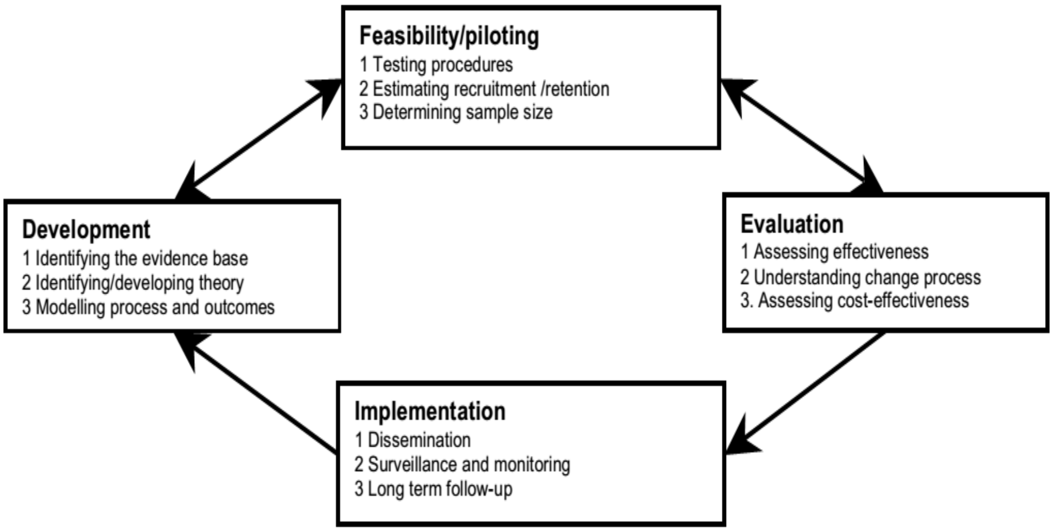


Figure 1-1. Key elements of the development and evaluation process

(Medical Research Council, 2008)

There are three steps in the development phase of a complex intervention: identifying the evidence base, identifying/developing theory, and modelling process and outcomes. First, it is suggested that the ideally method for identifying the relevant, existing evidence base be carrying out a systematic review. Then, be aware of the relevant theory is recognized as more likely to result in an effective intervention than is a purely empirical or pragmatic approach. Further, modelling a complex intervention prior to a full scale evaluation can provide important information about the design of both the intervention and the evaluation (Medical Research Council, 2008).

In the phase of assessing feasibility and piloting, contents includes testing procedures for their acceptability, estimating the likely rates of recruitment and retention of subjects, and the calculation of appropriate sample sizes.

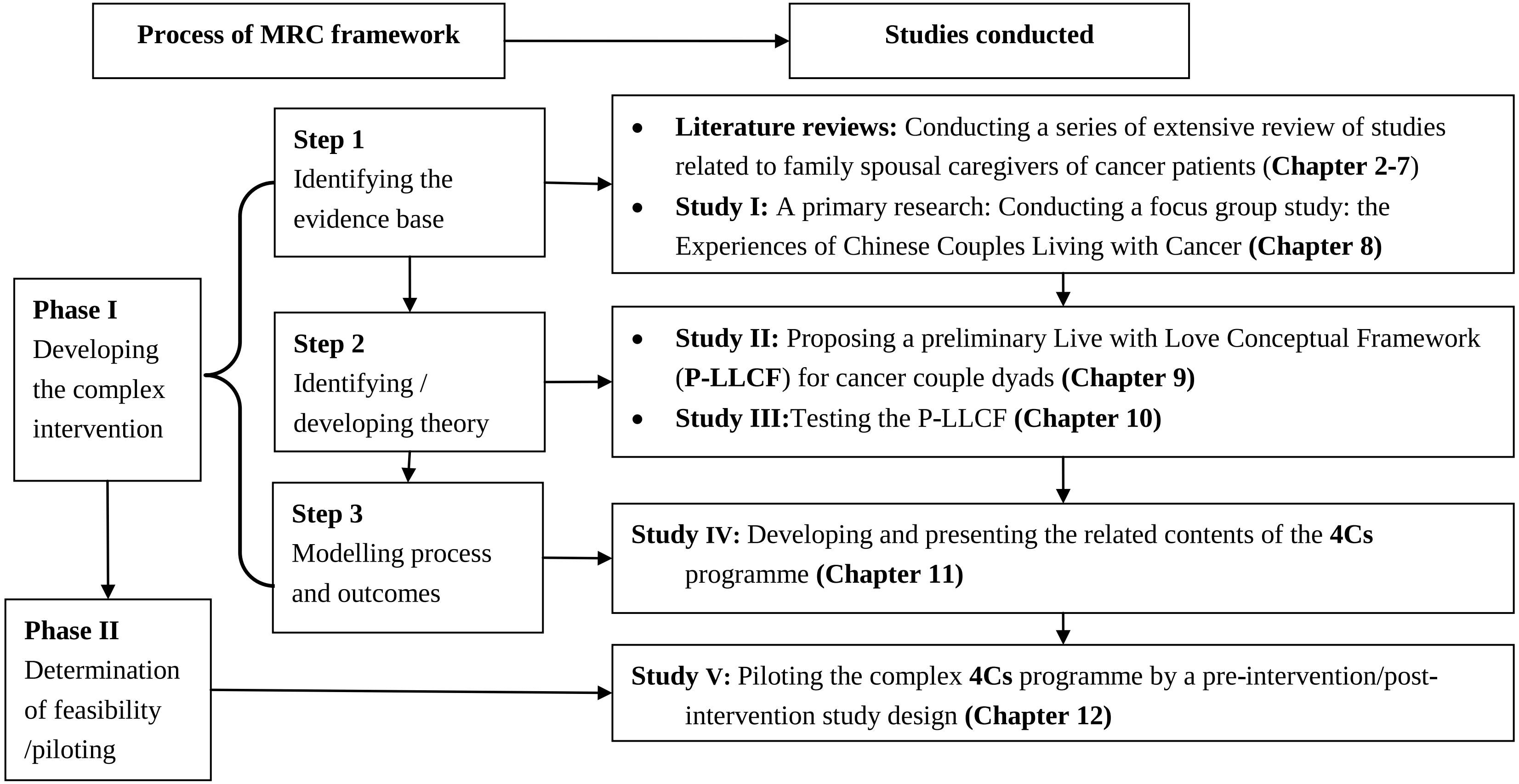
For evaluating a complex intervention, there are many study designs to choose from. It is recommended that be sure different designs suit different questions and different circumstances. More appropriate methodological choices come from awareness of the whole range of experimental and non-experimental approaches.

Regarding implementation and beyond, some methods are suggested, including publication in the research literature and getting the findings translated into routine practice or policy.

1.4.2 Studies conducted in developing and piloting the 4Cs programme

Of the four phases in the process of developing-evaluating-implementing a complex intervention, this project conducted the first two phases: development and determination of feasibility/piloting. Figure 1-2 outlines the key elements in the first two phases of developing and piloting an intervention according to the guidelines of the MRC framework, and corresponding studies conducted in developing and piloting the **4Cs** programme (and presented in this thesis).

In summary, the first two phases of the MRC framework in developing a complex intervention programme guided the process of this overall study. In phase I of the development of the **4Cs** programme, three steps were conducted: (1) identifying evidence: evidence identified from extensive reviews of the literature (**Chapter 2-7**) and a focus group interview study (**study I**); (2) identifying or developing a theory: a preliminary Live with Love Conceptual Framework (P-LLCF) was proposed **(study II**), and the P-LLCF was tested using mixed methods design (**study III**); and (3) modelling the process and outcomes: the **4Cs** programme was developed based on the P-LLCF (**study IV**). In phase II of determination of feasibility/piloting: the **4Cs** programme was piloted by a pre-intervention/post-intervention study design (**study V**).



- **Literature reviews:** Conducting a series of extensive review of studies related to family spousal caregivers of cancer patients (**Chapter 2-7**)
- **Study I:** A primary research: Conducting a focus group study: the Experiences of Chinese Couples Living with Cancer **(Chapter 8)**

- **Study II:** Proposing a preliminary Live with Love Conceptual Framework (**P-LLCF**) for cancer couple dyads **(Chapter 9)**
- **Study III:**Testing the P-LLCF **(Chapter 10)**

Study IV: Developing and presenting the related contents of the **4Cs** programme **(Chapter 11)**

Study V: Piloting the complex **4Cs** programme by a pre-intervention/post-intervention study design **(Chapter 12)**

Figure 1-2. Process of MRC framework and Studies conducted corresponding to MRC framework in developing and piloting the 4Cs programme

1.5 Outline of the thesis

This thesis is organized into three parts and thirteen chapters sequentially through the steps in the research process of (Part I) Introduction of the thesis and the adopted MRC framework, (Part II) Studies Conducted according to the process of MRC framework, and (Part III) Conclusions and Suggestions for future research.

Part I includes the introduction of the significance of developing and delivering a ‘Caring for Couples Coping with Cancer “**4Cs**” Programme’ in supporting couples coping with cancer as dyads, and the introduction of the adopted MRC framework (**Chapter 1**).

Part II, according to the process of MRC framework, as showed in figure 1-2, extensive reviews of literature on the phenomenon of spousal caregiver for cancer patients (**Chapter 2-7**), and five inter-related and sequential studies are presented (**Chapter 8-12**).

Before the conceptualization of this study, a review of literature on studies in Mainland China on spousal caregivers of cancer patients was attempted, but only a few studies can be identified specifically on spousal caregivers (Li & Loke, 2012). Although study on family caregivers of cancer patients in China has received extensive attention from clinicians and researchers, studies still in its infancy stage. For a better understanding of the spousal caregiving phenomenon, a series of review of studies related to family spousal caregivers of cancer patients was conducted. Chapter 2-7 provide an overview of the studies related to spousal caregivers for patients with cancer. The reviews of literature covered: spouses' experience of stress in caregiving for cancer patients (**Chapter 2**); a spectrum of hidden morbidity among spousal caregivers for cancer patients (**Chapter 3**); the positive aspects of spousal caregivers for cancer patients (**Chapter 4**); the mutuality of the spousal caregiver-cancer patient dyads (**Chapter 5**); existing couple-based Interventions for couples coping with cancer (**Chapter 6**), and **Chapter 7** provides a summary of the reviews of literature and the rational for the choice of methodology in conducting this project for dealing with the study gap identified in the literature reviews.

Guided by Medical Research Council framework, five inter-related and sequential studies include study I of identifying evidence from a focus group study (**Chapter 8**), study II of identifying or developing a theory: a preliminary Live with Love Conceptual Framework (P-LLCF) was developed (**Chapter 9**), and study III the testing of the P-LLCF (**Chapter 10**), study IV of modelling the process and outcomes: the **4Cs** programme was developed based on the P-LLCF (**Chapter 11**), and study V in determination of the feasibility and/or piloting: the **4Cs** programme was piloted by a pre-intervention/post-intervention study design (**Chapter 12**).

Finally, **Part III** draws the conclusions of this study and discusses the implications for nursing practice, as well as the limitations of the study, recommendations for future research, and reflection on the project (**Chapter 13**).

PART II STUDIES CONDUCTED ACCORDING TO THE PROCESS OF MRC FRAMEWORK

Chapter 2

LITERATURE REVIEW (I)

Spouses' experience of stress in caregiving for cancer patients*

2.1 Primary stressors

2.2 Secondary stressors

2.3 Appraisal

2.4 Cognitive-behavioral responses

2.5 Health and wellbeing

2.6 Summary

*The content of this Chapter was published:

Li, Q., Mak, Y.W., Loke, A.Y*. (2013). Spouses’ experience of caregiving for cancer patients: a literature review. *International Nursing Review*, 60(2), 178-187.

It has been reported that spouses are the predominant primary informal caregivers for cancer patients in the USA (Kurtz et al., 1995), and this is also the case in both Taiwan and in China (Chen et al., 2004). Demands are placed on the informal caregivers to meet the multidimensional needs of family members with cancer, including treatment monitoring; treatment-related symptom management; emotional, financial, and spiritual support; and assisting with personal and instrumental care (Given et al., 2001). As a consequence, spousal caregivers of cancer patients can experience high stress, potential burnout, depressive symptoms, poor health and unmet needs (Fitzell & Pakenham, 2010; Hagedoorn et al., 2008; Kim, Baker, & Spillers, 2007; Matthews, Baker, & Spillers, 2004; Perz, Ussher, Butow, & Wain, 2011). It has been reported that spousal emotional distress may be as high as or even higher than that of the patients themselves (Hagedoorn et al., 2008; Northouse, Mood, Templin, Mellon, & George, 2000).

The process of literature search and selections

A systematic search was conducted to identify the literature on the spousal caregiving experience of cancer patients, including those specifically addressing the gender differences in caregiving. The search included studies published in either English or Chinese from January 2000 to March 2012. The following computerized databases were searched: MEDLINE, CINAHL, Science Citation Index Expanded, Scopus, PsychINFO and the CAJ (China Academic Journal) Full-text Database. The key search terms used were ‘cancer’ or ‘oncology’ or ‘carcinoma’ AND ‘caregiver’ or ‘caregiving’ or ‘carer’ AND ‘gender differences’ or ‘gender’ AND ‘spouse’ or ‘couple’ or ‘partner’. Besides electronic searches, the reference lists of the identified studies were also hand-searched for further relevant studies; the publications of the prominent authors in this area were searched for relevant publications.

Data and literature were extracted from each of the included studies using a standard format: information on the literature, study method, study aims, samples/settings, and findings. The flow diagram of the search and selection process is outlined in figure 2-1. The characteristics of studies included in this review are summarized in appendices Table 2-1 (p.355).

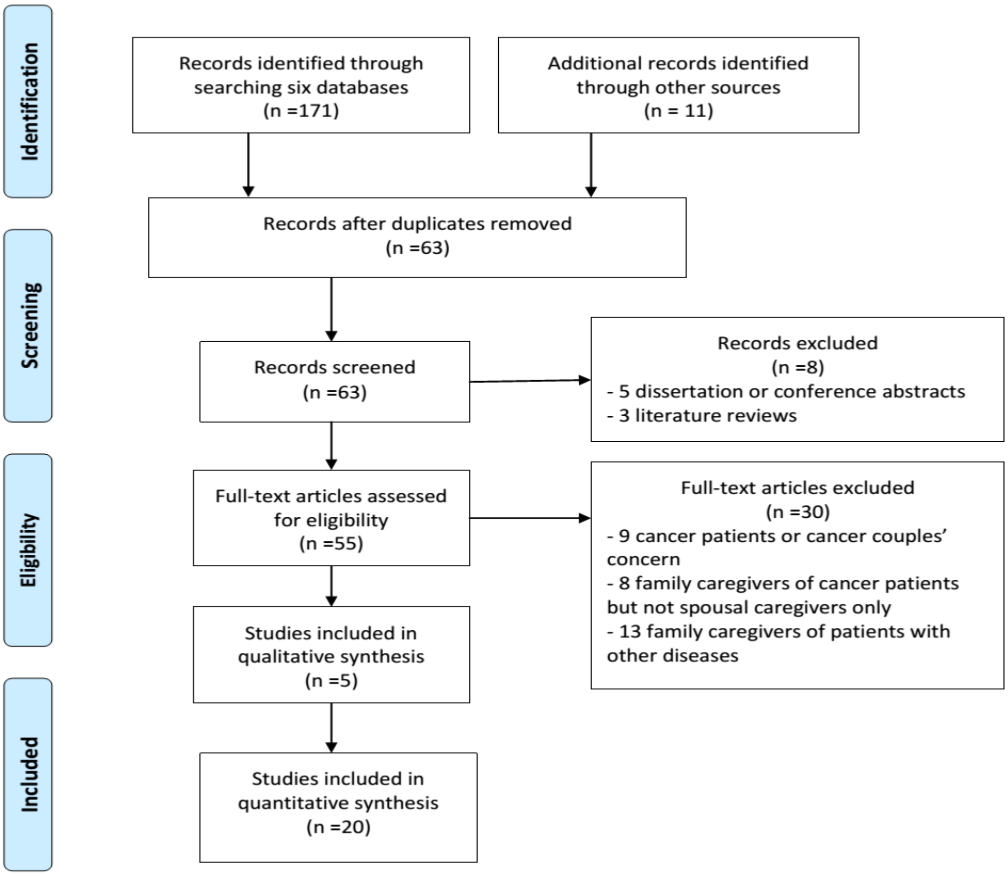


Figure 2-1. The flow diagram on identifying the literature

All of the 25 articles included in this review were published in peer-review journals. The impact factor of these journals ranges from 1.211 to 4.200. With exception of two journals, one is an official journal published by the European School of Oncology, and the other is a journal that “offers reviews of key neuropsychiatric topics for clinicians, with the aim of trying research findings to the needs of clinical practice” (JAMA 1997, p. 873). In all of these 20 quantitative articles, the study design were well defined; time point of data collection was specified; characteristics of the targeted population and sample size were clearly described; the analysis for confounding variables were properly adjusted; the outcomes and estimated significances were stated without obviously bias. For the five qualitative studies, the research questions were clearly stated; the research approaches applied were fit to the purpose of the study; the phenomenon were clearly described; the presentation of the findings was logical, consistent and easy to follow; the writing effectively promote understanding. In general, the 25 articles included in this review were considered of high quality.[1]

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[1] This method of quality assessment for studies was also applied to assess the quality of studies included in the following three Chapters of literature review (from Chapter 3 to Chapter 5). In general, the articles included in these reviews were considered of high quality.

Conceptual model of the cancer family caregiving experience

A model on cancer family caregiving experience (CFCE) is an expanded comprehensive model developed by Fletcher et al (2012) based on cancer family caregiving research published from 2000 to 2010. The model contains three main elements – the contextual factors and the cancer trajectory, as well as the stress process of the caregiving experience (Fletcher, Miaskowski, Given, & Schumacher, 2012). The ‘stress process’ element of this CFCE model was applied for scrutiny spouses' experience of caregiving for cancer patients. It consists of five constructs: primary stressors, secondary stressors, appraisal, cognitive-behavioral responses, and health and wellbeing outcomes (Figure 2-2). In this ‘stress process, the health and wellbeing outcomes are affected directly or indirectly by the other four constructs.

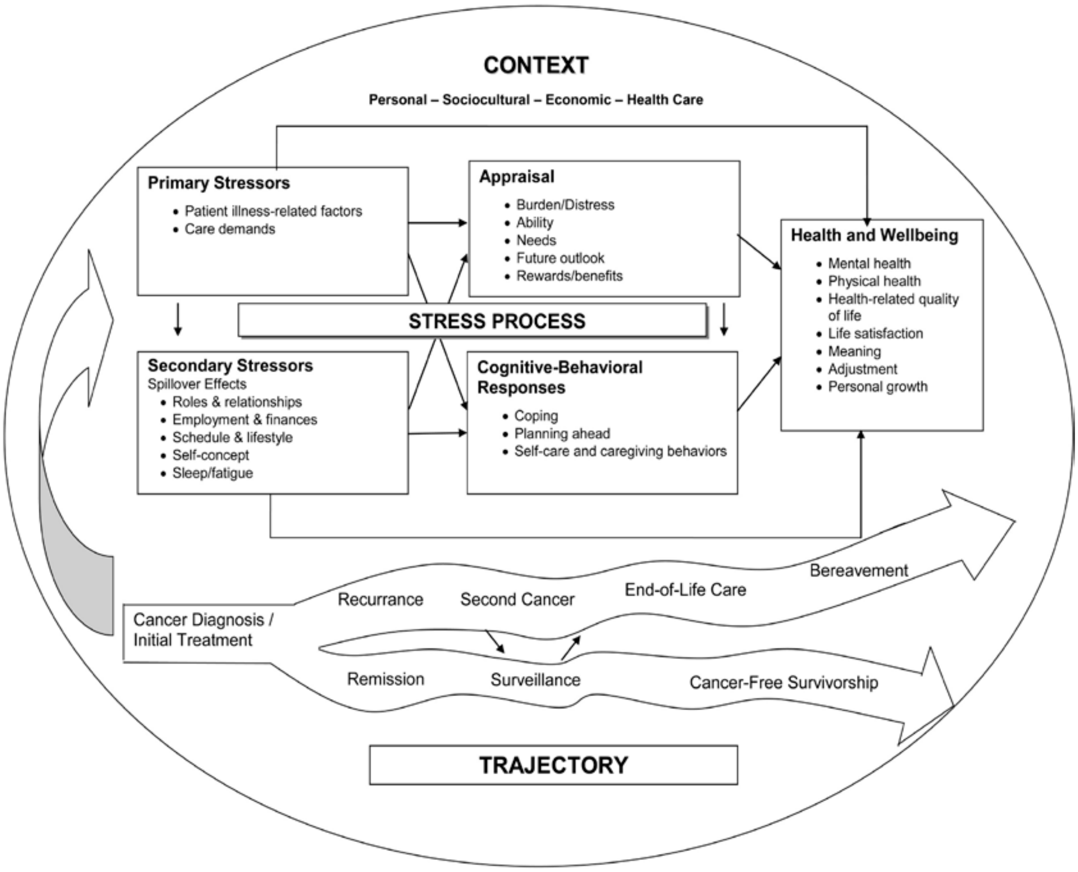


Figure 2-2. The cancer family caregiving experience: an updated and expanded conceptual model (CFCE)

(Fletcher et al, 2012)

2.1 Primary stressors

The primary stressors included ‘patient illness-related factors’ and ‘care demands’. The patient illness-related factors such as stage of the cancer, physical health, and care demands (dependency) were the primary stressors, and associated with caregivers’ physical and mental health. It was reported that spousal caregivers of patients with a more advanced stage of cancer had an elevated level of anxiety symptoms than spousal caregivers of patients with a less advanced cancer stage (Gustavsson-Lilius, Julkunen, Keskivaara, & Hietanen, 2007) . A correlation analysis showed that patients' physical health (r=0.23, $P<0.001$) was correlated with that of spousal caregivers, while patients' physical (r=0.18, $P<0.001$) and mental health (r=0.24, $P<0.001$) were correlated with spousal caregivers' mental health (Colgrove, Kim, & Thompson, 2007).

The objective measures of a patient's impairment or amount of care required were not strong predictors of caregiver depression (Haley, LaMonde, Han, Burton, & Schonwetter, 2003). One study revealed that patients' diagnosis and duration of illness were not significantly associated with caregivers' wellbeing, but instead patients' dependency was negatively related to caregivers' mental health and social functioning (Nijboer, Tempelaar, Triemstra, Sanderman, & van den Bos, 2001). As to caregiving demands, another study revealed that females performed more care tasks than male spousal caregivers ($P<0.05$), particularly household tasks.

2.2 Secondary stressors

Secondary stressors, also known as spillover effects, include 'role and relationship', 'schedule and lifestyle', 'sleep/fatigue', and 'employment and finance'.

The findings of a quantitative study showed that female spousal caregivers experienced more role problems than males one week post diagnosis (Psychosocial Adjustment to Illness Scale, PAIS, m=25.8 vs. 18.2) and 60 days (PAIS, m=23.4 vs. 20.7) and one year post surgery (PAIS, m=22.2 vs. 20.9) (Northouse et al., 2000). The strongest predictors of spousal caregivers' role problems were their own baseline role problems and level of marital satisfaction (Northouse et al., 2000). A qualitative study that explored male spousal caregivers coping with a partner’s gynecological cancer showed that the changing roles of men as carers could enhance or impede caregiving involvement (Maughan et al., 2002). Although males were unprepared to perform traditional female work in their role as carers for spouses with breast and gynecological cancers, they were satisfied with their role as caregivers and what they did for their spouse (Lopez et al., 2012).

Social and emotional support is grouped under ‘relationship’ as secondary stressors. A study on couples’ adjustment to colon cancer showed that when compared to male spousal caregivers, females perceived less social support at one week post diagnosis and at 60 days and one year post surgery, with Social Support Questionnaire scores m=92.6 vs. 99.8, m=93.8 vs. 98.4, and m=91.2 vs. 96.0 respectively (Northouse et al., 2000). Another study also reported that fewer female caregivers (51%) received help from family and friends than male caregivers (84%) (Kim, Loscalzo, Wellisch, & Spillers, 2006).

A study conducted in Israel revealed a different story, in that females reported receiving more support from family (Perceived Family Support, PFS m=16.47 vs. 15.62) and friends (Cancer Perceived Agents of Social Support, friends support scale CPASS m=3.31 vs. 2.76) than male spousal caregivers (Goldzweig et al., 2009). Another study showed that caregivers who had a higher level of social activities and greater subjective satisfaction with social support reported lower caregiver depression and greater life satisfaction (Haley et al., 2003).

A study on gender differences in the emotional support of spousal caregivers for patients with cancer showed that both male and female spousal caregivers provided the same high level of emotional support before surgery (The Berlin Social Support Scales (BSSS), m=3.77 vs. 3.71). However, over time, males provided a significant decline of emotional support one month after surgery (BSSS, m=3.71 vs. 3.54), whereas female spousal caregivers continued to extend emotional support at the same level as they had done before surgery (BSSS, m=3.77 vs. 3.74) (Luszczynska, Boehmer, Knoll, Schulz, & Schwarzer, 2007).

Studies have shown that caregivers suffered disruptions to their schedule due to caregiving. The impacts of this disruption on their schedule were decreased over 6 months, from the time of diagnosis to 3 and 6 months after diagnosis (Caregiver Reaction Assessment Scale-CRA, for females, m=2.43, 2.30, 2.06, and for males, m=2.38, 2.03, 1.96) respectively (Nijboer et al., 2000; Nijboer et al., 2001). Interviews with men who were taking care of their spouse with cancer revealed that changes in lifestyle in order to support their spouse in the journey, with insufficient time to work at their job (Lopez et al., 2012).

In a qualitative study, when male partners were asked to share their experience in caring for their partners, they reported tiredness and loss of sleep in the first six months of caregiving (Lopez et al., 2012). Male spousal caregivers also faced stressors such as fear of the unknown/uncertainty, lack of support, limited social contact, and fear of losing their partner. They also worried about their finances and had difficulty expressing their emotions (Lopez et al., 2012).

Overall, spousal caregivers suffered from spillover effects due to secondary stressors, such as role problems, lack of social and emotional support, disrupted schedule, and loss of sleep and fatigue.

2.3 Appraisal

Caregiving appraisal as a protective factor was examined as a predictor of depression and life satisfaction in spousal caregivers (Haley et al., 2003). Study results showed that caregivers who subjectively appraised caregiving tasks as lower stress and who found meaning and subjective benefits from caregiving had lower depression and higher life satisfaction (Haley et al., 2003).

The moderating (stress-buffering or aggravating) effect of spirituality on spousal caregivers' caregiving stress and mental and physical health was studied. It was reported that the negative impact of caregiving stress on mental health was less prominent for caregivers with higher levels of spirituality (slope=-0.72, $P<0.05$) than those with lower levels of spirituality (slope=-1.52, $P <0.001$) (Colgrove et al., 2007). Female spousal caregivers with higher self-efficacy ($r=-0.64$ $P<0.001$) and higher personal accomplishment ($r=-0.48$, $P<0.01$) experienced less stress in caregiving. These associations were not found in males ($r=-0.20$, $r=0.07$ respectively) (Hagedoorn, Sanderman, Buunk, & Wobbes, 2002). Less optimistic spousal caregivers of lung cancer patients had higher levels of depression at the time of treatment ($r=-0.34$, $P<0.01$) and one year after treatment ($r=-0.25$, $P<0.05$) (Pinquart & Duberstein, 2005).

Male spousal caregivers with higher levels of caregivers' esteem (Caregiver Reaction Assessment Scale, CRA self-esteem) ($\beta=0.18$, $P<0.001$) had lower levels of caregiving stress (The Pearlin Stress Scale) ($\beta=-0.10$, $P<0.05$) (Kim et al., 2006). Males were reported to have higher self-esteem, which protects them from stress. Other studies indicated that while female spousal caregivers reported decreased levels of self-esteem over time from the time of diagnosis and at 3 and 6 months (CRA self-esteem, m=4.24, 4.16, 4.10 respectively), males' self-esteem did not change over time while caregiving (m=4.16, 4.09, 4.08 respectively) (Nijboer et al., 2000; Nijboer et al., 2001) .

Caregivers' characteristics affect how spousal caregivers' appraisal of their caring experience. Spousal caregivers were affected by their ability to find meaning and benefits from caregiving, spirituality, self-efficacy, optimism, and self-esteem.

2.4 Cognitive-behavioral responses

Ability in coping, planning ahead, self-care and caregiving behaviors are the cognitive-behavioral responses that mediate stress in caregiving.

Men tend to be solution-driven (Fergus & Gray, 2009). Male spousal caregivers may be ashamed of their own emotional reactions in caregiving and find it difficult to express themselves or consider it as a sign of being 'crazy'. This leads to their using avoidance as a coping strategy (Lopez et al., 2012), while females were found to be more attentive to their emotions and were more likely to keep busy and try helping others (Holtslander & Duggleby, 2009). Studies on female spousal caregivers also reported that females were more likely to plan ahead, look to the future (Holtslander & Duggleby, 2009) or face tomorrow (Sutherland, 2009).

Female spousal caregivers who are more capable of self-care and exhibit more supportive and less unsupportive behavior were likely to experience less stress in caregiving (Hagedoorn et al., 2002). With greater attachment anxiety, female spousal caregivers provided more frequent tangible care ($\beta=0.15$, SE=0.07, $P<0.05$), whereas males provided less frequent tangible care ($\beta=-0.25$, SE=0.12, $P<0.05$) (Kim & Carver, 2007). With greater attachment security, females were likely to provide frequent emotional care ($\beta=0.23$, SE=0.11, $P<0.05$), whereas males with greater avoidance of attachment provided less frequent emotional care ($\beta=-0.29$, SE=0.09, $P<0.001$) (Kim & Carver, 2007).

The cognitive-behavioral responses of males and females were different. Female spousal caregivers were more capable of planning ahead, keeping busy by helping, and undertaking more tangible and emotional caregiving. Male spousal caregivers exercised avoidance and found it difficult to express their emotional reaction to caregiving, providing less tangible and emotional support.

2.5 Health and wellbeing

The health and wellbeing are the outcomes of a stress process affected directly or indirectly by primary and secondary stressors, appraisal, and cognitive-behavioral responses. This construct consisted of mental health, physical health, health-related quality of life, life satisfaction, meaning, adjustment, and personal growth.

For an in-depth understanding the outcomes of the caregiving experience and the related factors, the literature on negative and positive health outcomes were reviewed separately in Chapter 3 (A spectrum of hidden morbidity among spousal caregivers for cancer patients) and Chapter 4 (The positive aspects of spousal caregivers for cancer patients).

2.6 Summary

Of the 25 articles included in this review, no mixed study designs using quantitative and qualitative methods were identified. An in-depth understanding of the caregiver experience for cancer patients cannot be achieved from a quantitative study (Hagedoorn et al 2008). However, it should be made clear that there is no single best method to advance our understanding of couples confronting cancer. Important insights can be obtained from the coordinated use of multiple methods in the same study. A mixed study design of quantitative and qualitative methods may be valuable. Although samples included patients at various stages of cancer (Stages I/II/III), no study has been found to explore the whole trajectory of spousal caregiving experience, from the diagnosis of the cancer to bereavement care.

In summary, this review of literature identified that spousal caregivers of cancer patients suffered from high level of stress, including primary and secondary stressors in caregiving. The stress experience is mediated by how the caregivers appraise their situations, and what are their cognitive-behavioral responses. This better understanding of the spousal caregiving experience provides nurses with the information needed to develop interventions to support spousal caregivers to relieve their stress and to care for their loved ones with cancer.

Chapter 3

LITERATURE REVIEW (II)

A spectrum of hidden morbidity among spousal caregivers for cancer patients*

*The content of this Chapter was published:

Li, Q., Loke, A.Y.* (2013). A spectrum of hidden morbidities among spousal caregivers for patients with cancer, and differences between the genders: A review of the literature. *European Journal of Oncology Nursing*, 17(5), 578-587.

Many studies have reported on the negative consequences of caregiving, such as fatigue, loss of sleep, loss of appetite, and illness (Blum & Sherman, 2010; Dhruva et al., 2012). There are also consequences that may not be readily recognizable by both caregivers and health professionals until the caregiver falls ill. Caregivers have been reported to suffer from physical, mental, and social problem (Braun et al., 2007; Hagedoorn et al., 2008; Kurtz, Kurtz, Given, & Given, 2004; Matthews et al., 2004; Pitceathly & Maguire, 2003)

A review of the costs of family caregiving has shown that the caregiving role can be highly stressful and can lead to considerable psychological, social, economic, and health costs for the family caregiver (Haley, 2003). Spouse caregivers of cancer patients can experience high levels of stress, potential burnout, depressive symptoms, marital distress, poor health, and unmet needs (Braun et al., 2007; Chen et al., 2004; Hagedoorn et al., 2008; Kurtz et al., 1995; Nijboer et al., 1998). Showing concern and support for spousal caregivers is important since their mental and physical status affects their capacity to continue to provide care for an ill spouse (Northouse, Templin, & Mood, 2001).

According to the WHO's health model (Larson, 1999), health is 'a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity'. Where 'health' is lacking, but before illness has developed, a sub-optimal state of health – 'hidden morbidity' – can be considered to exist. In web dictionaries (Thesaurus and Encyclopedia), the term 'morbidity' has been defined as 'the relative incidence of a particular disease' and 'an abnormally gloomy or unhealthy state of mind'. The term 'hidden morbidity' used in this review refers to a condition that not known to health professionals and even to the person who is suffering from the sub-optimal condition (Braun et al., 2007).

The process of literature search and selections

A systematic search was conducted to identity articles published in English or Chinese from January 2000 to July 2012. Studies were located using electronic searches, a manual search, and an author search. The following computerized databases were searched: MEDLINE, CLINAHL, Science Citation Index Expanded, Scopus, PsychINFO, and China Academic Journals Full-text Database. The key search terms used were 'cancer' or 'oncology' or 'carcinoma' AND 'caregiver' or 'caregiving' or 'carer', AND 'gender differences' or 'gender' AND 'spouse' or 'couple' or 'partner'. The flow diagram o the search and selection process is outlined in Figure 3-1.

The characteristics of studies included in this review are summarized in appendices Table 3-1 (p.367). A synthesis of the findings of these studies focused on the following three main dimensions – mental, physical, and social – of the morbidities of caregivers according to the WHO's health model (Larson, 1999).

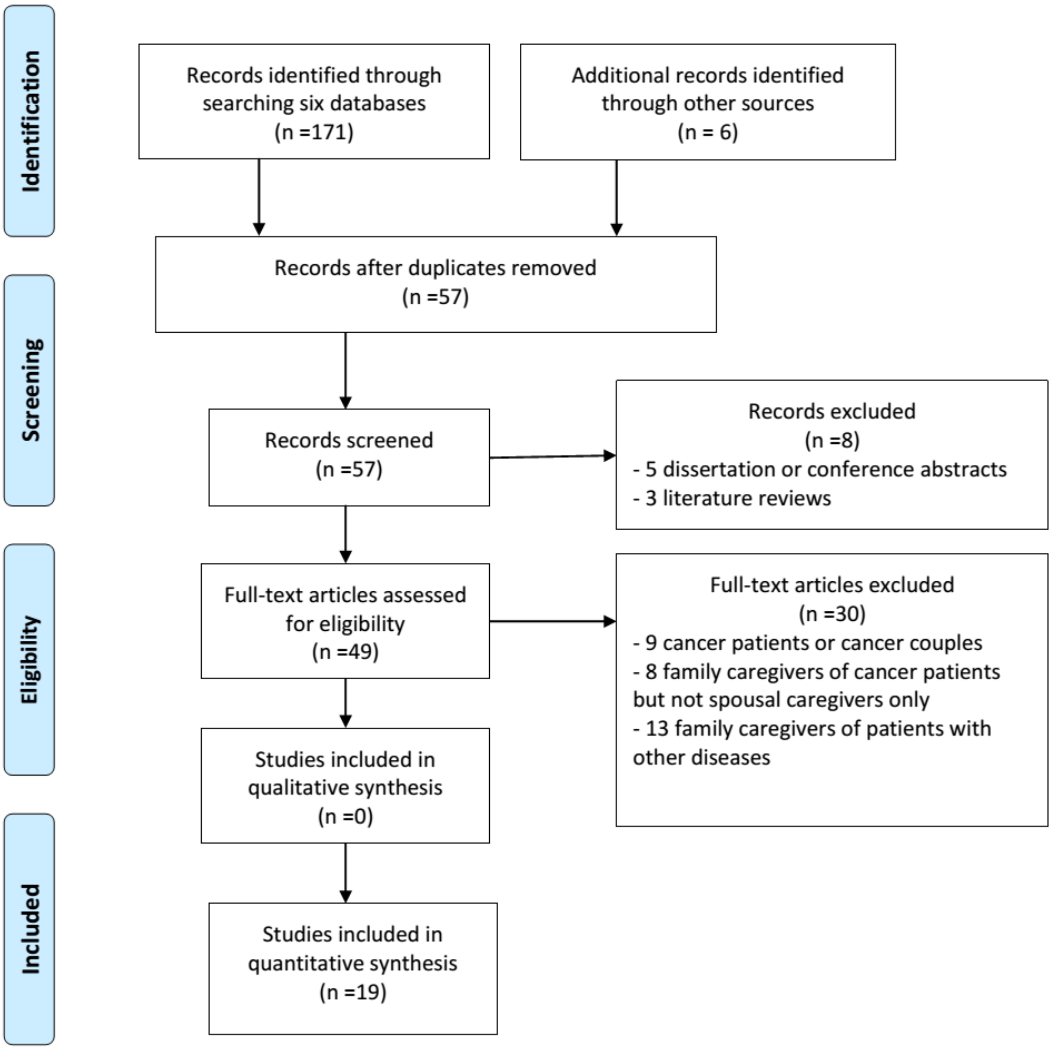


Figure 3-1. The flow diagram on identifying the literature

3.1 Mental morbidity

The mental morbidity of the caregivers refers to the high level of psychological distress, depression, anxiety, and poor mental well-being suffered by the caregivers.

Studies using the Epidemiological Studies Depression Scale (CES-D) to measure depression showed that female spousal caregivers experienced a higher level of psychological distress than males, with the mean=11.83 vs. 8.1 in one study (Hagedoorn, Buunk, Kuijer, Wobbes, & Sanderman, 2000) and m=12.93 vs. 7.50 in another study (Hagedoorn et al., 2002). One study reported that female spousal caregivers experienced depression when caring for patients with cancer (CES-D, m=17.73**)** (Haley et al., 2003). In a longitudinal study, increased levels of psychological distress prior to a scheduled surgery (CES-D, m=9.3 and 9.2) was reported for both female and male spousal caregivers. Three and six months after the surgery, while the distress levels of males returned to normal (m=7.8 and 7.3), females continued to have a high level of distress (m=11.3 and 10.3) (Tuinstra et al., 2004).

A study that adopted the Pearlin Stress Scale (PSS), showed that when compared to females, male spousal caregivers reported experiencing a lower level of stress (β=-0.10, P<0.05) (Kim et al., 2006). A study that explored the influence of correspondence in informational coping styles on the psychological reactions of married couples, which used the mental health inventory (MHI), reported that female spousal caregivers experienced slightly more psychological distress than their male counterparts (Barnoy, Bar-Tal, & Zisser, 2006). Another study on the spousal caregivers of patients with lung cancer, which used the Hamilton Depression Scale (HDS), also indicated that higher levels of depression at the time of treatment (t=4.31, P< 0.001) and one year after treatment (t=4.29, P< 0.01) in females was emerged when compared to male spousal caregivers (Pinquart & Duberstein, 2005).

A study using the Profile of Mood States (POMS) that involved of 131 couples with a partner who was suffering from various types of cancer and who was receiving a hematopoietic stem cell transplant (HSCT), reported that, when compared with male spousal caregivers, females were more depressed (0.98 vs. 0.57) and anxious (1.33 vs. 0.89) (Langer, Abrams, & Syrjala, 2003). The results of another study also supported the view that female spousal caregivers were more depressed and anxious than their male counterparts (Langer, 2003).

The study that explored the relationship between a strong ‘sense of coherence’ (SOC) and depression (the Beck Depression Inventory, BDI) and anxiety (the Endler Multidimensional Anxiety Scales, EMAS-State) also reported that female spousal caregivers were more depressed and had higher levers of anxiety at the time of the diagnosis of cancer (BDI, m=6.2 vs. 4.0; EMAS–state, m=39.5 vs. 33.5) and at 8 months post-diagnosis (BDI, m=6.0 vs. 3.9; EMAS–state, m=35.3 vs. 30.1) than male spousal caregivers (Gustavsson-Lilius et al., 2007).

There were two studies that focused on the mental well-being of caregivers (Colgrove et al., 2007; Nijboer et al., 2001). A study using the Medical Outcomes Study Short Form-36 (MOS-SF36) that examined the effects of spirituality on the stress and mental health of spousal caregivers showed that the female gender was associated with poorer mental health. However, the mental health score of the spousal caregivers (m=50.54) did not significantly differ from that of the published mean of the general population of the United States (m=50.00) (Colgrove et al., 2007).

Another study using the RAND 36-item Health Survey that examined the quality of life of caregivers who have cared for family members with colorectal cancer, reported that females experienced worse mental well-being within a 6-month period than their male counterparts (m=70.0 vs. 78.0) (Nijboer et al., 2001). In general, female spousal caregivers are more likely to experience poorer mental health (Colgrove et al., 2007) or worse mental well-being (Nijboer et al., 2001).

No gender differences in concurrent stress were reported in a study conducted in the USA. The Smilkstein Stress Scale (SSS) was used to assess the concurrent stress (the mean scores for females vs males were 16.8 vs. 14.6, 17.1 vs. 15.2, and 16.6 vs. 13.5 at one week after the diagnosis, 60 days, and one year post-surgery, respectively) (Northouse et al., 2000). Two studies that reported that female spousal caregivers experienced significantly lower levels of distress than males were conducted in Israel, and that the same instrument (the Brief Symptom Inventory, BSI) was used to measure psychological distress (m=65.0 vs. 59.2, and 61.5 vs. 55.7 in the two studies) (Baider, Ever-Hadani, Goldzweig, Wygoda, & Peretz, 2003; Goldzweig et al., 2009). In summary, female spousal caregivers are more likely to experience more mental morbidity than males, such as a higher level of psychological distress, depression, and anxiety and a lower level of mental well-being.

3.2 Physical morbidity

The physical morbidity of caregivers refers to their poor physical health or functioning. A study examined caregivers' physical health using the Medical

Outcomes Study Short Form-36 (MOS-SF36). The results revealed that although no gender differences was found with regard to the physical health of caregivers, their mean physical health score was significantly lower than that of the published mean of the US general population (m=47.01 vs. 50.00) (Colgrove et al., 2007).

Two studies, using the Caregiver Reaction Assessment Scale (CRA) (Nijboer et al., 2000) and the RAND 36-item Scale (Nijboer et al., 2001) respectively, examined the physical health of spouses who have cared for family members with colorectal cancer. A greater loss of physical strength in female spousal caregivers, when compared to their male counterparts, was experienced at the time of their patient’s diagnosis (CRA, m=2.03 vs. 1.76) and six months after the diagnosis (m=1.96 vs. 1.75) (Nijboer et al., 2000). When compared with their male counterparts, poorer physical functioning within a 6-month period in females was also reported in another study (RAND 36-items, m=78.8 vs. 85.2) (Nijboer et al., 2001). In conclusion, female spousal caregivers experienced greater loss of physical strength (Nijboer et al., 2000) and poorer physical functioning (Nijboer et al., 2001) than male spousal caregivers. However, no gender differences in physical health were found in one study (Colgrove et al., 2007).

To summarize, female spousal caregivers were more likely to suffer physical morbidity, such as a lower physical health score (Colgrove et al., 2007), poorer physical functioning (Nijboer et al., 2001), and a loss of physical strength (Nijboer et al., 2000), when compared to males.

3.3 Social morbidity

Four studies on social morbidity identified focused on marital relationships and social support (Goldzweig et al., 2009; Langer et al., 2003; Langer, Yi, Storer, & Syrjala, 2010; Northouse et al., 2000). There were three studies that used the DAS (Dyadic Adjustment Scale) (Langer et al., 2003; Langer et al., 2010; Northouse et al., 2000) to examine marital relationships. Two of them reported that marital satisfaction decreased over time among female spousal caregivers (m=41.76, 38.42, 34.44, 23.34 at pre-HSCT (hematopoietic stem cell transplant), 6 months, 1 year, and 5 years post-HSCT, respectively), but not among male spousal caregivers (DAS, m=41.06, 40.54, 40.44, and 39.63 at pre-HSCT, 6 months, 1 year, and 5 years post-HSCT, respectively) (Langer et al., 2003; Langer et al., 2010). When compared with males, female spousal caregivers also had a lower level of marital satisfaction at 1 year and 5 years after HSCT (DAS m=34.44 vs. 40.44, and 23.34 vs. 39.63 respectively) (Langer et al., 2003; Langer et al., 2010). This is in line with another study in that less marital satisfaction was reported in females at 60 days and 1 year post-surgery when compared to their male countparts (DAS, m=115.8 vs. 123.6, 112.4 vs. 121.6, respectively) (Northouse et al., 2000).

By contrast, a different result was reported in a study that focused on the marital satisfaction of 231 colorectal cancer couples, using the ENRICH Marital Satisfaction Scale (EMS). The results showed that male spousal caregivers experienced a lower level of marital satisfaction than females (m=3.66 vs. 3.72) (Goldzweig et al., 2009). Two studies reported that female spousal caregivers experienced less social support than their male counterparts (Langer et al., 2003; Northouse et al., 2000). A study on the adjustment of couples to colon cancer showed that female spousal caregivers perceived less social support than male ones at one week post-diagnosis, at 60 days post-diagnosis, and at one year post-surgery, with Social Support Questionnaire scores of m=92.6 vs. 99.8; m=93.8 vs. 98.4; and m=91.2 vs. 96.0, respectively (Northouse et al., 2000). Another study also reported that fewer female caregivers (51%) received help from family and friends than male caregivers (84%) (Langer et al., 2003).

Overall, social morbidity were reported in these studies. As to social morbidity in those with lower levels of marital satisfaction, three studies that measured marital satisfaction (DAS) reported that female spousal caregivers experienced a higher level of social morbidity than males, and that the level became worse over time (Langer et al., 2003; Langer et al., 2010; Northouse et al., 2000). Whereas one study that used EMS to measure marital satisfaction reported that male spousal caregivers had higher social morbidity than their female counterparts (Goldzweig et al., 2009). Regarding social morbidity in terms of social support, female spousal caregivers experienced less social support than males (Langer et al., 2003; Northouse et al., 2000).

3.4 Summary

The studies included in this review were cross-sectional and longitudinal in design. Given that a cross-sectional design cannot explore dynamic patterns and the direction of changes over time in the experience of spousal caregivers (Baider et al., 2003), a need exists for longitudinal studies to explore the whole trajectory of the experience of spousal caregivers from the time of the diagnosis of cancer to the bereavement phase. Although ten of the studies included in this review were longitudinal studies with observation times ranging from the time of diagnosis to 5 years, none of the studies explored the whole trajectory of the effort by the couples to cope with cancer. Different measurements were used in these studies to measure the same concept or type of morbidity. This not only affected the research outcomes, but also made it difficult to compare the findings of these studies. Most studies included in this review focused on negative experiences in caregiving. There is a dearth of literature focusing on the positive experiences of spouses caring for cancer patients.

In general, spousal caregivers of patients with cancer suffered from a wide spectrum of hidden morbidities, such as mental morbidity (higher levels of distress, depression, and anxiety, and lower levels of mental health), physical morbidity (lower level of physical health, poorer physical functioning, and the loss of physical strength), and social morbidity (lower marital satisfaction and lower levels of social support). Overall, it can be concluded that spousal caregivers of cancer patients are a high-risk or hidden morbidity population in all three dimensions of the WHO’s definition of health (Larson, 1999).

Chapter 4

LITERATURE REVIEW (III)

The positive aspects of spousal caregivers for cancer patients*

*The content of this Chapter was published:

Li, Q., Loke, A.Y.* (2013). The positive aspects of caregiving for cancer patients: a critical review of the literature and directions for future research. *Psycho-oncology*, 22, 2399-2407.

While most of the studies in this area have focused on the negative experiences of caregiving, several studies have discussed on the positive aspects of the caregiving experience. Caregivers have reported that the experience of caregiving made them feel good about themselves in that they were needed, caregiving added meaning to their lives, enabled them to learn new skills, and strengthened their relationship with the care-receiver and with other members of the family (Schulz & Sherwood, 2008). It has been reported that the five-year mortality rate is lower among the spousal caregiver provided emotional support to their cancer patients than among those who did not (Brown, Nesse, Vinokur, & Smith, 2003).

However, the positive experience of spousal caregiving for cancer patients has been relatively unexplored (Kim, Schulz, & Carver, 2007; Miller & Cafasso, 1992). The lack of acknowledgment of the positive aspects of caregiving seriously skews perceptions of the caregiving experience and limits the ability to acquire a full understanding of caregiving. This creates a barrier to enhancing caregiver adaptation and to developing interventions for caregivers who need help (Kramer, 1997). It is argued that a more holistic view of caregiving needs to be taken by considering its positive aspects or benefits (Hudson, Aranda, & Hayman-White, 2005; Louderback, 2000; Semiatin & O'Connor, 2012). Thus, a review of literature (Li & Loke, 2013a) was conducted to gain more insights and a full picture of the positive aspects of caregiving and to identify its determining factors (Carbonneau, Caron, & Desrosiers, 2010; Kramer, 1997). This better understanding can help professionals to enhance the adaptation and well-being of family caregivers, and to develop interventions to support the positive aspects and improve the quality of caregiving (Carbonneau et al., 2010; Kramer, 1997).

The positive aspects of caregiving were defined broadly as “the extent to which the caregiving role is appraised to enhance an individuals' life space and be enriching” (Kramer, 1997) (p. 219). This definition refers to the positive affective or practical returns that are experienced as a direct result of becoming a caregiver for cancer patients, including post-traumatic growth, benefit finding, optimism, positive effects, hope, and meaning in life (Coyne & Tennen, 2010; Schmidt, Raque-Bogdan, Piontkowski, & Schaefer, 2011).

The process of literature search and selections

A systematic search was conducted to identity literature on the positive aspects of the experience of spouses caring for cancer patients. The search included studies published in English or Chinese from January 1996 to July 2012. Studies were located using several strategies, starting with electronic searches. The following computerized databases were searched: MEDLINE, CLINAHL, Science Citation Index Expanded, Scopus, PsychINFO, and the China Academic Journals Full-text Database. The key search terms used were “cancer” or “oncology” or “carcinoma” AND “caregiver” or “caregiving” or “carer” AND “optimism” or “positive affect” or “benefit finding” or “hope” or “life meaning” or “post-traumatic growth.” In addition to electronic searches, the reference lists of identified studies were also manually searched for further relevant studies, and the publications of the leading author in this field were searched for relevant publications. Articles were selected according to the inclusion and exclusion criteria. The flow diagram of the search and selection process is outlined in Figure 4-1. The characteristics of studies included in this review are summarized in appendices Table 4-1 (p.374).

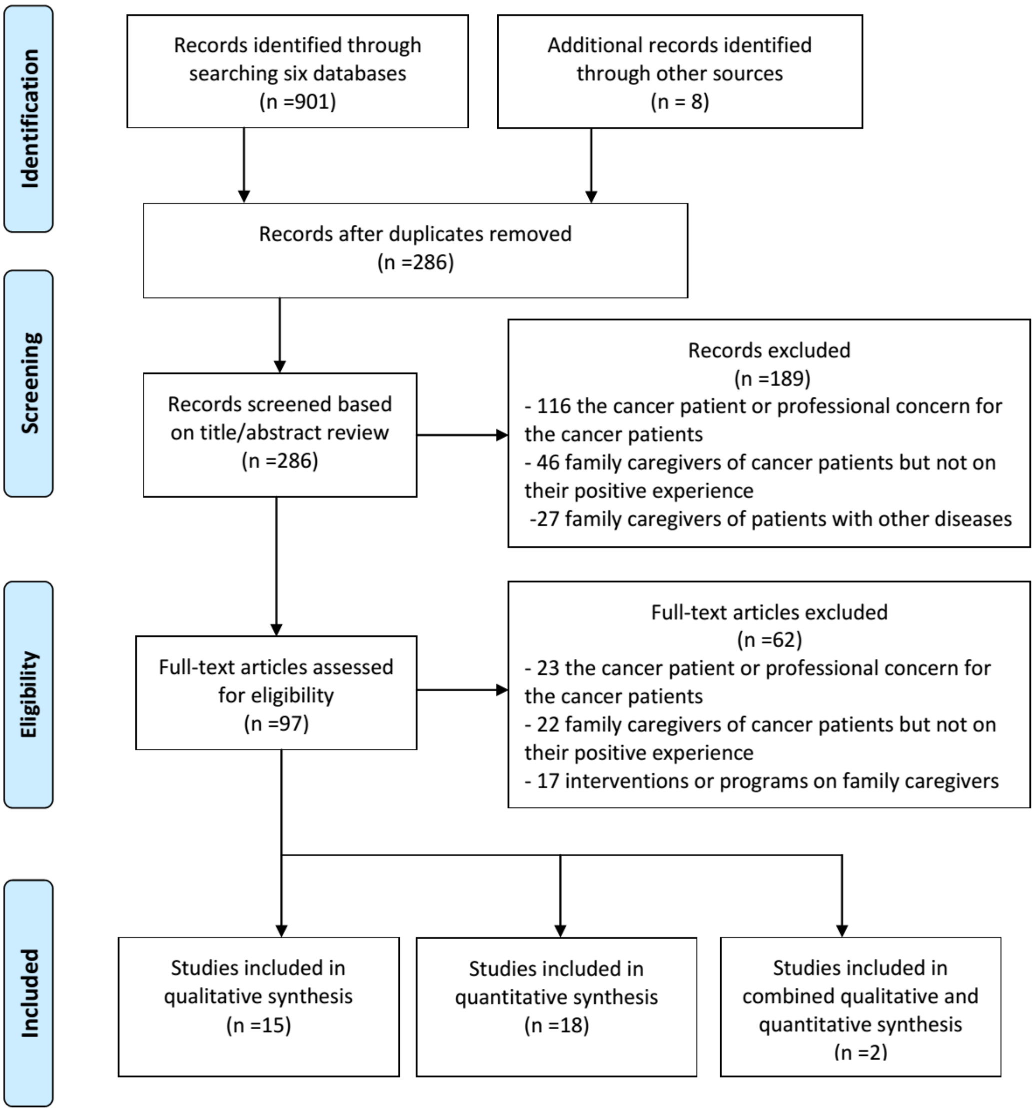


Figure 4-1. The flow diagram on identifying the literature

For a better and clearer understanding of the processes related to the development of positive aspects of caregiving in the caregivers' experience, the conceptual framework of the Positive Aspects of Caregiving (CFPAC) proposed by Carbonneau and colleagues in 2010 (Carbonneau et al., 2010) was adopted to guide this review

(Figure 4-2). The CFPAC contains three main domains: components of the positive aspects of caregiving, determining factors of the positive aspects of caregiving, and positive outcomes (Carbonneau et al., 2010). It was emphasized that “the various components of the conceptual framework are interdependent and all work together to reinforce the caregiver’s well-being and support their involvement” (Carbonneau et al., 2010) (p. 330).

To our knowledge, there is no conceptual framework on the positive aspects of caregiving developed specifically for family or spousal caregivers of cancer. Although the CFPAC was proposed for family caregivers of dementia, it was developed based on various studies, including cancer studies, on the positive aspects of family caregiving. Another model identified was the cancer family caregiving experience (CFCE) (Fletcher et al., 2012). As stated in Chapter 2, CFCE is developed based on cancer family caregiving research. However, only few constructs focusing on positive aspects of caregiving are included in the CFCE, which limits the presentation of the identified various kinds of positive aspects of caregiving phenomenon.

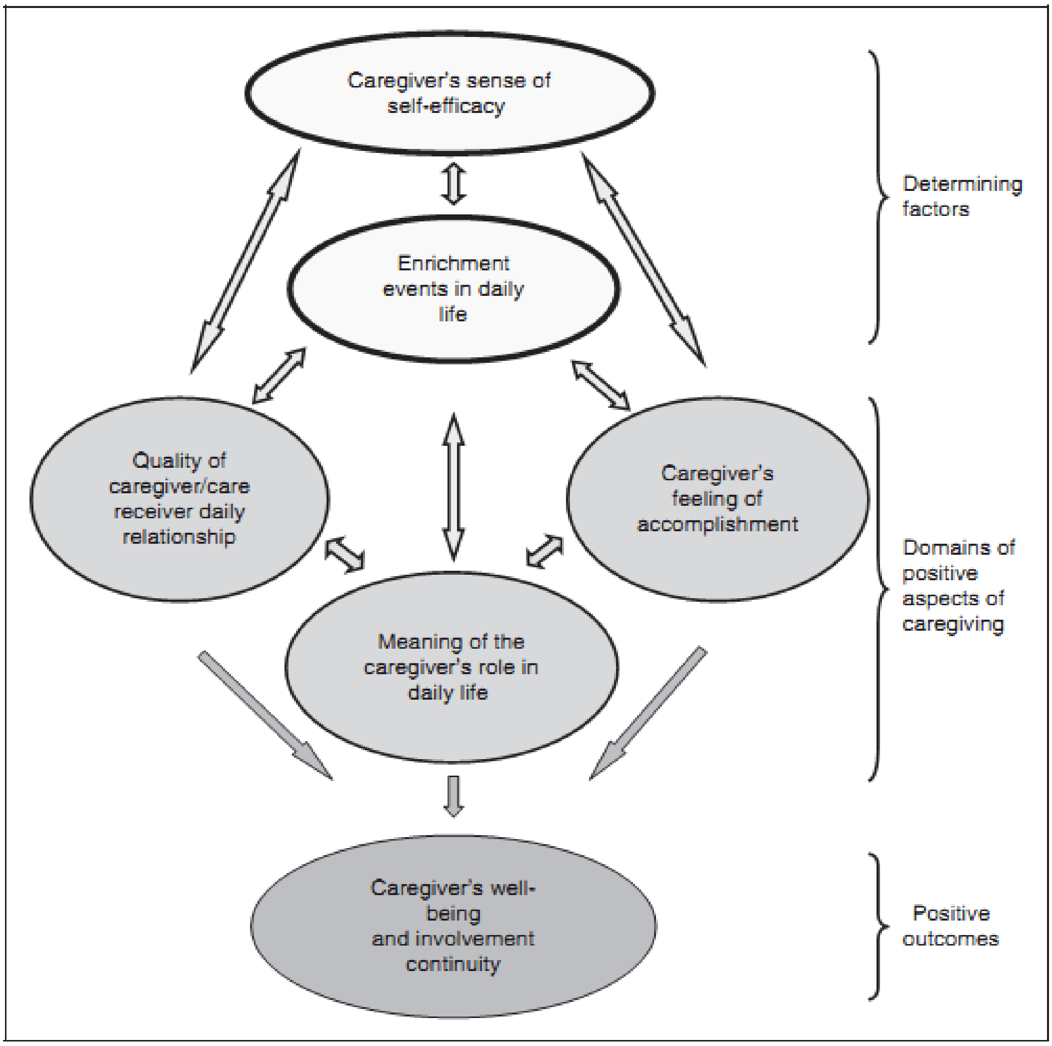


Figure 4-2. Conceptual framework of the positive aspects of caregiving (CFPAC) **(**Carbonneau, et al, 2010)

4.1 Positive aspects of caregiving

The domain of the “positive aspects of caregiving” includes three components: “the quality of the daily relationship of the caregiver/care-receiver,” “a feeling of accomplishment,” and “the meaning of the role in daily life” (Carbonneau et al., 2010).

4.1.1 Quality of the daily relationship of the caregiver/care-receiver

The quality of the daily relationship of the caregiver/care-receiver was proposed as a central component of the positive aspects of caregiving (Carbonneau et al., 2010). Caregivers reported that their relationship with the care-receiver and the whole family improved because of the caregiving process, and that the improvement in the relationship was reciprocal between the caregiver and care-receiver.

A mixed method study of 45 bereaved family caregivers, using a self-developed questionnaire and structured interviews, reported that some caregivers described their times of intimacy during the caring process in ways such as "… we fell more in love as the time got shorter and she became sicker" (Hudson, 2006) (p. 699). Over half of the caregivers (53%) emphasized that it is important to communicate openly with the patient (Hudson, 2006). Another mixed method study, using focus groups and a questionnaire survey also revealed that the caregivers experienced a sense of closeness to the patient and to the entire family during the caregiving process. As one of the caregivers stated, "we've definitely grown closer because of the time we've spent together" (Mangan, Taylor, Yabroff, Fleming, & Ingham, 2003) (p. 252). From interviews of family caregivers, it was also reported that, during the caring process the caregivers experienced a sense of closeness with the care-receiver and with other members of the family. The caregivers experienced stronger feelings of love and being closer together, resulting in an enhanced and deeper relationship with the care-receiver (Hudson, 2004; Ussher, Wong, & Perz, 2011; Wong & Ussher, 2009) and in improved family relationships (Koop & Strang, 2003; Wennman-Larsen & Tishelman, 2002). A study on couples coping with lung cancer showed that the couples experienced an increase in non-coital physical closeness and greater appreciation of their spouse (Lindau, Surawska, Paice, & Baron, 2011). Some spousal caregivers described having experienced improved communication and more appreciation for each other due to greater awareness of the limited time that they may have.

The positive aspect of an enhanced relationship between the caregiver and the care-receiver and other members of their family was also reported in quantitative studies. A study using the Positive Aspects of Caregiving Scale that evaluated the positive aspects of male spousal caregivers who cared for their wives with breast cancer, showed that husbands perceived their caregiving as a way to show their love, which brought them closer to their partners (Wagner, Tanmoy Das, Bigatti, & Storniolo, 2011). Using a self-developed questionnaire, another study that assessed the supportive care needs and positive outcomes of spousal caregivers of cancer patients showed that over 74.3% of the couples appreciated their relationships with others more; and 56.1% reported that they had benefited (e.g., through emotional support) from contact with other cancer survivors and their family members (Hodgkinson et al., 2007).

A study conducted in Japan explored the experience of primary caregivers caring for a terminal cancer patient at home. The findings showed that most of the primary caregivers (90%) reported a deepening of their bond with the care-receiver and other family members (Sano et al., 2007). Another study also conducted in Japan developed the Caregiving Consequences Inventory (CCI) to explore perceptions of the consequences of a bereaved family member caring for cancer patients. The results showed that the domain of “appreciation for others” was one of the positive consequences of caregiving (Sanjo et al., 2009). Caregivers expressed gratitude for the relationships and compassion that they developed, with comments such as: “I came to have more appreciation for others,” “I became more aware of love from other people,” and “I came to place greater value on relationships” (Sanjo et al., 2009).

Interviews of caregivers of cancer patients showed that the patient’s optimism had an impact on the caregiver’s optimism, coping, and well-being (Mehrotra & Sukumar, 2007). Caregivers felt that what they were doing was important to their loved ones and that caregiving was a way of showing love to their relatives (Mok, Chan, Chan, & Yeung, 2003).

Four studies focused on examining the growth of both caregivers and care-receivers since the diagnosis of cancer, using a posttraumatic growth inventory (PTGI) (Moore et al., 2011; Thornton & Perez, 2006; Weiss, 2004; Zwahlen, Hagenbuch, Carley, Jenewein, & Buchi, 2010). There were three studies that explored the association of PTG among couples coping with cancer (Thornton & Perez, 2006; Weiss, 2004; Zwahlen et al., 2010). For example, one study using a bivariate analysis indicated that the PTG of husbands was positively associated with the PTG of their wives with breast cancer ($r=0.20$, $P=0.04$, $n=69$) (Weiss, 2004). The other two studies reported a moderate degree of PTG associated with the cancer experience between spousal caregivers and care-receivers (Thornton & Perez, 2006; Zwahlen et al., 2010). One study that examined the correlation of PTG between family caregivers and care-receivers also found a significant correlation between the ratings of patients and caregivers on the PTGI subscales of spirituality ($r=0.38$, $P<0.02$) and personal strength ($r=0.44$, $P<0.004$) (Moore et al., 2011).

It is concluded that there is improvement and reciprocity in the relationship between caregiver and care-receiver.

4.1.2 Feeling of accomplishment

Two mixed method studies showed that caregivers feel a sense of accomplishment from the knowledge that their care made the patient feel more comfortable, the realization of their own capabilities, and a perception of personal satisfaction (Hudson, 2006); and from feeling respect and appreciation from their care-receiver (Mangan et al., 2003).

Findings from qualitative studies also supported the view that a feeling of accomplishment arises from the experience for cancer patients. A study on bereaved family caregivers of patients with advanced cancer reported that caregivers had a perception of accomplishment, such as a sense of personal growth, no feelings of guilt, and were able to express their grief more openly and freely as a result of having provided care for the patient (Koop & Strang, 2003). Another study found that Indian women who cared for relatives suffering from cancer reported that caregiving was a time when their relationship was tested, and that caregiving helped them to discover their hidden potential for patience, the strength to handle novel and difficult situations, and the ability to deal with multiple demands. It also helped them to learn to tolerate irritations/hassles (Mehrotra & Sukumar, 2007). Another study reported that the caregivers stated that caregiving had given them a sense of accomplishment when they saw their patients improve and felt themselves to have become stronger (Hudson, 2004).

Other qualitative studies reported various feelings of accomplishment, such as the discovery of personal strength and the knowledge that one is needed (Wong, Ussher, & Perz, 2009); and a sense of reward for doing something good (Wong & Ussher, 2009). Being present at the time of death was positioned as rewarding because it facilitated the process of saying goodbye, fostered the inclusion of others, provided closure, and was a spiritual experience (Wong & Ussher, 2009).

A feeling of accomplishment was also reported in quantitative studies, arising from a sense of personal growth (Hodgkinson et al., 2007; Wagner et al., 2011), a sense that one has done one's best (Sano et al., 2007), and a feeling of reward (Tang, 2009). A study conducted among husbands that evaluated positive aspects of their caring for wives undergoing active treatment for breast cancer, revealed that the husbands, on average, appraised their caregiving as an experience that produced both intrapersonal and interpersonal growth (Wagner et al., 2011). Another study also reported that a large proportion (70.9%) of spousal caregivers felt that they had grown as a person through the caregiving process (Hodgkinson et al., 2007).

In summary, various manifestations of a feeling of accomplishment were reported among family caregivers, such as feeling rewarded; discovering personal growth; perceiving personal satisfaction, feeling needed, and receiving respect and appreciation from their care-receivers.

4.1.3 Meaning of the role in daily life

The “meaning of the caregiver’s role in daily life” forms the cornerstone of the CFPAC (Carbonneau et al., 2010). Studies that focused on the meaning of the caregiver’s role in daily life addressed the aspects of keeping the life of patients and the family as normal as possible, changing values, and reprioritizing.

It was encouraging to caregivers of cancer patients when the everyday life of the patient and the family could be maintained as much as possible (Milberg & Strang, 2003; Wong & Ussher, 2009). In a mixed method study, bereaved family caregivers (n=45) stated that having control within their own home was one of the positive aspects of caring for the patient at home (Hudson, 2006). Interviews with caregivers for patients who had received an initial diagnosis of colorectal cancer found that caregivers thought that keeping the family’s and children’s routines as normal as possible was an important positive experience for them. To do this, they put on a brave face while silently worrying about the effects of the illness on the children, struggling to know the right thing to do, and dealing with extended family (Houldin, 2007). Several other qualitative studies found that caregiving was an opportunity for caregivers to experience a shift in perspective in terms of being more accepting of each day, being able to prioritize their life issues, and also finding meaning in their role through acknowledging the negative aspects of their experience (Mehrotra & Sukumar, 2007; Mok et al., 2003; Whisenant, 2011; Wong et al., 2009). Overall, caregivers of cancer patients reported that, no matter how difficult caregiving was, as long as they could keep the everyday life of the patient and the family as normal as possible, they would have a positive perception of the experience.

Studies using the Caregiving Consequences Inventory (CCI) showed that realizing meaning in life and reprioritizing one's values in life are recognized as the two positive domains of family caregiving for cancer patients (Kang et al., 2012; Sanjo et al., 2009). The meaning in life domain in the CCI included the following items: "I came to find purpose and meaning in life," "I have a better outlook on life," and "I came to realize that there is meaning in life no matter what happens." The reprioritization domain in the CCI consisted of following items: "I came to understand the brevity of life and to appreciate each day," "I came to notice what is really important in my life," and "I have learned the importance of being alive" (Sanjo et al., 2009). A change in life priorities (m=4.09) was rated as one of the highly positive elements among family caregivers of cancer patients (Park et al., 2012). To the end, keeping life as normal as possible, changing one's values, and reprioritizing meaning of the role in daily life were found that related to meaning of the caregiving role in daily life.

4.2 Determining factors of positive aspects of caregiving

The two determining factors of a positive caregiving experience of the CFPAC, 'daily enrichment events', and 'caregivers' sense of self-efficacy', are discussed below (Carbonneau et al., 2010). Other factors related to positive aspects of caregiving identified in the process of this review: hope, social support, religious coping, personal characteristics, and health care support, are grouped under the name of ‘contextual factors’ and discussed below.

4.2.1 Daily enrichment events

It was reported that daily enrichment events reinforce the positive aspects of caregiving (Carbonneau et al., 2010). This included taking time out for oneself, such as to go for a walk, to rest, or just to grieve privately away from the patient (Hudson, 2006; Mangan et al., 2003).

A study exploring the sources of strength and positive experiences of Indian women in the process of caregiving described several daily enrichment events (Mehrotra & Sukumar, 2007). The events were: (i) related to the improved health of care-receivers, such as getting a normal report of a blood investigation; (ii) interactions with significant others, for example talking to a friend who listened to their difficulties and provided emotional support; (iii) getting a temporary respite from caregiving and opportunities to engage in positive distractions, e.g., being able to take a few hours off from the caregiving role through soliciting others’ help and engaging in pleasurable activities (such as gardening) engaged in before the care-receiver was diagnosed with cancer; and (iv) the recollection of positive events of the past or positive aspects of one’s current life situation, and planning for future, e.g., talking about good times in the past and visualizing good things in the future (Mehrotra &

Sukumar, 2007). Overall, various enrichment events in daily life may help caregivers to experience positive aspects of caregiving, which can result in positive outcomes.

4.2.2 Caregiver’s sense of self-efficacy

A caregiver’s sense of self-efficacy is another determining factor of positive aspects of caregiving. A study examined the relationship between caregiver self-efficacy in managing the pain of advanced cancer patients and caregiver adjustment, using the caregiver version of the chronic pain self-efficacy scale (CSES) (Keefe et al., 2003). The findings showed that over half (57%) of the caregivers rated their self-efficacy in pain management as moderate (between 30~75 on a 0~100 scale). There were negative associations between caregiver self-efficacy in pain management and caregiver strain (the caregiver strain index (CSI), $r=-0.36$, $P<0.01$) and caregiver negative mood (the Profile of Mood States-B (POMS-B), $r=-0.31$, $P<0.05$). By contrast, there was a positive association between caregiver self-efficacy in pain management and caregiver positive mood (POMS-B, $r=0.41$, $P<0.01$). Thus, caregivers who gave a high rating to their self-efficacy in managing the pain of their cancer patient were much more likely to report lower levels of caregiver strain and negative mood, and higher levels of positive mood (Keefe et al., 2003).

4.2.3 Contextual factors

Hope in the caregiving experience was explored in four studies (Clayton, Butow, Arnold, & Tattersall, 2005; Holtslander & Duggleby, 2009; Milberg & Strang, 2003; Sutherland, 2009). A study that showed that caregivers of cancer patients had various hopes during their caregiving process, such as the hope of a miracle cure or of a spontaneous remission of the disease; the hope of effective pain and symptom control; and the hope of being well cared for and supported by health professionals, friends, and the community (Clayton et al., 2005). Caregivers also believed that there were ways of fostering coping and nurturing hope when discussing a patient’s prognosis and end of life issues with health professionals. It was also pointed out that “hoping for the best while preparing for the worst” is one of the strategies for coping in clinical practice (Clayton et al., 2005). Another study on the caregivers of cancer patients also reported that facing tomorrow and believing in the patient’s capacity to survive was one of the subthemes of hope (Sutherland, 2009).

Interviews from a qualitative study showed that through hope, caregivers projected meaningfulness into the future, and there was something potentially meaningful to look forward to (Milberg & Strang, 2003). This was in line with the findings of another study that explored the hope experience of the bereaved female spousal caregivers of cancer patients. The results showed that hope is a gradual process of regaining inner strength and building self-confidence to make sense of their situations (Holtslander & Duggleby, 2009). Through hope, the caregivers learned to stay positive and move ahead with their lives (Holtslander & Duggleby, 2009). In brief, hope is not only one of the factors allowing the caregivers of cancer patients to maintain a positive outlook, but also a factor that can be nurtured.

A relationship between social support and religious coping with positive aspects of caregiving was reported in several studies. A study reported that caregivers with a religious affiliation and caregivers who perceived greater family support were more likely to experience caregiver positivity (Kang et al., 2012). Another study also reported that social support and religious coping were related to greater positive affect ($r=0.10$, and 0.13 respectively, $P<0.01$) (Fitzell & Pakenham, 2010).

Another study showed that caregivers who reported frequently using positive methods of religious coping reported deriving more satisfaction than those who did not (Pearce, Singer, & Prigerson, 2006). In addition, the greater use of negative religious coping was associated with a poorer quality of life (SF-36, $\beta=-0.16$) and lower satisfaction ($\beta=-0.16$). It was concluded that negative religious coping was indirectly associated with caregiving outcomes through a reduction in the caregivers' perceived social support, optimism, and self-efficacy (Pearce et al., 2006).

Personal characteristics, such as the caregivers' esteem (Kim et al., 2007), gender, and motives (Kim, Carver, Deci, & Kasser, 2008) were also found to relate to the caregivers' well-being. A study showed that caregivers with higher esteem reported lower psychological distress ($B=-0.12$; $SE=0.05$), better mental functioning ($B=0.33$; $SE=0.13$), and better spiritual adjustment ($B=0.48$; $SE=0.10$) (Kim et al., 2007). Another study that examined predictions of the well-being of spousal caregivers as determined from their motives showed that male spousal caregivers scored higher on external caregiving motives than females, while females reported finding more benefits from the caregiving process than males (Kim et al., 2008). Among males, autonomous motives were related to less depression, and introjected motives were related to less life satisfaction and more depression. Among females, autonomous motives were related to the finding of greater benefits (Kim et al., 2008).

With respect to health care support, four studies focused on the family caregivers of cancer patients who had died at home (Hudson, 2004; Hudson, 2006; Sano et al., 2007; Tang, 2009). Support from health professionals, such as informational and emotional support, was recognized as one of the essential elements in benefitting individuals involved in the caregiving process. A study showed that 90% of the caregivers (n=112) reported that they had done their best in terms of providing caregiving at home, in that the patients had been able to live at home until the end of their life, with assistance from a palliative care service (Sano et al., 2007).

In summary, the domain of “determining factors” identified according to the CFPAC in this review included the component of “daily enrichment events” (taking time out, finding positive moments in daily life) and the component of “caregiver’s sense of self-efficacy.” These factors are important if caregivers of cancer patients are to improve the caregiving experience and perceive positive outcomes.

An additional component of “determining factors”, not included in the CFPAC, was identified and discussed as “contextual factors.” Given that the CFPAC mainly targeted the family caregivers of patients with dementia, it was noted that other contextual factors, such as support resources (social networks, emotional or social support), and the caregiver’s characteristics (e.g., age, gender or health status), “do little to further the understanding of the process that underlies the enhancement of positive aspects of caregiving” (Carbonneau et al., 2010) (p. 336). However, in the context of cancer caregiving, the inclusion of contextual factors would strengthen the domain of determining factors proposed in the CFPAC.

4.3 Positive outcomes

It was speculated that the positive aspects of caregiving, and enhancing factors contributing to a positive experience, will contribute to caregiver well-being and continuity in involvement. However, none of the studies identified that examined this domain of the CFPAC.

A study that summarized the domains of benefit finding and outcomes in caregiving among close family members of cancer survivors showed that the variables of religious coping ($m=2.85$, $P<0.001$) and social support ($m=3.15$, $P<0.001$) were significantly correlated to the domains of benefit finding. All six domains of the benefit finding score as well as the overall benefit finding score were uniquely associated with psychosocial variables (life satisfaction and depression, $P<0.001$) (Kim et al., 2007). Another study reported that the ability to find meaning and peace during the cancer experience may be an important part of the overall well-being of the spousal caregivers of cancer patients (Kim, Carver, Spillers, Crammer, & Zhou, 2011).

Overall, the review found that positive aspects of caregiving and their determining factors were related to the positive outcomes of caregivers. This is congruent with the viewpoint that various domains in the CFPAC are interdependent and all work together to reinforce the positive outcomes of caregivers (Carbonneau et al., 2010).

Although both positive and negative outcomes were reported by caregivers of cancer patient, benefit finding or the positive aspects of caregiving play an important role in improving the overall well-being of caregivers of cancer patients (Kim et al., 2007; Kim et al., 2011).

4.4 Summary

Of the 35 articles included in this review, only 7 articles were conducted in Asia countries. Although the findings from this review covered all three main domains of the CFPAC, the imbalance in the studies focusing on different domains is noteworthy. While most studies focused on components of the positive aspects of caregiving, no study specifically exploring the domain of positive outcomes was identified. Studies on caregivers of dementia and cancer patients led to an inconclusive finding on the determining factors of positive aspects of caregiving, including the experience of hope, social support, and religious coping, other personal characteristics, and the health care system.

It can be seen from the above review in Chapter 3 and Chapter 4 that spousal caregivers of cancer patients perceive both negative and positive experience during their coping process. These findings are an echo of the research progress on coping theory (Folkman & Moskowitz, 2000; Folkman, 2008). Accumulated evidence has showed that positive affect co-occurs with negative affect during chronic stress. Positive affect has its own important adaptational significance in the context of stress through the following mechanisms, including promoting creativity and flexibility in thinking and problem solving; facilitating the processing of important (e.g., self-relevant) information; serving as a buffer against adverse physiological consequences of stress; offseting the deleterious physiological effects of stress; and preventing clinical depression (Folkman & Moskowitz, 2000; Folkman, 2008).

Chapter 5

LITERATURE REVIEW (IV)

The mutuality of the spousal caregiver-cancer patient dyads*

5.1 Communication

5.2 Reciprocal influence

5.3 Caregiver-patient congruence

5.4 Summary

*The content of this Chapter was published:

Li, Q., & Loke, A. Y. (2014). A literature review on the mutual impact of the spousal caregiver-cancer patients dyads: ‘communication’, ‘reciprocal influence’, and ‘caregiver-patient congruence’. *European Journal of Oncology Nursing*, 18(1), 58-65. doi: http://dx.doi.org/ 10.1016/j.ejon.2013.09.003.

Informal family caregiving experience, which included spousal caregivers, however, in general is complex and the relationships are dynamic. This evolves and changes in both predictable and in unintended ways (Blum & Sherman, 2010). To varying degrees, cancer affects the couple as a unit, rather than as isolated individuals, leading to the couples to react to a cancer diagnosis as an “emotional system” (Hagedoorn et al., 2008). The diagnosis and treatment of cancer can change the relational dynamics between people with cancer and their intimate partners, which can have an impact on both the patients’ and their partners’ subjective well-being and ability to cope (Dankoski & Pais, 2007). There is a mutual impact of the couples on one another in their quality of life (QOL), psychological health and role adjustment (Kim et al., 2008; Northouse et al., 2000).

The focus of cancer care and its research has shifted its emphasis primarily on the individual experiences of patients or spousal caregivers, evolving toward an emphasis on the caregiver-patient dyads (Fletcher et al., 2012). With research beginning to shift the focus from individual to caregiver-patient dyads level, it is proposed that future work needs to focus on the transactions of caregivers and patients as care partners (Fletcher et al., 2012) (p.395). Two conceptual models were identified that targeted specifically on the caregiver-patient dyads in the cancer population.

One is the relationship intimacy model that addresses couple’s psychosocial adaptation to cancer (Manne & Badr, 2008). This model highlighted the importance of the couples’ relationship and their engagement in communication that sustains and

/or enhances the relationship during stressful times. A limitation of this model is that it has not incorporated other factors and how couples may be affected in their coping with cancer.

The other conceptual model proposed by Fletcher et al. conceptualizes the mutuality of the caregiver-cancer patient dyads (CCPD) as a function unit, and consisted of three dyad-level concepts —‘communication’: “a transactional process in which individuals create, share, and regulate meaning” (p395.); ‘reciprocal influence’: “the effect the two members of a dyad have on each other” (p394.); and ‘caregiver-patient congruence’: “the concept of congruence synthesizes individual data into a dyad variable, related to agreement, concordance, and their opposite, disparity” (p.394) (Fletcher et al. 2012). The caregiver-patient dyads as a unit is suggested as the focus and direction of research related to cancer family caregiving experience (Fletcher et al. 2012). The CCPD were adopted to present the results (Fletcher et al., 2012).

The process of literature search and selections

A systematic literature search was conducted to identity articles published in English or Chinese from January 2000 to December 2012, using key terms related specifically to spousal caregiver-patient dyads in cancer care. The key search terms used were ‘cancer’ or ‘oncology’ or ‘carcinoma’ AND ‘caregiver’ or ‘caregiving’ or ‘carer’ AND ‘dyad’ AND ‘spouse’ or ‘couple’ or ‘partner’. The databases searched included MEDLINE, CINAHL, Science Citation Index Expanded, Scopus, PsychINFO, and China Academic Journals Full-text Database. Apart from the electronic search, a manual search for the bibliography of related studies and an author search were also performed.

The eligibility and selection of the articles was assessed by screening records and assessing full-texts according to predefined inclusion and exclusion criteria. The flow diagram of the search and selection process is outlined in Figure 5-1.

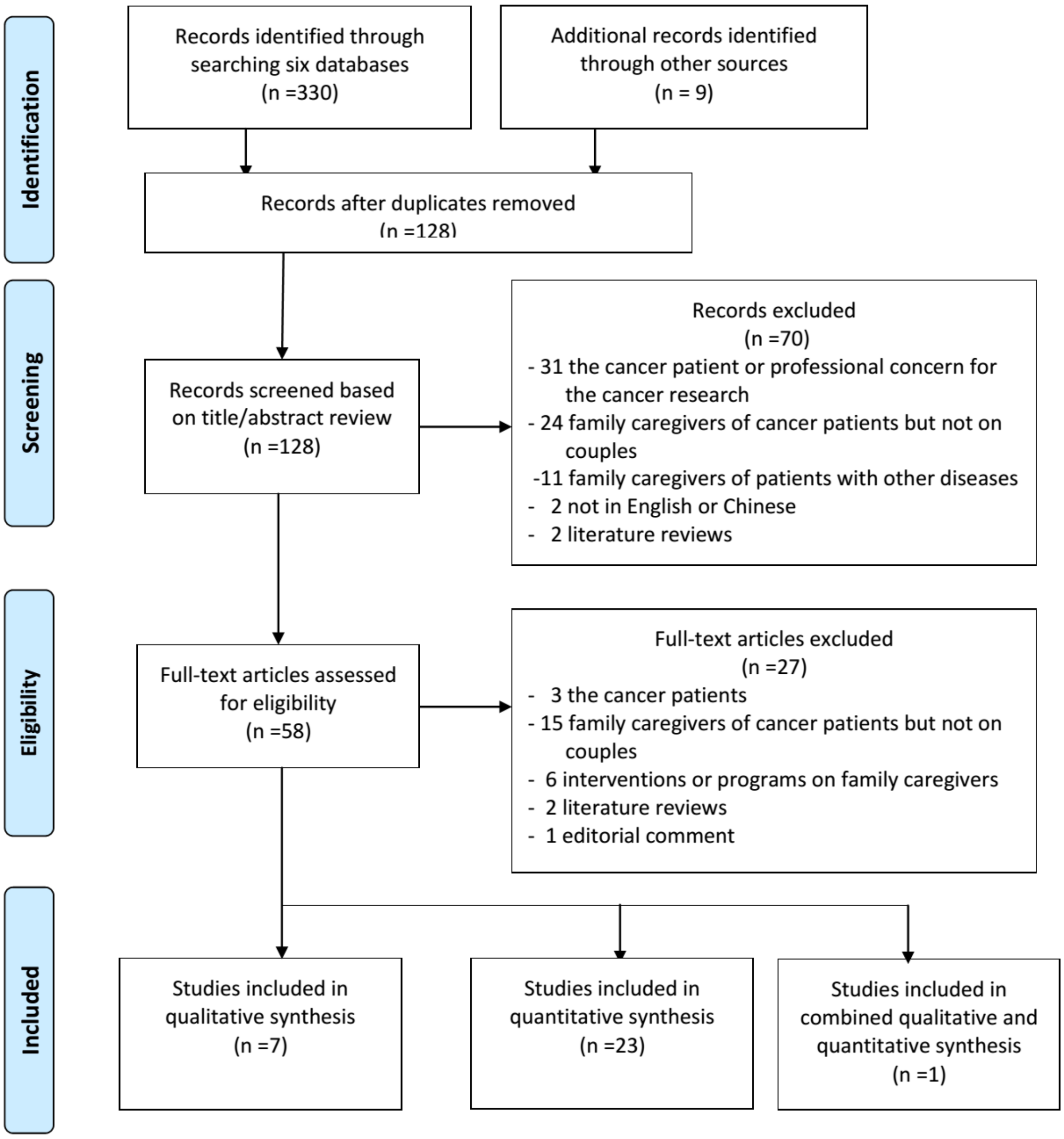


Figure 5-1. The flow diagram on identifying the literature

A total of 23 quantitative, 7 qualitative and 1 mixed method studies met the inclusive criteria and were included in this review. The characteristics of these studies are summarized in appendices Table 5-1 (p.394).

5.1 Communication

It was found that better communication between couples, such as relationship talk (Badr & Taylor, 2006; Badr, Acitelli, & Carmack Taylor, 2008; Lindau et al., 2011), open or mutual constructive spousal discussion (Badr & Taylor, 2009; Manne, Badr, Zaider, Nelson, & Kissane, 2010), and pattern of disclosure (Badr, Carmack, Kashy, Cristofanilli, & Revenson, 2010; Manne et al., 2004; Porter, Keefe, Hurwitz, & Faber, 2005; Sterba, Swartz, Basen-Engquist, Black, & Pettaway, 2011; Zhou et al., 2011) were related to lower distress, and better marital adjustment.

A study that focused on the effects of relationship talk on couples' psychosocial adaptation to lung cancer showed that patients and partners who reported more frequent relationship talk were less distress (effect size r=0.16) and greater marital adjustment over time (effect size r=0.21) (Badr et al., 2008) of both partners.

A qualitative study that focused on couples coping with lung cancer showed that participants who reported having open communication with their partners about their relationships functioning such as quality of the relationship, good memories, planning for the future, and problem solving, perceived fewer social constraints and better communication about cancer (Badr & Taylor, 2006). However, another qualitative study showed that most couples reported that they did not talked directly with their spouses about the effect of cancer on their relationship, although several people referred to increased awareness of non-verbal cues. For some couples “oral communication became more guarded in order to protect the patient or spouse from additional fear or stress; withholding of information was a commonly cited protective mechanism” while some couples described “improved communication due to an increased awareness of time and appreciation for each other” (Lindau et al., 2011) (p.183).

Studies on mutual constructive communication between couples showed that patients and partners who reported high levels (+1SD) of mutual constructive communication reported greater marital adjustment along the cancer trajectory (Badr & Taylor, 2009). The partners were more likely to report that the couple avoided open spousal discussions when patients with prostate cancer had poor erectile function, this in turn was associated with partners’ marital distress (Sobel’s Z=12.47, P=0.001) (Badr & Taylor, 2009). Another study reported that patients and spouses who reported greater baseline distress reported more negative baseline communication as well as lower levels of intimacy and greater distress over time (Manne, Badr, & Kashy, 2012). Mediation analyses showed that patients’ and spouses’ reports of more mutual constructive communication, less mutual avoidance and patient demand-partner withdraw were associated with less subsequent distress largely through the effects of intimacy (Manne et al., 2010; Manne et al., 2012).

Boehmer and Clark conducted a qualitative study on mutual communication between couples with prostate cancer. The findings revealed that although wives have a profound interest in their husbands' prostate cancer, there were little spousal communication about the implications of prostate cancer on their lives (Boehmer & Clark, 2001a). In particular, couples appear to talk little about their emotions, worries, and fears, such as physical changes, perceptions of changes in spouse, and sexuality. Usually, patients hide their feeling about the impact of the illness; and partners try to protect their husbands by hiding their emotions or avoiding questions. Interviews of couples coping with breast cancer showed that couples were ‘learning through struggling’: with mutual help and support, shared personal views of thinking about what is important for patients, and show mutual concern. However, husbands faced the communication challenges and inability to read their wives’ thoughts and feelings, which frustrated their wives. Consequently, both spouses felt depressed, burdened, and worried about sexual issues, and the future (Chung & Hwang, 2012).

A study between couples coping with prostate cancer showed that there were observed patterns of change in communication varied by time and role, with patients’ perceived levels of open communication decreased at a slower speed than their partners. The trajectories of change in the levels of open dyadic communication about cancer were marginally different between patients and partners (P=0.06) (Song et al., 2012).

One study explored the patterns of relationship, support, and communication in couples experiencing cancer. The findings showed that there were a variety of complex and interrelated changes in physical, emotional, and social experiences resulting from the diagnosis and progression of cancer. There are dyadic-level accommodations to living with advanced cancer, using the word ‘we’ to describe their experience… including living with uncertainty about the illness and the future; facing illness and dying trajectories and speak openly with their partner; search for shared meanings, understanding, narrative, or philosophical approach related to patients’ illness trajectory and ultimate prognosis. The importance of maintaining a positive or optimistic outlook was described by the couples as supportive in their attempts to cope with the cancer, and in their interactions with each other (Gardner, 2008).

A study that examined patterns of disclosure about cancer-related concerns between patients with gastrointestinal (GI) cancer and their spouses showed that there were interrelationships between couples disclosure, levels of holding back and intimacy (Porter et al., 2005). When patients reported high levels of disclosure to their spouse and low levels of holding back, both the patients and their spouses rated their relationship more intimate. Spouses’ higher levels of disclosure and lower levels of holding back was also related to higher levels of intimacy with the patient, and less avoidant in patients (Porter et al., 2005). Another study on couples’ disclosure and intimacy also showed that, for patient, perceived partner responsiveness partially mediated the association between partner disclosure and patient perceived intimacy. For partner, perceived patient responsiveness also mediated the association between self-disclosure, perceived patient disclosure and partner perceived intimacy (Manne et al., 2004).

In a qualitative study, Fergus and Gray (2009) explored the relationship challenges and vulnerabilities of the breast cancer couples. It was reported that couples' open communication is precluded because of the couples' personal characteristics and communication pattern. Patients' characteristics such as self-absorption, counter-dependency, exaggerated dependency, and over-controlling; and spouse caregivers' solution driven, unchecked anger, and not reaching out impeded the couples' communication and adjustment. While withholding-withdrawal, under-burdening, conflictual intentions were the barriers and pitfalls of relationship dynamics. Couples do also faced the challenges of negotiating support, accommodating changes in other, coping with sexual disruption, as well as death and separation.

In summary, satisfied communication between couples related to less distress, and better marital adjustment. Levels of distress in baseline, cancer-related symptom, role, and cancer trajectory were identified to relate to couples mutual communication.

5.2 Reciprocal influence

Multiple interrelated dimensions of well-being, including: QOL (Campbell et al., 2004; Chen et al., 2004; Galbraith, Pedro, Jaffe, & Allen, 2008; Song et al., 2012), self-efficacy (Campbell et al., 2004), mental health or psychological stress (Gilbar & Zusman, 2007; Kershaw et al., 2008; Kim et al., 2008; Sterba et al., 2011), emotion-focused coping (Gilbar & Zusman, 2007), role adjustment (Northouse et al., 2000), and marital satisfaction (Zhou et al., 2011), were illustrative of the concept of 'reciprocal influence' in that each member of the spousal caregiver-cancer patient dyads carries effect in these dimensions on each other.

A study showed that both the patients' total score of QOL and the social/family functional dimensions of QOL were associated with the total score and each dimension of their spousal caregivers' QOL (r=0.27–0.44) (Chen et al., 2004). It was also reported that cancer diagnosis, length of hospitalization, caregiving intensity and duration, marital satisfaction, and self-esteem in caregiving may have reciprocal influence on the correlations of QOL between couples (Chen et al., 2004).

Another study showed that there were correlations of QOL between patients and partners, which remained consistent during the patient's survivorship (r=0.25, 0.24, 0.23, and 0.23 at baseline, 4-, 8-, and 12-Months follow-ups). Couples' QOL also improved with an increase in their social support (P<0.001), cancer-related dyadic communication (P<0.001); and a decrease in the couples' uncertainty of illness (P<0.001), cancer-specific hormonal (P<0.001) and sexual symptoms (P<0.05) in the patient, and general symptoms (P<0.001) in both partners (Song et al., 2011).

A study that focused on the relationship of couples' self-efficacy showed that both patient and caregiver self-efficacy had the effect on the partners'wellbeing (Campbell et al., 2004). The findings reported that higher self-efficacy for physical function subscale scores in patients was negatively associated with anxiety (r=-0.39, P<0.05) and caregiver strain (r=-0.38, P<0.05) in partners. While higher self-efficacy for physical function subscale scores in partners was associated with better adjustment of patients to bowel symptoms (r=0.66, P<0.01), hormonal symptoms (r=0.42, P<0.01); and better mental health (r=0.32, P<0.05) (Campbell et al., 2004).

However, another study on couples coping with prostate cancer showed that patients and spouses' appraisal of self-efficacy only strongly influence their own adjustment (Kershaw et al., 2008). In that the patients with lower self-efficacy ($\beta=-0.31$) appraised their illness more negatively, while spouses with lower self-efficacy ($\beta=-0.46$) appraised their caregiving more negatively at 4 months. However, there is no reciprocal effect between couples in their self-efficacy.

Studies on mental health and/or psychological stress also showed that there were moderately interrelationships within the couples coping with breast cancer (Dorros, Card, Segrin, & Badger, 2010; Gilbar & Zusman, 2007), prostate cancer (Kershaw et al., 2008), prostate or breast cancer (Kim et al., 2008), and colon cancer (Northouse et al., 2000). A study explored the interdependence of distress outcomes in patients with breast cancer and their partners using reciprocal dyadic data. The result showed that depression, stress, and poor physical health between patients and their partners have medium similarity (latent rs 0.37, 0.36, and 0.37, respectively) (Dorros et al., 2010). The interaction of high levels of depression and high levels of stress in patients was associated with lowered physical health and well-being in their partners. There were no effects of the stress of partner to influence patients' physical health.

Findings from another study on patients with prostate cancer and their spouses also reported that there was a significant correlation and reciprocal effects between patients' and spouses' mental dimension of QOL ($r=0.25$, $P<0.05$) (Kershaw et al., 2008). Older age of the spouses were related to more patient negative appraisal of illness ($\beta=+0.43$) and more uncertainty in illness ($\beta=+0.32$). More (perhaps too much) spouses communication about disease was related to higher hopelessness in patients (β=+0.30). Another study on couples with prostate and breast cancer showed that there was evidence that partners were at least moderately similar in their levels of psychological distress (r=0.32, 0.27 for breast cancer, and prostate cancer respectively) (Kim et al., 2008).

Studies also showed that there were positive significant correlations between patients and spouses in terms of their emotion-focused coping (Gilbar & Zusman, 2007); and role adjustment (Northouse et al., 2000). A longitudinal study that focused on couples' patterns of adjustment to colon cancer reported that there were modest inter-correlations between patients' and spouses' role adjustment scores over time (all $P<0.05$). The strongest predictors of patients' role adjustment problems were their hopelessness and their spouses' problems in role adjustment; and the strongest predictors of spouses' role problems were spouses' own baseline role problems and level of marital satisfaction (Northouse et al., 2000).

A study that focused on the couples coping with prostate cancer reported that dyadic adjustment was associated with spouses' mood disturbance (r=−0.49, P=0.001), mental health functioning (r=0.35, P=0.02), sexual function (r=0.26, P=0.10), and sexual bother (r=0.44, P=0.003) (Sterba et al., 2011). While patients' symptoms were associated with worse physical health in spouses (β=-0.93, P=0.02) (Sterba et al., 2011). Another study showed that patients or partners who perceived their spouses as more supportive or less unsupportive had greater dyadic marital adjustment (Badr et al., 2010).

A study that examined the extent to which each partners' marital satisfaction was related to each individual's physical and mental health in a dyadic context of couples coping with prostate cancer. The results showed that both the patient's mental ($r=0.33$, $P<0.05$) and physical ($r=0.28$, $P<0.05$) health was positively related to their caregiver's marital satisfaction. However, the caregivers' mental and physical health was not significantly related to patients' marital satisfaction (Zhou et al., 2011).

Overall, multiple interrelationships between spousal caregiver-cancer patient dyads were found, including different dimensions of well-being and the dyadic adjustment. Factors that influence the interactions between couples were identified, including: the cancer diagnosis, cancer-related symptoms, length of hospitalization, and caregiving intensity and duration.

5.3 Caregiver-patient congruence

Congruence of patients and spouses was found in their perceptions on patients' health related quality of life (HRQoL) (Green, Wells, & Laakso, 2011; Sneeuw, Albertsen, & Aaronson, 2001), coping strategies (Green et al., 2011), disease appraisal (Merz et al., 2011), disease adjustment (Romero, Lindsay, Dalton, Nelson, & Friedman, 2008), and protective buffering (Langer, Brown, & Syrjala, 2009).

A mixed method study on couples coping with prostate cancer showed that there were dyadic correlations between patient and partner ratings of the patient's HRQoL in all six dimensions ($r=0.45$-0.73, all $P<0.001$) (Green et al., 2011). Partners rated the patient's emotional functioning (m=83.3, IQR=66.7–100.0) significantly worse than patients' own rating (m=83.3, IQR =75.0–100.0) (Z=-2.48, P<0.05). Whereas, patients' social functioning was rated significantly better by the partners (m=83.3, IQR=66.7–100.0) than by themselves (m=66.7, IQR=66.7–100.0) (Z =-2.48, P<0.05).

The same study examined the coping strategies of the couples. The results of the study showed that there was significant difference in use of coping strategies, where patients reported greater use of approach coping (m=2.7, IQR=2.0–3.1) than what their partners perceived (m=2.3, IQR=1.9–3.0) (Z=-2.06, P<0.05) (Green et al., 2011). The qualitative results also showed that to a certain extent there is agreement between patients and spouses in their responses to prostate cancer in terms of disease / treatment, interpersonal relationship, their appreciation of life, and life priorities (Green et al., 2011).

The findings from a study on disease appraisal of couples found that spouses of men with prostate cancer evaluate patients' physical and psychosocial functioning, symptoms and overall QOL with a reasonable degree of accuracy (r=0.40-0.75) (Sneeuw et al., 2001). There was exception, in that there was a low correlation for sexual functioning and sexual satisfaction.

Another study that examined the dyadic concordance of disease appraisal among prostate cancer patients and spouses showed that most couples, appraise most of the disease domains such as urinary or bowel function, and urinary or bowel bother, were concordant (r=0.41-0.83) (Merz et al., 2011). The only exception was of sexual bother, in which, partners perceived lower levels of sexual bother than the patients experienced. A general pattern was that couples who are in concordant dyads reported significantly better individual HRQoL outcomes than those in dyads in where spouses overestimated or underestimated characteristics of symptoms and disease. The extent of (dis)agreement of patient-partner appraisal of disease generally did not significantly predict dyadic adjustment (Merz et al., 2011).

Focus group interviews of men with metastatic prostate cancer and their partners in separate groups, also showed that there are incongruent between patients and their partners' perceptions on prostate cancer diagnosis. Patient frequently account the pre-diagnosis urinary and erectile symptoms; whereas partner accounts began with the diagnosis as the earliest event. It was also found that many men do not share their prostate-related health problems with their wives (Boehmer & Clark, 2001b).

A study among breast cancer patients and their partners reported moderate congruent between the husbands' perceptions of wives' adjustment to breast cancer and wives' self-reported adjustment. Incongruence within couples was related to wives' avoidant coping ($P<0.005$), and mood disturbance ($P<0.001$); but was not significantly correlated with wives' active behavioral or cognitive coping (P's >0.005) (Romero et al., 2008).

One study examined the consequences of protective buffering and desire to shield the patient-partner couples from distress. In a study of 80 couples with the patients receiving hematopoietic stem cell transplantation treatment (HSCT) for cancer

(Langer et al., 2009), there is moderate concordance between one dyad member's provision of buffering of his/ her partner and the other dyad member's received buffering. For patient-reported buffering of caregiver and caregiver-reported received buffering: the correlation were r=0.26, P=0.019 at T1 (pre-HSCT), and r=0.28, P=0.031 at T2 (50 days after-HSCT); for caregiver-reported buffering of patient and patient-reported received buffering: the correlation were r=0.38, P<0.001 and r=0.31, P=0.016 at T1 and T2 respectively. Patients who buffered primarily to protect their partner at T1 (pre-HSCT) reported increases in relationship satisfaction over time, but when they did so at T2 (50 days after-HSCT), their caregiver reported concurrent decreases in relationship satisfaction (Langer et al., 2009). The more participants (both the patients and spouses) buffered their partners at T2, the more they felt buffered, the lower their concurrent relationship satisfaction, and the poorer their mental health.

To summarize, there was moderate congruence among couples in their perceptions on patients' HRQoL, coping strategies, disease appraisal, disease adjustment, and protective buffering. In general, concordant in dyads related to better individual HRQoL outcomes (Merz et al., 2011), and relationship satisfaction (Langer et al., 2009). The inconsistent results, however, showed that there were incongruence within couples related to patients' avoidant coping and mood disturbance (Romero et al., 2008), and the extent of (dis)agreement of patient-partner disease appraisal (Merz et al., 2011).

5.4 Summary

Of the 31 articles included in this review, 25 studies were conducted in the United States; only three studies were conducted in Asian-countries (Chen, Chu, & Chen, 2004; Chung & Hwang, 2012; Gilbar & Zusman, 2007). Over 70% (22/31) of the studies focused on gender-specific cancers; only three studies that focused on multiple types of cancer (Gardner, 2008; Langer, Brown, & Syrjala, 2009; Romero, Lindsay, Dalton, Nelson, & Friedman, 2008). It is worth mentioning that there was the imbalance in the studies focusing on the three different concepts. While most studies focused on reciprocal influence and communication, only six studies focused on spousal caregiver-patient congruence. It is also noteworthy that there are inconclusive finding on the three concepts, including the reciprocal effect of self-efficacy (Campbell et al., 2004; Kershaw et al., 2008), and the effect of caregiver-patient congruence on dyadic adjustment (Langer et al., 2009; Merz et al., 2011).

It is revealed that satisfied communication between couples related to less distress, and better marital adjustment. There were multiple reciprocal influences and moderate congruence between spousal caregiver-patient dyads. It is also identified that there were inconsistence among studies that focused on couples' communication and caregiver-patient congruence. While most quantitative studies showed correlation and positive outcomes, e.g. more dyadic communication and congruence between couples, qualitative studies seems to report less dyadic communication and lower congruence (Boehmer & Clark, 2001b; Lindau et al., 2011).

Further analysis of the findings showed that the three concepts are interrelated and inseparable. For example, moderate open communication between couples may directly (Kershaw et al., 2008; Song et al., 2012) or indirectly enhance both patients' and partners' sense of self-efficacy (Campbell et al., 2004), benefit positive reciprocal influences, including QOL and dyadic adjustment (Manne et al., 2004; Porter et al., 2005). It is also reported that improving couples' communication patterns may be helpful in promoting dyadic congruence on different aspects of cancer care (Merz et al., 2011). Incongruence between couples may have a negative impact on spouses' mood and adaptation (Romero et al., 2008) and HRQoL (Merz et al., 2011).

Not only that the three concepts of spousal caregiver-patient dyads are interrelated, communication has been found to act as a fundamental element among the three concepts. Improved communication between couples may facilitate the reciprocal influences and promote congruence between couples, which in turn, can benefit the couples' caregiving outcomes. These findings suggest that spousal caregiver-patient dyads may benefit from couple-focused interventions that address dyadic-communication, which may improve their satisfaction with dyadic adjustment and QOL. Indeed, couple-based coping training intervention in facilitating communication has yielded promising results among dyads in which one member has cancer (Manne et al., 2011; McLean, Walton, Rodin, Esplen, & Jones, 2013; Northouse et al., 2007).

Chapter 6

LITERATURE REVIEW (V)

Couple-based Interventions for couples coping with cancer*

*The content of this Chapter was published:

Li, Q., & Loke, A. Y. (2014). A systematic review of spousal couple-based intervention studies for couples coping with cancer: direction for the development of interventions. *Psycho-Oncology*, *23*(7), 731-739. doi:10.1002/pon.3535.

The reviews of literature in the last few chapters showed that spousal caregivers of cancer patients perceive both negative and positive experience in their coping throughout the cancer trajectory. Based on the fact that family caregivers provide extraordinary uncompensated care that is physically, emotionally and socially demanding and results in negative health consequences, it has been suggested that family caregivers must be recognized as “care recipients” in their own right (Higginson & Gao, 2008), and interventions should be targeted at caregivers of patients with cancer (Given et al., 2004). Supportive intervention for caregivers should target on enhancing positive experience and reducing hidden morbidity (Li & Loke, 2013a; 2013b).

With the research focus on family caregiving shifting from the individual to the dyadic level, it has been suggested that the caregiver-patient dyad as a unit be the focus and direction of research and interventions on the caregiving experiences of families coping with cancer (Fletcher et al., 2012). Review of literature on the mutuality of the spousal caregiver-cancer patient dyads revealed that ‘communication’ may be the most crucial concept, interacting with the other two concepts ‘reciprocal influence’, and ‘caregiver-patient congruence’. Better communication between couples leads to better HRQoL, less distress and better marital role adjustment, and in turn facilitates better caregiving outcomes and health outcomes (Badr et al., 2008; Badr & Taylor, 2009; Boehmer & Clark, 2001a; Boehmer & Clark, 2001b; Dorros et al., 2010; Kershaw et al., 2008; Langer et al., 2009; Manne et al., 2010; Manne et al., 2012; Merz et al., 2011; Sterba et al., 2011). It is concluded that interventions to support couples in the context of cancer should enhance couples' communication as a vital and essential element to improve caregiving experience and health outcomes for both partners.

In order to gain a better understanding regarding the types of intervention, contents, approach, and outcome measurements of existing interventions for couples coping with cancer, a literature review was conducted specifically on couple-based interventions for couples coping with cancer.

The process of literature search and selections

Literature related to couple-based interventions was searched. The key words used were: "intervention" or "program" or "therapy" or “cope” or “coping” AND "cancer" or “oncology” or “carcinoma” AND "couple" or "partner" or "spouse” AND "carer" or "caregiving" or "caregiver". Literature published in English and Chinese from the establishment of the four respective databases (Science Citation Index Expanded (1970+), PsycInfo (1806+), Medline (1950+) via OvidSP, CINAHL database (1982+)) to March 2013 was included. A manual search of the references to the identified literature and author search were also conducted. The eligibility and selection of the articles were assessed by screening records and accessing the full texts according to predefined inclusion and exclusion criteria. The flow diagram of the search and selection process is outlined in Figure 6-1.

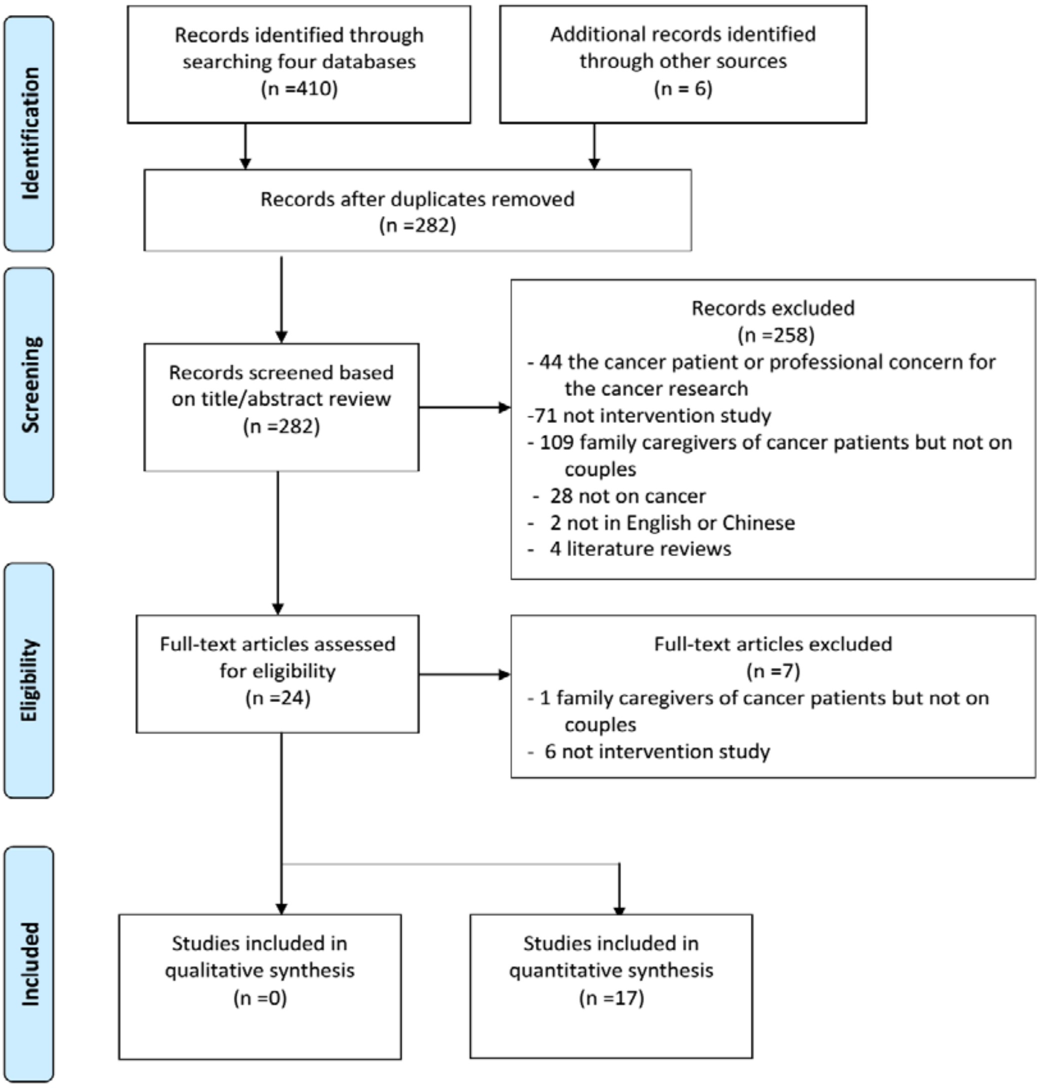


Figure 6-1. The flow diagram on identifying the literature

Criteria for inclusion and exclusion

The studies included in this review met the following criteria: articles published in English or Chinese from the establishment of the four databases searched to March 2013. The focus of the studies was on couple-based interventions, and outcome measures included both cancer patients and spousal caregivers. Commentaries, editorials, literature reviews and conference proceedings were not included in this review.

Data extraction and quality assessment

Data were extracted from each of the included studies using a standard format (see appendices tables 6-1,p.410, and 6-2, p.417). Quality assessment of the included studies was conducted by using the criteria proposed by the Effective Public Health Practice Project (EPHPP) (Thomas, Ciliska, Dobbins, & Micucci, 2004).

Six components, including selection bias, study design, confounders, blinding, data collection methods, and withdrawals and dropouts from each study were rated as strong, moderate, or weak according to a standardized guide (Thomas et al., 2004). As shown in appendices table 6-2 (p.417), four studies had a global rating of ‘strong’, whereas the remaining 13 were rated as ‘moderate’. The review of literature on couple-based interventions is presented in the following. Appendices table 6-1(p.410) summarized the characteristics of the identified interventions.

6.1 Characteristics of interventions

All 17 studies that focused on couple-based interventions for couples coping with cancer had been conducted in Western countries, namely the United States (n=11, 64.7%), Australia (n=2, 11.8%), Canada (n=2, 11.8%), the Netherlands (n=1, 5.9%), and Germany (n=1, 5.9%). Of the 17 studies, there were 12 randomized controlled trials (RCT) and 5 cohort studies.

Target population

The sample size of couples in these studies ranged from 9 to 263, involving a total of 1142 couples. The attrition rate ranged from 6% to 34%, with an average rate of 20%

(225/1142). The reasons given by the cancer dyads for refusing to participate in or dropping out of a couple-based intervention were the time issue, including being too busy, the time burden of the intervention, or having to complete a baseline questionnaire (Campbell et al., 2007; Heinrichs et al., 2012; Kuijer, Buunk, De Jong, Ybema, & Sanderman, 2004; Manne et al., 2011; McCorkle, Siefert, Dowd, Robinson, & Pickett, 2007; Porter et al., 2009); the intervention not meeting their expectations or refusal of group assignment (Heinrichs et al., 2012; Kuijer et al., 2004; Manne et al., 2011; McCorkle et al., 2007; Northouse et al., 2007); the spouse declining to provide data (McCorkle et al., 2007; Scott, Halford, & Ward, 2004); and living too far away from the intervention facilities (Baucom et al., 2009; Kayser, Feldman, Borstelmann, & Daniels, 2010).

The couples in these intervention studies were coping with prostate cancer (n=6, 35.3%), breast cancer (n=4, 23.5%), breast or gynecological cancer (n=2, 11.8%), gastrointestinal cancer (n=1, 5.9%), and multiple types of cancer (n=4, 23.5%). Twelve out of the 17 studies (70.5%) focused on gender-specified cancer.

Theoretical framework of interventions

Various theoretical frameworks were adopted to guide the design of the interventions. Most of these theoretical frameworks focused on the couple's relationship, including the Adaptation Model of Couples Functioning (Heinrichs et al., 2012), Emotionally Focused Therapy (McLean et al., 2008; McLean et al., 2013), Spiegel's Supportive-expressive Model (Collins et al., 2013), Equity Theory (Kuijer et al., 2004), the Relationship Intimacy Model (Manne & Badr, 2008; Manne et al., 2011), and the

Social-cognitive Processing Model of Emotional Adjustment to Cancer and Coping Theory (Scott et al., 2004). The exception was the Stress and Coping Model, which focused on the stress-coping process at the individual level (Northouse et al., 2007). Although these models were used in the articles included in this review, the majority of studies failed to describe how theory was used in the study. No specific theoretical framework on cancer dyads coping with cancer was found in the articles included in this review.

Intervention approaches and focuses

The couple-based interventions reviewed here can be classified under three broad categories according to their approaches: skills training (n=11, 64.7%), therapeutic counseling (n=6, 35.3%), and psycho-education (n=2, 11.8%) (Northouse, Katapodi, Song, Zhang, & Mood, 2010). It was common for the intervention protocols to include both skills training and psycho-education (n=11, 64.7%).

The focuses of the interventions for couples can be grouped under the focus of patient caregiving (n=7, 41.2%), caregiver self-care (n=7, 41.2%), and marital/family care (n=17, 100%).

Dosage of interventions and follow-up time frame

The interventions involved a mean of 6.2 sessions (range: 1-16 sessions). Face-to-face sessions lasted for an average of 79 minutes (range: 45-120 minutes), and telephone contact for an average of 32 minutes (range: 20-45 minutes). These interventions lasted for an average of 8.3 weeks (range: 1-24 weeks from the first to the last session). The follow-up periods of these interventions were: 12 months (n=6, 35.3%), 6 months (n=1, 5.9%), 3 months (n=4, 23.5%), 8 weeks (n=1, 5.9%), and immediately post intervention (n=5, 29.4%).

Delivery of the interventions

Nearly half of the interventions were delivered by psychologists (n=8, 47.1%), about one fourth by specially trained therapists or counselors (n=4, 23.5%), and the others by psychologists or social workers (n=2, 11.7%), nurses (n=2, 11.7%), and social workers (n=1, 5.9%). All of these studies developed and followed specific intervention protocols, and included regular reviews throughout the intervention program to maintain standards of treatment fidelity.

The majority of the interventions were delivered to couples face-to-face (n=13, 76.5%). Three (17.6%) were delivered using a combination of face-to-face and telephone contact. One (5.9%) intervention was delivered only by telephone. Of the 13 interventions delivered face-to-face, two were delivered in groups and the rest were delivered to couples at home or during visits to a clinic.

6.2 Outcomes of the interventions

The outcome measures of the interventions are summarized in Appendices table 6-2 (p.417). They can be discussed under three main dimensions – dyadic appraisal, dyadic coping, and dyadic adjustment – according to a development-contextual model of Couples Coping with Chronic Illness (CCCI) (Berg & Upchurch, 2007). CCCI extends the Stress and Coping Model (Folkman, 1997) by acknowledging the reciprocal nature of stress and coping within couples. This model consists of the three main domains of the coping process: dyadic appraisal, dyadic coping, and dyadic adjustment (Berg & Upchurch, 2007). Based on CCCI, the dyadic outcomes contain both individual-level outcomes, including those for caregivers and patients, and dyadic-level outcomes as a whole. The presentation of the following dyadic outcomes will be in the sequence of patients, spousal caregivers, and the couple as a unit.

6.2.1 Dyadic appraisal

Dyadic appraisal includes the appraisal of illness, self-efficacy, and communication, which was conceptualized as meaning both at individual and dyadic level. The individual level refers to how patients and their partners perceived and understood their ability to cope with cancer, and their emotional status; and the dyadic level refers to how couples reacted to cancer as a unit (Berg & Upchurch, 2007). Communication between couples affected couples' appraisal of their illness and efficacy.

A study examined how patients and spouses appraised the illness and caregiving experience using the Appraisal of Illness Scale (AIS), the Appraisal of Caregiving Scale (ACS), Beck's Hopelessness Scale (BHS) for appraising hopelessness, and the Mishel Uncertainty in Illness Scale (MUIS) for appraising uncertainty (Northouse et al., 2007). The study found that patients in the family intervention group reported less uncertainty about their illness than controls at 4 months (MUIS, m=56.9 vs. 60; $P<0.05$). Spouses in the intervention group gave a less negative appraisal of caregiving (ACS, m=2.29 vs. 2.44; P<0.01), had less uncertainty about the illness (MUIS, m=59.5 vs. 63.1; P<0.01), and felt less of a sense of hopelessness (BHS, m=2.47 vs.3.07; P< 0.05) than spouses in the control group at 4 months. The level of uncertainty continued to be lower for spouses in the intervention group than for spouses in the control group at 8 months (m=59.5 vs. 62.2; P=0.05) (Northouse et al., 2007). Another study also assessed the appraisal of hopelessness (BHS), but no significant results were found (McLean et al., 2013).

Two studies assessed self-efficacy in illness and symptom management, using the Self-Efficacy for Symptom Control Inventory (SESCI) (Campbell et al., 2007) and the Lewis Cancer Self-Efficacy Scale (LCSES) (Northouse et al., 2007). A study reported that spouses in the intervention group had higher self-efficacy concerning ways to manage symptoms of the illness than spouses in the control group at 4 months (LCSES, m=144.1 vs. 138.8; P<0.05) and 12 months (LCSES, m=143.8 vs. 137.8; P<0.05). Although there were no significant differences in self-efficacy between spouses in the intervention and control groups (effect size range: 0.03-0.30), a small-to-moderate effect size (0.30) was observed for SESCI, with spouses in the intervention group reporting higher self-efficacy than spouses in the control group (Campbell et al., 2007).

It was noteworthy that all of the interventions included promoting communication between a patient and the patient’s spouse as a means of improving coping and adjustment to cancer. However, only four studies assessed the couples’ patterns of communication, using the Lewis Mutuality and Interpersonal Sensitivity Scale

(LMISS) (Northouse et al., 2007), the Relationship Communication Scale (Manne et al., 2011), the Communication Subscale from the Partnership Questionnaire (Heinrichs et al., 2012), and qualitative interviews (Scott et al., 2004). All four studies reported greater improvements in communication between patients and spouses in the intervention group than in the control group immediately following the intervention. One study reported sustained improvements in communication for spouses in the intervention group compared to spouses in the control group at the 12-month follow-up point (Northouse et al., 2007).

6.2.2 Dyadic coping

Dyadic coping strategies are the ways in which both patients and their spouses attempted to cope with the disease. Five intervention studies assessed changes in coping strategies after the intervention to support coping. Of the two studies that used Brief Cope (BCOPE) (Collins et al., 2013; Northouse et al., 2007), one reported that spouses in the intervention group used more active coping strategies at 12 months than spouses in the control group (BCOPE, m=30.5 vs. 28.9; $P<0.05$) (Northouse et al., 2007).

The ways in which both partners coped were examined using the Ways of Coping Questionnaire-Cancer Version (WOC-CA) (Scott et al., 2004) measure. The results showed that patients in the intervention group made more efforts to cope than those in the control group immediately following the intervention, and that this was also the case at 12 months after the intervention (Scott et al., 2004). Another study reported that patients in the intervention group scored higher on the RFCS

(Relationship-Focused Coping Scale) than patients in the control group (least square means: 33.84 vs. 28.25, P = 0.028) (McLean et al., 2013).

Dyadic coping was measured using the Dyadic Coping Inventory (Heinrichs et al., 2012). It was found that couples who received a skill-training intervention maintained a high level of dyadic coping, whereas couples in the control group showed a decline across the post-intervention period and the first follow-up at 6 months, and a subsequent increase in dyadic coping at 12 months (Heinrichs et al., 2012).

6.2.3 Dyadic adjustment/outcomes

Dyadic adjustments are measured in four dimensions – quality of life (QOL) and mental, physical, and marital satisfaction – according to the World Health Organization’s health model (Larson, 1999).

Quality of life (QOL): Two studies assessed QOL using the Functional Assessment of Cancer Therapy-Breast (FACT-B) for breast cancer patients (Baucom et al., 2009; Kayser et al., 2010). One study showed an improvement in FACT-B functional well-being with effect sizes of 0.97 (pre-post intervention) and 1.14 (preintervention-12 months follow-up) (Baucom et al., 2009). The other study reported that the patients in the intervention arm had higher means on all of the subscales (Physical, Emotional, Social/Family, and Functional) and the total QOL scale than patients in the control arm at the 6- and 12-month follow-ups. The effect sizes ranged from 0.27 to 0.55 (Kayser et al., 2010). This study also assessed the QOL of the spouses using the

Quality of Life Questionnaire for Spouses (QL-SP) and the Illness Intrusiveness Rating Scale (IIRS) (Kayser et al., 2010). The findings showed that the spouses in the intervention arm consistently scored higher in emotional well-being and lower in illness intrusiveness than the spouses in the control arm. The effect sizes ranged from 0.26 to 0.54 (Kayser et al., 2010).

Another study examined the effect of a brief one-off supportive intervention on the quality of life of prostate cancer patients and their partners using FACT-P and SF-36 (Thornton, Perez, & Meyerowitz, 2004). The results showed that scores for the physical and functional well-being of patients worsened between pre-surgery and 3 weeks post-surgery, but improved between 3 weeks and 1 year post-surgery (Thornton et al., 2004). The same pattern was found in the subscale of role limitations due to physical health, emotional functioning, pain, energy, and social functioning assessed using SF-36 (Thornton et al., 2004). Spouses showed impairment in their role performance due to physical problems / emotional functioning at 3 weeks post-surgery compared to pre-surgery, and improvement in role performance between 3 weeks and 1 year post-surgery. The social functioning of the couples remained constant between pre-surgery and 3 weeks post-surgery, but the couples experienced better social functioning at 1 year than at 3 weeks post-surgery (Thornton et al., 2004).

The family intervention study of Northouse et al. (2007) also assessed the QOL of both patients and spouses using FACT-G and MOS SF-12. The findings indicated that spouses in the intervention group reported better physical QOL than controls at

8 months (m=44.9 vs. 42.9; P<0.05) and at 12 months (m=44.6 vs. 42.3; P<0.01) (Northouse et al., 2007). Spouses in the intervention group also had better SF-12 mental QOL scores (m=50.9 vs. 49; P<0.05) and overall FACT-G QOL scores (m=86.5 vs. 83.5; P<0.01) than those in the controls at 4 months, but not at 8 months or 12 months (Northouse et al., 2007). In the two studies that assessed general QOL using SF-36 for patients and partners, no significant findings were reported (Campbell et al., 2007; Mohr et al., 2003).

Mental health – psychological distress, depression, and benefit finding

Psychological distress was conceptualized as emotional distress, anxiety, depression, worry, negative thoughts, and/or negative moods. In the 15 studies that assessed psychological distress, different instruments were used (appendices table 6-2, p.417).

It has been reported from randomized control trials that patients in the intervention groups experienced a significant decrease in psychological stress compared to those in the control groups immediately following the intervention (Baucom et al., 2009; Heinrichs et al., 2012; Kuijer et al., 2004; McCorkle et al., 2007; Scott et al., 2004) and at the final follow-up (Baucom et al., 2009; Heinrichs et al., 2012; Kuijer et al., 2004; McCorkle et al., 2007; Scott et al., 2004; Thornton et al., 2004). Other RCT studies have also reported significant improvements in the psychological status of spouses in the intervention groups compared to those in the control groups immediately following the intervention (Baucom et al., 2009; Campbell et al., 2007; Kuijer et al., 2004; McCorkle et al., 2007); and at follow-up (Baucom et al., 2009; Kuijer et al., 2004; McCorkle et al., 2007). Besides RCT studies, there are also cohort studies reporting within-group improvements in the psychological distress of both patients and spouses after receiving the intervention (Collins et al., 2013; Manne & Badr, 2008; McLean et al., 2008; Mohr et al., 2003) or at follow-ups (Collins et al., 2013; McLean et al., 2008).

In terms of depression outcomes, three studies reported improvements in depression for both patients and their partners at the time points of immediately following the intervention (Kuijer et al., 2004; McCorkle et al., 2007; McLean et al., 2008) and at 3 (Kuijer et al., 2004; McCorkle et al., 2007; McLean et al., 2008) and 6 months (McCorkle et al., 2007) after the intervention. One study did not show any significant improvement in depression for either patients or partners (McLean et al., 2013).

There were three studies that assessed the couples' benefit finding using the revised Benefit-Finding Scale (BFS) (Collins et al., 2013) and the Posttraumatic Growth Inventory (PGI) (Baucom et al., 2009; Heinrichs et al., 2012). One study showed that patients reported relative gains in post-traumatic growth immediately post-intervention and at the one-year follow-up, while spouses showed an increase in posttraumatic growth at the one-year follow-up (Baucom et al., 2009). Another study reported more post-traumatic growth in both patients and partners at two time points: post-intervention and the one-year follow-up (Heinrichs et al., 2012).

Physical health – physical distress and sexual functioning

Physical distress was conceptualized as the impact of the diagnosis of cancer and the side-effects of treatment on the physical functioning, pain, fatigue, and sexual functioning of individuals. Of the four studies that assessed physical distress (Baucom et al., 2009; Campbell et al., 2007; Northouse et al., 2007; Thornton et al., 2004), one study among couples coping with breast cancer assessed the physical distress of patients using the Brief Fatigue Inventory (BFI), the Brief Pain Inventory (BPI), and the Rotterdam Symptom Checklist (RSC). The findings showed that patients in the intervention group reported more functional well-being (e.g., a greater ability to work and finding work more fulfilling), with large effect sizes: d=0.97 at posttest and d=1.14 at the 1-year follow-up, than those in the control group (Baucom et al., 2009).

Of the two studies using the Expanded Prostate Cancer Index Composite (EPIC) among prostate cancer patients, one reported improvements among patients in the intervention group of less bowel trouble (*d*=0.47), less urinary trouble (*d*=0.32), less sexual trouble (*d*=0.45), and fewer hormonal symptoms (*d*=0.38) than among patients in the control group immediately following the intervention (Campbell et al., 2007). Another study reported that spouses in the intervention group were significantly less affected by the patient's physical distress than spouses in the control group immediately following the intervention (Northouse et al., 2007).

Sexual functioning was conceptualized as the sexual function and satisfaction of patients and spouses since their diagnosis. Five studies assessed sexuality (Baucom et al., 2009; Campbell et al., 2007; McCorkle et al., 2007; Northouse et al., 2007; Scott et al., 2004). One study that assessed sexuality using the Sexual Self Schema (SSS) reported more improvements in sexuality for patients in the intervention group than for those in the control group immediately following the intervention and at the 12-month follow-up (Scott et al., 2004). One study using the Cancer Rehabilitation Evaluation System (CARES) reported greater improvements in sexual functioning among patients in the intervention group than among those in the control group at the 6-month follow-up (McCorkle et al., 2007), while for spouses, improvements in sexual functioning were reported immediately following the intervention and at the 6-month follow-up (McCorkle et al., 2007).

Marital satisfaction

Marital satisfaction was conceptualized as the quality of the marital relationship between patients and partners, and their satisfaction with the relationship.

Greater improvements in patients' marital satisfaction were reported in the intervention group than in the control group immediately following the intervention (Baucom et al., 2009; Heinrichs et al., 2012; Kuijer et al., 2004; Manne & Badr, 2008; McCorkle et al., 2007; McLean et al., 2013; Porter et al., 2009) and at the final follow-up (Baucom et al., 2009; Heinrichs et al., 2012; Kuijer et al., 2004; McCorkle et al., 2007; McLean et al., 2008). Greater improvements in the marital satisfaction of the spouses of cancer patients were also reported in the intervention group compared to spouses in the control group immediately following the intervention (Baucom et al., 2009; Heinrichs et al., 2012; Kuijer et al., 2004; Manne et al., 2011;

McCorkle et al., 2007; McLean et al., 2013), and at the final follow-up (Baucom et al., 2009; Heinrichs et al., 2012; Kuijer et al., 2004; McCorkle et al., 2007; McLean et al., 2008).

Marital satisfaction was measured using the Quality of Marriage Index (QMI) and the Miller Social Intimacy Scale (MSIS) (Porter et al., 2009). The findings of a study showed that both patients and spouses in the partner-assisted emotional disclosure intervention group reported increases in marital satisfaction after intervention when compared to patients and spouses in the education/support group. However, these positive effects of the partner-assisted emotional disclosure intervention on marital satisfaction occurred only when patients reported high levels of holding back from talking about cancer-related concerns to their spouse at baseline (Porter et al., 2009).

6.3 Summary

All 17 studies that focused on couple-based interventions for couples coping with cancer had been conducted in Western countries. The sample size in these studies ranged from 9 to 263 couples, with the attrition rate ranged from 6% to 34%. It was noteworthy that low response rate from eligible participants and high withdrawal rate was the most common reason, which led to otherwise “strong” articles being rated as “moderate” according to EPHPP criteria (Thomas et al., 2004). No specific theoretical framework on cancer dyads coping with cancer was found in the articles included in this review.

It is worth noting that none of these interventions were conducted in Asian countries. Also, although it has been reported that a group intervention can offer the participants an opportunity to meet with other caregivers and to share their experiences with people in similar situations (Hudson et al., 2008; Hudson et al., 2012; Hudson, Thomas, Quinn, Cockayne, & Braithwaite, 2009), a group approach was adopted in only one intervention (Shields & Rousseau, 2004).

The reviewed studies provided some valuable suggestions on developing interventions for couples coping with cancer. It was noted that while all of these studies focused on the couples’ communication and relationship, only about 40% focused on the subject of caregivers’ self-care. Caregivers often place the needs of the patient above their own; as a result, they often spend less time than they otherwise might have on maintaining their own physical, mental, and social health (Northouse et al., 2010), with possibly negative consequences for their health. Improving their self-care ability benefits not only caregivers but also their patients, and thus the couple as a dyad coping with cancer (Northouse et al., 2010). It is necessary to conduct a study to examine the self-care behaviors and physical health outcomes of spousal caregivers, if they are to continue to provide care for their partners with cancer.

All of the intervention studies included in the review reported positive outcomes to some extent, including improvements in the quality of life (Northouse et al., 2007), psychosocial distress (Baucom et al., 2009; S. Manne & Badr, 2008; McLean et al., 2008; Mohr et al., 2003), sexual functioning (Scott et al., 2004), and marital satisfaction of both the patients and their partners (Baucom et al., 2009; Kuijer et al., 2004; McCorkle et al., 2007; McLean et al., 2008). However, none of these interventions evaluated all the outcomes, which included the couples' appraisal of illness, coping strategies, mental and physical health, and marital satisfaction, as dyads in the same study.

A variety of measurements were used in these intervention studies to measure similar concepts or outcomes. For example, many measurements of psychological distress were used to measure stress. This not only affected the research outcomes, but also made it difficult to compare the findings of these intervention studies with one another.

Recommendations for future intervention program

Despite the fact that numerous models were adopted in the intervention studies included in this review, in the majority of studies there was a failure to describe how theory was used in the study. A dyadic theoretical framework on couples coping with cancer is lacking. Developing such a framework will not only make possible a better understanding of the related concepts in the context of couples coping with cancer, but also facilitate the development of interventions to support spousal caregiver-patient dyads in coping with cancer (Carbonneau, Caron, & Desrosiers, 2010).

All the interventions included in this review were conducted in western countries, thus it is recommended that similar studies be conducted in different cultures to help couples coping with cancer and to gain a better understanding of the effect of couple-based interventions on spousal caregiver-cancer patient dyads' caregiving experience in their coping with cancer in different cultures.

The attrition rate in these studies ranged from 6% to 34%, with an average rate of 20%. The barriers to taking part in these interventions, as reported by the couples, point to the need for greater flexibility in the content and delivery of interventions for couples coping with cancer. For instance, an intervention protocol (Porter et al., 2009) was found that although the intention was to schedule 4 sessions weekly, couples were given up to 8 weeks to complete the 4 sessions to accommodate delays because of the patient's medical condition and/or to coordinate sessions with other appointments at the medical centre.

In this study, the feasibility, applicability and acceptance of the program will be considered in the whole process. For instance, to meet target dyads' expectation, the programme was developed partly based on their needs and concerns, which was obtained through focus group study on spousal caregiver-cancer patient dyads.

Implications for intervention

Based on the results of this review and incorporated with the authors opinions, highlighted here are recommendations for healthcare professionals who seek to provide a couple-based intervention program that focuses on the couple as the unit of intervention and supports couples coping with cancer:

- Target population: spousal caregivers caring for patients with cancer; where the spouse is an active caregiver, the intervention should be provided to the couple as a unit: dyads.
- Theoretical framework and approaches of interventions: there should be a clear dyadic theoretical framework on couples' coping with cancer to guide the intervention, approaches, and outcome measures.
- Types and contents of interventions: the intervention should be a combination of skills training and a psycho-educational intervention; including marital/family support, skills training for patient care, and caregiver self-care.
- Dosage of interventions and follow-up: a reasonable intervention dosage (i.e., 6 weekly sessions of 90 minutes each); with at least 3 months of follow-up is recommended.
- Program flexibility: the barriers to taking part in interventions, and the reported attrition rates, point to the need for greater flexibility in the contents and mode of delivery of interventions for couples coping with cancer.
- Delivery of interventions: Interventions should be delivered by trained professionals, including nurses/counselors, psychiatrists, psychologists, and social workers using a face-to-face group mode.
- Outcomes of interventions: the outcomes of interventions should assess both partners' illness appraisals, strategies for coping, and health outcomes, including mental, physical, and marital satisfaction.

Conclusion

These findings highlight the positive outcomes of couple-based interventions that focus on couples coping with cancer. Future studies on couple-based interventions can be conducted in different cultures, such as in Asia. The feasibility, applicability, and acceptance of the program should be considered in the whole process of developing, delivering, and assessing couple-based programs. Collaboration between researchers and clinicians is crucial to ensure the development of effective and accessible interventions targeting couples coping with cancer.

Chapter 7

The spouse caregiving for cancer patients phenomenon

(Summary of the literature reviews and identification of research gaps)

The above literature reviews focused on five aspects, including spouses' experience of caregiving for cancer patients; a spectrum of hidden morbidity among spousal caregivers for cancer patients; the positive aspects of spousal caregivers for cancer patients; the mutuality of the spousal caregiver-cancer patient dyads; and couple-based Interventions for couples coping with cancer. It is based on these extensive reviews of literature, the research gaps in this area of research are identified.

7.1 Main findings

Spouses' experience of stress in caregiving for cancer patients (Chapter 2)

Spousal caregivers of cancer patients suffered from high level of stress, including primary and secondary stressors in caregiving. The stress experience is mediated by how the caregivers appraise their situations, and what are their cognitive-behavioral responses.

The patient illness-related factors such as stage of the cancer, physical health, and care demands (dependency) were associated with spousal caregivers’ physical and mental health. Spousal caregivers suffered from spillover effects due to secondary stressors, such as role problems, lack of social and emotional support, disrupted schedule, and loss of sleep and fatigue. Caregivers’ characteristics, including their ability to find meaning and benefits from caregiving, spirituality, self-efficacy, optimism, and self-esteem, affect spousal caregivers’ appraisal of their caregiving experience.

Hidden morbidity among spousal caregivers for cancer patients (Chapter 3)

Spousal caregivers of cancer patients are a high-risk or hidden morbidity population in all three dimensions of the WHO's definition of health. Spousal caregivers of cancer patients perceive both negative and positive experience during their coping process. Negative experience of caregiving included a wide spectrum of hidden morbidities, such as mental morbidity (higher levels of distress, depression, and anxiety, and lower levels of mental health), physical morbidity (lower level of physical health, poorer physical functioning, and the loss of physical strength), and social morbidity (lower marital satisfaction and lower levels of social support).

The positive aspects of spousal caregivers for cancer patients (Chapter 4)

Spousal caregivers for cancer patients experienced various positive aspects of caregiving, including an enhanced relationship with the care-receiver, the feeling of being rewarded, a sense of personal growth, and a perception of personal satisfaction. Daily enrichment events and self-efficacy on the part of the caregivers were identified as the determining factors in the positive aspects of caregiving.

These findings are an echo of the research progress on coping theory (Folkman & Moskowitz, 2000; Folkman, 2008). Accumulated evidence has showed that positive affect co-occurs with negative affect during chronic stress. Positive affect has its own important adaptational significance in the context of stress through the following mechanisms, including promoting creativity and flexibility in thinking and problem solving; facilitating the processing of important (e.g., self-relevant) information; serving as a buffer against adverse physiological consequences of stress; offseting the deleterious physiological effects of stress; and preventing clinical depression (Folkman & Moskowitz, 2000; Folkman, 2008).

The mutuality of the spousal caregiver-cancer patient dyads (Chapter 5)

Studies on the spousal caregiver-cancer patient dyads highlight the importance of a relationship perspective and communication within couples in the study of couples coping with cancer. It is recognized that communication may act as a fundamental element among the three concepts of caregiver-patient dyads. Better communication between couples will probably benefit the reciprocal influence and caregiver-patient congruence, which in turn have positive effects on couple's intimacy and coping, and to improve the caregiving outcomes. Targeting the spousal caregiver-patient dyads level, rather than the individual level, is important since strong spousal relationship have protective effects on psychological distress, QOL, and marital satisfaction. Couples may benefit from interventions that include a communication component that addresses both the patient's and the spouse's needs.

Couple-based Interventions for couples coping with cancer (Chapter 6)

It has been reported that interventions that focus on reducing negative impact or enhancing positive aspects of the caregiving experience, can improve the caregiving experience. It is reported that interventions focused on caregiver role development are more likely to be successful than those focused on factors such as caregivers' burden (Sorensen, Pinquart, & Duberstein, 2002). The meaning-focused coping (Folkman & Moskowitz, 2000; Folkman, 2008), including benefit finding and reminding, adaptive goal processes, reordering priorities, and infusing ordinary events with positive meaning, will be valuable to guide intervention development.

The majority of couple-based interventions applied the RCT, using cognitive-behavioral approach. The primary focuses of these interventions were psycho-educational, skills' training, and therapeutic counseling. The most common combinations of primary and secondary elements were those that included both psycho-educational and skills training. The content of the interventions for couples included marital/family care, patient caregiving and caregiver self-care.

7.2 Research gaps identified

Based on the literature review, it is found that although studies on spousal caregivers of cancer patients have been widely conducted, the study on spousal caregiver-cancer patient dyads is limited in terms of several aspects:

- Most studies mainly focused on the negative experience of caregiving, but there is a dearth of relevant literature focused on the positive experience of spousal caregivers' experience of cancer patients. (**Chapter 2,3**)
- The shift of study focus from an individual level to the caregiver-patient dyads raises a need to develop a dyadic model specifically on cancer caregiving. (**Chapter 5**)
- Although most of the caregivers are spouses of the patients with cancer, few programs were found specifically focused on supporting spousal caregivers for their caring of spousal with cancer and considered the couples as caregiver-patient dyads. (**Chapter 6**)

- Different measurements were used in studies to measure the same concept or type of outcome. There is a need to develop or translate the related measurements for better evaluating the intended outcomes specifically in Chinese culture. (**Chapter 2-6**)
- Most studies applied quantitative study design; there is a lack of qualitative or mixed study designs. (**Chapter 2-6**)
- Most of the intervention studies were conducted in the western countries. Few studies were found conducted in China which was focused on supporting spousal caregivers of cancer patients. (**Chapter 6**)

7.3 Conclusions and methodology clarification

These reviews provided some valuable suggestions on interventions to be developed for couples coping with cancer. However, few couple-based interventions have been found so far focused specifically on supporting spousal caregivers and cancer couples in their journey of living and coping with cancer as dyads. No one intervention reviewed above evaluated the outcomes from couples' appraisal, coping strategies, to different health outcomes, such as QOL, marital satisfaction.

Taking into account the complex experience, the hidden morbidities, and relational dynamics of cancer couples, it is concluded that the factors that have an impact on couples coping with cancer are complex and multi-faceted, and that there is a need for a complex intervention to support cancer dyads. It is the aim of the present study to develop, deliver and evaluate a complex intervention: "Caring for Couples Coping with Cancer (4Cs)" programme to support couples coping with cancer as dyads in

China. The MRC framework on developing and evaluating complex interventions was adopted in developing and evaluating this “Caring for Couples Coping with Cancer (**4Cs**)” Programme (Craig et al., 2008; Medical Research Council, 2000, 2008).

According to the MRC framework, it is considered beneficial and crucial to include both qualitative and quantitative studies in the lengthy process of developing, piloting, evaluating, reporting, and implementing a complex intervention (Craig et al., 2008). Therefore, a mixed method study design that includes both qualitative and quantitative approaches was applied in this study.

In phase 1 of developing the **4Cs** programme, the extensive reviews of literature and a focus group study were conducted to identify the existing evidence. Focus group interviews were conducted to gain a better understanding of the experiences of couples coping with cancer, including their concerns and needs regarding their experiences and roles. A Preliminary Conceptual Framework (P-CF) for cancer couple dyads was proposed and tested to guide the development of the **4Cs** programme and the choice of the outcome measures. A booklet was developed to address the couples’ needs during their experiences of coping with cancer.

In the phase of assessing feasibility and piloting, contents includes testing procedures for their acceptability, estimating the likely rates of recruitment and retention of subjects, and the calculation of appropriate sample sizes (Craig et al., 2008; Medical Research Council, 2000, 2008). In this study, a pre-intervention and post-intervention study was adopted to examine the feasibility and effectiveness of the **4Cs** programme. The reason of using pre-intervention and post-intervention study lies in that it can fit the study aims at (i) to determine the acceptability and feasibility of this **4Cs** Program based on recruitment rate, retention rate, and intervention compliance; (ii) to explore the effects of the **4Cs** program on variables and calculate effect size of related variables according to the paired scores of the outcome measures (pre-intervention / post-intervention).

To summarize, guided by the MRC framework, a mixed method study design was applied in the phase of developing the **4Cs** programme, while pre-intervention and post-intervention study was adopted in phase 2 of assessing feasibility and piloting this **4Cs** programme.

Chapter 8

STUDY I SUBSTANTIATING THE IDENTIFIED EVIDENCE BASE FROM REVIEW OF LITERATURES

The Experiences of Chinese Couples Living with Cancer: A Focus Group Study*

* The content of this Chapter was published:

Li, Q., Chiang, V. C. L., Xu, X., Xu, Y., & Loke, A. Y. (2014). The experiences of Chinese couples living with cancer: A focus group study. *Cancer Nursing*, doi:10.1097/NCC.0000000000000196.

8.1 Introduction

The extensive literature reviews conducted clearly showed that there is a need to develop a couple-based program specifically focused on supporting cancer couples for their coping with cancer as dyads. However, majority of these literatures reviewed were conducted in western country, the experience of spousal caregivers and cancer patients in China is under-studied or unknown. For a better understanding the reality and need of the caregiver-patient dyads in China, and the need of a client-oriented programme, the focus group study was conducted.

A diagnosis of cancer and its treatment will affect the patient as well as the patient’s family, particularly the patient’s spouse (Kayser, Watson, & Andrade, 2007). Spouses are the primary family caregiver for cancer patients in the United States (Kurtz, Kurtz, Given, & Given, 1995) and Taiwan (Chen, Chu, & Chen, 2004). A couple coping with cancer will experience changes that will require both members to reflect on their roles as an individual and as a couple (Dankoski & Pais, 2007). Throughout the cancer trajectory, the patient and his/her partner must together cope with the practical issues and difficulties that they encounter (Dankoski & Pais, 2007).

To varying degrees, cancer affects a couple as a unit, rather than as isolated individuals, causing them to react to a diagnosis of cancer as an “emotional system” (Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008). However, most research on coping with cancer has been about the impact of stressors on the physical, mental, and social health of individuals, rather than on what actually happens between couples coping with cancer as a unit (Badr, Acitelli, & Taylor, 2007). Not until recently has the focus of cancer care and research begun to shift from the individual experiences of patients or spousal caregivers to the experiences of caregiver-patient dyads coping together with cancer (Fletcher, Miaskowski, Given, & Schumacher, 2012; Miller & Caughlin, 2013; Song et al., 2012; Zhang, Zyzanski, & Siminoff, 2010) .

Those researching couple-based interventions have reported improvements in the coping behaviors of couples (Regan et al., 2012); however, quantitative research methods, including randomized controlled trials (RCT) (Baucom et al., 2009; Campbell et al., 2007) and cohort studies (McLean et al., 2008; Mohr et al., 2003) have primarily been employed in research on couples coping with cancer. Most of the interventions were developed according to professional norms without taking into account the perspectives and needs of the couples.

We have identified only one study of a couple-based intervention that was developed based on the concerns and needs of cancer couples in relation to their caring roles and experiences (Shields & Rousseau, 2004) . That preliminary study showed that the intervention produced positive changes in the patients' mental health and cancer-related stress (Shields & Rousseau, 2004). However, the study examined only breast cancer survivors and their spouses, and was conducted in the United States (Shields & Rousseau, 2004). Cultural differences are worth emphasizing, particularly in the context of cancer in Chinese culture. For instance, healthcare professionals usually talk about a patient's diagnosis with members of the patient's family before informing the patient. Also, in a collectivistic and patriarchal culture like that of the

Chinese, couples may be less demanding or more withdrawn when communicating with each other because partners, particularly women, tend to subordinate their own desires to the needs of the patient or of the couple as a whole (Christensen, Eldridge, Catta‐Preta, Lim, & Santagata, 2006).

It has been reported that focus group interviews could be a supplementary source of data in mixed-method studies and can also be used as a source of data for developing programs or interventions (Hennink, 2007; Liamputtong, 2011). A focus group study could also prevent program development activities from going off track (Liamputtong, 2011).

8.2 Objective

The aim in conducting this study was to gain a better understanding of the experiences of Chinese couples living with cancer, including their concerns and needs regarding their experiences and roles. This study will help healthcare providers to recognize couples as a focus of cancer care, and provide them with basic information for designing suitable interventions / programs to support such couples.

8.3 Methods

Study Design

We adopted a focus group study design to explore the experiences and needs of couples living with cancer. The focus group method can be used as a self-contained approach to examine research questions from the perspective of the participants as well as to explore new areas of research. How the participants interact in a group can reveal experiences and perspectives that might not otherwise be accessible to the researchers (Hennink, 2007; Liamputtong, 2011) .

Sampling and Data Collection

Purposive sampling (Sandelowski, 1995) in a large public hospital was carried out to recruit participants for this study. Table 8-1 shows the comparison of purposive sampling and convenience sampling approaches (Marshall, 1996) .

Table 8-1 The comparison of purposive and convenience sampling

	Purposive sampling*	**Convenience sampling**
Definition	The deliberate choice of an informant due to the qualities of the informant possesses.	The selection of the most accessible subjects.
Characteristics	The most common technique.	The least rigorous technique.
Strategies	The researcher actively selects the most productive sample to answer the research questions.	The least costly to the researcher, in terms of time, effort and money, but may result in poor quality data and lacks intellectual credibility.

* It was tried in this study to select and make sure the heterogeneity of the sample population according to the purposing sampling, e.g. suffering from different types of cancer, undergoing different kinds of treatment, different length of time since diagnosis, and at different age, etc.

The participants were Chinese married couples (>18 years old) where one partner in the couple had received a medical diagnosis of cancer and was being actively cared for by his / her spouse. The intention was to interview both patients and spousal caregivers together to obtain a deeper understanding of their experiences as dyads through their interactions during the interviews.

Excluded from the study were couples where the spousal caregiver had a serious physical condition (to the point of being unable to care for himself/herself), where at least one partner had a memory problem (defined as being unable to remember or to communicate and describe what had happened to them), and/or couples that were experiencing severe marital dysfunction unrelated to the cancer that warranted regular marital therapy.

A total of four focus group interviews of cancer patients and their spousal caregivers (SC) were conducted in January 2013. Characteristics of the patients and spousal caregivers are summarized in Table 8-2. Mean age of the participated patients and SC was 61 and 66 respectively, with their average lengths of marriage as 40-41 years. We did not target a specific length of time since diagnosis in order to include a group of participants for more comprehensive understanding of their experiences over time. The interviews were held in a conference room in the hospital ward to ensure a quiet environment and convenient access for the participants. The participants in the interviews were receiving active treatment and thus coming to the hospital regularly (groups 2-4); or had completed their active treatment in the hospital, but were easy to approach and did not find it inconvenient to travel to the hospital (group 1). None of the participants knew each other before the interviews. For those who were receiving treatment, they were assured for the fact that their interviews would not affect their care in any case. Each interview took around 90–120 minutes in duration (Morgan, 1997).Tables and chairs were arranged in a circle, which facilitated discussion among the participants in the group.

Table 8-2 The characteristics of the patients and spousal caregivers

Characteristics	Patients (P, n=11)	Spousal caregivers (SC, n=17)
Group 1	P1-5	SC 1-5
Group 2	P6, P7[a]	SC 6
Group 3	P8-10	SC 7[a] SC8-10
Group 4	P11	SC11-17
Mean age (range: years)[b]	61 (43-72)	66 (43-76)
Mean length of the marriage (range: years)[c]	40 (18-50)	41 (19-52)
Gender	Male: 6; Female: 5	Male: 8; Female: 9
Levels of education (n)	Undergraduate education (1) Middle schools (10)	Middle schools (11) Primary school (6)
Informed about the disease (n) [d]	Well informed (6) Partly informed (5)	Well informed (15) Partly informed (2)
Cancer types (n)	Gastric cancer (3); Lung cancer (2); Colon cancer (2); Breast cancer (2); Tonsil cancer (1); Kidney cancer (1)	
The average time since diagnosis	3.9 years (ranging from 2 months to 15 years)	
The median time since diagnosis	2 years and 8 months (32 months)	
The individual time since diagnosis (n) (M: month; Y: year)	2M(1), 3M(1), 6M(2), 2Y(1), 2Y and 8M(1), 3Y(2) 8Y(2), 15Y(1)	
The average length of time in their role as an SC	3.2 years (ranging from two months to 15 years) [e]	
The median time as an SC	2 years	
The individual time as an SC (n) (M: month; Y: year)	2M(1), 3M(2), 6M(3), 1.5Y (1), 2Y(2), 2Y and 8M(1), 3Y(3) 3.5Y (1), 8Y(2), 15Y(1)	

Note: [a] a single patient or spousal caregiver in the FG.

[b] Except for two patients (43 and 54 years old) and two spousal caregivers (43 and 57 years old) who were under the age of 60, all of the others were over 60 years old.

[c] Except for one patient and one spousal caregiver who were in their 18th and 19th years of marriage respectively, all of the others had been married for more than 30 years.

[d] Well informed: Patient fully understood his / her condition; or the SC was well informed about his / her spouse's disease

Partly informed: Patient was informed about the diagnosis of cancer, but not about the severity of his / her condition; or the SC was partly informed about his / her spouse's disease.

[e] All of the spousal caregivers reported that they spent more than eight hours a day providing care for their partners with cancer.

In the focus group sessions, we used a semi-structured question guide (Table 8-3) on issues relevant to the objectives of the study as an aid to dialogue. For all four focus groups, the trigger questions were about the perceptions of both the cancer patient and the patient's partner on their own experiences of living with cancer and managing the symptoms, and about their needs and the types of help that would benefit them most in day-to-day living. Where relevant, questions were also asked in response to the dialogues of the participants, which brought more discoveries about their experiences as represented by themes and subthemes. At the appropriate time, the moderator (the first author: QL, who is a Chinese; all authors had experiences in oncology nursing and/or qualitative study) clarified particularly unclear points, called for breaks, or redirected the participants if they were talking about issues not relevant to the study. All of focus group discussions were digitally recorded and subsequently transcribed.

Table 8-3 Guiding questions for each focus group interview

For couples (cancer patients and spousal caregivers)
1. What is your experience of living with cancer as a couple? In terms of your relationship and the ways you communicate, what has been the impact of this illness on your life? 2. As a patient or a caregiver, what are your unmet needs? 3. What kinds of help do you need that may improve your life? 4. How prepared do you feel to be a caregiver? 5. How do you manage the symptoms of cancer? 6. When you need information, where or to whom do you go to ask for help? Additional relevant questions were asked in response to the participants' dialogues.

An assistant focus group moderator (Krueger, 1994) who was the head nurse (the third author: XX, for groups 1-2; and the fourth author: YX, for groups 3-4) in the ward was invited to take notes, record relevant non-verbal communication, and assist with logistics (arranging for refreshments to be served and consent forms to be presented). At the end of each interview, the assistant moderator gave the participants a brief overview of the major issues that had been discussed. The participants were given the opportunity to clarify points or offer additional information about their experiences and thoughts. To gain a better understanding of the interviews, the moderator and assistant moderator held a 15-minute debriefing session that involved discussing their overall impressions, key quotes, and ideas from the interviews after the participants had left the room.

Data Analysis

A conventional approach (Hsieh & Shannon, 2005) to content analysis was applied in this study. Theoretically, the process of analyzing the data from the interviews actually begins as the data is being collected (Graneheim & Lundman, 2004). While the data are being analyzed, the researchers (QL, XX, and YX) immersed themselves in the data to allow new insights to emerge, and described these insights by developing inductive categories (themes) (Kondracki, Wellman, & Amundson, 2002). In this study, a computer-aided qualitative data analysis software (CAQDAS), NVivo (QSR International, Doncaster, Victoria, Australia), was used to aid in coding, sorting, and developing themes from the data. A conventional approach to content analysis contains the five steps of *transcribing, decontextualizing, synthesizing,* *theorizing, and recontextualizing* (Hsieh & Shannon, 2005; Stewart, Shamdasani, & Rook, 2007).

Transcribing. The focus group interviews were conducted in Chinese and were digitally recorded. For a transcript-based analysis, all of the data were prepared as verbatim transcripts in Chinese (Onwuegbuzie et al., 2009). All of the final versions of the transcripts were carefully checked for accuracy by two investigators who participate in the interviews.

Decontextualizing. This starts when the researcher repeatedly read all of the data to achieve immersion and obtain a sense of the whole (Tesch, 1990), as one would read a novel. Subsequently, the data were read word-by-word to derive codes (Miles & Huberman, 1994; Morse & Field, 1995) by first highlighting the exact words from text that appeared to capture key thoughts or concepts. Then, with the aid of nVivo, open coding were conducted, which is the “decontextualizing” of data by reducing the data to smaller meaningful units. The researcher continued to openly code the transcripts by considering codes that had already been developed (further coding and recoding). Existing codes were revised and new codes were developed when the data that encountered do not fit into the existing transcripts.

Synthesizing. As the number of open codes increased, the researcher began to discover emerging pattern/s and to ponder them in terms of their differences and similarities. This was the next step in the process of coding, by which meaningful open codes were grouped together and subcategories (subthemes) were created.

Theorizing. A further analysis were conducted through a higher level of classification and categorization of the data to develop core categories or themes, and by seeing the relationships among these higher-level themes, which can authentically and accurately represent the topic being studied.

Recontextualizing. Three researchers examined the final themes and subthemes to organize them into a hierarchical structure; and discussed how the discovered / developed themes presented in a framework or model might contribute insights for actual practice.

Trustworthiness

Four criteria of trustworthiness need to be met before a qualitative study is deemed to possess rigor: credibility, dependability, confirmability, and transferability (Lincoln & Guba, 1985). Several measures were adopted in this study to meet these criteria. Peer debriefing was performed to the codes developed by two researchers in the study team (the second author: VC; and fifth author: AL) to ensure the credibility and conformability of the data analysis. With the aid of nVivo, a clear audit trail was maintained for the findings on the experiences of the participants since their diagnosis. This contributed to the dependability and transferability of this study.

Ethical Considerations

In a qualitative study, ethics should be considered during the entire process of the study (Marshall & Rossman, 2011). In this study, ethical approval was obtained from the Human Ethics Committee of The Hong Kong Polytechnic University. Approval for access was obtained from the hospital in Wuxi city in which this study was conducted. Written informed consent was obtained from all of the participants, reconfirmed by their oral consent prior to the interviews to have the interviews digitally recorded. For anonymity, the names of the participants were replaced in the transcripts by special codes, e.g., P1, P2…. and SC1, SC2 …. and their identities were not revealed in any subsequent dissemination of the results. The researchers were very careful to protect the privacy and confidentiality of the participants. All of the collected data were stored in a locked cabinet accessible only by the authorized researchers. The data will be destroyed after the completion of the study.

8.4 Results

The characteristics of the sample are presented in Table 8-2. Four themes (communication dynamics, living with changes, negative and positive impacts, and network of support) and the related subthemes were identified and are summarized in Table 8-4.

Table 8-4 A framework of the themes and subthemes

Themes	Subthemes
1. Communication dynamics	Expressions of appreciation
	Compelling need for information
	Information censorship and the two-sided face
2. Living with changes	Change in roles
	Change in marital relationship
	Change in life plan
	Change in social activities

3. Negative and positive impacts	Side-effects of chemotherapy
	Caregiver burden
	Reciprocal caring / support
	Positive perspective and hope
4. Network of support	Family support
	Comrades in arms against cancer
	Healthcare professional support
	Governmental support

8.4.1 Communication Dynamics

The findings from the interviews with the patients and their spousal caregivers indicated that communication is crucial to coping with cancer. Some couples communicated better after the diagnosis of cancer. It brought them together, which made it easier for them to deal with the illness. Spousal caregiver 8 said,

> My husband was not good at communicating. However, after his diagnosis of cancer, he changed a lot. We now can share our thoughts, worries, and future plans, which makes me feel good about being able to take care of him. (Group 3, SC8)

Nevertheless, some caregivers also said that they had to exercise restraint and wished for better communication with the patient. They sacrificed their own needs and put up with whatever the patient said or did to them. Spousal caregiver 7 said,

> My wife is angry with everything, even when I have done my best to take care of her, which really makes me upset. However, what I can do is still put her

> needs first and put up with whatever she says and does to me, because she is a patient. I wish we could communicate better. (Group 3, SC7)

From the data, it was evident that the dynamics of communication between the patients and their spousal caregivers varied. The dynamics of communication was an essential aspect (a theme) of their experience of living and coping with cancer as a couple. We further identified three subthemes on communication dynamics, as shown in Table 8-5.

Table 8-5 Representative data of the subthemes of communication dynamics

Subthemes	**Supporting statements from the participants**
Expressions of appreciation	
● Statement of a patient	✓ My wife is very kind and has been taking care of me all the time after my diagnosis of cancer. I appreciate her very much. Although she never complains about being tired, I understand that it is not easy for her to take care of me. I wish that she could communicate more—even feel angry with me. (Group 1, P4)
● Response of a spousal caregiver	✓ He never expresses these things (what her husband P4 said above) to me. I am so impressed with what he (P4) said, which makes me feel that all I’ve done is worthwhile if only he can get well. (Group 1, SC4)
Compelling need for information	
● Need accurate/consistent information	✓ We have many friends who are healthcare professionals. However, I was really confused by the information that they provided to me, because the information is sometimes inconsistent. (Group 4, SC12)

● Need sufficient information	✓ If medical professionals or the hospital can provide a brochure to patients with relevant information on cancer and containing instructions, we would like to follow the instructions. This would protect us from being misled by other unauthorized information. (Group 1, SC2)
● Right time for information	✓ In the beginning, when I heard the diagnosis of cancer, I was dumbfounded and so was my spouse. During this period, it was impossible for us to absorb the information to make a decision on treatment. What we did was simply to respond to the doctors’ suggestions. After that, sufficient information would be helpful.

Information censorship and the two-sided face

● Keep the diagnosis a secret	✓ I think that family members should keep the diagnosis a secret from the patient for as long as possible. (Group 4, SC11)
● Informing the patient gradually	✓ It would be better to inform patients about their disease, which will make it easier for all of us to cope together. However, we need to inform them gradually according to each patient’s personality. (Group 1, SC2)
● Patients willing to know about the disease	✓ As a patient, I found that some families kept the disease a secret from the patient, which put an extra burden on both parties. I think that patients have the right to know what is going on, and their right to know should be respected. Doing so will relieve the burden on both patients and their families. (Group 1, P1)
● It is impossible to hide the diagnosis	✓ Although my spouse and family tried to hide the diagnosis from me, I realized that I suffered from cancer when I was admitted to the oncology ward. I could also recognize my disease from other patients in the same ward with whom I communicated. (Group 4, P11)

● Two-sided face of mutually “protecting”	✓ In fact, I knew my diagnosis and I also understand that my family did what they did, because they were just trying to protect me. What I can do is pretend that I do not know about the disease. This has made it difficult for us to communicate openly about the progression of the disease and to make treatment decisions together. (Group 4, P11)

Expressions of appreciation

Spousal caregivers said that hearing their partner express appreciation for their caring made them feel happy, which in turn facilitated the caring process.

Compelling need for information

The participants indicated that they needed accurate / consistent information about cancer. They were particularly dissatisfied with the inconsistencies in the information that they obtained from different sources, such as from different healthcare professionals and friends. Some participants also commented that they had not received sufficient information on the illness, particularly from healthcare professionals.

Regarding the importance of timing when receiving information from healthcare professionals, the participants stated that after they had moved past the stage of accepting the diagnosis of cancer, they need sufficient information and guidance to help them make decisions about treatment options.

Information censorship and the two-sided face

The participants acknowledged that there were benefits to informing patients of their disease, including the prognosis. However, the caregivers differed on how much patients should know about their cancer. Some wanted to protect the patient and said that they might keep the diagnosis a secret from the patient, while others gradually informed the patient about the diagnosis of cancer.

In contrast, the patients stated that they had the right to be informed about their own disease, and felt that knowing their own diagnosis would relieve the burden on the whole family. The patients held the view that if the diagnosis of cancer had been kept from them they would have found out about their disease anyway from the conversations of other patients in the ward, from the examination report, or simply from reminders sent from the oncology ward of the hospital. Some patients who had not been told about their disease put on a two-sided face and pretended that they did not know about it in order to “protect” their family members.

In essence, most of the participants acknowledged to some extent that it would be better to inform a patient so that the burden of living with cancer could be shared by the whole family. In fact, it was almost impossible to completely hide the diagnosis from the patients, who reluctantly put on a two-sided face for their families, which in turn made it impossible for both parties to communicate openly about their feelings and concerns about the disease.

8.4.2 Living with Changes

The couples who were interviewed also said that they had to cope with various changes in their life after receiving the diagnosis of cancer. These changes included the four aspects described in Table 8-6.

Table 8-6 Representative data of the subthemes of living with changes

Subthemes	Supporting statements from the participants
Change in roles	
● Gender difference in role changes	✓ Before being diagnosed with cancer my role was that of being the strong one in my family. I subsequently found that I had no time for it (to be the "strong one") and perceived a threat to my own independence. Now I need the help from my family, and this changed all of our life too (Group 3, P8, male). ✓ I used to get everything done properly, such as keeping the room clean and tidy, and getting the food ready before my husband returned home. However, after my diagnosis of cancer, I have not been able to perform these duties for the family. I did too much before, and he (SC) needs to "pay me back" now. (Group 1, P2, female)
● Changes in household roles	✓ Now my full-time job is to take care of my wife, which makes me feel that perhaps I owe my wife because in the past decades she took care of me and the family. (Group 1, SC2) ✓ I had never done household chores such as cooking, cleaning, and doing the laundry before my wife was diagnosed with cancer. Now I have to start from scratch and do whatever I possibly can to take care of her. (Group 4, SC12)
Change in marital relationship	
● Family closeness	✓ I can have dinner with my wife now, which makes us feel closer than before. I also think that the diagnosis of cancer is also an opportunity to bring the extended family and friends together. (Group 1, P5)

	✓ I think husband and wife should share the same fate during adversity, and we both need each other. Thus, we do the best we can for each other. (Group 2, SC6)
● Caregivers' unconditional acceptance of their ill partners	✓ My health is not important for the time being. I willingly take care of my husband and I am very happy to be with him every day. No matter how difficult it is, as long as he gets well, I will accept whatever he says and does to me. (Group 3, SC8)
● Benefit of being close	✓ Initially, I felt stressed with the diagnosis of the cancer, but I figured things out and felt better with the help of my husband. He is very kind to me, and takes care of me all the time, which makes me feel happy. And what I can do is do my best to cope with the disease. (Group 2, P6)
Change in life plan	✓ We have been married for 40 years. We were very poor many years ago and life was very difficult when we were raising our children. Now everything is getting better, and we hoped to enjoy our life because both of us are retired. . . . However, with the diagnosis of cancer, all of our life plans were upset, at least temporarily. We need to deal with the current situation. Our lives have been turned upside down. (Group 3, SC8)
Change in social activities	✓ I consider myself to be pretty extroverted. I've been doing business outside. Given my husband's diagnosis of cancer, I have to stay in the hospital to take care of him. I told my husband that I would handle my business again after his recovery because I had enjoyed in taking part in the social activities. (Group 4, SC13)

Change in roles

The patients and their spousal caregivers described the changes that had occurred in their role in the family, including gender roles, after the diagnosis of cancer. For instance, a male patient (Group 3, P8) stated that the diagnosis of cancer gave him no time to fulfill his role as “the strong one” in the family; while a female patient (Group 1, P2) mentioned not being able to properly do her duty of doing the household chores. After the diagnosis of cancer, male spousal caregivers needed to do household chores to help their spouses with cancer, even though they did not usually perform such tasks.

Change in marital relationship

The couples in this study experienced an improvement in their marital relationship. They felt that the diagnosis of cancer drew them closer together, and they were able to share their concerns and feelings of love more freely. Just being there to support each other and sharing time was integral to their relationship. In general, the spousal caregivers also put their partners before themselves. With this change, the patients also acknowledged that a sense of togetherness had helped them to cope with the stressful situation.

Change in life plan

Many patients were diagnosed with cancer through a routine medical examination when they were feeling unwell. The diagnosis of cancer and its treatment forced them to change their plans for their life, such as changing daily life routines, canceling scheduled travel plans, and generally shifting their activities to focus on coping with cancer.

Change in social activities

Social activities in this context refers to activities engaged in by the retired participants, such as getting together with friends, doing group exercises, and attending university classes for seniors. For those in their 40s and 50s, the main social activities could include going to work or engaging in business. For several couples, attending the focus group discussion was the first social event that they had taken part in since the diagnosis of cancer. Almost all of the spousal caregivers indicated that they were providing round-the-clock care for their partners with cancer, leaving them little time to participate in social activities.

8.4.3 Negative and Positive Impacts

The interviews showed that although the couples found the process of coping together with the changes brought about by cancer to be quite difficult, some of their experiences were both negative and positive. As a caregiver said,

> This disease affects us a lot. There are physical, mental, social, and financial burdens on the whole family. Physically, I feel unwell every time we are in the hospital, to say nothing of how the patients must suffer. I fainted when I heard about the diagnosis of cancer; and we have also worried about progress of the disease. For a family like ours, who live on a salary, the cancer treatments are a huge financial burden. Now the focus of our whole family is on his disease and treatment, which has been really difficult for us. Fortunately, he changed a lot after the diagnosis of cancer and he has been more communicative. We share

> our views easily now, which makes me feel happy although it is still difficult for us to cope with the disease…. (Group 3, SC8)

The theme of negative and positive impacts emerged from the data with four subthemes (Table 8-7).

Table 8-7 Representative data of the subthemes of negative and positive impacts

Subthemes	Supporting statements from the participants
Side-effects of chemotherapy	
● Manifestation in undergoing chemotherapy	✓ Because of the side-effects of chemotherapy, such as hair loss, my wife thought that she was ugly with no hair, so she did not want me to disclose her disease to others, even to extended family members, in the beginning of her treatments. (Group 3, SC7)
● Recalled suffering process	✓ “It was really a process of suffering. I would not comply with the chemotherapy if not to prolong my life.” (Group 1, P5)
Caregiver burden	
● Anxiety	✓ “I was anxious about everything to do with my wife, including the result of examinations, the reoccurrence of the cancer, and the long-term effects of cancer treatment.” (Group 1, SC2)
● Stress	✓ I was wondering in the beginning why it was my husband who suffered from cancer. As time went by, I accepted the situation. Then, I tried my best to help my husband and we’re coping with the cancer together. (Group 4, SC14)
● More stress for caregivers	✓ A patient (Group 4, P11) asked, “Could you please help my wife? She is more stressed out than I am.”
Reciprocal caring / support	
● Support from spousal caregiver	✓ My wife (a patient) appears fine, but I feel stressed and worried all the time. I’ve been anxious about everything for the many years of her cancer and treatment, particularly about

	her suffering, which gives me "heartache" (*xinteng* in Chinese). I wish I could suffer in her place. (Group 1, SC2)
● Support from the patients	✓ Although I am the patient, my husband was more stressed than me, and he needs my help to relieve his stress. (Group 1, P2)
Positive perspective and the hope	
● Family closeness and healthier lifestyle	✓ Patient 4 in Group 1 reported that "having cancer prompted him to live more healthily, including following a balanced diet, getting enough sleep, and exercising regularly."
● Normalizing the cancer	✓ As a patient (Group 1, P2) who had been diagnosed with cancer for 15 years noted, she made the effort to "live life to the fullest every day . . . ."
● Nurturing hope	✓ Patient 3 (Group 1) stated that the hope of good effects from the treatment and of prolonging his life spurred him on to comply with the treatment, no matter how difficult this was. ✓ Another patient (P1) in this group suggested that healthcare professionals should try to encourage and nurture hope in the patients.
● Living for the present	✓ Patient 8 (Group 3) described this as "For me, to live another day means to earn a day."

Side-effects of chemotherapy

Most patients in this study were undergoing chemotherapy. The participants described the different side-effects, including hair loss, a poorer self-image ("ugly," was how SC7 described his wife's feelings about herself), a reduced appetite, nausea, vomiting, and constipation. When the participants recalled the side-effects of chemotherapy, they described the process as one of suffering.

Caregiver burden

Couples coping with cancer described their efforts to face changes in their daily lives (the theme "living with changes"). They reported emotional and psychological changes. Anxiety was an emotion frequently experienced by the spousal caregivers. In addition, when facing the patients the spousal caregivers needed to pretend that the patients were fine (subtheme *information censorship and the two-sided face*). This situation placed a burden on the spousal caregivers. The caregivers experienced stress when they acknowledged the diagnosis of their spouses, and needed to cope with it. Furthermore, the spousal caregivers might actually experience more stress than the patients.

Reciprocal caring / support

Although there was some negative impact, the couples said that there was a sense of reciprocal support / caring between them. This might have made it easier for them to adjust and cope together with the cancer. The patients acknowledged the burden on their spouses. In addition to asking healthcare professionals for help (see the above subtheme of "caregiver burden"), the patients also recognized their own need to help and support their spouses.

Positive perspective and hope

The participants found some positive aspects to their experience of living with cancer, including the discovery that it brought the family together and that patients were motivated to lead a healthier lifestyle. Patients also "normalized" the presence of cancer by accepting and managing it in their feelings (emotion-focused coping), thereby minimizing its influence in their lives. As time and treatment progressed, some participants chose to incorporate the illness into their lives. Patients also explained that hope was crucial to sustaining the coping process. Nevertheless, with the uncertainty over their cancer, patients experienced a sense of needing to live for the present.

8.4.4 Network of Support

The interviews also revealed that both patients and spousal caregivers considered various kinds of support to be important in their experience of coping with cancer, e.g., nutritional and financial support. As a caregiver described,

> Although I am the principal caregiver of my partner in our family, all of the support that we receive from the people around us is essential for continuing the treatment. For instance, the nutritional guidance from the professionals and the suggestions from other patients in the ward, particularly those who were suffering from the same type of cancer, helped a lot during the period of ongoing chemotherapy. In addition, we need financial support. Fortunately, our children are good and they can offer us financial support for the time being, which has greatly lessened my burden. However, this is not a permanent solution. I hope that the government can pay more attention to cancer patients and can offer us financial support. (Group 4, SC13)

The theme of network of support emerged with the following four subthemes (Table 8-8).

Table 8-8 Representative data of the subthemes of network of support

Subthemes	Supporting statements from the participants
Family support	
● Support from children	✓ My children are very good. They did not only provide financial support for my treatment, but also try their best to take care of me whenever they are available, particularly during the time before and after my operation. (Group 3, P10)
● Financial support from family	✓ Our family will do whatever we can, even selling our house to pay for the cost of treatment, as long as the treatment can extend the life of my wife, because we understand that it is impossible to cure her cancer for the time being. (Group 3, SC7)
Comrades in arms against cancer	
● Comrades encourage and help each other	✓ We will tell other patients what to do to relieve the side-effects of chemotherapy, just as we were told by the staff when we first entered the ward. As wardmates, we help and encourage each other, which is a great support for us in coping with the disease. (Group 2, P7)
● “Been there” was helpful	✓ The information and support from other patients suffering from the same type of cancer is helpful for us in coping with the disease. When someone who has been there offers this kind of information to me, it enhances my confidence about coping with the disease together.
Support from healthcare professionals	
● Nurturing hope	✓ Even a nod or a greeting from healthcare personnel can make us feel warm and happy, which can boost our hopes of overcoming the suffering from the disease. (Group 1, P1)
● Nutritional guidance	✓ I feel that nutrition and food are very important to the cause of cancer and its treatment. But everyone seems to have a different opinion on what one should eat after chemotherapy.

		I think this is the most important problem. (Group 3, SC7)
Governmental support		
● Financial support	✓	Government and society should pay more attention to cancer research and cancer treatment. More investment in research on the causes of cancer is needed, which will help to prevent cancer. For those who have suffered from cancer, financial support from the government will help them to cope, and this will relieve their burden. (Group 2, SC6)
● Financial burden due to over-examination	✓	We did the computer tomography (CT) examination in another hospital just a few days ago, but the doctor here ordered another CT. This is really a financial burden for us. I am also concerned that too many examinations might hurt the patients physically, but we have no choice. (Group 3, SC7)

Family support

The participants acknowledged the central role of family members and relatives, particularly their children, during the trajectory of their illness. Some patients commented that although their spouses were the main caregivers, their children and some relatives also supported them in different ways at different times, such as during the perioperation period, or when their spouses did not feel well. Their children might help to take care of them, and their relatives also tried to offer assistance, e.g., by preparing food for them. Such family support did not only help them physically, but was also a driving force in supporting their struggle with cancer.

The majority of patients or couples in this study could not afford the financial cost of treatment. Financial support from family members was crucial. The participants also added that their families would financially support them if the treatment could extend the life of the patient.

Comrades in arms against cancer

The participants indicated that support from their peers (“wardmates”), particularly from those suffering from the same type of cancer as themselves, was crucial in the process of coping. Comradely support like that of comrades in arms against cancer helped to relieve them of their worries about the disease. It also helped them to learn some things from each other, such as how to deal with some forms of adversity, such as the side-effects of chemotherapy. The participants also thought that a comradely support system of those who have “been there” was helpful.

Support from healthcare professionals

Support and care from healthcare workers was found to be beneficial to the patients. Many participants stated that they needed professional care in such aspects as nutritional guidance, more information on the causes of cancer and how to protect themselves against cancer, help for their spousal caregivers, encouragement and the nurturing of hope to extend their life, and caring and understanding from nurses.

Nutritional guidance was mentioned by almost all of the participants. Many participants wanted more information on what food they should or should not eat after the diagnosis of cancer, after chemotherapy, and to prevent the recurrence of cancer. Despite having questions about what to eat during and after cancer treatment, the participants generally agreed that consuming more fresh fruits and vegetables, less meat, and less high-fat food was beneficial to their health, particularly as cancer survivors.

Governmental support

The participants stated that the medication to treat cancer was very expensive. They hoped that they could receive financial support from the government. They also complained about being forced to undergo too many examinations in hospital.

8.5 Discussion

Based on the unique perspectives of the participants, which were grounded on the data, four themes were identified in this study: communication dynamics, living with changes, negative and positive impacts, and network of support. On the basis of these four themes, two areas for discussion were identified: the experience of couples coping with cancer, and the concerns and caring needs of such couples.

8.5.1 The Experience of Couples Coping with Cancer

The findings showed that coping with cancer was a dyadic process and a burden for couples. The couples stated that they had experienced both negative and positive aspects in the process. The negative experiences had an impact on their physical, mental, and social health. This is consistent with the findings of other studies (Badr & Taylor, 2006; Blindheim, Thorsnes, Brataas, & Dahl, 2013; Chung & Hwang, 2012; Hagedoorn et al., 2008; Li & Loke, 2013a; Ohlsson-Nevo, Andershed, Nilsson, & Anderzen-Carlsson, 2012). These studies indicated that couples, particularly spousal caregivers, experienced physical, mental, and social morbidities in their journey of coping with cancer. The positive aspects of their experience included an improvement in their relationship, greater family closeness, a greater motivation to pursue a healthier lifestyle, and support in the form of meals and money from various sources. These aspects also echoed other studies conducted using either a qualitative (Holtslander & Duggleby, 2009; Mok, Chan, Chan, & Yeung, 2003) or quantitative (Hudson, 2004; Kim, Youngmee Schulz, Richard Carver,Charles S., 2007) approach.

Regarding the issue uncovered in this study of whether patients should be informed of their diagnosis of cancer ("communication dynamics"), healthcare professionals might need to consider Chinese cultural traits, such as telling the patients about their disease after first communicating with their families (Christensen et al., 2006). It was clear that, with regard to the dynamics of communication, providing the patients and / or their spousal caregivers with accurate information about their illness, as well as an appropriate amount of information and at the right time, could improve their experience of living with cancer. Healthcare professionals also need to pay more attention to female caregivers because they tend to subordinate their own desires to the needs of the patients (Christensen et al., 2006). This was also supported by the findings of this study, where the female caregivers appeared to be more likely to sacrifice themselves and take care of their partners with cancer.

Expressing appreciation between partners is not the usual pattern of communication in Chinese culture; but the couples in this study were able to openly express their appreciation towards each other in the interviews regarding changes in their life as a result of living with cancer. It was reported in a study that a couple's efforts to communicate could help to sustain and even enhance their relationship during times of stress (Manne & Badr, 2008). This supports the notion that communication might help spousal caregivers and their patients to cope with cancer, make adjustments, and obtain positive outcomes. Our finding revealed the subtheme of *expressions of appreciation* in the "communication dynamics" of the couples.

Some of the burden on the children of those couples who participated in this study (subtheme *family support* under "network of support") might have been due to the Chinese culture and the fact that most of the parents involved were retirees with no income. In Chinese culture, the Confucian idea of filial piety imposes an absolute obligation on adults to personally care for their elderly parents (Smith & Hung, 2012). If elderly parents are not sufficiently cared for, such behavior is considered shameful (Nuyen, 2004; Smith & Hung, 2012). For couples in their 40s and 50s, the diagnosis of cancer led to a huge financial burden, since they needed to support both their parents and their children. Similar to couples in their 70s, they were also dependent on their extended family for financial support.

8.5.2 The Concerns and Caring Needs of Couples

Another finding that needs to be addressed is the concerns of couples and their care needs. As we see from the subtheme *reciprocal caring/support,* in addition to attending to the individual needs of cancer patients, nurses should regard the cancer patients and their respective spousal caregivers as a dyadic unit of care during the trajectory of the disease. As a dyad, almost all of the couple participants indicated that they needed various sources of support from healthcare professionals, members of their extended family, and their comrades in arms against cancer. This finding corresponds with a literature review on family and caregiver needs across the course of the cancer trajectory (Given, Given, & Sherwood, 2012).

The patients in this study stated that being positive and sustaining hope was a crucial aspect of their journey of coping (subtheme *positive perspective and hope*). They called for healthcare professionals to help them to nurture hope. This finding is consistent with the study by Clayton et al. (2005), in which the caregivers of cancer patients were found to be in need of hope during the process of providing care. It is noteworthy that there was only one reference to a caregiver who talked about having a positive perspective and hope; the rest were references to patients. Nevertheless, this study found that the caregiver participants sacrificed themselves and put the needs of the patients before their own. As SC8 said, “No matter how difficult it is, as long as he gets well, I will accept whatever he says and does to me.” Health professionals and family members need to pay more attention to caring for the caregivers of cancer patients.

Based on the findings and the existing literature, we have drawn up a preliminary conceptualization of the overall experiences of couples living and coping with cancer (Figure 8-1).

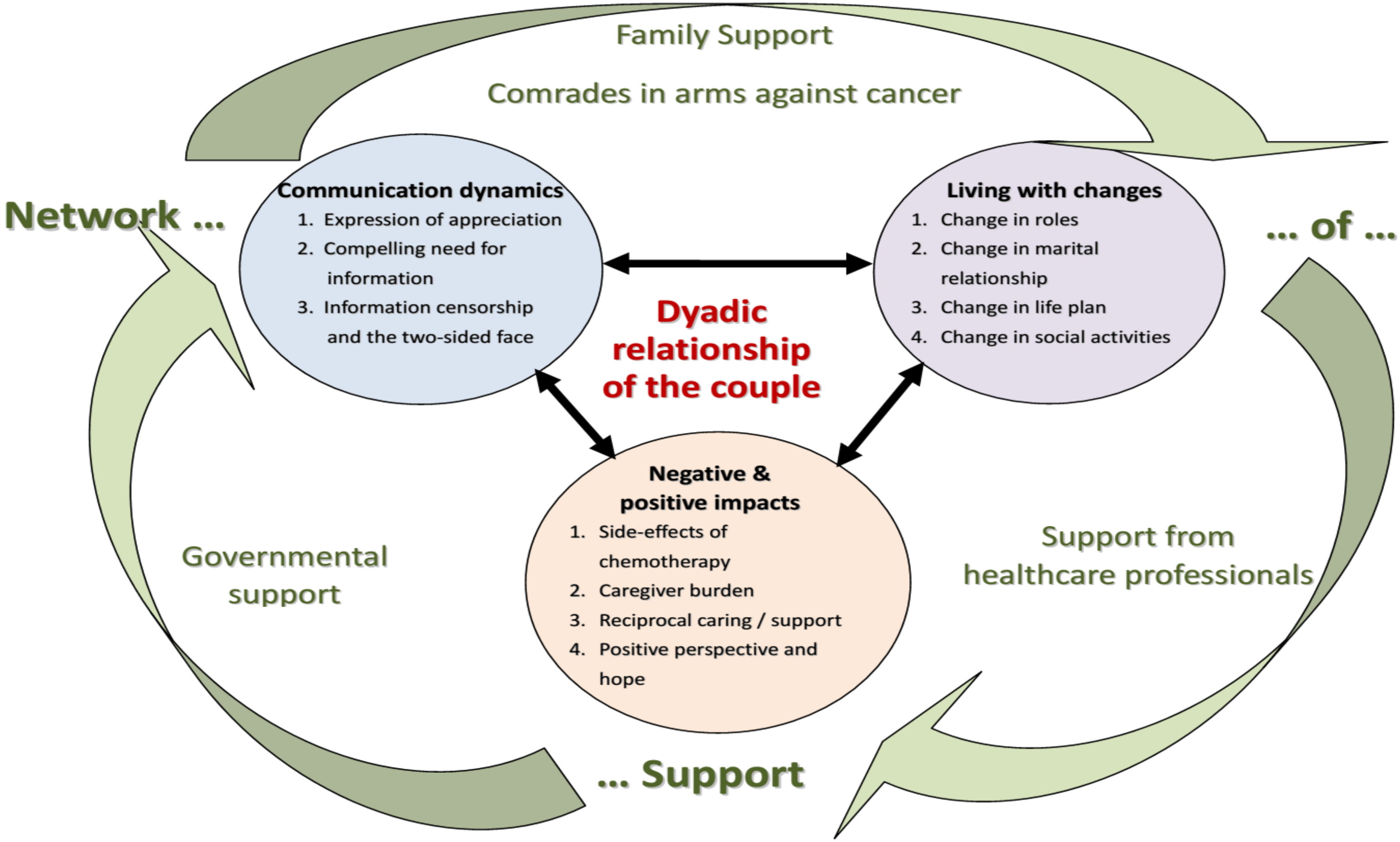


Figure 8-1. A preliminary conceptualization of the overall experiences of couples living and coping with cancer

The dyadic relationship of a couple when one of them has cancer is conceptualized as involving the interaction of three themes: communication dynamics, living with changes, and negative and positive impacts. Better communication is a valuable strategy to enhance those interactions in the dyads so that they can benefit couples who are struggling to cope with the disease. Successful communication between couples, such as expressions of appreciation, enhances the connection that couples feel with each other during the process of coping with the changes brought about by the diagnosis of cancer. The importance and benefits of communication during the cancer trajectory have also been identified in studies on survivors of cancer (Donovan-Kicken, Tollison, & Goins, 2012; Liu, Mok, & Wong, 2005).

In addition to *reciprocal caring / support* between two partners in the dyad under the theme “negative and positive impacts,” the dyad might require support from other people or parties in different contexts (represented by the fourth theme: “network of support” as external factors), such as extended family members and relatives, healthcare professionals, and so forth. Specific types of this kind of support were discovered in this study, i.e., *family support*, *comrades in arms against cancer*, *support from healthcare professionals*, and *governmental support*. The dyads perceived and / or experienced interactions in these relationships as ways of coping better and living with cancer.

In summary, Figure 8-1 represents the conceptualization that by improving communication and networks of support, the couples as a dyad living with cancer will be able to cope better with the disease. Successful communication satisfies the strong need that these couples have for information as they cope with changes in their lives, both negative and positive, as a result of one spouse having developed cancer. The internal interactions of the dyads and their external relationships with peers, relatives, and professional caregivers are represented by the complex pattern of four themes connected to each other.

Reflection on the Rigor of Studies

Although there have been debates on the criteria that should be used to evaluate the rigor of the qualitative studies (Emden & Sandelowski, 1998), there is in fact no "golden key" that can be used to judge the validity of every research study (Porter, 2007). The "confidence criterion" and realist approaches to validity can be used in the discipline of nursing, and seem more promising than current approaches (Porter, 2007). On the confidence criterion, we have kept one question in mind when presenting the findings of this study: "Do I have confidence in what I am presenting?" As described earlier with regard to the trustworthiness of this study (Lincoln & Guba, 1985), all final versions of the transcribed findings were examined and confirmed for accuracy by two researchers. The participants' voices were used to describe and present the findings. Doing so not only shows respect for the participants, but also helps readers to understand the findings. We feel confident about the presentation of the results of this study.

Verification strategies (Morse, Barrett, Mayan, Olson & Spiers, 2002) that ensured credibility and confirmability were applied in this study, such as methodological coherence, purposive sampling, theoretical thinking, and peer checking.

Dependability and transferability were assured with the establishment of an audit trail, which was aided by the use of nVivo. A rich description of the study was given using four themes and their subthemes as uncovered from the data. A preliminary conceptualization was also developed to illustrate the phenomenon of couples living and coping with cancer.

Another condition for the rigor of research studies proposed by nursing scholars is the "criteria of uncertainty" (Emden & Sandelowski, 1999). Researchers are expected to openly declare the uncertainty of one's work to acknowledge the current state of knowledge development. When conducting this study, we recognized that although qualitative research is "a never-ending" process, we still needed to ensure that we had adopted the best methodology to explore the research questions. The focus group method was used to examine research questions from the perspectives and interactions of the participants (Liamputtong, 2011), which fit well with the need to target multiple participants for this study. Focus group interviews were conducted to explore the experiences of Chinese couples living and coping with cancer from their own perspectives.

With regard to evidence-based nursing, we asked ourselves whether we had given a thorough description of our findings (Russell & Gregory, 2003). Apart from what has been mentioned above, we compared the findings of this study with the related literature in the discipline of nursing. Consistent and inconsistent findings were identified from the literature to verify our findings, and presented in the discussion section.

Limitations

In this study, of the four focus groups with spouses, the first three groups had collectively nine couples who were interviewed together, while the participants in the fourth group consisted of seven spouses and one patient. Although the themes that emerged from the analysis were found to be common ones among the couples who participated in this study, the lack of complete sets of couples in all of the groups, which came about because this was more convenient for the individual patients, might have prevented us from acquiring a deeper understanding of their experiences as dyads through their interactions during the interviews. Future studies should incorporate more complete sets of couples in each focus group and a wider range of settings to enhance the transferability of the study.

The focus group format naturally results in a wide range of responses among the participants in the group. Although in this study the focus group interviews yielded in-depth and rich data (which may not have been as easily obtained using other methods), there may have been variations in the way the interviews were conducted by the researchers. Some areas of discussion might have been probed in more depth than others in particular groups. The findings of this study should be interpreted with the specific purpose of the study in mind. The design was intended to provide better understanding of the experiences of Chinese couples living and coping with cancer in China, or couples of a similar ethnic background. The results can be used as a basis for developing intervention programs that are meaningful for this population.

8.6 Implications for Practice

Despite the limitations of this study, the findings indicate several potential implications for practice. First, data analyses of the focus group interviews indicate that couples demand that healthcare professionals provide them with information on the disease and its treatments. This is in line with another focus group study on the experiences of couples dealing with prostate cancer (Harden et al., 2002). There were also inconsistencies among the spousal partners and families on whether the patient had been informed of the diagnosis of cancer. It might be worthwhile noting from this study that there was no clear difference found in participants' responses based on time from diagnosis, for example, side-effects of chemotherapy. “Those who were undergoing chemotherapy described their experience of suffering, while for those who had finished and recalled their experience still perceived a sense of suffering over the process.” The similarity of responses regardless of time since diagnosis or treatment status would seem to be important to note specifically. It reminds that there is a need for healthcare professionals to offer sufficient and useful information to couples who are coping with cancer, particularly nutritional guidance for patients receiving chemotherapy, no matter how long they were diagnosed with cancer or if they were undergoing chemotherapy or had finished the chemotherapy. In addition, cultural differences need to be considered when offering information to patients.

This study also showed that spousal caregivers put their spouses before themselves during the trajectory of the disease. This suggests that healthcare professionals need to encourage and help spousal caregivers to take care of themselves while coping with the changes in their spouses.

All of the participants acknowledged that cancer had both positive and negative impacts on their quality of life as a couple. The participants called for healthcare professionals to nurture hope and help them to stay positive in coping with cancer. As indicated by the data, healthcare professionals should instill realistic hopes in couples (particularly in the patients) and help them to sustain a positive attitude with a focus on the future, not just on the present (subtheme *positive perspective and hope*).

In the future, studies might be conducted exploring the differences between how people with cancer and their healthcare professionals prefer to plan for the future, and how they would choose to incorporate a *positive perspective and hope* in the related intervention under the theme “negative and positive impacts.” Quantitative research might be undertaken in the future to investigate the effectiveness of interventions designed to support couples in which one partner has cancer, to help them to better cope with their current situation and plan for the future. Advocating for financial support from the government would also be helpful for couples coping with cancer.

Suggestions for Healthcare Professionals to Develop a Set of Couple-based Interventions

As stated in the beginning, one of the aims of this study was to gain a better understanding of the experiences of couples with cancer to help healthcare professionals recognize the concerns and needs of such couples and design suitable interventions / programs for them. With the themes uncovered from the analysis of the data in this study, an outline of such a program is given in Table 8-9.

Table 8-9 Recommendations of a couple-based intervention program for couples living with cancer

Categories	**Recommendations**
Overview of the program	✓ Both patients and family members have a great need for such a program ✓ The program needs to be feasible for a family
Timing of the intervention	✓ The earlier after the patients were informed about the disease, the better ✓ The contents need to be offered across the entire trajectory of the illness
Format of delivery	✓ Nurses need to be trained before conducting/implementing the program ✓ Face-to face and group interventions are highly recommended ✓ It is more desirable to have the couple as a dyad to join the program
Main contents	✓ Effective communication strategies and skills in the family ✓ Tailored information, e.g., on nutrition and symptom management

	✓ Education to enhance the ability of couples to accept the disease and have a reasonable outlook or understanding of the disease ✓ Exploring the psychological problems of spousal caregivers and providing help accordingly ✓ Spiritual and mental support ✓ Strategies on dealing with the sudden deterioration of the patient ✓ Strategies for preserving the energy of the couples ✓ Strategies for caregivers on self-care

8.7 Conclusion

This study explored the experiences of Chinese couples living and coping with cancer in China. The four themes identified from the interviews were communication dynamics, living with changes, negative and positive impacts, and network of support. The findings of this study are important for nursing practice in that they provide insights into the daily struggles of couples living with cancer, and also support the development of an intervention by healthcare professionals aimed at improving the experiences of couples in their trajectory of coping with cancer. It is suggested that healthcare providers be sensitive to the needs and concerns of couples. Healthcare providers also need to incorporate consistent methods of identifying and responding to couples during their trajectory of living and coping together with cancer. Although the results are not generalizable, they might be transferrable in similar settings. It is recommended that further studies be conducted on developing intervention programs that focus on the needs of these couples. Programs designed for improving communication and reducing stress based on this study might have the potential to improve the quality of life of couples when one member has cancer.

The findings of this primary focus group study not only contributes to the evidence base from the perspective of cancer couples, but also provides us with the information needed to choose the constructs to be included in the following step on the development of the conceptual framework.

Chapter 9

STUDY II IDENTIFYING / DEVELOPING THEORY

A Preliminary Conceptual Framework for Cancer Couple Dyads: Live with Love *

* The content of this Chapter was published:

Li, Q., & Loke, A. Y. (2015). A preliminary conceptual framework for cancer couple dyads: Live with love. *Cancer Nursing*, *38*(2), E27-36. doi:10.1097/NCC.0000000000000148.

9.1 Introduction

It is well accepted that the diagnosis of cancer and its treatment affect both patients and their family caregivers (Kayser, Watson, & Andrade, 2007), particularly spousal caregivers (Cain, MacLean, & Sellick, 2004; Glajchen, 2004; Pitceathly & Maguire, 2003). The diagnosis of cancer and its treatment can change the relational dynamics between people with cancer and their intimate partners, which can have an impact on the subjective well-being and ability to cope of both patients and their partners (Dankoski & Pais, 2007). The impact is felt in such areas as quality of life (QOL), psychological health, and role adjustment.(Kim et al., 2008; Northouse, Mood, Templin, Mellon, & George, 2000) This has caused the research and practice of cancer care to shift from an emphasis on the individual experiences of patients or spousal caregivers to those of caregiver-patient dyads (Fletcher, Miaskowski, Given, & Schumacher, 2012).

Studies on couple-based interventions have shown that various theoretical frameworks were adopted to guide the design of these interventions, including the Stress and Coping Model (Northouse et al., 2007), the Adaptation Model of Couples Functioning (Heinrichs et al., 2012), Emotionally Focused Therapy (McLean et al., 2008; McLean, Walton, Rodin, Esplen, & Jones, 2013), Spiegel's Supportive-expressive Model (Collins et al., 2013), Equity Theory (Kuijer, Buunk, De Jong, Ybema, & Sanderman, 2004), the Relationship Intimacy Model (Manne & Badr, 2008; Manne et al., 2011), and the Social-cognitive Processing Model of Emotional Adjustment to Cancer and Coping Theory (Scott, Halford, & Ward, 2004). Most of these theoretical frameworks focus on the couple's relationship, with the exception of one that focuses on the stress-coping process at the individual level. However, none of these frameworks specifically address the process and needs of couples coping with cancer at the dyadic level.

With research beginning to shift the focus from individual to caregiver-patient dyads, it is proposed that the conceptualization of a comprehensive framework that specifically addresses the process and needs of couples coping with cancer at the dyadic level is of paramount importance. It is intended in this study to develop such a conceptual framework to guide the direction and development of a supportive intervention that specifically addresses the dyads of couples coping with cancer. Such a framework should delineate the event and situation to be considered, the essential components to be included in the intervention, the specific approaches/strategies to be adopted, and the outcome indicators of program effectiveness.

9.2 Objective

The objective of this study was to develop a preliminary Conceptual Framework (P-CF) for Cancer Couple Dyads based on models or conceptual frameworks employed in related literature on spousal caregiving for patients with cancer. Developing such a framework will not only make possible a better understanding of concepts related to the situation of couples coping with cancer, but also facilitate the development of interventions to support caregiver-patient dyads in coping with cancer (Carbonneau, Caron, & Desrosiers, 2010).

9.3 Methods

The theoretical concept analysis process (Risjord, 2009; Walker & Avant, 2005) was applied to guide the development of the framework. As recommended by Walker and Avant (2005), extensive reviews of literature on different aspects and experiences of couples coping with cancer were taken into account (Chapter 2 to Chapter 8). The frameworks adopted in the selected studies were based on the context of cancer and family caregivers. The constructs and concepts that had been included in the previous five published reviews of the relevant literature (Chapter 2 to Chapter 6) were meticulously scrutinized. In addition, findings of the focus group study (Li et al., 2014) also provide us with the information needed to choose the constructs to be included on the development of the conceptual framework.

A matrix table was created to delineate the key constructs/components from each framework under scrutiny. The two researchers each carefully examined the included components and conceptual frameworks, scrutinizing each concept for its definition, attributes, antecedents, and consequences, and examining the interventions presented in the nine studies as exemplifying cases. This was done according to the suggested procedure for the construction of theories (Walker & Avant, 2005). The two researchers then sat together to discuss thoughts and ideas, and to resolve any disagreements. A critical and analytical process was adopted to appraise the conceptual implications of the selected frameworks, and brainstormed about ways to synthesize the broad range of concepts and variables into a preliminary conceptual Framework for Cancer Dyads.

9.4 Results

It was through the process of an extensive review that a number of frameworks on different aspects of the caring experience of spousal caregivers were identified (Chapter 2 to Chapter 6). These reviews of the literature on the spousal experience of providing care to cancer patients adopted the Stress and Coping Model (SCM) (Folkman, 1997), the Conceptual Framework of the Positive Aspects of Caregiving (CFPAC) (Carbonneau et al., 2010), the Relationship Intimacy Model (RIM) (Manne & Badr, 2008), a Development-Contextual Model of Couples Coping with Chronic Illness (CCCI) (Berg & Upchurch, 2007), and the Cancer Family Caregiving Experience Model (CFCE) (Fletcher et al., 2012).

These conceptual frameworks formed the basis of the development of this preliminary conceptual framework. Each of these frameworks and its included components were examined in detail to determine the essential characteristics of the caregiving and coping experience of cancer dyads. Those constructs and/or components that were considered worthwhile and significant were grouped, arranged, and tabulated under the identified key domains of the cancer dyads, and finally developed and proposed as the preliminary Conceptual Framework for Cancer Dyads.

9.4.1 The Selected Frameworks for Cancer and Couples: Key Constructs and Components

The key constructs and components of the five selected frameworks adopted in intervention studies for cancer and couples are discussed below.

Stress and coping model (SCM)

Among the various stress and coping frameworks, the Stress and Coping Model (SCM) is most widely adopted in studies related to stress from cancer (Folkman, 1997) (Figure 9-1). According to the model, coping is a process that unfolds in the context of an event or situation that is appraised as personally significant and as taxing or exceeding the individual's resources for coping (Lazarus & Folkman, 1984). The coping process is initiated in response to the individual's appraisal that important goals have been harmed, lost, or threatened (Folkman & Moskowitz, 2004). This appraisal takes place particularly at the outset of an event when the individual evaluates the personal significance of the event (primary appraisal) and options for coping (secondary appraisal) (Folkman, 2008).

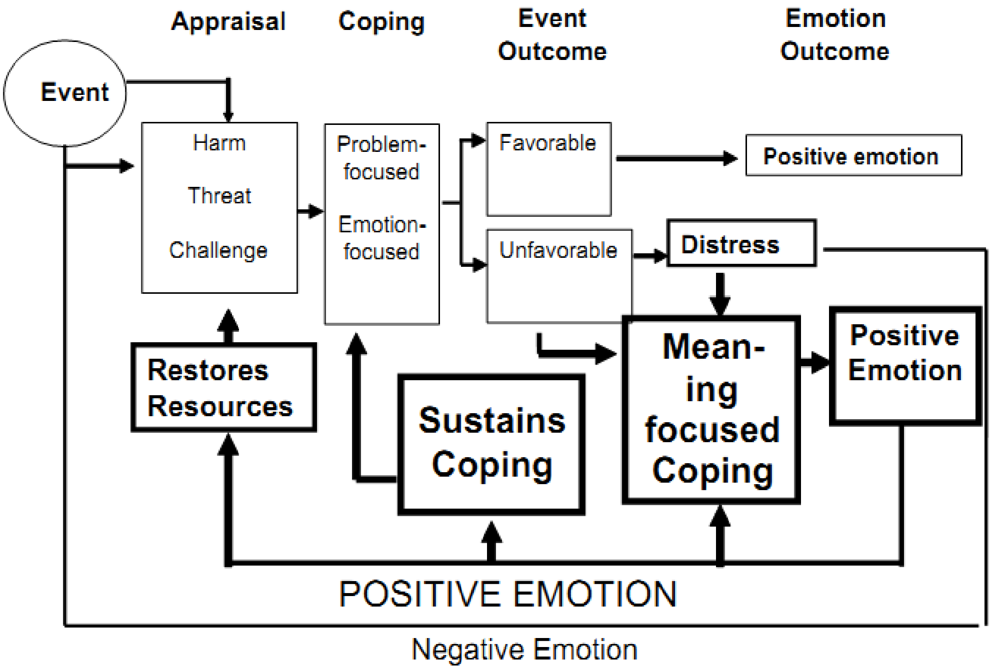


Figure 9-1. Revised stress and coping model (adapted from Folkman, S. 1997).

Coping can be characterized as problem-focused, emotion-focused, and meaning-focused coping. In problem-focused coping, attempts are made to alter a stressful situation using strategies such as information-seeking, planning, and problem-solving. Emotion-focused coping involves regulating situation-related emotions using strategies such as positive reappraisal or behavioral disengagement (Folkman & Moskowitz, 2004). Meaning-focused coping is appraisal-based coping in which the person draws on his or her beliefs, values, and existential goals to motivate and sustain coping and well-being during a difficult time, such as the period following a diagnosis of cancer (Folkman, 2008).

The outcomes of coping can be adaptive (positive reappraisal) or maladaptive (denial). The assumption is that individuals who are adaptive at coping can regain a sense of control over challenges and are less likely to experience stress than those who are maladaptive. In this sense, coping is not only a valuable concept that explains the variability in response to stress, but also serves as a portal for interventions, in that coping skills that lead to positive adaptions to the stressful situation can be learned. However, even though coping strategies might address, ease, and/or resolve the stressor, a favorable resolution might not be always possible in life-threatening illnesses such as cancer. It is proposed that the coping process should focus on fostering positive emotions despite the presence of negative feelings engendered by the unresolved stressor (Folkman, 1997). The adoption of meaning-focused coping could help the individual to find some benefits from the illness process or be reminded of the benefits he/she has received in life, learn adaptive goal processes, reorder life priorities, and infuse ordinary events with positive meanings (Folkman & Moskowitz, 2000; Folkman, 2008) .

The revised stress and coping model (Folkman, 1997) acknowledges that there is a place for positive emotions in the stress process, that is, that negative and positive emotions can both occur in event outcomes. There is considerable empirical evidence showing that positive and negative adaptive outcomes often co-occur among individuals diagnosed with cancer and their partners (Fletcher et al., 2012; Northouse, Kershaw, Mood, & Schafenacker, 2005). Positive affect has its own important adaptational significance in the context of stress through facilitating the processing mechanisms of important and self-relevant information, promoting creativity and flexibility in thinking and problem solving; buffering against the adverse physiological consequences of stress; off-setting the deleterious physiological effects of stress; and preventing clinical depression (Folkman & Moskowitz, 2000; Folkman, 2008).

The Stress and Coping Model is a conceptual basis for this preliminary Conceptual Framework (P-CF) for Cancer Couple Dyads in terms of the process of coping with stress, and includes the domains of event situation, coping, and outcomes. In the P-CF, the event specified in SCM are incorporated in the Event Situation domain; coping involving problem-, emotion-, and meaning-focused coping are incorporated in the Dyadic Coping construct under the domain of caregiver-patient dyads; and the fostering of positive emotional outcomes despite the presence of negative feelings engendered by the unresolved stressor (Folkman, 1997) will be adopted in the Dyadic Outcome construct of P-CF.

The conceptual framework of the positive aspects of caregiving (CFPAC)

The CFPAC (Figure 4-2, p.48) focuses on the positive aspects of family caregiving. Although the CFPAC was originally proposed and developed for family caregivers of people with dementia, the various studies that were referenced include studies on family caregivers for patients with cancer (Carbonneau et al., 2010). The CFPAC covers the domains of the positive aspects of caregiving, the determining factors, and the positive outcomes (Carbonneau et al., 2010).

The domain of the positive aspects of caregiving includes the components of: “the quality of the daily relationship of the caregiver/care-receiver,” “a feeling of accomplishment,” and “the meaning of the role in daily life.” The domain of the determining factors of the positive aspects of caregiving includes the components of “daily enrichment events” and “caregiver’s sense of self-efficacy.” The domain of the positive outcomes includes the components of “caregiver well-being” and “involvement continuity” (Carbonneau et al., 2010). Both well-being and involvement continuity were proposed to represent meaningful outcomes to consider in CFPAC.

It was emphasized that “the various domains and components of the conceptual framework are interdependent and work together to reinforce the caregivers’ well-being and support their involvement” (Carbonneau et al., 2010) (p. 330). The quality of the daily relationship of the caregiver/care-receiver will be considered under the Event Situation domain as components of the secondary stressor construct in P-CF. The determining factors, including the components of the daily enrichment events and the caregiver's sense of self-efficacy, are included in the mediators domain of P-CF. The positive aspects, including the caregiver's feeling of accomplishment and the meaning of the role in the daily life components of CFPAC, are included in the P-CF under the dyadic appraisal construct. The positive outcomes, including the components of "caregiver well-being" and "involvement continuity," are the components of the dyadic adjustment/outcomes construct in P-CF.

Despite the strengths of the Stress and Coping Model and the Positive Aspects of Caregiving Model, the focus of both models is on the caregiving experience at the individual level. With research beginning to shift in focus from the individual level to the caregiver-patient dyads level, it is time to consider conceptual work at the dyadic level.

The relationship intimacy model (RIM)

The RIM proposes that the relationship behaviors of couples influence the psychological adaptation of couples through their effects on relational intimacy, such as the feeling of emotional closeness with one's partner (Manne & Badr, 2008) (Figure 9-2).

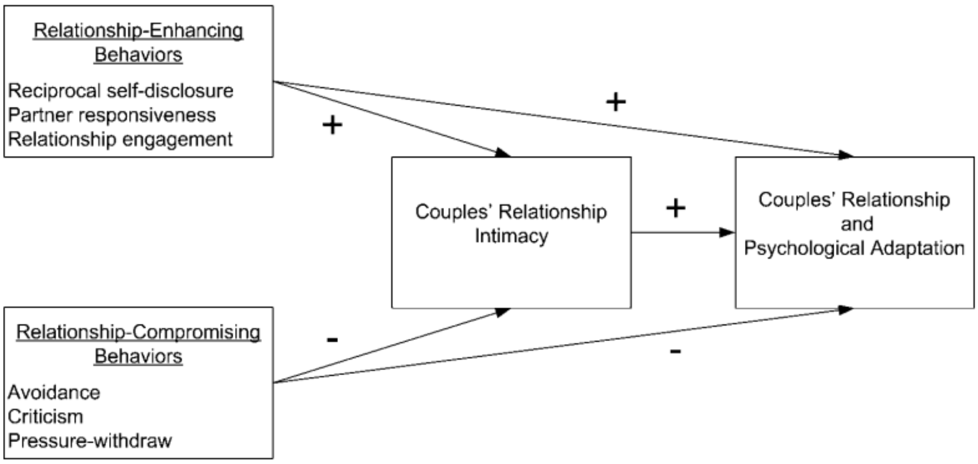


Figure 9-2. The relationship intimacy model of couple adaptation to cancer

(Manne S & Badr H.2008)

According to this model, relationship behaviors can be either “relationship-enhancing” or “relationship-compromising.” Relationship-enhancing behaviors include reciprocal self-disclosure, partner responsiveness, and relationship engagement. Relationship-compromising behaviors include avoidance, criticism, and pressure-withdraw, where one partner pressures the other to discuss concerns while the other partner withdraws.

This model highlights the importance of the couple’s relationship and their engagement in communication that sustains and/or enhances the relationship during stressful times. It supports the notion that communication can help caregiver-patient dyads to cope with cancer and improve outcomes. The three components of relationship-enhancing behaviors, namely reciprocal self-disclosure, partner responsiveness, and relationship engagement, are adopted in the P-CF under the domain of dyadic mediators. The outcome of couple relationship is included under the construct of dyadic adjustment in terms of marital satisfaction.

A development-contextual model of couples coping with chronic illness

A development-contextual model of Couples Coping with Chronic Illness (CCCI, Figure 9-3) (Berg & Upchurch, 2007) extends the Stress and Coping Model (Folkman, 1997) by acknowledging the reciprocal nature of stress and coping within couples. This model consists of the three main domains of the coping process: dyadic appraisal, dyadic coping, and dyadic adjustment (Berg & Upchurch, 2007) .

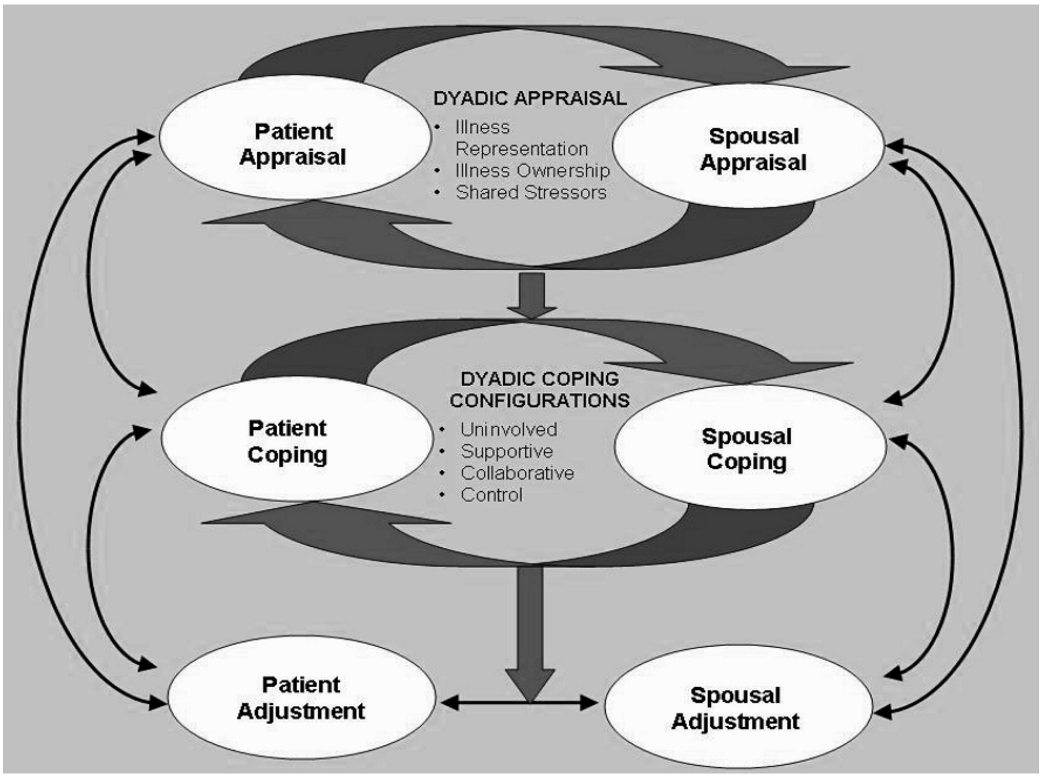


Figure 9-3. Dyadic appraisal, coping, and adjustment in couples

(Berg, C.A., Upchurch, R. 2007)

Dyadic appraisal refers to the components and representation of the illness, illness ownership, and whether the couple shared the stressors (Berg & Upchurch, 2007). Dyadic coping is conceptualized as a continuum of couple involvement ranging from the non-involvement of the spouse, that the patient perceives that he or she is alone in coping with the stressful event, to the over-involvement of the spouse, that the patient perceives the spouse as controlling, in that the spouse dominates the actions of the ill partner by taking charge and telling the partner what to do. In this continuum, supportive coping refers to the spouse providing emotional and/or instrumental support, and collaborative coping to the spouse being actively involved through joint problem solving. Although appraisal processes are depicted as being temporally prior to coping strategies, it is acknowledged that coping strategies most certainly affect appraisal processes. For example, the collaborative coping of the couples leads to the consideration that stressors are shared (Berg & Upchurch, 2007).

According to the model, dyadic appraisal and dyadic coping are anticipated to be predictive of dyadic adjustment. Supportive and collaborative dyadic coping strategies are associated with better adjustment when couples share the illness representations and the stressors (Berg & Upchurch, 2007). This model provides an understanding of how couples may together appraise and cope with the illness, in determining whether there will be positive spousal adjustment.

The domains in this model of dyadic appraisal, dyadic coping, and dyadic adjustment contributed to the development of the P-CF by defining the three constructs of the caregiver-patient dyads. The three main domains of the coping process, namely dyadic appraisal, dyadic coping, and dyadic adjustment, became the three constructs under the domain of caregiver-patient dyads. The components of dyadic appraisal in CCCI, including appraisal of the illness representations, illness ownership, and specific stressor appraisals identifying whether the spouse shares the stressful event, are components under the dyadic appraisal construct in P-CF. Meanwhile, supportive and collaborative dyadic coping are included as components under the construct of dyadic coping in P-CF.

Cancer Family Caregiving Experience Model

Cancer family caregiving experience (CFCE, Figure 2-2, p.22) is an expanded comprehensive model that was developed based on research on caregiving in families with cancer published from 2000 to 2010 (Fletcher et al., 2012). It addresses three main domains of caregiving: the stress process, contextual factors, and the cancer trajectory. The model suggests that the caregiver-patient dyad is the focus and direction of research on the caregiving experience of families with cancer (Fletcher et al., 2012).

The “stress process” domain stems from the classic stress and coping conceptual framework of SCM (Folkman, 1997). The domain of “stress process” of this CFCE consists of five broad constructs: primary stressors, secondary stressors, appraisal, cognitive-behavioral responses, health and well-being outcomes (Fletcher et al., 2012). The primary stressors include “patient illness-related factors” and “care demands.” Secondary stressors, also known as spillover effects, include “role and relationship,” “self-concept,” “schedule and lifestyle,” “sleep/fatigue,” and “employment and finance.” Appraisals of stressors are unique to the personal characteristics of the caregivers, including spirituality, self-efficacy, optimism, and caregivers’ esteem. Cognitive-behavioral responses were conceptualized as the ability to cope, plan ahead, self-care, and engage in caregiving behaviors that mediate stress in caregiving. Health and well-being are the outcomes of a stress process affected directly or indirectly by primary and secondary stressors, appraisals, and cognitive-behavioral responses. This construct consists of mental health, physical health, health-related quality of life, life satisfaction, meaning, adjustment, and personal growth.

The domain of contextual factors includes cultural, life stage, economic, and health system characteristics. The cancer trajectory is defined as the course of the disease process and treatment over time (Fletcher et al., 2012). In the CFCE model, the diagnosis of cancer initiates both the cancer trajectory and the stress process. Both are embedded in the contextual domain of personal, social, and health system contexts and are dynamic across time (Fletcher et al., 2012).

The caregiver-patient dyad is conceptualized by three dyad-level concepts: “communication,” “reciprocal influence,” and “caregiver-patient congruence” (Fletcher et al., 2012). “Communication” is “a transactional process in which individuals create, share, and regulate meaning,” (p.395) and “Reciprocal influence” is “the effect the two members of a dyad have on each other.” (p.394). Meanwhile, in “Caregiver-patient congruence” “the concept of congruence synthesizes individual data into a dyad variable, related to agreement, concordance, and their opposite, disparity" (Fletcher et al., 2012). It is emphasized that the caregiver-patient dyad has thus far been the object of less conceptualizing than the individual patient or caregiver, and should become the direction and focus of research. Therefore, it is an area for which a more comprehensive framework needs to be developed (Fletcher et al., 2012).

The components, such as illness-related factors and care demands in primary stressors; and role conflict, caregiver-patient relationship, schedule disruptions, loss of sleep, and fatigue in secondary stressors in the stress process domain of CFCE, constitute the primary and secondary stressors respectively in the Event Situation domain of P-CF. The cancer trajectory domain of CFCE has also been adopted under the construct of primary stressors. As for the contextual factors, including cultural, life stage, economic, and health system characteristics, this has been applied in the construct of secondary stressors under the Event Situation domain of P-CF.

The construct of cognitive-behavioral responses in the stress process domain falls under the construct of dyadic coping under the domain of caregiver-patient dyads in P-CF. Cognitive-behavioral responses include planning ahead, self-care and caregiving behaviors. The three dyad-level concepts of "communication," "reciprocal influence," and "caregiver-patient congruence" constitute components of the construct of dyadic appraisal. The constructs of health and well-being, which measure the physical and mental well-being of the dyads, fall under the dyadic adjustment/outcomes construct in P-CF. The caregiver-patient dyad as the focus and direction of the caregiving experience of families with cancer suggested by CFCE has been adopted as the domain of the caregiver-patient dyad in P-CF.

9.4.2 The Preliminary Live with Love Conceptual Framework for Cancer Couple Dyads

Based on the characteristics of the conceptual frameworks that were reviewed, we propose a preliminary Conceptual Framework (P-CF) for Cancer Couple Dyads to guide the development of a program for cancer dyads: the spousal caregiver and the cancer patient (see **Figure** 9-4). This P-CF contains three domains: Event Situation, Dyadic Mediators, and Caregiver-patient Dyads.

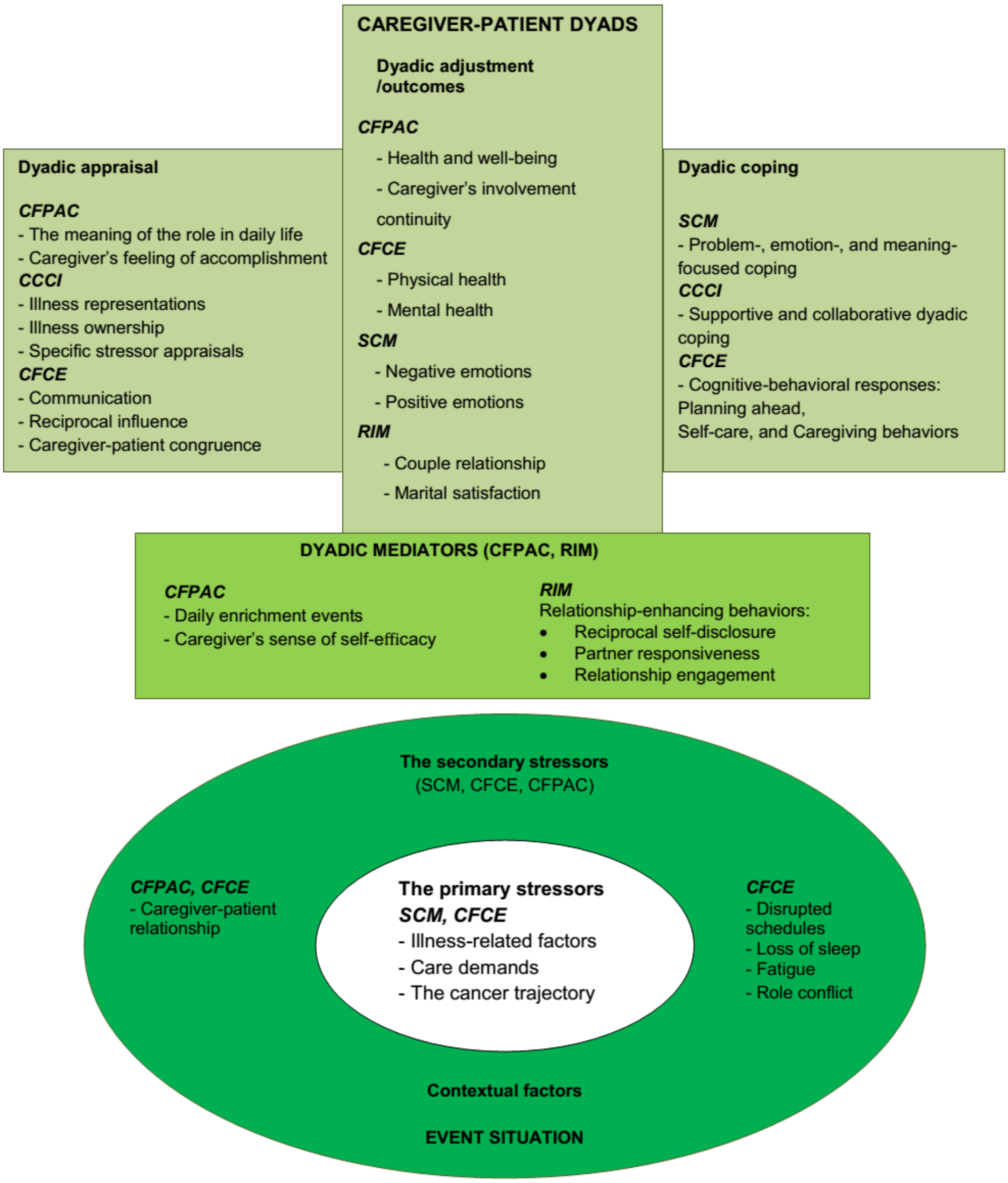


Figure 9-4.
A preliminary Live with Love Conceptual Framework (P-LLCF) for Cancer Couple Dyads

Legends:
CCCI: Couples Coping with Chronic Illness
CFPAC: Conceptual Framework of the Positive Aspects of Caregiving
CFCE: Cancer family caregiving experience
RIM: Relationship Intimacy Model
SCM: Stress and Coping Model

Event Situation

Based on the framework of SCM, CFPAC, and CFCE, the domain of Event Situation includes the two constructs of primary and secondary stressors (Carbonneau et al., 2010; Fletcher et al., 2012; Folkman, 1997). The primary stressors refer to factors related to the patient’s illness, such as the stage of the cancer, the patient’s physical health, care demands (dependency), and the cancer trajectory. Secondary stressors consist of role conflict, the caregiver-patient relationship, schedule disruptions, loss of sleep, fatigue, and contextual factors.

A previous literature review (Li, Mak, & Loke, 2013) also showed that the spousal caregivers of cancer patients suffered from high levels of stress in caregiving, arising from both primary and secondary stressors. The experience of stress was mediated by how the caregivers appraised their situations, and what their cognitive-behavioral responses were.

Factors related to the patient’s illness such as the stage of the cancer, physical health, and care demands (dependency) were associated with the physical and mental health of the spousal caregivers. Spousal caregivers suffered from spillover effects due to secondary stressors, such as role problems, lack of social and emotional support, disrupted schedules, and loss of sleep and fatigue. The characteristics of the caregivers, including their ability to find meaning and benefits from caregiving, spirituality, self-efficacy, optimism, and self-esteem, affected the spousal caregivers’ appraisal of their caregiving experience (Li et al., 2013).

It is worth considering contextual factors that may contribute to the experience of caregiving, including cultural influences, gender, age, and relationships with the patients. Studies have indicated that the complexity of cultural (Mangan, Taylor, Yabroff, Fleming, & Ingham, 2003) and culturally sensitive support (Mok, Chan, Chan, & Yeung, 2003) need to be considered when providing support to caregivers. Although the findings related to gender differences related to the caregivers' experience were inconclusive, in general, female caregivers suffered more than male spousal caregivers of cancer patients in all dimensions of hidden morbidity, such as physical, mental, and social morbidity (Li & Loke, 2013a). Older caregivers were reported to have a more positive outlook in such areas as perceived rewards (Kang et al., 2012), appreciation of life (Kim, Schulz, & Carver, 2007) , and stronger relationships with care-receivers (Lindau, Surawska, Paice, & Baron, 2011). Spousal caregivers were less likely than other family caregivers to report mastery over their lives (Kang et al., 2012), but there were no differences between spouses and other family members with respect to finding benefits from caregiving (Kim et al., 2007).

Dyadic Mediators

The dyadic mediators domain includes the following components: "daily enrichment events" and "caregiver's sense of self-efficacy" from CFPAC (Carbonneau et al., 2010); and relationship-enhancing strategies from RIM, including reciprocal self-disclosure, partner responsiveness, and relationship engagement (Manne & Badr, 2008).

According to the CFPAC (Carbonneau et al., 2010), the components of "daily enrichment events" and "caregiver's sense of self-efficacy" were identified as the two determining factors of the positive aspects of caregiving (Li & Loke, 2013b). Daily enrichment events were also reported to reinforce the positive aspects of caregiving (Carbonneau et al., 2010). These included taking time out for oneself to do such things as go for a walk, rest, or just grieve privately away from the patient (Hudson, 2006; Mangan et al., 2003) .

Findings from intimacy-enhancing interventions that applied relationship-enhancing strategies from RIM showed the effects on improving the perceptions of both patient and partner of the closeness of their relationship, including self-disclosure, perceived partner disclosure, partner responsiveness, and on reducing their levels of stress (Manne & Badr, 2008; Manne et al., 2011).

Caregiver-patient dyads

The main focus of this P-CF is the domain of caregiver-patient dyads (Berg & Upchurch, 2007; Folkman, 1997; Manne & Badr, 2008). The domain of caregiver-patient dyads includes three constructs: dyadic appraisal, dyadic coping, and dyadic outcomes. These three constructs are borrowed from CCCI (Berg & Upchurch, 2007).

Dyadic appraisal

The construct of dyadic appraisal conceptualized in this P-CF contains components from the CFPAC, CCCI, and CFCE. The components from CFPAC include the meaning of the role in daily life and caregivers' feeling of accomplishment (Carbonneau et al., 2010); the components from CCCI include the appraisal of the illness representations, illness ownership, and specific stressor appraisals identifying whether the spouse shares the stress from the stressful events (Berg & Upchurch, 2007); the components from CFCE include “communication,” “reciprocal influence,” and “caregiver-patient congruence” (Fletcher et al., 2012).

Dyadic coping

Dyadic coping is conceptualized from SCM, CCCI, and CFCE. The problem-, emotion-, and meaning-focused coping from SCM (Folkman, 1997), and the supportive and collaborative dyadic coping from CCCI (Berg & Upchurch, 2007) were included. Dyadic coping strategies include cognitive-behavioral responses from CFCE, such as planning ahead, self-care, and caregiving behaviours (Fletcher et al., 2012).

Dyadic Adjustment/Outcomes

Dyadic adjustment/outcomes are conceptualized from SCM, CFPAC, RIM, and CFCE. The following components were included: “caregiver well-being” and “involvement continuity” from CFPAC (Carbonneau et al., 2010); physical and mental health from CFCE (Fletcher et al., 2012); negative and positive emotions from SCM (Folkman, 1997); and marital satisfaction from the outcomes of a couple’s relationship in RIM (Manne & Badr, 2008).

There is growing recognition that cancer affects the couple as a unit, rather than as isolated individuals, leading to the couple’s reaction to a cancer diagnosis being characterized as an “emotional system” (Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008). It is reported that couples have a mutual impact on one another with regard to their quality of life (QOL), psychological health, and role adjustment (Kim et al., 2008; Northouse et al., 2000). A review of the literature on the mutual impact of spousal caregiver-cancer patient dyads highlights the importance of a relationship perspective and communication within couples in any study of couples coping with cancer (Li & Loke, 2014a).

9.4.3 The Naming of P-CF and the Diagram Symbolizing the Chinese Character for “Fortune”

When the authors were searching for a name for this P-CF for easy reference, the term “Love” came to mind. Love in this context is defined as “the active care and concern for the growth to wholeness of the human person.” “Live with Love” was coined with the intention of evoking the deep inner love that couples have for each other. It is hoped that couples will love and be loved in the process of coping with cancer together, easing the hardships brought about by the serious illness of one of the partners. Without the feeling of loving and being loved, the act of caregiving would not exist. With these thoughts in mind, the framework was given the name of a preliminary Live with Love Conceptual Framework (P-LLCF).

The three domains of Event Situation, Dyadic Mediators, and Caregiver-patient Dyads were arranged as shown in the Figure 9-4. Event Situation, including primary stressors and secondary stressors, is located at the bottom of the diagram, which means that the Event Situation acts as an “action wheel” for the cancer couple dyad’s process of coping. The Dyadic Mediators situated above the “action wheel” act as “leverage” to balance or off-set the stressors leading to the dyadic appraisal, coping, and adjustment of the cancer couple dyads.

It is important to note that there are direct and indirect inter-relationships among the three domains of event situation, dyadic mediators, and caregiver-patient dyads. The same relationships may exist among the three constructs of dyadic appraisal, dyadic coping, and dyadic adjustment in the caregiver-patient dyads domain.

Positive dyadic adjustment/outcomes are the ultimate goal and the central focus of cancer couple dyads. The two constructs of dyadic appraisal and dyadic coping at each side of the dyads adjustment/outcomes category are to be weighted to maintain the balance of the whole caregiving experience of the dyads, as shown in the Figure 9-4. The resulting preliminary framework for cancer couple dyads resembles the Chinese character "吉," meaning "fortune." The intervention program guided by this framework can lead to positive outcomes in the caregiving experience of caregiver-patient dyads, with improvements in communication, dyadic appraisal, coping, and outcomes throughout the cancer trajectory, facilitating and guiding the dyads to continuously "Live with Love."

9.5 Discussion

This Live with Love conceptual framework sheds new light on the study of cancer couple dyads. As described earlier, Love in this context is defined as "The active care and concern for the growth to wholeness of the human person." To our knowledge, this is one of the first conceptual frameworks to specifically focus on a couple's Love in the context of cancer. This P-LLCF has the potential to be useful in developing support programs and services based on this cancer couple dyads' perspective. The various components in this P-LLCF will work together to benefit the couple's Love, namely to produce positive dyadic adjustment/outcomes for spousal caregiver-patient dyads in their journey of coping with cancer. According to the framework, supportive couple-based interventions that focus on the various domains and constructs depicted in P-LLCF (including the domains of Event Situation and Dyadic Mediators, and the constructs of Dyadic Appraisal and Dyadic Coping under the domain of Caregiver-patient Dyads) will facilitate the couple's Love in terms of positive dyadic adjustment/outcomes.

Limitations

It is essential to acknowledge several constraints in the development of this P-LLCF. A search of the relevant literature on couples coping with cancer was carried out using four electronic databases that provided comprehensive coverage of key nursing, and health-affiliated journals published. Publication bias could not be avoided in the literature search process.

This P-LLCF was developed based on the assumption that the relationship of caregivers and patients will be strengthened by the cancer/caring experience. It is also the intention of evoking the deep inner love that couples have for each other, and that the couples could find benefits from the illness including feeling of emotional closeness, and relational intimacy. However, there must be scenarios that patient-carer dyads have been separated and only come together due to the illness; that the carers feel burdened, guilty, take on without choice, or are resentful of the situation. Future research is needed to test if interventions developed based on this P-LLCF will benefit these different scenarios among patients and carers.

Future Research Directions

This P-LLCF includes both dyadic level and individual level components. It is proposed that direct and indirect inter-relationships exist among the three domains of event situation, dyadic mediators, and caregiver-patient dyads. The same relationships may exist among the three constructs of dyadic appraisal, dyadic coping, and dyadic adjustment in the domain of caregiver-patient dyads. Future research is needed to explore these inter-relationships among different domains, constructs, or components from a dyadic-level perspective.

Although it is expected that the components in this P-LLCF will work together to lead to positive dyadic adjustment for spousal caregiver-patient dyads in their journey of coping, it is unrealistic for practitioners to focus on all of the components at the same time. More research is needed to identify the outcomes of interventions that focus primarily on a single component, and also the outcomes of interventions that focus on different combinations of different components.

9.6 Conclusions and Implications for Nursing

A preliminary Conceptual Framework ‘Live with Love for Cancer Couple Dyads’ has been proposed. This framework is a potentially valuable guide for developing related interventions for cancer couple dyads. These include educational interventions on event situations (primary and secondary stressors); psychological interventions on dyadic mediators (couples’ self-efficacy and relationship-enhancing behaviors); and skill training for couples on self-disclosure. Such interventions will improve dyadic outcomes such as the well-being, positive emotions, and relationship of the couples.

The exploration of the inter-relationships among different components will aid the development of supportive couple-based interventions in the context of cancer. Future research is needed to assess the effects of interventions on dyadic adjustment, as well as the feasibility and applicability of this framework for cancer dyads. The Caring for Couples Coping with Cancer “4Cs” program has been developed based on this P-LLCF to proceed with the testing of this framework.

Chapter 10

STUDY III TESTING THE IDENTIFIED FRAMEWORK

Testing a Preliminary Live with Love Conceptual Framework for Cancer Couple Dyads: a mixed-methods study*

***** The content of this Chapter was published:

Li, Q., Xu, Y., Zhou, H., & Loke, A. Y. (2015). Testing a Preliminary Live with Love Conceptual Framework for Cancer Couple Dyads: a mixed-methods study. *European Journal of Oncology Nursing*, Article first published online: 29 APR 2015. DOI: 10.1016/j.ejon.2015.03.010.

10.1 Introduction

The focus of cancer research on family caregiving shifting from the individual to the dyadic level (Fletcher et al., 2012) has led to the development of various conceptual frameworks that were adopted to guide the design of couple-based interventions (Li and Loke., 2014b), such as the Stress and Coping Model (Northouse et al., 2007), the Adaptation Model of Couples Functioning (Heinrichs et al., 2012), Emotionally Focused Therapy (McLean et al., 2008; McLean, et al., 2013), Spiegel's Supportive-expressive Model (Collins et al., 2013), Equity Theory (Kuijer et al., 2004), and the Relationship Intimacy Model (Manne & Badr, 2008; Manne et al., 2011). However, most of these theoretical frameworks focus on the couple's relationship, with the exception of one that focuses on the stress-coping process at the individual level (Northouse et al., 2007), and none of these frameworks specifically address the process and needs of couples coping with cancer at the dyadic level.

The accumulation of data on spousal caregivers of cancer patients, such as they are the primary informal caregivers of cancer patients, and are at high risk of hidden morbidities points to the special need to develop such a dyadic conceptual framework that addresses the multiple dimensions of the concerns and needs of spousal caregiver-patient dyads, and guide the development of an intervention program to support couples coping with cancer (Cain, MacLean, & Sellick, 2004; Glajchen, 2004; Li & Loke, 2013; Pitceathly & Maguire, 2003). It is with this intention that a preliminary Live with Love Conceptual Framework (P-LLCF) for Cancer Couple Dyads was proposed based on extensive reviews of the literature and of models or conceptual frameworks employed in related literature on spousal caregiving for patients with cancer (Li & Loke, 2015). This chapter presents the findings of a study that examined the proposed P-LLCF by testing the included concepts, statements, and theories.

There are three domains in the proposed P-LLCF: Event Situation, Dyadic Mediators, and Caregiver-patient Dyads (Li & Loke, 2015). Event Situation refers to the context and related stressors experienced by cancer couple dyads, which is located at the bottom of the conceptual framework. The Dyadic Mediators, in the middle of the conceptual framework, act as “leverage” to balance or off-set the stressors to the caregiver-patient dyads. It is proposed that there are direct and indirect inter-relationships among the three domains. The ultimate goal and the central focus of this P-LLCF are positive dyadic adjustment/outcomes.

Further, it is proposed that the central focus of the P-LLCF is on the relationships among the four dyadic level constructs under the domains of Dyadic Mediators and Care-giver-patient Dyads: Dyadic Mediators, Dyadic Appraisal, Dyadic Coping, and Dyadic Adjustment/Outcomes. The two constructs of Dyadic Appraisal and Dyadic Coping at each side of the Dyads Adjustment/Outcomes construct will be weighted to maintain a balance in the caregiving experience of the dyads. The domain of Dyadic Mediators can also interrelate with these three constructs (Li & Loke, 2015).

According to Walker and Avant (2005), there are four levels of theory development, namely metatheory (focused on philosophical and methodological questions related to the development of a theory base for nursing), grand nursing theories (consisted of global conceptual frameworks defining broad perspectives for practice and ways of looking at nursing phenomena based on these perspective), middle-range theory (emerged to fill the gaps between grand nursing theories and nursing practice), and practice theory (a practice-oriented level of theory, which delineated modalities for practice)(p.6-16).

Since the P-LLCF deals with the spousal caregiver-cancer patient dyads to guide the development of the program in supporting their coping with cancer as dyads, it can be classified as a practice theory. Like any other theory, the proposed P-LLCF needs to be tested in practice and to be refined. In the present chapter the P-LLCF was tested adopting both qualitative and quantitative approaches for data collection. The data were analyzed on the basis of Walker and Avant's (2005) approach that focuses on testing concepts, statements, and theory.

10.2 Objective

Accordingly, the aims of the analysis presented in this chapter were three-fold: (i) testing concepts: to determine if the evidence from the focus group study on cancer couple dyads supports the P-LLCF in terms of the representation, relevance, and attributes of the concepts based on concepts testing; (ii) testing statements: to examine if there exists the inter-relationship among variables included in the P-LLCF; and (iii) testing theory: to explore whether the quantitative data from the cancer couples support and fit the assumption that Event Situation directly or indirectly influences the outcomes of Caregiver-patient Dyads through Dyadic

Mediators; and the Dyadic Mediators, Dyadic Appraisal, and Dyadic Coping are interrelated, and work together to benefit the Dyadic Outcomes.

10.3 Method

This is a mixed-methods study to test the proposed P-LLCF by adopting the approaches of analyzing concepts, statements and testing theories.

Study design and subjects

The testing of the P-LLCF concepts (aim 1) focused on the re-analysis of a conceptual framework that had been developed on the basis of a focus group interview with cancer couples, conducted to explore the experiences of Chinese couples living with cancer (Li et al., 2014).

It worth noting that contents related to the original findings of this focus group study have been previously published (Li et al., 2014). The final conceptualization of the findings of the study, presented as a Preliminary Conceptualization of the Overall Experiences (P-COE, Figure 8-1, p.147) of couples living and coping with cancer, rather than the raw data, was used to re-analyze and to determine if the evidence from the focus group study on cancer couple dyads supports the P-LLCF in terms of the representation, relevance, and attributes of the concepts.

The testing of the P-LLCF's statements and theory (aims 2 and 3) was based upon a quantitative cross-sectional analysis. The cancer couples that participated in this part of the study were recruited from an oncology hospital in Wuxi City, China, by convenience sampling. The study was conducted from November 2013 to July 2014.

The criteria for inclusion in the study were as follows: (i) Chinese adult married couples (age >18 years old); (ii) a medical diagnosis of any type of cancer in one partner; (iii) the spouse is the primary caregiver, who provides informal care to the cancer patient; (iv) both partners agreed to take part in the study. The spousal caregiver was defined and identified by the cancer patient as his or her married partner and primary source of physical and emotional support since the diagnosis of cancer. Excluded from the study were cancer couples with the following characteristics: (i) spousal caregivers who are unable to care for themselves due to chronic illness, or who suffer from a serious physical or mental illness, including cancer; and (ii) those unable to communicate with interviewers in Putonghua (the language commonly spoken in China).

The number of respondents was determined according to the requirements of the structural equation modeling (SEM) analysis method that had been employed in the present study. When using structural equation modeling (SEM) to analyze data, the sample size should be from N≥50-8x to N=104+x independent variables (Tabachnick and Fidell., 2013), p. 123). Since a total of about 120 items were included in the independent variables, the sample size was calculated to be ≥ 224 individuals, or 112 caregiver-patient dyads. Taking into account an estimated refusal rate of about 20%, a total of 135 cancer dyads were approached.

Instrument

The related instruments have been selected based on the constructs of the P-LLCF. Multiple measures concerning the domains of Event Situation, Dyadic Mediators, Dyadic Coping, Dyadic Appraisal, and Dyadic Adjustment/Outcomes were included in the instrument to be completed separately by the spousal caregivers and cancer patients.

Event Situation

A demographic and background information sheet was used to collect information from both the patients and their spousal caregivers on their primary and secondary stressors. The following information was solicited: (i) Demographic data: age, gender, duration of marriage, and level of education; (ii) Clinical data: type of cancer, time since diagnosis, whether or not the patient has been informed of the diagnosis of cancer, health status, and the duration of the role as spousal caregiver.

Dyadic Mediators

Self-efficacy was used to reflect dyadic mediators, which were measured using the 12-item Cancer Behavior Inventory (CBI-B) (Heitzmann et al., 2011). The CBI-B is a measure of self-efficacy for coping with cancer derived from the longer 33-item version (Merluzzi et al., 2001). The CBI-B consists of four factors: (1) maintaining independence and positive attitude; (2) participating in medical care; (3) coping and stress management; and (4) managing affect. The Cronbach α coefficient of the 12-item CBI-B ranged from 0.84 to 0.88. Validity was demonstrated through positive correlations with measures of quality of life and optimism (Heitzmann et al., 2011), and negative correlations with measures of depression and sickness impact (Heitzmann et al., 2011).

Dyadic Coping

The 37-item Dyadic Coping Inventory (DCI) was used to assess dyadic coping. The DCI assesses dyadic coping as perceived by (i) each partner about their own coping, (ii) each partner's perception of the other's coping, and (iii) each partner's view of how they cope as a couple (Gmelch et al., 2008; Bodenmann., 2008). Based on assessments of the instrument in three different languages, involving 216 German-speaking, 378 Italian-speaking, and 198 French-speaking participants, the DCI ranged in reliability from 0.50 to 0.92 (Ledermann et al., 2010). The translation of the DCI into Chinese was done by the first author. Three bilingual (Chinese and English) psychological and nursing scholars then validated this Chinese version of the DCI. The face validity of the Chinese version DCI was assessed by three Chinese nursing fellows with extensive experience in cancer nursing. The internal consistency of the DCI was established by Cronbach's $\alpha = 0.857, 0.889$ ($n = 117$) for cancer patients and spousal caregivers respectively.

Dyadic Appraisal

Couple communication was used to assess Dyadic Appraisal, measured by the 15-item Cancer-Related Communication Problems within Couples Scale (CRCP) (Kornblith et al., 2006). The CRCP is used to assess whether patients and their partners have difficulty talking about cancer with each other. The scale has demonstrated high reliability for both cancer patients and spouses (Cronbach's α=0.87, 0.81 respectively) (Kornblith et al., 2006). Again, the English version was translated into Chinese according to the same process as described earlier in translating the DCI. The internal consistency of the CRCP was established by Cronbach's α = 0.805, 0.737 (n =117) for cancer patients and spousal caregivers respectively.

Dyadic Outcomes

According to the P-LLCF, the Dyadic Outcomes include the couples' physical and mental health, negative and positive emotions, and marital satisfaction.

Physical and mental health: The Medical Outcomes Study 12-item short form (MOS SF-12) (version 2) (Ware, Kosinski, & Keller, 1996) was used to measure physical and mental health. The two components (Physical Component Summary, PCS; and Mental Component Summary, MCS) of the 12-item versions achieved R squares of 0.905 with PCS and 0.938 with MCS of the SF-36 in a cross-validated Medical Outcomes Study. Test-retest (2-week) correlations of 0.89 and 0.76 were observed for the SF-12 PCS and MCS respectively, in the general U.S. population (n = 232).

Negative emotions: The Hospital Anxiety and Depression Scale (HADS) (ZIGMOND & SNAITH, 1983) was used to measure negative emotions. The HADS is a validated and widely used self-reported measure; it assesses individuals' self-perceived levels of depression and anxiety. It can be used to identify patients with elevated levels of symptoms and disorders that may be clinically relevant. The

Cronbach’s alpha for HADS anxiety varied from 0.68 to 0.93 (mean 0.83) and for HADS depression from 0.67 to 0.90 (mean 0.82) (Bjelland et al., 2002).

Positive emotions: The revised Benefit-Finding Scale (BFS) (Antoni et al., 2001) was used to measure positive emotions. The revised BFS is a 17-item measure that assesses perceptions of the positive contributions that resulted from the cancer experience. It has been validated in both cancer patients (Kinsinger et al., 2006) and caregivers of cancer patients (Cronbach's α=0.95) (Kim et al., 2007).

Marital Satisfaction: The 14-item Revised Dyadic Adjustment Scale (RDAS) was used to measure the marital satisfaction of the cancer couples. The RDAS is widely used to evaluate both individual and dyadic adjustments in distressed relationships (Crane et al., 2000; Busby et al., 1995). Scores range from 0 to 69, with higher scores (≥48) indicating greater relationship satisfaction (Crane et al., 2000). The coefficient alpha for the total RDAS was 0.90 (Busby et al. 1995).

Of the seven instruments used in this study, the DCI and CRCP were translated from English into Chinese for this study and were found to be of good reliability in this study; the remaining five are Chinese versions and have already been applied in Chinese populations.

Data collection procedure

Before the commencement of the cross-sectional study, nurses were given a training session on the details of the study and provided with explanations of the items in the instruments. The oncologists in the hospital identified the cancer couples in accordance with the criteria for eligibility. Couples who met the criteria for inclusion were approached in the oncology wards when they were admitted for chemotherapy treatments. After their written informed consent was obtained, couples were invited to complete the questionnaires separately with the help of a trained nurse. According to their preference, they filled out the questionnaires in a private room of an in-patient ward or in the nurse's office, in privacy and away from possible disturbances. The questionnaire took about 20-30 minutes to complete.

Research ethics

Ethical approval for this study was granted by the Human Ethics Committee of The Hong Kong Polytechnic University, and approval for access was obtained from the participating hospital in Wuxi. The informed written consent of the participants was obtained prior to the study. They were clearly told that their participation was voluntary, and that they were free to withdraw from the study at any time for any reason, with no penalty. Apart from that some of the couples who completed the questionnaire expressed that the multiple measurements in the questionnaire were tiresome, this research did not result in any other undue discomfort to the subjects. The participants were assured of confidentiality and anonymity. Only the members of the study research team have access to the data that they provided.

Data Analysis

The testing and analysis of this P-LLCF was guided by the process of analyzing theoretical concepts for constructing theories (Walker & Avant, 2005), including testing concepts, statements, and theories. Although the three types of testing are treated separately, there is a great deal of overlap.

Testing concepts

The validation of concepts was guided by three questions (Walker & Avant, 2005): (1) Is there evidence that the concept represents a phenomenon in reality? (2) What evidence is there that the concept is relevant to practice, in terms of client needs, clinical outcomes, or other meaningful clinical criteria? (3) What evidence supports the purported attributes of the concepts? The final conceptualization of the findings of the previously published focus study, presented as a Preliminary Conceptualization of the Overall Experiences (P-COE) of couples living and coping with cancer (Li et al., 2014) were re-analyzed to determine if the evidence from the focus group study on cancer couple dyads supports the P-LLCF in terms of the representation, relevance, and attributes of the concepts based on concepts testing.

Analytic process of yielding the P-LLCF and the P-COE: The process of analyzing theoretical concepts was applied to guide the step of identifying/developing the P-LLCF (Risjord, 2009; Walker & Avant, 2005) (Chapter 9). A conventional approach (Hsieh & Shannon, 2005) to content analysis was applied in the focus group study of yielding the P-COE of couples living and coping with cancer (Chapter 8).

The process to compare and analyze the P-COE with the P-LLCF: There were two steps in the process of comparing and analyzing the P-COE with the P-LLCF. The first step was to identify areas of consistency and agreement between the focus group study and the P-LLCF. For doing so, the P-COE was scrutinized for consistency and agreement against the P-LLCF using concept analysis. In the second step, the strategies for analyzing both the concepts and theories (Walker & Avant, 2005) were applied to compare and analyze the P-COE of couples living and coping with cancer derived from the focus group study, with the P-LLCF to be tested. Where applicable, the compare and analysis focused on origins, meaning (identifying concepts, examining definitions and use: attributes, antecedents, and consequents, statements, and examining relationships), usefulness, and generalizability or transferability.

Testing statements

The empirical validity of theories' statements is usually tested using descriptive-correlational or experimental methods (Walker & Avant., 2005). Accordingly, a correlational analysis was applied to test the correlation among different variables included in the P-LLCF. Analyses were performed using the Statistical Package for the Social Sciences, version 21.0 (SPSS, Chicago, Illinois, USA), with the level of significance set at $P<0.05$. The findings were applied to examine if there exists the inter-relationship among variables included in the P-LLCF.

Testing theories

Testing theories is more challenging than testing statements because of the greater complexity of relationships inherent in theories. In testing theories, how well the results of studies fit with the theories needs to be evaluated (Walker & Avant, 2005). Structural equation modeling (SEM) was used as a method for testing of the theory.

SEM is a multilevel latent variable modeling analysis used for theory testing to reflect the breadth and consistency of models (Hoyle, 2011), it has also been used to test theoretical framework in health care (Rathert et al. 2009).

The relationship of the three domains (Event Situation, Dyadic Mediators, and Caregiver-patient Dyads) and the relationship of the four dyadic level domains/constructs (Dyadic Mediators, Dyadic Appraisal, Dyadic Coping, and Dyads Adjustment/Outcomes in the P-LLCF (Figure 9-4, p.174), were verified using structural equation modeling (SEM) as the method for analyzing the data (Hoyle., 2011). Structural equation modeling (SEM) was carried out using Amos 21.0. Three indices were used to evaluate the fit of the model: Chi-Square X^2 with an insignificant P value ($P>0.05$); a confirmatory fit index (CFI) value of above 0.95; and a root mean square error of approximation (RMSEA) value of less than 0.08, were considered to be indicative of good model fit (Hooper et al., 2008). Findings of the SEM were applied to explore whether the quantitative data from the cancer couples support and fit the assumption that Event Situation directly or indirectly influences the outcomes of Caregiver-patient Dyads through Dyadic Mediators; and the Dyadic Mediators, Dyadic Appraisal, and Dyadic Coping are interrelated, and work together to benefit the Dyadic Outcomes.

10.4 Results

10.4.1 Characteristics of samples

Qualitative samples

A total of four focus group interviews were conducted for cancer patients (P) and their spousal caregivers (SC) in January 2013. A total of 28 participants (11 P & 17 SC) from all groups were included in this focus group study. Details please refer to the previous publication on this study (Li et al., 2014, Chapter 8) .

Quantitative samples

Of the 135 couples approached by trained nurses, 18 declined to take part in the study. The remaining 117 couples were recruited as subjects for this study. The characteristics of the 117 cancer couples included in this analysis are shown in Table 10-1. They were couples coping with digestive system cancer (e.g., esophageal, gastric, liver, and colorectal cancer, n=65, 55.6%), lung cancer (n=35, 29.9%), urogenital system cancer (e.g., kidney, prostate cancer, n=13, 11.1%), and others (n=4, 3.4%).

Table 10-1 The characteristics of the patients and spousal caregivers

Characteristics	**Patients (P, n=117)**	**Spousal caregivers (SC, n=117)**
Mean age (years)	57.7 (ranging from 26-79, SD=11.4)	56.8 (ranging from 29-76, SD = 10.7)
Gender (n)	Male: 78; Female: 39	Male: 39; Female: 78
Duration of marriage (years)	31.8 (ranging from 4-52, SD=10.9)	
Levels of education (n, percent)	Primary school or less (59, 50.4%) High school (44, 37.6%) University or above (14, 12.0%)	Primary school or less (62, 53.0%) High schools (44, 37.6%) University or above (11, 9.4%)
Religion (i.e. Buddhists, or Christian) (n, percent)	Yes (30, 25.6%) No (87, 74.4%)	Yes (29, 24.8%) No (88, 75.2%)

Monthly family income (in RMB, n, percent)	< 2000 (18, 15.4%); **2001～6000 (75, 64.1%)**; 6001～10000 (18, 15.4%); 10001～15000 (4, 3.4%); >15000 (2, 1.7%)	
Financial burden of the family due to the treatment of cancer	**Serious (71, 60.7%)**; Normal (41,35.0%); Mild (4, 3.4%); None (1, 0.9%)	
Cancer types (n, percent)	**Digestive system cancer** (**65, 55.6%**); Lung cancer (35, 29.9%), Urogenital system cancer (13, 11.1%), Others (4, 3.4%).	
Stage of cancer (n, percent)	III (45, 38.5%); IV (72, 61.5%)	
The average time since diagnosis or the duration in their role as a SC(n, percent) *	13.2 months (ranging from 1-192 months, SD=22.96)	< 6 months (62, 53.0%) 6 months ~2 years (38, 32.5%) 2~5 years (12, 10.3%) > 5 years (5, 4.3%)
Informed about the disease (n, percent) **	Well informed (86, 73.5%) Partly informed (31, 26.5%)	Well informed (95, 81.2%) Partly informed (22, 18.8%)
Health status (n, percent)	Feels well: good (42, 35.9%) As usual (56, 47.9%) Not fells well: bad (19, 16.2%)	Feels well: good (55, 47.0%) As usual (54, 46.2%) Not fells well: bad (8, 6.8%)

Note: SD=standard deviation

*The average time since diagnosis of the cancer and the duration in their role as a SC are the same, just in different time unit, the former is described as months, while the time period for the latter.

** Well informed: Patient fully understood his/ her condition; or the SC were well informed about their spouses’ disease

** Partly informed: Patient was informed about the diagnosis of cancer, but not about the severity of his / her condition; or SC were partly informed about their spouses’ disease.

10.4.2 Testing concepts

A strategy for analyzing concepts was adopted. For consistency and agreement, the proposed P-LLCF was appraised using the P-COE from the focus group interviews with couples coping with cancer. A quick glance at the two frameworks, i.e. the P-LLCF (Figure 9-4, p.174) and the P-COE (Figure 8-1, p.147), gives the impression that the two are more different than similar. In Figure 9-4 (p.174), the proposed P-LLCF consists of three domains: Event Situation, Dyadic Mediators, and Caregiver-patient Dyads; while in Figure 8-1 (p.147), the themes that were identified from the focus group interviews with couples coping with cancer are: communication dynamics, living with changes, negative and positive impacts, and network of support.

Similarities and consistencies between the P-LLCF and the P-COE were found when the process of analysing theoretical concepts was adopted to scrutinise each concept or construct raised by the two processes. Table 10-2 shows the corresponding components of the P-COE from the focus group interviews with the constructs in the P-LLCF of the process of concept testing. The corresponding components were denoted using CD for Communication Dynamics, LC for life changes, NPI for negative and positive impacts, and NS for network support.

The results of the analysis of the consistency and agreement of the concepts in the P-LLCF with the P-COE showed that the theme of Communication Dynamics (CD) from the focus group study is found throughout all three domains in the P-LLCF, from event situation, dyadic mediators, to caregiver-patient dyads. The theme of living with change (LC) and the network of support (NS) affect how well the couples will cope in the same three domains of the P-LLCF throughout the process. Negative and positive impacts (NPI) emerge as the outcomes in the caregiver-patient dyads (Table 10-2).

Table 10-2 Components of P-LLCF* that correspond with the P-COE**

Themes and sub-themes in the P-COE	**Domains and constructs in the P-LLCF**
1. **Communication dynamics (CD)** ✓ Expression of appreciation ✓ Compelling need for information ✓ Information censorship and the two-sided face	1. **Event situation** ✓ The primary stressors • Illness-related factors (LC) • Care demands (LC) ✓ The secondary stressors • Caregiver-patient relationship (CD) • Disrupted schedules (LC) • Role conflict • Contextual factors (e.g. family, social support) (NS)
2. **Living with changes (LC)** ✓ Change in roles ✓ Change in marital relationship ✓ Change in life plan ✓ Change in social activities	2. **Dyadic mediators** ✓ Daily enrichment events (LC) • Relationship-enhancing behaviours (CD) • Reciprocal self-disclosure (CD) • Relationship engagement (CD, NS)
3. **Network of support (NS)** ✓ Family support ✓ Comrades in arms against cancer ✓ Healthcare professional support ✓ Governmental support	3. **Caregiver-patient dyads** ✓ ***Dyadic appraisal*** • Caregiver's feeling of accomplishment (NPI) • Communication (CD) • Reciprocal influence (NPI)

4. **Negative and positive impacts (NPI)** ✓ Side-effects of chemotherapy ✓ Caregiver burden ✓ Reciprocal caring / support ✓ Positive perspective and hope	✓ ***Dyadic coping*** • Supportive and collaborative dyadic coping (CD) • Planning ahead LC) ✓ ***Dyadic adjustment/outcomes*** • Negative emotions (NPI) • Positive emotions (NPI) • Couple relationship (NS) • Marital satisfaction (LC)

* P-LLCF: a Preliminary Live with Love Conceptual Framework for cancer couple dyads;
**P-COE: a Preliminary Conceptualization of the Overall Experiences of couples living and coping with cancer.

The two conceptual frameworks of P-LLCF and P-COE for Chinese couples coping and living with cancer were then compared in terms of the origins and meaning of the identified concepts; definitions and the use of attributes, antecedents, consequents; and statements, relationships, usefulness, and generalizability or transferability. The results of this analysis are outlined in Table 10-3.

The analysis and the findings from the comparison showed that (i) while the P-LLCF was derived from studies conducted at the system level, the P-COE was derived from the experiences of cancer couples in China, at the cancer dyads level. Nevertheless, the concepts identified in the P-LLCF are reflected in the findings from the focus group interviews on the experience of couples coping and living with cancer in China. (ii) The findings from the focus group study are evidence that the concepts of the P-LLCF are relevant in practice, with regard to the need that Chinese cancer couples have for support for living with changes, and the positive and negative impacts throughout the trajectory of living with cancer. (iii) The findings from the focus group study substantiate the attributes of the concepts included in the P-LLCF in terms of coping together, sharing and communicating, and reciprocal caring. In summary, these findings provide the evidence of the representation, relevance, and attributes of the concepts of the P-LLCF.

Table 10-3 Analysis of the concepts and theories of the P-LLCF* and P-COE**

Contents	P-LLCF*	P-COE**
Origins		
■ Method and basis of developing the framework	✓ Theoretical concept analysis: focusing on the literature; ✓ A deductive synthesis based on models or conceptual frameworks employed in related literature on spousal caregiving for patients with cancer.	✓ Colloquial concept analysis: focusing on people; ✓ An inductive synthesis based on the findings of focus group interviews with Chinese cancer couple dyads.
■ Purpose of developing the related theory or framework	✓ To make possible a better understanding of concepts related to the situation of couples coping with cancer; ✓ To facilitate the development of interventions to support caregiver-patient dyads in coping with cancer.	✓ To gain a better understanding of the experiences of Chinese couples coping with cancer; ✓ To explore the concerns and needs of cancer couples with respect to the caring role and the experiences of couples coping with cancer.
Meaning		
■ Identify concepts	✓ see Table 10-2	✓ See Table 10-2
■ Examine definitions and use	All of the concepts have been carefully defined and are used consistently throughout the paper.	All of these themes and sub-themes have been described and are supported by statements from the participants.
• Attributes***	✓ A process of coping together; ✓ Sharing and communication; ✓ Relationship-enhancing behaviors; ✓ Dealing with the event situation, such as contextual	✓ A process of coping together; ✓ Sharing and communication; ✓ Reciprocal caring/support within couples; ✓ Support from other people or parties in different

	factors, including cultural influences, life stage, economic, and health system characteristics, to successfully support couples coping with cancer.	contexts, such as family support, as comrades in arms against cancer, support from healthcare professionals, and governmental support.
• Antecedents***	✓ Medical diagnosis of any type of cancer in one partner;	✓ Medical diagnosis of any type of cancer in one partner;
	✓ The spouse is the primary caregiver who provides informal care to the cancer patient;	✓ The spouse is the primary caregiver who provides informal care to the cancer patient;
	✓ To communicate with each other.	✓ To communicate with each other.
• Consequences***	An improvement in mental and physical condition, and in marital relationship; More feeling of positive emotions, and less feeling of negative emotions.	An improvement in the ability of the couple to cope with cancer together, e.g., by having a positive perspective and experiencing hope.
■ Identify statements	✓ There are direct and indirect inter-relationships among the three domains of event situation, dyadic mediators, and caregiver-patient dyads;	✓ The dyadic relationship of a couple when one of them has cancer is conceptualized as involving the interaction of three themes: communication dynamics, living with changes, and negative and positive impacts.
	✓ The same relationships may exist among the three constructs of dyadic appraisal, dyadic coping, and dyadic adjustment in the caregiver-patient dyads domain.	✓ Better communication is a valuable strategy to enhance those interactions in the dyads so that they can benefit couples who are struggling to cope with the disease.
	✓ The intervention program guided by this framework can lead to positive outcomes in the caregiving experience of caregiver-patient dyads, with improvements in	✓ Successful communication between couples, such as expressions of appreciation, enhances the connection that couples feel with each other during the process of

	communication, dyadic appraisal, coping, and outcomes throughout the cancer trajectory, facilitating and guiding the dyads to continuously “Live with Love.”	coping with the changes brought about by the diagnosis of cancer.
■ Examine relationships	The various components in this P-LLCF identified that communication works to benefit the couple’s love, namely to produce positive dyadic adjustment/outcomes for spousal caregiver-patient dyads in their journey of coping with cancer.	By improving communication and networks of support, the couples as a dyad living with cancer will be able to cope better with the disease.
Usefulness	✓ This Live with Love conceptual framework sheds new light on the study of cancer couple dyads; ✓ This P-LLCF has the potential to be useful in developing support programs and services based on the perspective of cancer couple dyads.	✓ These findings provide insights into the daily struggles of couples living with cancer; ✓ It also support the development of an intervention aimed at improving the experiences of couples in their trajectory of coping with cancer.
Generalizability or Transferability	Although this P-LLCF has not been tested or verified through research, it has the potential to be applied to couples coping with chronic diseases of various kinds, not just to cancer dyads.	Although the results are not generalizable, they might be transferrable in similar settings.

* P-LLCF: a Preliminary Live with Love Conceptual Framework for cancer couple dyads;

**P-COE: a Preliminary Conceptualization of the Overall Experiences of couples living and coping with cancer;

***Although the three terms of **Attributes, Antecedents**, and **Consequences** were used here for the analysis of meaning, the analysis here refers to the meaning of the whole framework, not only to that of a single concept.

10.4.3 Testing statements

A descriptive-correlational analysis was applied to test the empirical validity of statements in the P-LLCF through the relationship of correlation among the variables included to test statements in study aim 2. Table 10-4 shows the correlation matrix of all of the measured variables for both the patients and their spousal caregivers in the cross-sectional study. The matrix was organized by ordering variables of patients in the left and top, and the variables of spousal caregivers in the right and bottom of the table.

In general, there was a strong correlation of all variables within patients or spousal caregivers, but not so high correlation between variables pertaining to the patients and spousal caregivers. Of the total of 153 correlations, a large proportion (109/153=71.24%) were identified as statistically significant. These findings provide evidence that an inter-relationship exists among the variables included in the P-LLCF.

Table 10-4 Pearson correlations among study variables (n=117)

Variables[c]	Variables of patients (P)									Variables of spousal caregivers (SC)								
	DCI	**Anxiety**	**Dep**	**RDAS**	**PCM**	**MCS**	**BF**	**CBI**	**CRCP**	**DCI**	**Anxiety**	**Dep**	**RDAS**	**PCS**	**MCS**	**BF**	**CBI**	**CRCP**
DCI-P	1																	
Anxiety-P	-.192[a]	1																
Dep-P	-.255[b]	.837[b]	1															
RDAS-P	.301[b]	-.197[a]	-.218[a]	1														
PCS-P	-.016	-.392[b]	-.393[b]	-.021	1													
MCS-P	.186[a]	-.409[b]	-.348[b]	.179	.030	1												
BF-P	.303[b]	-.285[b]	-.303[b]	.557[b]	.063	.266[b]	1											
CBI-P	.239[b]	-.408[b]	-.385[b]	.336[b]	.285[b]	.291[b]	.457[b]	1										
CRCP-P	-.280[b]	.208[a]	.240[b]	-.047	.144	-.228[a]	-.146	-.111	1									
DCI-SC	.528[b]	-.166	-.190[a]	.360[b]	-.049	.164	.376[b]	.326[b]	-.231[a]	1								
Anxiety-SC	-.124	.479[b]	.382[b]	-.187[a]	-.262[b]	-.302[b]	-.317[b]	-.314[b]	.178	-.194[a]	1							
Dep-SC	-.126	.458[b]	.460[b]	-.162	-.235[a]	-.315[b]	-.308[b]	-.269[b]	.159	-.183[a]	.820[b]	1						
RDAS-SC	.268[b]	-.259[b]	-.200[a]	.520[b]	-.066	.090	.440[b]	.310[b]	-.165	.469[b]	-.324[b]	-.346[b]	1					
PCS-SC	-.034	-.222[a]	-.221[a]	.005	.352[b]	.041	-.020	.100	.101	.025	-.277[b]	-.283[b]	.014	1				
MCS-SC	.115	-.237[b]	-.270[b]	.213[a]	-.088	.256[b]	.263[b]	.256[b]	-.185[a]	.187[a]	-.289[b]	-.328[b]	.254[b]	-.462[b]	1			
BF-SC	.249[b]	-.206[a]	-.228[a]	.296[b]	-.041	.113	.669[b]	.327[b]	-.231[a]	.388[b]	-.410[b]	-.457[b]	.476[b]	-.034	.308[b]	1		
CBI-SC	.139	-.270[b]	-.233[a]	.295[b]	.081	.205[a]	.499[b]	.674[b]	-.105	.402[b]	-.302[b]	-.337[b]	.373[b]	.133	.287[b]	.489[b]	1	
CRCP-SC	-.029	.135	.085	.010	-.004	-.182[a]	-.199[a]	-.162	.445[b]	-.157	.202[a]	.205[a]	-.222[a]	.172	-.211[a]	-.242[b]	-.112	1

a. Correlation is significant at the 0.05 level (2-tailed);

b. Correlation is significant at the 0.01 level (2-tailed).

c P=patient, SC=spousal caregivers, DCI= Dyadic Coping Inventory, Dep=Depression, RDAS= Revised Dyadic Adjustment Scale, PCS= Physical Component Summary MCS=Mental Component Summary, BF=Benefit finding, CBI = Cancer Behavior Inventory, CRCP= Cancer-Related Communication Problems

10.4.4 Testing theories

Structural equation modeling (SEM) was applied to test theory described in study aim 3 using the dyadic data of both the patients and their spousal caregivers in the cross-sectional study.

Figure 10-1 is a theoretical model estimation for testing that the Event Situation will directly or indirectly impact the caregiver-patient Dyadic Outcomes through the mediation of Dyadic Mediators. As shown in Figure 10-1, the three domains of Event Situation, Dyadic Mediators, and Dyadic Outcomes acted as latent variables. The observed variables, pertaining to Event Situation, included variables of primary and secondary stressors (patient's level of education, type of cancer, being informed of the patient's disease, health status of the patient, duration of the marriage, and duration in the role as spousal-caregiver). Dyadic Mediators were formulated by the self-efficacy of both the patients and spousal caregivers. Dyadic Outcomes were formulated and estimated using five sub-models for the respective variables for both patients and their caregivers: Model 1: Physical Component Summary (PCS); Model 2: Mental Component Summary (MCS); Model 3: Anxiety and Depression; Model 4: Benefit Finding; and Model 5: Marital Satisfaction (RDAS).

Figure 10-2 is the second theoretical model that was estimated for testing study aim 3 in that Dyadic Mediators, Dyadic Appraisal, and Dyadic Coping are interrelated and work together to benefit Dyadic Outcomes. Four latent variables were included in this theoretical model. The two latent variables, Dyadic Mediators and Dyadic Outcomes, were formulated in the same way as those in theoretical model 1. The two latent variables, Dyadic Appraisal and Dyadic Coping, were respectively formulated using the Cancer-Related Communication Problems within Couples Scale (CRCP) and the Dyadic Coping Inventory (DCI) of both the patients and spousal caregivers.

Five sub-models (models 6-10) for the respective variables for both patients and their caregivers were also estimated for this testing, as shown in Figure 10-2. The five theoretical sub-models were: Model 6: Physical Component Summary (PCS); Model 7: Mental Component Summary (MCS); Model 8: Anxiety and Depression; Model 9: Benefit Finding; and Model 10: Marital Satisfaction (RDAS).

The maximum likelihood method was applied in estimating covariance matrices in all of the ten models included in figure 10-1 (models 1 to 5) and figure 10-2 (model 6-10). All ten models resulted in convergence and showed goodness of fit to the data and variables. The ten models present the related notes and indices for the ten models. For all of the ten sub-models, the indices of Chi-Square X^2 had an insignificant P value ($P>0.05$); confirmatory fit indexes (CFI) were valued above 0.95; and the root mean square error of approximation (RMSEA) values were less than 0.08 (Table10-5). The relations were also estimated and showed goodness of fit, as indicated by the virtual line in Figure 10-1. Although testing theory is complex, and the relationships among these variables included in above models are complicated, it can be cautiously concluded that the findings provide evidence that (1) the Event Situation will have a direct or indirect impact on caregiver-patient Dyadic Outcomes through Dyadic Mediators; and (2) Dyadic Mediators, Dyadic

Appraisal, and Dyadic Coping are interrelated and work together to benefit Dyadic Outcomes.

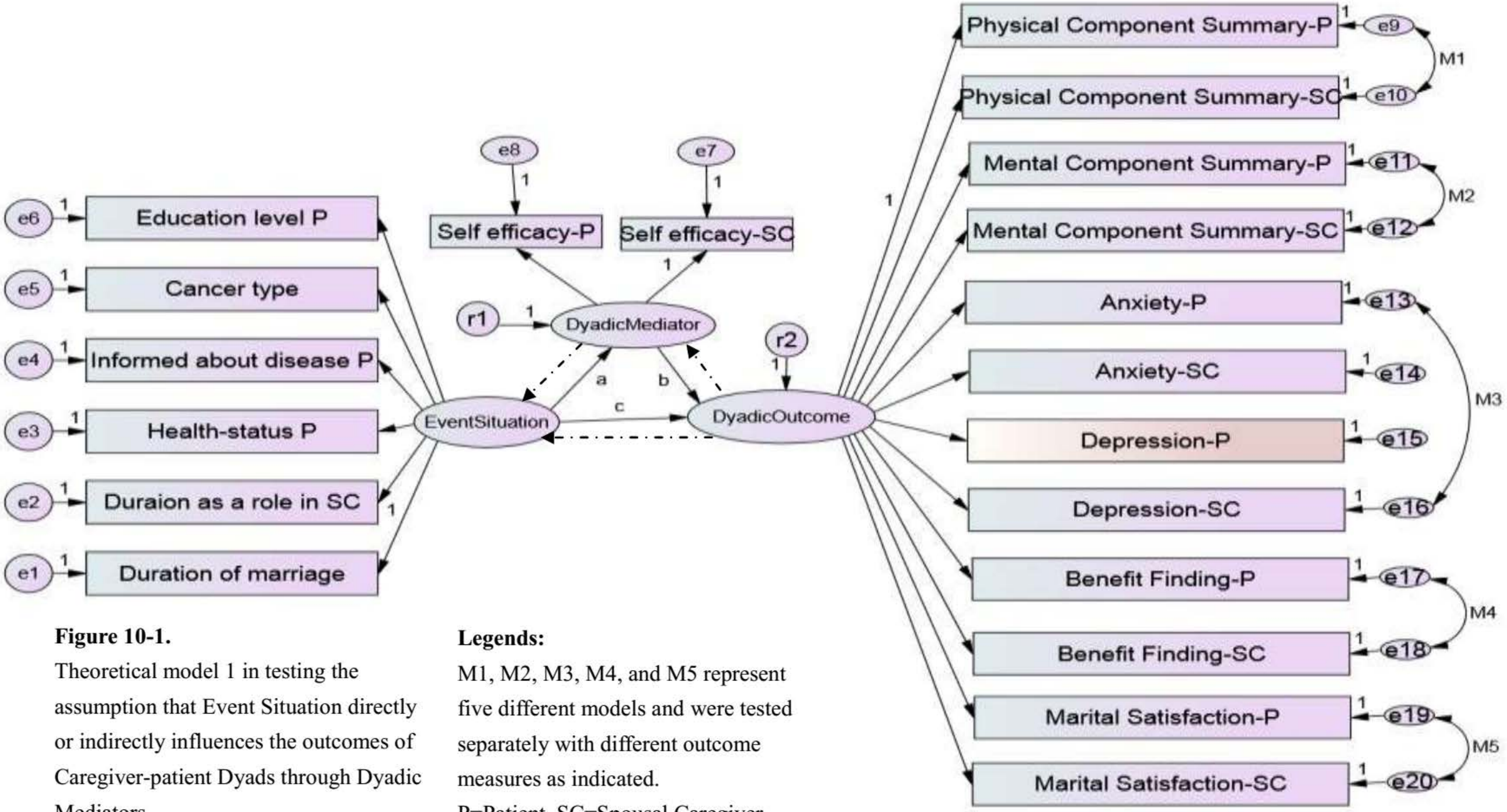


Figure 10-1.

Theoretical model 1 in testing the assumption that Event Situation directly or indirectly influences the outcomes of Caregiver-patient Dyads through Dyadic Mediators

Legends:

M1, M2, M3, M4, and M5 represent five different models and were tested separately with different outcome measures as indicated.

P=Patient, SC=Spousal Caregiver

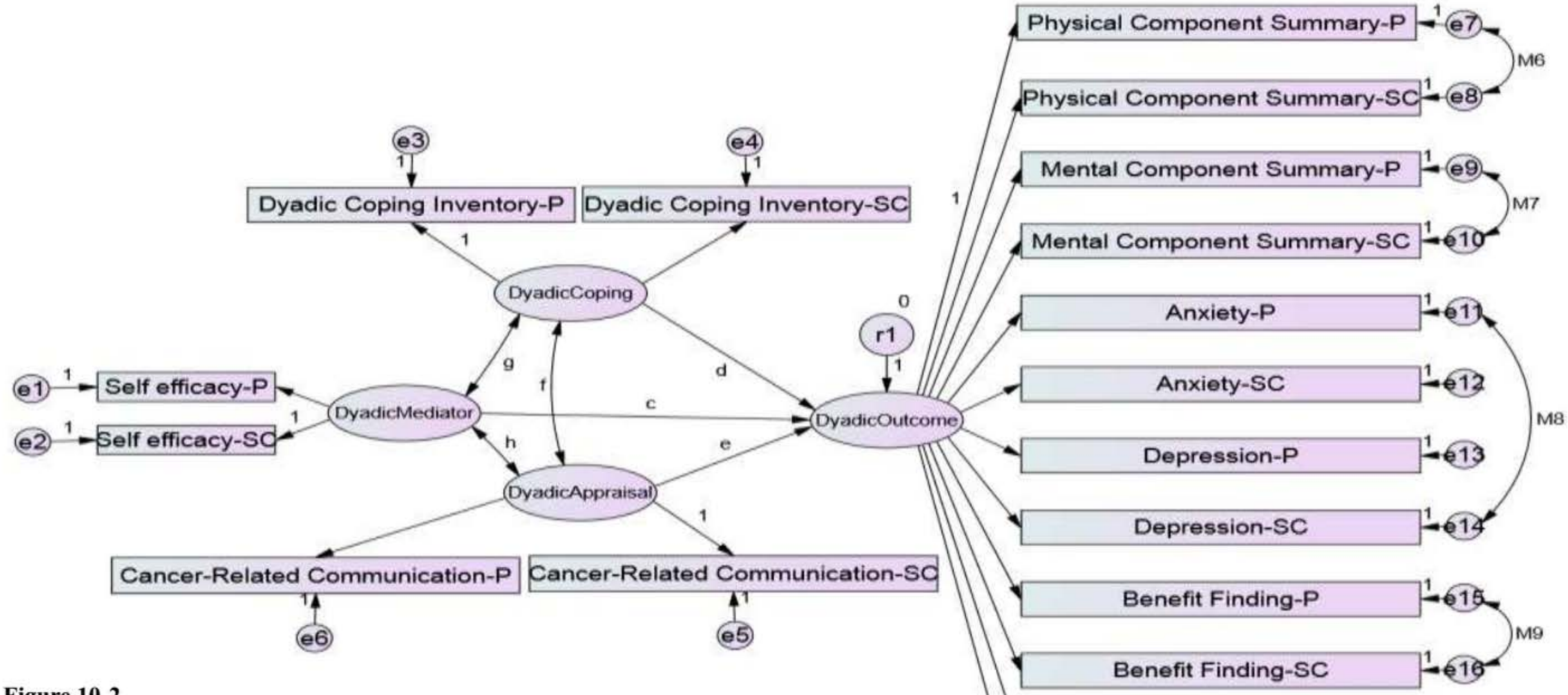


Figure 10-2.

Theoretical model 2 in testing the assumption that Dyadic Mediators, Dyadic Appraisal, and Dyadic Coping are interrelated, and work together to benefit the Dyadic Outcomes

Legends:

M6, M7, M8, M9, and M10 represent five different models and were tested separately with different outcome measures as indicated.

P=Patient, SC=Spousal Caregiver.

RDAS= Revised Dyadic Adjustment Scale.

Table 10-5 Standardized path coefficients and fit statistics of ten models

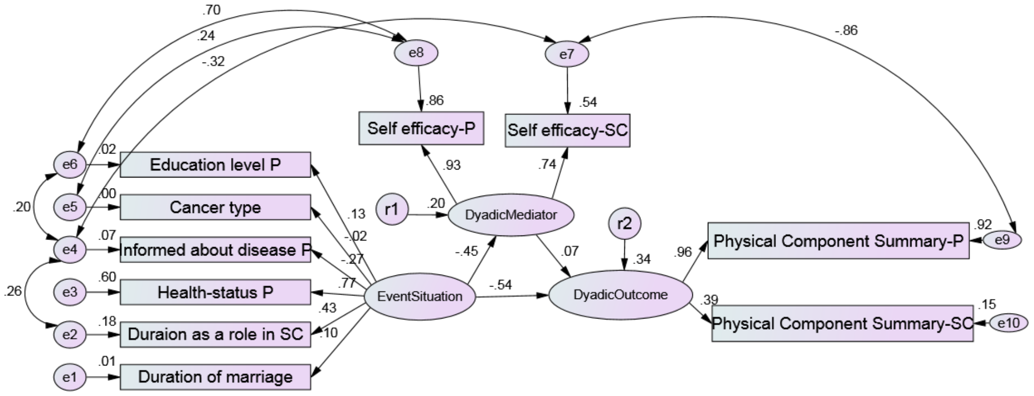
Indicates	**Models 1-5 for testing theoretical model 1**					**Models 6-10 for testing theoretical model 2**				
	M 1	**M 2**	**M 3**	**M 4**	**M5**	**M 6**	**M7**	**M 8**	**M 9**	**M 10**
Outcome variables	PCS	MCS	HADS	BF	RDAS	PCS	MCS	HADS	BF	RDAS
Number of distinct sample moments:	55	55	78	55	55	36	36	55	36	36
Number of distinct parameters to be estimated	29	30	36	28	27	24	21	32	25	25
Degrees of freedom	26	25	42	27	28	12	15	23	11	11
Event Situation → Dyadic Mediator (a)	-0.45	-0.48	**-0.45****	-0.51	**-0.48****	---	---	---	---	---
Event Situation → Dyadic Outcome (b)	-0.54	0.17	**0.42****	0.31	0.04	---	---	---	---	---
Dyadic Mediator → Dyadic Outcome (c)	0.07	**0.77****	**-0.23***	**0.83*****	**0.53****	**0.99****	**0.68****	**-0.86*****	**0.70*****	**0.44***
Dyadic Coping → Dyadic outcome (d)	---	---	---	---	---	-0.41	-0.07	0.02	0.31	**0.70****
Dyadic Appraisal → Dyadic outcome (e)	---	---	---	---	---	0.50	**-0.65***	**0.40***	-0.28	-0.04
Dyadic Appraisal ↔ Dyadic Coping (f)	---	---	---	---	---	-0.27	-0.33	-0.31	-0.30	-0.31
Dyadic Mediator ↔ Dyadic Coping (g)	---	---	---	---	---	**0.43***	**0.47****	**0.39***	**0.51****	**0.46****
Dyadic Mediator ↔ Dyadic Appraisal (h)	---	---	---	---	---	-0.16	-0.21	-0.17	-0.16	-0.18
Chi-square X^2	29.734	28.843	42.636	31.605	36.740	19.541	20.029	28.716	11.902	12.778
Probability level **(P>0.05)**	**0.278**	**0.271**	**0.444**	**0.247**	**0.125**	**0.076**	**0.171**	**0.190**	**0.371**	**0.308**
a confirmatory fit index **(CFI>0.95)**	**0.979**	**0.976**	**0.999**	**0.981**	**0.953**	**0.960**	**0.973**	**0.988**	**0.997**	**0.992**
a root mean square error of approximation **(RMSEA＜0.08)**	**0.035**	**0.036**	**0.015**	**0.038**	**0.052**	**0.074**	**0.054**	**0.046**	**0.027**	**0.037**

Note: PCS=physical component summary; MCS=mental component summary; HADS=anxiety and depression; BF=benefit finding; RDAS=Revised Dyadic Adjustment Scale (reflecting marital satisfaction).

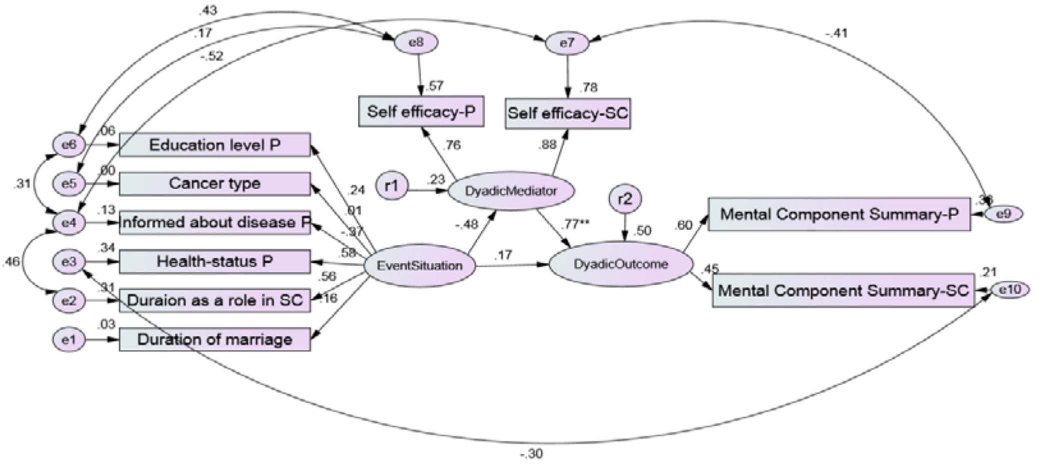
*** P＜0.05; ** P＜0.01; *** P＜0.001.**

Figure 10-3. Five sub-models (sub-model 1-5) in testing the assumption that Event Situation directly or indirectly influences the outcomes of Caregiver-patient Dyads through Dyadic Mediators

1. Sub-model 1, PCS

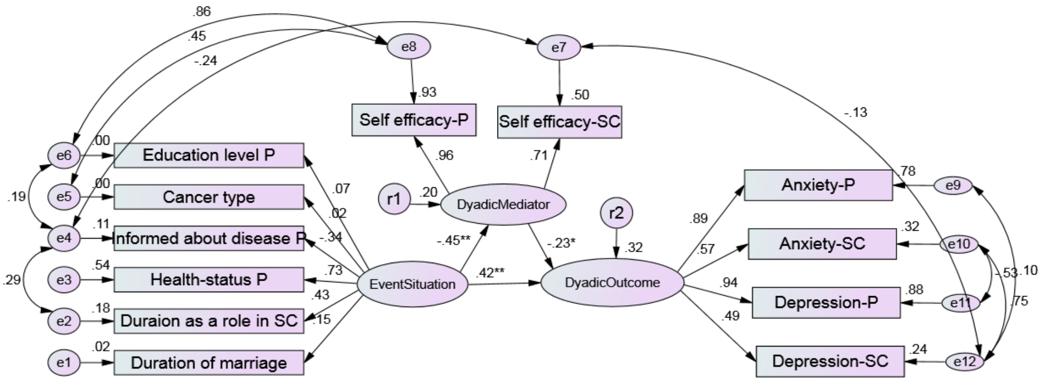


2. Sub-model 2, MCS



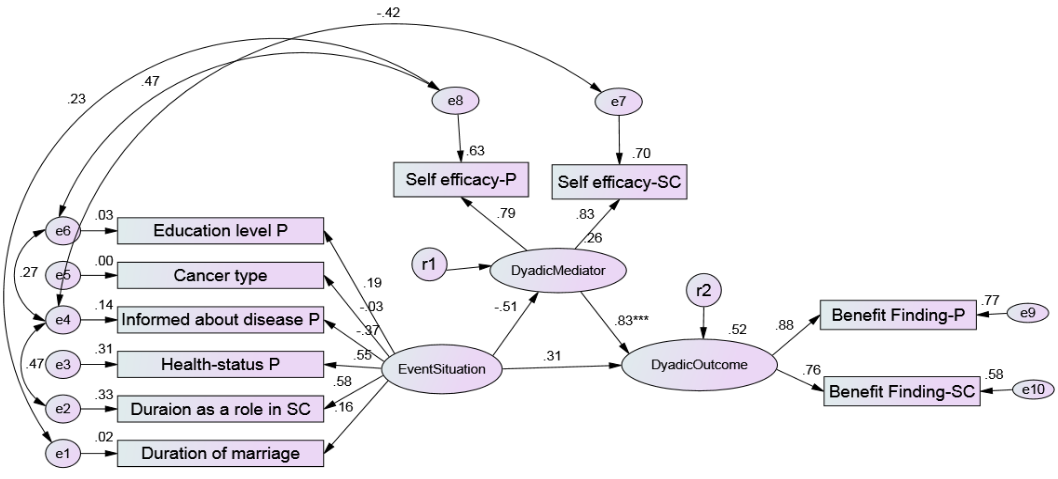
**P<0.01

3. Sub-model 3, HADS



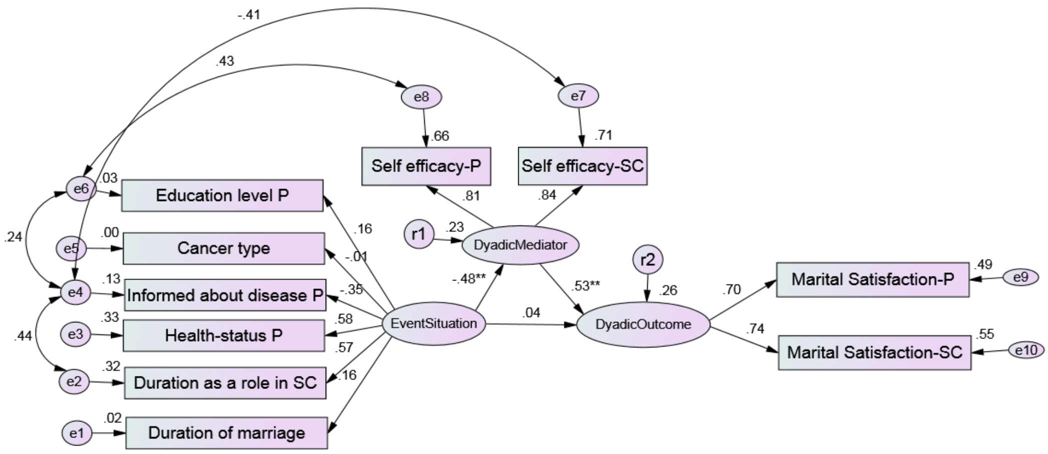
**P<0.05; **P<0.01*

4. Sub-model 4, Benefit finding



****P<0.001*

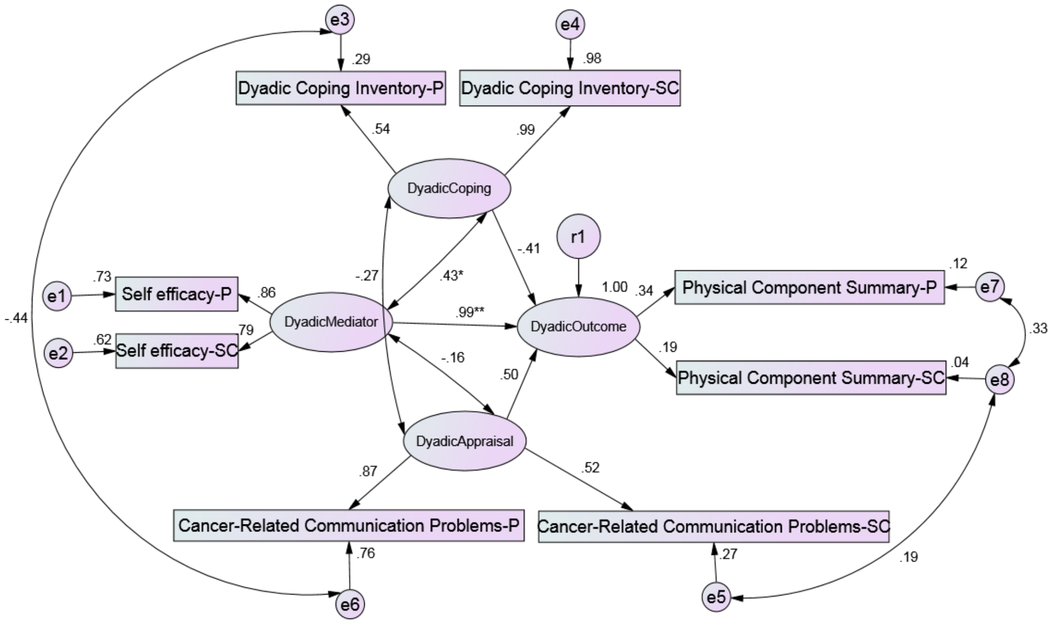
5. Sub-model 5, RDAS



***P<0.01*

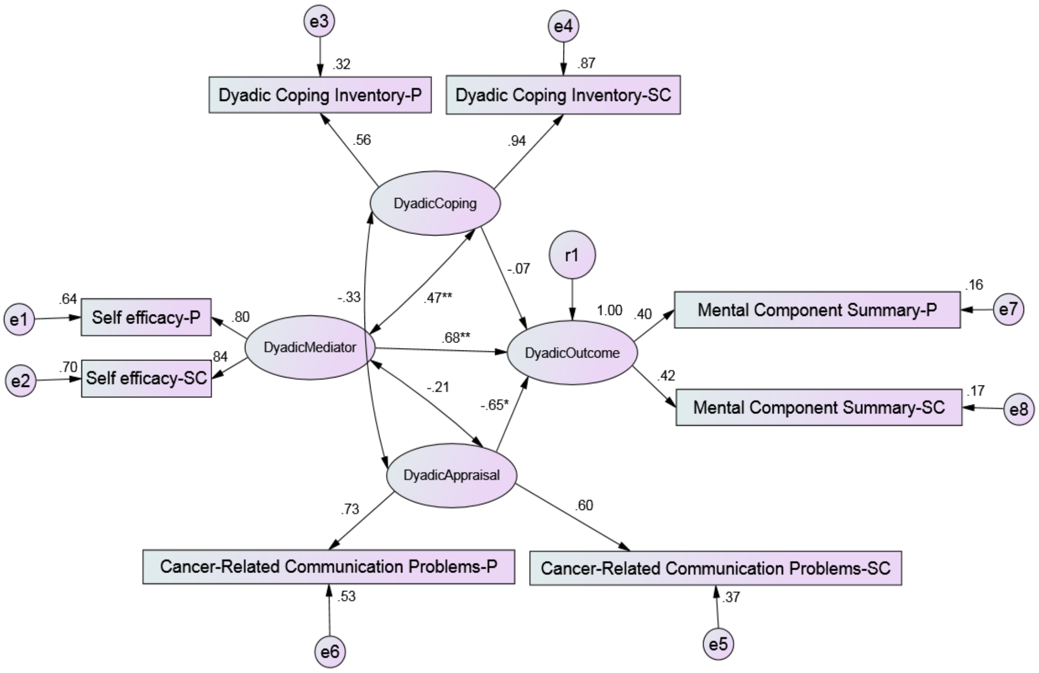
Figure 10-4. Five sub-models (sub-model 6-10) in testing the assumption that Dyadic Mediators, Dyadic Appraisal, and Dyadic Coping are interrelated, and work together to benefit the Dyadic Outcomes

6. Sub-model 6, PCS



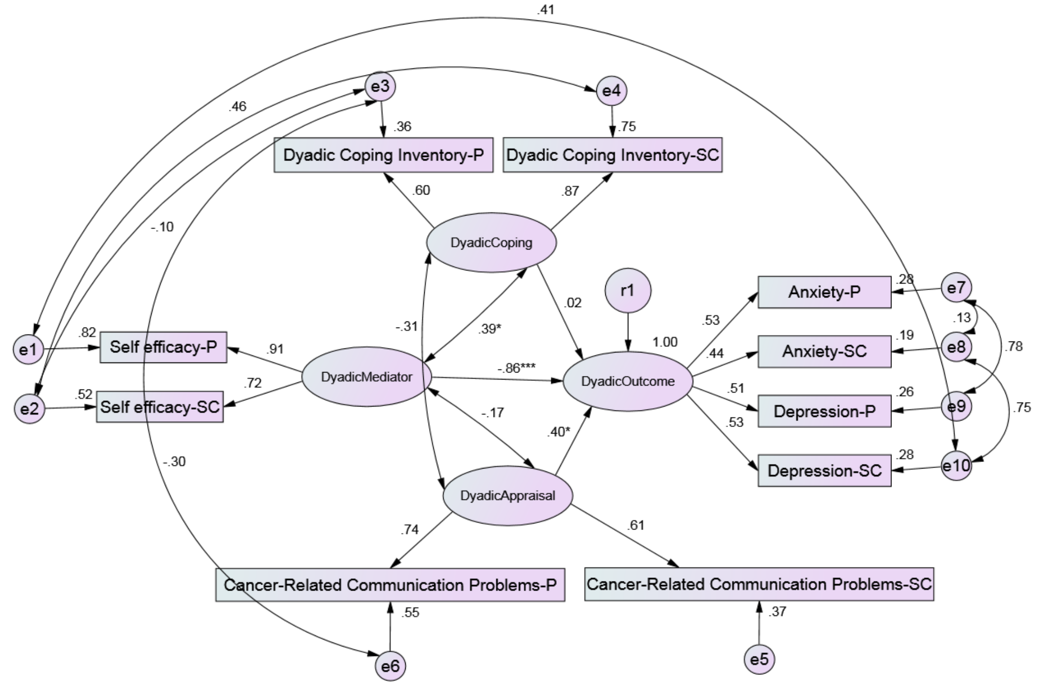
**P<0.05; **P<0.01*

7. Sub-model 7, MCS



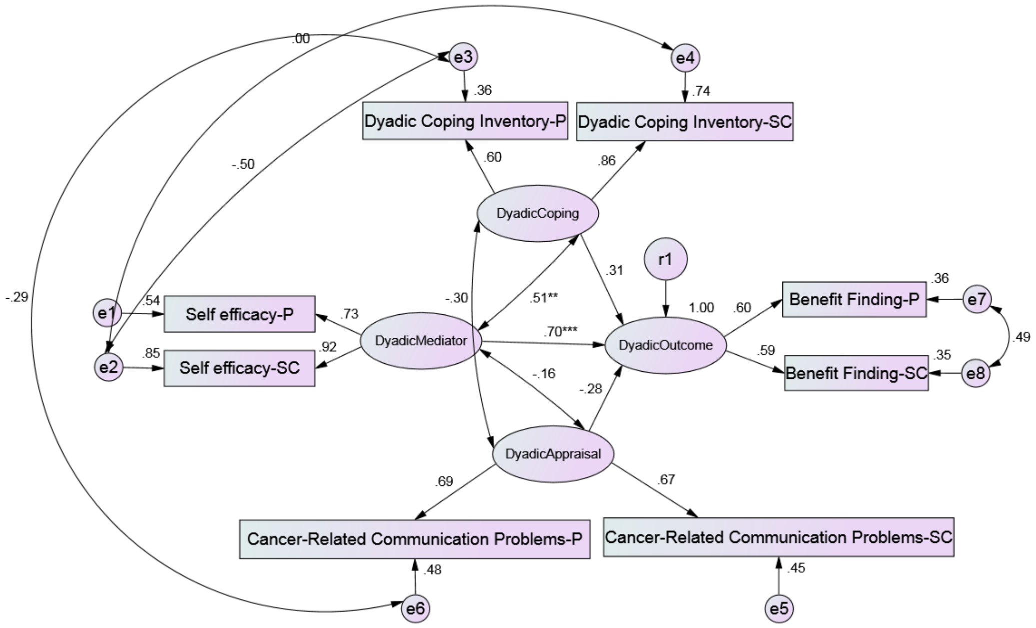
**P<0.05; **P<0.01*

8. Sub-model 8, HADS



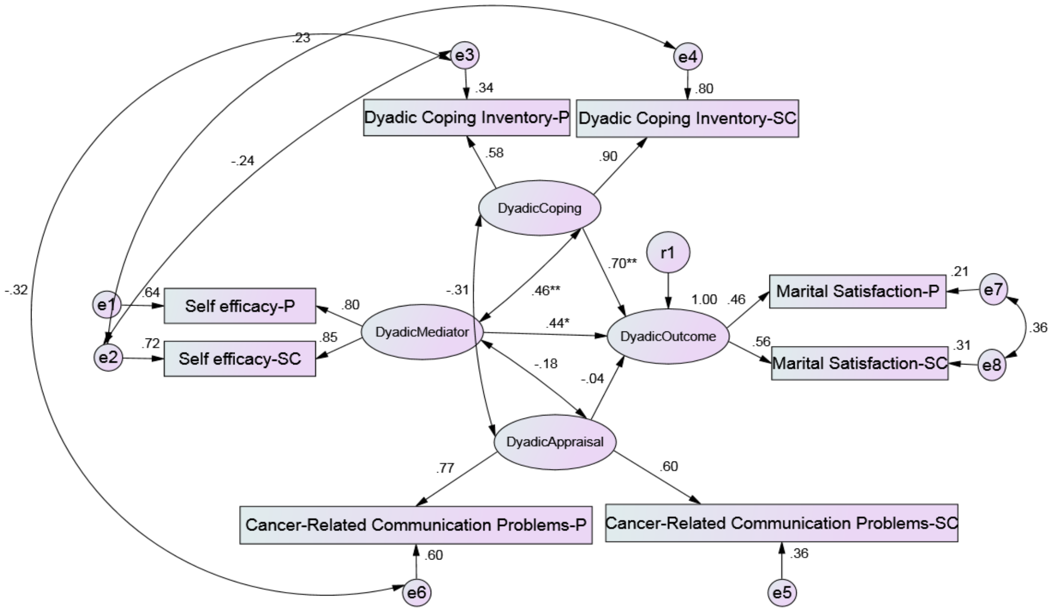
**P<0.05; ***P<0.001*

9. Sub-model 9, Benefit Finding



***P<0.01; ***P<0.001*

10. Sub-model 10, RDAS



**P<0.05; **P<0.01*

10.5 Discussion

The purpose of the present study was to empirically test the concepts, statements and theory of the Preliminary Live with Love Conceptual Framework (P-LLCF) for Cancer Couple Dyads (Li & Loke., 2015) on the basis of qualitative and quantitative studies, adopting the analysis of their findings according to Walker and Avant's (2005) approach and Structural equation modelling (SEM).

The evidence from this study supports the proposed Preliminary Live with Love Conceptual Framework (P-LLCF). It can be concluded that: (1) the P-LLCF can represent a phenomenon in reality – in the case, the experience of Chinese cancer couple dyads; the concepts identified in the P-LLCF are relevant to the related phenomenon; and attributes of the concepts are consistent with those identified in the focus group interview study of Chinese cancer couple dyads; (2) inter-relationships exist among the variables included in the P-LLCF; (3) the Event Situation has a direct or indirect impact on caregiver-patient Dyad Outcomes through Dyadic Mediators; the Dyadic Mediators, Dyadic Appraisal, and Dyadic Coping are interrelated and work together to benefit the Dyadic Outcomes.

The P-LLCF is supported by the result of the testing of the concepts by re-analyzing a conceptual framework that was developed on the basis of a focus group interview among Chinese couples, and testing of the P-LLCF's statements and theory based on a quantitative cross-sectional analysis. Although the conceptual framework was derived from international study, it is not out of expectation that the experience and concerns among spousal caregivers for patient with serious illness are universal.

A brief and integrative summary of the main findings

Study aim 1: testing concepts

The findings of the first step in analyzing the consistency and agreement of the P-LLCF with the P-COE support the study aim 1 in that the P-COE of the focus group study serves the purpose of providing scrutiny of the P-LLCF. It is confirmed that the focus group study shared similar concepts and components as the P-LLCF and supported the latter’s structures. Further analysis of the concepts and theories of the P-LLCF and P-COE (Table 10-3) helps to draw the conclusion on the three questions for concepts testing (Walker and Avant, 2005). To summarize, the study aim 1 is supported by the findings of the concepts and theory analysis of the two frameworks: the P-LLCF and a Preliminary Conceptualization of the Overall Experiences (P-COE) of couples living and coping with cancer (Li et al., 2014). The evidence from the focus group study on cancer couple dyads supports the representation, relevance, and attributes of the concepts in the P-LLCF.

Study aim 2: testing statements

The results of the descriptive-correlational analysis show the inter-relationship among the variables included in P-LLCF, and partly support the empirical validity of the statements in the P-LLCF. Statistically significant correlations were identified not only among variables within patients or spousal caregivers, but also between patients and spousal caregivers. This is consistent with findings from a review of the literature on how spousal caregiver-cancer patient dyads cope and adjust with cancer, with reciprocal influences and congruence found between the spousal caregiver-patient dyads (Li & Loke., 2014a). The review also reported that a satisfying pattern of communication between couples was related to lower levels of distress and better marital adjustment.

Study aim 3: testing theory

The main focuses of the two SEM theoretical models were the middle part on the relationship of the latent variables. In SEM theoretical model 1 (figure 10-1), it shows that the directional effect of event situation on dyadic outcomes takes two forms in the model: (1) event situation has a direct effect on dyadic outcomes as indicated by the horizontal path along the bottom of middle part in the diagram; and (2) event situation has an indirect effect on dyadic outcomes through dyadic mediator. That is dyadic mediator serves as an intervening variable, or mediator, through which the effect of event situation on dyadic outcomes is transmitted. Thus, the findings from this SEM estimation support the study aim 3 in that the Event Situation has a direct or indirect impact on caregiver-patient Dyad Outcomes through Dyadic Mediators.

In SEM theoretical model 2 (figure 10-2), the three latent variables, including dyadic mediator, dyadic coping, and dyadic appraisal, are connected by two-directional arrows, which indicates that the three variables inter-related each other, or work together. The directional arrows between dyadic mediator and dyadic outcome, dyadic coping and dyadic outcome, dyadic appraisal and dyadic outcome indicate that there are direct effects among these variables. Consequently, although complicated relationships exist among these variables, such as Dyadic Mediators, Dyadic Appraisal, Dyadic Coping, and Dyadic Outcomes, the findings from the

SEM partly supported the study aim 3 in that Dyadic Mediators, Dyadic Appraisal, and Dyadic Coping are interrelated and work together to benefit Dyadic Outcomes. Nevertheless, the relationships between these domains and variables deserve further exploration.

Limitations and Future Research Directions

Although the findings of this mixed-methods study provide evidence supporting the P-LLCF, the inclusion of Chinese participants of this study may limit the generalizability of the results to populations with different cultural backgrounds. Further studies should be conducted to validate the P-LLCF in the context of different cultures, to enhance the generalizability of the P-LLCF.

The minimum number of subjects was recruited for this study. The relatively small sample size did not allow the variables to be fully examined. It is suggested that the "results from SEM analyses based on the smaller samples typical of research in social and personality psychology must be interpreted with caution, including acknowledgment that the findings are only suggestive until replicated using data from suitably large samples" (Hoyle., 2011) (p. 72). Future studies and tests involving several institutions and larger sample sizes are highly recommended.

The conventional sampling approach in this study in identifying couples who attended the oncology clinic together, may lead to potential bias recruiting those couples who had a better relationship to begin with and were willing to be interviewed. This is an aspect of limitation on subject recruitment inherent in studies on married couples (Schildmann & Higginson, 2011), in that couples who were not in good term would not have agreed to take part in intervention study to support their spouse. Hence one must be caution in interpreting the results of this study.

The choice of the measurements for the domains also deserves mention. The domains in the P-LLCF (Event Situation, Dyadic Mediators, and Caregiver-patient Dyads) and the constructs (primary and secondary stressors, Dyadic Appraisal, Dyadic Coping, and Dyadic Adjustment/Outcomes) cannot be evaluated directly as latent variables. These domains and constructs were evaluated indirectly using observable/measurable variables. One should note that different choices of measurements for the same latent variables may affect the outcomes. Further studies are needed to examine the best measurements for these latent variables that have been included in the P-LLCF.

This was a cross-sectional study design in that the findings cannot infer causation among variables. Longitudinal research, particularly on couple-based intervention programs developed based on the P-LLCF, is highly recommended to further test this framework, and may provide richer and causal inferences to the variables.

10.6 Implications for Practice

Despite the limitations of this study, the findings of this study point to several potential implications for practice. First, the analysis of the P-LLCF and P-POE on Chinese couples coping and living with cancer has cultural implications, and this is a factor that deserves to be considered when applying the P-LLCF to populations from other cultures.

Second, the theory analyses of the two frameworks indicate that couples have various demands of other parties and receive support from them, including their extended family, as comrades in arms against cancer, healthcare professionals, and the government. Healthcare professionals caring for patients with cancer should keep in mind that couples should be treated as “people” – that is, they should be provided with information on the disease and its treatments, and supported as a “holistic as individuals” and as couples. The focus should not only be on the disease.

10.7 Conclusion

This study empirically tested a proposed Preliminary Live with Love Conceptual Framework (P-LLCF) for Cancer Couple Dyads (Li & Loke., 2015) using both qualitative and quantitative approaches. The findings and analyses of the study provide some evidence in support of the three aims from the testing of concepts, statements, and theories. The findings of this study are important for nursing practice in that they not only provide evidence supporting the P-LLCF, but also offer healthcare professionals strategic implications for the adoption of the P-LLCF in practice.

Chapter 11

STUDY IV MODELLING THE PROCESS AND OUTCOMES

The development of a complex intervention: 'Caring for Couples Coping with Cancer "4Cs" Programme'$^{\Delta}$

$^{\Delta}$ The content of this Chapter was submitted:

Li, Q., Xu, Y., Zhou, H., & Loke, A. Y. (2014). The development of a complex intervention program to support couples coping with cancer. *cancer nursing* (Submitted on May 13, 2015).

11.1 Introduction

With advanced cancer treatments, a large proportion (68%) of individuals diagnosed with cancer can expect to live for five years after the diagnosis (Jemal et al., 2011). The burden of care usually falls on family caregivers, particularly on the spouse (Cain, MacLean, & Sellick, 2004; Glajchen, 2004; Pitceathly & Maguire, 2003). Given that spousal caregivers are most likely to be the primary caregivers, who are willing to make sacrifices in caring for their partner, they may be especially vulnerable (Montgomery & Kosloski, 1994).

The spousal caregivers of cancer patients are at a high risk of developing hidden morbidities according to the World Health Organisation's definition of the psychological, physical, and social dimensions of health (Larson, 1999). A review has shown that spousal caregivers of patients with cancer suffer from a wide spectrum of hidden morbidities, including mental morbidity (distress, depression, and anxiety), physical morbidity (low levels of physical health, physical functioning, and physical strength), and social morbidity (lower levels of marital satisfaction and social support) (Li & Loke, 2013a). However, spousal caregivers receive little support to perform their vital role of caring for their partner with cancer (Given, Given, & Kozachik, 2001).

The experience of spousal caregivers, however, is complex and relationships are dynamic (Blum & Sherman, 2010). The diagnosis and treatment of cancer may pose a strain on the relational dynamics of cancer couples. It can have an impact on the subjective well-being and ability to cope of both the patient and his/her spouse

(Dankoski & Pais, 2007). The findings from a review of how spousal caregiver-cancer patient dyads are coping and adjusting revealed that the process of coping with cancer affected both parties, with reciprocal influences and congruence between the spousal caregiver-patient dyads. It also showed that a satisfying pattern of communication between couples was related to lower levels of distress and better marital adjustment (Li & Loke, 2014a).

Taking into account the hidden morbidities and relational dynamics of cancer couples, it is concluded that the factors that have an impact on couples coping with cancer are complex and multi-faceted, and that there is a need for a complex intervention to support cancer dyads.

A complex intervention is an intervention that consists of various components that act independently or inter-dependently (Campbell et al., 2000; Craig et al., 2008), and whose function and process are standardised (Hawe, Shiell, & Riley, 2004). It is considered beneficial and, indeed, crucial to include both qualitative and quantitative studies in the lengthy process of developing, piloting, evaluating, reporting, and implementing a complex intervention (Craig et al., 2008).

11.2 Objective

The aim of this study is to develop an acceptable, feasible, and potentially effective intervention program to support couples coping with cancer as the unit of intervention in China.

11.3 Method

This is a narrative report to describe in detail a methodology process through which a complex intervention to support couples coping with cancer as the unit in China was developed, and to provide a detail description of the components of this complex intervention.

The Medical Research Council's framework (MRC) on developing and evaluating complex interventions was adopted in developing this 'Caring for Couples Coping with Cancer "**4Cs**" programme' (Craig et al., 2008; Medical Research Council, 2000, 2008). There are four phases in the process of developing-evaluating-implementing a complex intervention: development, determination of feasibility/piloting, evaluation, and implementation. Details on MRC framework have been described in Chapter 1. This Chapter focuses on the first phase in the development of a 'Caring for Couples Coping with Cancer "**4Cs**" programme', particularly the third step in of modelling an intervention according to the guidelines of the MRC framework.

11.4 The methodology process of developing a complex intervention

This section presents steps in the development of a complex intervention according to the MRC framework, namely: (1) identifying evidence: evidence identified from reviews of the literature (see **Chapter 2-7**) and a focus group interview study (**Chapter 8**); (2) identifying or developing a theory: a preliminary Live with Love Conceptual Framework (P-LLCF) was developed (**Chapter 9**) and tested (**Chapter 10**); and (3) modelling the process and outcomes of the **4Cs** programme.

11.4.1The identified evidence

The first step in developing an intervention in accordance with the MRC (2008) was to identify the existing evidence through extensive reviews of the literature and by conducting a focus group study.

Reviews of the literature

In attempt to identify existing evidence of relevance to the subject of spousal caregivers of cancer patients in mainland China, a review of the literature on related studies in China was attempted. Studies focusing on the psychological status, quality of life, caregiving burden, and social support of family caregivers were identified, but only a few intervention studies focusing specifically on spousal caregivers were found. The conclusion is that, although family caregivers of cancer patients in China have received attention from clinicians and researchers, studies on the subject are still in the stage of infancy (Li & Loke, 2012).

For a better understanding of the phenomenon of spousal caregiving, a series of extensive reviews of the literature related to spousal caregivers of cancer patients was then conducted. These reviews of the literature covered the following aspects: (1) the stress experienced by spouses in caring for cancer patients (Li, Mak, & Loke, 2013); (2) the spectrum of hidden morbidities among spousal caregivers of cancer patients (Li & Loke, 2013a); (3) the positive aspects of spousal caregiving for cancer patients (Li & Loke, 2013b); (4) the mutuality of the impact between spousal caregiver-cancer patient dyads (Li & Loke, 2014a); and (5) couple-based interventions for couples coping with cancer (Li & Loke, 2014b). The results of these extensive reviews of the literature contribute to a strong evidence base of studies related to spousal caregiving for patients with cancer. These series of reviews of the relevant literature have implications for the development of couple-based interventions.

Although there have been quite a few studies on the spousal caregivers of cancer patients, these studies have the following limitations:

- Most of these studies focused on the negative experience of caregiving, with only a few focusing on the positive experience of spouses caring for a partner with cancer (Li & Loke, 2013a; 2013b; Li et al., 2013).
- The focus of cancer research has shifted from the experience of the individual to that of the caregiver-patient dyad, raising the need to place the emphasis of care on couples as dyads, and to develop a dyadic model specifically for cancer caregiving (Li & Loke, 2014a; 2014b; 2015).
- Most relevant studies adopted a study design that is quantitative in nature, and lack the kind of in-depth understanding of the couples that comes from a qualitative study or a mixed-methods study (Li & Loke, 2013; 2014a; 2014b; 2015; Li et al., 2013).
- Although the primary caregiver of patients with cancer is the spouse, few intervention programmes focused specifically on supporting spousal caregivers in their caregiving activities, or on the couples as caregiver-patient dyads (Li & Loke, 2014a).

- Most of the intervention studies were conducted in Western countries. None conducted in China focusing on supporting the spousal caregivers of patients with cancer were found (Li & Loke, 2014b; Li & Loke, 2012).

Recommendations for a cancer couple-based intervention programme

A review of intervention studies highlighted the positive outcomes of interventions that focus on couples coping with cancer as dyads (Li & Loke, 2014b). Recommendations for healthcare professionals who seek to support couples coping with cancer as the unit of intervention are given below.

- Target population: Active spousal caregivers and cancer patient dyads. Interventions should be provided to the couple as a unit.
- Theoretical framework of interventions: None, but there should be a comprehensive dyadic theoretical framework on couples coping with cancer to guide the development of an intervention and outcome measures (Li & Loke, 2015).
- Approaches and contents of interventions: Interventions should consist of both skills training and psycho-educational support; including skills training for patient care, coping, caregiver self-care, and marital/family support.
- Dosage of interventions and follow-up: Six weekly sessions of 90 minutes each is considered a reasonable intervention dosage; follow-up sessions for at least 3 months are recommended.
- Programme flexibility: Programme rigidity was identified as a barrier to participating in interventions and as contributing to attrition. This points to

the need for greater flexibility in the contents and mode of delivery of interventions for couples coping with cancer.

- Delivery of interventions: Interventions should be delivered by trained professionals in a face-to-face mode of group intervention. These professionals may include nurses/counsellors, psychiatrists, psychologists, and social workers.
- Outcomes of interventions: The outcomes of interventions should include appraisals of the illnesses, strategies for coping, and health outcomes of the partners, including their mental, physical, and marital satisfaction.

These reviews provided a foundation for evidence on the subject of couples coping with cancer, identified gaps in the studies, and provided valuable suggestions on interventions that could be developed focusing on couples coping with cancer. Few couple-based interventions were found that focused specifically on supporting those caring for a spouse with cancer. None of the interventions included in the reviews of the literature evaluated the outcomes of an intervention from the perspective of couples, in terms of their appraisal of the situation, coping strategies, and various health outcome measures, such as QOL and marital satisfaction.

A primary research study—the Experiences of Chinese Couples Living with Cancer

Focus group interviews were conducted among cancer couple dyads (Li et al., 2014) to gain a better understanding of the experience of Chinese couples coping with cancer, and to explore their experience, concerns, and needs.

Based on the themes and sub-themes identified using a conventional content analysis of focus group interviews with cancer couple dyads in China (Li et al., 2014), a preliminary conceptualisation of the couples’ overall experience of living and coping with cancer was drawn up (Figure 8-1, p.147). As shown in Figure 8-1 (p.147), the dyadic relationship of cancer dyads is conceptualised as an interaction involving communication dynamics, living with changes, and experiencing the negative and positive impacts of coping with cancer. By improving communication and support networks, couples with cancer as dyads will be able to better cope with cancer. The internal interactions of the dyads and their external relationships with peers, relatives, and professional caregivers are represented by a complex pattern of connected themes.

The findings of this primary focus group study not only contribute to the evidence base from the perspective of cancer couples, but also provide us with the information needed to choose the constructs to be included in the following step on the development of the conceptual framework.

11.4.2 The proposed theory

According to the MRC (2008), the second step in developing an intervention involves identifying or developing a conceptual framework. It is in this step that a preliminary Live with Love Conceptual Framework (P-LLCF) was proposed (Li & Loke, 2015) for cancer couple dyads.

The preliminary Live with Love Conceptual Framework (P-LLCF)

A dyadic model that addresses multiple dimensions of the concerns and needs of spousal caregiver-patient dyads is needed to guide the development of an intervention for couples coping with cancer. In accordance with the procedure for constructing theories, the process of analysing theoretical concepts (Risjord, 2009; Walker & Avant, 2005) was applied by scrutinising the concepts and components of the conceptual frameworks in the literature that had been included in the reviews on spousal caregiving for patients with cancer. Each concept and component was scrutinised for its definition, attributes, antecedents, and consequences, and their consistency in the context of cancer couple dyads was examined. A matrix table was created to delineate the relationship between these key concepts and components in formulating the preliminary Live with Love Conceptual Framework (P-LLCF) for Cancer Couple Dyads (Li & Loke, 2015).

The proposed P-LLCF consists of three domains: Event Situation, Dyadic Mediators, and Caregiver-patient Dyads (Figure 9-4, p.174). As shown in Figure 9-4 (p.174), Event Situation, at the bottom of the conceptual framework, refers to the context and related stressors experienced by cancer couple dyads. The Dyadic Mediators act as 'leverage' to balance or off-set the stressors leading to the Dyadic appraisal, Coping, and Adjustment of the cancer couple dyads at the top of the conceptual framework.

Positive dyadic adjustment/outcomes are the ultimate goal and the central focus of the cancer couple dyads framework. The two constructs of Dyadic Appraisal and Dyadic Coping at each side of the Dyads Adjustment/Outcomes construct are to be weighted to maintain a balance in the caregiving experience of the dyads, as shown in Figure 9-4 (p.174). The resulting preliminary framework for cancer couple dyads resembles the Chinese character ‘吉’, meaning ‘fortune’. The intervention programme guided by this framework can lead to positive outcomes in the caregiving experience of the caregiver-patient dyads, with improvements in dyadic appraisal and dyadic coping, and in health, caregivers’ involvement and continuity, positive emotions, and couple relationship and marital satisfaction throughout the cancer trajectory, helping the couples to ‘Live with Love’.

11.4.3 The developed ‘Caring for Couples Coping with cancer “(4Cs)” Programme’

In the third step of the MRC framework for developing a complex intervention, a ‘Caring for Couples Coping with Cancer “4Cs” Program’ and education booklet were developed according to the P-LLCF proposed in step 2. A review of the literature on couple-based intervention studies for couples coping with cancer was also conducted to direct the development of the intervention (Li & Loke, 2014b). Table 11-1 outlines the three steps in developing an intervention according to the MRC framework, and corresponding elements in developing the **4Cs** program.

Table 11-1 The three steps to developing a complex intervention according to the MRC and the steps to developing the 4Cs Programme

Steps in the MRC framework for developing a complex intervention	**Steps taken to develop the 4Cs Programme**
Identifying the evidence base	✓ Conducting a series of extensive reviews of studies related to the spousal caregivers of cancer patients ✓ Primary research: Conducting a focus group study: the Experiences of Chinese Couples Living with Cancer
Identifying/developing a theory	✓ Proposing a preliminary Live with Love Conceptual Framework (P-LLCF) for cancer couple dyads
Modelling process and outcomes	✓ Developing and presenting the related contents of the 4Cs programme.

11.5 The components of this 4Cs program

The related contents of the 4Cs programme are presented below according to the CONSORT 2010 checklist (Schulz, Altman, Moher, & CONSORT Group, 2010) where applicable. They include information on the trial design, participants, interventions, outcomes, and sample size.

11.5.1 Trial design

A mixed-methods study that includes qualitative and quantitative approaches is planned. Before undertaking a full-scale randomised controlled trial (RCT) intervention study to deliver and evaluate the **4Cs** programme, a pre-post pilot trial has been conducted in the second phase of the MRC framework to test the feasibility of the **4Cs** programme, which aims to provide support to couples coping with cancer.

11.5.2 Participants

The target population of the complex intervention will be married couples in which one of the partners has been diagnosed with cancer and the spouse is the primary caregiver. The criteria for inclusion in the study are: (1) Chinese married couples (aged 18 years and older); (2) who live in Wuxi city; (3) one of the pair of whom has been diagnosed with cancer and who has a life expectancy of at least six months; (4) where the spouse is the primary caregiver for the partner with cancer; (5) and both of whom have agreed to take part in the study. The spousal caregiver is defined and identified by the cancer patient as his or her married partner and primary source of physical and emotional support since the diagnosis of cancer. Cancer couples will be excluded if the spousal caregiver is unable to care for himself/herself due to chronic illness, or suffers from a serious physical or mental illness, including cancer.

11.5.3 Study Settings

This study will be conducted in an oncology hospital in Wuxi city, Jiangsu, China. The oncologists in the hospital will be responsible for screening couples in accordance with the inclusion criteria. Couples who meet the eligibility criteria will be approached in oncology wards, and will be given an explanation of the intervention programme and the purpose of the research. Only those couples who sign a consent form indicating their willingness to participate in the study will be included.

11.5.4 Interventions

Essential components

The Essential components and focus of the '**4Cs**' intervention programme have been developed based mainly on the P-LLCF for Cancer Couple dyads (Figure 11-1). It takes into account the three domains of the P-LLCF: Event Situation, Dyadic Mediators, and Caregiver-patient Dyads. This programme consists of six weekly sessions, with each session lasting for 90 minutes. The main contents of the sessions of the **4Cs** programme are: primary stressors (section 1); secondary stressors (section 2); dyadic mediator (section 3); dyadic appraisal (section 4); dyadic coping (section 5); and a programme overview (section 6). The session titles, aims/contents, and approaches adopted are listed in Table 11-2.

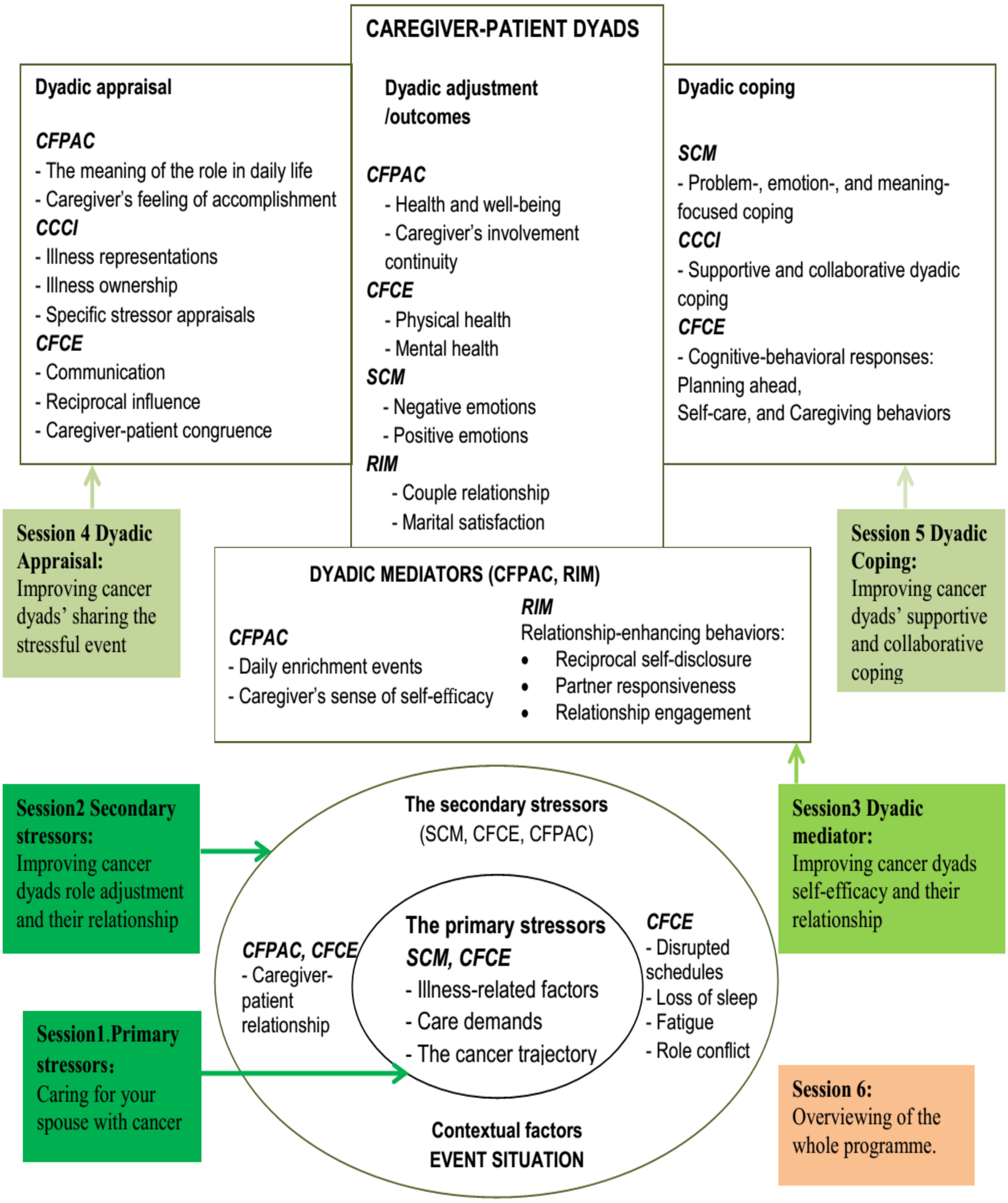


Figure 11-1. The essential components and focus of the '**4Cs**' programme developed based on a preliminary Live with Love Conceptual Framework (P-LLCF) for Cancer Couple Dyads

Legends:
CCCI: Couples Coping with Chronic Illness
CFPAC: Conceptual Framework of the Positive Aspects of Caregiving
CFCE: Cancer family caregiving experience
RIM: Relationship Intimacy Model
SCM: Stress and Coping Model
4Cs: Caring for Couples Coping with Cancer

Table 11-2 Title, aims/contents, and approaches of the programme sessions

Session number, main focus, and title	**Aims/contents**	**Approaches**		
		PE	**ST**	**CBT**
1. **Primary stressors;** Caring for your spouse with cancer	- To present key strategies relating to *illness-related factors* and *care demand*;	√	√	
	- To help cancer dyads to gain more confidence in responding to the physical and psychosocial issues of both patients' and caregivers;	√	√	√
	- To outline the services available from the cancer caring team and other support services.	√		
2. **Secondary stressors;** Improving the role adjustment of cancer dyads and their relationship	- To facilitate the role conflict and adjustment of cancer dyads by providing them with verbal and written information about typical aspects and common issues associated with their *roles* as an individual cancer patient and / or a spousal caregiver, and as a dyad within the relationship;	√	√	
	- To support cancer dyads by focusing specific attention on their needs, including having enjoyable experiences, getting enough sleep, following a healthy diet, getting enough exercise, and having a good relationship;	√	√	
	- To reinforce the role of the cancer care service.	√		
3. **Dyadic mediator;** Improving the self-efficacy of cancer dyads and their relationship	- To help cancer dyads to appreciate the daily enrichment events;	√	√	√
	- To elevate the dyads' sense of self-efficacy;	√	√	√
	- To encourage the cancer dyads to practise relationship-enhancing behaviours, including self-disclosure and being responsive to one's partner;	√	√	√
	- To improve cancer-related communication between couples by educating them to take the view of 'hoping for the best, preparing for the worst'.	√	√	

4. **Dyadic appraisal;** Improving the sharing by cancer dyads of stressful events	- To help cancer dyads to acknowledge the meaning of their role in daily life and to give caregivers a feeling of accomplishment;	√		√
	- To facilitate the sharing by dyads of stressful events by helping them to appraise presentations of the illness, the ownership of the illness, and specific stressors;	√	√	√
	- To help the dyads to understand strategies for maintaining a good relationship: ‘communication’, ‘reciprocal influence’, ‘caregiver-patient congruence’.	√	√	
5. **Dyadic coping;** Improving supportive and collaborative coping by cancer dyads	- To improve supportive and collaborative coping of cancer dyads by facilitating meaning-focused coping strategies for benefit finding, benefit reminding, adaptive goal processes, reordering priorities, and infusing ordinary events with positive meaning;	√	√	√
	- To promote self-care on the part of spousal caregivers by encouraging them to plan ahead and enhance their physical and mental health by promoting regular ‘time outs’, enjoyable experiences, enough sleep, a healthy diet, exercise, and advice on relaxation strategies.	√	√	√
6. Overview of the whole programme.	- To help cancer dyads to review the main contents of the programme and to address any problems that they might have.	√	√	√

PE, Psycho-educational, SK, Skills training, CBT, Cognitive-behavioural therapy

Intervention approaches

The approaches that will be adopted in this couple-based intervention programme are Psycho-education (PE), Skills Training (ST), and Cognitive Behavioural Therapy (CBT). Psycho-education (PE) is a professionally delivered treatment modality that integrates and synergises psychotherapeutic and educational interventions (Lukens & McFarlane, 2004). The care recipients, including both the patient and spousal caregiver, are considered partners with the healthcare provider in the intervention relationship. The psycho-education is based on the premise that the more knowledgeable the care recipients are about the related event, the more positive the health-related outcomes will be for care recipients (Lukens & McFarlane, 2004). In this programme, psycho-education is defined as protocols whose primary focus is to provide information on primary and secondary stressors, including illness-related factors (such as symptom management); care demands (such as physical aspects of patient care); the role conflicts of patients or caregivers; as well as the caregiver-patient relationship.

Skills training (ST) is defined as 'the teaching of specific verbal and nonverbal behaviors and the practicing of these behaviors by the patient' (Medical Dictionary, 2013). In this programme, skills training is defined as protocols that focus primarily on the development of problem-, emotion- and meaning-focused coping skills, the self-care behaviours of the caregivers, and the relationship-enhancing strategies of the cancer dyads.

Cognitive Behavioural Therapy (CBT) is a psychotherapeutic approach that helps patients (cancer dyads) understand the thoughts and feelings that influence behaviours. CBT is commonly used to treat a wide range of disorders, including depression and anxiety (Cherry, 2013). CBT is based on the idea that a person's thoughts and feelings play a fundamental role in his/her behaviour. The goal of CBT is to teach patients (cancer dyads) that while they cannot control every aspect of the world around them, they can take control of how they interpret and deal with things in their environment (Cherry, 2013).

In this study, the therapist will actively stimulate perspective taking, cognitive restructuring, and behavioural exercises. The therapist and one of the researchers of this study is a medical doctor who treats cancer patients and is also qualified as a psycho-counsellor in mainland China.

Delivery of intervention

This programme consists of six weekly sessions, each of 90 minutes in duration. The face-to-face group intervention will be delivered by the researcher/therapist and by nurses who have been provided with extensive training on the intervention programme. The education sessions will be semi-structured, with a mix of didactic instruction (used sparingly) and group sharing and interactions. Sufficient time for questioning, commenting, clarification, and dialogue will be an essential feature of each session. It is anticipated that four to six cancer dyads will be included in each programme.

Education Booklet

A guidebook for the spousal caregivers titled '**Live with Love: Hope for the best, prepare for the worst**' has been developed based on the reviews of the literature, and the preliminary conceptual framework will be used to complement the group intervention programme. The guidebook will provide spousal caregivers with easy access to written information on common concerns about caring for a partner with cancer. The main contents of the booklet are shown in Table 11-3.

Table 11-3 Contents of the booklet: Live with Love: Hope for the best, prepare for the worst

Title	**Contents**
Primary stressors ❖ Taking care of your spouse with cancer	✓ Helping with medications ✓ Providing hygiene care ✓ Assisting with eating and drinking ✓ Help with other 'technical' care ✓ Use of special equipment ✓ Dealing with common symptoms - Pain (including concern about opioids and hastening death); Nausea; Constipation; Breathlessness; Fatigue; Delirium ✓ Emotional care ✓ Spiritual care at the end of life ✓ How much should patients be told about their illness? ✓ Available cancer care resources
Secondary stressors ❖ Being a caregiver—what is it about?	✓ The Role of the Caregiver ✓ Helping to Manage Your Loved One's Treatment ✓ Helping Your Loved One With Practical Matters ✓ Providing Emotional Support ✓ Caregiving Under Difficult Circumstances ✓ Taking Care of Yourself - Staying Healthy - Getting Emotional Support - Getting Help With Caregiving Responsibilities - Maintaining hope when the situation

	seems hopeless - Feeling overwhelmed? It's time to relax! - Taking a break
Dyadic mediator ❖ Caring for your relationships	✓ Sense of self-efficacy ✓ Reciprocal self-disclosure ✓ Partner responsiveness ✓ Relationship engagement ✓ Family meetings ✓ Your relationship with the person you are caring for ✓ Involving children ✓ Your relationship with family and friends
Dyadic appraisal ❖ Sharing the stressful event	✓ The meaning of their role in daily life ✓ Caregivers' feeling of accomplishment; ✓ The illness representations ✓ Illness ownership ✓ Specific stressors ✓ Communication ✓ Reciprocal influence ✓ Caregiver-patient congruence
Dyadic coping ❖ Improving supportive and collaborative coping	✓ Problem-, emotion and meaning-focused coping - Benefit finding - Benefit reminding - Adaptive goal processes, - Reordering priorities - Infusing ordinary events with positive meaning ✓ Cognitive-behavioural responses - Planning ahead - Self-care - Caregiving behaviours

Quality assurance

Strategies will be implemented to ensure that the protocols of the intervention are adhered to, and the intervention will be provided in a uniform manner to ensure treatment fidelity. These strategies will include training nurses in the intervention and protocol; writing a detailed outline of the intervention; audio-taping randomly selected sessions for quality checks; and holding a monthly discussion meeting among the members of the research group.

Outcomes measures

The section on outcome measures will be completed separately by the spousal caregivers and the cancer patients. Nurses in the oncology unit will assist those who require help completing the questionnaire. Information on the demographics and characteristics of both the patients and their spousal caregivers will be collected at baseline.

The outcome measures have been selected based on the constructs of the ‘caregiver-patient dyads’ of the P-LLCF, and are intended to be measured at baseline (T0) and after the completion of the ‘4Cs’ programme (T1) for the following pilot study in this project. These outcome measures include the following items: couples’ self-efficacy, dyadic coping strategies, communication, physical and mental health, depression, benefit finding, and marital satisfaction. The correlation of the outcome variables with components included in the P-LLCF is summarised in Table 11-4. Please refer to the Chapter 10 for details on these instruments.

Table 11-4 Correlating the outcome measures of the 4Cs programme with components in the P-LLCF*

Outcome variables	**Instruments & source**	**Correlation with components in the P-LLCF**
Self-Efficacy	The 12-item Cancer Behaviour Inventory (CBI-B) (Heitzmann et al., 2011)	- Dyadic mediators: caregivers sense of self-efficacy (CFPAC)* (Carbonneau et al., 2010) - Dyadic outcomes: caregivers' involvement continuity (CFPAC)* (Carbonneau et al., 2010)
Communication	The 15-item Cancer-Related Communication Problems within Couples Scale (CRCP) (Kornblith et al., 2006)	- Dyadic appraisal: communication, reciprocal influence, and caregiver-patient congruence (CFCE) * - Dyadic outcomes: couple relationship (RIM)* (Manne & Badr, 2008)
Dyadic coping strategies	The 37-item Dyadic Coping Inventory (DCI) (Bodenmann, 2008; Gmelch et al., 2008)	Dyadic coping - Problem-, emotion-, and meaning-focused coping (SCM)* (Folkman, 1997) - Supportive and collaborative dyadic coping (CCCI)* (Berg & Upchurch, 2007).
Physical and mental health	The Medical Outcomes Study 12-item short form (MOS SF-12) (version 2) (Ware, Kosinski, & Keller, 1996)	Dyadic outcome: physical and mental health (CFCE)* (Fletcher et al., 2012)
Depression	The 14-item Hospital Anxiety and Depression Scale (HADS) (ZIGMOND & SNAITH, 1983)	Dyadic outcome: negative outcomes (SCM)* (Folkman, 1997)
Benefit-Finding	The revised 17-item Benefit-Finding Scale (BFS) (Antoni et al., 2001)	Dyadic outcome: positive outcomes (SCM)* (Folkman, 1997)

Marital Satisfaction	The 14-item Revised Dyadic Adjustment Scale (RDAS) (Busby, Crane, Larson, & Christensen, 1995; Crane, Middleton, & Bean, 2000)	Dyadic outcome: marital satisfaction (RIM)* (Manne & Badr, 2008)

* **P-LLCF**: Preliminary-live with love conceptual framework; **CFPAC**: Conceptual Framework of the Positive Aspects of Caregiving; **CFCE**: Cancer family caregiving experience; **RIM**: Relationship intimacy model; **SCM**: stress and coping model; **CCCI**: couples coping with chronic illness.

Sample Size

As no previous intervention study of cancer dyads can be identified, the sample size in this pilot study (the pre- and post-tests on the intervention group) was calculated using G-power 3.1.9.2 based on the conventional method for conducting an analysis of power (Faul, Erdfelder, Lang, & Buchner, 2007). Assuming a two-sided type I error of 5%, with 90% power, and a medium effect size (d=0.50) to detect the difference between constant outcome measures (pre test-post test), it is estimated that at least 44 couples would be required. Taking into account an estimated dropout rate of about 20%, a total of 53 cancer dyads will be recruited. The results of the pilot study, such as the effect size, will then be used to calculate the sample size for the full-scale RCT evaluation.

11.6 Discussion

Guided by the MRC framework for developing complex interventions (Craig et al., 2008; Medical Research Council, 2000, 2008), this is a report on the development of the **4Cs** intervention programme, which adopts the following three steps: identifying the evidence base, identifying/developing a theory, and modelling processes and outcomes.

According to the guidance provided by the MRC (Craig et al., 2008; Medical Research Council, 2008), “Best practice is to develop interventions systematically, using the best available evidence and appropriate theory, then to test them using a carefully phased approach…” (Craig et al., 2008) (p. 980). This is the process that was adopted in developing the **4Cs** programme. Given that this **4Cs** programme was developed based on the preliminary Live with Love Conceptual Framework (P-LLCF), and that the P-LLCF was developed according to the extensive existing evidence, including findings from reviews of the literature and interviews with cancer couples, this **4Cs** programme should be an effective, feasible, and acceptable programme.

This programme was designed to consist of six sessions, each with a different focus. According to the P-LLCF (Li & Loke, 2015), there are direct and indirect interrelationships among the three domains of Event Situation, Dyadic Mediators, and Caregiver-patient Dyads. The same relationships may exist among the three constructs of dyadic appraisal, dyadic coping, and dyadic adjustment in the domain of caregiver-patient dyads. Thus, it can be inferred that these components of the ‘**4Cs**’ programme, which were developed based on the P-LLCF, act both independently and inter-dependently. For instance, the section that focuses on primary stressors can act independently as a simple intervention to benefit couples coping with cancer, while also acting inter-dependently with other sections to support outcomes for couples. This ‘**4Cs**’ programme that was developed is considered a complex intervention, since it contains various components (Campbell et al., 2000) and these components act both independently and inter-dependently (Lewin, Glenton, & Oxman, 2009).

While qualitative study conducted alongside a quantitative study in a randomised controlled trial remains uncommon (Lewin et al., 2009), it is recognised that a mixture of methods incorporating both qualitative and quantitative approaches during the process of developing, evaluating, and implementing a complex intervention is needed. It is highly recommended that in an RCT study of the **4Cs** programme, a qualitative approach such as a focus group study should be undertaken as part of the evaluation. This qualitative study should include both couples who adhere to the intervention programme and those who drop out or do not participate in the programme, to gain a better understanding of the degree to which the programme is accepted, and the reasons for this and for the barriers to participating in the programme (Craig et al., 2008).

The **4Cs** couple-based intervention programme was developed in accordance with the P-LLCF (Li & Loke, 2015), incorporating the various domains and constructs depicted. The intervention programme is intended to facilitate positive dyadic adjustment/outcomes among cancer couples in their journey of coping. The outcome measures include the couples’ self-efficacy, dyadic coping strategies, communication, physical and mental health, depression, benefit finding, and marital satisfaction (Table 11-4). It is crucial that the intervention programme be piloted and evaluated, and the outcomes tested, before the randomised control trial of the intervention programme is implemented in clinical settings as directed by the MRC framework (Craig et al., 2008).

It is crucial that the intervention program be piloted and evaluated, and the outcomes tested, before the randomized control trial of the intervention program is implemented in clinical settings as directed by the MRC framework (Medical Research Council, 2008). It is worth noting that the phases and steps in the updated MRC framework (Medical Research Council, 2008) no longer are linear, which give better opportunities to redevelop the intervention if needed after the pilot. If necessary, redevelop or some changes may need to the program after the pilot according to the MRC framework (Medical Research Council, 2008).

Limitations

Given that this is the first development of a complex intervention for cancer couple dyads in China, the acceptability of the procedures of the programme, and the recruitment and retention of participants to achieve the proposed number of participating dyads, remain uncertain.

11.7 Recommendations for future research

Following the phase of developing a complex intervention, there remains the process of determining its feasibility/piloting, and evaluating and implementing the intervention as prescribed by the guidance given by the MRC (Craig et al., 2008). Before implementing a complex intervention, the intervention needs to be tested for feasibility/piloting, and to be evaluated. It is recommended that a pilot study be conducted of the **4Cs** intervention to evaluate the programme.

A pre-intervention and post-intervention pilot trial has been designed to test the feasibility of the **4Cs** programme, including the acceptability of the procedures, the validity, reliability and feasibility of the instruments, the recruitment and retention of participants, and identification of the appropriate sample size.

Given that this **4Cs** programme has been developed mainly based on the P-LLCF, and that the P-LLCF was proposed based on an extensive review of the literature, further testing of the P-LLCF constructs using the pilot intervention would be highly recommended. Structural equation modelling (SEM) can be applied to test the P-LLCF. The Actor Partner Interdependence Model (APIM) (Atkins, 2005) can be used to guide the SEM using Amos (21.0).

11.8 Conclusion

A potentially acceptable, feasible, and effective ‘Caring for Couples Coping with Cancer “**4Cs”** Programme’ was developed using the guidelines of the MRC framework on developing and evaluating complex interventions. This was done with supporting evidence from numerous reviews of the relevant literature, the findings of a focus group study on cancer couple dyads, and a proposed preliminary Live with Love Conceptual Framework (P-LLCF). Future research is needed to pilot and evaluate the feasibility, modelling, and outcomes of this **4Cs** programme.

Chapter 12

STUDY V DETERMINATION OF FEASIBILITY/PILOTING

A couple-based complex intervention for patients with advanced cancer and their spousal caregivers: a pilot study*

***** The content of this Chapter was published:

Li, Q., Xu, Y., Zhou, H., & Loke, A. Y. (2014). A couple-based complex intervention for Chinese spousal caregivers and their partners with advanced cancer: an intervention study. *Psycho-oncology,* Article first published online: 23 MAR 2015 DOI: 10.1002/pon.3809.

12.1 Introduction

The diagnosis of cancer and its treatment has a major impact on both patients and their family caregivers (Kayser, Watson, & Andrade, 2007), particularly the spousal caregivers (Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008). Recognition has been growing that cancer affects couples as unit, rather than as isolated individuals (Hagedoorn et al., 2008), leading to the primary focus of research on cancer care to shift from the individual experiences of patients or spousal caregivers to the dyadic level (Fletcher, Miaskowski, Given, & Schumacher, 2012). Evidence suggests that the caregiver-patient dyad as a unit should be the focus and direction of caregiving interventions for families coping with cancer (Li & Loke, 2014a).

A review of the literature has identified positive outcomes from couple-based interventions that focus on couples coping with cancer (Li & Loke, 2014b). It has been suggested that couple-based interventions studies be conducted in other societies, such as those in Asia. The experience of spousal caregivers and cancer couples, however, is complex and relationships are dynamic (Blum & Sherman, 2010). The diagnosis and treatment of cancer may pose a strain on the relational dynamics of cancer couples, which can be complex (Dankoski & Pais, 2007). Thus, there is a need for a complex intervention to support cancer dyads.

The preliminary Live with Love Conceptual Framework

According to the Medical Research Council’s (MRC) framework on developing and evaluating complex interventions (Craig et al., 2008; Medical Research Council, 2000), identifying/developing theory is one of the three essential steps in the development of a complex intervention. In view of the need for a dyadic theoretical framework to guide the development of a couple-based intervention for couples coping with cancer (Li & Loke, 2014b), a preliminary Live with Love Conceptual Framework (**P-LLCF**) for Cancer Couple Dyads was developed (Li & Loke, 2014a; Li & Loke, 2014b) (Chapter 9, Figure 9-4, p.174).

The proposed P-LLCF consists of three domains: Event Situation, Dyadic Mediators, and Caregiver-patient Dyads (Li & Loke, 2015). Event Situation, at the bottom of the conceptual framework, refers to the context and related primary and secondary stressors experienced by cancer couple dyads. The Dyadic Mediators act as “leverage” to balance or off-set the stressors to the caregiver-patient dyads at the top of the conceptual framework. The domain of Caregiver-patient Dyads consists of three constructs: Dyadic Appraisal, Dyadic Coping, and Dyadic Adjustment/Outcomes. The central focus of the P-LLCF is on the relationships among the four dyadic-level domains/constructs: Dyadic Mediators, Dyadic Appraisal, Dyadic Coping, and Dyadic Adjustment/Outcomes. The two constructs of Dyadic Appraisal and Dyadic Coping at each side of the Dyads Adjustment/Outcomes construct will be weighted to maintain a balance in the caregiving experience of the dyads. The domain of Dyadic Mediators can also interrelate with these three constructs. It is important to note that positive dyadic adjustment/outcomes are the ultimate goal and the central focus of the P-LLCF.

The purpose of this study was to examine the acceptability and feasibility of a "Caring for Couples Coping with Cancer '**4Cs**' Program" that was developed based on the P-LLCF, to support couples in China coping with cancer as dyads.

12.2 Research aims

The aims of this intervention study were three-fold: (i) to determine the acceptability and feasibility of this **4Cs** Program based on recruitment rate, retention rate, and intervention compliance; (ii) to examine the effects of the **4Cs** program on self-efficacy (dyadic mediator), coping strategies (dyadic coping), cancer-related communication problems (dyadic appraisal), physical and mental health, negative and positive emotions, and marital satisfaction (dyadic outcomes) for spousal caregivers-cancer patient dyads; and (iii) to explore whether the effects of the **4Cs** intervention provide evidence to support the constructs of the P-LLCF, in that the dyadic mediators, dyadic coping, and dyadic appraisal work together to benefit the dyadic outcomes.

12.3 Method

This is an intervention study to examine the feasibility and effectiveness of a "Caring for Couples Coping with Cancer (4Cs)" program.

Participants

The target population of this intervention was married couples in which one of the partners had been diagnosed with cancer and the spouse was the primary caregiver. Cancer couples were recruited by convenience sampling from an oncology hospital in Wuxi City, China. The intervention study was conducted from November 2013 to October 2014.

The criteria for inclusion in the study were as follows: (i) Chinese adult married couples (age >18 years old); (ii) a medical diagnosis of any type of cancer in one partner; (iii) the spouse is the primary caregiver, who provides informal care to the cancer patient; (iv) both partners agreed to take part in the study. The spousal caregiver was the person defined and identified by the cancer patient as his or her married partner and primary source of physical and emotional support since the diagnosis of cancer. Excluded from the study were cancer couples with the following characteristics: (i) spousal caregivers who are unable to care for themselves due to chronic illness, or who are suffering from a serious physical or mental illness, including cancer; and (ii) those unable to communicate with the interviewers in Mandarin (the official language of China).

Calculation of sample size: As no similar intervention study has been conducted among cancer dyads, the size of the sample in this study was calculated using G-power 3.1.9.2 based on the conventional method of power analysis (Faul, Erdfelder, Lang, & Buchner, 2007). Assuming a two-sided type I error of 5%, with 90% power, and a medium effect size (d=0.50) to detect the difference in constant outcome measures (pre- and post-test), it was estimated that at least 44 dyads would be required. When using structural equation modeling (SEM) to analyze data, the sample size should be from $N \geq 50\text{-}8x$ to $N=104+x$ independent variables (Tabachnick & Fidell, 2013, p. 123). Since a total of 120 items were included in the questionnaire, the sample size was calculated to be ≥ 224 individuals, or 112 caregiver-patient dyads. Taking into account an estimated refusal rate of about 20%, a total of 135 cancer dyads needed to be approached.

Caring for Couples Coping with cancer '(4Cs)'Programme

The essential components of the "**4Cs**" program were developed based on the P-LLCF for Cancer Couple Dyads (see Chapter 11,Figure 11-1, p.241). The components that were included took into account the three domains of the P-LLCF: Event Situation, Dyadic Mediators, and Caregiver-patient Dyads. The resulting program consisted of six weekly sessions, with each session lasting for 90 minutes. The main focus of the sessions in the **4Cs** programme were: primary stressors (section 1); secondary stressors (section 2); dyadic mediator (section 3); dyadic appraisal (section 4); dyadic coping (section 5); and a program overview (section 6). The session titles, outlines, and contents are listed in Table 12-1.

Table 12-1 Main contents and delivering outline of the 4Cs programme

Session	Delivering outline
1.**Primary stressors** Caring for your spouse with cancer	- Introduce the research team and provide overview of the programme; - Conduct icebreaker: getting to know each other (couple introduction); - Present key strategies relating to illness-related factors and care demand **(booklet)**; - Help cancer dyads to gain more confidence in responding to both patients' and caregivers' physical and psychosocial issues; - Outline the services available from the cancer caring team and other support services; - **Homework:** Discuss what aspects benefit your situation in this session (chapter 1 of Booklet); and what aspects you need more information.

2. **Secondary stressors** Improving cancer dyads role adjustment and their relationship	- Present materials on the role as the caregiver **(booklet)**; - Present strategies for self-caring of both patients and spousal caregivers **(booklet)**; - Help cancer dyads to identify their needs, including enjoyable experiences, enough sleep, healthy diet, exercises, and dyad relationship; - Reinforce the role of the cancer care service; - **Homework:** Discuss your feeling about your role as a caregiver or cancer patient with your loved one; try to find the way to improve it with your partner.
3. **Dyadic mediator** Improving cancer dyads self-efficacy and their relationship	- Present materials on daily enrichment events and sense of self-efficacy **(booklet)**; - Discuss the daily enrichment events and self-efficacy of couples experience on their process of coping with cancer; - Introduce relationship-enhancing behaviors and lead group in focusing on self-disclosure exercise **(booklet)**; - Reflect the value of self-disclosure: express of oneself and open communication; - Discuss the view of "**hope for the best, prepare for the worst**"; - **Homework:** Discuss about how you feel about your relationship after the diagnosis of cancer, try to find the way to improve your relationships, express love, appreciation, and forgiveness.
4. **Dyadic Appraisal** Improving cancer dyads' sharing the stressful event	- Present materials on the meaning of their role in daily life and caregivers feeling of accomplishment **(booklet)**; - Discuss the meaning of their role in daily life and caregivers feeling of accomplishment; - Introduce dyadic appraisal on sharing stressors, and discuss how couples appraised their stressors **(booklet)**; - Present materials on maintaining their mutual relationship: 'communication', 'reciprocal influence', 'caregiver-patient congruence'; and strategies on improving cancer-related communication between couples **(booklet)**; - Practice and reflect the communication strategies between couples; - **Homework:** To discuss if you have communication troubles? If yes,

	please try to figure out the way to handle them.
5. **Dyadic coping** Improving cancer dyads' supportive and collaborative coping	- Present materials on problem-, emotion-, and meaning-focused coping strategies **(booklet)**; - Practice meaning-focused coping strategies in group and reflect the positive meaning of their coping experience; share enjoyable experiences; - Share spousal caregivers' self-care strategies in group; - Reflect the effective coping strategies and share coping tips; - **Homework:** Share with your partner on how you are each coping; talk about choices you can make together.
6. O**verviewing of the whole programme**	- Review the main contents of the program; - Discuss and address the dyads problem if any; - Sharing their experience and recommendations about the program.

The couple-based intervention program adopted the approaches of Psycho-education (PE) (Lukens & McFarlane, 2004), Skills Training (ST) (Medical Dictionary, 2013), and Cognitive Behavioral Therapy (CBT) (Cherry, 2013). The face-to-face group intervention was delivered by the researcher/therapist. The education sessions were semi-structured, with a mix of didactic instruction (used sparingly), group sharing, and interactions. Three to eight cancer dyads were included in each group.

A guidebook for the cancer couples titled **"Live with Love: Hope for the best, prepare for the worst,"** which had been developed based on reviews of the literature, and the P-LLCF (Li & Loke, 2015) was used to complement the group intervention. The guidebook provided cancer couples with easy access to written information on common concerns about their coping with cancer as a dyad. The guidebook also acted as a protocol manual for therapists to standardize the implementation of the **"4Cs"** program across various intervention groups. The main contents of the booklet were presented in table 11-3 (Chapter 11,p.246).

Quality Assurance: Strategies were implemented to ensure that the protocols of the intervention were adhered to, and the intervention was delivered in a uniform manner to ensure treatment fidelity. These strategies included training nurses in the intervention and protocol, writing a detailed outline of the intervention, and holding a monthly discussion meeting among the members of the research group.

Instruments

Multiple instruments measuring the domains of Event Situation, Dyadic Mediators, Dyadic Coping, Dyadic Appraisal, and Dyadic Adjustment/Outcomes were included in the questionnaires, which the spousal caregivers and cancer patients were asked to complete separately. (See Chapter 10).

The self-efficacy, which reflects dyadic mediator was evaluated using the 12-item Cancer Behaviour Inventory (CBI-B) (Heitzmann et al., 2011). The 37-item Dyadic Coping Inventory (DCI) was used to assess dyadic coping (Bodenmann, 2008; Gmelch et al., 2008). The Cancer-Related Communication Problems within Couples Scale (CRCP) was used to measure communication between the couples, reflecting the dyadic appraisal (Kornblith et al., 2006). The couples' QOL in terms of physical and mental health, negative and positive emotions, and marital satisfaction were assessed using the Medical Outcomes Study 12-item short form (MOS SF-12) (version 2) (Ware, Kosinski, & Keller, 1996), the Hospital Anxiety and Depression

Scale (HADS) (ZIGMOND & SNAITH, 1983), the revised Benefit-Finding Scale (BFS) (Antoni et al., 2001), and the 14-item Revised Dyadic Adjustment Scale (RDAS) (Busby, Crane, Larson, & Christensen, 1995; Crane, Middleton, & Bean, 2000) respectively.

Procedure

Before the commencement of the study, ethical approval was obtained from the Human Ethics Committee of The Hong Kong Polytechnic University and access approval was obtained from the hospital. Nurses were given a training session on the details of the study and provided with explanations of the items in the instruments. The oncologists in the hospital identified the cancer couples in accordance with the criteria for eligibility. Couples who met the criteria for inclusion were approached in the oncology wards after their written informed consent was obtained to indicate that they were willing to participate in the study.

The collecting of data was conducted by two trained head nurses at two time points: at baseline (**T0**) and after the completion of the "**4Cs**" program (**T1-6weeks**). Information on the demographics and characteristics of both the patients and their spousal caregivers were collected at baseline. The outcome measures were completed separately by the spousal caregivers and the cancer patients. The two head nurses assisted those who required help completing the questionnaire.

Data Analysis

Data analyses included both descriptive and inferential statistical methods. Descriptive statistics such as frequencies, percentages, means, and standard deviations were used to describe the characteristics of the subjects and the outcome variables. The acceptability and feasibility of the intervention was evaluated by computing summary statistics on the recruitment and retention rates of the participants, and their compliance with the intervention.

A repeated measures analysis of variance was applied to assess the effects of the **4Cs** program, with time (T0 vs. T1) and role (cancer patients vs. spousal caregivers) as within-subject variables to control for the correlated nature of the data. The main effects of time (to assess the effectiveness of the intervention for dyads), role (to assess differences in the effectiveness of the intervention between cancer patients and spousal caregivers), and time-by-role interactions (to assess the effectiveness of the intervention with regard to the interaction between time and role) were examined. Estimates of effect size (Cohen’s *d*) were calculated based on the paired scores of the outcome measures (pre-intervention/post-intervention) for cancer patients and spousal caregivers (Cohen, 1998). Analyses were performed using the Statistical Package for the Social Sciences, version 21.0 (SPSS, Chicago, Illinois, USA), with the level of significance set at P<0.05. Missing data of all items (measured in pre and post assessment) were <5%. Mean substitution was applied to handle the missing data (Schlomer, Bauman, & Card, 2010).”

A further analysis using structural equation modeling (SEM) was guided by the Actor Partner Interdependence Model (APIM) (Atkins, 2005) using Amos 21.0 to examine whether the outcome measures at T1 (post-intervention) supported the constructs within the P-LLCF. In the APIM, the effect of an individual's own characteristics (e.g., self-efficacy) on their own outcomes (i.e., marital satisfaction) is considered an actor effect, while the effect of an individual's own characteristics on their partner's outcomes is considered a partner effect. Three indices were used to evaluate the goodness of fit of the model: Chi-Square X^2 with an insignificant P value ($P>0.05$), a confirmatory fit index (CFI) value of above 0.95, and a root mean square error of approximation (RMSEA) value of less than 0.08 were considered to be indicative of good model fit (Hooper, Coughlan, & Mullen, 2008).

12.4 Results

12.4.1 The acceptability and feasibility of this 4Cs Program

A consort diagram illustrates the flow of participants into the study (Figure 12-1).

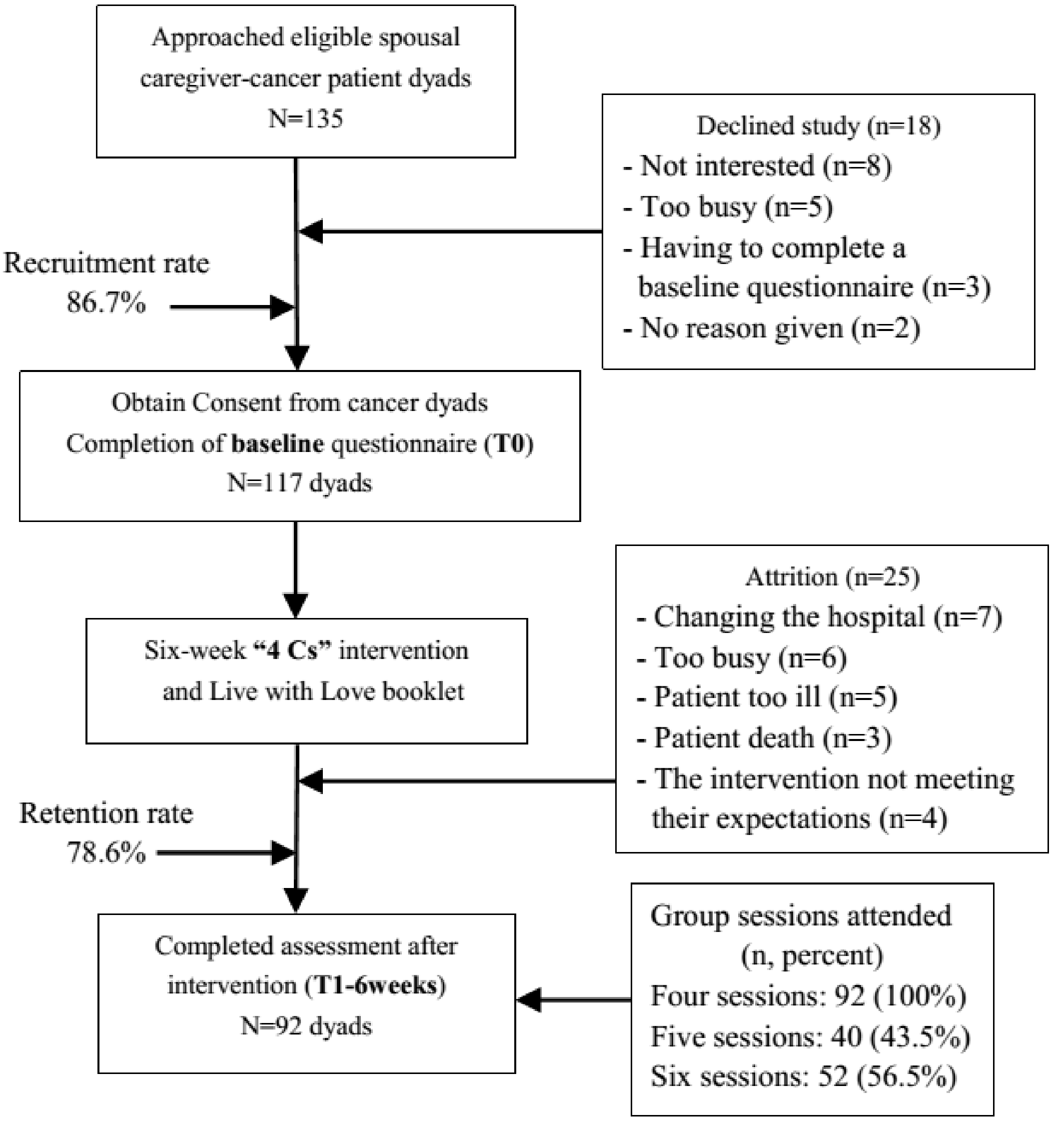


Figure 12-1. Consort diagram illustrating flow of participants into study

Of the 135 couples approached by trained nurses, 18 declined to take part in the study. The reasons given by the cancer dyads for refusing to participate in the **4Cs** program were that they were not interested in the intervention or that the intervention was not meeting their expectations (n=8), they were too busy or the intervention posed too much of a time burden (n=5), they did not want to complete a baseline questionnaire (n=3), or no reason was given (n=2). The remaining 117 couples were recruited as subjects for this study (recruitment rate=86.7%). The characteristics of the 117 cancer couples included in this analysis are shown in Table 10-1(Chapter 10, p.199). Table 10-1 indicates that although 53.0% of the couples were in their early stage of coping with cancer (< 6 months), all of the patients had advanced cancer. Most of the couples (55.6%) were coping with digestive system cancer (e.g., esophageal, gastric, liver, or colorectal cancer). Most of the families (60.7%) experienced a serious financial burden due to the cost of treating the cancer.

Of the 117 dyads in the baseline sample, 92 completed the intervention and completed the T1 follow-up assessment (retention rate=78.6%). A total of 25 dyads did not complete the study due to the death of the patients (n=3), the excessive illness of the patients (n=5), the changing of hospitals (n=7), the failure of the intervention to meet their expectations (n=4), or because they were too busy to participate in the intervention sessions (n=6). Baseline comparisons were conducted between the 92 dyads who completed the follow-up (final sample) and those dyads that were lost to the follow-up (n=25 dyads, missing sample) with regard to their demographic data, medical data, and outcome measures. The results indicated that the couples who did not complete the intervention had a significantly higher level of self-efficacy to begin with than those who did (M=90.80 vs. M=79.58, t=3.275, P=0.002). No other significant findings were identified in the demographic data between the missing sample and the final sample.

Intervention compliance refers to the number and percentage of couples who participated in the six group sessions. Of the 92 dyads, 92 (100%), 40 (43.5%), and 52 (56.5%) of the dyads participated in four, five, and six sessions, respectively. Telephone contact was made with those who did not participate in the group sessions, in an attempt to understand the situation and to offer a brief intervention and guidance to the couples in coping with cancer when needed. Those couples who missed their own group sessions were encouraged to attend other group sessions. Based on the findings of a focus group study among couples living with cancer that cancer couples are willing to help their comrade in arms against cancer (Li et al., 2014), the phone calls were made in offering the support needed and the opportunity for couples to remain in the intervention. When there are couples who like to attend the other group session, permission was obtained from the couples in the group, the therapist was also cautious in that the new members would not affect the function of existing groups.

12.4.2 The effects of the 4Cs program

Table 12-2 presents a comparison of the effects of the 4Cs program between T0 and T1. The analysis showed that the couples experienced significant increases in their overall (total) self-efficacy ($P<0.01$), the dyadic coping inventory ($P<0.05$), the physical component summary of SF-12 ($P<0.05$), and positive emotions on benefit findings ($P<0.05$) after the intervention. They also experienced significant decreases in their overall (total) cancer-related communication problem ($P<0.05$) and anxiety ($P<0.01$). Significant differences were also identified between patients and their spousal caregivers. Patients had a significantly higher level of increase in the mean CBI-B (MD= +5.1, d=0.41) than spousal caregivers (MD= +1.4, d=0.19) ($P<0.05$). Spousal caregivers had a significantly higher level of increase in physical component summary score ($P<0.01$), and much greater level of decrease in anxiety ($P<0.05$) than the patients. No significant interaction effects of time by role were seen in any of the outcome measures. Although marginal differences were found for MCS of SF-12 by time ($P=0.079$) and depression by role ($P=0.062$), no significant main effects of time, role, or interaction effects for MCS of SF-12, depression, and marital satisfaction were identified (Table 12-2).

Table 12-2 The preliminary effects of the 4Cs program

		Means (standard deviations)				Significance (P)			Effect Sizes (ES)	
		Patients		Spousal caregivers (SC)		Main and interaction Effect*			Patients	SC
Outcomes		Time 1	Time 2	Time 1	Time 2	Time	Role	Time by Role	Cohen's d	Cohen's d
Dyadic mediators										
Self-efficacy (CBI-B)		79.6 (20.0)	84.7(16.1)	86.1(17.7)	87.5(15.0)	**.009**[b]	**.037**[a]	.140	0.41	0.19
Dyadic coping										
Dyadic coping inventory (DCI)		125.6(14.2)	128.1(14.3)	123.5(14.6)	125.7(16.0)	**.011**[a]	.252	.897	0.28	0.26
Dyadic appraisal										
Communication (CRCP)		9.2(2.8)	8.4(3.0)	9.2(2.9)	8.9(2.8)	.042[a]	.414	.381	0.30	0.13
Dyadic outcomes										
Physical and mental health (SF-12)	PCS	38.0 (9.8)	38.7(9.7)	42.3(11.1)	44.6(7.5)	**.048**[a]	**.000**[b]	.262	0.10	0.31
	MCS	41.5 (7.7)	42.9(7.3)	42.8(14.2)	43.7(13.2)	.079	.479	.677	0.24	0.13
Negative emotions (HADS)	Anxiety	7.3(4.2)	6.6(3.8)	8.6(4.5)	7.6(4.5)	**.006**[b]	**.043**[a]	.663	0.26	0.32
	Depression	6.8(4.6)	6.4(4.4)	8.1(5.1)	7.4(4.8)	.108	.062	.671	0.13	0.21
Positive emotions (BFS)		62.1 (12.8)	64.8(11.7)	64.8(13.1)	66.1(11.0)	**.023**[a]	.196	.385	0.31	0.16
Marital satisfaction (RDAS)		42.5 (9.4)	43.2(9.0)	44.3(10.1)	45.4(10.3)	.179	.107	.790	0.12	0.16

*The main effects of time: the overall effectiveness of the intervention for dyads; The effect of role: differential effectiveness of the intervention between cancer patients and spousal caregivers; Time -by-Role interactions; the interaction effectiveness of the intervention between time and role

a P<0.05; b P<0.01

CBI-B= the 12-item Cancer Behavior Inventory (CBI-B); CRCP=cancer related communication problems；SF-12=The Medical Outcomes Study 12-item short form；PCS= Physical Component Summary; MCS= Mental Component Summary; HADS= he Hospital Anxiety and Depression Scale；BFS= Benefit-Finding Scale; RDAS= Revised Dyadic Adjustment Scale

Figure 12-2. Nine figures for interaction effects of time by role

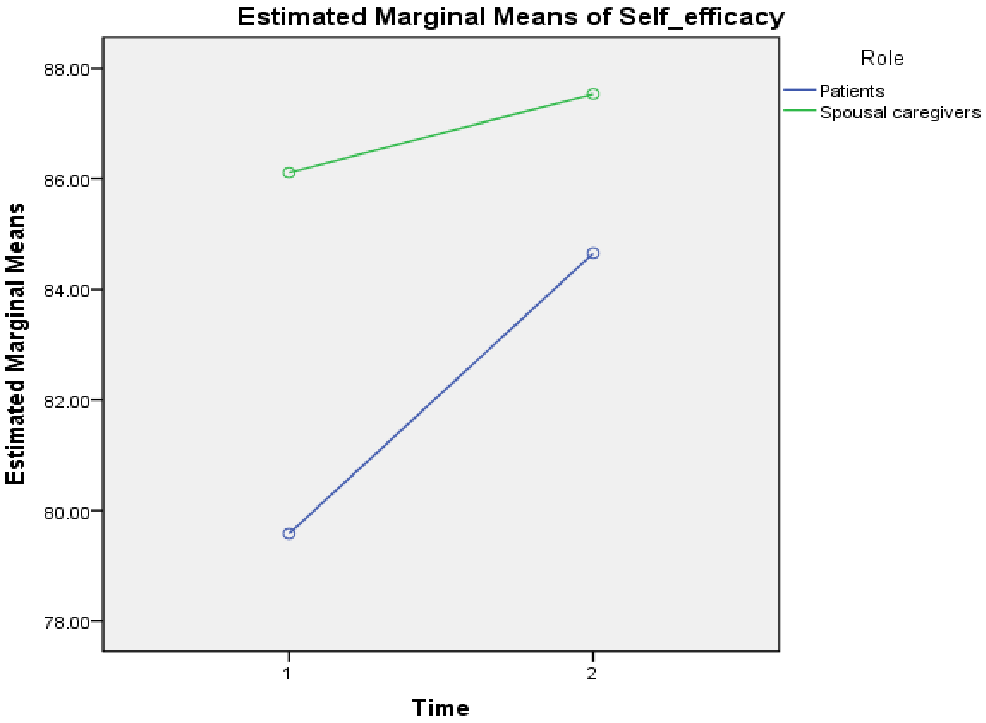


Figure 12-2 (No 1). Self-efficacy

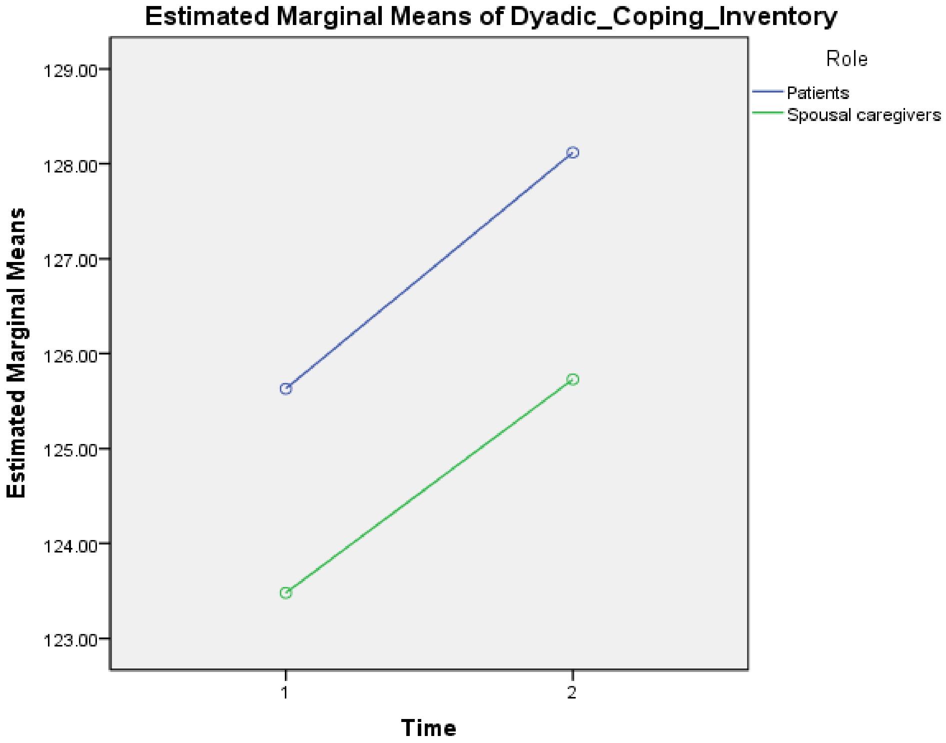


Figure 12-2 (No 2). Dyadic coping inventory (DCI)

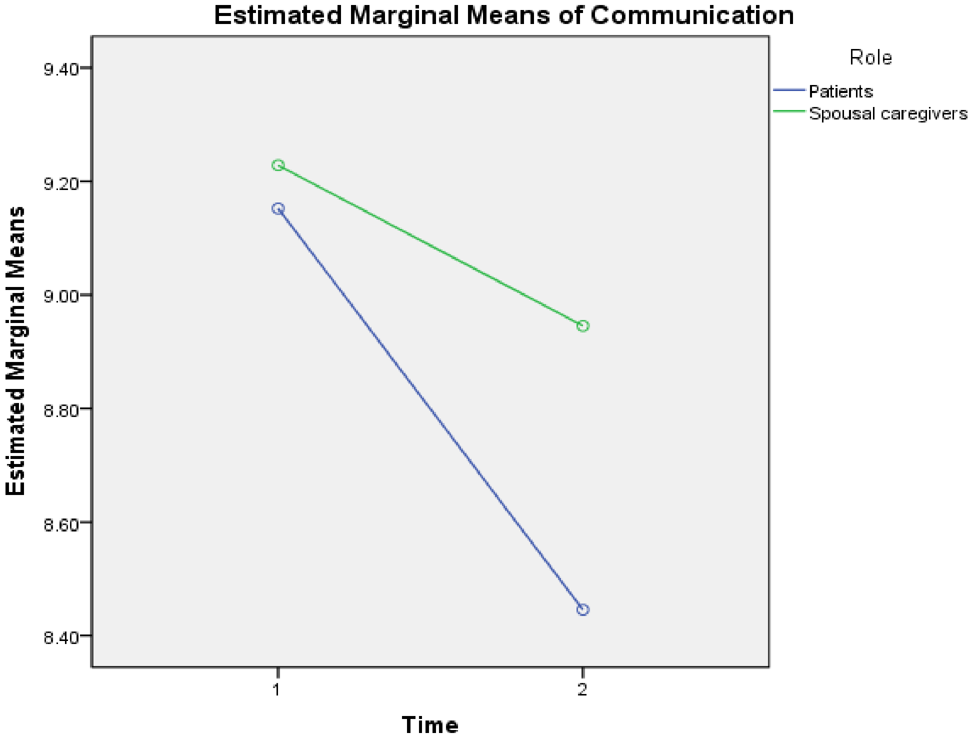


Figure 12-2 (No 3). Communication

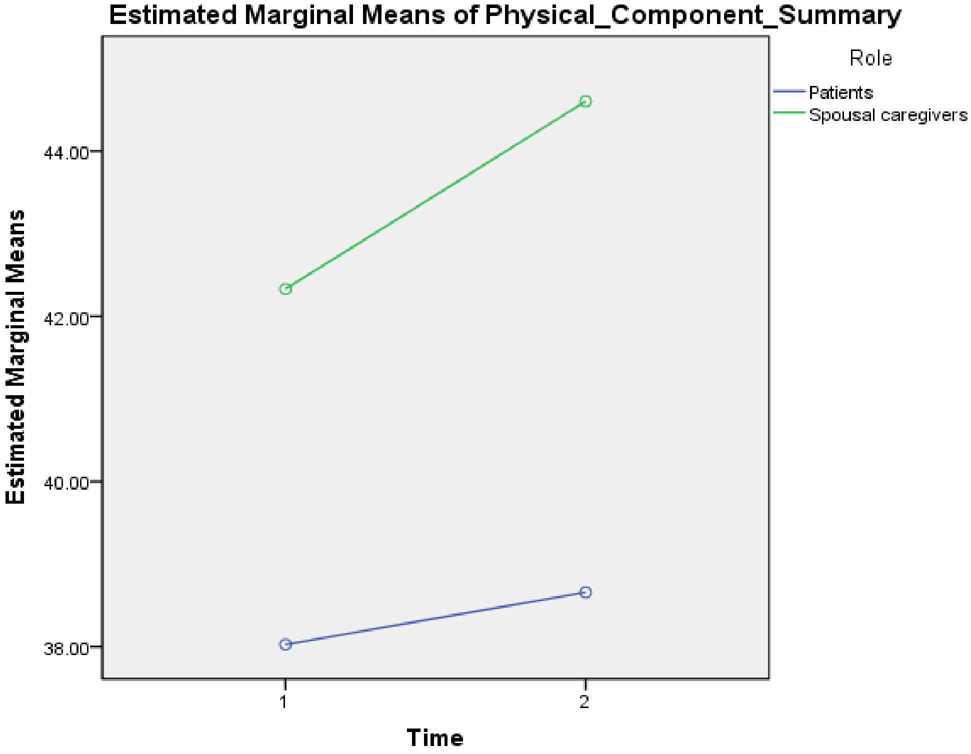


Figure 12-2 (No 4). Physical Component Summary (PCS)

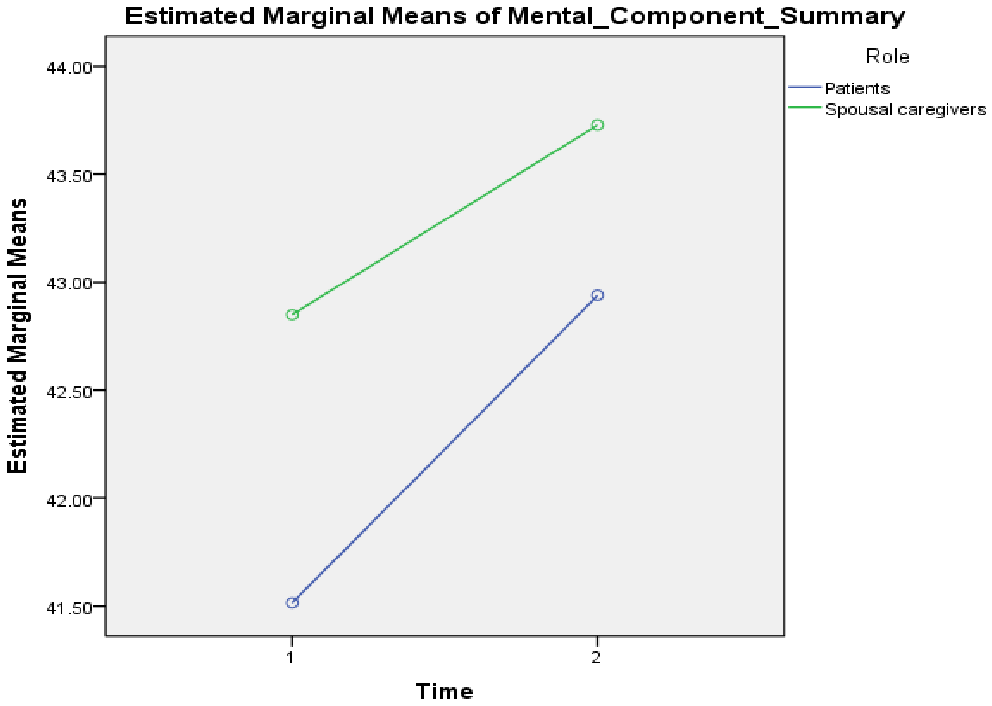


Figure 12-2 (No 5). Mental Component Summary (MCS)

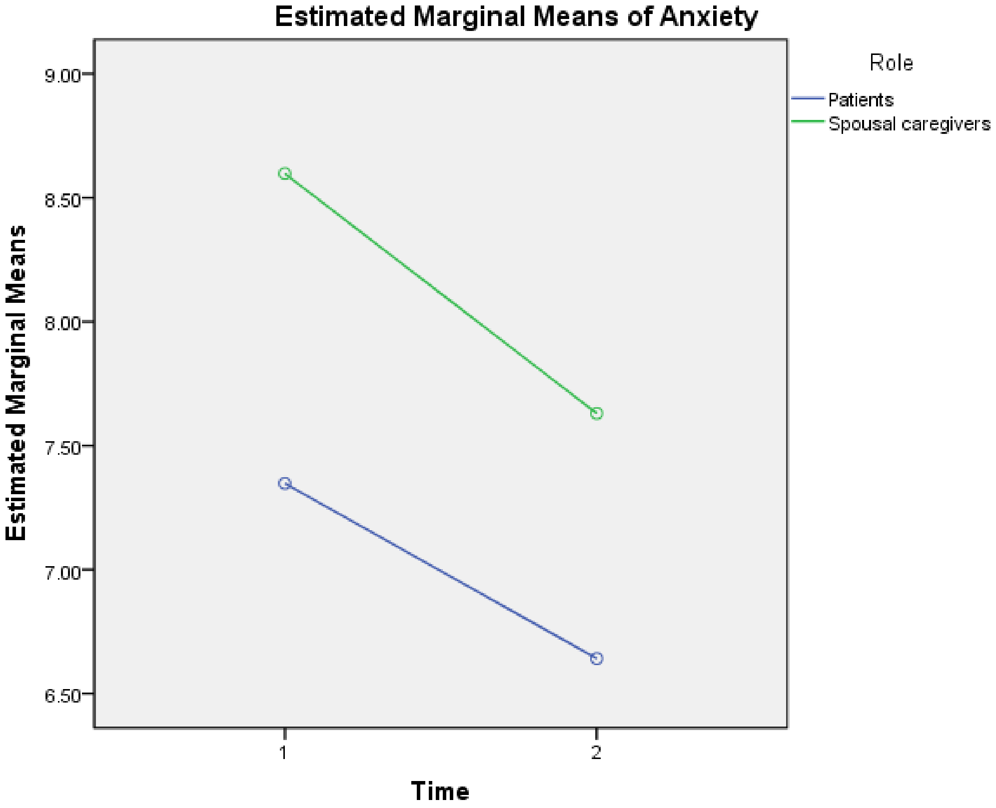


Figure 12-2 (No 6). Anxiety

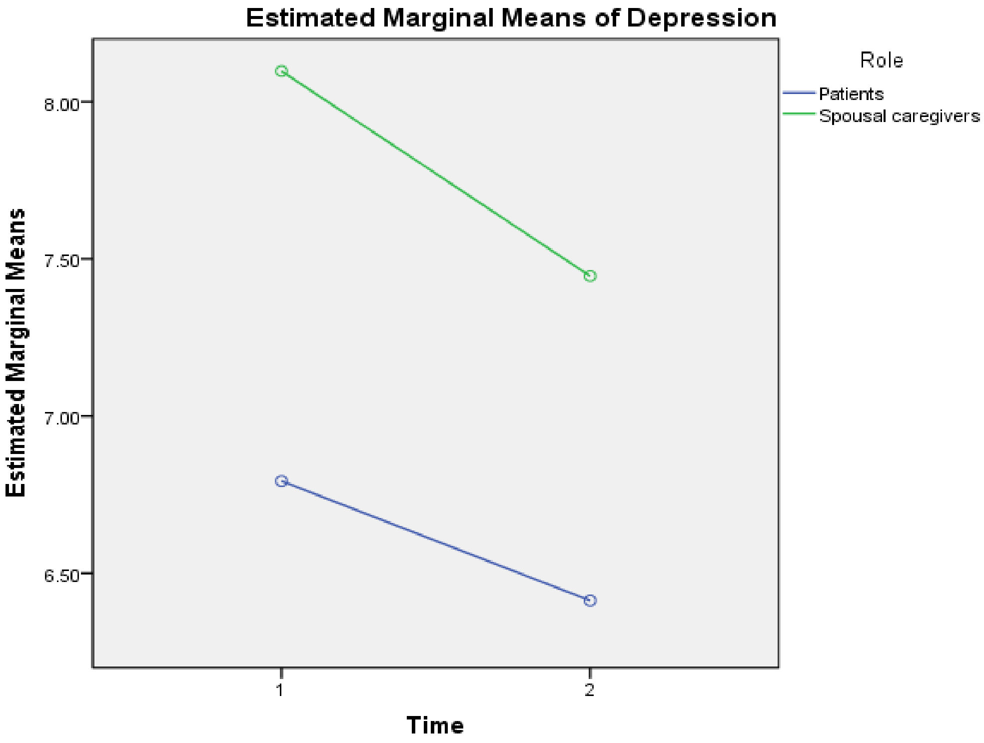


Figure 12-2 (No 7). Depression

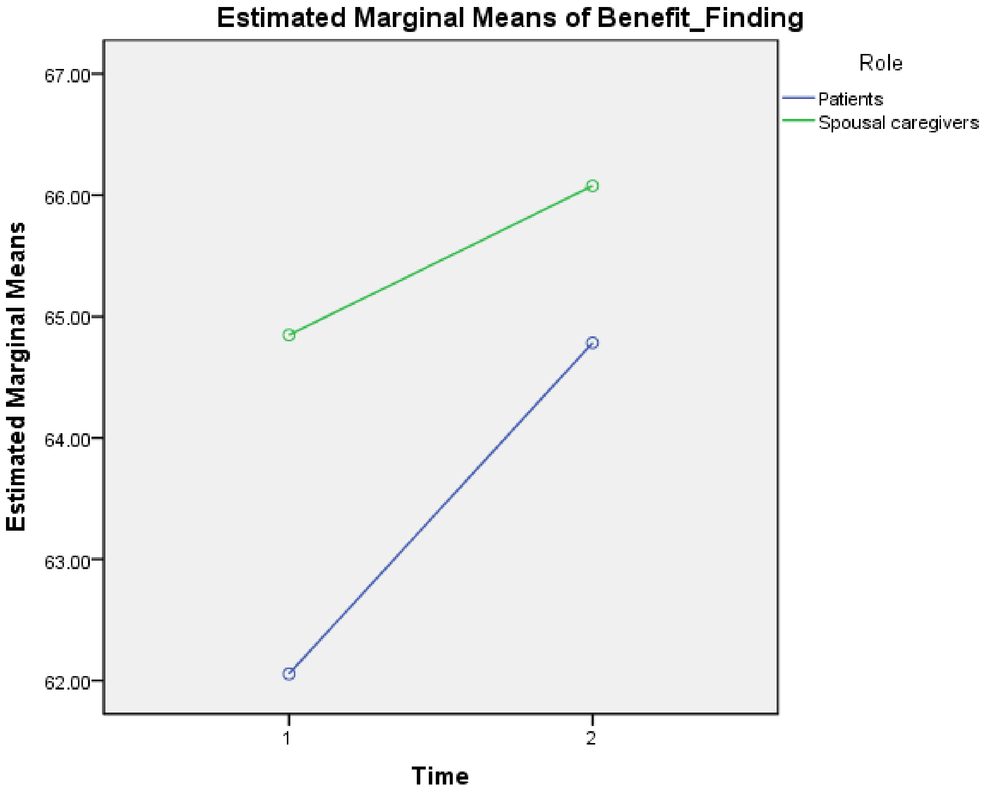


Figure 12-2 (No 8). Benefit finding

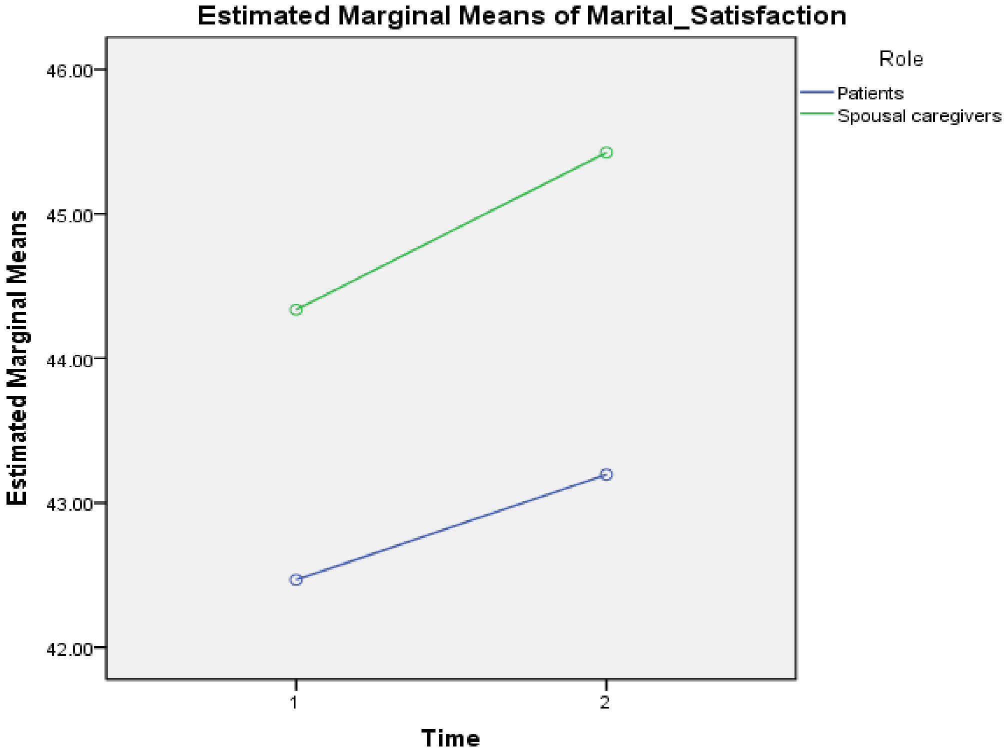


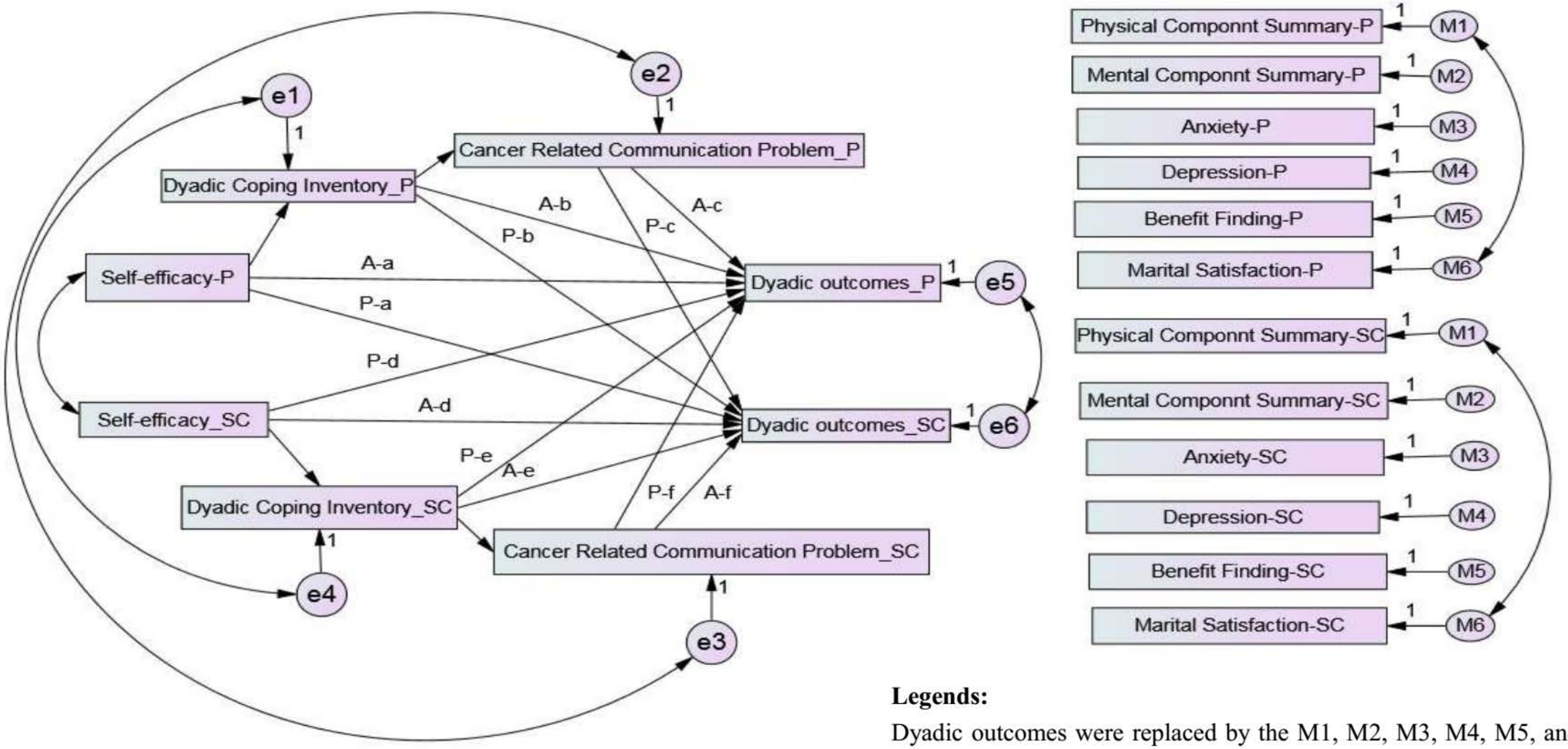
Figure 12-2 (No 9). Marital satisfaction

The overall effect sizes calculated in this study ranged from medium to small (Table 12-2). The effect sizes for patients ranged from medium for self-efficacy (*d=0.41)*, benefit findings (*d=0.31*), and the cancer-related communication problem (*d=0.30)*, to small for the dyadic coping inventory (*d=0.28*), anxiety (*d=0.26*), and mental component summary (*d*=0.24). Effect sizes for spousal caregivers included medium for anxiety (*d=0.32*) and physical component summary (*d=0.31*), and small for the dyadic coping inventory (*d=0.26*), depression (*d=0.21*), and self-efficacy (*d=0.19).* Although no significant main effects from time, role, or interaction effects for marital satisfaction were identified, small effect sizes for marital satisfaction were observed for patients (0.12), and spousal caregivers (0.16), respectively.

12.4.3 Supporting evidence for the constructs in the P-LLCF

Structural equation modeling (SEM) was carried out to examine whether the outcome measures at T1 (6 weeks after the intervention) provide evidence to support the constructs of the P-LLCF, in that the dyadic mediators, dyadic coping, and dyadic appraisal work together to benefit the dyadic outcomes.

Figure 12-3 shows the theoretical testing of the P-LLCF. As shown, Dyadic Mediators (self-efficacy) through Dyadic Coping (dyadic coping inventory, DCI), and Dyadic Appraisal (cancer-related communication problem, CRCP), directly or indirectly impacted on the outcome measures as actor effects (from A-a to A-f) and/or as partner effects (from P-a to P-f) in the six models, respectively. The dyadic outcomes in the six models (Model 1-6) were: Physical Component Summary (PCS); Mental Component Summary (MCS); Anxiety; Depression; Benefit Finding (positive emotion); and Marital Satisfaction (RDAS).



Legends:

Dyadic outcomes were replaced by the M1, M2, M3, M4, M5, and M6 respectively in six different models as indicated in the Figure.

A-a, A-b, A-c, A-d, A-d, A-e, A-f stands for Actor effects;

P-a, P-b, P-c, P-d, P-e, P-f stands for Partner effects;

P=Patients, SC=Spousal Caregivers

Figure 12-3. Theoretical Structural equation modeling (SEM) model for testing P-LLCF
P-LLCF=Preliminary Live with Love Conceptual Framework

The maximum likelihood method was applied in estimating covariance matrices in all of the six models (models 1 to 6, Figure 12-4). All six models resulted in convergence and showed goodness of fit to the data and variables. Table 12-3 presents the related notes and indices for the six models. For all of the six sub-models, the indices of Chi-Square X^2 had an insignificant P value ($P>0.05$), confirmatory fit indexes (CFI) were valued above 0.95, and the root mean square error of approximation (RMSEA) values were less than 0.08 (Table 12-3). To summarize, the findings of the SEM provide support for the outcome measures at T1 (after the intervention) in that the couples' dyadic mediators (self-efficacy), dyadic coping (DCI), and dyadic appraisal (CRCP) interrelate and work together to impact both actor and partner effects on dyadic outcomes to various degrees.

Table 12-3 Standardized path coefficients and fit statistics of six models

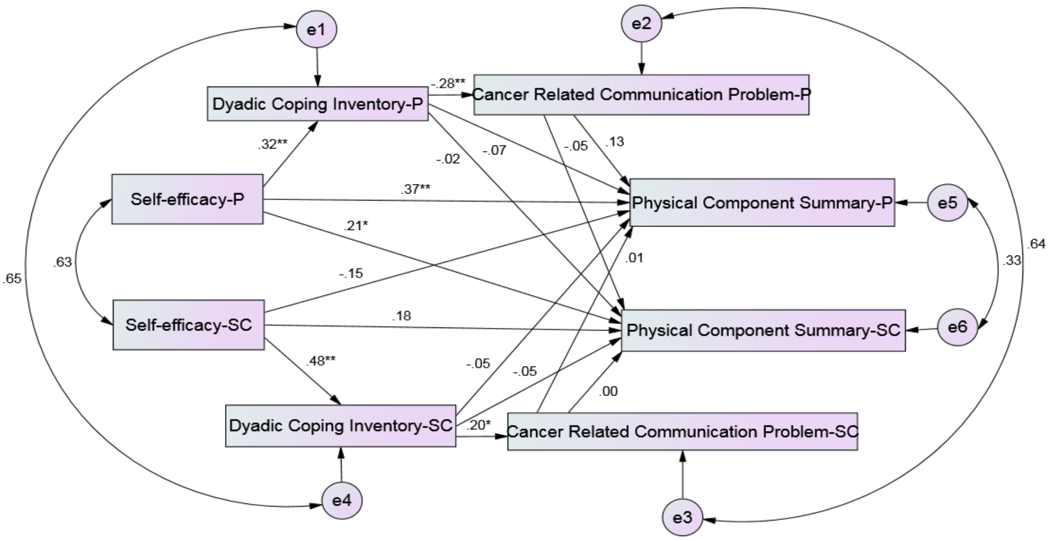
Indicates	**M 1**	**M 2**	**M 3**	**M 4**	**M5**	**M6**
Dyadic Outcome Variables	PCS	MCS	Anx	Dep	BF	RDAS
Number of distinct sample moments:	36	36	36	36	36	36
Number of distinct parameters to be estimated	28	28	28	28	28	28
Degrees of freedom	8	8	8	8	8	8
SE_P → DCI_P	**.323**[b]	**.323**[b]	**.323**[b]	**.323**[b]	**.323**[b]	**.323**[b]
DCI_P → CRCP_P	**-.282**[b]	**-.282**[b]	**-.282**[b]	**-.282**[b]	**-.282**[b]	**-.282**[b]
SE_SC → DCI_SC	**.484**[b]	**.484**[b]	**.484**[b]	**.484**[b]	**.484**[b]	**.484**[b]
DCI_SC → CRCP_SC	**-.204**[a]	**-.204**[a]	**-.204**[a]	**-.204**[a]	**-.204**[a]	**-.204**[a]
SE_P → DO_P (A-a)	**.371**[b]	.092	**-.366**[b]	**-.219**[a]	.138	**.340**[b]
SE_P → DO_SC (P-a)	**.207**[a]	**.272**[a]	**-.452**[b]	**-.453**[b]	-.059	-.019
DCI_P → DO_P (A-b)	-.074	**.338**[b]	-.062	**-.262**[a]	**.241**[a]	**.214**[a]
DCI_P → DO_SC (P-b)	-.015	.199	.109	-.049	**.213**[a]	**.207**[a]
CRCP_P → DO_P (A-c)	.134	-.047	-.041	-.002	-.090	.070
CRCP_P → DO_SC (P-c)	-.047	.022	.041	-.049	.127	**.314**[b]
SE_SC → DO_SC (A-d)	.179	.156	-.049	.006	**.440**[b]	.029
SE_SC → DO_P (P-d)	-.152	**.364**[b]	-.145	**-.228**[a]	.158	.039
DCI_SC → DO_SC (A-e)	-.053	-.169	-.155	-.051	**.246**[a]	.149
DCI_SC → DO_P (P-e)	-.049	**-.353**[b]	**.226**[a]	.146	.140	.148
CRCP_SC → DO_SC (A-f)	.003	-.084	-.014	.030	-.098	**-.227**[a]
CRCP_SC → DO_P (P-f)	.009	.106	.107	-.017	.080	-.100
Chi-square X^2	3.985	3.985	3.985	3.985	3.985	3.985
Probability level **(P>0.05)**	**0.858**	**0.858**	**0.858**	**0.858**	**0.858**	**0.858**
a confirmatory fit index **(CFI>0.95)**	**1.000**	**1.000**	**1.000**	**1.000**	**1.000**	**1.000**
a root mean square error of approximation (**RMSEA<0.08**)	**0.000**	**0.000**	**0.000**	**0.000**	**0.000**	**0.000**

Note: CRCP=Cancer Related Communication Problem; DCI=Dyadic Coping Inventory; DO=Dyadic Outcomes; M1 to M6 represent six different sub-models. M1: PCS=physical component summary; M2: MCS=mental component summary; M3: Anx=anxiety; M4: Dep=depression; M5: BF=benefit finding; M6: RDAS=Revised Dyadic Adjustment Scale (reflecting marital satisfaction); P=Patients; SC=Spousal Caregivers; SE=Self Efficacy.

[a] P<0.05; [b] P<0.01.

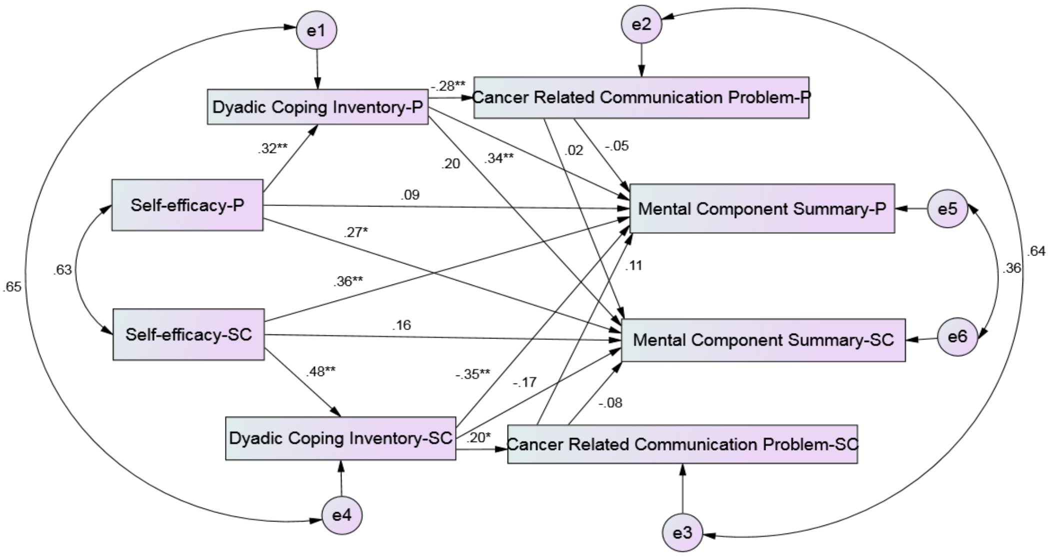
Figure 12-4. Six sub-models (sub-model 1-6) for testing P-LLCF

Sub-Model 1 PCS



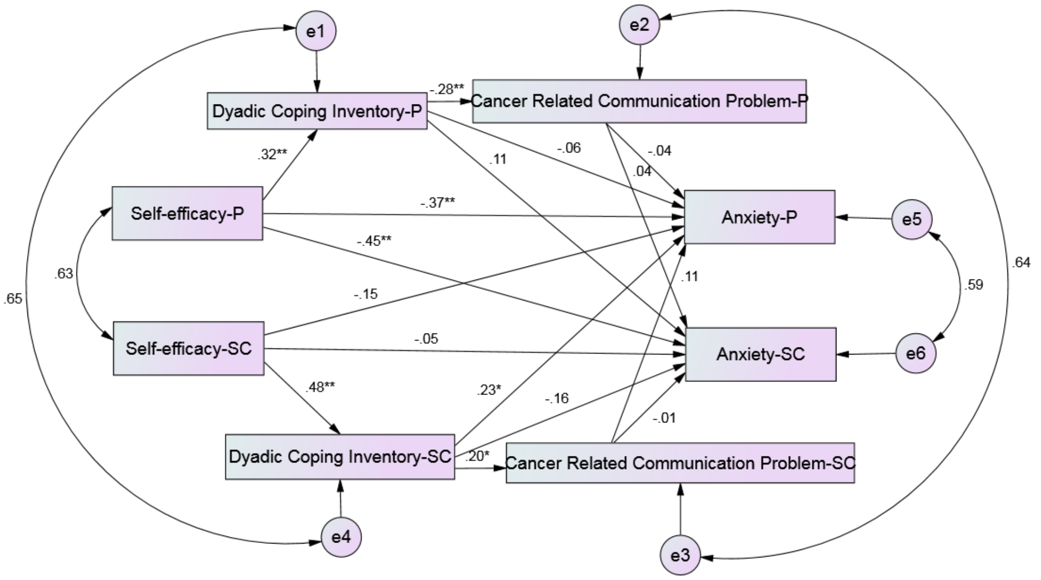
**P<0.05; **P<0.01*

Sub-Model 2 MCS



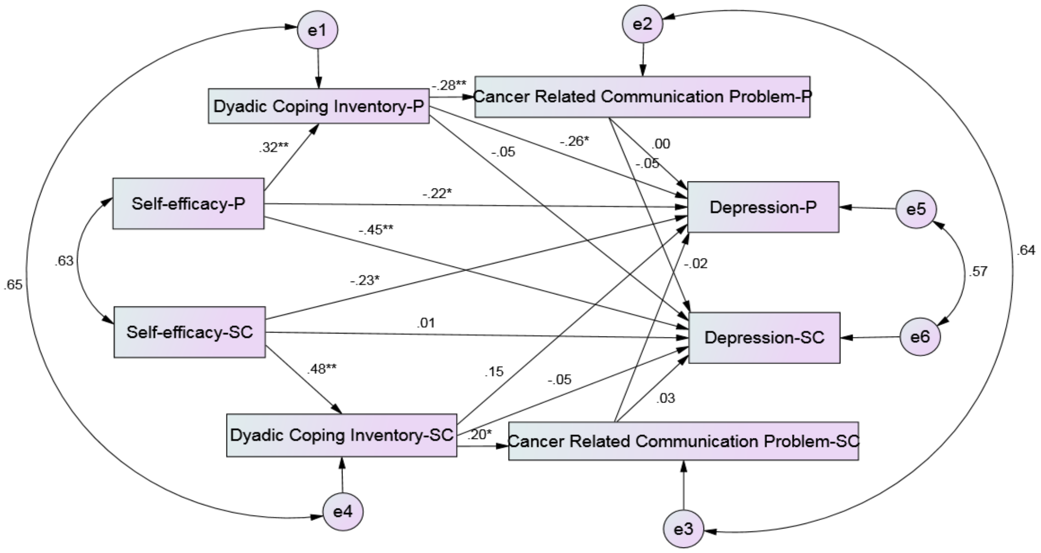
**P<0.05; **P<0.01*

Sub-Model 3 Anxiety



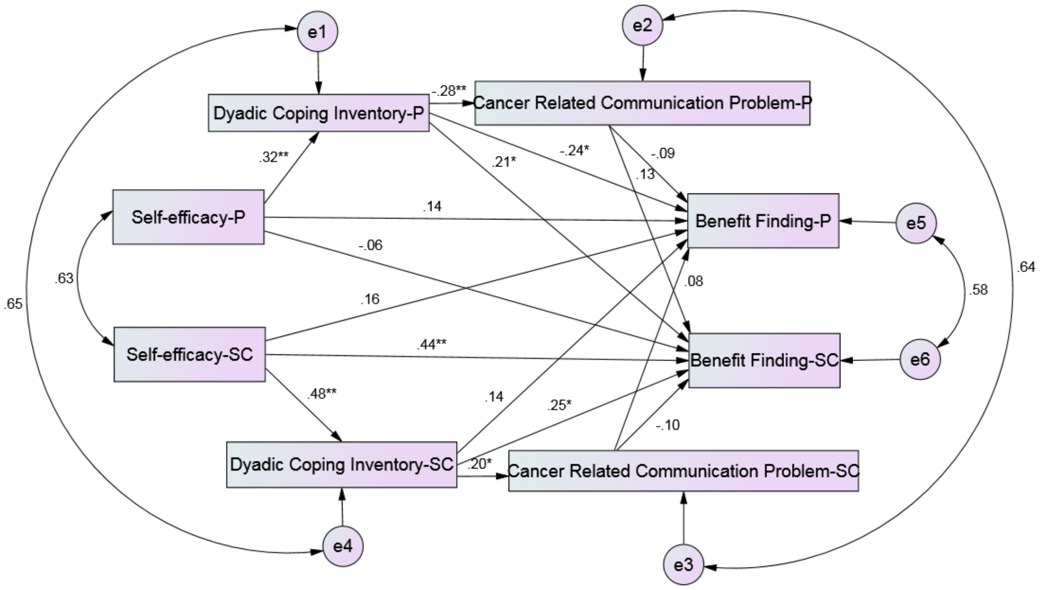
**P<0.05; **P<0.01*

Sub-Model 4 Depression



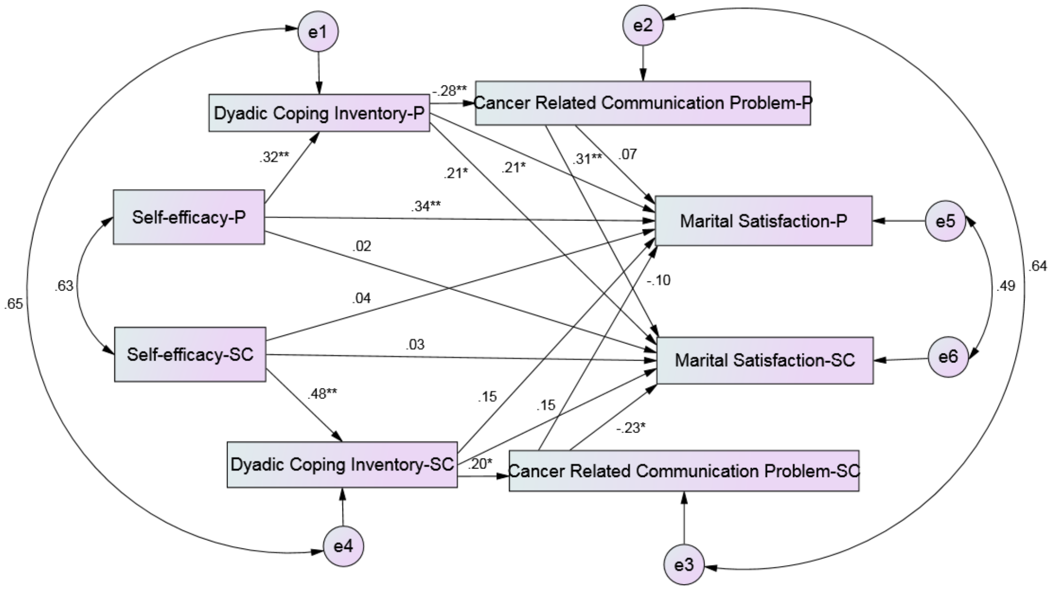
**P<0.05; **P<0.01*

Sub-Model 5 Benefit finding



**P<0.05; **P<0.01*

Sub-Model 6 RDAS



**P<0.05; **P<0.01*

12.5 Discussion

To our knowledge, the present study is the first attempt in mainland China to investigate the feasibility of a complex couple-based intervention to support cancer couples coping with the illness as dyads. The findings of this study achieved the aims of the proposed study in identifying: (i) the acceptability and feasibility of the **4Cs** program; (ii) the effectiveness of the **4Cs** program; and (iii) evidence supporting the findings on the P-LLCF.

12.5.1The acceptability and feasibility of this 4Cs Program

Intervention acceptability and feasibility was evaluated based on participants' recruitment, retention, and intervention compliance. The recruitment rate of 86.7% of this program was higher when compared to other family interventions for cancer patients and family caregivers (68%-80%) (Northouse, Kershaw, Mood, & Schafenacker, 2005; Northouse et al., 2007). The retention rate of 78.6% was around the same as the average retention rate of 80% (ranging from 66% to 94%) in a review of couple-based intervention studies (Li & Loke, 2014b). The intervention compliance was reported to be 92 out of 117 dyads, with all of the dyads having attended at least four group sessions and over half (56.5%) all six sessions. The rate of compliance prompted the researchers to consider that a four-session program may be more acceptable to dyads. Nevertheless, it may be cautiously concluded that the **4Cs** program is acceptable and feasible with regard to recruitment, retention, and intervention compliance.

Couples were also encouraged to attend the sessions of other groups if they missed or had a time clash with their own sessions. This offered program flexibility, and increased intervention compliance. It is worth noting that telephone contacts were made with all of those who could not participate in the group sessions to support the couples in their coping with cancer. While this was done out a desire of the researcher to help the couples, it was an extraordinary burden in terms of time and effort for the researcher/therapist. If those couples who attended the sessions of other groups and received telephone support are considered, the intervention compliance would increase to 100% for all of the participants in six sessions. Although this approach for telephone contacts may not be taken as compliance, these contacts offer feasibility and flexibility of the program. Given that couples are burdened with caregiving activities and face time constraints, it is conclude that offering flexibility for the program sessions is needed to decrease the barriers to completing interventions (Li & Loke, 2014b), thus increasing the retention rate of the intervention program.

The significantly higher level of self-efficacy of patients in the lost-to-follow-up sample than of those who adhered to the program indicated that the program is needed and benefited those who need enhancement in self-efficacy, who are not confident about their ability to cope with cancer. A further study is needed to test if the intervention should target cancer patients with lower self-efficacy as a criterion for recruitment.

12.5.2 The effects of the 4Cs program

Improvement was seen in the majority of the outcome variables of dyadic mediator, dyadic coping, dyadic appraisal, and dyadic outcomes.

Dyadic mediator

The results of this study showed that the self-efficacy of both spousal caregivers and patients improved. Self-efficacy was identified as a primary outcome measure that also had actor or partner effects on the majority of the outcome measures. It is also identified with the highest effect size (0.41) across all variables in this study.

No couple-based intervention study to improve self-efficacy in dyads was found (Heitzmann et al., 2011). There was one study that examined a family intervention for prostate cancer patients and their partners that assessed self-efficacy in illness and symptom management using the Lewis Cancer Self-Efficacy Scale (LCSES) (Northouse et al., 2007). It was reported that spouses in the intervention group had higher self-efficacy concerning how to manage illness symptoms than spouses in the control group at 4 months (LCSES, m=144.1 vs. 138.8; $P<0.05$) and 12 months (LCSES, m=143.8 vs. 137.8; $P<0.05$) after intervention. This is somewhat similar to the results of this present study, where self-efficacy was identified as a primary outcome measure.

Dyadic coping

Couples reported significantly higher level of dyadic coping according to the DCI after the intervention. This result is in accordance with another couple-based skills training intervention studies, which found that couples who received a skill-training intervention maintained a high level of dyadic coping (Heinrichs et al., 2012). The DCI assesses dyadic coping as perceived by (i) each partner about his/her own coping, (ii) each partner about the other’s coping, and (iii) each partner of how they cope as a couple (Bodenmann, 2008; Gmelch et al., 2008). Thus, the improvement in the DCI after the **4Cs** intervention benefited the couples together as dyads in coping.

Dyadic appraisal

The scores for the Cancer Related Communication Problem (CRCP) between cancer patients and spousal caregivers decreased significantly ($P<0.05$) after the intervention. The CRCP is used to assess whether patients and their partners have difficulty talking about cancer with each other (Kornblith et al., 2006). Thus, a decrease in the CRCP score indicates improved communication between patients and their spousal caregivers. Similar improvements in communication between patients and spouses have also been reported in other couple-based intervention studies in which the communication within cancer couples was assessed using the Lewis Mutuality and Interpersonal Sensitivity Scale (LMISS) (Northouse et al., 2007), the Relationship Communication Scale (Manne et al., 2011), and the Communication Subscale from the Partnership Questionnaire (Heinrichs et al., 2012). The finding of a review of couple-based intervention studies on couples coping with cancer indicated that in all of the intervention studies that were included, promoting communication between cancer patients and their spouses was a means of improving coping and adjustment to cancer (Li & Loke, 2014b). The better communication of the couples in this **4Cs** intervention study is consistent with those studies.

Dyadic outcomes

The results of this **4Cs** intervention program showed that couples experienced improved dyadic outcomes in the physical component summary (PCS) of SF-12, anxiety, and benefit findings. These findings are generally consistent with the results of a Web-based program (Northouse et al., 2014). The finding in this study that the spousal caregivers experienced greater improvement in the PCS than did the patients is inconsistent with that of another study that reported that the QOL physical function of the patients improved significantly more over time than that of the family caregivers (Northouse et al., 2014). That the PCS in the spousal caregivers in the present study was higher may be due not only to the fact that most of the patients in this study were in an advanced cancer stage, which may have impacted their PCS, but also because this **4Cs** intervention focused on helping spousal caregivers take good care of themselves. Compared to an improvement in PCS of SF-12, only marginal difference for MCS of SF-12 by time (P=0.079) seems unexpected. This may result from the fact that (1) all of the patients had advanced cancer, and (2) most of the families (60.7%) experienced a serious financial burden due to the cost of treating the cancer. The marginal difference may also due to the short follow-up time period (six-weeks).

The results of this study showed that spousal caregivers had significantly higher levels of anxiety (P<0.05) than the patients, although both partners reported decreases in their level of anxiety after the **4Cs** program. This was consistent with the findings of a cohort study that reported within-group improvements in the anxiety levels of both patients and spouses after they had received the intervention (Mohr et al., 2003), a focus group study on couples coping with cancer (Li et al., 2014), and a review of relevant literature (Hagedoorn et al., 2008). A similar report on improvements in benefit findings (positive emotions) was also identified for both couple-based intervention studies (Baucom et al., 2009; Heinrichs et al., 2012) and qualitative studies (Li et al., 2014; Molassiotis, Chan, Yam, Chan, & Lam, 2002).

The lack of any significant change in marital satisfaction was unexpected. This was inconsistent with the findings of previous couple-based interventions (McLean et al., 2008; McLean, Walton, Rodin, Esplen, & Jones, 2013). Couples in a focus group study also revealed an improved marital relationship during the journey of coping together with cancer (Li et al., 2014). This unexpected finding may perhaps be related to the characteristics of the sample in this study, including the diagnosis of advanced cancer and the serious financial burden on the family due to the cost of treatment. Another reason may due to the adoption of the Revised Dyadic Adjustment Scale (RDAS) in measuring marital satisfaction among couples in China, which may need to be amended for cultural relevance.

In summary, the results of the present study indicated that the **4Cs** program was effective in the majority of the outcome variables of dyadic mediators, dyadic coping, dyadic appraisal, and dyadic outcomes. The overall effect sizes ranged from small to medium (0.10~0.41).

12.5.3 The evidence supporting the P-LLCF

Given that the **4Cs** program was developed based on the P-LLCF, the acceptance, feasibility, and effectiveness of the intervention, as described earlier, is evidence that goes some way towards supporting the P-LLCF.

Further, the results of the SEM also support the P-LLCF in that the outcome measures at T1 (6 weeks post-intervention) indicate that Dyadic Mediators (self-efficacy), through Dyadic Coping (DCI) and/or Dyadic Appraisal (CRCP) have a direct or indirectly impact on the dyadic outcome variables acting as actor effects and/or partner effects in all six dyadic outcome models.

To summarize, it can be concluded from the findings of this intervention study that: (i) this **4Cs** program is acceptable and feasible; (ii) the **4Cs** program is effective on the majority of the variables of dyadic mediators (self-efficacy), dyadic coping (DCI), dyadic appraisal (CRCP), and dyadic outcomes (QOL in terms of physical health, anxiety, and benefit findings), with small to medium effect sizes for both cancer patients and spousal caregivers; and (iii) the findings from the post **4Cs** intervention (T1) provides evidence to support the P-LLCF in that the dyadic mediators, dyadic coping, and dyadic appraisal work together to benefit the dyadic outcomes.

Limitations and Future Research Directions

The present study makes new contributions to couple-based interventions on cancer couple dyads; however, it is essential to acknowledge that this study has limitations. The first limitation of this pre- and post-intervention study design is the bias inherent in all non-randomized studies (Schildmann & Higginson, 2011). Without a control group, factors other than the intervention could have an impact on the results of the study. Further testing of this program in a large, multisite RCT study is highly recommended. When testing a complex intervention, such as this **4Cs** program, it is considered beneficial and, indeed, crucial to include both qualitative and quantitative studies (Craig et al., 2008). It has been clearly stated that “Quantitative methods allowed statistical analysis of the impact of contextual variables on the outcome measures, while qualitative methods provided rich data to enhance understanding of precursory factors affecting the intervention effect” (Chan, Richardson, & Richardson, 2012) (p. 236).

That this study was conducted among a Chinese population may limit the generalizability of the results among populations of different cultural backgrounds. Further studies should be conducted both to test this program in different cultural contexts and to enhance the generalizability of the P-LLCF. In addition, the heterogeneity of the sample population, who were suffering from different types of cancer and undergoing differents kinds of treatment, may have influenced the effects of the intervention. Stratified sampling of those with a specific type of cancer and in a specific stage of cancer is highly recommended for a future study.

The minimum number of subjects was recruited for this study using SEM (Dorros, Card, Segrin, & Badger, 2010). The relatively small sample size did not allow the variables to be fully examined. Future studies and tests involving several institutions and larger sample sizes are highly recommended.

The choice of the outcome measurements also deserves mention. Three couples declined to take part in the program because of the requirement to complete a baseline questionnaire. Some of the couples who completed the questionnaire stated that the multiple measurements in the questionnaire were tiresome, and most took about 20-30 minutes to complete the questionnaire. Consideration should be given to shortening the questionnaire.

12.6 Implications for Practice

Despite the limitations of this study, the promising findings of this study point to several potential implications for practice. First, the SEM analysis of the outcome measures indicates that there are actor and partner effects between cancer patients and spousal caregivers. Treating couples as dyads in practice may be important and have positive effects on the cancer couples. It is also important to note that it is of such great significance for a patient to receive support from his spouse that getting good support from friends or other family members does not compensate for inadequate spousal support (Pistrang & Barker, 1995).

Second, the finding that spousal caregivers experienced more anxiety than did the patients also alerts healthcare professionals of the need to pay more attention to spousal caregivers, who often sacrifice their own health in the process of providing care, and to provide support to enhance self-care on the part of the caregiver. It was emphasized in a study that improving the self-care ability of caregivers benefits not only caregivers but also their patients, and thus the couple as dyad coping with cancer (Northouse et al., 2010).

The essential components of this **4Cs** program and its outcome measures covered all of the aspects included in the P-LLCF. In providing support to cancer couples, the intervention is labor intensive, although the comprehensiveness of the intervention is beneficial to cancer couples. This type of intervention should be included as part and parcel of the service provided to couples (and family members) when a member of their family is diagnosed with cancer instead of being considered an extraordinary service.

12.7 Conclusion

This study investigated and identified the acceptability, feasibility, and effectiveness of a Caring for Couples Coping with Cancer (4Cs) program using an intervention design. This feasibility study is arguably an essential step in the development and testing of an intervention, prior to conducting a large-scale evaluation (Craig et al., 2008).

Although this study showed generally positive effectiveness across the majority of outcome variables, including dyadic mediators, dyadic coping, dyadic appraisal, and dyadic outcomes, a further evaluation of this **4Cs** program in a large, multisite RCT is needed. It is also suggested that it is crucial for a mixed-methods study design to include both qualitative and quantitative studies for a further in-depth evaluation the program.

PART III CONCLUSIONS AND SUGGESTIONS FOR FUTURE RESEARCH

Chapter 13

Summary of the thesis

13.1 Introduction

This thesis focuses on the first two phases: development and determination of feasibility/piloting in developing-evaluating-implementing a complex intervention according to the Medical Research Council’s (MRC) framework (2008). In addition to extensive reviews of literature, FIVE separate inter-related and sequential studies were conducted and presented (Study I to Study V) accordingly to reflect the phases and steps. Figure 13-1 illustrates these steps taken and studies conducted corresponding to the MRC framework.

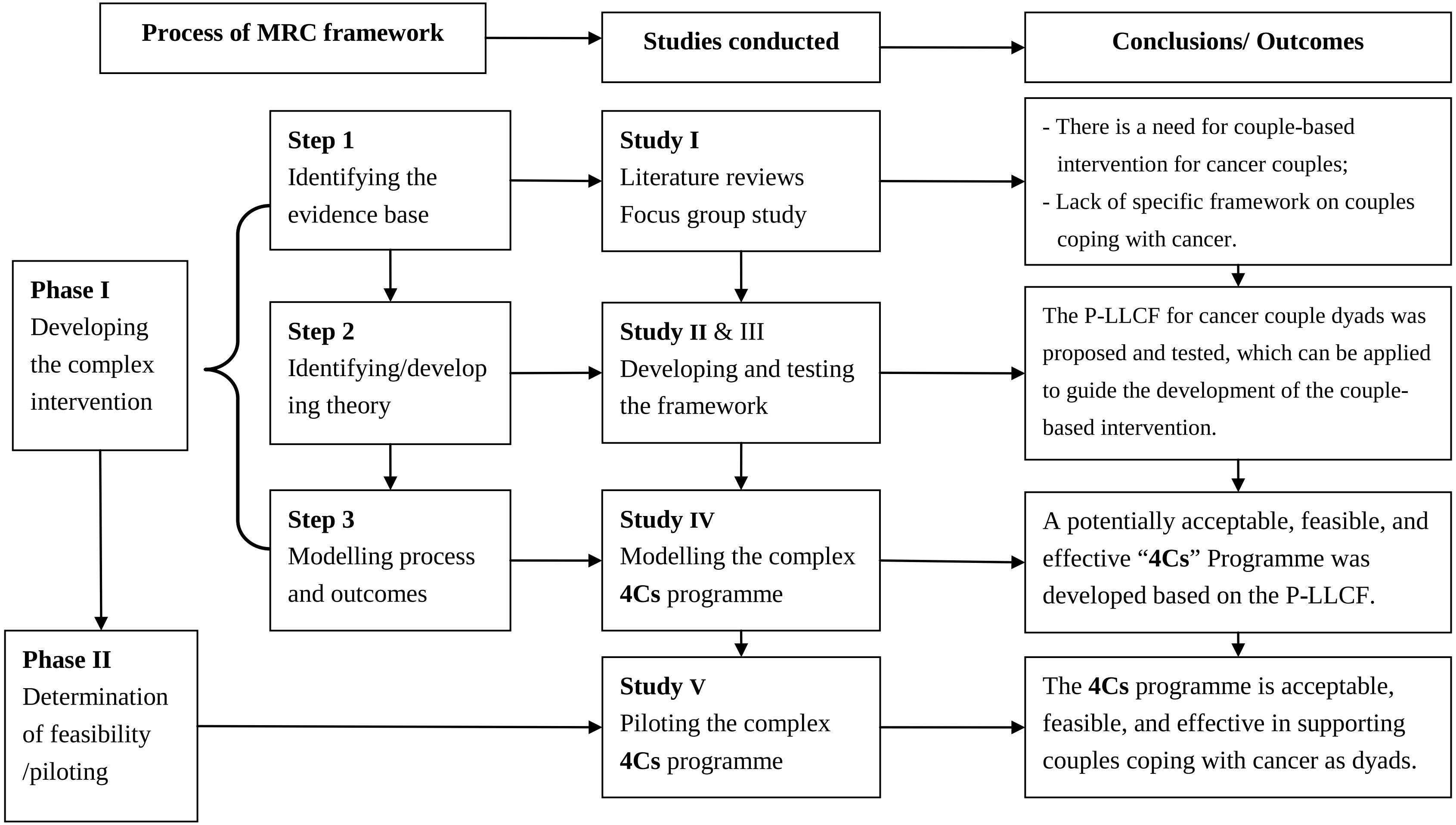


Figure 13-1. Steps taken and Studies conducted corresponding to MRC framework

13.2 Main findings

PHASE I: DEVELOPING THE COMPLEX INTERVENTION

STEP I: IDENTIFYING EVIDENCE-BASE

Reviews of literature (Chapter 2 -7) and Focus group study (Chapter 8-study I)

Chapter 7 described the main finding and study gap identified from the extensive reviews of literature. It was identified that few couple-based interventions have been found so far focused specifically on supporting spousal caregivers and cancer couples in their journey of living and coping with cancer as dyads. These reviews provided some valuable suggestions on interventions to be developed for couples coping with cancer. The shift of study focus from an individual level to the caregiver-patient dyads also raises a need to develop a dyadic model specifically on cancer caregiving.

The focus group interviews with cancer patients and spousal caregivers identified four themes and 15 subthemes after a conventional content analysis. The four themes include communication dynamics, living with changes, negative and positive impacts, and network of support. Based on the findings, a preliminary conceptualization of the couples' experience of coping and living with cancer as a whole was drawn. The participants in the study also expressed their need of a couple-based intervention. This study provided insights to healthcare professionals regarding daily struggles of couples living with cancer, and the development of intervention program to support these couples.

STEP II: IDENTIFYING /DEVELOPING THEORY

Developing and testing the framework (Study II & III- chapter 9-10)

Chapter 9 illustrated the proposed Preliminary Live with Love Conceptual Framework (P-LLCF) for Cancer Couple dyads, which was developed based on the conceptual frameworks adopted in related literature on spousal caregiving for patients with cancer, and finding from the focus group study. This P-LLCF sheds new light on the study of cancer couple dyads. It will be potentially valuable for guiding the related research and development of interventions on cancer couple dyads. The exploration of the inter-relationships among different components will aid the development of supportive couple-based interventions in the context of cancer. Future research is needed to assess the effects of interventions on dyadic adjustment, as well as the feasibility and applicability of this framework for cancer dyads.

Based on the findings and suggestions from **Chapter 9**, the P-LLCF using both qualitative and quantitative approaches was then tested (**Chapter 10**). Finding showed that the results of the concept analysis demonstrated that the P-LLCF can represent a phenomenon in reality: in this case the experience of Chinese cancer couple dyads. The concepts identified in the P-LLCF are relevant to the phenomenon under scrutiny, and attributes of the concepts are consistent with those identified in the focus group study involving Chinese cancer couple dyads. The quantitative approach showed that inter-relationships exist among the components included in the P-LLCF, and that the event situation will impact the outcomes of caregiver-patient dyads directly or indirectly through Dyadic Mediators. The dyadic mediators, dyadic appraisal, and dyadic coping are interrelated and work together to benefit the dyadic outcomes.

This study provides evidence that supports the interlinked components and the relationship included in the P-LLCF. The findings of this study are important in that they provide healthcare professionals with guidance and directions according to the P-LLCF on how to plan supportive programs or strategies for couples coping with cancer.

STEP III: MODELLING PROCESS AND OUTCOMES

Study IV Modelling the complex 4Cs programme (Chapter 11)

Guided by the MRC guidelines, a potentially effective, feasible, and acceptable ‘Caring for Couples Coping with Cancer “**4Cs**” Programme’ to support couples coping with cancer as dyads was developed. A study was conducted to pilot and evaluate the feasibility, modelling, and outcomes of this 4Cs programme.

The Essential components and focus of the ‘**4Cs**’ intervention programme have been developed based mainly on the P-LLCF for Cancer Couple dyads. It takes into account the three domains of the P-LLCF: Event Situation, Dyadic Mediators, and Caregiver-patient Dyads. This programme consists of six weekly sessions, with each session lasting for 90 minutes. The main contents of the sessions of the **4Cs** programme are: primary stressors (section 1); secondary stressors (section 2); dyadic mediator (section 3); dyadic appraisal (section 4); dyadic coping (section 5); and a programme overview (section 6). A guidebook for cancer couples titled **'Live with Love: Hope for the best, prepare for the worst'** has also been developed based on the reviews of the literature and the P-LLCF, which was used to complement the group intervention programme.

Although the development of the "**4Cs"** Programme' was conducted with supporting evidence from numerous reviews of the relevant literature, the findings of a focus group study on cancer couple dyads, and the proposed preliminary Live with Love Conceptual Framework (P-LLCF), which may be potentially acceptable, feasible and effective, it is needed to pilot and evaluate the feasibility, modelling, and outcomes of this **4Cs** programme.

PHASE II DETERMINATION OF FEASIBILITY/PILOTING

Study V Piloting the complex 4Cs programme (Chapter 12)

A pre- and post-intervention study design was conducted among cancer patients and their spousal caregivers. Among the 135 couples approached, a total of 117 dyads were successfully recruited at baseline, with 92 dyads successfully followed-up at 6 weeks. An information booklet and six face-to-face group sessions of the **4Cs** program were offered to couples as dyads.

Findings revealed that the recruitment and retention rates were 86.7% and 78.6%, respectively. Significant improvements were seen in the couples' scores on overall (total) self-efficacy ($P<0.01$), CRCP ($P<0.05$), DCI ($P<0.05$), the physical component summary (PCS) of SF-12 ($P<0.05$), anxiety ($P<0.01$), and benefit findings ($P<0.05$) from baseline to 6 weeks post-intervention. Spousal caregivers scored significantly higher on self-efficacy ($P<0.05$), the physical component summary ($P<0.01$), and anxiety ($P<0.05$) than the patients. No significant effects on time and role of marital satisfaction were identified. The overall effect sizes calculated in this study ranged from medium to small. The SEM of all six models resulted in convergence and showed goodness of fit to the data and variables, supportive of the constructs in the P-LLCF.

This study provides evidence suggesting that the **4Cs** program is acceptable, feasible, and effective in supporting cancer couples coping with the illness as dyads. Although a generally positive effect was identified in the pre- and post-intervention outcome measures, further evaluation of this **4Cs** program in a large, multisite RCT is needed to provide substantial evidence.

In summary, it can be seen that the findings from the five conducted studies supported one after another. However, it is worth noting that their relationship is not a simple linear recurrence relation, they may inter-related and supported in a more complicated and cycle model. Consequently, more attention deserves to pay on the further evaluating and implementation of the programme.

13.3 Implication for practice

It is suggested that healthcare providers to treat couples as a unit in practice may be important and create positive effects on cancer couples. Healthcare professionals also need to (1) be sensitive to the couples' needs and concerns; (2) offer sufficient and useful information to couples who are coping with cancer; (3) encourage and help spousal caregivers to take care of themselves while coping with the changes in their spouses; and (4) instill realistic hopes in couples and help them to sustain a positive attitude with a focus on the future, not just on the present.

Further research focusing primarily on a single intervention component or focus and the related primary outcome measure is needed. It is also needed to assess the outcome of interventions that focus on different components, and to develop measurements to assess dyadic adjustment / outcomes in nursing practice in future research.

13.4 Limitations and future research recommendation

The present study makes new contributions to couple-based interventions on cancer couple dyads; however, it is essential to acknowledge that this study has several limitations.

Reviews of literature

The review of the literature that was conducted to identify an evidence base did not include studies published in languages other than English or Chinese, which may lead to a potential bias.

Focus group study (Chapter 8, study I)

Of the four focus groups with spouses, the first three groups had collectively nine couples who were interviewed together, while the participants in the fourth group consisted of seven spouses and one patient. Although the themes that emerged from the analysis were found to be common ones among the couples who participated in this study, the lack of complete sets of couples in all of the groups, which came about because this was more convenient for the individual patients, might have prevented us from acquiring a deeper understanding of their experiences as dyads through their interactions during the interviews. Future studies should incorporate more complete sets of couples in each focus group and a wider range of settings to enhance the transferability of the study.

The focus group format naturally results in a wide range of responses among the participants in the group. Although in this study the focus group interviews yielded in-depth and rich data (which may not have been as easily obtained using other methods), there may have been variations in the way the interviews were conducted by the researchers. Some areas of discussion might have been probed in more depth than others in particular groups. The findings of this study should be interpreted with the specific purpose of the study in mind. The design was intended to provide better understanding of the experiences of Chinese couples living and coping with cancer in China, or couples of a similar ethnic background. The results can be used as a basis for developing intervention programs that are meaningful for this population.

Developing the P-LLCF (Chapter 9, study II)

This P-LLCF was developed based on the assumption that the relationship of caregivers and patients will be strengthened by the cancer/caring experience. It is also the intention of evoking the deep inner love that couples have for each other, and that the couples could find benefits from the illness including feeling of emotional closeness, and relational intimacy. However, there must be scenarios that patient-carer dyads have been separated and only come together due to the illness; that the carers feel burdened, guilty, take on without choice, or are resentful of the situation. Future research is needed to test if interventions developed based on this P-LLCF will benefit these different scenarios among patients and carers.

Testing the P-LLCF (Chapter 10, study III)

Although the findings of this mixed-methods study partly support the P-LLCF, the focus group interviews of the qualitative study that were conducted among Chinese cancer couples may limit the generalizability of the results to populations with different cultural backgrounds. Further studies should be conducted to validate the P-LLCF in the context of different cultures, to enhance the generalizability of the P-LLCF.

The minimum number of subjects was recruited for this study. The relatively small sample size did not allow the variables to be fully examined. Future studies and tests involving several institutions and larger sample sizes are highly recommended.

The conventional sampling approach in this study in identifying couples who attended the oncology clinic together, may lead to potential bias recruiting those couples who had a better relationship to begin with and were willing to be interviewed. This is an aspect of limitation on subject recruitment inherent in studies on married couples (Schildmann and Higginson, 2011), in that couples who were not in good term would not have agreed to take part in intervention study to support their spouse. Hence one must be caution in interpreting the results of this study.

The choice of the measurements for the domains also deserves mention. The domains in the P-LLCF (Event Situation, Dyadic Mediators, and Caregiver-patient Dyads) and the constructs (primary and secondary stressors, Dyadic Appraisal, Dyadic Coping, and Dyadic Adjustment/Outcomes) cannot be evaluated directly as latent variables. These domains and constructs were evaluated indirectly using observable/measurable variables. One should note that different choices of measurements for the same latent variables may affect the outcomes. Further studies are needed to examine the best measurements for these latent variables that have been included in the P-LLCF.

This was a cross-sectional study design in that the findings cannot infer causation among variables. Longitudinal research, particularly on couple-based intervention programs developed based on the P-LLCF, is highly recommended to further test this framework, and may provide richer and causal inferences to the variables.

Developing the 4Cs programme (Chapter 11, study IV)

Although guided by the MRC framework, as the first development of a complex intervention for cancer couple dyads in China, the acceptability of the procedures of the programme, and the recruitment and retention of participants to achieve the proposed number of participating dyads, remain uncertain.

Piloting the 4Cs programme (Chapter 12, studyV)

One limitation of this pre-intervention and post-intervention study design is the bias inherent in all non-randomized studies (Schildmann & Higginson, 2011). Without a control group, factors other than the intervention could have an impact on the results of the study. Further testing of this program in a large, multisite RCT study is highly recommended.

Again, that this study was conducted among a Chinese population may limit the generalizability of the results among populations of different cultural backgrounds. Further studies should be conducted both to test this program in different cultural contexts and to enhance the generalizability of the P-LLCF. In addition, the heterogeneity of the sample population, who were suffering from different types of cancer and undergoing different kinds of treatment, may have influenced the effects of the intervention. Stratified sampling of those with a specific type of cancer and in a specific stage of cancer is highly recommended for a future study. The relatively small sample size did not allow the variables to be fully examined. Future studies and tests involving several institutions and larger sample sizes are highly recommended.

Regarding the outcome measurements, three couples declined to take part in the program because of the requirement to complete a baseline questionnaire. Some of the couples who completed the questionnaire stated that the multiple measurements in the questionnaire were tiresome, and most took about 20-30 minutes to complete the questionnaire. Consideration should be given to shortening the questionnaire.

13.5 Reflection on the project

Identifying research topic

In the very beginning of my study, my supervisor and I had several meetings to get to know each other and discussed on the potential valuable and meaningful research topic for my PhD project. We explored into our common research interest, clinical and teaching experience, and identified several potential research areas. My supervisor was also mindful that we ***need to identify a research 'program' for my lifelong research direction beyond graduation.***

During our discussion, it was revealed that besides being a nurse academic, I am also a qualified psycho-counsellor, and have written text books on communication skills. I had also practiced as a physician in internal medicine treating cancer patients, and published research papers related to cancer care. We found that we both were very much interested in couple relationship, and how illness may affect a married couple's coping. This also matched very well with my supervisor's research interests related to family and women's health. We were excited and agreed that my PhD project should be somewhere related to ***married couples*** and ***cancer***.

We were not clear as what kind of research has been done for married couples and cancer, and what needs to be done. We so decided to start with extensive review of literatures on related studies to gain ***a better understanding of the phenomenon to identify the direction*** for my PhD project.

The Medical Research Council (MRC) Framework as guidance

As we know that an intervention will be developed for this PhD study, ***the MRC framework*** for developing and evaluating complex interventions came into place. According to the MRC framework, it is our plan to identify evidence, identify/develop theory, and modeling the process and outcomes. It was my plan to adopt the ***MRC framework in the presentation of my thesis.***

Conducting series of review of literatures for the understanding of the phenomena

A series of review of literature were then started. Given that the potential targeting population of my study would be the Chinese spousal caregivers of cancer patients, the first review of literature intended to review the studies conducted in Mainland China on spousal caregivers of cancer patients. However, while we found some studies on family caregivers of cancer patients, few were specifically on spousal caregivers (Li & Loke, 2012). It was found that although family caregivers of cancer patients in China have received extensive attention from clinicians and researchers, studies still in its infancy stage. ***This is the only review paper that was published in Chinese, when I encountered difficulty to write a manuscript in English at the beginning of my study.***

A series of reviews of literature related to spousal caregivers of cancer patients was then conducted for a better understanding of the spousal caregiving phenomenon globally. In the review of literature on spouses' experience of caregiving for cancer patients, it was found that the spouse for cancer patients had both negative and positive experiences. There were vast body of research on the topic; consequently, three papers were published that covered ***the aspects of spousal caregivers for cancer patients***: “spouses' experience of caregiving”, “a spectrum of hidden morbidity among spousal caregivers for cancer patients”, and “the positive aspects of spousal caregivers for cancer patients”.

During this process, it took me several months to figure out how to present the comprehensive findings in the related studies. Although I really enjoyed the learning process guided by my supervisor in writing these reviews, being the first time writer of manuscripts in English, I believe it is not only a painful process for me but also for my supervisor. I still could remember that in between the scribbles all over my paper submitted to my supervisor, I could not help but laugh when I saw my supervisor written “I am lost”, “I am lost again…” I had doubt at the time if I could ever published in English, I even doubt if I could ever graduate with my PhD. Nevertheless, ‘***giving-up’ is not a word in my dictionary or my personality***. I told myself it could be a positive experience and opportunity for growth, though it broke my ‘comfort zone’. My supervisor also kept encouraging me and guiding me on the track. It is quite many rounds of revisions and re-writes that the manuscripts were completed. Thinking back now, I really appreciate my supervisor’s not giving me up at those days.

From the first three reviews, we found that the couples experience their situations not only at the individual level but there were ***mutual impacts*** between the couples, coping with cancer as dyads. Further review of literature to explore the concept of ‘mutuality’ between the spousal caregiver-cancer patient dyads was then conducted. It was at this point that my supervisor and I decided that we should ***shift the target population of my study from spousal caregivers to caregivers-patient dyads***.

We were unsure if there were interventions focusing on caregivers-patient dyads as target population. A review was conducted specifically on ***couple-based interventions for couples coping with cancer*** to gain a better understanding regarding the types, contents, approach, and outcome measurements of existing interventions for couples coping with cancer. However, few programs were found specifically focusing on the cancer couples as caregiver-patient dyads.

Reflecting on this process of reviews, we travelled from ‘unclear’ to a clear direction and focus of my research direction. These five reviews of literatures laid the crucial fundamental for our understanding of the phenomena of cancer couples coping as dyads, and shed light on the path of this PhD study. ***A dyadic model specifically on cancer caregiving to guide the development of intervention is clearly needed***. This framework will also be useful in guiding the development of an intervention to support couples coping with cancer as dyads.

A focus group study to identify the receptive of Chinese cancer couples for intervention

The reviews demonstrated a need for couple-based program to support cancer couples for their coping with cancer as dyads. However, majority of these studies were conducted in western country, the experience of spousal caregivers and cancer patients in China is under-studied and their receptive to intervention was uncertain. For a better understanding the reality and need of the caregiver-patient dyads in China, the focus group study was conducted.

The interviews of the cancer couples in China taught me a lot! I was impressed by the couples' willingness to share their experiences in coping with cancer as dyads; they were even willing to support other couples in the group. The stories of their struggles in this unexpected life event touched my heart, and ***convinced me that these couples were receptive to help and needed the support from health professional***.

A construction and naming of a dyadic conceptual framework

The review of relevant intervention studies showed that although the interventions adopted various theoretical frameworks to guide their design, there was no theoretical framework specifically addresses the process and needs of couples coping with cancer at the dyadic level. We then proposed the preliminary framework for Cancer Couple dyads to guide the development of a theory-directed intervention specifically for cancer couple dyads.

The way how my supervisor and I together came up with the framework is worth mentioning. We gathered all the frameworks identified, printed the framework diagrams on big A3 size papers, spread on a big table in one of our School's conference room, we then created a matrix table to delineate the key constructs/components from each framework under scrutiny, and to discuss and resolve any disagreements. Keeping in mind of the findings from all the reviews of literature and the expressed views from the interviewed couples, we brainstormed about ways to synthesize the broad range of concepts and variables into a preliminary conceptual Framework for Cancer Dyads. It was till midnight that we finally came to the skeleton of a preliminary framework. ***The resulting preliminary framework for cancer couple dyads appeared in front of us resembles the*** *Chinese character "吉," meaning "fortune"*, exactly what we wanted to see among the cancer couples. The thought of this gave us much excitement! Although we were really tired, and the process was also extremely painful, ***this memory lives vividly in my mind (probably in my supervisor's too) as a joyful, creative, and rewarding moment of our joint venture***!!!

The preliminary framework 'baby' was born. The creators (parents) were searching for a name for this preliminary framework for easy reference. With the hope that couples will love and be loved in the process of coping with cancer together, the framework was given the name of a ***Preliminary Live with Love Conceptual Framework (P-LLCF).*** We do hope that this is the name of the framework other researchers in the field will refer to in their study when adopting our framework.

Secretly, the name P-LLCF was given with an underlying reason. The family names of the two 'creators' of this framework are "**Li** and **Lo**ke", when transforming the first two letters into "**Li**ve with **Lo**ve", gives the names of the baby framework.

The Caring for Couples Coping with Cancer Programme – 4Cs

After constructing the framework, the content of a ***'Caring for Couples Coping with Cancer Programme'*** "**4Cs**" was delineated to provide support to the couples. The intervention programme was carried out in Wuxi, China, to establish the acceptability, feasibility, and effectiveness of the programme.

In Wuxi, where I implemented this meaningful study, was also where the lonely and boring road began! From July to November, 2013, I worked on the detailed content of the programme, finalizing the questionnaires, writing the "Live with Love" booklet, and paid numerous visits to the hospital ***to negotiate patient access and arrangements***.

The delivery of programme was rewarding. I was encouraged by the couples who waited for me on the day of group sessions, and those who expressed their gratitude. The communication I had with the couples made me felt as if I were a member of their families. I was touched by every special story that the couples shared with me. For those who could not attend the group sessions, I made telephone calls to contact them with the intention to provide support if needed. Although it cost extraordinary time and effort, I felt the time was well spent and meaningful. It was my wish to help the couples ***"to live caring and being cared"***.

Looking back, I wish I conducted a process evaluation to get a better understanding of the intervention process, to gain insight into how this intervention can be optimized and what made the intervention successful. Also, I was too ambitious and unrealistic to focus on all of the constructs and outcome measurements of the P-LLCF in one single intervention study. The questionnaire was also a bit long for the couples.

The art of thesis presentation

When it came to the time for thesis writing, I did not expect to have much difficulty, since I had published papers on almost every single step of my research study: from reviews of literature, development and testing of the framework, to development of a complex intervention program.

To me, I am proud of the meaningful and fruitful project in my PhD study, however, knowing the way to present the works I have done ***is an art***. This art is to present my study in a logical manner for those who have not been involved in the study process to understand why we did what we did.

When I am near to the completion of my PhD study, I realize that I have not only conducted a project for my PhD study, but also started the beginning of my research into cancer care. This research topic is a beginning study opening up a door to a program of research in my career path. This is exactly the intention "***to identify a research 'program' for a lifelong research direction beyond graduation".***

Summary of insight – surviving the PhD study

- ✓ It is important to identify a research study leading to a program of research

- ✓ It is important to identify a research of interest that one is enthusiastic about, and fits with one’s own clinical background
- ✓ Gain a comprehensive understanding of the existing research on the selected topic for direction of research
- ✓ Start writing at the beginning of the study and produce manuscripts at each step of your study (these publications will constitute the PhD thesis, don't wait till at the end of study to start writing)
- ✓ Learning from the supervisor’s and reviewers’ comments (they may ask questions that are difficult to answer but make you think more of your study) – don’t be discouraged
- ✓ Be creative, and positive
- ✓ One needs to start writing in order to gain confidence in writing for publications
- ✓ Love your study and respect your study participants (the participants helped me in finishing my study, I give them the service needed in return- fair deal)
- ✓ PhD is only the beginning, not the end!

13.6 Summary

Guided by the Medical Research Council’s (MRC) framework, this project has conducted the first two phases: development and determination of feasibility/piloting in developing and piloting the 4Cs programme. Findings provide evidence that suggest the 4Cs programme is acceptable, feasible, and effective in supporting cancer couples coping with cancer as dyads. General positive effectiveness across majority outcome variables was identified from pre-intervention to post-intervention.

However, further evaluating of this 4Cs programme in a large, multisite RCT is needed before its implementation.

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Appendices

*English and Chinese versions included

Table 2-1 Summary of studies on stress-process of spousal caregiving for cancer patients

Quantitative studies

Authors	**Aims**	**SD**	**Samples/Gender of SC/ Time Points**	**Instrument Used**	**Significant Findings**
Baider et al. 2003 (Israel)	To identify and compare the psychological distress of couples with prostate and breast cancer	C	118 prostate cancer couples; 169 breast cancer couples. **Time point:** 23.3 months after diagnosis.	- The Brief Symptom Inventory (BSI, to assess symptoms of psychological distress); - Perceived Family Support (PFS).	- MCG were significantly more distressed (BSI, m=65.0) than FCG (BSI, m=59.2). - MCG received more family support than the FCG (PFS, m=14.4 vs. 13.7).
Barnoy et al. 2006 (Israel)	To examine the influence of correspondence in informational coping style on the psychological reaction of cancer patients and their spouses	C	98 couples SCG: males 45, females 53. **Time point:** in the course of ambulatory chemotherapy, with 27.3 months after diagnosis	- The Miller Behavioral Style Scale (MBSS, to assess information seeking style, i.e., monitors/blunters); - The Mental Health Inventory (MHI, Veit & Ware, 1983) to assess psychological well-being and psychological distress.	- FCG experienced more psychological distress than MCG (MHI, m= 5 vs. 6). - Caregivers' higher blunting was associated with higher psychological distress ($b = .31$, $t = 3.67$, $p < .01$). - A higher correspondence in level of blunting between caregivers and patients was associated with a higher psychological distress and a lower well-being in caregivers ($b = .17$, $t = 2.13$, $p < .05$ and $b = -.22$, $t = 2.29$, $p < .05$, respectively).

Colgrove et al. 2007 (USA)	To examine the moderating effects of spirituality and gender spousal caregivers' mental and physical health	C	403 couples SCG: males 184, females 219. **Time point:** approximately 2 years after diagnosed with cancer.	- Functional Assessment of Chronic Illness Therapy-Spirituality (FACIT-Sp); - Pearlin Stress Scale (PSS); - Medical Outcomes Study Short Form-36 (MOS-SF36).	- Caregiving stress (PSS, m=6.67) was associated with poor mental functioning (SF36, m=50.54), which was less prominent among caregivers with a high level of spirituality (stress-buffering effect). - No gender differences were found in stress-buffering or aggravating effects of spirituality on mental and physical health of caregivers.
Goldzweig et al. 2009 (Israel)	To assess psychological distress and gender difference among middle- and older-aged colorectal cancer patients and their healthy spouses	C	231 couples SCG: males 90, females 141. **Time point:** 2-6 years after diagnosis.	- The Brief Symptom Inventory (BSI); - Impact of Event Scale (IES); - Perceived Family Support (PFS); - the ENRICH Marital Satisfaction Scale; - Cancer Perceived Agents of Social Support (CPASS).	- MCG were more distressed than FCG (BSI, m= 61.48 vs. 55.70). - MCG also reported receiving more support from their wives than did the female caregivers (CPASS: spouse scale, m= 4.27vs. 4.03). - FCG had higher level of marriage satisfaction than MCG (ENRICH, m=3.72vs. 3.66). - FCG also had a lower level of marriage satisfaction than their husbands (ENRICH, m=3.72 vs. 3.91). - MCG reported higher levels of marriage satisfaction than their wives (ENRICH, m=3.66 vs. 3.63).

Gustavsson-Lilius et al. 2007 (Finland)	To investigate the sense of coherence (SOC)–distress association in cancer patients and their partners	L	123 couples SCG: males 68, females 55. **Time points:** at the time of diagnosis (T1); 8 (T2) and 14 (T3) months post diagnosis.	- A 12-item Finnish short version of the original 29-item Orientation to Life Questionnaire (OLQ, to assess SOC); - The Beck Depression Inventory (BDI); - Endler Multidimensional Anxiety Scales (EMAS-State).	- FCG had more depression at T1 and T2 than MCG (BDI, m= 6.2 vs. 4.0 and 6.0 vs. 3.9), and anxiety symptoms at all three time points (EMAS –state, m= 39.5 vs. 33.5, 35.3 vs. 30.1 and 37.3 vs. 30.8 respectively). - No gender differences were found regarding the change of SOC in caregivers. - Spousal caregivers SOC was negatively related to patients' level of anxiety (r = - 0.18) and depression (r = - 0.21) at 14-month follow-up. - Spousal caregivers' own baseline SOC and follow-up SOC were negatively related to their own distress symptoms at all assessment points (r's varied from 0.43 to 0.51). - Patient follow-up SOC was positively related to their spousal caregivers follow-up SOC (r=.24), and negatively related to spousal caregivers follow-up depression (r=-.21) and anxiety (r=-.27).
Hagedoorn et al. 2000 (Netherlands)	To further knowledge on gender and role differences relating to psychological distress and quality of life of couples dealing	C	Patient Association (PAS, 105 couples, SCG: 34 males, 71 females), Hospital (HS, 68 couples, SC: 36 males, 2 females), healthy control (80 couples). **Time points:** time	- Epidemiological Studies Depression Scale (CES-D); - Cantril's Ladder (for QOL);	- FCG perceived more psychological distress (CES-D, m= 11.83 vs. 8.1 in PAS and m=12.50 vs. 7.56 in HS respectively) and a lower quality of life (QOL, m=7.09 vs. 7.55 in PAS and m=6.84 vs. 7.69 in HS respectively) than MCG.

	with cancer		since diagnosis: 5.02 (PAS) and 2.81 (HS) years.		
Hagedoorn et al. 2002 (Netherlands)	To examine identity-relevant stress as a possible explanation for gender difference of psychological distress	C	68 couples; SCG: males 36, females 32. **Time point:** couples were in treatment or check-up.	- Partners' self-efficacy in providing support (Kuijer et al, 2000); - A subscale of the Maslach Burnout Inventory(MBI); - Social Support List; - Epidemiological Studies Depression Scale (CES-D, Dutch translation).	- FCG reported stronger feelings of personal accomplishment than MCG (MBI, m= 29.18 vs. 25.64). - FCG also scored higher on distress than MCG (CES-D, m= 12.93 vs. 7.50). - No gender differences were found in caregivers' self-efficacy and their supportive and unsupportive behavior. - FCG who reported to have higher self-efficacy in providing support experienced less stress in caregiving. This association was not found in MCG.
Haley et al. 2003 (USA)	To examine the risk factors and protective factors as predictors of family caregiver well-being	C	40 couples of patients with dementia and 40 couples of patients with lung cancer SCG: 16 males, 64 females. **Time point:** within 14 days after the patient's admission to hospice.	- Epidemiological Studies Depression Scale (CES-D); - Life Satisfaction Index-Z (LSIZ).	- Female gender, caregiver health problems, and negative social interactions were risk factors for poorer caregiver well-being. - Caregivers had a high level of depression (CES-D, m= 17.73, scores over 15 have been found to be strong associated with clinical depressive disorders) and a low level of life satisfaction (LSIZ, m=14.64, far below published means for older adults). - FCG had higher depression (r=0.29, p<0.01) and lower life satisfaction (r =0.27, p<0.05) than MCG.

Kim et al. 2006 (USA)	To examine how the caregiver's perception of providing care to a spouse with cancer differs by gender	C	429 couples SCG: males 190, females 239. **Time point:** 2 years after diagnosis.	- Caregiver Reaction Assessment Scale (CRA), to assess caregiver's esteem; - Medical Outcomes Study Short Form-36; - The Pearlin Stress Scale (Pearlin et al., 1990).	- Mean score of caregive's esteem and caregiving stress was 30.79 and 6.68 respectively. - Compared to FCG, MCG were likely to report higher levels of caregiver's esteem (r=0.18, p<0.01), which in turn was related to lower levels of caregiving stress (r=0.09, p<0.05). - The care-recipient's physical functioning directly influenced caregiving stress, regardless of caregiver's gender. - The majority of MCG reported that they received help from family and friends (84%), whereas only half (51%) of the FCG reported receiving such help.
Kim et al. 2007 (USA)	To explore gender differences in the associations of attachment qualities and the level of caregiving involvement and difficulties in caregiving	C	400 couples SCG: males 192; females 208. **Time point:** approximately 2.1 years after diagnosed with cancer.	- Measure of Attachment Quality (MAQ); - 17-items self-developed care tasks scale: frequencies and difficulties.	- Interaction between attachment security and the frequency of emotional care: greater security of attachment of FCG related to providing more frequent emotional care, whereas among MCG, greater avoidance related to less frequent emotional care. - Interactions between attachment anxiety and frequencies of tangible and medical care: more anxiously attached FCG provided more frequent tangible care, whereas more anxiously attached MCG provided less frequent medical care.
Kim et al. 2008 (USA)	To examine the prediction of caregiver well-being from the	C	314 couples. SCG: males 154; females 160.	- Measure of Attachment Quality (MAQ); - 8-items self-developed	- Autonomous motives for caregiving were reported mostly. - Attachment security (assessed with respect to the

	relationship qualities and from motives		**Time point:** approximately 2.2 years after diagnosed with cancer.	Reasons for Providing Care (RPC); - Measure of Benefit Finding; - Satisfaction with Life Scale; - Epidemiological Studies Depression Scale (CES-D).	spouse) related positively to autonomous motives for caregiving and finding benefit in caregiving; attachment anxiety related to introjected motives for caregiving and more depression. - MCG scored higher on external caregiving motives than FCG, and FCG reported more benefit finding than MCG. Among MCG, autonomous motives related to less depression, and introjected motives related to less life satisfaction and more depression. Among FCG, autonomous motives related to greater benefit finding.
Langer et al. 2003 (USA)	To examine the changes and dyadic differences of marital satisfaction and negative affect over time after SCT(Stem Cell Transplantation)	L	Pre-transplant (131 couples, 65males), 6 months post-transplant (78 couples), 1 year post-transplant (76 couples, 40 males). A non-medical group as a normative sample.	- The Profile of Mood States (POMS); - The Dyadic Adjustment Scale(DAS); - The Short Form 36 Health Survey (HSSF36, patients only).	- FCG were more depressed (POMS, m=0.98 vs. 0.57) and anxious (POMS, m=1.33 vs. 0.89) as compared to MCG. - With respect to marital satisfaction, couples were matched in their perceptions of the relationship prior to transplantation but grew mismatched over time. - Change in caregiver's marital satisfaction (from pre-transplant to 1 year post-transplant) was predicted only by caregivers' gender, not patient physical, nor psychosocial characteristics. - FCG were less satisfied with their marital satisfaction than male caregivers (DAS, m=38.45vs. 41.38).
Langer et al. 2003 (USA)	To explore the effects of gender and role	L	131 Couples hematopoietic stem cell transplant	- The Profile of Mood States (POMS).	Female caregivers reported greater depression and anxiety than male caregivers. - In gender-specific normative comparisons, male and

	(patient/spouse) on mood disturbance in the cancer setting		(HSCT). A nonmedical sample for normative comparison. **Time point:** before HSCT, 6 months, 1 year, and 2 years after HSCT.		female patients and male caregivers showed elevations in negative affect before transplant ($P < 0.01$) but not after ($P > 0.05$). - Female caregivers, in contrast, showed elevations at multiple time points ($P < 0.01$), suggesting slower resolution of distress over time.
Langer et al. 2010 (USA)	To examine the trajectory of marital adjustment, satisfaction and dissolution among hematopoietic stem cell transplant (HSCT) couples	L	121 Couples pre-HSCT. SCG: males 63, females 58; A nonmedical sample for normative comparison. **Time points:** before HSCT, 6 months, 1 ,2,3 and 5 years after HSCT.	- The Dyadic Adjustment Scale(DAS, at the first five time points, at five years, only the satisfaction subscale of the DAS); - The Profile of Mood States (POMS, to assess pre-transplant emotional distress)**.**	- Marital dissolution was uncommon (four divorces since the transplant among 55 participating 5-year survivors, 7%). - Dyadic satisfaction was stable over time for male caregivers, but not for female caregivers who reported reductions in marital satisfaction at all time points relative to baseline. - FCG reported lower levels of marital satisfaction at multiple time points: 6 months (DAS, m=38.42 vs. 40.54), 1 year (DAS, m=34.44 vs. 40.44) and 5years (DAS, m=23.34 vs. 39.63) post transplant than MCG.
Luszczynska et al. 2009 (Germany)	To examine the function of gender in support transactions in	L	173 couples SCG: males 65, females 108. **Time points:**	- The Berlin Social Support Scales (BSSS).	- Support provided decreased for male caregivers, but remained high in female caregivers when compared the support provided before surgery and at 1 months after surgery (BSSS, m=3.71 vs. 3.54 for MCG; 3.77 vs. 3.74 for FCG).

	the context of mainly GI cancer surgery		during the week before surgery (T1), 1 month (T2), and 6 months (T3) after surgery.		
Nijboer et al. 2000 (Netherlands)	To describes patterns of caregiving experiences in partners of cancer patients with over a 6-month period	L	148 couples SCG: males 54, females 94. **Time point:** the time of patient's diagnosis (T0), 3 months (T1) and 6 months (T2) thereafter.	- The Rotterdam Symptom Check List (RSCL); - The short-form 16- item list of the Central Bureau of Statistics; - Epidemiological Studies Depression Scale (CES-D); - Caregiver Reaction Assessment Scale (CRA).	- FCG perceived a more negative impact on loss of physical strength as compared to MCG (CRA loss of physical strength, m=2.03 vs. 1.76, m=1.96 vs. 1.75 at T0 and T2 respectively). - FCG reported a less positive influence on self-esteem over time (CRA self-esteem, m= 4.24, 4.16, 4.10 at T0, T1 and T2 respectively). - Older ages (CRA self-esteem, m= 4.26, 4.14, 4.11 at T0, T1 and T2 respectively) and high SES group (CRA self-esteem, m= 4.10, 3.97, 3.96 at T0, T1 and T2 respectively) also experienced a less positive influence on self-esteem over time.
Nijboer et al. 2001 (Netherlands)	To examine patterns and determinants of three dimensions of caregiver's health of newly diagnosed colorectal cancer patients	L	148 couples SCG: males 54, females 94. **Time points:** T0 (as soon as possible after patient's diagnosis); T1 (three months after T0) and	- RAND 36-item Health Survey; - Groningen Activity Restriction Scale (GARS); - Caregiver Reaction Assessment Scale (CRA).	- Physical functioning declined within a 6-month period in FCG (RAND, m=78.8 vs. 84.3), while no change was observed in MCG (RAND, m=85.2 vs. 84.5). - FCG with a low income reported a poorer physical functioning over time, while for MCG the role of income showed to be of less importance in predicting patterns of physical functioning.

			T2 (three months after T1).		- FCG with a low income reported a worse mental functioning than MCG with a low income.
Northouse et al. 2000 (USA)	To explore couples' patterns of adjustment to colon cancer during the first year following surgery	L	56 couples SCG: males 22; females 34. **Time points:** one week (T0) post diagnosis, at 60 days (T1) and one year (T2) post surgery.	- The Smilkstein Stress Scale (SSS); - The Family APGAR, Social Support Questionnaire (SSQ); - The Dyadic Adjustment Scale (DAS, assessed at T1 and T2); - The Beck Hopelessness Scale (BHS); - Mishel Uncertainty in Illness Scales; - The Brief Symptom Inventory (BSI); - Psychosocial Adjustment to Illness Scale (PAIS).	- There were no main effects (i.e. of role, gender, or time) for concurrent stress and no interaction effects. - Although no statistically significant gender differences were found on the level of concurrent stress reported by caregivers, female caregivers reported the relatively higher levels of concurrent stress at all three time points than MCG (SSS, m=16.8 vs.14.6, 17.1 vs. 15.2, and 16.6 vs. 13.5 at T0, T1 and T2 respectively). - FCG reporting less marital satisfaction (DAS, m=115.8 vs. 123.6, 112.4 vs. 121.6 at T1 and T2 respectively), more role problems (PAIS, m=25.8 vs.18.2, 23.4 vs. 20.7 and 22.2 vs. 20.9 at T0, T1 and T2 respectively), and less social support (SSQ, m=92.6 vs. 99.8, 93.8 vs.98.4, 91.2 vs. 96.0 at T0, T1 and T2 respectively) than MCG. - The results of family functioning (The Family APGAR) for female and male spousal caregivers were 21.3 vs. 22.6, 21.8 vs. 22.0 and 20.6 vs. 21.9 at T0, T1 and T2 respectively.
Pinquart et al. 2005 (Germany)	To assess how optimism and pessimism relate to depressive symptoms in	L	138 and 60 couples at two time points respectively SCG: males 48, 21, females 90, 39 at T1	- The Life Orientation Test (LOT); - Hamilton Depression Scale (HDS, for SCG);	- FCG had higher levels of depression at T1 (t (137) = 4.31, p < 0.001, and T2 (t (59)=4.29, p< 0.01) than MCG; - At T1, SCG of patients with advanced cancer stages were more depressed than other SCG (t (137) =2.87,

	spouses of lung cancer patients		and T2 respectively **Time points:** during treatment time (T1) and one year after (T2)	- Epidemiological Studies Depression Scale (CES-D, for patients).	p< 0.05). Patients' depressed symptoms at T1 had a trend to associated with depression of SCG (r=0.16, p< 0.06). - Less optimistic (r= -0.34, p<0.01, r= -0.25, p<0.05 at T1 and T2 respectively) and more pessimistic (r= 0.39, p<0.01, r= 0.44, p<0.001 at T1 and T2 respectively) SCG showed higher levels of depression. - Higher levels of optimism were associated with a marginally significant stronger decline in depressive symptoms in SCG of stage III to IV cancer patients (B=0.65, p <0.08).
Tuinstra et al. 2004 (Netherlands)	To examine patterns of psychological distress in couples facing colorectal cancer within 6 months after surgery	L	137 couples SCG: males 48, females 89. **Time points:** within 2 weeks after surgery (T1), 3 (T2) and 6 (T3) months after T1.	- Epidemiological Studies Depression Scale (CES-D).	- Female and male caregivers reported similar levels of distress at T1 (CES-D, m=9.3 vs. 9.2). At 3 and 6 months after surgery, FCG appeared to be more distressed than MCG (CES-D, m=11.3 vs. 7.8, and 10.3 vs. 7.3 respectively).
Zwahlen et al. 2010 (Switzerland)	To examine factors influencing positive effects in couples facing a cancer diagnosis	C	224 couples SCG: males 95, females 121. **Time point:** 18 months (1-265)	- Germen version of Posttraumatic Growth Inventory (PTGI); - Demographic variables; - Medical variables.	- All three investigated factors—gender, role (patient vs. partner) and the dyad (belonging to any of the 224 couples)—significantly contributed to variation in PTGI total scores and subscales. Variability between couples (factor dyad) appeared stronger than variability between patient and partner participants (factor role, m=22.86 vs. 20.17) and between male

			since diagnosis.		and female participants (factor gender, m=22.38 vs. 20.59). Male patient–female partner pairs showed greater association (r=0.36, p<0.00) in their experience of PTG than female patient–male partner pairs (r=0.25, p<0.02). - Correlations also suggested that, regardless of the gender and role composition, patients and partners may experience parallel growth.

Abbreviations: C, Cross-sectional study; FCG, Female Caregivers; L, Longitudinal study; m, Mean; MCG, Male Caregivers; SCG, Spousal Caregivers; SD, Study design

Qualitative studies

Authors	**Aims**	**SD**	**Informants**	**Significant Findings**
Fergus et al.2009 (Canada)	To investigate the impact of breast cancer on heterosexual relationships	G	- 9 MCG and 19 breast cancer women	- Personal characteristics that impeded couple adjustment, (1) Patients: self-absorption, counter-dependency, exaggerated dependency and over-controlling; (2) Spouse: solution driven, unchecked anger, not prioritizing patient and not reaching out. - Relationship dynamics that can impede couple adjustment: (1) Pitfalls: communication barriers, withholding-withdrawal, under-burdening and conflictual intentions; (2) Challenges: negotiating support, accommodating changes in other, coping with sexual disruption, incorporating death and separation

Holtslander, et al.2009 (Canada)	To explore the experience of hope from the perspective of older women who are bereaved following caregiving for a spouse with terminal cancer	G	13 SCG (bereaved females)	- Participants defined hope as a gradual process of regaining inner strength and building self-confidence to make sense of their completely changed situations. - Positive aspect of caregiving reported were: learning to stay positive and move ahead with their lives. The participants' main concern was losing hope, which they dealt with by searching for new hope through finding balance (finding hope in relationships, keeping busy, releasing the pain), new perspectives (letting go of the past, being grateful, staying positive), and new meaning and purpose (taking control a little bit, helping others, looking to the future). - The emerging theory is conceptualized as a spiral within the complex social context of bereavement after caregiving.
Lopez et al. 2011 (UK)	To explore male partners' experience of caring for their partners with breast and gynecologic cancer over a 1-year period	L	- 15 MCG whose partners were diagnosed with breast or gynecologic cancer. - **Time points**: at beginning of treatment (T1) and at 3 (T2), 6 (T3), and 12 (T4) months.	- Impact of caregivers' experiences over time observed as following: - From 0 to 3 months mainly was breaking bad news. - From 0 to 6 months included (1) tiredness, pain, loss of sleep;(2) physical & searching for information; (3) searching for alternative treatment. - From 0 to 9 months mainly was unpreparedness for female work. - From 0 to12 months included (1) fear of losing partner;(2) fear of the unknown/ uncertainty; (3) lack of support and limited social contact; (4) worrying about finances; (5) difficulty expressing emotions.
Maughan et al. 2011 (UK)	To investigate how men cope with a partner's gynaecological cancer, and to compare partner's perspectives on gynecological	G	- Six MCG of wives with gynaecological cancer; - The selection criteria required that the woman should have experienced	- The results illuminate issues surrounding the sharing of a cancer diagnosis, offering an insight into the care processes (the normalisation process; changing roles: men as carers) that enhance or impede partner involvement. - Life after cancer: women and partners viewed the future differently. Women's flirtation with death made some of them feel more self-assertive, perhaps on the grounds that they could no longer afford to waste time, given the uncertainty of their futures.

	cancer		gynecological cancer at least 6 months previously, and should have received curative major pelvic surgery.	- Couples varied in their ability to adapt to this change.
Sutherland. 2009 (Canada)	To explore the meaning of being in transition to end-of-life care among female partners of spouses with cancer	P	Eight female partners	-The findings centered on three major concepts: meaning making, anticipatory mourning, and hope. - Subthemes of meaning making included: our relationship, significance of his life, and searching for understanding. - Subthemes of anticipatory mourning included: partners undertook the burden of caring, experienced an uncertain path and were looking for hope. - Subthemes of hope included: faced tomorrow and confirmed their capacity to survive. -Participants shouldered the responsibility of adjusting spouses' hopes in order to help them to cope.

Abbreviations: FCG, Female Caregivers; G, Grounded theory; L, Longitudinal study; MCG, Male Caregivers; P, Phenomenological perspective; SCG, Spousal Caregivers; SD, Study design.

Table 3-1 Summary of studies on hidden morbidities of spousal caregiving for cancer patients

Authors	Aims	SD	Samples/Gender of SC/ Time Points	Instrument Used	Significant Findings
Baider et al. 2003 (Israel)	To identify and compare the psychological distress of couples	C	118 prostate cancer couples; 169 breast cancer couples.	- The Brief Symptom Inventory (BSI, to assess symptoms of psychological distress).	- MCG were significantly more distressed (BSI, m=65.0) than FCG (BSI, m=59.2).

	with prostate and breast cancer		**Time point:** 23.3 months after diagnosis.		
Barnoy et al. 2006 (Israel)	To examine the influence of correspondence in informational coping styles on the psychological reactions of cancer patients and their spouse as the main caregiver	C	98 couples SCG: males 45, females 53. **Time point:** in the course of ambulatory chemotherapy, 27.3 months after diagnosis.	- The Mental Health Inventory (MHI, Veit & Ware, 1983) to assess psychological well-being and psychological distress.	- FCG experienced more psychological distress than MCG (MHI, m= 5 vs 6).
Colgrove et al. 2007 (USA)	To examine the moderating effects of spirituality and gender on the mental and physical health of spousal caregivers	C	403 couples SCG: males 184, females 219. **Time point:** approximately 2 years after being diagnosed with cancer.	- Functional Assessment of Chronic Illness Therapy-Spirituality (FACIT-Sp); - Pearlin Stress Scale (PSS); - Medical Outcomes Study Short Form-36 (MOS-SF36).	- Caregiving stress (PSS, m=6.67) was associated with poor mental functioning (SF36, m=50.54), which was less prominent among caregivers with a high level of spirituality (stress-buffering effect). - No gender differences were found in stress-buffering or aggravating effects of spirituality on the mental and physical health of caregivers.
Goldzweig et al. 2009 (Israel)	To assess psychological distress and gender differences among middle-aged and older colorectal cancer patients and	C	231 couples SCG: males 90, females 141. **Time point:** 2-6 years after diagnosis.	- The Brief Symptom Inventory (BSI); - the ENRICH Marital Satisfaction Scale (EMS).	- MCG were more distressed than FCG (BSI, m= 61.48 vs 55.70). - FCG had a higher level of marriage satisfaction than MCG (EMS, m=3.72 vs 3.66).

	their healthy spouses				
Gustavsson-Lilius et al. 2007 (Finland)	To investigate the sense of coherence (SOC) –distress association among cancer patients and their partners	L	123 couples SCG: males 68, females 55. **Time points:** At the time of diagnosis (T1); 8(T2) and 14 (T3) months post-diagnosis.	- Orientation to Life Questionnaire (OLQ, to assess SOC); - The Beck Depression Inventory (BDI); - Endler Multidimensional Anxiety Scales (EMAS-State).	- FCG had more depression at T1 and T2 than MCG (BDI, m= 6.2 vs 4.0 and 6.0 vs 3.9), and anxiety symptoms at all three time points (EMAS – state, m=39.5 vs 33.5, 35.3 vs 30.1 and 37.3 vs 30.8, respectively). - No gender differences were found regarding the change of SOC in caregivers.
Hagedoorn et al. 2000 (Netherlands)	To further knowledge on gender and role differences relating to the psychological distress and quality of life of couples dealing with cancer	C	Patient Association (PAS, 105 couples, SCG: 34 males, 71 females), Hospital (HS, 68 couples, SC: 36 males, 2 females), healthy control (80 couples). **Time points:** time since diagnosis: 5.02 (PAS) and 2.81 (HS) years.	- Epidemiological Studies Depression Scale (CES-D); - Cantril's Ladder (for QOL).	- FCG perceived more psychological distress (CES-D, m= 11.83 vs 8.1 in PAS and m=12.50 vs 7.56 in HS, respectively) and a lower quality of life (QOL, m=7.09 vs 7.55 in PAS and m=6.84 vs 7.69 in HS, respectively) than MCG.
Hagedoorn et al. 2002 (Netherlands)	To examine identity-relevant stress as a possible explanation for gender differences in psychological distress	C	68 couples; SCG: male 36, female 32. **Time point:** couples were in treatment or check-up.	- Epidemiological Studies Depression Scale (CES-D, Dutch translation).	- FCG scored higher on distress than MCG (CES-D, m=12.93 vs 7.50).

Haley et al. 2003 (USA)	To examine the risk factors and protective factors as predictors of family caregiver well-being	C	40 couples of patients with dementia and 40 couples of patients with lung cancer SCG: 16 males, 64 females. **Time point:** within 14 days after the patient's admission to a hospice.	- Epidemiological Studies Depression Scale (CES-D); - Life Satisfaction Index-Z (LSIZ).	- Caregivers had a high level of depression (CES-D, $m= 17.73$, scores over 15 have been found to be strongly associated with clinical depressive disorders) and a low level of life satisfaction (LSIZ, $m=14.64$, far below published means for older adults). - FCG had s higher level of depression ($r=0.29$, $p<0.01$) and lower life satisfaction ($r =0.27$, $p<0.05$) than MCG.
Kim et al. 2006 (USA)	To examine how the caregiver's perception of providing care to a spouse with cancer differs by gender	C	429 couples SCG: males 190, females 239. **Time point:** 2 years after diagnosis.	- Caregiver Reaction Assessment Scale (CRA), to assess caregiver's esteem; - The Pearlin Stress Scale (Pearlin et al., 1990).	- The mean score of caregiver's esteem and caregiving stress was 30.79 and 6.68, respectively. - Compared to FCG, MCG were more likely to report higher levels of caregiver esteem ($\beta =0.18$, $p<0.001$), which in turn was related to lower levels of caregiving stress ($\beta=-0.10$, $p<0.05$).
Kim et al. 2007 (USA)	To explore gender differences in the association between attachment qualities and the level of involvement in caregiving and difficulties in caregiving	C	400 couples SCG: males 192; females 208. **Time point:** approximately 2.1 years after being diagnosed with cancer.	- Measure of Attachment Quality (MAQ); - 17-item self-developed care tasks scale: frequencies and difficulties.	- Interaction between attachment security and the frequency of emotional care: greater security of attachment of FCG related to providing more frequent emotional care, whereas among MCG, greater avoidance related to less frequent emotional care. - Interactions between attachment anxiety and frequencies of tangible and medical care: more anxiously attached FCG provided more frequent tangible care, whereas more

					anxiously attached MCG provided less frequent medical care.
Langer et al. 2003 (USA)	To examine the changes and dyadic differences in marital satisfaction and negative affect over time after SCT (Stem Cell Transplantation)	L	Pre-transplant (131 couples, 65 males), 6 months post-transplant (78 couples), 1 year post-transplant (76 couples, 40 males). A non-medical group as a normative sample.	- The Profile of Mood States (POMS); - The Dyadic Adjustment Scale (DAS); - The Short Form 36 Health Survey (HSSF36, patients only).	- FCG were more depressed (POMS, m=0.98 vs 0.57) and anxious (POMS, m=1.33 vs 0.89) as compared to MCG. - With respect to marital satisfaction, couples were matched in their perceptions of the relationship prior to transplantation but grew mismatched over time. - FCG were less satisfied with their marital satisfaction than male caregivers (DAS, m=38.45 vs 41.38).
Langer et al. 2003 (USA)	To explore the effects of gender and role (patient /spouse) on mood disturbances in the cancer setting	L	131 hematopoietic stem cell transplant (HSCT) couples. A nonmedical sample for normative comparison. **Time point:** before HSCT, 6 months, 1 year, and 2 years after HSCT.	- The Profile of Mood States (POMS).	- Female caregivers reported greater depression and anxiety than male caregivers. - Male caregivers showed elevations in negative affect before transplant ($P < 0.01$) but not after ($P > 0.05$). - Female caregivers, in contrast, showed elevations at multiple time points ($P < 0.01$).
Langer et al. 2010 (USA)	To examine the trajectory of marital adjustment and satisfaction among hematopoietic stem	L	121 Couples pre-HSCT. SCG: male 63, female 58; A nonmedical sample for	- The Dyadic Adjustment Scale (DAS, at the first five time points, at the 5-year point, only the satisfaction subscale of the DAS).	- FCG reported lower levels of marital satisfaction at multiple time points: 6 months (DAS, m=38.42.29 vs 40.54), 1 year (DAS, m=34.44 vs 40.44) and 5 years (DAS, m=23.34 vs 39.63) post-transplant

	cell transplant (HSCT) couples – as a function of role and gender		normative comparison. **Time points:** before HSCT, 6 months, 1, 2, 3, and 5 years after HSCT.		than MCG.
Luszczynska et al. 2007 (Germany)	To examine the function of gender in support transactions mainly in the context of GI cancer surgery	L	173 couples SCG: males 65, females 108. **Time points:** During the week before surgery (T1), 1 month (T2), and 6 months (T3) after surgery.	- The Berlin Social Support Scales (BSSS).	- Support provided decreased for male caregivers, but remained high in female caregivers when compared the support provided before surgery and at 1 month after surgery (BSSS, m=3.71 vs 3.54 for MCG; 3.77 vs 3.74 for FCG).
Nijboer et al. 2000 (Netherlands)	To describe patterns of caregiving experiences in the partners of cancer patients over a 6-month period	L	148 couples SCG: males 54, females 94. **Time point:** the time of the patient's diagnosis (T0), 3 months (T1) and 6 months (T2) thereafter.	- Caregiver Reaction Assessment Scale (CRA).	- FCG perceived a more negative impact on the loss of physical strength as compared to MCG (CRA loss of physical strength, m=2.03 vs 1.76, m=1.96 vs 1.75 at T0 and T2, respectively).
Nijboer et al. 2001 (Netherlands)	To examine patterns and determinants of three dimensions of the health of caregivers of newly diagnosed colorectal	L	148 couples SCG: males 54, females 94. **Time points:** T0 (as soon as possible after the	- RAND 36-item Health Survey.	- Physical functioning declined within a 6-month period in FCG (RAND, m=78.8 vs 84.3), while no change was observed in MCG (RAND, m=85.2 vs 84.5).

	cancer patients		patient’s diagnosis), T1 (three months after T0), and T2 (three months after T1).		
Northouse et al. 2000 (USA)	To explore couples’ patterns of adjustment to colon cancer during the first year following surgery	L	56 couples SCG: males 22; females 34. **Time points:** one week (T0) post-diagnosis, at 60 days (T1) and one year (T2) post-surgery.	- The Smilkstein Stress Scale (SSS); - The Dyadic Adjustment Scale (DAS, assessed at T1 and T2).	- Although no statistically significant gender differences were found in the level of concurrent stress reported by caregivers, female caregivers reported relatively higher levels of concurrent stress at all three time points than MCG (SSS, m=16.8 vs14.6, 17.1 vs 15.2, and 16.6 vs 13.5 at T0, T1, and T2, respectively). - FCG reported less marital satisfaction (DAS, m=115.8 vs 123.6, 112.4 vs 121.6 at T1 and T2, respectively) than MCG.
Pinquart et al. 2005 (Germany)	To assess how optimism and pessimism relate to depressive symptoms in spouses of lung cancer patients	L	138 and 60 couples at two time points, respectively SCG: males 48, 21, females 90, 39 at T1 and T2, respectively. **Time points:** during treatment time (T1) and one year after (T2).	- Hamilton Depression Scale (HDS, for SCG).	- FCG had higher levels of depression at T1 (t (137) = 4.31, $p < 0.001$, and T2 (t (59)=4.29, $p < 0.01$) than MCG; - At T1, SCG of patients in advanced stages of cancer were more depressed than other SCG (t (137) =2.87, $p < 0.05$).

Tuinstra et al. 2004 (Netherlands)	To examine patterns of psychological distress in couples facing colorectal cancer within 6 months after surgery	L	137 couples SCG: males 48, females 89. **Time points:** within 2 weeks after surgery (T1), 3 (T2) and 6 (T3) months after T1.	- Epidemiological Studies Depression Scale (CES-D).	- Female and male caregivers reported similar levels of distress at T1 (CES-D, m=9.3 vs. 9.2). At 3 and 6 months after surgery, FCG appeared to be more distressed than MCG (CES-D, m=11.3 vs 7.8, and 10.3 vs 7.3, respectively).

Abbreviations: C, Cross-sectional study; FCG, Female Caregivers; L, Longitudinal study; SCG, m, Mean; MCG, Male Caregivers; Spousal Caregivers; SD, Study design;

Table 4-1 Summary of studies on positive experience and related factors of spousal caregivers for cancer patients

Quantitative studies

Authors	Aims	SD	Samples/ Time Points	Instrument Used	Significant Findings
Fitzell et al. 2010 (Australia)	To examine relations between stress and coping predictors and negative and positive adjustment outcomes in colorectal cancer	C	- 622 CG; - 522 (84.0%) SCG **Time point:** 80% within 6 months of diagnosis.	- A single item caregivers' global stress appraisal, 5-items challenge appraisal, and 3- items control; - the 6-item Social Support Questionnaire(SSQ 6); - the 28-item Brief Cope; - the Bradburn Affect Balance	- Related factors reported included: after controlling for the effects of relevant caregiving parameters (caregiver age, gender and paid employment status, care-recipient quality of life, cancer stage), better caregiver adjustment was related to higher social support, lower stress and higher challenge appraisals, and less reliance on avoidance and substance use coping. - Social support availability and satisfaction were

	caregivers.			Scale(for positive affect); - The 5-item Satisfaction with Life Scale; - The Positive States of Mind Scale (PSOM); - A 4-point scale (1 poor to 4 excellent) for subjective health status.	positively related to all positive adjustment outcomes (r=0.14 to 0.36, all p<0.01). - Appraisal: stress appraisal was inversely related to all positive adjustment outcomes (r=-0.20 to -0.35, p<0.01). Challenge appraisal was positively correlated with positive affect (r=0.17, p<0.01), life satisfaction(r=0.15, p<0.01). Control appraisal was positively related to positive affect (r=0.11, p<0.01), health (r=0.10, p<0.01) and marginally correlated with PSOM (r=0.09, p<0.05). - Coping strategies, avoidance and substance use were inversely related to all positive adjustment outcomes (r= -0.12 to -0.31, p<0.01). Religious coping and seeking social support were related to greater positive affect (r=0.10 and 0.13, p<0.01). Problem-solving coping was related to lower PSOM (r=-0.12, p<0.01). Humor was marginally positively correlated with positive affect (r=0.08, p<0.05).
Hodgkinson et al. 2007 (Australia)	To assess the supportive care needs and positive outcomes of partners and cancer survivors	C	- 154 SCG **Time point:** 4.2 years post cancer diagnosis.	- Self-developed Supportive care needs and positive outcomes. The measures contain 35 need items, six positive change items and an open-response item.	- PAC reported by SCG n (%) as following: I realize how precious life is 120 (81.1); I focus more on things that are important 119 (80.4); I appreciate my relationships with others more 110 (74.3); I have grown as a person 105 (70.9); I have made lots of positive changes in my life 93 (62.8); I have benefited from contact with other cancer survivors and/or families 83 (56.1). - There was a significant correlation between PAC levels in partners and survivors (r=0.44, p<0.01).

Kang et al. 2012 (Korea)	To examine factors associated with positive consequences for family caregivers who served as caregivers of terminal cancer patients	C	- 501 bereaved CG - 230 (46.5%) SCG **Time point:** the patient died between 2 and 6 months of the survey date.	- The Caregiving Consequences Inventory (CCI). Framework	- PAC reported were: mastery, appreciation for others, meaning in life, and reprioritization. The mean scores for the mastery, the appreciation for others, the meaning in life, and the reprioritization domains were 5.3, 6.0, 6.0, and 6.0 respectively. - Factors associated with PAC for bereaved CG included: older age, female gender, and having a religion were associated with some domains of perceived rewards, but being a spouse of a patient was negatively associated with some domains of perceived rewards. Caregivers of deceased spouses were less likely to report mastery over their lives compared with family members who were not spouses (aOR= 0.53; 95% CI, 0.29–0.97). Receiving bereavement care was significantly associated with positive outcome in all four perceived reward.
Keefe, et al. 2003 (USA)	To examine the relationship between caregiver self-efficacy for pain management of advanced cancer patients and measures of both caregivers' and patients' adjustment	C	- 63 CG; - 57 (90.0%) SCG **Time point:** patients' life expectancy of less than 6 months	- A caregiver version of the chronic pain self-efficacy scale (CSES); - The Profile of Mood States-B (POMS-B); - The caregiver strain index (CSI); - The brief pain inventory (BPI); - The Functional Assessment of Cancer Therapy-General	- Caregivers rated their self-efficacy in pain management as moderate. Some caregivers rated their self-efficacy in helping the patient manage pain as quite high (e.g.24% at >75 on a 0–100 scale), whereas others rated theirs as quite low (19% at <30 on a 0–100 scale). - There were negative associations between CSES and caregiver strain (CSI, r=-0.36, p<0. 01), and caregiver negative mood (POMS-B, r=-0.31, p<0. 05). There was a positive association between caregiver self-efficacy in pain management and caregiver positive mood (r=0.41, p<0. 01).

				(FACT-G).	- There was a significant negative relationship between CSES and patient's score on the physical well-being scale (FACT-G, the higher scores indicate poorer physical well-being). No correlation was found between CSES and family/social wellbeing (FACT-G). There were also no significant relationships between CSES and patient ratings of usual pain or worse pain.
Kim et al. 2007 (USA)	To examine the association of the caregivers' appraisal with their own quality of life	C	- 448 CG; -351 (78.3%) SCG **Time point:** approximately 2.07 years after diagnosed with cancer.	- the caregiver's esteem subscale of the Caregiver Reaction Assessment(CRA); - Quality of Life: Profile of Mood States-Short Form (POMS-SF); the Medical Outcomes Study 36-Item Short Form Health Survey (MOS SF-36); the Functional Assessment of Chronic Illness Therapy-Spirituality (FACIT-SP).	- Mean score for caregiver's esteem was 30.90(subscale of CRA); mean score for quality of life was 1.87 for psychological distress (POMS-SF), 50.35 and 48.15 for mental functioning and physical functioning respectively (MOS SF-36), and 35.39 for spiritual adjustment (FACIT-SP). - CG with higher esteem reported lower psychological distress (unstandardized coefficient B =-0.12; SE = 0.05) and better mental functioning (B = 0.33; SE =0.13) and spiritual adjustment (B = 0.48; SE = 0.10).
Kim et al. 2007 (USA)	To characterize the domains of benefit finding in caregiving among close family members	C	- 779 CG; -514 (66.0%) SCG **Time point:** approximately 2.2	- Medical Outcomes Study Short Form-36 (MOS-SF36). - the Pearlin Stress Scale - Three psychosocial characteristics of caregivers	- Six domains of benefit finding (BFS) in caregiving were identified: acceptance (m=3.51), empathy (m=3.55), appreciation (m=2.88), family (m=3.34), positive self-view (m=3.30), and reprioritization (m=3.35). - For "overall" benefit finding (BFS, m=3.33), CG

	of cancer survivors and to relate the domains of benefit finding in cancer caregiving to other psychosocial variables		years after diagnosed with cancer.	included sociodemographic characteristics, religious coping (the religious coping subscale of the Brief COPE), and social support (the Interpersonal Support Evaluation List). - the 17-item Benefit Finding Scale (BFS) - Psychological adjustment included a positive (the Satisfaction With Life Scale) and a negative indicator (Epidemiologic Studies Depression Index, CES-D).	who reported greater caregiving stress (β=0.01, p<0.05), were less educated (β=-0.09, p<0.01), used religion or spirituality (β=0.35, p<0.001) to cope with the stress associated with their relative's cancer, and had greater social support (β=0.20, p<0.001) were more likely to report overall greater benefit finding in caregiving. - Religious coping (m=2.85, β ranged from 0.21to 0.44, p<0.001) and social support (m=3.15, β ranged from 0.11 to 0.22, p<0.001) variables were significant correlates of benefit finding domains. - The overall and all the six domains of benefit finding score were uniquely associated with psychosocial variables (life satisfaction and depression (β ranged from 0.12-0.29, p<0.001).
Kim et al. 2008 (USA)	To examine the prediction of caregiver well-being from the relationship qualities and from motives	C	314 SCG. **Time point:** approximately 2.2 years after diagnosed with cancer. Just correlation results no others	- Measure of Attachment Quality(MAQ); - 8-items self-developed Reasons for Providing Care (RPC); - Measure of Benefit Finding; - Satisfaction with Life Scale; - Epidemiological Studies Depression Scale (CES-D).	- Autonomous motives for caregiving were reported mostly. - Attachment security (assessed with respect to the spouse) related positively to autonomous motives for caregiving and finding benefit in caregiving; attachment anxiety related to introjected motives for caregiving and more depression. - Gender differences: males scored higher on external caregiving motives than females, and females reported more benefit finding than males. Among males, autonomous motives related to less depression, and introjected motives related to less life satisfaction and more depression. Among females, autonomous

					motives related to greater benefit finding.
Kim et al. 2011 (USA)	To examine individual and dyadic associations of SWB with the QOL of couples dealing with cancer	C	361 couples **Time point:** approximately 2.2 years after diagnosed with cancer. Just correlation results no others	- Spiritual well-being (SWB) was measured by the 12-item Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being. This scale includes three subcomponents of faith, meaning, and peace. - QOL: the Medical Outcomes Study 36-Item Short Form Health Survey (MOS-SF36).	- Actor and Partner Interdependence Model analyses revealed that each person's SWB was the strongest correlate of his or her own mental health (higher SWB, better mental health). Each person's SWB was also positively related to his or her partner's physical health. - The ability to find meaning and peace may be an important part of overall well-being during the cancer experience for both survivors and caregivers.
Moore et al. 2011 (USA)	To examine the correlation between the patient and caregivers' posttraumatic growth (PTG)	C	- 202 patients with hepatocellular or cholangio carcinoma; - 83 CG; - 52 (63%) SCG **Time point:** 1-4 weeks of diagnosis.	- Posttraumatic Growth Inventory (PTGI)	CG reported PTG as a result of their loved one's diagnosis of cancer. A correlation between the patient and caregivers' ratings of their own PTG were found to be significant on the spirituality (r=0.38, p<0.02) and the personal strength subscale (r=0.44, p<0.004). A trend toward significance was also found on the overall PTGI subscale (r=0.30, p<0.06).
Park et al. 2012	To investigate the determinants	C	- 139 CG;	- caregiver support	- Caregivers' positivity was most highly rated in 'change in priorities (4.09±0.84)', followed by 'closer

(Korea)	of the positivity of family caregivers of Korean terminal cancer patients		- 69 (49.6%) SCG **Time points:** terminally ill	- the Caregiver Reaction Assessment Scale(to assess caregivers’ burden) - Caregiver positivity was evaluated using three questions developed by Higginson et al.	relationship’ (3.80±0.94), and ‘sense of achievement’ (3.10±1.07). - Determinants of the positivity: CG with a religious affiliation reported a greater sense of achievement (β =0.442). Male caregivers (β=0.403), caregivers with a religious affiliation (β =0.469), and those who perceived a higher burden of ‘disrupted schedule’ (β =0.388) were more likely to report a closer relationship during the caregiving experience, while those who perceived a greater lack of family support were less likely to report a closer relationship (β =0.364). Caregivers with a religious affiliation (β =0.374) and who perceived a higher burden of ‘disrupted schedule’ (β =0.296) were more likely to report a ‘change in priorities’ during the caregiving experience, while those who perceived a greater lack of family support were less likely to report a ‘change in priorities’ (β =0.268).
Pearce et al. 2009 (USA)	To investigate the association between religious coping (RC), mental health and the caring experience, as well as potential	C	- 162 CG; - 99 (61.1%) SCG **Time points:** terminally ill	- The Brief RCOPE; - The General Self-Efficacy Scale (GSES); - The Life Orientation Test-Revised (LOT); - A shortened form of the Interpersonal Support Evaluation List (ISEL); - Perceived competence and	- Direct relationship between religious coping and PAC: CG who reported frequently using positive RC methods reported deriving more satisfaction from caregiving (r=0.24, p<0.01). In addition, CG who used negative RC methods reported lower levels of social support (ISEL, r= -0.20, p<0.01), optimism (LOT, r= -0.40, p<0.0001) and self-efficacy (GSES, r= -0.18, p<0.05). The linear and logistic regression analyses also showed that greater use of negative RC was associated with poorer quality of life (SF-36, β = –0.16), lower satisfaction (One question for the study,

	explanatory mechanisms, among informal caregivers of terminally ill cancer patients			caregiver satisfaction, one item for each was developed for this study. - Short Form-36 Health Survey Questionnaire (SF-36) ;	β = –0.16). - Potential mediating factors of religious coping, (1) positive RC was not significantly associated with the proposed mediating variables. (2) Negative RC was indirectly associated with the caregiving outcomes through a reduction in caregivers' perceived social support, optimism and self-efficacy.
Sanjo et al. 2009 (Japan)	To validate an instrument for measuring bereaved family members' perceptions of caregiving consequences	C	- 189 and 109 bereaved CG for two parts respectively; - 87 (46.0%) and 47 (43.1%) SCG respectively **Time points:** Mean time since patient's death was 15 months.	- Caregiving Consequences Inventory (CCI) ; - Overall reward scale; - The Life Orientation Test—Revised (LOT-R); - The General Health Questionnaire-12-item version (GHQ-12) to measure the degree of psychological distress; - A retest was conducted	- Four perceived reward domains: 'mastery', 'appreciation for others', 'meaning in life', and 'reprioritization', and one perceived burden domain were identified. - The respondents with more education (total reward score of CCI, m=5.0 vs. 5.4 for more vs. less education), less faith (total reward score of CCI. m=5.1 vs. 5.5 for less vs. more faith), and less optimism (total reward score of CCI, m=5.1 vs. 5.5 for less vs. more optimism) reported fewer perceived rewards, thus demonstrating known group validity. - In addition, perceived reward had little or no correlation with psychological distress. The psychometric properties of this scale were good (a=0.78–0.93, ICC=0.60–0.73) and construct validity was supported (GFI=0.929; AGFI=0.819; CFI=0.749; RMSEA=0.097). Conclusions: The CCI is valid for measuring caregiving consequences from the bereaved family member's perspective in Japan. Furthermore, it is

					important to use perceived rewards and burdens as a measure of caregiving consequences for improving the quality of the caregiving and bereavement experience.
Sano et al. 2007 (Japan)	To clarify the care experience of primary caregivers when caring for a terminal cancer patient in the home with the assistance of a home palliative care service	C	- 74 CG; - 44 (59.5%) SCG **Time points:** 14 months since the death of patient	- Self-developed Questionnaire for the study. The questionnaire sought information in the following areas: respondent characteristics and care experience.	PAC reported were: a deepening of their bond with the patient and that the bond of other family members deepened (90%); the burden of caregiving was not too great or not felt at all (60%); the patient retained his or her own personal qualities to the end (90%); that they had done their best in their caregiving and judged that home care had been beneficial for the deceased, for the primary caregiver him/herself, and for other family members (90%);.
Tang, 2009 (Taiwan)	To compare outcomes of the two groups of Taiwanese CG of patients with cancer who are terminally ill, those who eventually died at home and those who died at hospital.	L	- 187 CG; - 81 (43.3%) SCG; - 31 (16.6%) patients died at home and 156 (83.4%) died at a hospital. **Time point:** every 2 weeks until the patients died (time	- the Caregiver Reaction Assessment (CRA); - the Chinese version of the 20-item Center for Epidemiological Studies--Depression Scale (CES-D); - Caregiver Quality of Life Index--Cancer (CQOLC).	CG whose relative died at home provided significantly more intensive assistance (p=0.05) than their counterparts did, and caregiving more negatively impacted their finances (p=0.007). However, caregiving did not impact their health, daily schedule, perceived family support, or depressive symptoms to a greater negative extent. Instead, there is a trend (not significant) for these caregivers to enjoy higher quality of life, to feel more rewarded, and to find more positive meaning in providing caregiving at home than do CG whose relative died in hospital.

			since diagnosis, 22.95 months)		
Thornton et al.2006 (USA)	To examine posttraumatic growth (PTG) in men treated for prostate cancer and their partners 1 year after surgery	L	- 67 partners and 82 survivors of prostate cancer **Time point:** at presurgery, 3 weeks, 6 months, and 1 year postsurgery	- The Posttraumatic Growth Inventory (PTGI); - The Brief COPE; - The Positive and Negative Affect Schedule (PANAS); - Impact of Events Scale (IES); - The Rand 36-Item Health Survey 1.0 (Rand-36).	- Partner PTGI total score, m =49.40; Relating to Others, m = 17.00; New Possibilities, m = 8.90; Personal Strength, m = 9.80; Appreciation of Life, m=9.30; Spiritual Change, m = 4.40. - Survivor and partner scores were correlated to a modest degree, and their ratings correspond to endorsing a mild-to-moderate degree of PTG associated with the cancer experience. - The results of hierarchical multiple regression predicting partner PTG 1 year post-surgery showed that less education (p=0.03), being partnered to an employed patient (p= 0.006), higher avoidance symptoms of stress (subscale of IES) at pre-surgery (p=0.04), and using positive reframing coping (p= 0.03) were significantly associated with higher PTG. - Correlation of PTG and QoL, PTG was negatively correlated with physical functioning (r = -0.24) and general health (r = -0.25) at pre-surgery and 1 year post-surgery (r= -0.30 and □-0.33, respectively), all p's<0.05. The correlations between PTG and QoL 1 year post-surgery were no longer significant after controlling for pre-surgery levels (r = -0.19, p = 0.14, and r =□-0.21, p = 0.09, respectively). No other correlations were significant for partners.
Wagner et al. 2011	To evaluate positive aspects	C	- 40 husbands of	Positive Aspects of Caregiving Scale	- The Positive Aspects of Caregiving Scale demonstrated that husbands, on average, appraised

(USA)	of husbands during their breast cancer wives' active treatment		women undergoing chemotherapy for breast cancer **Time point:** during active cancer treatment		their caregiving as an experience that produced both intrapersonal and interpersonal growth. - The total score ranged from 6 to 24, and the average score in this sample was 18.95 (SD, 2.20). The mean score for the six items was 3.05 for feel needed, 3.15 for grow as person, 3.68 for show love for partner, 3.33 for feel closer to partner, 3.45 for learn about breast cancer, and 2.30 for become involved with groups/organizations respectively.
Weiss T. 2004 (USA)	To identify the social context factors that are associated with personal growth in husbands of breast cancer survivors	C	72 husbands of patients with breast cancer. **Time point:** 38.7 months since diagnosis	- Posttraumatic Growth Inventory (PTGI); - Social support questionnaire-Brief (SSQ); - Quality of relationship inventory (QRI). The measure has three scales: Support, Depth-of-commitment, and Conflict; - Exposure to a model of positive changes; - Stressfulness of the event.	- posttraumatic growth (PTG) positive life changes in the aftermath of the trauma - Bivariate analyses indicated that husbands' PTG was positively associated with SSQ-Number scores (m=3.06, r=0.28, p=0.01, n=67), greater marital support (QRI-support, m=3.46, r=0.24-0.38, p<0.02 to 0.001, n=67) and depth of commitment (QRI-depth, m=3.65, r = 0.23 to 0.36, p <0.02 to 0.001,n=65), greater PTG in wife (r=0.20, p=0.04, n=69), shorter time since diagnosis (r= -0.24, p=0.046, n=67) and breast cancer meeting DSM-IV criteria for traumatic stressor (r=0.36, p=0.003, n=69). - Multiple regression analysis revealed that the significant predictors of husbands' PTG were depth of marital commitment (β=0.33, p<0.05), wife's PTG (β = 0.24, p<0.05), and breast cancer as a DSM-IV trauma (β = 0.32, p<0.01). This model accounted for 42% of the variance in husbands' PTGI scores.

Zwahlen et al. 2010 (Switzerland)	To examine factors influencing positive effects in couples facing a cancer diagnosis	C	224 couples **Time point:** Time since diagnosis 18 months(1-265)	- Germen version of Posttraumatic Growth Inventory (PTGI); - Demographic variables; - Medical variables	- All three investigated factors—gender, role (patient vs. partner) and the dyad (belonging to any of the 224 couples)—significantly contributed to variation in PTGI total scores and subscales. Variability between couples (factor dyad) appeared stronger than variability between patient and partner participants (factor role) and between male and female participants (factor gender). - Role and gender analysis showed that patients demonstrated higher levels of PTG than partners; and female anticipants scored higher on PTGI than males. Male patient–female partner pairs showed greater association in their experience of PTG than female patient–male partner pairs. - Correlations also suggested that, regardless of the gender and role composition, patients and partners may experience parallel growth.

Abbreviations: C, Cross-sectional study; CG, Caregivers; FCG, Female Caregivers; L, Longitudinal study; m, Mean; MCG, Male Caregivers; SCG, Spousal Caregivers; SD, Study design.

Qualitative studies

Authors	**Aims**	**SD**	**Informants**	**Significant Findings on PAC**
Clayton, et al. 2005 (Australia)	To explore possibility of fostering coping and nurturing hope when discussing prognosis and end-of-life (EOL) issues with terminally ill cancer patients and their CG	FG	- 19 patients (P) with far advanced cancer and 24 CG from 3 palliative care (PC) services, and 22 PC health professionals (HPs). - 11 (58%) SCG	- All participant groups believed there were ways of fostering coping and nurturing hope when discussing prognosis and EOL issues. - Themes on ways of helping patients with a limited life expectancy to cope were: 1) emphasize what can be done: a) control of physical symptoms; b) emotional support, care, and dignity; and c) practical support), 2) explore realistic goals (act now rather than later), and 3) discuss day-to-day living. - Themes on ways of fostering hope: the balance between truth telling and nurturing hope, and the spectrum of hope. - All these themes were raised by the P, CG, and HPs. However, there were some differences of opinion within the three participant groups. - The Spectrum of Hope included: hope of a miracle cure or spontaneous disease remission (H/P/C) ; hope of living longer than expected (H/P/C); hope of making it to certain events or achieving goals (H/P/C); hope of every day living (H/P/C); hope in the person's worth as an individual and finding meaning in their own life (H/P); hope it the healing of relationships and having special times with family and friends (H); hope of good pain and symptom control (H/P/C) ; hope of being well cared for and supported (H/P/C); hope in finding spiritual meaning (H); hope of a peaceful death (H/P).
Holtslander, et al.2009 (Canada)	To explore the experience of hope from the perspective of older women who are bereaved following caregiving	G	13 SCG (female)	- Participants defined hope as a gradual process of regaining inner strength and building self-confidence to make sense of their completely changed situations. - PAC reported were: learning to stay positive and move ahead with their lives. The participants' main concern was losing hope, which they dealt with by searching for new hope through finding balance (finding hope in relationships,

	for a spouse with terminal cancer			keeping busy, releasing the pain), new perspectives (letting go of the past, being grateful, staying positive), and new meaning and purpose (taking control a little bit, helping others, looking to the future). - The emerging theory is conceptualized as a spiral within the complex social context of bereavement after caregiving.
Houldin. 2007 (USA)	To investigate the effect of advanced-stage colorectal cancer from the perspective of caregivers at the time of a loved one's initial diagnosis	D	- 14 CG - 12 (86%) SCG	- PAC reported were: changing priorities, increasing responsibilities, struggling with an inability to plan, dealing with personal effects, positive in relationship and sexuality, staying positive (trying to go on living, dealing with things as they come, controlling emotions, using faith, and talking to friends), maintain a positive attitude and optimism, to use of avoidance to preserve a positive focus, search for meaning, not placing blame in remaining positive, open and honest with everybody. -Attempting to Keep Family and Children's Routines as Normal as Possible: worrying about the effect on children, struggling to know the right thing to do, giving children the positive side, and dealing with extended family. -After a colorectal diagnosis, many CG put on a brave face while silently struggling with significant sources of distress and attempting to meet the needs of their loved ones with cancer and families.
Hudson. 2004 (Australia)	To explore positive aspects and challenges associated with caring for a dying relative at home	interview	- 47 CG - 30 (65%) SCG	- 60% of CG were readily able to identify PAC of the role, such as to be together with the patients (becoming closer), been given an opportunity, seeing patients improve, feel stronger, personal growth. - All CG were able to identify challenges: their own ill health, family circumstances, insufficient skills to manage patient symptoms, limited time for themselves and inadequate support from health professionals. - Continuity, role definition, information, access to resources, symptom management education and time to talk face to face appear to be key factors that may lessen the likelihood of negative psychosocial sequelae for family

				caregivers.p64
Koop, et al. 2003 (Canada)	To explore the experience of bereavement following home-based family caregiving for persons with advanced cancer	I	- 15 CG - 9 (60%) SCG	- Caregivers reported both positive (e.g., feelings of accomplishment, improved family relationships, no guilt, personal growth, sense of personal confidence and self-efficacy, sense of reality during bereavement, freedom to express grief more openly) and negative (e.g., haunting images, feelings of failure) outcomes that they attributed to having cared for their family member. - Overall, positive outcomes predominated and bereaved family members reported satisfaction with having provided care for their loved one who had died.
Lindau, et al. 2011 (USA) spousal	To explore health-care provider, patient, and partner perspectives on the effects of lung cancer on physical and emotional intimacy and sexual relationship	D	- Eight cancer-care providers and 13 couples affected by lung cancer.	- Most cancer-care providers and couples affected by lung cancer believed intimacy and sexuality issues were salient, yet few reported discussing these. - Couples described PAC included an increase in non-coital physical closeness and appreciation of the spouse. - Some individuals described improved communication due to an increased awareness of time and appreciation for each other. - Age was perceived as an important factor influencing the relationship between lung cancer and intimacy.
Mehrotra, et al. 2007 (India)	To explore sources of strength and positive experience in the process of caregiving from the perspectives of Indian women caring for relatives suffering from cancer	P	- 20 CG - 9 (45%) SCG	- 75% of the CG reported personal changes as being positive fallout of the care-giving role. - PAC reported were: a testing time that facilitated discovering their hidden potential for patience, strength to handle novel and difficult situations, and deal with multiple demands; awareness and appreciation of support received resulted in the knowledge that there were people who could be relied upon and enhanced a sense of belonging and being cared for; learning to tolerate minor irritations/hassles; experiencing a perspective shift in terms of being more

				accepting of each day and also being able to prioritize their life issues; experience of feeling closer to God, of being “cared for and supported by Him” while being “tested by Him” at the same time. - The occurrence of positive moments were: (a) events related to care recipients’ health that fostered hope, e.g., getting a normal report of a blood investigation; (b) interactions with significant others resulting in feelings of being cared for,e.g., talking to a friend who listened to their difficulties and provided emotional support; (c) temporary respite from caregiving and opportunities to engage in positive distraction, e.g., being able to take a few hours off from the caregiving role through soliciting others’ help and engaging in another inherently pleasurable activity, e.g., gardening; and (d) recollection of positive memories of the past or positive aspects of current life situation and planning for future, e.g.,talking with others about good times in the past, realizing how things are not as bad as they could have been, and visualizing good things in future such as celebrating a festival. - Intrapersonal sources of strengths included: religious beliefs and practices, positive appraisal of the caregiver role in terms of “value”, prior experience of caregiving. Religious beliefs and practices were linked with positive appraisals of care-giving demands and experience of hope. - Interpersonal sources of strengths included: family, medical fraternity, friends, care recipients and fellow caregivers.
Milberg, et al. 2003 (Sweden)	To describe and interpret the construct of meaningfulness in next of kin of cancer patients who are in advanced palliative home care	HA	-19 CG - 15 (79%) SCG	- Elements that facilitated meaningfulness included comfort, retaining everyday life, action, commitment, and hope, which were of great importance for creating a perception of self-transcendence and that the best possible was done. - Comfort: it was positive to CG to perceive that the patient experienced comfort, but comfort of other family member was also important. - Retaining Everyday Life: It was encouraging to CG when the everyday life of

				the patient and the family could be retained as much as possible. - Action: Action comprised serving, protecting and also a means of distraction, mostly as regards the patient, but sometimes also regarding the family. Protecting the patient from negative feelings was done by being "strong" and not showing signs of stress, and by hiding feelings. - Hope: through hope, CG projected meaningfulness into the future, and then there was something potentially meaningful to look forward to.
Mok, et al. 2003 (Hong Kong China)	To describe the caregiving process and the impact of being the main caregiver for a terminally ill patient with cancer	G	- 24 CG whose family members had died within 6 months to 1 year before the study; - 17 (71%) SCG	- CG felt that they were doing was important to their loved ones and therefore meaningful to them as caregivers. - PAC reported were: a way of showing love to their relatives; change of worldviews and treasure their lives.
Sutherland N.2009 (Canada)	To explore the meaning of being in transition to end-of-life care among female partners of spouses with cancer	P	Eight female partners	-The findings centered on three major concepts: meaning making, anticipatory mourning, and hope. - Subthemes of meaning making included: Our Relationship, Significance of His Life, and Searching for Understanding. - Subthemes of anticipatory mourning included: partners undertook the Burden of Caring, experienced an Uncertain Path and were Looking for Hope. - Subthemes of hope included: Faced Tomorrow and confirmed their Capacity to Survive. -Participants shouldered the responsibility of adjusting spouses' hopes in order to help them to cope.

Ussher, et al.2010 (Australia)	To examine the nature and consequences of cancer on the relationship between informal carers and the person with cancer		- 62 CG; - 48 (77%) SCG	- PAC of the changed relationship included feelings of love and being closer together, resulting in relationship enhancement. - Women were more likely to report changes in the person with cancer and to mourn the previous relationship, while more men reported relationship enhancement.
Wennman-Larsen, et al. 2002 (Sweden)	To explore hopes and expectations of family caregivers for cancer patients at the end of life	N	- 11 CG; - 9 (82%) SCG	PAC reported were: avoiding long trips to the hospital or avoiding anxiety they described as resulting from not being able to be more or less constantly close to their family member. - Theme on role transition in becoming a CG: Many CG described the first period after discharge as being a time of uncertainty and turbulence. Several analogies were made with the initial period at home after delivery of a first-born child. Stories were told and re-told about specific challenging situations involved in learning the caregiver role. - Theme on transition to a new life situation of CG - Critical points addressed by CG included: needing someone to talk to, needing time of one's own and dealing with new areas, for example having to learn household or economical skills.
Whisenant M. 2011 (USA)	To explore the experience of informal caregivers of patients with a primary brain tumor	D	- 20 CG of patients with primary brain tumors; - 14 (70%) SCG	- Energy sources identified by the Model of informal caregiving dynamics were: commitment, expectation management, role negotiation, self-care, new insight, and role support. - PAC reported were: self-affirming, loving connection by recognizing their own ability to manage behavioral problems, an opportunity to prepare for the patient's loss of cognitive and functional abilities and eventual death, a feeling of accomplishment in being able to gauge behavior, found meaning in their role

				through acknowledging the negative aspects of their experience. - Conclusions: Commitment, expectation management, role negotiation, self-care, new insight, and role support motivate CG of patients with primary brain tumors in a unique way.
Wong, et al.2009 (USA)	To examine the positive aspects of caring as subjectively constructed by bereaved informal cancer carers	P	- 23 bereaved informal cancer CG - 14 (61%) SCG	- PAC reported were: the discovery of personal strength, through adversity, acceptance, and necessity; the deepening of their relationship with the person for whom they cared; - Personal growth through altered relationships with others and altered perspectives on living. - Many participants gave accounts of focusing on these positive benefits when they reflected on their caring experiences.
Wong, et al.2009 (USA)	To explore the positive meanings of providing palliative care at home by bereaved informal cancer carers	P	- 22 bereaved informal cancer CG; - 14 (64%) SCG	- PAC reported were: enabled them to construct positive meanings associated with their participation in the dying process, as a result to ascribe subjectively meaningful interpretations to their loved ones' death and their sense of loss, a sense of reward for doing something good, meeting the expressed needs of the patient, continuing with normal life as much as possible, improving the conditions of the relationship and meeting cultural expectations of the right thing to do. - Being present at the point of death was positioned as rewarding because it facilitated the process of saying goodbye, fostered inclusion of others, provided closure and was a spiritual experience. - These findings suggest that there are positive and rewarding aspects associated with providing informal cancer care in a palliative context, and these aspects were pertinent and meaningful for carers in their endeavours to reconcile the difficulties and loss they experienced. P274

Abbreviations: C, case study; CG, Caregivers; D, Descriptive; FG, Focus Groups; G, Grounded theory; HA, Hermeneutic Approach; I, interpretive study; II, Individual Interviews; L, Longitudinal study; P, Phenomenological perspective; PAC, Positive Aspects of Caregiving; SCG, Spousal Caregivers; SD, Study design.

Combined Quantitative and Qualitative Studies

Authors	Aims	SD	Sample Size (n)/ Type	Instrument Used	Significant Findings on PAC
Hudson. 2006 (Australia)	To explore CG perceptions of their loved one's death and how well they were coping	Survey and interviews	- 45 bereaved CG - 28 (62.2%) SCG	Self-developed questionnaire and a structured interview	- PAC: 84% of CGs stated having PAC; - PAC reported were: made the patient more comfortable, realizing their own capabilities and having control within their own home, times of intimacy during the caring process, and personal satisfaction. - Advice from bereaved CG for future CG included: accepting as much help as possible from a variety of people (57%), personal strength (30%), open communication with the patient (53%), preparing emotionally and practically for the death and for the time after death (23.3%), taking time out for themselves (43%), utilizing respite caregivers and protecting the patient from too many visitors.
Mangan, et al. 2003 (USA)	To explore caregiving experience near the end of life of cancer patients	Survey and FG	- 17 active and 15 bereaved CG; - 11 (64.7%) active and 13 (86.7%) bereaved SCG	- general health-related quality of life (SF-12); - Epidemiological Studies Depression Scale (CES-D);	- Both active (m=57.0 vs. 49.7) and bereaved caregivers (m=49.6 vs. 46.6) reported levels of physical functioning within the normal range of the general population on the SF-12. - Active caregivers reported more depressive symptoms (CES-D, m=22.1 vs. 16) and poorer levels of mental health (SF-12, m=33.9 vs. 50.45) than the general population on these

				- semi-structured focus group guide	standard measures. - PAC was defined as what caregivers view as positive aspects that have come out of their caregiving experience. - PAC reported were: the respect they felt for their patients, showing appreciation for their vulnerability, closeness to the patient and the entire family. - CG reported behaviors to enhance well-being included: regular exercise, health checkups, and religious activities. P254

Abbreviations: C, Cross-sectional study; CG, Caregivers; FG, Focus groups; PAC, Positive Aspects of Caregiving; SCG, Spousal Caregivers; SD, Study design.

Table 5-1 Summary of studies on caregiver-patients dyads: the spousal caregivers and cancer patients

Quantitative studies

Authors	Aims	SD	Samples/ Time Points	Instrument Used	Main focus and Significant Findings
Badr, et al. 2008 USA	To examine the effects of relationship talk on couples' psychosocial adaptation to lung cancer.	L	167 couples (one with lung cancer); **Time point**: baseline (within 4-weeks of treatment	- A brief measure of relationship talk in the context of cancer based on qualitative interviews; - The Dyadic Adjustment Scale (DAS);	**Communication** - Patients and partners who reported more frequent relationship talk had less distress (effect size r=0.16) and greater marital adjustment over time (effect size r=0.21). Satisfaction with the frequency of relationship talk was associated with lower baseline distress for patients and partners (effect size r=0.25).

			initiation for newly diagnosed lung cancer); 3 and 6 Ms later.	- The Brief Symptom Inventory (BSI, a 53-item assessment tool used to assess PD determined by the individual's score on the Global Severity Index [GSI]).	- Over time, greater communication regarding the relationship was related to less distress in the partner (effect size r=0.15) than in the cancer patient.
Badr, et al. 2009 USA	To examine whether associations between sexual dysfunction and psychosocial adjustment vary depending on spousal communication patterns.	C	116 couples (men with PC). **Time point**: less than 1 year to 22 years since diagnosis (m=4.56 years).	- The International Index of Erectile Function (IIEF); - The Female Sexual Function Index (FSFI); - The Dyadic Adjustment Scale (DAS); -The Centers for Epidemiological Studies Depression scale (CESD); - The Communication Patterns Questionnaire (CPQ).	**Communication** - Patients' and their partners' sexual function was moderately to highly correlated (r=0.30–0.74). When patients had poor erectile function, their partners were more likely to report that the couple avoided open spousal discussions; this in turn was associated with partners' marital distress (Sobel's Z=12.47, p=0.001). - Patients and partners who reported high levels (+1SD) of mutual constructive communication reported greater marital adjustment, regardless of their own sexual satisfaction. In contrast, greater sexual dissatisfaction was associated with poorer marital adjustment in patients and partners who reported low levels (-1SD) of mutual constructive communication (p<0.05).
Badr, et al. 2010 USA	To evaluate whether common dyadic coping was associated with less cancer-related distress	L	191Couples (women with BC) **Time points:** at the start of treatment for MBC	- Dyadic Coping Questionnaire (FDCT-N，Fragebogen zur Erfassung des Dyadischen Copings als Tendenz); - The 15-item Impact of Event	**Reciprocal influence** - Patients' and partners' cancer-related distress scores (IES) were significantly correlated at each assessment, but their cancer-related stress communication was not. - Regardless of role, individuals who perceived their spouses as more supportive and less unsupportive had

	and greater dyadic adjustment		(baseline), and 3 and 6 Ms later.	Scale (IES); - The 7-item, short version of Dyadic Adjustment Scale (DAS-7).	greater dyadic adjustment (DAS-7). - Holding perceptions of supportive and unsupportive coping constant, patients and partners who used more common positive dyadic coping, and less common negative dyadic coping experienced greater dyadic adjustment.
Campbell et al. 2004. USA	To examine the relationship between patient and partner ratings of self-efficacy for symptom control and QOL	C	40 couples (African American men with PC). **Time points:** time since surgery averaged 17.9 Ms (SD 14.9).	- The Self-Efficacy for Symptom Control Inventory; - The Expanded PC Index Composite (EPIC); - The Physical Function and Mental Health scales of the SF36; - The Profile of Mood States-Short Form (POMS-SF); - The Caregiver Strain Index (CSI).	**Reciprocal influence** - Higher self-efficacy for physical function subscale scores in patients was associated with less anxiety (r=-0.39, p<0.05) and caregiver strain (r=-0.38, p<0.05) in partners. - Higher total self-efficacy scores in partners was associated with better adjustment to bowel function (r=0.46, p<0.01); and higher self-efficacy for physical function subscale scores in partners was associated with better adjustment to bowel (r=0.66, p<0.01) and hormonal symptoms (r=0.42, p<0.01) and better mental health (r=0.32, p<0.05) in patients.
Chen et al.2004. Taiwan	To examine the correlation between QOL in cancer patients and that of their spouse caregivers	C	121 couples (one with a variety of cancers) **Time points:** time since diagnosis ranged from 1 to	- The Functional Assessment of Cancer Therapy Scale-General (FACT-G); - The Caregiver QOL Index (CQLI) ; - The Kansas Marital satisfaction Scale (KMSS);	**Reciprocal influence** - The social/family and functional dimensions of patient QOL (FACT-G) and total score for patient QOL were associated with each dimension of their caregivers' QOL (CQLI) and with the total score (r=0.27–0.44). -Physical and emotional dimensions of patients' QOL did not significantly influence spouse caregivers' QOL

			228 Ms with a median of 17 Ms.	- The self-esteem subscale of the Caregiver Reaction Assessment Scale (CRA).	for any dimension nor for the total score. Factors influencing the association between patients' and caregivers' overall QOL included cancer diagnosis, length of hospitalization, caregiving intensity and duration, marital satisfaction, and caregiving self-esteem.
Dorros et al. 2010 USA	To test whether interdependence in dyads living with BC could account for person–partner crossover effects in distress outcomes	C	95 couples (one with BC) **Time points:** 33% had Stage I BC, 53% Stage II, and 14% Stage III	- Center for Epidemiological Studies–Depression Scale (CES-D); - Index of Clinical Stress; - Short Form Health Survey.	**Reciprocal influence** - There is medium similarity of depression, stress, and poor physical health between women and their partners (latent rs 0.37, 0.36, and 0.37, respectively). - The interaction of high levels of depression coupled with high levels of stress in women with BC was associated with lowered physical health and well-being in their partners. - There were no partner effects for stress predicting physical health.
Galbraith et al. 2008 USA	To describe health-related outcomes for couples dealing with PC	L	216 Couples (men with PC) **Time points:** before the patient started treatment and 6, 12 and 18 Ms after treatment.	- The Quality-of-Life Index (QLI) ; - The Medical Outcomes Study General Health Survey (SF-36); - The Dyadic Adjustment Scale (DAS).	**Reciprocal influence** - Patients' scores were associated with partners' scores more than 50% of the time throughout the study. The patients' scores on all outcome measures predicted 63% of their partners' scores on the corresponding variable (r=0.19-0.65). Relationship satisfaction was the most strongly related variable between patient and partner (r=0.65, 0.63, 0.58, 0.51 at before treatment, 6, 12, and 18 Ms after treatment). - Cross-lag analyses suggest that couples' scores demonstrate a reciprocal pattern of influence between the dyads throughout the study.

Gilbar et al. 2007 Israel	To assess the correlation among couples in terms of coping strategies and PD	C	- 57couples (women with BC,) **Time point:** 3-12 Ms after diagnosis.	- The Brief Symptom Inventory (BSI); - A short 30-item Hebrew version of the COPE scale; a problem-focused (PF) scale; and an emotion-focused (EF) scale.	**Reciprocal influence** - Positive significant correlations were found between patients and spouses in PD (BSI) (r=0.28; p<0.01) and emotion-focused (EF) coping (r=0.35; p<0.001).
Kershaw et al. 2008 USA	To assess whether baseline antecedent variables predicted subsequent appraisal and how that appraisal predicted coping and QOL for PC patients and their spouses.	L	- 121 couples (men with PC); - 67% of the patients were newly (8 Ms) diagnosed, 20 % advanced, and 13% had a biochemical recurrence (67 Ms from both). **Time points**: baseline, 4-M, and 8-M follow-up.	- QOL: MOS SF-12(version2); - Coping: the 28-item Brief COPE; - Appraisal variables: separate 27-item Appraisal of Illness or Appraisal of Caregiving Scales; the 20-item true/false Beck Hopelessness Scale; the 28-item community version of the Mishel Uncertainty in Illness Scale; - Self-Efficacy Scale; - The 32-item Lewis Mutuality and Interpersonal Sensitivity Scale; - 16-item Symptom Scale of the OSQ;	**Reciprocal influence** - There was a significant correlation between patients' and spouses' mental QOL (r=0.25, p<0.05), but no relationship between patients' and spouses 'physical QOL (r=0.07, p=0.45). - Spouse partner effects found including: 1) Older spouses (β=+0.43) were related to more patient negative appraisal of illness at 4 M; and more uncertainty (β=+0.32); 2) Patients had higher hopelessness if their spouses reported more communication (β=+0.30); 3)More baseline symptoms in patients (β=+0.31) were related to more spouse avoidant coping at 8 Ms; 4)More patient uncertainty at 4 Ms (β=+0.29) related to more spouse active coping. - Spouses benefited from more communication with their husbands, and, patients who reported more communication with their spouses had less hopelessness. However, when spouse-caregivers reported communicating more about the illness, the patients subsequently reported more hopelessness.

Kim et al.2008 USA	To examine the dyadic effects of PD on the QOL of couples dealing with cancer.	C	168 couples (one with breast or PC) **Time points:** an average of 2.15 years (SD=0.4 year)	- The 37-item Profile of Mood States-Short Form (POMS-SF); - The Medical Outcomes Study 36-Item Short Form Health Survey (MOS SF-36); .	**Reciprocal influence** - PD was moderately correlated for both types of cancer dyads (r=0.32, 0.27 for BC, and PC respectively). - At the dyadic level a greater dissimilarity in PD was only associated with poorer mental health of wife caregivers of PC survivors. For men, a greater dissimilarity in PD was associated with better physical health.
Langer et al. 2009 USA	To examine the intra- and inter-personal consequences of protective buffering and motivations (desire to shield themselves and their partner from distress)	L	80 couples (one with a variety of cancers receiving hematopoietic stem cell transplantation (HSCT)) **Time points:** Pre-HSCT (T1), 50 days after HSCT (T2).	- Protective Buffering (PB); - Dyadic Adjustment Scale (DAS); - Short Form 36 Health Survey (SF-36, Version 2).	**Congruence** - There is moderate concordance between one dyad member's buffering of his/ her partner and the other dyad member's received buffering: r= .26, p = .019 at T1, and r = .28, p = .031 at T2 for patient-reported buffering of caregiver and caregiver-reported received buffering; and r = .38, p < .001 and r= .31, p = .016 for caregiver-reported buffering of patient and patient-reported received buffering at T1 and T2, respectively. - The more participants buffered their partners at T2, and the more they felt buffered, the lower their concurrent relationship satisfaction and the poorer their mental health. - As to the motivations, patients who buffered primarily to protect their partner at T1 reported increases in relationship satisfaction over time, but when they did so at T2, their caregiver reported concurrent decreases in relationship satisfaction.

Manne et al. 2004 USA	To evaluate interpersonal process model of intimacy in couples coping with BC	C	98 couples (women with BC) **Time points:** time since surgery averaged 4 Ms (SD=2).	-Perceived self-disclosure; -Perceived partner disclosure; - Perceived partner responsiveness; - Perceived intimacy. Ratings were adapted from Laurenceau et al.'s work (1998).	**Communication** - For patients, perceived partner responsiveness partially mediated the association between partner disclosure and intimacy, but self-disclosure was not significantly associated with responsiveness or intimacy. - For partners, perceived patient responsiveness mediated the association between self-disclosure and perceived partner disclosure and intimacy. - For patients, partner disclosure predicted patient feelings of intimacy, because this type of disclosure was associated with greater feelings of acceptance, understanding, and caring.
Manne et al. 2010 USA	To evaluate intimacy as a mechanism for the effects of relationship communication on couples' PD.	C	75 couples (men with localized PC). **Time point:** within one year since diagnosis	- Communications Pattern Questionnaire (CPQ); - Dyadic Adjustment Scale (DAS); - Personal Assessment of Intimacy in Relationships (PAIR); - Brief Symptom Inventory-18.	**Communication** - The association between mutual constructive communication, mutual avoidance, and patient demand-partner withdraw and distress could be accounted for by their influence on relationship intimacy. - Intimacy did not mediate associations between self-disclosure, holding back, and partner demand-patient withdraws communication and distress.
Manne et al. 2012	To assess whether the way couples communicate	L	139 couples (one with lung cancer (LC) or head and neck cancer	- Positive communication: Self-disclosure and perceived partner disclosure; Sharing concerns;	**Communication** - Patients and spouses who reported greater baseline distress reported more negative baseline communication

USA	about cancer and their perceptions of relationship intimacy influenced both partners' adjustment.		(HNC)). **Time point:** m=1.2 years since diagnosis for baseline (T1), 3 (T2) and 6 (T3) Ms for follow up.	- Negative communication: Mutual avoidance; Demand-withdraw communication (DW); Spouse unsupportive behavior; - Personal Assessment of Intimacy in Relationships- Intimacy subscale, PAIR; - PD (BSI);	as well as lower levels of intimacy and greater distress over time. - Mediation analyses showed patients' and spouses' reports of positive spousal communication were associated with less subsequent distress largely through their effects on intimacy.
Merz et al. 2011 USA	To examine whether dyadic concordance on characteristics of PC was related to health-related QOL (HRQOL), PD, and marital adjustment in PC patients and their partners	C	164 couples (men with PC) **Time point:** m=5.26 Ms since diagnosis.	- The 20-item UCLA PCI measures urinary, bowel and sexual function and bother for PC patients (Litwin et al., 1998). - Medical Outcomes Study Short-Form Health Survey (SF-36); - Dyadic Adjustment Scale (DAS).	**Congruence** - Patient and partner scores on each measure (appraisal ratings) were positively correlated (r = 0.41-0.83). Most couples, in most appraisal domains, were concordant. With the exception of sexual bother (SB), the mean patient-partner (dis)agreement was 13 points, with partners perceiving that patients experienced lower levels of SB than the patients experienced in actuality. - There was a general pattern of patients and partners in concordant dyads, versus those in dyads in which spouses maximized or minimized PC characteristics, reporting significantly better individual HRQOL outcomes. - Patient-partner appraisal (dis)agreement generally did not significantly predict dyadic adjustment.
Northouse et al.	To explore couples'	L	56 couples (one with colon cancer);	- The Smilkstein Stress Scale; - The Family APGAR, Social	**Reciprocal influence** - On the BSI, partners' concurrent emotional distress

2000 USA	patterns of adjustment to colon cancer during the first year following surgery		**Time points:** one week post diagnosis, at 60 days and one year post surgery.	Support Questionnaire; - The Dyadic Adjustment Scale (DAS); - The Beck Hopelessness Scale (BHS); - Mishel Uncertainty in Illness Scales; - The Brief Symptom Inventory (BSI); - Psychosocial Adjustment to Illness Scale.	scores were related only at 60 days post surgery ($p<0.05$). There was one predictive correlation across partners' emotional distress scores; i.e. spouses' distress scores at 60 days were related to patients' distress scores at one year ($p<0.05$). - Modest intercorrelations were found between patients' and spouses' adjustment scores over time. - The strongest predictors of patients' role adjustment problems were hopelessness and spouses' role problems. The strongest predictors of spouses' role problems were spouses' own baseline role problems and level of marital satisfaction.
Porter et al. 2005. USA	To examine patterns of disclosure about cancer-related concerns between patients with gastrointestinal (GI) cancer and their spouses.	C	- 45 dyads (A sample of 47 GI cancer patients and 45 of their spouses) **Time points:** time since diagnosis less than one year to more than 10 years	- A modified version of a measure developed by Pistrang and Barker (1995) to assess disclosure; - A shortened version of the Impact of Events Scale (IES); - A 13-item scale developed by Manne et al. (1997) to assess perceived partner avoidance and criticism; - The Miller Social Intimacy Scale (MSIS); - The Revised Barrett–Lennard Relationship	**Communication** - When patients reported high levels of holding back, their spouses reported higher levels of avoidance of thoughts and reminders of the patient's cancer. - Patients who reported high levels of holding back perceived their spouse to be less empathic and more avoidant and critical. - When patients reported high levels of disclosure, spouses perceived the patient as less avoidant. - When patients reported high levels of disclosure to their spouse and low levels of holding back, both they and their spouses rated their relationship as much more intimate. - When the spouse reported higher levels of disclosure,

				Inventory; - the Functional Assessment of Cancer Therapy (FACT); - The Caregiver Strain Index (CSI).	patients reported better relationships with their doctors. - When spouses reported high levels of holding back, patients reported lower levels of intimacy in the relationship. - Spouses who reported high levels of disclosure and low levels of holding back reported high levels of intimacy with the patient; and perceived the patient to be less avoidant.
Romero et al. 2008 USA	To examine the relationships among wives' coping strategies, the extent of congruence between wives' and husbands' perceptions of wives' adjustment, and wives' mood disturbance	C	45 couples (women with Stage I or II BC); **Time point:** within 3 Ms of diagnosis	- The 32-item version of the Coping Responses Inventory; - The Sickness Impact Profile (SIP); - The short version of the Profile of Mood States (POMS).	**Congruence** - Incongruence was positively correlated with wives' avoidant coping (p<0.005), and mood disturbance (p<0.001); but was not significantly correlated with wives' active behavioral or cognitive coping (p's >0.005). - T tests for matched pairs did not reveal a significant sample-wide discrepancy between wives' reports and husbands' perceptions of adjustment, t(43)=0.79,p=0.43. These variables were moderately and significantly correlated, r(44)= 0.38, p = 0.01; suggesting that, on average, husbands' perceptions of wives' adjustment to BC were moderately similar to wives' self-reported adjustment. - Husbands' over- or under-estimation of wives' adjustment may have a negative impact on wives' mood.
Sneeuw et al. 2001	To examine the extent of agreement in	C	72 couples (men with metastatic PC)	- European Organization for Research and Treatment of Cancer Quality of Life	**Congruence** - 5 of the 21 patient-proxy comparisons we noted

The Netherlands	health related QOL ratings provided by patients with cancer and their spouses.		- **Time points:**	Questionnaire-C30; - A prostate cancer specific questionnaire module	systematic differences in the mean score with spouses rating more impairment in patients than patients indicated. - Most patient-proxy correlations were 0.40 to 0.75, indicating moderate to good agreement in patient and spouse ratings. - A low patient-proxy correlation of less than 0.40 was noted only for the 2 measures of sexual function and satisfaction.
Song et al.2011, USA	To examine the relationship between QOL in PC patients and their partners.	L	- 134 couples (men with PC); - **Time points:** Baseline, and 4-, 8-, and 12-M follow-ups.	- The Functional Assessment of Chronic Illness Therapy general scale (FACT-G). - The Lewis Mutuality and Interpersonal Sensitivity Scale (MIS) ; - The Personal Resource Questionnaire (PRQ); - The Mishel Uncertainty in Illness Scale. - Symptom Distress: the Expanded PC Index Composite (EPIC); partners: a four-item IPIC (spousal version);	**Reciprocal influence** - Correlations of QOL between patients and partners that remained consistent during PCa survivorship, with the correlation coefficients 0.25, 0.24, .023, and 0.23 at baseline, 4-, 8-, and 12-Ms follow-ups. - Patients' lower education level, partners' older age, higher family income, and localized cancer at baseline were associated with better QOL in couples. - Couples' QOL improved with an increase in their social support (P<0.001) and open communication (P<0.001), and with a decrease in their uncertainty (P<0.001), PCa-specific hormonal (P<0.001) and sexual symptoms (P<0.05) in the patient, and general symptoms (P<0.001) in both partners. - QOL scores for couples increased by about 4.2 points when their open communication scores increased by one standard deviation.

Song et al.2012, USA	To examine the patterns of change in dyadic communication between patients with PC and their partners.	L	- 134 couples (men with PC); - **Time points:** Baseline, and 4-, 8-, and 12-M follow-ups.	- The 23-item Lewis Mutuality and Interpersonal Sensitivity Scale (MIS); - The Personal Resource Questionnaire (PRQ); - The 28-item Mishel Uncertainty in Illness Scale. - The 50-item Expanded PC Index Composite (EPIC) ; partners: a four-item IPIC (spousal version);	**Communication** - Patients and partners reported similar levels of open communication at the time of diagnosis. Communication reported by patients and partners decreased over time in a similar trend, regardless of phase of illness; The results of time linear ($p<0.01$) and squared ($p=0.06$) effects indicated that couples' perceived communication decreased over time in a somewhat curvilinear trend. - The significant interactions between time (linear and squared) and role ($p<0.01$ and $p<0.05$, respectively) suggested that the observed patterns of change in communication varied by role (i.e. patient vs. spouse). Patients' perceived levels of open communication decreased at a slower speed than their partners. - The trajectories of change in the levels of open dyadic communication about cancer were marginally different between patients and partners ($p=0.06$).
Sterba et al. 2011 USA	To examine QOL in spouses of men with PC and the relationship with the men's symptoms	L	43 couples (men with PC); **Time points:** at baseline and 6, 12, 18, and 24 Ms.	- Women's QOL: Mood disturbance (the Profile of Mood States instrument); Mental and physical health (the SF-36); the Sexual Function subscale; - Men's symptoms; the Southwest Oncology Group's; - Treatment-Specific Symptoms Scale	**Reciprocal influence** - Dyadic adjustment was associated with women's mood disturbance ($r=-0.49$, $p=0.001$), mental health functioning ($r=0.35$, $p=0.02$), sexual function ($r=0.26$, $p=0.10$), and sexual bother ($r=0.44$, $p=0.003$). - Men's symptoms were associated with worse physical health in wives ($\beta=-0.93$, $p=0.02$). Women reported worse sexual function at 18 and 24 Ms compared with baseline ($\beta=-13.0$, $p=0.02$), but ratings of sexual bother were unrelated to time, treatment, and men's symptoms.

				- The Dyadic Adjustment Scale (DAS).	
Zhou et al. 2011 USA	To examine the extent to which each individual's physical and mental health relates to marital satisfaction in a dyadic context	C	31 couples (men with PC); **Time points:** time since diagnosis: m=31.1 Ms.	- the MOS SF-36 Health Survey; - The Dyadic Adjustment Scale (DAS).	**Reciprocal influence** - Both the patient's mental (r= 0.33, p<0.05) and physical (r= 0.28, p<0.05) health was positively related to their caregiver's marital satisfaction. - However, the caregivers' mental and physical health was not significantly related to the patient's marital satisfaction.

Abbreviations: BC, Breast Cancer; C, Cross-sectional study; L, Longitudinal study; m, Mean; M, Month; PC, Prostate Cancer; PD, Psychological Distress; QOL, Quality of Life; SD, Study Design.

Qualitative studies

Authors	**Aims**	**SD**	**Informants**	**Main focus and Significant Findings**
Badr et al. 2006 USA	- To assess the effect of lung cancer and its treatment on spousal relationships, with a special emphasis on spousal communication.	G	13 patients with lung cancer and 12 spouses.	**Communication** - These couples experienced a wide variety of social constraints; including denial, avoidance, and conflict that can hinder open spousal communication. Specifically, patients and spouses reported trouble discussing continued tobacco use, cancer-related symptoms, prognosis, and the emotional effects of lung cancer on the spouse. - Despite these constraints, participants who reported talking with their partners about their relationships functioning (communication and spousal support), including quality of the relationship, relationship memories, planning for the future, and problem solving, reported fewer constraints and better communication about cancer.

Boehmer et al. 2001a USA	- To explore the perceptions of men with metastatic PC and the views of their wives regarding the changes caused by PC and its treatment.	FG	20 men with PC and 7 of their spouses.	**Communication** - The participants' accounts indicate little spousal communication about the implications of PC on their lives. In particular, couples appear to talk little about their emotions, worries, and fears, such as physical changes, perceptions of changes in spouse, and sexuality. Usually, the patients hide their feeling about the impact of the illness, and partners also reported to protect their husbands by hiding their emotions or avoiding questions. - Although wives have a profound interest in their husbands' PC, actual communication about the disease, its treatment, and the feelings it evokes may be less than we believe.
Boehmer et al. 2001b USA	To explore men's and their wives' perceptions of the PC diagnosis and their role in treatment decision-making.	FG	7 married men with metastatic PC and their spouses.	**Congruence** - The stories of receiving the diagnosis and deciding on treatment that were told by the men and their wives' were differed in significant (not congruent). Many men do not share their prostate-related health problems with their wives and some men choose their treatment without much spousal consideration. - There are three types of treatment decision processes: one type of eliminating their wives is that men who talk exclusively with their doctor; and two types of decision processes that involve men's wives, including the physician initiated and wives actively joined.
Chung, et al. 2012 Korea	To explore the experiences of women with BC and their spouses in South Korea.	D	7 women with primary BC without metastasis or recurrence and their spouses.	**Communication** - The core construct found in the experiences of couples were 'Learning Through Struggling'. With mutual help and support, shared personal views of thinking about what is important for patients, show mutual concern. - Notably, husbands' communication challenges and inability to read their wives' thoughts and feelings seemed to motivate them to provide simple reassurance to be optimistic, which frustrated their wives, who reported, 'you never know me' or 'you are not the patient' as expressed in the study. - Both spouses felt depressed, burdened, and worried about sexual issues, communication, and the future.

Fergus et al. 2009 Canada	To investigate the impact of BC on couples' relationships	FG	19 women with BC and 11 spouses.	**Communication** - Two higher-order categories of Personal Characteristics (both patient and partner) and Relationship Dynamics that impeded couple adjustment defined the overall theme of Relationship Vulnerabilities. - Personal characteristics: (1) Patients: Self-absorption; Counter-dependency; Exaggerated dependency; Over-controlling; (2) Spouse: Solution driven; Unchecked anger; Not prioritizing patient; Not reaching out. Relationship dynamics: (1) Pitfalls: Communication barriers; Withholding-withdrawal; Under-burdening; Conflictual intentions; (2) Challenges: Negotiating support; Accommodating changes in other; Coping with sexual disruption; Incorporating death and separation.
Gardner, DS. 2008 USA	To explore patterns of relationship, support, and communication in couples where one partner is diagnosed with advanced and terminal cancer	FG	- 35 couples (one with a wide variety of cancer).	**Communication** -A variety of complex and interrelated changes were described, including physical, emotional, and social experiences resulting from the diagnosis and progression of the cancer. - Dyadic-level accommodations to living with advanced cancer, using "we"… including living with uncertainty (about the illness and the future); illness and dying trajectories (facing dying, speak openly with their partner); search for shared meanings (shared understanding, narrative, or philosophical approach related to patients' illness trajectory and ultimate prognosis). - The importance of maintaining a positive or optimistic outlook, keeping things positive and working together; help each other; positive thinking can support the couple in their attempts to cope with the cancer, and in their interactions with each other, health care personnel and other social relations.
Lindau, et al. 2011 USA	To explore patient and partner communication about intimacy and sexuality relationship in the	D	- 13 couples (one with lung cancer).	**Communication** Most individuals reported that they had not talked directly with their spouses about lung cancer's effect on the relationship, although several people referred to increased awareness of non-verbal cues. For many couples, oral communication became more guarded in order to protect the patient or spouse from additional fear or stress; withholding of information was a commonly cited protective mechanism. Some

	context of lung cancer			individuals described improved communication due to an increased awareness of time and appreciation for each other. (p.183)

Abbreviations: BC, Breast Cancer; D, Descriptive; FG, Focus Groups; G, Grounded Theory. PC, Prostate Cancer; SD, Study Design;

Combined Quantitative and Qualitative Studies

Authors	**Aims**	**SD**	**Samples/ Time Points**	**Instrument Used**	**Main focus and Significant Findings**
Green, et al. 2011 Australia	To investigate coping and quality of life in men with prostate cancer and their partners	Survey and interviews	- 105 men with PC and 85 spouses. **Time points:** time since diagnosis 26 (1-156) Ms.	- The European Organization for research and treatment of Cancer Core Quality of Life Questionnaire (QLQ-C30); - The Brief COPE (Carver 1997); - Self-developed open-ended questions	**Congruence** - There are dyadic correlations between patient and partner ratings of the patient's HRQoL in all six dimensions (r=0.45-0.73, all p <0.001). - Partners rated the patient's emotional functioning (m = 83.3, IQR = 66.7–100.0) as significantly worse than patients themselves (m = 83.3, IQR =75.0–100.0), Z =-2.48, P < 0.05. However, patients' social functioning was rated significantly better by the partners (m = 83.3, IQR = 66.7–100.0) than by patients (m = 66.7, IQR = 66.7–100.0), Z =-2.48, P < 0.05. - There was no significant difference between patient and partner in the mean ratings for avoidant strategies, but s significant difference in use of approach coping strategies, Z =-2.06, P < 0.05. Patients reported greater use of approach coping (m = 2.7, IQR = 2.0–3.1) than did their partners (m = 2.3, IQR = 1.9–3.0).

Abbreviations: HRQoL, Health Related Quality of Life; m, Mean; M, Month; PC, Prostate Cancer; SD, Study Design.

Table 6-1 Characteristics of couple-based interventions

Author country	**SD**	**Target population (diagnosis of cancer, No. of couples, attrition %)**	**Intervention type* Contents of intervention**	**Dosage of intervention (No. of sections, time of each section, the duration of intervention, and the length of follow-up)**	**Delivery of intervention (who and how) Approaches of intervention /Theoretical framework**
Baucom et al. (2009) USA	RCT	Stage I or II BC; 14; 14% (distance to the hospital)	- **ST**; PE - Relationship Enhancement (RE) vs. usual care; - RE emphasis on **communication skills** for problem-solving & emotional expressiveness. **- Patient caregiving**: medical education; provide emotional and patient self-esteem support; **- Marital/family care**: communication for decision-making; sharing feelings; sexual adaptation; **- Caregiver self-care**: Skills for mutual problem solving; emotional support; find meaning.	6; 75- minute biweekly; 12 weeks; Pretest, posttest, one year follow-up;	- Intervention delivered by advanced doctoral psychological students in therapist's office; - Face-to-face (each couple); - Cognitive-behavioral approach.
Campbell et al. (2007) USA	RCT	PC; 40; 25% (difficulty scheduling a time when both partners	- **ST**; PE - Coping Skills Training (CST) vs. usual care; - CST focused on problem-solving skills, training in cognitive & behavioral coping skills. **- Patient caregiving**: information regarding cancer's physical, emotional, and social side effects; **- Marital/family care**: Effects of cancer on marital	6; 60-minute weekly; 6 weeks; Pretest, posttest.	- Intervention delivered by a trained, African-American, doctoral level medical psychologist; - Telephone-based (speakerphones provided for joint participation); - Cognitive-behavioral approach.

		were available)	relationship and Communication skills; plan mutually pleasant activities; **- Caregiver self-care**: Progressive muscle relaxation, activity-rest cycles, and cognitive restructuring.		
Collins, et al. (2013) Australia	cohort	early stage PC; 12; 17% (	- **TC;** PE -Single-arm, pre-post Cognitive Existential Couple Therapy (CECT) pilot intervention; **- Patient caregiving**: physical and psychological changes, changing care needs, managing symptoms; Understanding changes in life as a result of PC, reordering priorities, reviewing existential outlook **- Marital/family care**: communication patterns; Investigating ways of promoting support from others; examining ways to cope better – by patient, partner and the couple. **- Caregiver self-care**: Investigating ways of promoting support from others.	6; 90-minute weekly; 6 weeks; Pretest, posttest.	- Intervention delivered by mental health professionals (clinical psychologists and psychiatrists); - Face-to-face (each couple); - Cognitive-behavioral approach; **Theoretical framework:** Spiegel's supportive–expressive model
Heinrichs, et al (2012) Germany	RCT	stages I, II, or III breast or gynecological cancer; 72; 33% (intervention not perceived as useful, refusal of group	- **ST**, PE - Relationship Skills Program—Side by Side vs. Couples control program (CCP); - Side by Side teaches individual and relationship skills for partners as they address the female's breast and gynecological cancer. The centerpieces of the intervention are communication skills and dyadic coping training. 60% of the total intervention time was used for dyadic skills and topics and approximately 30% of the intervention time for individual skills and topics. - CCP: The couples received a set of written educational	4; 120 minutes biweekly; 8weeks; Pretest, posttest, 6 months and 12 months after intervention (1 session, 120 minutes for CCP)	- Intervention delivered by a psychological therapist in the couples' home; - Face to face (each couple) - Cognitive-behavioral approach; **Theoretical framework:** an adaptation model of couples functioning

		assignment, too much time burden, patient died, separated)	materials about breast or gynecological cancer, and the therapist was instructed to listen to each individual's concerns and attend to them nonverbally and in a paraphrasing manner.		
Kayser, et al (2010) USA	RCT	early stage BC; 63; 25% (too far from hospital)	- **ST**, PE - Partners in Coping Program (PICP) vs. Standard Social Work Services (SSWS, control group); - PICP improve coping ability, supportive communication, assessing couples' social support, and caring for children; **- Patient caregiving**: Personal Coping and Preserving Physical and Psychological Health; **- Marital/family care**: Integrating Tasks of Illness into a Couple's Daily Routine; Communication; Supportive Exchanges; Enhancing Intimacy and Sexual Functioning **- Caregiver self-care**: Personal Coping and Preserving Physical and Psychological Health; learning new coping skills, such as relaxation techniques.	9; 60-minute biweekly; over an average of **5 months;** Pretest, 6-months, one year follow-up.	- Intervention delivered by masters-level clinical social workers receiving 8-hour training before starting the intervention ; - Face-to-face sessions (each couple); - Cognitive-behavioral approach;
Kuijer et al. (2004) Netherlands	RCT	Various forms of cancer; 59; 34% (time restrictions, program did not meet their expectation)	- **TC**, ST - Intervention trial and wait-list control group; - Intervention arm focuses on improving relationship equity; Mutual support to reduce sense of inequity; enhance relationship quality and well-being. - Booklet with homework assignments was used.	5; 90-minute biweekly; 10 weeks; Pretest (T0), one week (T1), and 3-months (T2) after intervention.	- Intervention delivered by psychologist; - Face-to-face sessions (each couple); - Cognitive-behavioral approach; **Theoretical framework:** equity theory
Manne &	Cohort	Early stage of	- **ST**, PE	5;	- Intervention delivered by an

Badr (2008) USA		BC; 16; 12%	Intimacy-Enhancing Couples' Therapy (IECT), focus on relationship-enhancing behaviors by improving reciprocal disclosure and responsiveness, viewing the illness in relationship terms.	60-minute weekly; 5 weeks Pre-intervention and one week after intervention	unspecified therapist trained in specific intervention content; - Face-to-face sessions (each couple); **Theoretical framework:** The relationship intimacy model
Manne et al. (2011) USA	RCT	Localized PC; 71; 21% (too much time burden, program did not meet their expectation)	- **ST**, PE - Intimacy-enhancing therapy (IET) vs. usual care; - IET focused on improving couples' ability to comfortably share their thoughts and feelings regarding cancer, promote mutual understanding and support regarding their own and one another's cancer experience, facilitate constructive discussion of cancer concerns, and to enhance and maintain emotional intimacy. Sessions contained didactic content, in-session skill practice, and home practice assignments.	5; 90 minute; 5 weeks; 8 weeks after baseline assessment	- Intervention delivered by an unspecified therapist trained in specific intervention content; - Face-to-face sessions (each couple); **Theoretical framework:** The relationship intimacy model
McCorkle et al. (2007) USA	RCT	PC; 126; 15% (asked too many questions, dissatisfaction with group assignment, urinary incontinence, spouse refused to participate)	- **PE,** ST - Standardized Nursing Intervention Protocol (SNIP) vs. Usual care; - SNIP for patients and partners following a radical prostatectomy. Focus on monitoring /managing symptoms, teaching self-care, counseling patients and family members; promoting marital communication.	8 in home 90 minutes; 8 telephone 45 minutes; 8 weeks; Baseline, three and six months after intervention	- Intervention delivered by advanced practice nurses and board certified nurse practitioners trained in specific intervention content; - Face to face and telephone

McLean et al. (2008) Canada	Cohort	Various forms of cancer; 16; 6%	- **TC**, ST Adaptation of Emotionally Focused Couple Therapy (EFT) emphasizes the sharing of emotions, normalizing feelings of separation.	8; 60 minutes 8 weeks Baseline (T0), after four Sessions (T1), after eight sessions (T2), and 3 months post-intervention follow-up (T3).	- Intervention delivered by doctoral-level psychologists with some training in EFT (in clinical office); - Face to face (each couple); **Theoretical framework:** Emotionally Focused Therapy.
McLean et al. (2013) Canada	RCT	Various forms of cancer; 42; 14%	- **TC**, ST - Emotionally Focused Couple Therapy (EFT) vs. usual care. - Adaptation of Emotionally Focused Couple Therapy (EFT) emphasizes the sharing of emotions; normalizing feelings of separation; assessing couple's need for decision making; understanding physical changes and decline in the patient that result in further role changes; reviewing one's life and existential issues that include meaning, value, and spirituality.	8; 60 minutes 8 weeks Baseline (T0), post intervention (T1), and 3 months post-intervention follow-up (T2).	- Intervention delivered by doctoral-level psychologists with some training in EFT (in clinical office or hospital room); - Face to face (4-5 coupes in each group); **Theoretical framework:** Emotionally Focused Therapy.
Mohr et al. (2003) USA	Cohort	Various forms of cancer; 9; 33% (death of the patient)	- **TC**, ST - One arm pre-post intervention - Focus on facilitating shifts in beliefs, goals and values, facilitating conversations about death and dying, increasing intimacy and emotional support.	8; 50-60 minutes 8 weeks Pre- post intervention.	- Intervention delivered by PhD-level psychologist or clinical social worker, no intervention-specific training undertaken (in home); - Face to face (each couple);
Northouse et al. (2007) USA	RCT	PC; 263; 17% (refusal of group	- **PE,** ST - FOCUS program (intervention) vs. usual care; - FOCUS program: family involvement, optimistic attitude, coping effectiveness, uncertainty reduction and	3 home visits 90-minute; 2 phone calls 30-minutes;	- Intervention delivered by masters-level nurse, trained in the FOCUS program; - Face to face home visit and phone

		assignment)	symptom management; the intervention targeted couples’ communication, hope, coping, uncertainty, and symptom management. **Patient caregiving**: Assist patient with managing care needs, provide support; communicate with health care providers; **Marital/family care**: Open communication; mutual support, healthy lifestyle behaviors; maintain optimism and manage uncertainty as a team. **Caregiver self-care**: Maintain self-health, effective coping with stress; maintain social support system; use available resources effectively.	10 weeks Baseline, 4-month, 8- month, and 12-month follow-up,	calls; **Theoretical framework:** Stress and coping
Porter et al. (2009) USA	RCT	Gastrointestinal cancer; 130; 21% (death/declining health, lack of time, distance)	- **ST**, PE - Partner-assisted emotional disclosure (PAED) vs. Partner-assisted educational (EDU) intervention received general cancer information only; - PAED focused on decreasing the ‘holding back’ of cancer-related disclosures to partners, increasing relationship quality and intimacy, decreasing psychological distress; 4 weekly face-to-face sessions with masters-level social worker or psychologist	4; 75 minutes for the first session and 45 minutes for 2-4 sessions; 8 weeks Pre-post intervention	- Intervention delivered by masters-level social worker or psychologist; - Face to face (each couple);
Scott, et al (2004) Australia	RCT	Primary BC or gynecological cancer; 94; 20% (partners declined to provide data)	- **ST**, PE - Three-arm intervention: medical information education (MI), patient coping training (PC), and couple-coping training (CanCOPE); - Arm 1: MI intervention: educational materials regarding patients’ particular cancer and associated treatments, no specific psychological intervention	MI intervention: five 15-minute phone calls; PC intervention: four 2-hour sessions: pre & post-surgery, 1 week & 6-months	-Interventions delivered by three female psychologists - MI intervention: phone calls; - PC intervention: face-to-face; - CanCOPE: home visits plus telephone calls. **Theoretical framework:** Social-

			provided, medical information booklets; - Arm 2: PC intervention: combined MI intervention with supportive counseling and education in coping skills; - Arm 3: CanCOPE: same as PC intervention, but undertaken with couples focus on teaching of supportive communication skills.	after; two 30-minute phone calls 1 & 3-months post-surgery; CanCOPE: Five 2-hour joint home visits plus two 30 minutes telephone calls (7 weeks plus 6 months follow up); Pre-post intervention, 6 months and 12 months follow up.	cognitive processing model of emotional adjustment to cancer; coping theory
Shields & Rousseau (2004) USA	Cohort	BC; 48; 25%	- **TC**, ST 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; Arm 2: 1-session workshop intervention (as above) Arm 3: No treatment control group.	1 and 2 sessions Pre-post intervention, and 3 months follow up.	- Interventions delivered face-to-face by unspecified therapist; - Group format (3-5couples in each group);
Thornton et al (2004) USA	RCT	PC; 65; 19%	- **ST**, PE 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.	1; 45 minutes One-off Pre-surgery, 3 weeks, and 1 year after surgery	- Interventions delivered face-to-face by unspecified counselor;

			Arm 2: Usual care (control group)		

Abbreviations: BC: Breast Cancer; PC: Prostate Cancer; RCT: Randomized Controlled Trial; SD: Study Design
Intervention type*: PE: Psycho-education; ST: Skills training; TC: Therapeutic counseling. Listed the primary and secondary focus

Table 6-2 Outcomes of couple-based interventions

Author	**outcome measurements (*indicates patient only; # indicates partner only)**	**Significant outcomes: * <.05; **<.01** **Cohen's d (between group comparisons)**	**MQ***
Baucom et al. (2009)	- Psychological Distress: BSI (Brief Symptom Inventory), PGI (Posttraumatic Growth Inventory); -*QOL: FACT-B (Functional Assessment of Cancer Therapy-Breast); SIS (self-acceptance and perceived partner's acceptance of the women); - *Physical distress: BFI (Brief Fatigue Inventory); BPI (Brief Pain Inventor); RSC (Rotterdam Symptom Checklist); - Marital satisfaction: QMI (Quality of Marriage Index); DISF-SR (Derogatis Inventory of Sexual Functioning);	For **patients**: 10 variables were assessed across individual psychological, medical, and relationship domains, resulting in 20 effect sizes for post-test and 1-year follow-up. The findings favored RE on 19 out of these 20 effect sizes. The median interpolated effect size across all patient measures at post-test was 0.61, and 0.69 at 1-year follow-up. For **partners**: completed four measures at analogous time points, resulting in eight between-group effect sizes which favored RE on seven of the 8 comparisons. At post-test, the interpolated median effect size for partners was 0.35, and 0.33 at 1-year follow-up.	S
Campbell et al. (2007)	- Self-Efficacy for Symptom Control Inventory (SESCI); - QOL: SF-36*; EPIC *: the Expanded PC Index Composite; POMS-SF#: the Profile of Mood States-Short Form; CSI#: the Caregiver Strain Index.	For **patients**: CST produced moderate to large treatment effects for QOL related to bowel bother (*d* =0.47), urinary bother (*d* =0.32), sexual bother (*d* =0.45), and hormonal symptoms (*d* =0.38). **Partners** who underwent CST reported less caregiver strain, depression, and fatigue, and more vigor, with moderate effect sizes (0.26, 0.46, 0.39,	M

		and 0.40 respectively) observed that approached conventional levels of statistical significance.	
Collins, et al. (2013)	- Psychological Distress: MHI: The Mental Health Inventory; IES-R: The Impact of Events Scale – Revised; - Marital satisfaction: FRI: The Family Relationship Index; CSI: The Cancer Support Inventory; - Coping: BCOPE: Brief Cope; - Benefit finding: The revised Benefit-Finding Scale	The overall negative impact of the PC experience, as measured by IES-R, was lower at time 2 (after CECT) than at time 1 (before CECT) in patients and in partners (p = 0.013). Other significant effects included a decrease in avoidance (p = 0.021) and in hyper arousal (p = 0.019) at time 2 in both patients and partners, indicating **improved psychological function** after CECT intervention.	M
Heinrichs et al. (2012)	- Psychosocial Distress: QSC-R23*: the Questionnaire on Stress in Cancer Patients; fear of progression questionnaire; avoidance in dealing with the illness; - Benefit finding: The posttraumatic growth inventory; - Marital satisfaction: QMI (quality of marriage index); - Communication: the communication subscale from the partnership questionnaire; - Dyadic coping: The dyadic coping inventory	- **Patients** receiving Side by Side showed larger reductions in fear of progression, and **couples** reported less avoidance in dealing with the cancer, more posttraumatic growth, and better relationship skills relative to the Couples Control Program. - All differences favoring Side by Side disappeared by 16 months after the diagnosis. - **Short-term** changes in functioning may be improved by enhancing couples' dyadic skills during acute medical treatment of the disease.	M
Kayser, et al (2010)	- QOL: FACT-B*: The Functional Assessment of Cancer Therapy–Breast; QL-SP#: The Quality of Life Questionnaire for Spouses; IIRS #: The Illness Intrusiveness rating Scale.	6 months: **Patients** Physical well-being *d* = 0.34; Emotional well-being *d* =0 .33; Social well-being *d* = 0.32; Functional well-being *d* = 0.40; Total FACT-B *d* = .38; **Partners** Emotional well-being *d* = 0.54; Illness intrusiveness *d* = 0.38 12 months: **Patients** Physical well-being *d* = 0.47; Emotional well-being *d* =0.55; Social well-being *d* = 0.27; Functional well-being *d* = 0.34; Total FACT-B *d* =0.44; **Partners** Emotional well-being *d* =0.38; Illness	M

		intrusiveness d = 0.26	
Kuijer et al. (2004)	- Depression: the Center of Epidemiological Studies Depression Scale (CES-D); - Marital satisfaction: 0-10 Ladder	One week after intervention: **Patients** Depression d = 1.1; Marital satisfaction d =0 .63; **Partners** Depression d = 0.02; Marital satisfaction d = 1.09 3 months after intervention: **Patients** Depression d = 0.45; Marital satisfaction d = 0.19; **Partners** Depression d = 0.10; Marital satisfaction d = 0.18	M
Manne & Badr (2008)	- Psychological Distress: Mental Health Inventory (MHI), Impact of Events Scale (IES); - Marital satisfaction: Personal Assessment of Intimacy in Relationships inventory (PAIR).	^ Pre-post within group comparison 6 Weeks: **Patients** MHI (Distress)* d = 0.71; IES (Intrusiveness)* d = 0.37; IES (Avoidance)* d = .025; PAIR (perceived partner responsiveness)* d = 0.36; PAIR (cancer-specific closeness) d = 0.15; **Partner** MHI (Distress)* d = 0.79; IES (Intrusiveness)* d = 0.96; IES (Avoidance)* d = 0.84.	M
Manne et al. (2011)	- Psychological Distress: Mental Health Inventory (MHI), Impact of Events Scale (IES); - Marital satisfaction: Dyadic Adjustment Scale (DAS); Personal Assessment of Intimacy in Relationships inventory (PAIR); - Relationship communication	**Patients:** there were three significant moderator effects found for self-disclosure (t (67) = −4.09; p = 0.0001), perceived partner disclosure (t (67) = −3.43; p = 0.0010), and perceived responsiveness (t (62) = −2.20; p = 0.0314). **Partners:** After controlling for covariates, there were a significant (t interaction between intervention group and baseline in cancer-specific distress (IES) (65) =−2.91; p = 0.005); baseline relationship satisfaction (DAS) (t (63) = −4.24; p< 0.0001); baseline relationship intimacy and treatment condition was significant (t (66) =−4.16; p < 0.0001); mutual constructive communication (t (63) = −3.17;p = 0.0023) and demand-withdrawal communication (t (61) =−2.50; p = 0.0150).	M
McCorkle et al. (2007)	- Depression: CES-D;	3 months: **Patients** Depression d = 0.23; Marital satisfaction d =0 .10; **Partners** Depression d = 0.11; Marital satisfaction d = 0.41; Sexual	S

	- Marital satisfaction: Cancer Rehabilitation Evaluation System (CARES)	Functioning *d* = 0.27. 6 months: **Patients** Depression *d* = 0.21; Marital satisfaction *d* = 0.34; Sexual Functioning *d* =0 .34 **Partners** Depression *d* = 0.39; Marital satisfaction *d* =0.63; Sexual Functioning *d* = 0.51.	
McLean et al. (2008)	- Depression: symptoms of depression (Beck Depression Inventory-II (BDI-II), Beck Hopelessness Scale (BHS); - Marital satisfaction: Revised Dyadic Adjustment Scale (RDAS).	^Comparisons to baseline scores After eight sessions: **Patients** BDI-II *d* = 0.33; BHS *d* = 0.23; RDAS *d* = 1.07; **Partners** BHS *d* = 0.16; RDAS *d* = 0.67 3 months post intervention: **Patients** BDI-II *d* = 0.54; BHS *d* =0.17; Marital satisfaction *d* = 0.84; **Partners** BDI-II *d* = 0.29; BHS *d* = 0.18; Marital satisfaction *d* = 0.76.	M
McLean et al. (2013)	- Depression: Beck Depression Inventory-II (BDI-II), Beck Hopelessness Scale (BHS); - Caregiver Burden Scale CBS#; - Marital satisfaction: RDAS; - Coping: Relationship-Focused Coping Scale (RFCS)*	8 weeks: **Patients** Marital satisfaction** *d* = 1.65; Coping* *d* = .36; **Partners** Marital satisfaction** *d* = 2.03 3 months post intervention: **Patients** Marital satisfaction** *d* = 1.32; Coping* *d* = .37; **Partners** Marital satisfaction** *d* = 1.22	S
Mohr et al. (2003)	- Anxiety: authors own measure (distress & worry about dying); - Depression: BDI-II; - QOL: SF-36; - Marital satisfaction: authors own positive/negative scale.	^ Pre-post within group comparison Eight weeks: **Patients** Anxiety (distress about dying) *d* =0.54; Marital satisfaction (positive) *d* = 0.74; **Partner** Anxiety (worry about dying) *d* = 0.38	M
Northouse et al. (2007)	- QOL: Functional Assessment of Cancer Therapy-General (FACT-G), SF-12, Expanded PC Index	4-months: **Patients** ***MUIS** *d* = 0.22; ***LMISS** *d* = *0*.22; **Partners** SF-12M/FACT-G *d* = 0.25, 0.26; Appraisal (all): *d* = 0.27/0.32; LCSES *d* =	S

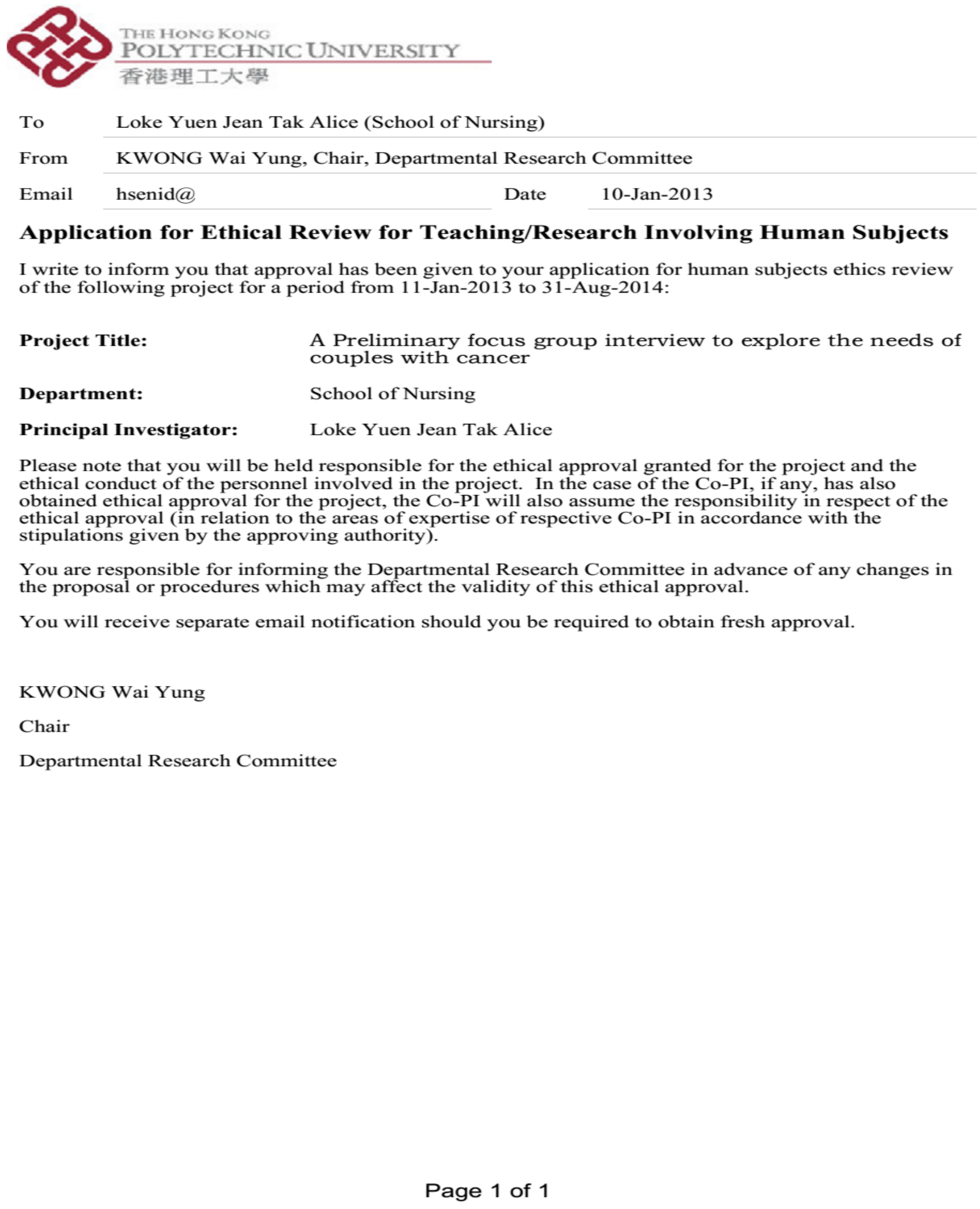
	Composite (EPIC); - Appraisal: MUIS (Mishel Uncertainty in Illness Scale), BHS (Beck Hopelessness Scale), AIS (Appraisal of Illness or appraisal of caregiving Scales); - Coping: Orientations to Problems Experienced (Brief-COPE); - Self-Efficacy*: Lewis Cancer Self-Efficacy Scale (LCSES); - Communication: Lewis Mutuality and Interpersonal Sensitivity Scale (LMISS).	0.26; LMISS *d* = 0.31, EPIC (urinary, symptom distress) *d* = 0.30, 0.34 12 months: **Partners** LCSES *d* = 0.27, BriefCOPE (active coping) *d* = 0.28, LMISS *d* = 0.29, SF-12P *d* = 0.32.	
Porter et al. (2009)	- Psychological distress: Profile of Mood States- Short Form (POMS-SF); - Marital satisfaction: Quality of Marriage Index (QMI); Miller Social Intimacy Scale (MSIS).	Post-intervention **Patients:** QMI**; MSIS* Compared with an education/support condition, the partner-assisted emotional disclosure condition led to improvements in relationship quality (B = 0.10; SE=0.03 [P < .0001]) and intimacy (B = 0.56; SE=0.28 [P = .02]) for couples in which the patient initially reported higher levels of holding back from discussing cancer-related concerns.	M
Scott, et al (2004)	- Psychological distress: Impact of Event Scale (IES); - Sexuality: Psychosocial Adjustment to Illness Scale - Self Report (PAIS-SR); Sexual Self Schema (SSS), Brief Index of Sexual Functioning (BISF); - Coping: Revised Ways of Coping Questionnaire-Cancer Version (WOC-CA); - Communication: qualitative interviews	^ Comparisons between CanCOPE and PC Post-intervention **Patients** Coping** *d* = 0.25; IES (Avoidance)* *d* = 0.36; SSS *d* = 0.56; BISF (Desire) *d* = 0.50; **Partners** Coping* *d* = 0.36 12 months **Patients** Coping* *d* = 0.82; IES (Avoidance)* *d* = 0.55; SSS *d* = 0.39; BISF (desire) *d* = 0.08; **Partners** Coping* *d* = 0.61	M

Shields & Rousseau (2004)	- Psychological distress: SF-12; Impact of Event Scale (IES); - Marital satisfaction: RDAS	n/a (sample size are too small) The 2-session format showed the most promise for producing positive change in mental health functioning (SF-12) and cancer-related stress (IES).	M
Thornton et al (2004)	− QOL: SF-36, FACT-P*; − Physical Distress: Urinary Incontinence Scale (UIS); - Psychological distress: Positive and Negative Affect Schedule (PANAS), the Impact of Event Scale (IES); perceived stress scale (PSS); − Marital satisfaction: RDAS	3 weeks: **Patients** FACT-P (social/family well-being)* *d* =0.58; - Patients experienced reprieve from emotional distress and negative effect immediately following surgery despite worsened physical functioning. Partner quality of life and psychosocial adjustment scores were generally more constant from pre-surgery to post-surgery, with improvements noted 1 year later. - For both patients and partners, cancer-specific stress symptoms declined progressively over the year.	M

Abbreviations: MQ: Methodological Quality; M: Moderate; S: Strong

Methodological Quality*(Thomas et al. 2004): The quality of the studies included in this review was assessed using the criteria described by the Effective Public Health Practice Project (EPHPP) (Thomas et al. 2004). Six components from each study are rated as strong, moderate, or weak according to a standardized guide. These components were: selection bias, study design, confounders, blinding, data collection methods, and withdrawals and dropouts. The overall rating for each study was determined by assessing the six component ratings. Those with no weak ratings and at least four strong ratings were considered strong. Those with less than four strong ratings and one weak rating were considered moderate. Finally, those with two or more weak ratings were considered weak. As showed in the table, four studies had a global rating of ‘strong’, whereas the remaining 13 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 and high withdraw rate, which led to otherwise ‘strong’ articles being rated as ‘moderate’.

Appendix I Ethics Approval Letter for Focus Group Study



THE HONG KONG
POLYTECHNIC UNIVERSITY
香港理工大學

To Loke Yuen Jean Tak Alice (School of Nursing)

From KWONG Wai Yung, Chair, Departmental Research Committee

Email hsenid@ Date 10-Jan-2013

Application for Ethical Review for Teaching/Research Involving Human Subjects

I write to inform you that approval has been given to your application for human subjects ethics review of the following project for a period from 11-Jan-2013 to 31-Aug-2014:

Project Title: A Preliminary focus group interview to explore the needs of couples with cancer

Department: School of Nursing

Principal Investigator: Loke Yuen Jean Tak Alice

Please note that you will be held responsible for the ethical approval granted for the project and the ethical conduct of the personnel involved in the project. In the case of the Co-PI, if any, has also obtained ethical approval for the project, the Co-PI will also assume the responsibility in respect of the ethical approval (in relation to the areas of expertise of respective Co-PI in accordance with the stipulations given by the approving authority).

You are responsible for informing the Departmental Research Committee in advance of any changes in the proposal or procedures which may affect the validity of this ethical approval.

You will receive separate email notification should you be required to obtain fresh approval.

KWONG Wai Yung

Chair

Departmental Research Committee

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Appendix II Information Sheet for Focus Group Study

INFORMATION SHEET

A Preliminary focus group interview to explore the needs of couples with cancer

You are invited to participate in a study supervised by Prof. Alice Yuen Loke, Dr Wan-chaw Shae, and Dr. Yim-wah Mak, and conducted by Qiuping Li, who is a PhD student of the School of Nursing, The Hong Kong Polytechnic University.

The purpose of these preliminary focus groups interviews is to explore cancer couples' concerns and needs related to their caring role and experience; and to identify barriers faced by health professionals in providing caregiver support. Interviews will be conducted among couples coping with cancer (dyads), the patients with cancer and spousal caregivers separately (if applicable), physicians and nurses respectively. Each focus group interview will last two hours or less, which will be audiotaped.

Focus group has been proved to be an effective and time-saving method to generate a rich understanding of participants' experiences and beliefs. During the focus group discussion, however, you may have concerns about any discomfort or your personal privacy will be leaked. To minimize the possible adverse consequences, researchers will draw up measures to protect your privacy before the group interview. Such as boundaries will be set to define the acceptable limits of the discussion in advance; all of the participants among the group members will be informed or told to maintain confidentiality of all information within the group. If you experience any discomfort during the interview, you can talk to researcher at any time for help.

You have rights to withdraw from the study at any time during the study without any penalty. All information related to you will be kept confidential by assigning a code number or fictitious name for you to prevent the information to be identified. Only the researcher will have access to the tape-recording and transcription, and these records will be destroyed after conclusion of the project.

If you have any complaints about the conduct of this research study, please do not hesitate to contact Dr Virginia Cheng, Secretary of the Human Subjects Ethics Sub-Committee of The Hong Kong Polytechnic University in person or in writing (c/o Research Office of the University) stating clearly the responsible person and department of this study. If you would like more information about this study, please contact Qiuping Li or her supervisor Prof Alice Yuen Loke.

Thank you for participating in this study.

Student Investigator

Li Qiuping

Appendix II Information Sheet for Focus Group Study (Chinese version)

有关资料

探讨癌症病人及配偶相关需求的前期质性研究

诚邀您参加由袁桢德博士、佘雲楚博士和麥艷華博士负责监督，李秋萍同志负责执行的研究计划。李秋萍同志是香港理工大学护理学院学生。

这项研究的目的是了解医疗专业人员，如肿瘤专科医生、护士，癌症病人及配偶照顾者对癌症看护的体会及经历，以期为制订以改善癌症病人及家属（配偶照顾者）状况的干预措施及指导手册提供依据，并为初步制订的干预措施及指导手册提供修改建议。研究活动包括对以上各组人员，如医生、护士、癌症病人及配偶进行分组讨论收集其想法及建议。每组讨论时间大约持续 2 小时左右。在讨论过程中将会对讨论内容进行录音，以期为后期的研究分析提供依据。

质性研究（小组讨论）已被证实是有效的一种高效、省时，以收集不同人群对某一现象的认识、感受及经历的有效方法，同时可以通过小组讨论对某一现象较为深入的分析，获得较为有价值的信息。然而在讨论期间，您可能担心出现紧张不适或您的个人隐私会被泄露。为减少这些可能的不良后果，在小组讨论之前研究者会制订相关措施以保护您的隐私。如果在讨论过程中有出现任何不适，可以随时与李秋萍同志联络,寻求帮助。

您享有充分的权利在研究开始之前或之后决定退出这项研究，而不会受到任何对您不正常的待遇或被追究责任。凡有关您的资料将会保密及加上编码。所有资料，只有研究人员得悉。待研究结束将会对所有资料进行销毁处理。

如果您对这项研究有任何的不满，可随时与香港理工大学人类实验对象操守小组委员会秘书陈博士联络(地址：香港理工大学研究事务处转交)。如果您想获得更多有关这项研究的资料，请与李秋萍同志联络，或联络她的导师袁桢德博士。

谢谢您参与这项研究°

主要研究员(PI)

李秋萍

Appendix III Consent Form for Focus Group Study

CONSENT TO PARTICIPATE IN RESEARCH

A Preliminary focus group interview to explore the needs of couples with cancer

I ________________________ hereby consent to participate in the captioned research supervised by Prof. Alice Yuen Loke, Dr Wan-chaw Shae, and Dr. Yim-wah Mak and conducted by Qiuping Li.

I understand that information obtained from this research may be used in future research and published. However, my right to privacy will be retained, i.e., my personal details will not be revealed.

The procedure as set out in the attached information sheet has been fully explained. I understand the benefits and risks involved. My participation in the project is voluntary.

I acknowledge that I have the right to question any part of the procedure and can withdraw at any time without penalty of any kind.

Name of participant (patient) ________________________________

Signature of participant (patient) ________________________________

Name of spouse ________________________________

Signature of spouse ________________________________

Name of researcher Li Qiuping

Signature of researcher ________________________________

Date ________________________________

Appendix III Consent Form for Focus Group Study (Chinese version)

参与研究同意书

探讨癌症病人及配偶相关需求的前期质性研究

本人________同意参加由袁桢德博士、佘雲楚博士和麥艷華博士负责监督，李秋萍同志执行的研究项目。

我理解此研究所获得的资料可用于未来的研究和学术交流。 然而我有权保护自己的隐私，我的个人资料将不能泄漏。

我对所附资料的有关步骤已经得到充分的解释。我理解可能会出现的风险。我是自愿参与这项研究。

我理解我有权在研究过程中提出问题, 并在任何时候决定退出研究而不会受到任何不正常的待遇或被追究责任。

参加者（病人）姓名:

参加者（病人）签名:

配偶姓名:

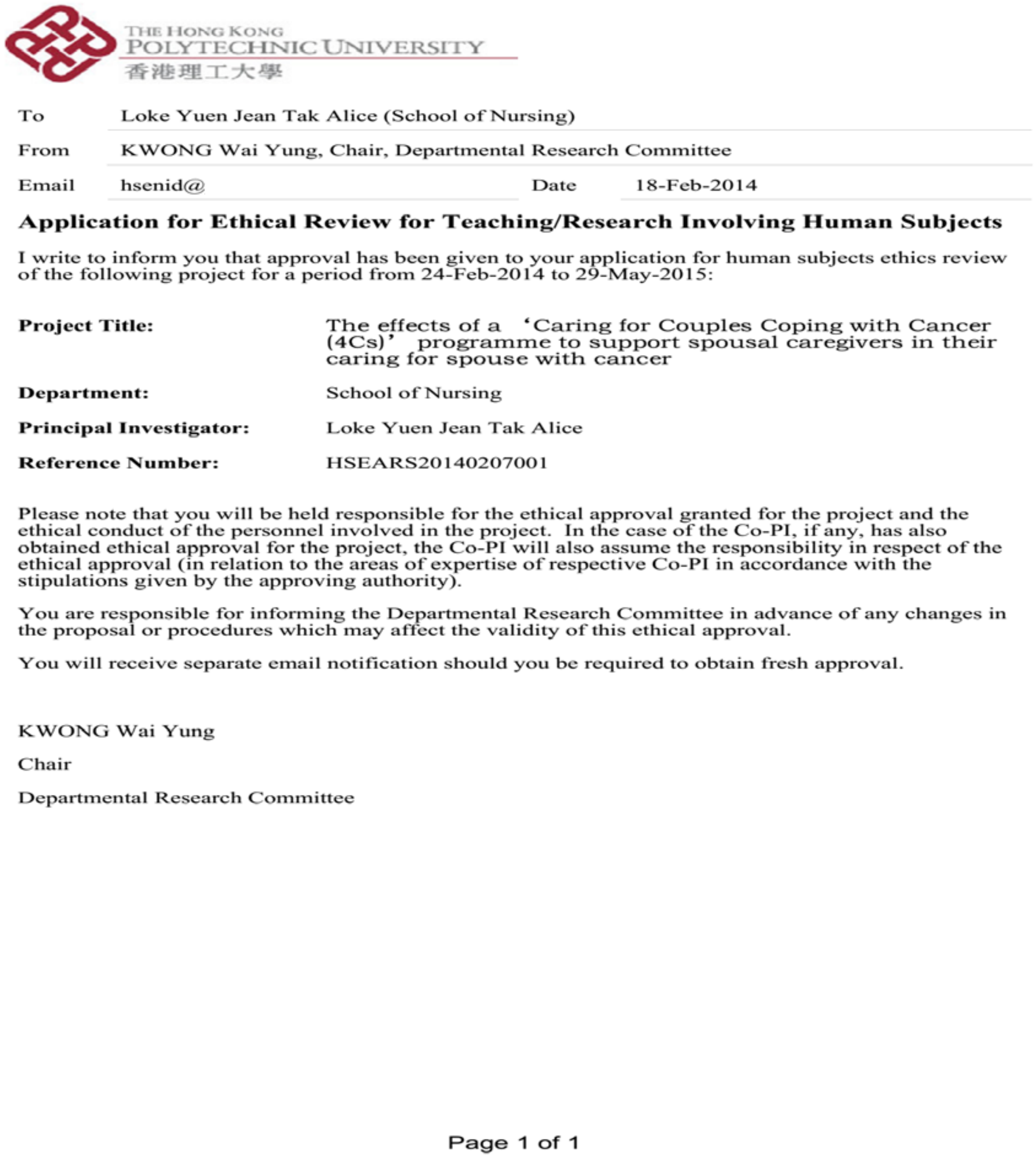
配偶签名:

研究人员姓名: 李秋萍

研究人员签名:

日期:

Appendix IV Ethics Approval Letter for Pre-Post Pilot Study



THE HONG KONG
POLYTECHNIC UNIVERSITY
香港理工大學

To Loke Yuen Jean Tak Alice (School of Nursing)
From KWONG Wai Yung, Chair, Departmental Research Committee
Email hsenid@ Date 18-Feb-2014

Application for Ethical Review for Teaching/Research Involving Human Subjects

I write to inform you that approval has been given to your application for human subjects ethics review of the following project for a period from 24-Feb-2014 to 29-May-2015:

Project Title:	The effects of a 'Caring for Couples Coping with Cancer (4Cs)' programme to support spousal caregivers in their caring for spouse with cancer
Department:	School of Nursing
Principal Investigator:	Loke Yuen Jean Tak Alice
Reference Number:	HSEARS20140207001

Please note that you will be held responsible for the ethical approval granted for the project and the ethical conduct of the personnel involved in the project. In the case of the Co-PI, if any, has also obtained ethical approval for the project, the Co-PI will also assume the responsibility in respect of the ethical approval (in relation to the areas of expertise of respective Co-PI in accordance with the stipulations given by the approving authority).

You are responsible for informing the Departmental Research Committee in advance of any changes in the proposal or procedures which may affect the validity of this ethical approval.

You will receive separate email notification should you be required to obtain fresh approval.

KWONG Wai Yung

Chair

Departmental Research Committee

Page 1 of 1

Appendix V Information Sheet for Pre-Post Pilot Study

INFORMATION SHEET

The effects of a 'Caring for Couples Coping with Cancer (4Cs)' programme to support spousal caregivers in their caring for spouse with cancer

You are invited to participate in a study supervised by Prof. Alice Yuen Loke, Dr Wan-chaw Shae, and Dr. Yim-wah Mak, and conducted by Qiuping Li, who is a PhD student of the School of Nursing, The Hong Kong Polytechnic University.

The purpose of the research project is to develop, deliver and evaluate a 'Caring for Couples Coping with Cancer (4Cs)' programme aims to support couples coping with cancer as dyads. You are invited to complete a questionnaire at two different time points: before you receive any service/intervention from us (**T0-baseline**), and 6 weeks after the completion of the service/intervention (**T1-6weeks**).

The intervention programme will be six weekly sections, and 90 minutes in each section. To minimize the possible adverse consequences, researchers /professional personals will conduct consultation as required; Measures will be taken to protect your privacy and confidentiality before the group intervention. Such as boundaries will be set to define the acceptable limits of the group discussion in advance; all of the participants among the group members will be informed or told to maintain confidentiality of all information within the group. If you experience any discomfort during the interview, you can talk to researcher at any time for help.

You have rights to withdraw from the study at any time during the study without any penalty. All information related to you will be kept confidential by assigning a code number or fictitious name for you to prevent the information to be identified. Only the researcher will have access to the tape-recording and transcription, and these records will be destroyed after conclusion of the project.

If you have any complaints about the conduct of this research study, please do not hesitate to contact Dr Virginia Cheng, Secretary of the Human Subjects Ethics Sub-Committee of The Hong Kong Polytechnic University in person or in writing (c/o Research Office of the University) stating clearly the responsible person and department of this study. If you would like more information about this study, please contact Qiuping Li or her supervisor Prof Alice Yuen Loke.

Thank you for participating in this study.

Student Investigator

Li Qiuping

Appendix V Information Sheet for Pre-Post Pilot Study (Chinese version)

有关资料

以夫妻为基础的癌症干预对癌症患者及配偶照顾者的效果研究

诚邀您参加由袁桢德博士、佘雲楚博士和麥艷華博士负责监督，李秋萍同志负责执行的研究计划。李秋萍同志是香港理工大学护理学院学生。

这项研究的目的是评估以夫妻为基础的干预对癌症患者及配偶照顾者的效果。您将邀请在干预开始之前和干预结束时各填写一些问卷。

该干预项目是一个为期 6 周的夫妻共同参与的干预活动。这 6 周的干预是要每周进行 1 次 90 分钟的干预活动。为减少可能的不良后果，在小组讨论之前研究者会制订相关措施以保护您的隐私。如果在讨论过程中有出现任何不适，可以随时与李秋萍同志联络，寻求帮助。

您享有充分的权利在研究开始之前或之后决定退出这项研究，而不会受到任何对您不正常的待遇或被追究责任。凡有关您的资料将会保密及加上编码。所有资料，只有研究人员得悉。待研究结束将会对所有资料进行销毁处理。

如果您对这项研究有任何的不满，可随时与香港理工大学人类实验对象操守小组委员会秘书陈博士联络(地址：香港理工大学研究事务处转交)。如果您想获得更多有关这项研究的资料，请与李秋萍同志联络，或联络她的导师袁桢德博士。

谢谢您参与这项研究。

主要研究员(PI)

李秋萍

Appendix VI Consent Form for Pre-Post Pilot Study

CONSENT TO PARTICIPATE IN RESEARCH

The effects of a ‘Caring for Couples Coping with Cancer (4Cs)’ programme to support spousal caregivers in their caring for spouse with cancer

I ________________________ hereby consent to participate in the captioned research supervised by Prof. Alice Yuen Loke, Dr Wan-chaw Shae, and Dr. Yim-wah Mak and conducted by Qiuping Li.

I understand that information obtained from this research may be used in future research and published. However, my right to privacy will be retained, i.e., my personal details will not be revealed.

The procedure as set out in the attached information sheet has been fully explained. I understand the benefits and risks involved. My participation in the project is voluntary.

I acknowledge that I have the right to question any part of the procedure and can withdraw at any time without penalty of any kind.

Name of participant (patient) ________________________

Signature of participant (patient) ________________________

Name of spouse ________________________

Signature of spouse ________________________

Name of researcher Li Qiuping

Signature of researcher ________________________

Date ________________________

Appendix VI Consent Form for Pre-Post Pilot Study (Chinese version)

参与研究同意书

以夫妻为基础的癌症干预对癌症患者及配偶照顾者的效果研究

本人__________同意参加由袁桢德博士、余雲楚博士和麥艷華博士负责监督，李秋萍同志执行的研究项目。

我理解此研究所获得的资料可用于未来的研究和学术交流。 然而我有权保护自己的隐私，我的个人资料将不能泄漏。

我对所附资料的有关步骤已经得到充分的解释。我理解可能会出现的风险。我是自愿参与这项研究。

我理解我有权在研究过程中提出问题, 并在任何时候决定退出研究而不会受到任何不正常的待遇或被追究责任。

参加者（病人）姓名: ____________________

参加者（病人）签名: ____________________

配偶 姓名 : ____________________

配偶 签名: ____________________

研究人员姓名: 李秋萍

研究人员签名: ____________________

日期: ____________________

Appendix VII Questionnaires for both Patients and Spousal caregivers

Section 1: Demographic and background information

- Demographic data: age, sex, duration of marriage, personal income of both partners, housing (own, rental), children, education level and employment status;
- Clinical data: date of cancer diagnosis, cancer site and stage, treatment;
- Pre-cancer family role: decision-making, major breadwinner, financial, caregivers health status, marital satisfaction.

Section 2:
Health Survey Questionnaire (SF-12)

The following questions are to assess your opinion, feeling and ability to perform daily activities. Please choose the answer that is closest to your condition for each question.

1. In general, would you say your health is:

O Excellent O Very good O Good O Fair O Poor

2. During the past four weeks, how much did pain interfere with your normal work including both outside the home and housework, would you say…?

O Extremely O Quite a bit O Moderately O A little bit O Not at all

3. How much of the time during the past four weeks did you have a lot of energy? Would you say...?

O All of the time O Most of the time O Some of the time
O A little of the time O None of the time

4. During the last four weeks, how much of the time has your physical health or emotional problems interfered with your social activities, like visiting with friends, relatives, etc.?

O All of the time O Most of the time O Some of the time
O A little of the time O None of the time

The following items about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?	Yes, limited a lot	Yes, limited a little	No, Not limited at all
5. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling or playing golf?	☐	☐	☐
6. Climbing several flights of stairs	☐	☐	☐

How much of the time during the past four weeks, have you had any of the following problems with your work or other regular activities as a result of your ***physical*** *health?*	All the time	Most of the time	Some of the time	A little of the time	None of time
7. Accomplished less than you would like?	☐	☐	☐	☐	☐
8. Were limited in the kind of work or other activities you could do?	☐	☐	☐	☐	☐

How much of the time during the past four weeks, have you had any of the following problems with your work or other regular daily activities as a result of any ***emotional*** *problems, such as feeling depressed or anxious?*	All the time	Most of the time	Some of the time	A little of the time	None of time
9. Accomplished less than you would like?	☐	☐	☐	☐	☐
10 Did you have trouble doing work or other activities as carefully as usual?	☐	☐	☐	☐	☐
How much of the time during the past four weeks, that you feel how things have been with you?	All the time	Most of the time	Some of the time	A little of the time	None of time
11. Have you felt calm and peaceful?	☐	☐	☐	☐	☐
12. Have you felt downhearted and blue?	☐	☐	☐	☐	☐

Self-Efficacy:

The following questions are to assess the confidence you had in your ability to perform a specific behavior related to coping with cancer 'now or sometime in the near future'. These questions were formatted into a nine-point Likert scale (1 ='not at all confident', 5='moderately confident', and 9='totally confident'). Please rate the answer from 1 to 9 that is closest to your condition for each question.

	Items	1 ='not at all confident', 5='moderately confident', and 9='totally confident' Rating from 1----------------------------- 9								
1.	Maintaining independence	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**
2.	Maintaining a positive attitude	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**
3.	Maintaining work activity	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**
4.	Remaining relaxed throughout treatments and not allowing scary thoughts to upset me	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**
5.	Coping with physical changes	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**
6.	Actively participating in treatment decisions	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**
7.	Sharing feelings of concern	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**
8.	Expressing negative feelings about cancer	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**
9.	Maintaining a sense of humor	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**
10.	Seeking consolation	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**
11.	Asking physicians questions	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**
12.	Managing nausea and vomiting	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**

Section 3: Dyadic Coping Inventory (DCI)

This scale is designed to measure how you and your partner copy with stress. Please indicate the first response that you feel is appropriate. Please be as honest as possible.

Please response to any item by marking the appropriate case, which is fitting to your personal situation. There are no false answers.

	How you communicate your stress to your partner?	Never/ very rarely	Rarely	Some-times	Often	Very Often
1.	I let my partner know that I appreciate his/her practical support, advice, or help.	☐	☐	☐	☐	☐
2.	I ask my partner to do things for me when I have too much to do.	☐	☐	☐	☐	☐
3.	I show my partner through my behaviour when I am not doing well or when I have problems.	☐	☐	☐	☐	☐
4.	I tell my partner openly how I feel and that I would appreciate his/her support.	☐	☐	☐	☐	☐
	What your partner does when you are feeling stressed?					
5.	My partner shows empathy and understanding to me.	☐	☐	☐	☐	☐
6.	My partner expresses that he/she is on my side.	☐	☐	☐	☐	☐
7.	My partner blames me for not coping well enough with stress.	☐	☐	☐	☐	☐
8.	My partner helps me to see stressful situations in a different light.	☐	☐	☐	☐	☐
9.	My partner listens to me and gives me the opportunity to communicate what really bothers me.	☐	☐	☐	☐	☐
10.	My partner does not take my stress seriously.	☐	☐	☐	☐	☐
11.	My partner provides support, but does so unwillingly and unmotivated.	☐	☐	☐	☐	☐
12.	My partner takes on things that I normally do in order to help me out.	☐	☐	☐	☐	☐
13.	My partner helps me analyze the situation so that I can better face the problem.	☐	☐	☐	☐	☐
14.	When I am too busy, my partner helps me out.	☐	☐	☐	☐	☐
15.	When I am stressed, my partner tends to withdraw.	☐	☐	☐	☐	☐
	How your partner communicates when he/she is feeling stressed?					
16.	My partner lets me know that he/she appreciates my practical support, advice, or help.	☐	☐	☐	☐	☐
17.	My partner asks me to do things for him/her when he has too much to do.	☐	☐	☐	☐	☐
18.	My partner shows me through his/her behaviour that he/she is not doing well or when he/she has problems.	☐	☐	☐	☐	☐
19.	My partner tells me openly how he/she feels and that he/she would appreciate my support.	☐	☐	☐	☐	☐

	My partner tells me openly how he/she feels and that he/she would appreciate my support.	Never/ very rarely	Rarely	Some-times	Often	Very Often
20.	show empathy and understanding to my partner.	☐	☐	☐	☐	☐
21.	I express to my partner that I am on his/her side.	☐	☐	☐	☐	☐
22.	I express to my partner that I am on his/her side.	☐	☐	☐	☐	☐
23.	I tell my partner that his/her stress is not that bad and help him/her to see the situation in a different light.	☐	☐	☐	☐	☐
24.	I listen to my partner and give him/her space and time to communicate what really bothers him/her.	☐	☐	☐	☐	☐
25.	I do not take my partner’ s stress seriously.	☐	☐	☐	☐	☐
26.	When my partner is stressed I tend to withdraw.	☐	☐	☐	☐	☐
27.	I provide support, but does so unwillingly and unmotivated because I think that he/she should cope with his/her problems on his/her own.	☐	☐	☐	☐	☐
28.	I take on things that my partner would normally do in order to help him/her out.	☐	☐	☐	☐	☐
29.	I try to analyze the situation together with my partner in an objective manner and help him/her to understand and change the problem.	☐	☐	☐	☐	☐
30.	When my partner feels he/she has too much to do, I help him/her out.	☐	☐	☐	☐	☐
	What you and your partner do when you are both feeling stressed?					
31.	We try to cope with the problem together and search for ascertained solutions.	☐	☐	☐	☐	☐
32.	We engage in a serious discussion about the problem and think through what has to be done.	☐	☐	☐	☐	☐
33.	We help one another to put the problem in perspective and see it in a new light.	☐	☐	☐	☐	☐
34.	We help each other relax with such things like massage, taking a bath together, or listening to music together.	☐	☐	☐	☐	☐
35.	We are affectionate to each other, make love and try that way to cope with stress.	☐	☐	☐	☐	☐
	How you evaluate your coping as a couple?					
36.	am satisfied with the support I receive from my partner and the way we deal with stress together.	☐	☐	☐	☐	☐
37.	I am satisfied with the support I receive from my partner and I find as a couple, the way we deal with stress together is effective.	☐	☐	☐	☐	☐

Section 4: positive and negative emotion

The Hospital Anxiety and Depression Scale (HAD)
This questionnaire is designed to help your doctor to know how you feel. Read each item and underline the reply which closest to how you have been feeling in the past week.
Don’t take too long over your replies; your immediate reaction to each item will probably be more accurate than a long thought out response.

Items	3	2	1	0
1. I feel tense or ‘wound up’	☐ Most of the time	☐ A lot of the time	☐ From time to time, occasionally	☐ Not at all
2. I still enjoy the things I used to enjoy	☐ Hardly at all	☐ Only a little	☐ Not quite so much	☐ Definitely as much
3. I get a sort of frightened feeling as if something awful is about to happen:	☐ very definitely and quite badly	☐ Yes, but not too badly	☐ A little, but it doesn’t worry me	☐ Not at all
4. I can laugh and see th e funny side of things	☐ Not at all	☐ Definitely not so much now	☐ Not quite so much now	☐ As much as I always could
5. Worrying thoughts go through my mind:	☐ A great deal of the time	☐ A lot of time	☐ From time to time but not too often	☐ Only occasionally
6. I feel cheerful	☐ Not at all	☐ Not often	☐ Sometimes	☐ Most of the time
7. I can sit at ease and feel relaxed	☐ Not at all	☐ Not often	☐ Usually	☐ Definitely
8. I feel as if I am slowed down:	☐ Nearly all the time	☐ Very often	☐ Sometimes	☐ Not at all
9. I get a sort of frightened feeling like ‘butterflies’ in the stomach	☐ Very often	☐ Quite often	☐ Occasionally	☐ Not at all
10.I have lost interest in my appearance:	☐ Definitely	☐ I don’t take so much care as I should	☐ I may not take quite as much care	☐ I take just as much care as ever
11.I feel restless as if I have to be on the move:	☐ Very much indeed	☐ Quite a lot	☐ Not very much	☐ Not at all
12.I look forward with enjoyment to things	☐ Hardly at all	☐ Definitely less than I used to	☐ Rather less than I used to	☐ As much as I ever did
13. I get sudden feelings of panic	☐ Very often indeed	☐ Quite often	☐ Not very often	☐Not at all
14.I can enjoy a good book or radio or TV programme:	☐ Very seldom	☐ Not often	☐ Sometimes	☐ Often

Benefit finding

17 Items for Benefit finding of **cancer caregivers**

The following items are to assess potential benefit that you might be derived from the experience of having provided care for the survivor through his /her cancer experience. For each item, please indicate below the approximate extent that comes closest to your experience.

Having provided care for the survivor through his/her cancer experience has. . .	Not at all	A little	Moder ately	Quite a bit	extre mely
1. Taught me how to adjust to things I cannot change.	**1**	**2**	**3**	**4**	**5**
2. Helped me take things as they come.	**1**	**2**	**3**	**4**	**5**
3. Led me to be more accepting of things.	**1**	**2**	**3**	**4**	**5**
4. Shown me that all people need to be loved.	**1**	**2**	**3**	**4**	**5**
5. Made me more aware and concerned for the future of all human beings.	**1**	**2**	**3**	**4**	**5**
6. Taught me that everyone has a purpose in life.	**1**	**2**	**3**	**4**	**5**
7. Made me realize the importance of planning for my family's future.	**1**	**2**	**3**	**4**	**5**
8. Contributed to my overall emotional and spiritual growth.	**1**	**2**	**3**	**4**	**5**
9. Led me to meet people who have become some of my best friends.	**1**	**2**	**3**	**4**	**5**
10.Helped me become more aware of the love and support available from other people.	**1**	**2**	**3**	**4**	**5**
11. Brought my family closer together.	**1**	**2**	**3**	**4**	**5**
12. Made me more sensitive to family issues.	**1**	**2**	**3**	**4**	**5**
13. Led me to deal better with stress and problems.	**1**	**2**	**3**	**4**	**5**
14. Taught me to be patient.	**1**	**2**	**3**	**4**	**5**
15.Helped me become a stronger person, more able to cope effectively with future life challenges.	**1**	**2**	**3**	**4**	**5**
16. Helped me realize who my real friends are.	**1**	**2**	**3**	**4**	**5**
17. Helped me become more focused on priorities, with a deeper sense of purpose of life.	**1**	**2**	**3**	**4**	**5**

17 Items Assessing Benefit Finding in Regard **to Having Had Cancer**

The following items are to assess potential benefit that you might be derived from the experience of having had cancer. For each item, please indicate below the approximate extent that comes closest to your experience.

Having had cancer. . .	Not at all	A little	Moder ately	Quite a bit	extre mely
1. Has led me to be more accepting of things.	**1**	**2**	**3**	**4**	**5**
2. Has taught me how to adjust to things I cannot change.	**1**	**2**	**3**	**4**	**5**
3. Has helped me take things as they come.	**1**	**2**	**3**	**4**	**5**
4. Has brought my family closer together.	**1**	**2**	**3**	**4**	**5**
5. Has made me more sensitive to family issues.	**1**	**2**	**3**	**4**	**5**
6. Has taught me that everyone has a purpose in life.	**1**	**2**	**3**	**4**	**5**
7. Has shown me that all people need to be loved.	**1**	**2**	**3**	**4**	**5**
8. Has made me realize the importance of planning for my family's future.	**1**	**2**	**3**	**4**	**5**
9. Has made me more aware and concerned for the future of all human beings.	**1**	**2**	**3**	**4**	**5**
10. Has taught me to be patient.	**1**	**2**	**3**	**4**	**5**
11. Has led me to deal better with stress and problems.	**1**	**2**	**3**	**4**	**5**
12. Has led me to meet people who have become some of my best friends.	**1**	**2**	**3**	**4**	**5**
13. Has contributed to my overall emotional and spiritual growth.	**1**	**2**	**3**	**4**	**5**
14. Has helped me become more aware of the love and support available from other people.	**1**	**2**	**3**	**4**	**5**
15. Has helped me realize who my real friends are.	**1**	**2**	**3**	**4**	**5**
16. Has helped me become more focused on priorities, with a deeper sense of purpose in life.	**1**	**2**	**3**	**4**	**5**
17. Has helped me become a stronger person, more able to cope effectively with future life challenges.	**1**	**2**	**3**	**4**	**5**

Section 5: relationship: Communication and marital relationship

Cancer-related communication problems

The following items are to assess your feeling or experience of communicate cancer-related problems with your partners. Please indicate the items that come closest to your experience.

Communication items	Sometimes to often true	Not true to sometimes true
1. My spouse understands what it was like for me to be treated for cancer.	n/a	
2. I don’t talk about my cancer problems with my spouse because he/she gets upset when I do.		n/a
3. My spouse doesn’t ask how cancer affected my life.		n/a
4. I can’t talk about cancer with my spouse because I get too upset.		n/a
5. I never know when my spouse wants to talk about my having cancer and when he/she does not.		n/a
6. We discuss/discussed what treatment I should have.	n/a	
7. I can tell my spouse anything that is on my mind about my having cancer.	n/a	
8. My spouse doesn’t want to upset me by talking about how he/she is feeling about my having cancer.		n/a
9. My spouse and I talk about our worries about whether my cancer treatment worked.	n/a	
10. I don’t tell my spouse how scared I am about having cancer.		n/a
11. I talk over with my spouse about how cancer treatment has changed my body (e.g. removal of breast, uterus or prostate).	n/a	
12. I confide in my friends more than my spouse about my cancer experience.		n/a
13. I talk with my spouse about what to do if my condition should get significantly worse.		n/a
14. When it comes to cancer, I only tell my spouse what he/she wants to hear.		n/a
15. I don’t talk with my spouse about how cancer affects me sexually.		n/a

n/a = Not applicable.
Items were worded as a positive or negative communication item, so that a problem was indicated by either being ‘sometimes true’‘to often true’, or ‘not true’ to ‘sometimes true’.

The following items are to assess your feeling or experience of communicate cancer-related problems with your mate with cancer. Please indicate the items that come closest to your experience.

Communication items	Sometimes to often true	Not true to sometimes true
1. My spouse or partner understands how I feel about him/her having cancer.	n/a	
2. My spouse or partner gets upset when I talk about my feelings about him/her having cancer.		n/a
3. My spouse or partner doesn't ask about how him/her having cancer affects my life.		n/a
4. I can't talk about cancer with my spouse or partner because I get too upset.		n/a
5. I never know when my spouse or partner wants to talk about cancer and when he/she doesn't.		n/a
6. We discuss/discussed what treatment he/she should have.	n/a	
7. I can tell my spouse or partner anything that is on my mind about his/her having cancer.	n/a	
8. My spouse or partner doesn't talk about cancer with me because he/she doesn't want me to get upset.		n/a
9. My spouse or partner and I talk about our worries about whether his/her treatment worked.	n/a	
10. I don't tell my spouse or partner how scared I am because he/she has cancer.		n/a
11. I talk over with my spouse about how I feel about how cancer treatment changed his/her body (e.g. removal of breast, uterus or prostate).	n/a	
12. I confide in my friends more than my spouse or partner about my feelings about his/her having cancer.		n/a
13. I talk with my spouse about what to do if he/she should get significantly worse.	n/a	
14. When it comes to cancer, I only tell my spouse or partner what he/she wants to hear.		n/a
15. I don't talk with my spouse or partner about how his/her having cancer affects me sexually.		n/a

n/a = Not applicable.
Items were worded as a positive or negative communication item, so that a problem was indicated by either being 'sometimes true''to often true', or 'not true' to 'sometimes true'.

The RDAS

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

	Always Agree	Almost Always Agree	Occasionally Agree	Frequently Disagree	Almost Always Disagree	Always Disagree
1. Religious matters	**5**	**4**	**3**	**2**	**1**	**0**
2. Demonstrations of affection	**5**	**4**	**3**	**2**	**1**	**0**
3. Making major decisions	**5**	**4**	**3**	**2**	**1**	**0**
4. Sex relations	**5**	**4**	**3**	**2**	**1**	**0**
5. Conventionality (correct Or proper behavior)	**5**	**4**	**3**	**2**	**1**	**0**
6. Career decisions	**5**	**4**	**3**	**2**	**1**	**0**

	All the time	Most of the time	More often than not	Occasionally	Rarely	Never
7. How often do you discuss or have you considered divorce, separation, or terminating your relationship?	**0**	**1**	**2**	**3**	**4**	**5**
8. How often do you and your partner quarrel?	**0**	**1**	**2**	**3**	**4**	**5**
9. Do you ever regret that you married (or lived together)?	**0**	**1**	**2**	**3**	**4**	**5**
10. How often do you and your mate "get on each other's nerves''?	**0**	**1**	**2**	**3**	**4**	**5**

	Every day	Almost Every day	Occasionally	Rarely	Never
11. Do you and your mate engage in outside interests together?	**4**	**3**	**2**	**1**	**0**

	Never	Less than once a month	Once or twice a month	Once or twice a week	Once a day	More often
12. Have a stimulating exchange of ideas	**0**	**1**	**2**	**3**	**4**	**5**
13. Work together on a project	**0**	**1**	**2**	**3**	**4**	**5**
14. Calmly discuss some thing	**0**	**1**	**2**	**3**	**4**	**5**

Appendix VIII **Questionnaires for Patients (Chinese version)**

病人调查问卷　　编号：

尊敬的病人朋友：

您好！本问卷旨在了解患病对您的身体及心理状况的影响，给我们更好地为您服务提供依据。本调查所有问题均不涉及能确认您身份的信息，答案无对错之分，请您根据自己的实际情况在您认为最合适的答案的代码上打勾（ √ ）。我们会完全对您所填内容保密。您的参与不仅有利于您的疾病的治疗和康复，而且将会对其他病人的治疗产生积极的影响和巨大的贡献。衷心感谢您的合作！

祝您早日康复，生活幸福！

第一部分 一般情况调查

年龄		性别		结婚年限		疾病诊断	

您被诊断为该病有 ______月或 _____年， 若在化疗期间，为第____疗程

此次住院为　□ 初次发现　□ 复发

1. 您的受教育程度：

□ 没有受过教育　□ 小学　□ 中学　□ 本科　□ 研究生以上

2. 您的宗教信仰：

□ 佛教　□ 道教　□ 基督教　□ 无宗教信仰　□ 其他

3. 您了解自己的病情吗？

□ 完全不了解　□ 知道一点　□ 非常了解

4. 您目前接受的主要治疗方案

□ 化疗　□ 化疗+放疗　□ 手术+化疗　□ 其他

5. 自觉目前健康状况

□ 良好　□ 一般　□ 较差　□ 差

6. 您以前得过什么疾病？

□ 无　□ 有

7.　您本次住院前的工作状态：

□ 在职　□ 下岗或待业　□ 病退或退休　□ 务农　□ 其他

8.　您配偶的工作状态：

□ 在职　□ 下岗或待业　□ 病退或退休　□ 务农　□ 其他

9.　您配偶的受教育程度：

□ 没有受过教育　□ 小学　□ 中学　□ 本科　□ 研究生以上

10.　您子女的受教育程度：（若有多个子女可多选，若受教育程度相同，请注明人数）

□ 没有受过教育　□ 小学　□ 中学　□ 本科　□ 研究生以上

11.　患病前谁是您家里的经济支柱？

□ 我　□ 配偶　□ 子女

12.　患病前您家重要事情一般由谁做主？

□ 我　□ 配偶　□ 子女

13.　您的家庭月收入为：

□ 小于1000元　□ 1000～3000元　□ 3000～5000元　□ 5000元～

14.　您家里住房情况为：

□ 自购　□ 租住　□廉租房

15.　疾病给您家庭带来的经济压力

□ 较重　□ 一般　□ 较轻

16.　您的医保可报销医疗费用的多少：

□ 无医保　□ 小于30%　□ 30%-50%　□ 50%-80%　□ 80%-100%

17.　总体来说您如何评价此次患病前您与配偶的关系：

□ 很好　□ 一般　□ 不好

18.　总体来说患病后您与配偶关系发生了哪种变化？

□ 变好　□ 无变化　□ 变坏

第二部分 身体及心理状况

(I) SF-12 调查问卷

请尽量选一个您认为最适合的答案，在答案后面的 □ 中打“√”。

1. 总体来讲，您的健康状况是：

□ 非常好　□ 很好　□ 好　□ 一般　□ 差

2. 在**过去四个**星期里，身体上的**疼痛**影响您的**正常工作**了吗（包括上班工作和家务活动）？

□ 有极大影响　□ 有较大影响　□ 有中度影响　□ 有一点影响　□ 根本没有影响

3. 在**过去四个**星期里，您感觉到精力充沛持续的时间？

□ 所有的时间　□大部分时间　□ 部分时间　□ 小部分时间　□ 根本没有

4. 在**过去四个**星期里，您的身体健康或情绪不好在多大程度上影响了您与家人、朋友、邻居或集体的正常社交活动？

□ 所有的时间　□大部分时间　□ 部分时间　□ 小部分时间　□ 根本没有

以下这些问题都与日常活动有关。您的健康状况是否限制了这些活动？如果有限制，程度如何？	有很多限制	有一点限制	根本没限制
5. 适度活动（如移桌子、扫地、做操等）？	□	□	□
6. 上几层楼梯？	□	□	□

在**过去四个星期里**，您的工作和日常活动有没有因为身体健康的原因而出现以下这些问题？如果有，程度如何？	所有的时间	大部分时间	部分时间	小部分时间	根本没有
7. 本来想要做的事情**只能完成一部分**？	□	□	□	□	□
8. 减少了工作或其他活动的**时间**？	□	□	□	□	□
在**过去四个星期里**，您的工作和日常活动有没有因为情绪（如感到消沉或者忧虑）而出现以下问题？如果有，程度如何？					
9. 本来想要做的事情**只能完成一部分**？	□	□	□	□	□
10 · 做工作或其他活动不如平时**仔细**？	□	□	□	□	□
在**过去四个星期里**，您的感觉如何以及您的情况如何？					
11. 您觉得**平静**吗？	□	□	□	□	□
12. 您觉得**情绪低落**吗？	□	□	□	□	□

（II） 自我效能问卷

以下问题是了解您在现在或不久的将来应对癌症时的信心。答案没有对和错之分，请根据您的实际情况进行选择，在相应栏内打“√”。

	问题	**每个问题的答案从 1 到 9（1=‘完全没有信心’，5=‘有适度信心’，9 = ‘非常有信心’）。 1------------------------------ 9**								
1.	保持独立性	1	2	3	4	5	6	7	8	9
2.	保持积极的态度	1	2	3	4	5	6	7	8	9
3.	维护工作活动	1	2	3	4	5	6	7	8	9
4.	整个治疗保持放松，可以避免可怕的想法让我感到不安	1	2	3	4	5	6	7	8	9
5.	应对身体的变化	1	2	3	4	5	6	7	8	9
6.	积极参与治疗决策	1	2	3	4	5	6	7	8	9
7.	关注分担忧虑	1	2	3	4	5	6	7	8	9
8.	表达对癌症相关负面情绪	1	2	3	4	5	6	7	8	9
9.	保持幽默感	1	2	3	4	5	6	7	8	9
10.	寻求安慰	1	2	3	4	5	6	7	8	9
11.	向医生提问	1	2	3	4	5	6	7	8	9
12.	处理恶心和呕吐	1	2	3	4	5	6	7	8	9

第三部分 双向应对量表

本量表用来测评您和您的伴侣是如何应对压力。请在答题时根据您个人的情况做出最佳选择。请尽量诚实答题，答案无对错之分。

	您如何与您伴侣沟通您的压力?	极少	很少	有时	经常	非常频繁
1.	我让他/她知道，我很感谢他/她实际的支持、建议和帮助。	□	□	□	□	□
2.	当我比较忙的时候，我会请他/她帮忙。	□	□	□	□	□
3.	当我做得还不够好或者当我遇到问题时，我会通过我的行为让他/她知道。	□	□	□	□	□
4.	我坦诚地告诉他/她我的真实感受并会感谢他/她的支持。	□	□	□	□	□
	当您有压力时，您的伴侣如何做?					
5.	他/她能感受并理解我的压力。	□	□	□	□	□
6.	他/她会告诉我他/她在我身边。	□	□	□	□	□
7.	他/她责备我没有很好应付压力。	□	□	□	□	□
8.	他/她帮助我从不同角度看待压力情境。	□	□	□	□	□
9.	他/她注意倾听我诉说，让我有机会沟通困扰我的原因。	□	□	□	□	□
10.	他/她没有认真对待我的压力。	□	□	□	□	□
11.	他/她提供支持，但是不情愿或不积极。	□	□	□	□	□
12.	为了帮助我应对困境，他/她分担通常需要我做的事情。	□	□	□	□	□
13.	他/她可以帮助我分析情况，以使我更好地面对问题。	□	□	□	□	□
14.	当我太忙时，他/她可以帮助我。	□	□	□	□	□
15.	当我有压力时，他/她倾向于回避。	□	□	□	□	□
	当您的伴侣有压力时，他/她如何与您沟通？					
16.	他/她让我知道他/她感谢我实际的支持，建议，和帮助。	□	□	□	□	□
17.	当他/她比较忙的时候，他/她会请我帮忙。	□	□	□	□	□
18.	当他/她做得还不够好、或者当他/她有问题时，他/她会通过他/她的行为告诉我。	□	□	□	□	□

19.	他/她坦诚地告诉我有关他/她的真实感受并会感谢我对他/她的支持。	□	□	□	□	□
	当您的伴侣有压力时，您如何做?	极少	很少	有时	经常	非常频繁
20.	我能感受并理解他/她的压力。	□	□	□	□	□
21.	我会告诉他/她，我就在他/她身边。	□	□	□	□	□
22.	我责备他/她没有很好应付压力。	□	□	□	□	□
23.	我告诉他/她也许情况并没有那么糟糕并帮助他/她从不同角度看待压力情境。	□	□	□	□	□
24.	我注意倾听他/她诉说，让他/她有机会沟通困扰他/她的原因。	□	□	□	□	□
25.	我没有认真对待他/她的压力。	□	□	□	□	□
26.	当他/她有压力时，我倾向于回避。	□	□	□	□	□
27.	我不情愿或不主动地提供支持，因为我认为他/她应该自己处理自己的问题。	□	□	□	□	□
28	为了帮助他/她应对困境，我会承担通常需要他/她做的。	□	□	□	□	□
29.	我会试图与他/她一起客观地分析情况，以使他/她能理解和改变困境。.	□	□	□	□	□
30.	当他/她太忙时，我可以帮助他/她。	□	□	□	□	□
	当您与您的伴侣都有压力时，您们如何做？					
31.	我们试着共同面对问题并寻找问题的解决方案。	□	□	□	□	□
32.	我们一起认真地讨论所面临的问题及需要采取的应对措施。	□	□	□	□	□
33.	我们相互帮助，使双方从不同角度正确地分析问题。	□	□	□	□	□
34.	我们一起从事一些活动,如按摩、沐浴、或听音乐，以帮助放松身心。	□	□	□	□	□
35.	我们彼此深爱对方，可以用爱的方式来应对压力。	□	□	□	□	□
	作为一对夫妻，您如何评价您们的应对方式？					
36.	我对我的伴侣提供的支持，以及我们一起应对压力的方式感到满意。	□	□	□	□	□
37.	我对我的伴侣提供的支持很满意，同时我觉得我们一起应对压力的方式是有效的。	□	□	□	□	□

第四部分 正性和负性情绪体验

（I） 益处发现量表

下列项目是评估您可能从癌症的经历中体验到的潜在好处。对于每个项目，请注明最接近您体验的近似程度。

从癌症体验中．．．	完全没有	有一点	中等程度	很多	非常多
1. 使我更接受现实。	1	2	3	4	5
2. 教会我如何适应自己不能改变的事情。	1	2	3	4	5
3. 学会顺其自然。	1	2	3	4	5
4. 使我的家庭更加紧密联系在一起。	1	2	3	4	5
5. 使我更关心家庭事宜。	1	2	3	4	5
6. 理解生活中每个人都有其生存意义。	1	2	3	4	5
7. 让我知道每个人都需要爱。	1	2	3	4	5
8. 使我意识到为家庭未来计划的重要性。	1	2	3	4	5
9. 让我更加认识和关心全人类的未来。	1	2	3	4	5
10. 教会了我要有耐心。	1	2	3	4	5
11. 使我能更好地应对压力和面对困难。	1	2	3	4	5
12. 使我结识更多朋友。	1	2	3	4	5
13. 使我得到精神和心理的全面成长。	1	2	3	4	5
14. 使我更加感受到来自他人的爱和支持。	1	2	3	4	5
15. 帮助我认识到谁是我真正的朋友。	1	2	3	4	5
16. 使我更专注什么是优先事情，对人生目标有更深感受。	1	2	3	4	5
17. 使我成为一个更坚强的人，能够有效应对未来生活的挑战。	1	2	3	4	5

（II）HAD情绪评估量表

情绪在大多数疾病中起着重要作用，如果医生了解您的情绪变化，他们就能给您更多的帮助。请您阅读以下各个项目，在其中最符合您上个月以来的情绪评分上打“√”。对这些问题的回答不要做过多的考虑，立即做出的回答会比考虑后再回答更切合实际。

项　目	3	2	1	0
1. 我感到紧张（或痛苦）	□几乎所有时候	□ 大多数时候	□ 有时	□ 根本没有
2. 我对以往感兴趣的事情还是有兴趣	□基本上没有了	□ 只有一点儿	□ 不像以前那样多	□ 肯定一样
3. 我感到有点害怕，好像预感到有什么可怕事情要发生	□ 非常肯定和十分严重	□ 是有，但并不太严重	□ 有一点，但并不使我苦恼	□ 根本没有
4. 我能够哈哈大笑，并看到事物好的一面	□ 根本没有	□ 现在肯定是不太多了	□ 现在已经不大这样了	□ 我经常这样
5. 我的心中充满烦恼	□ 大多数时间	□ 常常如此	□ 时时，但并不经常	□ 偶然如此
6. 我感到愉快	□ 根本没有	□ 并不经常	□ 有时	□ 大多数
7. 我能够安闲而轻松地坐着	□ 根本没有	□ 并不经常	□ 经常	□ 肯定
8. 我对自己的仪容（打扮自己）失去兴趣	□ 肯定	□ 并不像我应该做到的那样关心	□ 我可能不是非常关心	□ 我仍像以往一样关心
9. 我有点坐立不安，好像感到非要活动不可	□ 确实非常多	□ 是不少	□ 并不很多	□ 根本没有
10. 我对一切都是乐观地向前看	□ 几乎从来不这样做	□ 很少这样做	□ 并不完全是这样做的	□ 差不多是这样做的
11. 我突然发现恐慌感	□ 确实很经常	□ 时常	□ 并非经常	□ 根本没有
12. 我好像感到情绪在渐渐低落	□ 几乎所有的时间	□ 很经常	□ 有时	□ 根本没有
13. 我感到有点害怕，好像某个内脏器官变坏了	□ 非常经常	□ 很经常	□ 有时	□根本没有
14. 我能欣赏一本好书或一项好的广播或电视节目	□ 很少	□ 并非经常	□ 有时	□ 常常

第五部分 沟通及婚姻关系

(I) 癌症相关沟通问题

下列项目是评估您和配偶在沟通与癌症相关问题时的感受或经验。请注明最接近您体验的项目。

	沟通项目	经常	有时	没有
1.	我的配偶理解我接受癌症治疗的感受。	□	□	□
2.	我不会与配偶谈论有关癌症的问题，因为这样做会使他/她忧虑。	□	□	□
3.	我的配偶没有问及癌症如何影响我的生活。	□	□	□
4.	我不会与配偶谈论有关癌症的问题，因为这样做会使我忧虑。	□	□	□
5.	我不知道配偶何时愿意或不愿意谈论有关癌症的问题。	□	□	□
6.	我们讨论/或曾讨论我应该接受哪种治疗方法。	□	□	□
7.	我可以与配偶谈论所有与癌症相关的想法。	□	□	□
8.	为避免给我带来烦恼/忧虑，我的配偶不会谈及他/她对我患癌症的感受。	□	□	□
9.	我和配偶谈论有关癌症治疗是否有效的忧虑。	□	□	□
10.	我不告诉我的配偶我对癌症有多么害怕。	□	□	□
11.	我和我的配偶谈论癌症治疗导致我身体上的改变（例如乳房，子宫或前列腺切除）。	□	□	□
12.	与配偶相比，我更愿意与朋友倾诉我的抗癌感受。	□	□	□
13.	我与配偶商谈当我的病情恶化时应如何应对。	□	□	□
14.	当谈到癌症，我只告诉我的配偶他/她希望听到的信息。	□	□	□
15.	我不与我的配偶谈论癌症对我的性体验的影响。	□	□	□

(II) 修订版婚姻适应量表

许多人在婚姻中会有意见不一致。请对以下题目注明最近似您与您配偶意见同意或不一致的程度。

	总是同意	几乎完全同意	偶尔同意	有时不同意	几乎完全不同意	总是不同意
1. 宗教信仰	5	4	3	2	1	0
2. 性爱表示	5	4	3	2	1	0
3. 做出重要的决定	5	4	3	2	1	0
4. 性关系	5	4	3	2	1	0
5. 传统观念和习俗	5	4	3	2	1	0
6. 有关职业的决定	5	4	3	2	1	0

	总是如此	大部分时间	比较多时间	偶尔	极少	从来没有
7. 与配偶讨论离婚、分居等	0	1	2	3	4	5
8. 与配偶吵架时间	0	1	2	3	4	5
9. 后悔结婚（或同居）	0	1	2	3	4	5
10. 和配偶令对方心烦时间	0	1	2	3	4	5

	每天	几乎每天	偶尔	极少	从来没有
11. 与配偶一同外出进行社交活动	4	3	2	1	0

	从不	少于每月一次	每月一次或两次	每周一次或两次	第天一次	经常
12. 有启发性或激动性的意见交流	0	1	2	3	4	5
13. 一起进行一件事或计划	0	1	2	3	4	5
14. 冷静地讨论事情	0	1	2	3	4	5

Appendix IX **Questionnaires for Spousal caregivers (Chinese version)**

配偶调查问卷　　编号：

尊敬的病人配偶：

您好！本问卷旨在了解您在照顾病人过程中的感受、及照顾病人对您的生存质量、健康状况的影响，给我们更好地为您和您的家人服务提供依据。本调查所有问题均不涉及能确认您身份的信息，答案无对错之分，请您根据自己的实际情况在您认为最合适的答案的代码上打勾（ √ ）。我们会完全对您所填信息保密。衷心感谢您的合作！

第一部分 一般情况调查

年龄		性别		民族		结婚年限	
病人诊断				与病人关系			
籍　贯							

1. 您的受教育程度：

□ 没有受过教育　□ 小学　□ 中学　□ 本科　□ 研究生以上

2. 您的宗教信仰：

□ 佛教　□ 道教　□ 基督教　□ 无宗教信仰　□ 其他

3. 照顾病人前的工作状态：

□ 在职　□ 下岗或待业　□ 病退或退休　□ 务农　□ 其他

4. 您了解病人的病情和愈后吗？

□ 完全不了解　□ 知道一点　□ 非常了解

5. 自觉健康状况

□ 良好　□ 一般　□ 较差　□ 差

6. 您以前得过什么疾病？

□ 无　□ 有

7. 您照顾亲属的总时间

□＜6 月　□6 月～2 年　□2～5 年　□＞5 年

8. 每天照顾时间

□＜2 h　□2-4 h　□4-6 h　□6-8h　□＞8 h

9. 疾病对您未来生活计划的影响

□改变生活计划：如改变度假或旅游安排　□没有影响
□疾病促使与病人的关系变得更为亲密

第二部分 身体及心理状况

(I) SF-12 调查问卷

请尽量选一个您认为最适合的答案，在答案后面的 □ 中打“ √ ”。

1. 总体来讲，您的健康状况是：

□ 非常好 □ 很好 □ 好 □ 一般 □ 差

2. 在**过去四个**星期里，身体上的**疼痛**影响您的**正常工作**了吗（包括上班工作和家务活动）？

□ 有极大影响 □ 有较大影响 □ 有中度影响 □ 有一点影响 □ 根本没有影响

3. 在**过去四个**星期里，您感觉到精力充沛持续的时间？

□ 所有的时间 □大部分时间 □ 部分时间 □ 小部分时间 □ 根本没有

4. 在**过去四个**星期里，您的身体健康或情绪不好在多大程度上影响了您与家人、朋友、邻居或集体的正常社交活动？

□ 所有的时间 □大部分时间 □ 部分时间 □ 小部分时间 □ 根本没有

以下这些问题都与日常活动有关。您的健康状况是否限制了这些活动？如果有限制，程度如何？	有很多限制	有一点限制	根本没有限制
5. 适度活动（如移桌子、扫地、做操等）？	□	□	□
6. 上几层楼梯？	□	□	□

在**过去四个星期里**，您的工作和日常活动有没有因为身体健康的原因而出现以下这些问题？如果有，程度如何？	所有的时间	大部分时间	部分时间	小部分时间	根本没有
7. 本来想要做的事情**只能完成一部分**？	□	□	□	□	□
8. 减少了工作或其他活动的**时间**？	□	□	□	□	□
在**过去四个星期里**，您的工作和日常活动有没有因为情绪（如感到消沉或者忧虑）而出现以下问题？如果有，程度如何？					
9. 本来想要做的事情**只能完成一部分**？	□	□	□	□	□
10·做工作或其他活动不如平时**仔细**？	□	□	□	□	□
在**过去四个星期里**，您的感觉如何以及您的情况如何？					
11. 您觉得**平静**吗？	□	□	□	□	□
12. 您觉得**情绪低落**吗？	□	□	□	□	□

（II）自我效能问卷

以下问题是了解您在现在或不久的将来应对照顾癌症亲人时的信心。答案没有对和错之分，请根据您的实际情况进行选择，在相应栏内打“√”。

	问题	**每个问题的答案从 1 到 9（1=‘完全没有信心’，5=‘有适度信心’，9 =‘非常有信心’）。** **1------------------------------ 9**								
1.	保持独立性	1	2	3	4	5	6	7	8	9
2.	保持积极的态度	1	2	3	4	5	6	7	8	9
3.	维护工作活动	1	2	3	4	5	6	7	8	9
4.	整个照顾期间保持放松，可以避免可怕的想法让我感到不安	1	2	3	4	5	6	7	8	9
5.	协助应对病人身体的变化	1	2	3	4	5	6	7	8	9
6.	积极参与治疗决策	1	2	3	4	5	6	7	8	9
7.	关注分担忧虑	1	2	3	4	5	6	7	8	9
8.	表达照顾癌症病人相关负面情绪	1	2	3	4	5	6	7	8	9
9.	保持幽默感	1	2	3	4	5	6	7	8	9
10.	寻求安慰	1	2	3	4	5	6	7	8	9
11.	向医生提问	1	2	3	4	5	6	7	8	9
12.	协助处理病人恶心和呕吐	1	2	3	4	5	6	7	8	9

第三部分 双向应对量表

本量表用来测评您和您的伴侣是如何应对压力。请在答题时根据您个人的情况做出最佳选择。请尽量诚实答题，答案无对错之分。

	您如何与您伴侣沟通您的压力?	极少	很少	有时	经常	非常频繁
1.	我让他/她知道，我很感谢他/她实际的支持、建议和帮助。	□	□	□	□	□
2.	当我比较忙的时候，我会请他/她帮忙。	□	□	□	□	□
3.	当我做得还不够好或者当我遇到问题时，我会通过我的行为让他/她知道。	□	□	□	□	□
4.	我坦诚地告诉他/她我的真实感受并会感谢他/她的支持。	□	□	□	□	□
	当您有压力时，您的伴侣如何做?					
5.	他/她能感受并理解我的压力。	□	□	□	□	□
6.	他/她会告诉我他/她在我身边。	□	□	□	□	□
7.	他/她责备我没有很好应付压力。	□	□	□	□	□
8.	他/她帮助我从不同角度看待压力情境。	□	□	□	□	□
9.	他/她注意倾听我诉说，让我有机会沟通困扰我的原因。	□	□	□	□	□
10.	他/她没有认真对待我的压力。	□	□	□	□	□
11.	他/她提供支持，但是不情愿或不积极。	□	□	□	□	□
12.	为了帮助我应对困境，他/她分担通常需要我做的事情。	□	□	□	□	□
13.	他/她可以帮助我分析情况，以使我更好地面对问题。	□	□	□	□	□
14.	当我太忙时，他/她可以帮助我。	□	□	□	□	□
15.	当我有压力时，他/她倾向于回避。	□	□	□	□	□
	当您的伴侣有压力时，他/她如何与您沟通?					
16.	他/她让我知道他/她感谢我实际的支持，建议，和帮助。	□	□	□	□	□
17.	当他/她比较忙的时候，他/她会请我帮忙。	□	□	□	□	□
18.	当他/她做得还不够好、或者当他/她有问题时，他/她会通过他/她的行为告诉我。	□	□	□	□	□

19.	他/她坦诚地告诉我有关他/她的真实感受并会感谢我对他/她的支持。	□	□	□	□	□
	当您的伴侣有压力时，您如何做?	极少	很少	有时	经常	非常频繁
20.	我能感受并理解他/她的压力。	□	□	□	□	□
21.	我会告诉他/她，我就在他/她身边。	□	□	□	□	□
22.	我责备他/她没有很好应付压力。	□	□	□	□	□
23.	我告诉他/她也许情况并没有那么糟糕并帮助他/她从不同角度看待压力情境。	□	□	□	□	□
24.	我注意倾听他/她诉说，让他/她有机会沟通困扰他/她的原因。	□	□	□	□	□
25.	我没有认真对待他/她的压力。	□	□	□	□	□
26.	当他/她有压力时，我倾向于回避。	□	□	□	□	□
27.	我不情愿或不主动地提供支持，因为我认为他/她应该自己处理自己的问题。	□	□	□	□	□
28	为了帮助他/她应对困境，我会承担通常需要他/她做的。	□	□	□	□	□
29.	我会试图与他/她一起客观地分析情况，以使他/她能理解和改变困境。.	□	□	□	□	□
30.	当他/她太忙时，我可以帮助他/她。	□	□	□	□	□
	当您与您的伴侣都有压力时，您们如何做?					
31.	我们试着共同面对问题并寻找问题的解决方案。	□	□	□	□	□
32.	我们一起认真地讨论所面临的问题及需要采取的应对措施。	□	□	□	□	□
33.	我们相互帮助，使双方从不同角度正确地分析问题。	□	□	□	□	□
34.	我们一起从事一些活动,如按摩、沐浴、或听音乐，以帮助放松身心。	□	□	□	□	□
35.	我们彼此深爱对方，可以用爱的方式来应对压力。	□	□	□	□	□
	作为一对夫妻，您如何评价您们的应对方式?					
36.	我对我的伴侣提供的支持，以及我们一起应对压力的方式感到满意。	□	□	□	□	□
37.	我对我的伴侣提供的支持很满意，同时我觉得我们一起应对压力的方式是有效的。	□	□	□	□	□

第四部分 正性和负性情绪体验

(I) 益处发现量表

下列项目是评估您可能从癌症的经历中体验到的潜在好处。对于每个项目，请注明最接近您体验的近似程度。

从照顾亲人的癌症体验中. . .	完全没有	有一点	中等程度	很多	非常多
1. 使我更接受现实。	1	2	3	4	5
2. 教会我如何适应自己不能改变的事情。	1	2	3	4	5
3. 学会顺其自然。	1	2	3	4	5
4. 使我的家庭更加紧密联系在一起。	1	2	3	4	5
5. 使我更关心家庭事宜。	1	2	3	4	5
6. 理解生活中每个人都有其生存意义。	1	2	3	4	5
7. 让我知道每个人都需要爱。	1	2	3	4	5
8. 使我意识到为家庭未来计划的重要性。	1	2	3	4	5
9. 让我更加认识和关心全人类的未来。	1	2	3	4	5
10. 教会了我要有耐心。	1	2	3	4	5
11. 使我能更好地应对压力和面对困难。	1	2	3	4	5
12. 使我结识更多朋友。	1	2	3	4	5
13. 使我得到精神和心理的全面成长。	1	2	3	4	5
14. 使我更加感受到来自他人的爱和支持。	1	2	3	4	5
15. 帮助我认识到谁是我真正的朋友。	1	2	3	4	5
16. 使我更专注什么是优先事情，对人生目标有更深感受。	1	2	3	4	5
17. 使我成为一个更坚强的人，能够有效应对未来生活的挑战。	1	2	3	4	5

（II）HAD 情绪评估量表

情绪在大多数疾病中起着重要作用，如果医生了解您的情绪变化，他们就能给您更多的帮助。请您阅读以下各个项目，在其中最符合您上个月以来的情绪评分上打“√”。对这些问题的回答不要做过多的考虑，立即做出的回答会比考虑后再回答更切合实际。

项　目	3	2	1	0
1. 我感到紧张（或痛苦）	□几乎所有时候	□ 大多数时候	□ 有时	□ 根本没有
2. 我对以往感兴趣的事情还是有兴趣	□基本上没有了	□ 只有一点儿	□ 不像以前那样多	□ 肯定一样
3. 我感到有点害怕，好像预感到有什么可怕事情要发生	□ 非常肯定和十分严重	□ 是有，但并不太严重	□ 有一点，但并不使我苦恼	□ 根本没有
4. 我能够哈哈大笑，并看到事物好的一面	□ 根本没有	□ 现在肯定是不太多了	□ 现在已经不大这样了	□ 我经常这样
5. 我的心中充满烦恼	□ 大多数时间	□ 常常如此	□ 时时，但并不经常	□ 偶然如此
6. 我感到愉快	□ 根本没有	□ 并不经常	□ 有时	□ 大多数
7. 我能够安闲而轻松地坐着	□ 根本没有	□ 并不经常	□ 经常	□ 肯定
8. 我对自己的仪容（打扮自己）失去兴趣	□ 肯定	□ 并不像我应该做到的那样关心	□ 我可能不是非常关心	□ 我仍像以往一样关心
9. 我有点坐立不安，好像感到非要活动不可	□ 确实非常多	□ 是不少	□ 并不很多	□ 根本没有
10. 我对一切都是乐观地向前看	□ 几乎从来不这样做	□ 很少这样做	□ 并不完全是这样做的	□ 差不多是这样做的
11. 我突然发现恐慌感	□ 确实很经常	□ 时常	□ 并非经常	□ 根本没有
12. 我好像感到情绪在渐渐低落	□ 几乎所有的时间	□ 很经常	□ 有时	□ 根本没有
13. 我感到有点害怕，好像某个内脏器官变坏了	□ 非常经常	□ 很经常	□ 有时	□根本没有
14. 我能欣赏一本好书或一项好的广播或电视节目	□ 很少	□ 并非经常	□ 有时	□ 常常

第五部分 沟通及婚姻关系

(I) 癌症相关沟通问题

下列项目是评估您作为照顾者与您配偶在沟通癌症相关问题时的感受或经验。请注明最接近您体验的项目。

	沟通项目	经常	有时	没有
1.	我的配偶理解我对他/她患癌的感受。	□	□	□
2.	我不会与配偶谈论有关他/她患癌的问题，因为这样做会使他/她忧虑。	□	□	□
3.	我的配偶没有问及他/她患癌症如何影响我的生活。	□	□	□
4.	我不会与配偶谈论有关他/她患癌的问题，因为这样做会使我忧虑。	□	□	□
5.	我不知道配偶何时愿意或不愿意谈论有关癌症的问题。	□	□	□
6.	我们讨论/或曾讨论他/她应该接受哪种治疗方法。	□	□	□
7.	我可以与配偶谈论所有与他/她所患癌症相关的想法。	□	□	□
8.	为避免给我带来烦恼/忧虑，我的配偶不会谈及他/她所患癌症的感受。	□	□	□
9.	我和配偶谈论有关他/她所患癌症治疗是否有效的忧虑。	□	□	□
10.	我不告诉我的配偶我对他/她患癌症有多么害怕。	□	□	□
11.	我和我的配偶谈论癌症治疗导致他/她身体上的改变（例如乳房，子宫或前列腺切除）。	□	□	□
12.	与配偶相比，我更愿意与朋友倾诉有关我对他/她患癌的感受。	□	□	□
13.	我与配偶商谈当他/她的病情恶化时应如何应对。	□	□	□
14.	当谈到癌症，我只告诉我的配偶他/她希望听到的信息。	□	□	□
15.	我不与我的配偶谈论他/她所患癌症对我的性体验的影响。	□	□	□

（II）修订版婚姻适应量表

许多人在婚姻中会有意见不一致。请对以下题目注明最近似您与您配偶意见同意或不一致的程度。

	总是同意	几乎完全同意	偶尔同意	有时不同意	几乎完全不同意	总是不同意
1. 宗教信仰	5	4	3	2	1	0
2. 性爱表示	5	4	3	2	1	0
3. 做出重要的决定	5	4	3	2	1	0
4. 性关系	5	4	3	2	1	0
5. 传统观念和习俗	5	4	3	2	1	0
6. 有关职业的决定	5	4	3	2	1	0

	总是如此	大部分时间	比较多时间	偶尔	极少	从来没有
7. 与配偶讨论离婚、分居等	0	1	2	3	4	5
8. 与配偶吵架时间	0	1	2	3	4	5
9. 后悔结婚（或同居）	0	1	2	3	4	5
10. 和配偶令对方心烦时间	0	1	2	3	4	5

	每天	几乎每天	偶尔	极少	从来没有
11. 与配偶一同外出进行社交活动	4	3	2	1	0

	从不	少于每月一次	每月一次或两次	每周一次或两次	第天一次	经常
12. 有启发性或激动性的意见交流	0	1	2	3	4	5
13. 一起进行一件事或计划	0	1	2	3	4	5
14. 冷静地讨论事情	0	1	2	3	4	5