The role of spousal supportive behaviors in couples' adaptation to colorectal cancer

Dagan, Meirav

Publication date:
2014

Citation for published version (APA):
Dagan, M. (2014). The role of spousal supportive behaviors in couples' adaptation to colorectal cancer

The Role of Spousal Supportive Behaviors in Couples’ Adaptation to Colorectal Cancer

Meirav Dagan

Colophon
Book cover and Lay out design: Ishay Halmut
ISBN: 978-90-367-6930-3
ISBN: 978-90-367-6929-7 (electronic version)

Print by: Lovebird design and printing solutions

The research reported in this thesis was funded by the Dutch Cancer Society (RUG 2002-2581). The study was conducted within the research institute SHARE (University medical center Groningen, University of Groningen). The print of this thesis was financially supported by the research institute SHARE, the faculty of Medical Sciences (UMCG), and the University of Groningen.

The Role of Spousal Supportive Behaviors in Couples' Adaptation to Colorectal Cancer

PhD thesis

to obtain the degree of PhD at the
University of Groningen
on the authority of the
Rector Magnificus Prof. E. Sterken
and in accordance with
the decision by the College of Deans.

This thesis will be defended in public on

Wednesday 30 April 2014 at 16.15 hours

by

Meirav Dagan

born on 12 November 1980

in Jerusalem, Israel

Supervisors

Prof. M. Hagedoorn
Prof. R. Sanderman

Assessment committee

Prof. C. Finkenauer
Prof. A.J Oldehinkel
Prof. K.MG Schreurs

Contents

Chapter 1

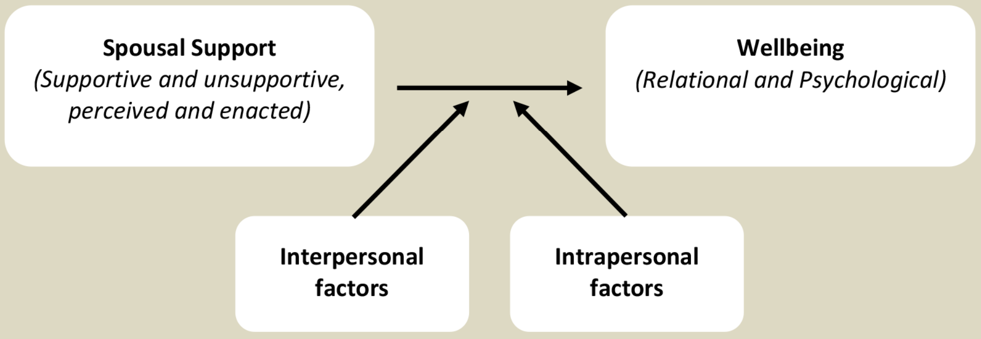
General Introduction

I promise to support you in times of sickness and in times of health

The diagnosis of cancer begins a period of significant distress and adjustment for both patients and their spouses. To cope better with the distress, both partners are expected to support each other. However, this is not always the case and sometimes even well-meant support may hamper adjustment. The goal of the current thesis is to expand the knowledge on under what condition spousal support affects the emotional and relational wellbeing of couples coping with colorectal cancer.

In this introduction to my thesis, I will start with providing a short overview of the importance of spousal support to couples' adaptation and present the framework of the current thesis (see Figure 1). Next, I will describe three issues that are important to consider when examining spousal support in couples coping with cancer. Specifically, the first issue is considering cancer as a dyadic process, the second is viewing patients and their partners as support receivers as well as support providers, and the third is examining supportive versus unsupportive spousal behavior. Thereafter, I will review the literature and provide the theoretical background for three (i.e., inter- and intrapersonal) factors that will be examined in the current thesis. Each factor will be examined separately in the different empirical chapters. Specifically, in chapter 2 we will examine an interpersonal factor, namely past spousal supportiveness, while in chapter 3 and 4 we will examine two intrapersonal factors, namely a sense of personal control and need for emotional expression, respectively. Finally, I will describe a common methodological issue that is important to consider when conducting a couples-based study (especially in the context of cancer), namely couples' recruitment. This issue will be covered by chapters 5 and 6.

Figure 1 The empirical study framework



Spousal support

In the cancer literature, social support is among the most-studied factors contributing to emotional and relational wellbeing. Specifically, it plays an important role in adjustment to a cancer diagnosis. To cope better with this hectic period, patients but also their intimate partners rely on each other's support. Intimate partners are especially important sources of emotional support, and findings suggest that support from others cannot compensate for lack of support from an intimate partner (e.g., Coyne & DeLongis, 1986; Pistrang & Barker, 1995). A substantial body of research has established links between spousal support and outcomes, such as psychological wellbeing (e.g., Pistrang & Barker, 1995), relational wellbeing (e.g., Hagedoorn et al., 2000) and relationship intimacy (e.g., Manne, Badr, & Kashy, 2012).

One may assume that if only partners were more supportive and helpful, couples' levels of wellbeing would increase. However, this is an oversimplification of reality. This thesis strives to reveal target subgroups of people at high risk for poor adaptation to cancer (i.e., vulnerable) because they tend to depend more strongly on the support of their partner. Accordingly, we examined the question "Who needs and benefits from a supportive partner the most?" from different directions. Using a longitudinal observational design, we will focus on how the behavior of one partner helps or hinders the other partner's adaptation to cancer. Specifically, we will examine three factors (i.e., inter- and intrapersonal) that may play a role in the support-wellbeing association.

Although it is widely accepted that the examination of spousal support in this context of cancer requires an understanding of *cancer as a dyadic process*, focusing on *both patients and their partners as support receivers and providers*, and comparing *supportive versus unsupportive spousal behavior*, to date these notions are not fully integrated in the research. To begin to fill this gap, the current thesis draws attention to the importance of addressing these topics when examining different moderation models. These three topics will be integrated (when applicable) in the different empirical chapters. In the following paragraphs I will describe the above mentioned topics and specifically state in which chapters they will be adopted.

Cancer as a dyadic process

The diagnosis of cancer begins a period of significant distress and adjustment for both patients and their partners. Patients need to cope with the cancer diagnosis and treatment side effects, while their partners need to cope with worries about the potential loss of their significant other, their ability to provide support, and alterations in social and family roles.

Historically, research on adaptation to cancer has focused on how patients or partners adjust to cancer from an individualistic perspective. This perspective overlooks the interdependency between patients and their partners. Previous studies provided compelling evidence that cancer affects both patients' and their partners' psychological wellbeing (e.g., Tuinstra et al., 2004). Acknowledging the dyadic perspective of chronic illness such as cancer has stimulated research on how couples cope with stressors. The dyadic perspective has advanced the social support perspective by noting how spouses may frequently share stressors (appraising illness as "ours" rather than "mine"), pool resources, and actively engage in joint coping efforts (e.g., Berg & Upchurch, 2007; Bodenmann, 2005; Kayser, Watson, & Andrade, 2007). *Dyadic coping* can be defined as *one partner's attempt to help reduce the external stress perceived by his/her partner and a common endeavor to cope with stress that originates inside the relationship* (Bodenmann, 2000 as cited in Herzberg, 2013). According to the dyadic perspective, dyadic coping has two primary objectives: to reduce stress for each partner and to enhance relationship quality (Bodenmann, 2005). The current thesis values this perspective and adopts it when possible (i.e., chapters 2 and 3).

Patients and their partners as support receivers and providers

Traditionally social support theories view cancer patients as the focal person and the partner as a source of support. Also in everyday life patients are usually seen as the recipients of support, while their partners are seen as the primary caregivers by their social environment. Accordingly, partners often report receiving less support than patients (e.g., Northouse, Mood, Templin, Mellon, & George, 2000). Nonetheless, distress in partners is well-documented (e.g., Lambert, Jones, Girgis, & Lecathelinais, 2012), also in the context of couples' coping with colon cancer (e.g., Nijboer, Triemstra, Tempelaar, Sanderman, & van den Bos, 1999; Northouse et al., 2000). Specifically in the context of colorectal cancer, it was found that specific treatment side effect (i.e., having a stoma; see Box 1 for more information about *colorectal cancer basic facts, treatment and side effects*) was related with partners' distress (Nijboer et al., 2000). Moreover, partners' distress might adversely affect their ability to support patients, which in turn will impact patients' adjustment. Accordingly, it has been recognized repeatedly in the literature that in couples dealing with cancer, both the patients and their partners should be considered as recipients as well as providers of support (e.g., Badr, Carmack, Kashy, Cristofanilli, & Revenson, 2010; Manne & Badr, 2008). Cancer patients are indeed patients, but they are also still spouses who can be motivated to continue their role as supportive partners in the midst of recovering from illness (Kayser, Sormanti, & Strainchamps, 1999). In line with this idea and to address the gap in the literature, chapters 2 and 3 will examine both patients' and partners' supportive behaviors when predicting couples' adaptation to cancer. It is important to note that originally, we aimed to examine both patients and partners supportive behaviors in all chapters. However, this was not possible in chapter 4 because of methodological issues. Specifically, in chapter 4 we were able to examine only the patients' conversation in which the healthy partner is assigned to the role of the support provider and the patient is assigned to the role of the support receiver (we reflect on that in the general discussion, see chapter 7 pages 101-102).

Supportive versus unsupportive spousal behavior

Until recently, most of the spousal support literature in the context of cancer has emphasized the benefits of interpersonal relationships, with much less attention to the strains that also occur within relationships. An important issue in spousal support research concerns the determinants of whether a supportive behavior will be perceived as supportive and whether it will exert stress-buffering effects. However, marital interactions may entail both **supportive and unsupportive** spousal behavior (e.g., Hagedoorn, Sanderman, Buunk, & Wobbes, 2002; Hinnen, Ranchor, Baas, Sanderman, & Hagedoorn, 2009; Manne, 1999). Additionally, research indicates that unsupportive behaviors are distinct from supportive behaviors and independently predict psychological adjustment (Manne & Zautra, 1989). Furthermore, even well-meant support can be carried out in a manner that reduces, and even reverses, its intended effects. Therefore, in chapters 2 and 3 we examined the impact of supportive as well as unsupportive spousal behavior, rather than merely focusing on the positive aspect of spousal support.

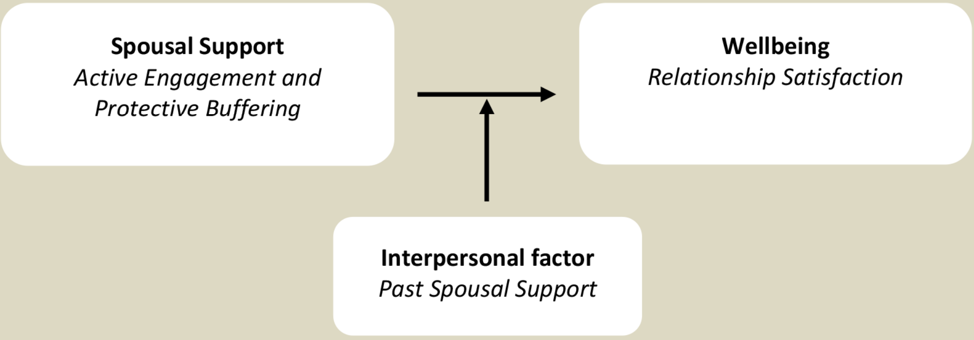
Part 1: Spousal Supportive behaviors - Empirical Examination

The first part of the current investigation includes examining the role of different inter- and intrapersonal factors in the relationship between spousal supportive behaviors and well-being. Specifically, first we will examine to role of *past spousal supportiveness* (an interpersonal factor) in the relationship between spousal supportive behaviors and relational wellbeing (i.e., relationship satisfaction). Next, we will examine the roles of *sense of personal control*, and *need for emotional expression* (intrapersonal factors) in the relationship between spousal supportive behaviors and emotional wellbeing (i.e., depressive symptoms).

Interpersonal factor: *the role of past spousal supportiveness*

When couples are facing a stressor, such as cancer, the stress management resources of both partners may be activated to maintain or restore a state of homeostasis within the marital relationship. But even before that, during the course of marital relationship, most partners are facing aversive episodes in which their significant other is expected to display supportive behaviors. According to the **attribution theory** a displayed behavior can either be attributed to stable, internal characteristics of a person or to some external factor(s) in the environment or situation (Heider, 1958). Meaning that, a behavior displayed by one partner may vary it its effect on the other partner depending on the attributions that are made by the other partner (for a review see Bradbury & Fincham, 1990). In the context of cancer, the degree to which a spouse is perceived by his / her partner as being supportive before the cancer diagnosis (i.e., past spousal supportiveness) might affect the relationship between one partner's current behavior and his/her partner's satisfaction. Individuals who have a positive global perception of the relationship have a tendency to make benign attributions about their partner's behavior, probably to maintain their satisfaction with the relationship. In chapter 2, we will examine if the association between current behaviors and relationship satisfaction depends on the global perception of past spousal supportiveness (see Figure 2). Specifically, we will examine whether individuals with low past spousal supportiveness perceptions are at higher risk for poor relational wellbeing than individuals with high past spousal behavior.

Figure 2 The Role of Past Spousal Support in Support-Relational Wellbeing Association (Chapter 2)



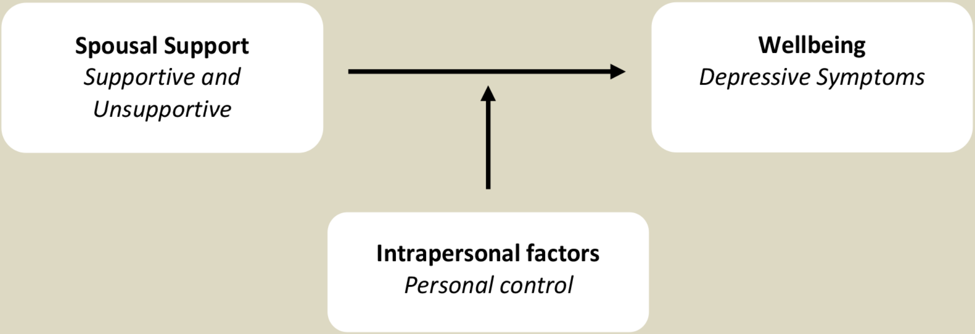
Intrapersonal factors: *Sense of personal control*

Although patients' individual characteristics as well as partners' supportive behaviors may separately affect patients' level of depressive symptoms, it is also conceivable that they conjointly affect them. This possibility has received limited attention in the literature thus far. One study that examined this found that low levels of positive support or high levels of negative support in combination with a poor physical condition may lead to negative psychosocial outcomes (Hagedoorn et al., 2000).

According to ***the optimal matching model of social support***, support is most beneficial when it matches the specific needs or goals of the stressed individual (Cutrona, 1990). This model especially focuses on the match between the type of stressful event and the type of social support needed. The most influential dimension with regard to a need for social support is the *controllability*. According to the model, when an event is uncontrollable (i.e. nothing can be done to prevent the event or lessen its consequences), emotional support is the most beneficial type of support. In contrast, when an event is controllable (i.e., individuals can prevent its occurrence or consequences) the most beneficial type of support will be a type that will foster an effective instrumental action (e.g., informational and tangible support). The short overview presented in Box 1 regarding the diagnosis of colorectal cancer, treatment, and its side effects clearly demonstrates that the period after a colorectal cancer diagnosis may be very distressing. Additionally, a cancer diagnosis, regardless of type or site, raises feelings of fear and loss of control (uncertainty and unpredictability) in patients and their partners.

Hence, in chapter 3, we will examine the role of patients' and partners' **sense of personal control** in the support-distress association (see Figure 3). Specifically, we will examine whether partners' supportive behaviors that "match" the needs of people low in personal control are beneficial in terms of reducing levels of depressive symptoms. Personal control refers to the belief that life is not ruled by fate, but that one is personally able to influence the outcomes of important events or situations in life. It was previously suggested that personal control might determine the way social support is being used (cf. Sandler & Lakey, 1982) additionally, it was found that people low in personal control are at higher risk for stress and depression than individuals high in personal control (e.g., Stiegelis et al., 2003). We propose that people low in control need spousal support the most, and therefore are thought to be at higher risk for distress if their partners is not forthcoming with support. Thus, the group of people low in control can be identified as a vulnerable subgroup.

Figure 3 The Role of Personal Control in Support-Depressive Symptoms Association (Chapter 3)

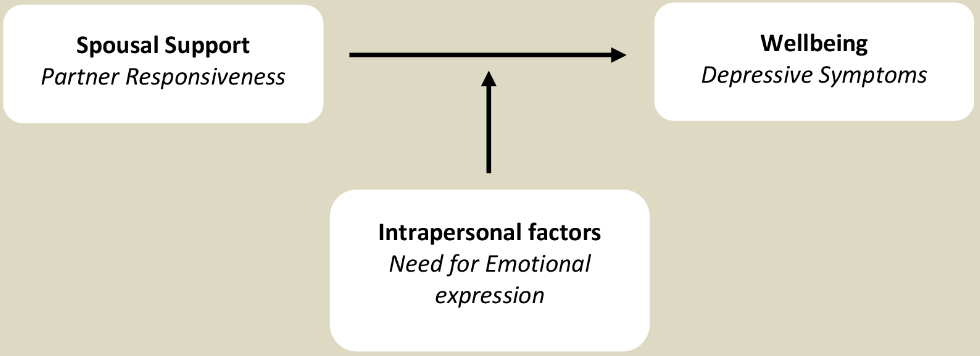


Intrapersonal factors: *Need for emotional expression.*

In general cancer patients are encouraged not to hold back and to openly express their emotions and concerns to their partners (cf., Cordova, Cunningham, Carlson, & Andrykowski, 2001; Figueiredo, Fries, & Ingram, 2004; Iwamitsu et al., 2003) despite the fact that different people have different needs to express their emotions. Some have a high need for emotional expression and therefore want to share their emotions with people close to them while others do not. Following the matching hypothesis, different types of support or responses may have different effects on individuals high versus low in a need for emotional expression. People with a high **need for emotional expression** wish to talk with others when facing a stressful event. Following the **vulnerability hypothesis**, they can be identified as a vulnerable subgroup of people who need and benefit from spousal support the most and therefore, might be at higher risk for distress when their partners is not forthcoming with support. In chapter 4, we will examine whether partners' unmatched supportive behavior (i.e., low partner responsiveness) is harmful, especially for people high in need for emotional expression, in terms of elevating levels of patients' depressive symptoms (see Figure 4).

One may assume that actual responsive behaviors will have strong correlations with the perception of these behaviors. However, perceptions are often biased (e.g., Agnew, Loving, & Drigotas, 2001; Collins & Feeney, 2000; Kruger, 1999) and for example affected by attributions. Furthermore, it was shown that, individuals' perceptions of the amount of support they obtained from their spouse was only moderately correlated with the support their spouse reported providing (Abbey, Andrews, & Halman, 1995) and with the actual support provided, as coded by objective coders (Collins & Feeney, 2000; Feeney, 2004; Priem, Solomon, & Steuber, 2009). Previous studies have relied exclusively on self-report measurements. To begin to fill this gap, in chapter 4 we will examine **actual supportive behavior** (i.e., partner responsiveness) as coded by objective coders.

Figure 4 The Role of Need for Emotional Expression in Support-Depressive Symptoms Association (Chapter 4)



Part 2: Recruitment couples to psycho-oncological studies

The second part of the current investigation (i.e., chapters 5 and 6) has been evolved as a result of conducting our empirical study. Specifically, the study faced higher refusal rates than anticipated and while writing the papers for the current thesis we were confronted with questions (mostly from reviewers) regarding the low Couples' Response Rate (CRR) in our sample (CRR ≤ 31%). To put our CRR in a broader perspective, we started seeking for literature regarding response rates in our field. To our surprise, although many researchers are confronted with similar challenges when recruiting couples, till now no study has examined this issue systematically.

As researchers, we are well aware to the methodological problems of a low CRR. We know that, the inability to successfully obtain and retain research participants may have a profound effect on the study's validity and ability to generalize findings. Additionally, even though there is no official minimum response rate for publication, a 60% response rate is sometimes presented as a minimum golden standard (Fincham, 2008) that might affect editors' decision regarding a publication. We were wondering how other couples' researchers are handling this challenge. Therefore, the first aim of chapter 5 is to examine the average couples' response rate (CRR; all analyzed couples divided by the number of eligible partnered patients/couples approached) in observational studies of couples coping with cancer. The second goal of chapter 5 is to establish how many researchers report the CRR and how many report other more favorable rates instead of CRR.

While reviewing the literature it became apparent that some studies succeeded more than others to include couples in their studies. In chapter 6 we followed up on the results from our systematic review and examined factors that may be related to CRR (e.g., study design, approach size, ways of approaching participants). We believe that reflecting on that eventually will contribute to more efficient recruitment of couples. Therefore, to help couples' researchers in the future, the aim of chapter 6 is to examine factors that are associated with couples' participation and provide recommendations for future research.

In the Netherlands, approximately 12,760 people are diagnosed annually with colon cancer and approximately one third of them are diagnosed with rectal cancer. After prostate and lung cancer colon cancer is the most common type of cancer in men. In women, colon cancer is the second most common type after breast cancer (Kanker.nl, 2013). Incidence and death rates for colorectal cancer increase with age. Overall, 81% of new cases occur in individuals 60 years and older (Kanker.nl, 2013). The survival rate has improved in the past decades as results of improvement in screening and treatment. The 10-year survival rate is about 53% with highest survival rates in early detection (stage I, more than 90%) and lowest in metastatic disease (stage IV, about 9%) (Kanker.nl, 2013).

Most people with colon cancer, particularly in earlier stages, will have some type of surgery to remove the tumor. Surgery can cause fatigue (possibly for an extended period), constipation or diarrhea, sexual side effects, such as erectile dysfunction in men (after more extensive operations for rectal cancer), and a temporary or permanent colostomy. A colostomy is an operation to create a small opening on the surface of the abdomen in order to divert the flow of faeces. Sometimes when a section of the colon or rectum is removed, the reconnection of the healthy parts is not possible immediately. Most patients who require a colostomy need it only temporarily, until the colon or rectum heals from surgery (usually in 6 to 8 weeks). However, approximately 1 in 8 people with rectal cancer require a permanent stoma (American Cancer Society, 2013; National Cancer Institute, 2006). A temporary or permanent stoma can cause fear of leakage and lowered self-confidence that affects participation in social activities and cause a withdrawal from intimate contact (Persson & Hellstrom, 2002; Persson, Severinsson, & Hellstrom, 2004).

After surgery often a combination of additional treatments methods are required such as chemotherapy or radiation, depending on the characteristic of the tumor. Side effects of radiation therapy for colorectal cancer include mild skin irritation, nausea, diarrhea, rectal irritation, the urge to defecate, bladder irritation, fatigue, or sexual problems. General side effects from chemotherapy are rather intrusive, including fatigue, nausea and vomiting, diarrhea, loss of appetite, hair loss, swelling and rashes, mouth sores, and numbness, tingling, or blistering of the hands and feet.

Box 1 Colorectal cancer basic facts, treatment and side effects

Reference List

Abbey, A., Andrews, F. M., & Halman, L. J. (1995). Provision and receipt of social support and disregard: What is their impact on the marital life quality of infertile and fertile couples? *Journal of Personality and Social Psychology, 68*(3), 455-469. doi:10.1037/0022-3514.68.3.455

Agnew, C. R., Loving, T. J., & Drigotas, S. M. (2001). Substituting the forest for the trees: Social networks and the prediction of romantic relationship state and fate. *Journal of Personality and Social Psychology, 81*(6), 1042-1057. doi:10.1037/0022-3514.81.6.1042

Badr, H., Carmack, C. L., Kashy, D. A., Cristofanilli, M., & Revenson, T. A. (2010). Dyadic coping in metastatic breast cancer. *Health Psychology, 29*(2), 169-180.

Berg, C. A., & Upchurch, R. (2007). A developmental-contextual model of couples coping with chronic illness across the adult life span. *Psychological Bulletin, 133*(6), 920-954.

Bodenmann, G. (2005). Dyadic coping and its significance for marital functioning. In T. A. Revenson, K. Kayser & G. Bodenmann (Eds.), (pp. 33-49). Washington, DC US: American Psychological Association. doi:10.1037/11031-002

Bradbury, T. N., & Fincham, F. D. (1990). Attributions in marriage: Review and critique. *Psychological Bulletin, 107*(1), 3-33. doi:10.1037/0033-2909.107.1.3

Collins, N. L., & Feeney, B. C. (2000). A safe haven: An attachment theory perspective on support seeking and caregiving in intimate relationships. *Journal of Personality and Social Psychology, 78*(6), 1053-1073.

Cordova, M. J., Cunningham, L. L. C., Carlson, C. R., & Andrykowski, M. A. (2001). Social constraints, cognitive processing, and adjustment to breast cancer. *Journal of Consulting and Clinical Psychology, 69*(4), 706-711. doi:10.1037/0022-006X.69.4.706

Coyne, J. C., & DeLongis, A. (1986). Going beyond social support: The role of social relationships in adaptation. *Journal of Consulting and Clinical Psychology, 54*(4), 454-460.

Cutrona, C. E. (1990). Stress and social support: In search of optimal matching. *Journal of Social and Clinical Psychology, 9*(1), 3-14.

Feeney, B. C. (2004). A secure base: Responsive support of goal strivings and exploration in adult intimate relationships. *Journal of Personality and Social Psychology, 87*(5), 631-648.

Figueiredo, M. I., Fries, E., & Ingram, K. M. (2004). The role of disclosure patterns and unsupportive social interactions in the well-being of breast cancer patients. *Psycho-Oncology, 13*(2), 96-105. doi:10.1002/pon.717

Fincham, J. E. (2008). Response rates and responsiveness for surveys, standards, and the journal. *American Journal of Pharmaceutical Education, 72*(2), 43.

Hagedoorn, M., Kuijer, R. G., Buunk, B. P., DeJong, G. M., Wobbes, T., & Sanderman, R. (2000). Marital satisfaction in patients with cancer: Does support from intimate partners benefit those who need it most? *Health Psychology, 19*(3), 274-282. doi:10.1037/0278-6133.19.3.274

Hagedoorn, M., Sanderman, R., Buunk, B. P., & Wobbes, T. (2002). Failing in spousal caregiving: The 'identity-relevant stress' hypothesis to explain sex differences in caregiver distress. *British Journal of Health Psychology, 7*, 481-494.

Heider, F. (1958). *The psychology of interpersonal relations*. Hoboken, NJ US: John Wiley & Sons Inc. doi:10.1037/10628-000

Herzberg, P. Y. (2013). Coping in relationships: The interplay between individual and dyadic coping and their effects on relationship satisfaction. *Anxiety, Stress, and Coping, 26*(2), 136-153. doi:10.1080/10615806.2012.655726; 10.1080/10615806.2012.655726

Hinnen, C., Ranchor, A. V., Baas, P. C., Sanderman, R., & Hagedoorn, M. (2009). Partner support and distress in women with breast cancer: The role of patient awareness of support and level of mastery. *Psychology & Health, 24*(4), 439-455.

Iwamitsu, Y., Shimoda, K., Abe, H., Tani, T., Kodama, M., & Okawa, M. (2003). Differences in emotional distress between breast tumor patients with emotional inhibition and those with emotional expression. *Psychiatry and Clinical Neurosciences, 57*(3), 289-294. doi:10.1046/j.1440-1819.2003.01119.x

Kayser, K., Sormanti, M., & Strainchamps, E. (1999). Women coping with cancer: The influence of relationship factors on psychosocial adjustment. *Psychology of Women Quarterly, 23*(4), 725-739. doi:10.1111/j.1471-6402.1999.tb00394.x

Kayser, K., Watson, L. E., & Andrade, J. T. (2007). Cancer as a 'we-disease': Examining the process of coping from a relational perspective. *Families, Systems, & Health, 25*(4), 404-418. doi:10.1037/1091-7527.25.4.404

Kruger, J. (1999). Lake wobegon be gone! the 'below-average effect' and the egocentric nature of comparative ability judgments. *Journal of Personality and Social Psychology, 77*(2), 221-232. doi:10.1037/0022-3514.77.2.221

Lambert, S. D., Jones, B. L., Girgis, A., & Lecathelinais, C. (2012). Distressed partners and caregivers do not recover easily: Adjustment trajectories among partners and caregivers of cancer survivors. *Annals of Behavioral Medicine, 44*(2), 225-235. doi:10.1007/s12160-012-9385-2

Manne, S., & Badr, H. (2008). Intimacy and relationship processes in couples' psychosocial adaptation to cancer. *Cancer, 112*(11), 2541-2555.

Manne, S. L. (1999). Intrusive thoughts and psychological distress among cancer patients: The role of spouse avoidance and criticism. *Journal of Consulting and Clinical Psychology, 67*(4), 539-546.

Manne, S. L., & Zautra, A. J. (1989). Spouse criticism and support: Their association with coping and psychological adjustment among women with rheumatoid arthritis. *Journal of Personality and Social Psychology, 56*(4), 608-617.

Manne, S., Badr, H., & Kashy, D. A. (2012). A longitudinal analysis of intimacy processes and psychological distress among couples coping with head and neck or lung cancers. *Journal of Behavioral Medicine, 35*(3), 334-346. doi:10.1007/s10865-011-9349-1

Nijboer, C., Triemstra, M., Tempelaar, R., Sanderman, R., & van den Bos, G. (1999). Determinants of caregiving experiences and mental health of partners of cancer patients. *Cancer, 86*(4), 577-588. doi:10.1002/(SICI)1097-0142(19990815)86:4<577::AID-CNCR6>3.0.CO;2-S

Nijboer, C., Triemstra, M., Tempelaar, R., Mulder, M., Sanderman, R., & Bos, G. A. M. v. d. (2000). Patterns of caregiver experiences among partners of cancer patients. *The Gerontologist, 40*(6), 738-746. doi:10.1093/geront/40.6.738

Northouse, L. L., Mood, D., Templin, T., Mellon, S., & George, T. (2000). Couples' patterns of adjustment to colon cancer. *Social Science & Medicine, 50*(2), 271-284. doi:10.1016/S0277-9536(99) 00281-6

Pistrang, N., & Barker, C. (1995). The partner relationship in psychological response to breast cancer. *Social Science & Medicine, 40*(6), 789-797.

Priem, J. S., Solomon, D. H., & Steuber, K. R. (2009). Accuracy and bias in perceptions of emotionally supportive communication in marriage. *Personal Relationships, 16*(4), 531-551. doi:10.1111/ j.1475-6811.2009.01238.x

Sandler, I. N., & Lakey, B. (1982). Locus of control as a stress moderator: The role of control perceptions and social support. *American Journal of Community Psychology, 10*(1), 65-80.

Stiegelis, H. E., Hagedoorn, M., Sander-man, R., van, d. Z., Buunk, B. P., & van, d. B. (2003). Cognitive adaptation: A comparison of cancer patients and healthy references. *British Journal of Health Psychology, 8*(3), 303-318.

Tuinstra, J., Hagedoorn, M., Van Sonderen, E., Ranchor, A. V., Van, d. B., Nijboer, C., & Sanderman, R. (2004). Psychological distress in couples dealing with colorectal cancer: Gender and role differences and intracouple correspondence. *British Journal of Health Psychology, 9*(4), 465-478. doi:10.1348/1359107042304588

Part 1

Empirical Studies - Spousal Support in Couples Coping with Colorectal Cancer

Chapter 2

Relationship Satisfaction in Couples Confronted with Colorectal Cancer: the Interplay of Past and Current Spousal Support

Mariët Hagedoorn,
Meirav Dagan,
Eli Puterman,
Christiaan Hoff,
Jeroen Meijerink,
Anita DeLongis,
Robbert Sanderman

Journal of Behavioral Medicine, (2011), 34, 288-297

I promise to support you in times of sickness and in times of health

Coping with cancer is considered to be a dyadic affair, meaning that patients' adjustment is affected by their partners' behavior and adjustment, and vice versa (Berg & Upchurch, 2007; Coyne & DeLongis, 1986; Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008; Manne & Badr, 2008). Although it is widely accepted that the examination of this dyadic coping process requires an understanding of the interpersonal context in which it occurs, to date few empirical studies have addressed this issue (Berg & Upchurch, 2007). To begin to fill this gap, this study investigates past spousal supportiveness –i.e., the degree to which the spouse was generally responsive to the individual's needs before the couple was confronted with cancer– as an interpersonal factor in marital adjustment after a cancer diagnosis. Specifically, we will argue that spousal supportive behavior after a cancer diagnosis is associated with relationship satisfaction in patients as well as partners, in the short-term and possibly over time, depending on past spousal supportiveness.

Research on close relationships has shown that couples' behavior during their interactions has an influence on a variety of important relationship outcomes, including relationship satisfaction (e.g., Bradbury, Campbell, & Fincham, 1995; Christensen & Heavey, 1990; Henry, Berg, Smith, & Florsheim, 2007; Manne, Ostroff, Sherman, Heyman, Ross, & Fox, 2004) (For a review, see Bradbury & Karney, 1993). For example, in the context of coping with breast cancer, women were found to be more satisfied with their relationships when their husbands showed more acceptance and less hostility during problem-solving conversations (Manne et al., 2004). In a similar vein, survey studies have shown significant associations between current supportive behavior of partners and relationship satisfaction in patients (Hagedoorn, Kuijer, Buunk, Dejong, Wobbes, & Sanderman, 2000; Hinnen, Hagedoorn, Ranchor, & Sanderman, 2008; Kuijer, Ybema, Buunk, De Jong, Thijs-Boer, & Sanderman, 2000; Langer, Brown, & Syrjala, 2009) (See also, Bodenmann, Pihet, & Kayser, 2006; Wunderer & Schneewind, 2008). Specifically, spousal active engagement, defined as discussing feelings and engaging in joint problem solving, was found to be positively associated with relationship satisfaction in patients. In contrast, spousal protective buffering, which includes hiding worries and fears and avoiding talking about the disease, was found to be negatively associated with relationship satisfaction in patients.

However, it has been recognized that a behavior displayed by one partner in a marital interaction may vary in its effect on the other partner and the relationship as a function of how this latter partner understands or perceives the behavior (for reviews, see Bradbury & Fincham, 1990; Bradbury, Fincham, & Beach, 2000). There is ample evidence that benign attributions about partner behavior, such as ascribing negative partner behavior to external causes and ascribing positive partner behavior to stable characteristics of the spouse, are positively associated with relationship satisfaction. This has been found both with respect to global attributions about partner behavior (e.g. Fincham & Bradbury, 1987; 1993; Fincham, Bradbury, Arias, Byrne, & Karney, 1997; Graham & Conoley, 2006) and attributions about specific partner behaviors or intentions (Waldinger & Schulz, 2006). It can be assumed that the association between attributions and relationship satisfaction is reciprocal. However a longitudinal study (i.e., eight assessments in four years) among newlyweds has shown that “initial levels of attributions predicted changes in marital satisfaction more than initial satisfaction predicted changes in attributions” (Karney & Bradbury, 2000; p. 295).

Based on Heider’s work (1958), McNulty and Karney (2001) have described attributional processes within close relationships as one way in which individuals coordinate their specific and global perceptions of their partners and relationships. Attributional processes are stimulated especially if a specific partner behavior is negative or unexpected (Holtzworth-Munroe & Jacobson, 1985). One example of this occurs when partners show a lack of active engagement after a cancer diagnosis, while they are expected to show involvement in discussions of feelings and to engage in joint problem solving. Individuals who have a positive global perception of the relationship have a tendency to make benign attributions about their partner’s behavior, supposedly to maintain their satisfaction with the relationship. In line with this, prior studies have shown that individuals who scored high on overall perceived support within a relationship interpreted the same behaviors of significant others as more supportive than did individuals who scored low on overall perceived support (Lakey & Cassady, 1990; Lakey & Dickinson, 1994; Pierce, Sarason, & Sarason, 1992; Ross, Lutz, & Lakey, 1999). For example, in one experimental study of undergraduates and their mothers (Pierce et al., 1992), students were asked to give an unanticipated speech. Before and after their speech, they received standardized supportive notes they believed were written by their mother. Students who perceived their mothers as generally highly supportive (measured one week before the experiment), felt more supported by the notes than students who perceived their mothers generally to be less supportive. In a similar vein, past spousal supportiveness may stimulate benign attributions of current spousal supportive behavior after a cancer diagnosis, especially if the behavior is negative, and consequently moderate the association between current spousal behavior and relationship satisfaction.

Overview of the Current Study

In the beginning of their intimate relationships, people usually report high levels of satisfaction. However, this may change over time. Even high-functioning, happy couples face challenges and stressful events that may impact their relationship negatively.

Long-term outcomes of a relationship may depend, in part, on how people integrate problems, stressful events, and one another's responses to such events, with their more global evaluations of the relationship (McNulty & Karney, 2001). A diagnosis of cancer in one member of the couple and both partners' subsequent supportive behavior may be considered such a challenge.

Based on the ideas outlined above, we expect current spousal supportive behaviors to be associated with current and future relationship satisfaction in patients as well as partners. These associations, however, are thought to depend on their perceptions of past spousal supportiveness. Past spousal supportiveness is considered to be a global evaluation of the relationship within which current spousal supportive behaviors need to be coordinated. We did not measure attributions, but assume that patients and partners, who perceive past spousal supportiveness to be high rather than low, make benign attributions for one another's low levels of active engagement and high levels of protective buffering. As a consequence, we expect to find these individuals to be able to maintain high levels of relationship satisfaction even if spousal active engagement is low and spousal protective buffering is high. In contrast, we expect those who perceive past spousal supportiveness to be low, not be able to do so. Hence, we hypothesize that spousal active engagement is positively associated with relationship satisfaction in patients as well as partners, but only if past spousal supportiveness is perceived to be relatively low. Spousal protective buffering is hypothesized to be negatively associated with relationship satisfaction, again only if past spousal supportiveness is perceived to be relatively low. Relatively low levels of relationship satisfaction are expected in individuals who report low levels of spousal active engagement or high levels of spousal protective buffering combined with low levels of past spousal supportiveness. The interplay of past and current spousal support on relationship satisfaction will be examined cross-sectionally as well as longitudinally.

Methods

Participants and Procedures

Participants were newly diagnosed persons with colorectal cancer and their intimate partners who were recruited from oncology clinics at eight participating hospitals in the three northern provinces of the Netherlands. These couples (n = 88) took part in a longitudinal study that included an observation task. Couples completed questionnaires at three assessment times, namely approximately three, five, and nine months after diagnosis. The current study reports on the first (i.e., acute phase) and last (i.e., post-treatment phase) assessments. The couples received an information letter and an informed consent form during an outpatient visit from their physician or nurse. A research assistant was available by phone to answer potential questions about the study.

Couples who returned the consent form to the investigators were contacted by phone and received a baseline questionnaire. The research procedures were approved by the Medical Ethical Committees of all hospitals involved.

Patients with colorectal cancer were eligible if they were waiting for treatment or recently underwent surgery, were currently in an intimate relationship, and were between 18 and 75 years of age. Inclusion criteria for couples were fluency in Dutch, no documented hearing or cognitive impairments, and informed consent of both partners. A total of 280 couples were eligible, of which 88 expressed a willingness to participate and filled out the baseline questionnaire. Comparisons between patients who declined participation and those who participated did not show sex, $Chi^2(1, 260) = 1.08$, $p = .30$, nor age differences, $t(236) = 1.82$, $p = .07$. Follow-up data are available for 70 couples. Comparisons between couples who completed the follow-up assessment and those who were lost to follow up revealed no significant differences in any of the baseline variables under study.

The sample includes 29 female patients and 59 male patients and their partners. Most couples were married (88%) and the mean length of their relationship was 33 years (*SD* = 13; range = 4 – 56). Patients and partners had a mean age of 61 (*SD* = 10.0). The level of education of participants varied from elementary school to university degree: 12% finished elementary school only, 60% received secondary education, and 27% received higher vocational education or a university degree. About 18% of the participants had a paid job. The majority of the men were retired (51% of the patients, 69% of the partners), whereas the modal occupation for women was homemaker (38% of the patients, 34% of the partners).

Fifty percent of the patients were diagnosed with colon cancer and the other half with rectal cancer. The stage of the cancer varied: 19% stage I, 29% stage II, 45% stage III and 7% stage IV. The majority (n = 55; 63%) of the patients had received surgery and 20 of these patients received a colostomy. Forty patients were scheduled to have an (other) operation in the near future, of which (at least) 12 would receive a colostomy. About 36% of the patients had received or were still undergoing chemotherapy (n = 8), radiotherapy (n = 18), or chemoradiation (n = 4). Most patients reported that they believed they had a reasonable (28%) to high (68%) chance of being cured. The majority of the patients reported co-morbidities (61%) and many partners (85%) also indicated health complaints, such as hypertension, chronic back pain, and arthritis.

Measures

Spousal Active Engagement and Protective Buffering. Both patients and partners were asked to estimate to what extent the other one currently adopts active engagement and protective buffering strategies (e.g., patient active engagement is rated by the partner and partner active engagement is rated by the patient) in coping with the cancer experience. These measures were developed by Buunk, Berkhuysen, Sanderman, Nieuwland, and Ranchor (1996) and have been used extensively (De Ridder, Schreurs, & Kuijer, 2005; Hagedoorn et al., 2000; Hinnen et al., 2008; Hinnen, Hagedoorn, Sanderman, & Ranchor, 2007; Kuijer et al., 2000). The active engagement scale consists of five items (e.g. 'My partner asks me how I feel' and 'My partner tries to discuss it with me openly') and six items measure protective buffering (e.g. 'My partner just waves my worries aside' and 'My partner tries to act as if nothing is the matter'). All items were answered on a five-point scale ranging from *never* (1) to *very often* (5). Cronbach's alpha for the spousal active engagement scale was .83 (patients) and .85 (partners). Cronbach's alpha for the spousal protective buffering scale was .68 (patients) and .79 (partners).

Past Spousal Supportiveness. Participants completed the Mutual Communal Behaviors Scale (MCBS; Williamson & Schulz, 1995; Williamson, Shaffer, & Schulz, 1998). The MCBS consists of five items that evaluate past communal behaviors directed toward the other individual (e.g., "If my partner was feeling bad, I tried to cheer him/her up," "I went out of my way to help my partner ") and five items that evaluate past communal behaviors directed toward the respondent (e.g., "My partner seemed to enjoy responding to my needs," "My partner did things just to please me"). Participants were instructed to indicate the frequency of these behaviors before the cancer diagnosis on a four-point scale ranging from *never* (1) to *always* (4). The MCBS has good psychometric properties and is stable over time (Williamson & Schulz, 1995). A factor analysis of the current data supported the two factor structure (explaining 57% of the variance), indicating a factor for provided communal behavior (eigenvalue = 1.139) and one for received communal behavior (eigenvalue = 4.560). We used the latter factor as an indicator of past spousal supportiveness (α = .80 for patients; .83 for partners).

Relationship satisfaction. Participants' relationship satisfaction was assessed with the marital quality subscale of the Maudsley Marital Questionnaire (MMQ; Arrindell, Boelens, & Lambert, 1983; Crowe, 1978). This scale consists of 10 items, such as "Do you get enough warmth and understanding from your partner?", "How often do you consider divorcing your partner?". The items were answered on 9-point scales (ranging from 0 to 8), with higher scores indicating higher levels of satisfaction. The scale showed high internal consistency for both patients (α = .91 at baseline and .88 follow-up) and partners (α = .91 at baseline and .92 at follow-up).

Data Analysis

Analyses were done using HLM v6 software (Raudenbush & Bryk, 2002) and employed the dyadic data analytic approaches described by Kenny, Kashy, and Cook (2006). All data were centered around the sample mean prior to applying the files to the HLM v6 package (Kenny, Kashy, & Cook, 2006; Kreft, Deleeuw, & Aiken, 1995) and two dummy coded variables were created, one for patients (1=patient, 0=partner) and one for partners (1=partner, 0=patient) (Laurenceau & Bolger, 2005). Next, we created separate predictor variables for patients and partners by multiplying each level 1 predictor variable by the dummy coded variables. Within the statistical package HLM, data were entered uncentered for each equation. The general intercept was removed and replaced with the dummy coded variables ‘patients’ and ‘partners’ (Kenny et al., 2006; Laurenceau & Bolger, 2005). Using this approach, we examined associations between current spousal supportive behavior (CSSB) and relationship satisfaction (RS) for patients and their partners within the same model. Past spousal supportiveness (PSS) was included as a moderator and we performed separate analyses for active engagement and protective buffering. The model is presented as following:

$$\begin{aligned} RS_{ij} = {} & B_{0j}(Patient) + B_{0j}(Partner) + B_{1j}CSSB_{Patient} \\ & + B_{1j}CSSB_{Partner} + B_{2j}PSS_{Patient} + B_{2j}PSS_{Partnert} \\ & + B_{3j}CSSB{*}PSS_{Patient} + B_{3j}CSSB{*}PSS_{Partner} + eij \end{aligned}$$

In the longitudinal analyses, relationship satisfaction at follow-up was predicted by baseline current spousal supportive behavior (i.e., active engagement or protective buffering) and past spousal supportiveness, and their interaction, controlling for baseline relationship satisfaction.

Results

Bivariate Associations

Correlations among the variables under study are presented in Table 1. Sex and role differences were found only for spousal active engagement. Specifically, male patients (M = 4.15, SD = 0.60) reported higher levels of spousal active engagement than did female patients (M = 3.74, SD = 0.77), $t(86)$ = 2.76, p = .007. In addition, patients reported higher levels of spousal active engagement than did partners, $F(1, 86)$ = 5.34, p = .023. Demographic and illness variables, including age, education, duration of the relationship, type of cancer (i.e., colon or rectal cancer), cancer stage, surgery before baseline (yes/no), were not related to any of the study variables.

Table 1 Pearson Correlations, Means and standard deviations for the variables under study

	1	**2**	**3**	**4**	**5**	***Mean***	***SD***
1. Past Spousal Supportiveness	**.41*****	.36***	-.08	.45***	.58***	3.12	0.51
2. Spousal Active Engagement	.48***	**.32****	-.54***	.41***	.49***	4.01	0.68
3. Spousal Protective Buffering	-.12	-.51***	**.27***	-.24*	-.42***	2.24	0.62
4. Relationship Satisfaction at Baseline	.65***	.58***	-.32**	**.30****	.85***	7.00	1.04
5. Relationship Satisfaction at Follow-Up	.53***	.53***	-.17	.69***	**.36****	6.87	1.09
Mean	3.05	3.81	2.16	6.89	6.79		
SD	0.54	0.67	0.69	0.98	1.05		

Note. Patient statistics are presented above the diagonal and partner statistics below the diagonal. Correlations between patient and partner variables are presented on the diagonal.

$^{*}p < .05$, $^{**}p < .01$, $^{***}p < .001$

Cross-sectional Analyses

Spousal Active Engagement and Past Spousal Supportiveness. The first analysis revealed main effects for active engagement and past spousal supportiveness. Specifically, patients as well as partners who reported more spousal active engagement, $B_{patients} = 0.42$, $SE = 0.14$, $t(164) = 3.00$, $p = .004$, ES $r = .23$ and $B_{partners} = 0.50$, $SE = 0.16$, $t(164) = 3.22$, $p = .002$, ES $r = .29$, and more past spousal supportiveness, $B_{patients} = 0.87$, $SE = 0.27$, $t(164) = 3.26$, $p = .002$, ES $r = .25$ and $B_{partners} = 0.81$, $SE = 0.16$, $t(164) = 5.03$, $p < .001$, ES $r = .37$, were more satisfied with their relationships (see Table 2). Importantly, these main effects were qualified by a two-way interaction between spousal active engagement and past spousal supportiveness, $B_{patients} = -0.86$, $SE = 0.35$, $t(164) = -2.50$, $p = .014$, ES $r = .19$ and $B_{partners} = -0.47$, $SE = 0.20$, $t(164) = -2.35$, $p = .020$, ES $r = .18$. To better understand these interactions, we calculated the simple slopes for the associations between spousal active engagement and relationship satisfaction at two levels of past spousal supportiveness (i.e., ± 1 standard deviation from its mean) for patients and partners, separately. As depicted in Figure 1, spousal active engagement was associated with greater relationship satisfaction in patients if past spousal supportiveness was relatively low, $B = 0.88$, $SE = 0.28$, $t(164) = 3.14$, $p = .002$. This association was not significant if spousal active engagement was relatively high, $B = -0.03$, $SE = 0.17$, $t(164) = -0.17$, $p = 0.867$. In other words, especially the combination of low levels of spousal active engagement and low past spousal supportiveness was associated with relatively low levels of relationship satisfaction. The same pattern was found for partners, that is spousal active engagement was associated with greater relationship satisfaction in partners if past spousal supportiveness was relatively low, $B = 0.75$, $SE = 0.20$, $t(164) = 3.71$, $p < .001$. This association was not significant if spousal active engagement was relatively high, $B = 0.26$, $SE = 0.17$, $t(164) = 1.49$, $p = 0.139$.

Spousal Protective Buffering and Past Spousal supportiveness. In addition to the main effects of past spousal supportiveness reported above, this analysis also revealed main effects for spousal protective buffering, although only approaching significance for patients. Patients, $B = -0.34$, $SE = 0.18$, $t(162) = -1.92$, $p = .057$, ES $r = .15$, and partners, $B = -0.34$, $SE = 0.12$, $t(162) = -2.93$, $p = .004$, ES $r = .22$, who reported more protective buffering by the spouse reported less relationship satisfaction. The results also showed an interaction effect for patients, $B = 1.10$, $SE = 0.41$, $t(162) = 2.67$, $p = .009$, ES $r = .21$, but not for partners, $B = 0.25$, $SE = 0.28$, $t(162) = 0.87$, $p = .387$, ES $r = .07$. As depicted in Figure 2, spousal protective buffering was associated with lower relationship satisfaction in patients if past spousal supportiveness was relatively low, $B = -0.92$, $SE = 0.26$, $t(162) = -3.54$, $p = .001$. This association was not significant if past spousal supportiveness was relatively high, $B = 0.23$, $SE = 0.30$, $t(162) = 0.780$, $p = .437$. In other words, the combination of high levels of spousal protective buffering and low past spousal supportiveness was especially associated with relatively low levels of relationship satisfaction.

Figure 1 Association between spousal active engagement and relationship satisfaction at baseline in patients as a function of past spousal supportiveness

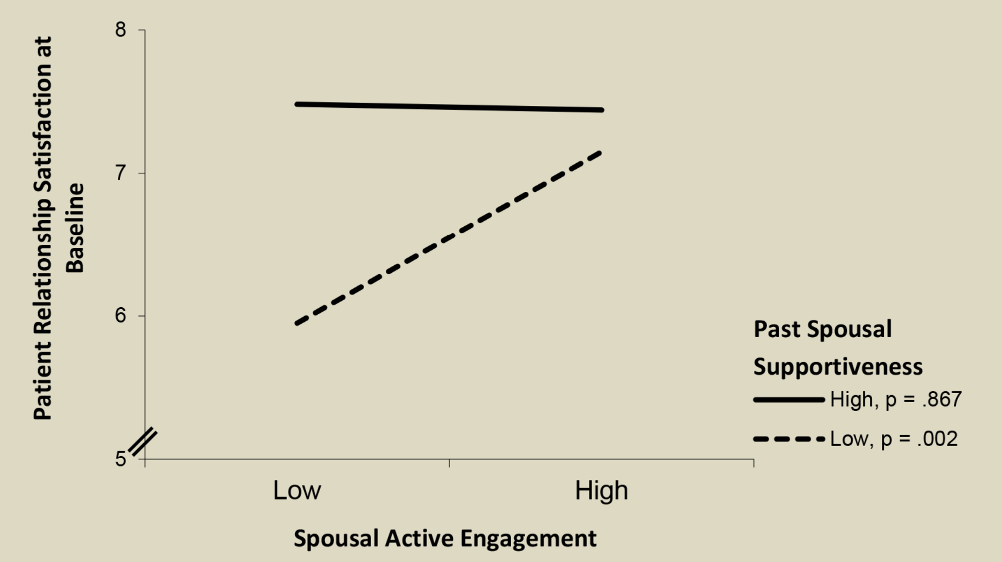


Figure 2 Association between spousal protective buffering and relationship satisfaction at baseline in patients as a function of past spousal supportiveness

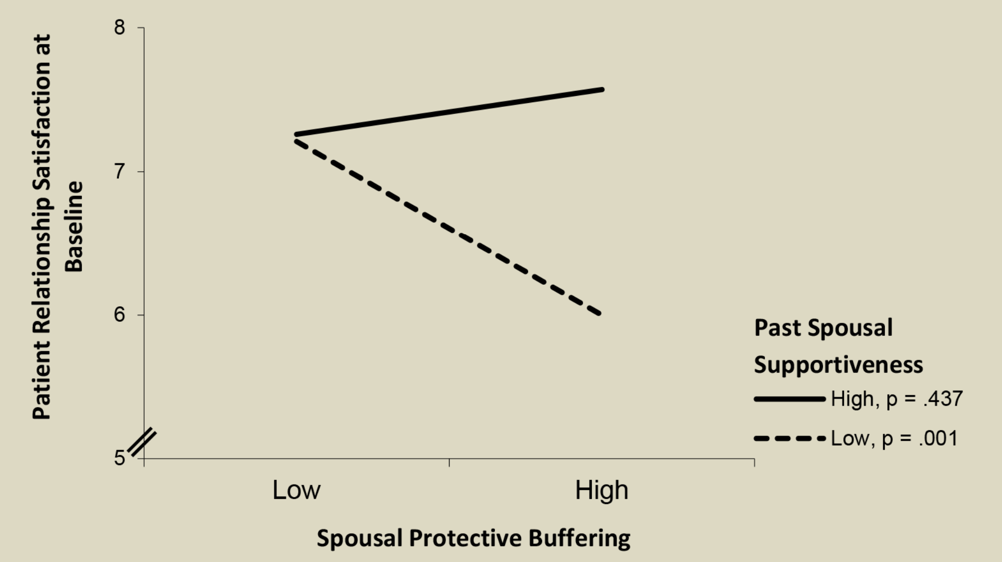


Table 2 Hierarchical Linear Model (HLM): Concurrent associations between spousal support and relationship satisfaction as a function of past spousal supportiveness

	Patient Relationship Satisfaction					**Partner Relationship Satisfaction**				
	B	**SE**	**t**	**p**	**ES (r)**	**B**	**SE**	**t**	**p**	**ES (r)**
Active Engagement Analysis[a]										
Intercept	7.00	0.09	75.02	<.001	-	7.00	0.08	87.20	<.001	-
Past Spousal Supportiveness (PSS)	0.87	0.27	3.26	.002	.25	0.81	0.16	5.03	<.001	.37
Spousal Active Engagement (SAE)	0.42	0.14	3.00	.004	.23	0.50	0.16	3.22	.002	.29
PSS x SAE	-0.86	0.35	-2.50	.014	.19	-0.47	0.20	-2.35	.020	.18
Protective Buffering Analysis[b]										
Intercept	7.01	0.09	81.18	<.001	-	6.91	0.08	90.19	<.001	-
Past Spousal Supportiveness (PSS)	0.77	0.26	2.94	.004	.23	1.14	0.17	6.68	<.001	.46
Spousal Protective Buffering (SPB)	-0.34	0.18	-1.92	.057	.15	-0.34	0.12	-2.93	.004	.22
PSS x SPB	1.10	0.41	2.67	.009	.21	0.25	0.28	0.87	.387	.07

Note. Effect size r for each t was computed with the following equation: r = sqrt[t2/(t2+df)]. [a] df = 164; [b] df = 162

Longitudinal Analyses

Spousal Active Engagement and Past Spousal Supportiveness. The first prospective analysis revealed no effects other than a main effect of relationship satisfaction at baseline, for both patients, $B = 0.84$, $SE = 0.14$, $t(131) = 6.07$, $p < .001$, ES $r = .47$, and partners, $B = 0.64$, $SE = 0.23$, $t(131) = 2.83$, $p = .006$, ES $r = .24$ (see Table 3).

Spousal Protective Buffering and Past Spousal Support. In addition to the main effect of relationship satisfaction at baseline, the second prospective analysis yielded a significant main effect of spousal protective buffering for patients, $B = -0.29$, $SE = 0.13$, $t(130) = -2.16$, $p = .033$, ES $r = .19$. This finding indicates that more spousal protective buffering at baseline was associated with less future satisfaction in patients. For partners, we found an interaction between protective buffering and past spousal supportiveness, $B = -0.67$, $SE = 0.25$, $t(130) = -2.73$, $p = .008$, ES $r = .23$. As depicted in Figure 3, spousal protective buffering at baseline was associated with lower future relationship satisfaction in partners if past spousal supportiveness was relatively high, $B = -0.37$, $SE = 0.12$, $t(130) = -3.13$, $p = .003$. This association was not significant if partner past spousal supportiveness was relatively low, $B = 0.34$, $SE = 0.21$, $t(130) = 1.64$, $p = .102$. These findings suggest that instead of mitigating the negative association between spousal protective buffering and relationship satisfaction, past spousal supportiveness strengthens this negative association over time.

Figure 3 Association between spousal protective buffering and relationship satisfaction at follow-up in partners as a function of past spousal supportiveness, controlling for baseline relationship satisfaction

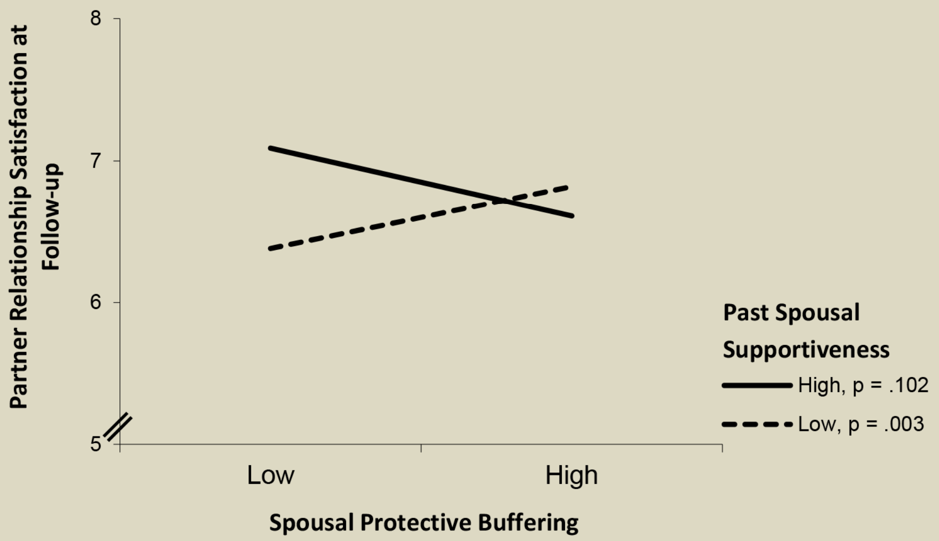


Table 3 Hierarchical Linear Model (HLM): Prospective associations between spousal support and future relationship satisfaction as a function of past spousal supportiveness

	Patient Relationship Satisfaction at Follow-up					Partner Relationship Satisfaction at Follow-up				
	B	**SE**	**t**	**p**	**ES (r)**	**B**	**SE**	**t**	**p**	**ES (r)**
Active Engagement Analysis[a]										
Intercept	6.71	0.09	76.08	<.001	-	6.73	0.11	59.00	<.001	-
Baseline Relationship Satisfaction	0.84	0.14	6.07	<.001	.47	0.64	0.23	2.83	.006	.24
Past Spousal Supportiveness (PSS)	0.12	0.25	0.49	.623	.04	0.31	0.25	1.24	.219	.11
Spousal Active Engagement (SAE)	0.12	0.13	0.88	.378	.08	0.18	0.20	0.91	.363	.08
PSS x SAE	-0.10	0.31	-0.33	.739	.03	0.15	0.28	0.54	.591	.05
Protective Buffering Analysis[b]										
Intercept	6.73	0.07	89.83	<.001	-	6.73	0.09	76.42	<.001	-
Baseline Relationship Satisfaction	0.81	0.12	6.71	<.001	.51	0.70	0.19	3.73	<.001	.31
Past Spousal Supportiveness (PSS)	0.19	0.18	1.03	.304	.09	0.24	0.24	1.03	.308	.09
Spousal Protective Buffering (SPB)	-0.29	0.13	-2.16	.033	.19	-0.01	0.11	-0.13	.897	.01
PSS x SPB	0.01	0.17	0.05	.961	<.01	-0.67	0.25	-2.73	.008	.23

Note. Effect size r for each t was computed with the following equation: r = sqrt[t2/(t2+df)]. [a] df = 131; [b] df = 130

Discussion

The goal of the current study was to examine the role of past spousal supportiveness as a moderator of the link between current spousal supportive behavior and relationship satisfaction in couples coping with cancer. Overall, the cross-sectional findings are in line with the proposed mitigating effect of past spousal support. Specifically, spousal active engagement was associated with greater relationship satisfaction in patients and partners only if past spousal supportiveness was relatively low. In a similar vein, we found that spousal protective buffering was associated with lower relationship satisfaction in patients only if past spousal supportiveness was relatively low. Put differently, in the context of low spousal supportiveness, individuals reported low levels of relationship satisfaction if current spousal active engagement was low and/or current spousal protective buffering was high. If past spousal support was high, both patients and partners rated the quality of their relationship relatively high, regardless of their spouses’ current supportive behavior.

As we pointed out in the introduction, previous research has shown that individuals who perceived overall support to be high interpreted the same current behaviors of a significant other as more supportive than did individuals who perceived overall support to be low (Lakey & Cassady, 1990; Lakey & Dickinson, 1994; Pierce et al., 1992; Ross et al., 1999). Such an attributional process in which general perceptions of the spouse or the relationship influence the interpretation of current behaviour could explain our results. Individuals who felt highly supported by their spouse in the past –i.e., before the cancer diagnosis– may have made benign attributions for their partners' current behavior. Specifically, they may have ascribed the high levels of active engagement and low levels of protective buffering to stable characteristics of the spouse, while low levels of active engagement and high levels of protective buffering were ascribed to external causes. Such a benign attribution would enable individuals to maintain their relationship satisfaction by allowing or sustaining the belief that the necessary spousal support will be forthcoming in the future.

With respect to spousal protective buffering, we found the hypothesized effect for patients, but not for partners. Perhaps the psychosocial oncological context provides an explanation. At baseline, the couples were still in the acute phase, during which the patient was recovering from treatment or still undergoing treatment. At this time, the caregiving role may have been especially salient for partners. More specifically, partners may have felt a strong need to take care of the patient. In order to fulfill their caregiving role, however, partners may depend on their ill spouses for information about patients’ worries, feelings, and needs. Therefore, partners who perceived relatively high levels of spousal protective buffering may have felt thwarted in their efforts to fulfill the caregiving role, even if they perceived past spousal supportiveness to be relatively high. As a consequence, partners who perceived relatively high levels of spousal protective buffering may have felt less satisfied with their relationship than partners who perceived relatively low levels of spousal protective buffering.

We should use caution when interpreting the longitudinal findings as these were less consistent. Specifically, spousal active engagement was not found to be associated with changes in marital satisfaction, while spousal protective buffering was, albeit the pattern of results differed somewhat for patients and partners. Future relationship satisfaction in patients was lower if their partners used relatively high levels of protective buffering, regardless of whether their partners had been supportive in the past. The follow-up assessment reflects the period in which patients generally try to resume normal life. Perhaps, this is more difficult for patients who perceived relatively high levels of spousal protective buffering during treatment. These patients may hold their partners partly responsible for having difficulty to come to terms with their disease which is reflected in lower relationship satisfaction scores. Our findings suggest that the shutting down of lines of communication represented by high levels of protective buffering leave long lasting effects on patients perceptions of their relationships. On the other hand, our findings for active engagement indicate that the effects are limited to the acute phase, suggesting that the negative effects of a partner’s failure to engage in active engagement may be time-limited and easier for patients to recover from once the acute period of need is over. For partners, it appears that over time the negative association between protective buffering and marital satisfaction was even stronger if patients had been supportive in the past. Those partners who perceived their spouses as supportive prior to diagnosis and as low in protective buffering post-diagnosis evidenced the highest levels of relationship satisfaction. Overall, the longitudinal findings seem to suggest that there are limits to individuals’ tendency to use benign attributions and to show forgiveness for their partners’ unresponsiveness.

Relatively few previous studies have examined associations of active engagement and protective buffering in relation to relationship satisfaction over time, and these have reported nonsignificant associations in a sample of patients with breast cancer (Hinnen et al., 2008), a sample of couples in which one partner received a hematopoietic stem cell transplantation (Langer et al., 2009), and a sample of healthy couples (Bodenmann et al., 2006). Obviously, further longitudinal work is needed to fully understand possible consequences of spousal behavior, such as active engagement and protective buffering –possibly in combination with spousal supportiveness before the onset of illness– on marital functioning over time.

This study has several noteworthy strengths, such as a longitudinal design and data obtained from both members of couples coping with colorectal cancer, which were analyzed taking into account their interdependency. However, this study has also some limitations. First, although our cross-sectional findings are in line with our hypotheses based on attributional processes in marriage, we did not measure the participants' attributions regarding current spousal supportive behavior. Second, the retrospective assessment of past spousal support may have influenced the findings. It may be that participants' perceptions of past spousal support are colored by their perceptions of current spousal behavior. In other words, the retrospective assessment of past spousal support may have increased the associations with current spousal behavior. Third, the response rate was not very high, which may have introduced some bias. Perhaps only couples who showed high marital functioning participated in our study. However, there are no indications that this was the case. Specifically, the scores of our sample on relationship satisfaction were comparable to the scores of a reference group of Dutch adults (Schroevers, Ranchor, & Sanderman, 2004). Furthermore, it points out a broader problem recognized in this literature, namely that it is difficult to recruit couples; it is not uncommon for studies of couples dealing with cancer, especially longitudinal and observational studies, to report relatively low response rates (Badr & Taylor, 2009; Hinnen, Ranchor, Sanderman, Snijders, Hagedoorn, & Coyne, 2008; Langer et al., 2009; Manne et al., 2004). Nevertheless, replication in larger studies with higher response rates that include measurements of the attributional process would be an important next step to further increase our knowledge of dyadic coping with cancer.

To conclude, our cross-sectional results indicate that relationship satisfaction can be maintained if past spousal supportiveness is high, even if the partner is currently not very responsive to the individual’s needs. However in the long run, hiding concerns and minimizing the other partner’s concerns appears to be harmful in that it is negatively associated with future relationships satisfaction. Therefore, it may be helpful to encourage couples to be actively engaged and to reduce protective buffering. Indeed, previous intervention studies for couples dealing with cancer that focused on dyadic coping have shown that both relationship satisfaction and emotional well-being may improve in patients and their partners (Baucom et al., 2009; Kuijer, Buunk, De Jong, Ybema, & Sanderman, 2004). Overall, our research supports the idea that dyadic coping processes should be understood in the interpersonal context in which these occur.

Reference List

Arrindell, W. A., Boelens, W., & Lambert, H. (1983). On the psychometric properties of the Maudsley Marital Questionnaire (MMQ): Evaluation of self-ratings in distressed and 'normal' volunteer couples based on the Dutch version. *Personality and Individual Differences, 4,* 293-306.

Badr, H. & Taylor, C. L. C. (2009). Sexual dysfunction and spousal communication in couples coping with prostate cancer. *Psycho-Oncology, 18,* 735-746.

Baucom, D. H., Porter, L. S., Kirby, J. S., Gremore, T. M., Wiesenthal, N., Aldridge, W., Fredman, S. J. et al. (2009). A couple-based intervention for female breast cancer. *Psycho-Oncology, 18,* 276-283.

Berg, C. A. & Upchurch, R. (2007). A developmental-contextual model of couples coping with chronic illness across the adult life span. *Psychological Bulletin, 133,* 920-954.

Bodenmann, G., Pihet, S., & Kayser, K. (2006). The relationship between dyadic coping and marital quality: A 2-year longitudinal study. *Journal of Family Psychology, 20,* 485-493.

Bradbury, T. N., Campbell, S. M., & Fincham, F. D. (1995). Longitudinal and behavioral-analysis of masculinity and femininity in marriage. *Journal of Personality and Social Psychology, 68,* 328-341.

Bradbury, T. N. & Fincham, F. D. (1990). Attributions in marriage - Review and critique. *Psychological Bulletin, 107,* 3-33.

Bradbury, T. N., Fincham, F. D., & Beach, S. R. H. (2000). Research on the nature and determinants of marital satisfaction: A decade in review. *Journal of Marriage and the Family, 62,* 964-980.

Bradbury, T. N. & Karney, B. R. (1993). Longitudinal-study of marital interaction and dysfunction - Review and analysis. *Clinical Psychology Review, 13,* 15-27.

Buunk, B. P., Berkhuysen, M. A., Sanderman, R., Nieuwland, W., & Ranchor, A. V. (1996). Actieve betrokkenheid, beschermend bufferen en overbescherming: Meetinstrumenten voor de rol van de partner bij hartrevalidatie. [The role of the partner in heart disease: Active engagement, protective buffering, and overprotection]. *Gedrag & Gezondheid, 24,* 304-313.

Christensen, A. & Heavey, C. L. (1990). Gender and social-structure in the demand withdraw pattern of marital conflict. *Journal of Personality and Social Psychology, 59,* 73-81.

Coyne, J. C. & DeLongis, A. (1986). Going beyond social support - the role of social relationships in adaptation. *Journal of Consulting and Clinical Psychology, 54,* 454-460.

Crowe, M. J. (1978). Conjoint marital-therapy - controlled outcome study. *Psychological Medicine, 8,* 623-636.

De Ridder, D. T. D., Schreurs, K. M. G., & Kuijer, R. G. (2005). Is spousal support always helpful to patients with asthma or diabetes? A prospective study. *Psychology & Health, 20,* 497-508.

Fincham, F. D. & Bradbury, T. N. (1987). The impact of attributions in marriage - A longitudinal analysis. *Journal of Personality and Social Psychology, 53,* 510-517.

Fincham, F. D. & Bradbury, T. N. (1993). Marital satisfaction, depression, and attributions - A longitudinal analysis. *Journal of Personality and Social Psychology, 64,* 442-452.

Fincham, F. D., Bradbury, T. N., Arias, I., Byrne, C. A., & Karney, B. R. (1997). Marital violence, marital distress, and attributions. *Journal of Family Psychology, 11,* 367-372.

Graham, J. M. & Conoley, C. W. (2006). The role of marital attributions in the relationship between life stressors and marital quality. *Personal Relationships, 13,* 231-241.

Hagedoorn, M., Kuijer, R. G., Buunk, B. P., Dejong, G. M., Wobbes, T., & Sanderman, R. (2000). Marital satisfaction in patients with cancer: Does support from intimate partners benefit those who need it the most? *Health Psychology, 19,* 274-282.

Hagedoorn, M., Sanderman, R., Bolks, H. N., Tuinstra, J., & Coyne, J. C. (2008). Distress in couples coping with cancer: A meta-analysis and critical review of role and gender effects. *Psychological Bulletin, 134,* 1-30.

Heider, F. (1958). *The psychology of interpersonal relations*. New York: John Wiley.

Henry, N. J. M., Berg, C. A., Smith, T. W., & Florsheim, P. (2007). Positive and negative characteristics of marital interaction and their association with marital satisfaction in middle-aged and older couples. *Psychology and Aging, 22,* 428-441.

Hinnen, C., Hagedoorn, M., Ranchor, A. V., & Sanderman, R. (2008). Relationship satisfaction in women: A longitudinal case-control study about the role of breast cancer, personal assertiveness, and partners' relationship-focused coping. *British Journal of Health Psychology, 13,* 737-754.

Hinnen, C., Hagedoorn, M., Sanderman, R., & Ranchor, A. V. (2007). The role of distress, neuroticism and time since diagnosis in explaining support behaviors in partners of women with breast cancer: results of a longitudinal analysis. *Psycho-Oncology, 16,* 913-919.

Hinnen, C., Ranchor, A. V., Sanderman, R., Snijders, T. A. B., Hagedoorn, M., & Coyne, J. C. (2008). Course of distress in breast cancer patients, their partners, and matched control couples. *Annals of Behavioral Medicine, 36,* 141-148.

Holtzworth-Munroe, A. & Jacobson, N. S. (1985). Causal attributions of married-couples - When do they search for causes - What do they conclude when they do. *Journal of Personality and Social Psychology, 48,* 1398-1412.

Karney, B. R. & Bradbury, T. N. (2000). Attributions in marriage: State or trait? A growth curve analysis. *Journal of Personality and Social Psychology, 78,* 295-309.

Kenny, D. A., Kashy, D. A., & Cook, W. L. (2006). *Dyadic data analysis*. New York: Guilford Press.

Kreft, I. G. G., Deleeuw, J., & Aiken, L. S. (1995). The effect of different forms of centering in hierarchical linear-models. *Multivariate Behavioral Research, 30,* 1-21.

Kuijer, R. G., Buunk, B. P., De Jong, G. M., Ybema, J. F., & Sanderman, R. (2004). Effects of a brief intervention program for patients with cancer and their partners on feelings of inequity, relationship quality and psychological distress. *Psycho-Oncology, 13,* 321-334.

Kuijer, R. G., Ybema, J. F., Buunk, B. P., De Jong, G. M., Thijs-Boer, F., & Sanderman, R. (2000). Active engagement, protective buffering, and overprotection: Three ways of giving support by intimate partners of patients with cancer. *Journal of Social and Clinical Psychology, 19,* 256-275.

Lakey, B. & Cassady, P. B. (1990). Cognitive-processes in perceived social support. *Journal of Personality and Social Psychology, 59,* 337-343.

Lakey, B. & Dickinson, L. G. (1994). Antecedents of perceived support - Is perceived family environment generalized to new social relationships. *Cognitive Therapy and Research, 18,* 39-53.

Langer, S. L., Brown, J. D., & Syrjala, K. L. (2009). Intrapersonal and interpersonal consequences of protective buffering among cancer patients and caregivers. *Cancer, 115,* 4311-4325.

Laurenceau, J. P. & Bolger, N. (2005). Using diary methods to study marital and family processes. *Journal of Family Psychology, 19,* 86-97.

Manne, S. & Badr, H. (2008). Intimacy and relationship processes in couples' psychosocial adaptation to cancer. *Cancer, 112,* 2541-2555.

Manne, S., Ostroff, J., Sherman, M., Heyman, R. E., Ross, S., & Fox, K. (2004). Couples' support-related communication, psychological distress, and relationship satisfaction among women with early stage breast cancer. *Journal of Consulting and Clinical Psychology, 72,* 660-670.

McNulty, J. K. & Karney, B. R. (2001). Attributions in marriage: Integrating specific and global evaluations of a relationship. *Personality and Social Psychology Bulletin, 27,* 943-955.

Pierce, G. R., Sarason, B. R., & Sarason, I. G. (1992). General and specific support expectations and stress as predictors of perceived supportiveness - An experimental study. *Journal of Personality and Social Psychology, 63,* 297-307.

Raudenbush, S. W. & Bryk, A. S. (2002). *Hierarchical linear models: Applications and data analysis methods (Second Edition)*. Newbury Park, CA: Sage.

Ross, L. T., Lutz, C. J., & Lakey, B. (1999). Perceived social support and attributions for failed support. *Personality and Social Psychology Bulletin, 25,* 896-908.

Schroevers, M. J., Ranchor, A. V., & Sanderman, R. (2004). The role of age at the onset of cancer in relation to survivors' long-term adjustment: A controlled comparison over an eight-year period. *Psycho-Oncology, 13,* 740-752.

Waldinger, R. J. & Schulz, M. S. (2006). Linking hearts and minds in couple interactions: Intentions, attributions, and overriding sentiments. *Journal of Family Psychology, 20,* 494-504.

Williamson, G. M. & Schulz, R. (1995). Caring for a family member with cancer - past communal behavior and affective reactions. *Journal of Applied Social Psychology, 25,* 93-116.

Williamson, G. M., Shaffer, D. R., & Schulz, R. (1998). Activity restriction and prior relationship history as contributors to mental health outcomes among middle-aged and older spousal caregivers. *Health Psychology, 17,* 152-162.

Wunderer, E. & Schneewind, K. A. (2008). The relationship between marital standards, dyadic coping and marital satisfaction. *European Journal of Social Psychology, 38,* 462-476.

I promise to support you in times of sickness and in times of health

Chapter 3

Spousal Support and Changes in Distress Over Time in Couples Coping with Cancer: The Role of Personal Control

Meirav Dagan
Robbert Sanderman
Marike C. Schokker
Theo Wiggers
Peter C. Baas
Michiel van Haastert
Mariët Hagedoorn

Journal of Family Psychology, (2011), 25, 310-318

A cancer diagnosis can be stressful and upsetting for patients as well as their partners. More specifically, it has been shown that both members of a couple may be emotionally affected by a cancer diagnosis (Hagedoorn, Buunk, Kuijer, Wobbes, & Sanderman, 2000; Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008). Over time, however, most patients and partners adapt well (Hinnen, Ranchor, Baas, Sanderman, & Hagedoorn, 2009). Social support has long been considered one of the most important factors in this adaptation process. For the most part, studies have indeed demonstrated a positive association between social support and well-being (e.g., Blaney et al., 1997; Demange et al., 2004; Helgeson & Cohen, 1996). Moreover, intimate partners are especially important sources of support. In fact, findings suggest that support from acquaintances cannot compensate for a lack of spousal support (Coyne & DeLongis, 1986). According to the developmental contextual coping model developed by Berg and Upchurch (2007), patients' appraisals of their illness and its consequences, and their adjustment to this are influenced by their partners, and vice versa. Furthermore, it has been recognized that, in couples dealing with cancer, both the patients and their partners should be considered as recipients as well as providers of support (Badr, Carmack, Kashy, Cristofanilli, & Revenson, 2010; Manne & Badr, 2008). Despite this understanding, to date only a few empirical studies have addressed this issue on a dyadic level. More specifically, the majority of the studies have treated the patient as the focal person and the partner as a source of support (Berg & Upchurch, 2007). In the present study, we applied a dyadic approach by examining whether perceived spousal supportive and unsupportive behavior[1] shortly after a cancer diagnosis is associated with changes in distress over time in both patients and their partners.

Marital interactions may entail both supportive and unsupportive spousal behavior (e.g., Hagedoorn, Sanderman, Buunk, & Wobbes, 2002; Hinnen et al., 2009; Manne, 1999). It has been suggested that when investigating psychological outcomes among persons with cancer, researchers need to pay attention to the impact of unsupportive spousal behavior rather than merely focusing on the positive aspect of social support (cf. Manne, Taylor, Dougherty, & Kemeny, 1997). Furthermore, unsupportive spousal behavior has been found to have a greater impact than supportive spousal behavior on psychological distress in both healthy persons (Vinokur & Van Ryn, 1993) and in persons diagnosed with cancer (Manne et al., 1997). Therefore, we were interested in the associations between perceived supportive as well as unsupportive spousal behavior and changes in distress over time.

It is an oversimplification of reality to assume that if only partners were more supportive and helpful, couples' levels of distress would be alleviated. Some researchers have suggested that people may vary in terms of the extent to which they are able to benefit from having a supportive partner (e.g., Hinnen et al., 2009; Reich & Zautra, 1991). Therefore, one possible way to obtain greater insight into support processes is to take a closer look at the possible moderators of the support-distress association (cf. Frazier, Tix, & Barnett, 2003; Martire, Stephens, Druley, & Wojno, 2002; Pearlin, Menaghan, Lieberman, & Mullan, 1981; Reich & Zautra, 1991). Previous literature has suggested that individuals' sense of personal control or mastery,[2] might be an important factor qualifying the support-distress association (e.g., Hinnen et al., 2009; VanderZee, Buunk, & Sanderman, 1997). Individuals' sense of personal control refers to the extent to which individuals believe that they are able to control or influence outcomes in their lives (Pearlin et al., 1981). Perceived personal control is neither just a dispositional characteristic nor only shaped by environmental factors (Peterson & Stunkard, 1989). It has been found to be relatively stable over time, but specific events either reinforce or weaken perceptions of control (Wolinsky, Wyrwich, Babu, Kroenke, & Tierney, 2003). For example, a cancer diagnosis, may exert a temporary negative effect on personal control (Ranchor et al., 2010). Some researchers have integrated the construct of personal control into different stress models in order to explain individual differences in terms of distress when dealing with stressful events (e.g., Pearlin & Pioli, 2003). In addition, there are a considerable number of studies which have shown that individuals who feel more control over their lives are less at risk for stress and depression than individuals who feel that they have less control (e.g., Badger, 2001; Ben-Zur, 2002; Stiegelis et al., 2003; VanderZee et al., 1997).

It has been suggested that people relatively high in control possess more of the coping skills and abilities required to resolve difficult circumstances than those relatively low in control (Dalgard, BjØrk, & Tambs, 1995). For example, people relatively high in control were found to report more adaptive coping strategies such as active coping (Ben-Zur, 2002; cf. Elfström & Kreuter, 2006; cf. Elliott, Trief, & Stein, 1986). Moreover, people relatively high in control may feel that they are able to resolve problems by themselves (cf. Rotter, 1966). Individuals relatively low in control, on the other hand, may feel rather powerless in terms of their ability to control outcomes by means of their own behavior and, therefore, may depend more on the support and help of their intimate partners. Indeed, it was found that people relatively low in control reported more use of coping strategies such as social reliance (Elfström & Kreuter, 2006). As a consequence, people relatively low in control can be expected to be more responsive to spousal behavior when dealing with difficult circumstances.

The few studies that have investigated the moderating role of perceived personal control in the support-distress association presented cross-sectional findings among patients (Hinnen et al., 2009) and the general population (VanderZee et al., 1997) as well as longitudinal results in the context of negative life events in the general population (Dalgard et al., 1995). Their findings are consistent with our line of reasoning. For example, it was demonstrated that only among people relatively low in control did social support reduce the risk of developing depression when exposed to stressful events (Dalgard et al., 1995). In addition, based on the concept of person-environment fit, it has been suggested that incongruence between the social environment, such as spousal supportive behavior, and the individual's characteristics, such as sense of personal control, may result in negative outcomes (Martire et al., 2002). We argue that for individuals relatively low in control, perceptions of unsupportive spousal behavior do not fit with their needs and, therefore, may result in relatively high levels of distress. One study provided some support for this notion by showing that, in the short term, women with breast cancer who received more negative support (i.e., unnoticed protective buffering) from their partners reported more distress than did women who received less negative support from their partners, but only when they were relatively low in control (Hinnen et al., 2009).

To the best of our knowledge, our study is the first to examine the sense of personal control as a moderator in the support-distress association longitudinally among couples, considering both patients' and partners' perspectives as recipients of spousal support. Our aim is to examine whether individuals relatively low in control might be identified as a target subgroup that would benefit from supportive spousal behavior the most, but would also be the subgroup most aversely affected by unsupportive behavior. In practice, this knowledge may lead to more optimal referrals of couples for specific interventions focusing on spousal support.

We tested the following hypotheses with respect to changes in the level of distress over time, using multi-level analytic techniques that take the interdependency between patients and partners into account. Our approach is novel in that we test our hypotheses for both patients and partners, treating both members of the dyad as support providers as well as support receivers. We hypothesize that perceived spousal supportive behavior is negatively associated with future distress, especially for those relatively low in personal control (Hypothesis 1). Perceived spousal unsupportive behavior is hypothesized to be positively associated with future distress, especially for those relatively low in personal control (Hypothesis 2). Overall, individuals relatively high in control are expected to report relatively low levels of distress regardless of their spouses' behavior.

Methods

Procedure and Participants

The participants were patients newly diagnosed with colorectal cancer and their intimate partners, recruited from eight hospitals in the north of the Netherlands. These couples (n = 70) took part in a longitudinal study on "couples' adaptation to cancer" and filled out questionnaires at two assessment points: approximately three (at baseline) and nine months (at follow-up) after diagnosis (Hagedoorn et al., 2011). Couples received the baseline questionnaire after they gave their informed consent. The research procedures were approved by the Medical Ethical Committees of all hospitals involved.

Out of 280 couples who met the eligibility criteria, which included being fluent in Dutch, having no documented hearing or cognitive impairments, and with informed consent given by both partners, 88 couples were willing to participate and went on to fill out the baseline questionnaire. We compared patients who declined participation with patients who participated and we found no gender, $Chi^2 (1, 260) = 1.08$, $p = .30$, or age differences, $t (236) = 1.82$, $p = .07$. Follow-up data was available for 70 heterosexual couples. Table 1 presents the demographic characteristics of patients and partners. We compared couples who completed the follow-up assessment to those who were lost to follow-up and found no significant differences in any of the baseline variables under study.

Measurements

Demographic and medical characteristics were retrieved from patients' medical files and from patients and partners own reports.

Perceived spousal supportive behavior and unsupportive behavior were measured at baseline with the two subscales of the Interaction of Social Support List (Kempen & Van Eijk, 1995; van Sonderen, 1993). Both partners were asked to indicate how often their partner engaged in supportive and unsupportive behavior towards them. The two subscales included four items for supportive behavior and seven items for unsupportive behavior. Examples of supportive items are: "Can you talk with your partner openly and share your feelings with him/her?" and "Does your partner give you daily practical support?" Unsupportive items followed the general format: "How often does your partner…" Examples of unsupportive items are: "…make disapproving remarks towards you?" and "…break an engagement with you?" and "…treat you unfairly?" The items were completed on a four-point scale ranging from 1 (*rarely or never*) to 4 (*very often*). With respect to both measurements, the scores were averaged within subjects into a single index, with a higher score indicating a higher frequency of supportive and unsupportive behavior (for Cronbach's α values, see Table 2)[3].

Table 1 Demographic and medical characteristics of patients and partners

Variables	Patients				Partners			
	M	*(SD)*	*N*	*(%)*	*M*	*(SD)*	*N*	*(%)*
Married (in years)	34	(13)	62	(87)	34	(13)	62	(87)
Age (in years)	61.2	(10)			60.3	(10)		
Gender (male)			52	(74.3)			18	(25.7)
Morbidity			47	(67.1)			47	(67.1)
Level of education								
Elementary school			7	(10)			7	(10)
Secondary education			40	(57.1)			47	(67.1)
Higher education			23	(32.9)			16	(22.9)
Working status								
Paid job			27	(38.6)			21	(30)
Retired			27	(38.6)			17	(24.3)
Cancer diagnosis								
Rectal cancer			37	(52.8)				
Colon cancer			30	(42.9)				
Cancer stage								
Stage I			11	(15.5)				
Stage II			22	(31)				
Stage III			31	(43.7)				
Stage IV			2	(2.8)				
Treatment (at baseline)								
Surgery			45	(64.3)				
Colostomy			16	(22.9)				
Chemotherapy			7	(10)				
Preoperative radiotherapy			14	(20)				
Chemoradiation			4	(5.7)				
Treatment (at follow-up)								
Chemotherapy			1	(1.4)				
Radiotherapy			11	(15.7)				

Personal control was assessed at baseline with the Seven-Item Mastery List (Pearlin et al., 1981), reflecting the perceived personal control over events and situations in life. The Mastery Scale is often used in the context of chronic illness as a predictor of adjustment. A sample item is: “Sometimes I feel that I am being pushed around in life.” All items were completed on a four-point scale ranging from 1 *(completely disagree)* to 5 *(completely agree)* (for Cronbach’s α values, see Table 2).

Psychological distress was assessed twice, approximately three months (at baseline) and nine months (at follow-up) after diagnosis, by using the Center for Epidemiologic Studies Depression Scale. The CES-D (Dutch translation by Bouma, Ranchor, Sanderman, & van Sonderen, 1995; Radloff, 1977) consists of twenty self-report items measuring the frequency of depressive symptoms, has good psychometric properties, and is widely used in studies of distress in cancer patients and their partners (for an overview, see a meta-analysis by Hagedoorn et al., 2008). All 20 items were completed on a four-point scale ranging from 0 *(rarely or never)* to 3 *(almost always)*. Examples are: “Last week, I felt afraid” and “Last week, I felt lonely.” Item scores were summed within subjects into a single index, with a higher score indicating higher level of distress (for Cronbach’s α values, see Table 2).

Statistical Analysis

Our data consists of two levels, namely, dyads at Level 2 and individuals (i.e., patients and partners) nested within a dyad at Level 1. To adequately analyze our data, we used MLwiN software (Rasbash, Charlton, Browne, & Healy, 2010). Before reading the files into MLwiN, we centered all the data around the sample mean and calculated interaction terms based on these centered variables (Aiken & West, 1991; cf. Kenny, Kashy, & Cook, 2006). In addition we created two dummy variables, one for patients (1=patient, 0=partner) and one for partners (1=partner, 0=patient). Following the two-intercept approach (Kenny et al., 2006), we created two separate sets of predictor variables (one for patients and one for partners) by multiplying each Level 1 predictor variable by the dummy coded variables. At Level 1, the general intercept was removed and replaced with the dummy variables “patients” and “partners” (Kenny et al., 2006). This procedure with the dummy variables allowed us to estimate the within-person effects on patients and partners within one model, while taking into account the non-independence of patient and partner data.

Results

Univariate and Bivariate Analysis

Table 2 presents the correlations and the means for patients and partners for the variables under study. A higher sense of personal control was moderately associated with lower levels of distress for both patients and partners. The associations between patients' perceived supportive and unsupportive spousal behavior and distress were not significant, except for the rather weak positive association between unsupportive behavior and distress at follow-up. Partners' perceptions of supportive and unsupportive spousal behavior were moderately associated with distress, except for the association between supportive behavior and baseline distress. Furthermore, patients' perceptions of supportive and unsupportive spousal behavior were both moderately positively associated with partners' perceptions of spousal behavior. It can also be seen from the table that, on average, patients and partners score similarly on the different scales. Overall, there was

Table 2 Pearson Correlations between patients and partners, means and standard deviations for all the variables in the study

Variables	1	2	3	4	5	*M*	*SD*	*α*
1. Personal control	**.19**	.11	-.24*	-.47**	-.36**	3.46	0.75	.78
2. Perceived supportive behavior	.28*	**.25***	-.37**	-.11	-.13	3.33	0.47	.52
3. Perceived unsupportive behavior	-.18	-.52**	**.31***	.17	.26*	1.42	0.40	.67
4. Distress (at baseline)	-.29*	-.11	.32**	**.05**	.60**	13.29	9.23	.87
5. Distress (at follow-up)	-.31**	-.24*	.35**	.59**	**.22**	9.92	7.98	.86
M	3.50	3.32	1.41	12.82	11.01			
SD	0.65	0.53	0.32	8.66	8.90			
α	.73	.83	.74	.88	.91			

Note. Patient statistics are presented above the diagonal and partner statistics below the diagonal. Correlations between patient and partner variables are presented on the diagonal. The numbers in bold represent the diagonal.

$^{*}p < .05$, $^{**}p < .01$

a decrease in distress over time for patients, paired-*t*(67) = 3.62, *p* =.001, and for partners, paired-*t*(68) = 1.87, *p* = .066, albeit only approaching significance for the latter group.

Testing the Hypotheses

To avoid over-fitting the model, we created two separate models, one for supportive behavior and one for unsupportive behavior[4]. To test our first hypothesis, that is, perceived spousal supportive behavior will be negatively associated with future distress, especially for those relatively low in personal control, we created Model 1 (see Table 3). In this model we included patients' and partners' perceptions of personal control, spousal supportive behavior, and the interaction terms as predictors of patients' and partners' distress at follow-up. We examined the associations between distress (at baseline and follow-up) and the demographic and medical variables listed in Table 1[5]. Except for gender and morbidity[6], none of these variables showed a significant correlation with distress. Therefore, only gender and morbidity were included as covariates in the final model. Since we were interested in changes in distress over time, we also controlled for the baseline level of distress. Model 1 can be specified in the following function: $Y_{ij} = \beta_{0j}$(Patient) + β_{0j}(Partner) + β_1(Patient Baseline Distress)$_j$ + β_1(Partner Baseline Distress)$_j$ + β_2(Patient Gender)$_j$ + β_2 (Partner Gender)$_j$ + β_3(Patient Morbidity)$_j$ + β_3(Partner Morbidity)$_j$ + β_4(Patient Perceived Supportive Behavior)$_j$ + β_4(Partner Perceived Supportive Behavior)$_j$ + β_5(Patient Personal Control)$_j$ + β_5(Partner Personal Control)$_j$ + β_6(Patient Perceived Supportive Behavior x Personal Control)$_j$ + β_6(Partner Perceived Supportive Behavior x Personal Control)$_j$+ e_{ij}, where Y_{ij} is distress at follow-up of a member of Couple j.

As can be seen in Table 3, for both patients and partners the interaction between perceived spousal supportive behavior and personal control at baseline predicted follow-up distress. We calculated and plotted the regression slopes for patients and partners at two levels of personal control: high (+ 1 *SD*) and low (- 1 *SD*). Figure 1 depicts the results for partners. The negative association between perceived spousal supportive behavior and follow-up distress was significant in partners relatively low in control (*B* = -5.671, *p* < .05), but not in partners relatively high in control (*B* = 2.787, *p* = .32). Similar findings were observed for patients (see Figure 2). Perceived spousal supportive behavior was negatively associated with follow-up distress, but only for patients relatively low in control (*B*= -5.206, *p* <.05). The association was not significant for patients relatively high in control (*B* = 2.795, *p* = .20).

To test our second hypothesis, that is, that perceived spousal unsupportive behavior will be positively associated with future distress, especially for those relatively low in personal control, we created Model 2 (see Table 4). In this model, we replaced perceived spousal supportive with perceived spousal unsupportive behavior. Again, patients' and partners' gender, morbidity, and baseline distress were included in the model as covariates. Table 4 shows an interactive effect for spousal unsupportive behavior and personal control on follow-up distress, but only for partners. As depicted in Figure 3, perceived spousal unsupportive behavior was positively associated only with partners' distress at follow-up and only for partners relatively low in control (*B* = 10.38, *p* <0.001). The association was not significant for partners relatively high in control (*B* = 0.29, *p* = .93).

Table 3 Hierarchical linear model one: associations between supportive behavior and distress at follow-up

Variable	***B***	***SE***	***t***	***r***	***pv***
Patient distress (at follow-up)					
Intercept patient	10.27	1.02	10.06	.68	**<.001**
Distress (at baseline)	.46	.10	4.81	.41	**<.001**
Gender	-.02	.90	-.02	.00	.98
Morbidity	-2.25	1.65	-1.36	.13	.17
Perceived spousal supportive behavior (PSSB)	-1.21	1.60	-.75	.07	.45
Personal control	-1.01	1.18	-.86	.08	.39
PSSB X Personal control	5.81	2.43	2.40	.22	**<.05**
Partner distress (at follow-up)					
Intercept partner	10.96	1.12	9.76	.67	**<.001**
Distress (at baseline)	.52	.10	5.41	.45	**<.001**
Gender	-.54	.94	-0.58	.05	.56
Morbidity	-1.85	1.72	-1.07	.10	.28
Perceived spousal supportive behavior (PSSB)	-1.44	1.55	-.93	.08	.35
Personal control	-.95	1.26	-0.76	.07	.45
PSSB X Personal control	6.80	1.92	3.55	.31	**<.001**

Note. Effect size *r* for each *t* was computed with the following equation: $r = \mathrm{sqrt}[t^2/(t^2+df)]$. *df* = 115

Discussion

The aim of this prospective study was to expand our knowledge of spousal support and the course of distress over time both for patients with colorectal cancer and their partners. Overall, our findings suggest that people relatively low in control are more responsive to perceived spousal behavior than people relatively high in control. More

Table 4 Hierarchical linear model two: associations between unsupportive behavior and distress at follow-up

Variable	*B*	*SE*	*t*	*r*	*pv*
Patient distress (at follow-up)					
Intercept patient	10.52	1.07	9.88	.68	**<.001**
Distress (at baseline)	.44	.10	4.53	.39	**<.001**
Gender	-.16	.94	-.17	.02	.86
Morbidity	-2.14	1.71	-1.26	.12	.21
Perceived spousal unsupportive behavior (PSUB)	2.61	2.04	1.28	.12	.20
Personal control	-.75	1.24	-.60	.06	.55
PSUB X Personal control	.44	2.58	.17	.02	.86
Partner distress (at follow-up)					
Intercept partner	10.68	1.23	8.72	.63	**<.001**
Distress (at baseline)	.42	.11	3.93	.34	**<.001**
Gender	-1.49	1.05	-1.43	.13	.15
Morbidity	-1.32	1.80	-.73	.07	.46
Perceived spousal unsupportive behavior (PSUB)	5.34	2.67	2.00	.18	**<.05**
Personal control	-1.18	1.28	-.92	.09	.36
PSUB X Personal control	-8.11	3.28	-2.47	.22	**<.05**

Note. Effect size *r* for each *t* was computed with the following equation: $r = \text{sqrt}[t^2/(t^2+df)]$. $df = 115$

specifically, our findings provide consistent support for the first hypothesis by showing that persons who perceived more spousal supportive behavior reported less distress over time, especially those relatively low in control. Our second hypothesis was supported only for partners. That is, partners' perceptions of patients' unsupportive behavior was associated with more distress over time, but only for partners relatively low in control. This suggests that both patients and partners relatively low in control may benefit more from supportive spousal behavior, and partners relatively low in control may even be harmed by unsupportive spousal behavior.

Put differently, our findings demonstrated that people relatively high in control showed relatively low levels of distress regardless of their perceptions of their spouses' behavior. This is in line with the argument that people relatively high in control feel they can control their life by their own behavior (cf. Rotter, 1966), most probably because they possess coping skills required for their adaptation (Elfström & Kreuter, 2006). For example, it has been found that people relatively high in control use more adaptive coping strategies (i.e., assimilation strategies) than people relatively low in control (Ben-Zur, 2002; Elfström & Kreuter, 2006; Elliott et al., 1986; Henselmans et al., 2010; Jopp & Schmitt, 2010).

Figure 1 Interaction between perception of patients' supportive behaviour and partners' distress over time, moderated by partners' personal control

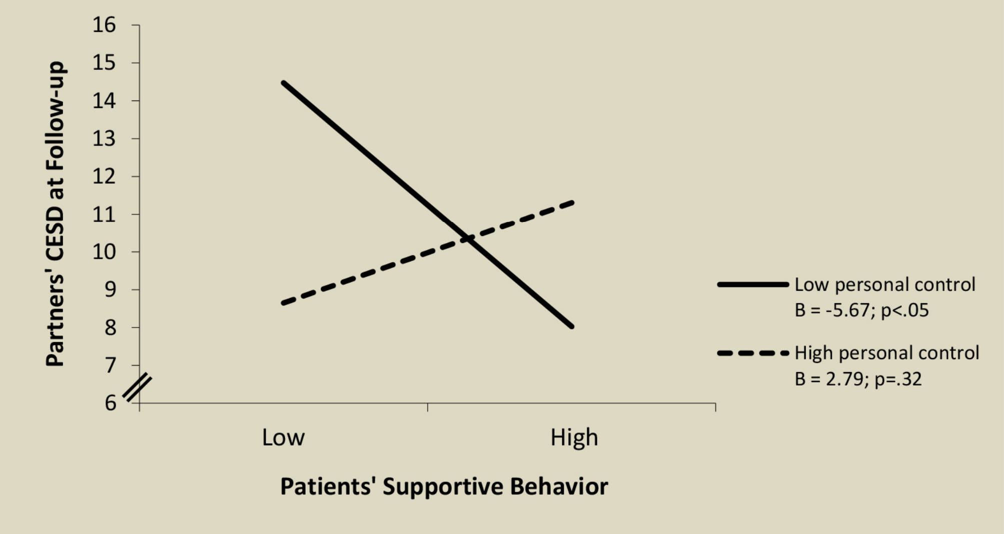


Figure 2 Interaction between perception of partners' supportive behaviour and patients' distress over time, moderated by patients' personal control

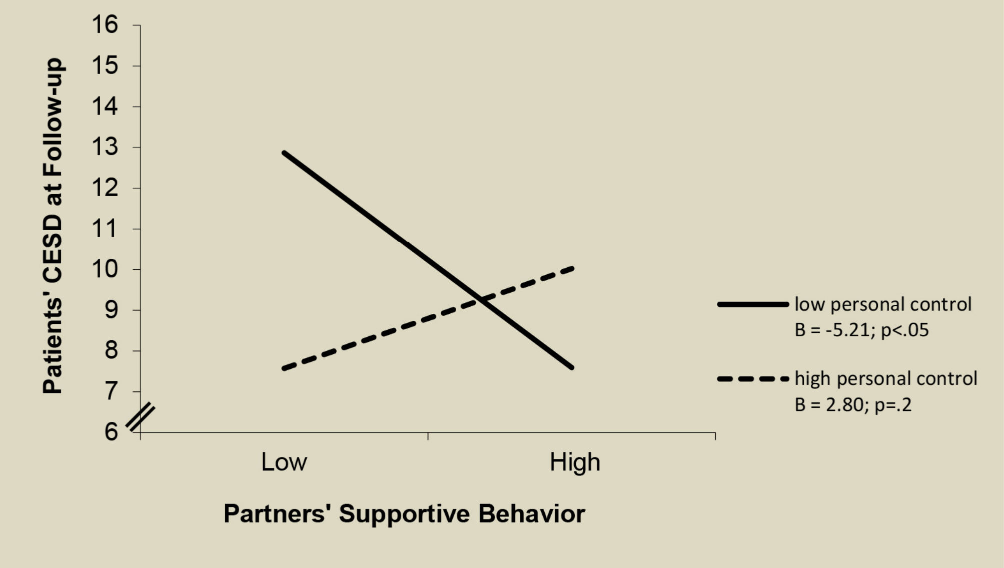
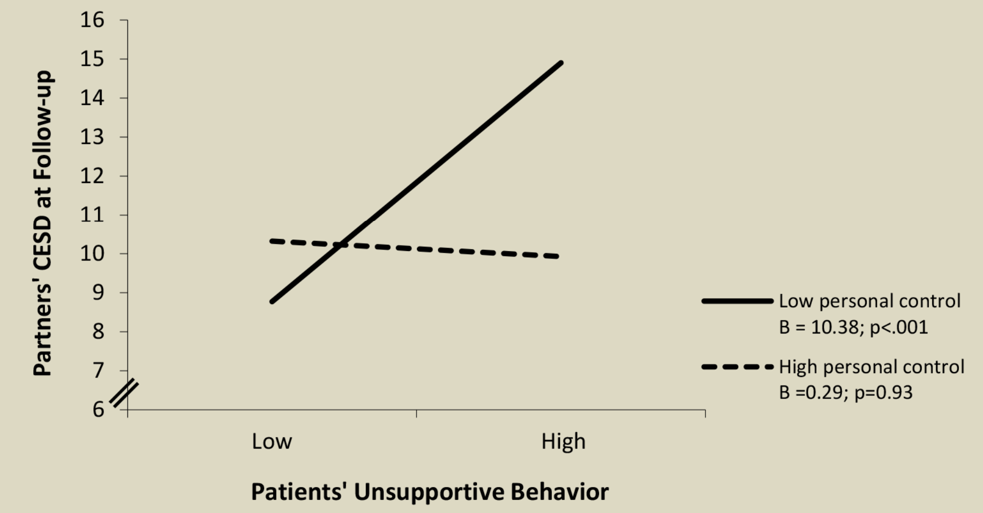


Figure 3 Interaction between perception of patients' unsupportive behaviour and partners' distress over time, moderated by partners' personal control



As a consequence, people relatively high in control may benefit less from a supportive spouse than people relatively low in control who depend on others to deal with stressful events (cf. Dalgard et al., 1995; cf. VanderZee et al., 1997). In the current study, we did not measure the specific coping skills and abilities required for better adjustment to cancer that people relatively high in control are thought to possess and that people relatively low in control are deficient in. A promising avenue for future studies to provide further insight into the possible underlying mechanisms might be to focus on such skills and abilities and to test a mediated moderation model (cf. Preacher, Rucker, & Hayes, 2007). That is, a model in which the interactive effect of perceived supportive and unsupportive spousal behavior and personal control on distress are explained by coping skills.

Our findings with respect to unsupportive spousal behavior suggest that, for partners relatively low in control, perceiving criticism or antagonism from the patients is distressing. However, for patients relatively low in control, perceiving such unsupportive spousal behavior does not seem to be harmful. This different finding for patients and partners might be related to the care-giving role. Perhaps for partners relatively low in control, perceiving unsupportive behavior from the patients indicates that they are failing as care-givers and, therefore, may elevate their distress. This is in line with the suggestion that receiving negative support might intensify caregivers' negative feelings such as fear or self-blame (Rauktis, Koeske, & Tereshko, 1995). Partners may feel more obliged to support the patients than the other way around and, consequently, perceiving unsupportive spousal behavior might harm partners more than patients. Furthermore, it was found that feelings of insecurity and incompetence with respect to their care-giving role were associated with female caregivers' own levels of distress (cf. Hagedoorn et al., 2002; Martire, Stephens, & Townsend, 1998). Future studies are needed to replicate these results and examine our explanation by focusing more on the unique role characteristics of patients versus partners.

Our findings are not only consistent with the results of the few previous studies on personal control as a moderator of the social support-distress link carried out in the general population (e.g., Dalgard et al., 1995; VanderZee et al., 1997), but also with the results of previous researches that examined peoples' vulnerability as a moderator of the spousal support-distress association. For example, previous studies have shown that vulnerable patients (in terms of a weak promotion focus, or poor psychological and physical condition) may benefit more from supportive partners, whereas they may be harmed more by unsupportive partners (cf. Hagedoorn et al., 2000; cf. Schokker, Links, Luttik, & Hagedoorn, 2010). The current study contributes to the existing literature by showing that the associations between perceived spousal supportive and unsupportive behavior and distress are qualified by personal control. This is an important step towards answering the question: For whom does the receipt of supportive and absence of unsupportive behavior from their intimate partner increase psychological well-being? Importantly, we have also contributed to the dyadic literature of couples coping with illness by demonstrating that perceived spousal behavior is not only associated with distress in patients, but also with distress in partners.

The current study has several noteworthy strengths. First, our study made use of a dyadic approach, in which we (a) regarded both patients and partners as a source of support and (b) examined in one model both patients' and partners' distress as a function of spousal behavior. Taking into account the interdependency between patients and partners, we made use of a sophisticated statistical technique (MLwiN; Kenny et al., 2006). In addition, we applied a longitudinal design that allowed us to predict follow-up distress, while controlling for the level of distress at baseline. Even though we cannot draw causal conclusions, an association between baseline support and changes in distress over time, depending on personal control, provides much more insight into the support process than a simple cross-sectional association.

As to the interpretation of the findings, a number of limitations should also be noted. First, we had a relatively low response rate. This may have biased our sample towards couples who showed less distress at baseline. However, de facto, the levels of distress in the current sample were higher than the levels that were found in a previous study among a different sample of couples coping with colorectal cancer (Tuinstra et al., 2004). A second limitation of the current study is the relatively low reliability of the supportive spousal behavior questionnaire (SSL) for patients. This should be improved in future studies. Third, we have only evaluated perceived behavior; thus, we measured neither patients' nor partners' actual behavior. However, it is plausible to assume that perceived spousal behavior is based, at least to some extent, on actual behavior. Previous studies have supported this notion by showing a moderate agreement within couples with respect to the way spousal support was provided (Hagedoorn et al., 2000; Kuijer et al., 2000). A fourth related issue is that although we adopted a dyadic perspective, this perspective is restricted to the effect of each spouse's perception of the other's behavior on his or her own distress levels (i.e., actor effect). Also, this approach may have introduced same-method variance, in a sense that a relatively high personal control perception may underlie the reporting of receiving support, or vice versa. A cross-partner effect design could have overcome this limitation. Therefore, we encourage future studies to include the providers' perceptions of supportive behavior and also examine, on a dyadic level, the interaction between the partner effect of support provision and the actor effect of personal control.

Our findings may have some clinical implications. We would recommend that interventions reflect the important role of patients as providers of support to their intimate partners and not only as receivers of support. Additionally, patients (or partners in general) should be encouraged not only to pay attention to the amount of positive support they provide to their spouse, but also to the amount of disapproval, hostility, enmity, and other unsupportive behavior they engage in. In this respect, interventions for couples dealing with cancer that target the exchange of support within couples appear to be promising in reducing distress (Kuijer, Buunk, De Jong, Ybema, & Sanderman, 2004). Couples with at least one partner relatively low in control might be especially good candidates for such couple interventions.

Footnotes

[1] In the current study, we were interested in how partners perceived their spouses' behavior. Thus, when we discuss supportive and unsupportive spousal behavior, we refer to the actual support behavior from the receivers' point of view.

[2] Several related constructs and associated measurements have been proposed to examine perceived sense of personal control, including Pearlin's (1981) Mastery and Rotter's (1966) Locus of Control scales. We use the first measure, but also cite relevant findings on external versus internal locus of control (cf. low versus high sense of personal control).

[3] We have examined whether the reliability for the patients' perceptions of spousal supportive behavior scale could be improved by dropping particular items but found that this did not result in a notable change in the reliability of the scale.

[4] We have examined whether including marital satisfaction as a covariate in the model could change the result but found that this did not lead to a notable change in the results. To avoid overfitting the model, we did not include marital satisfaction as a covariate in the final analyses presented here.

[5] To evaluate the associations between distress and demographic and medical variables, we used zero-order correlations (for years married and age), Spearman rank-order correlations (for level of education and cancer stage), and t-tests (for gender, morbidity, working status, cancer diagnosis, and whether or not they were undergoing treatment at baseline and follow-up)

[6] To assess morbidity, patients and partners were asked to indicate whether they had health complaints or not on a checklist of 26 chronic medical conditions. For patients, morbidity was coded as present if patients indicated they had health complaints for at least one medical condition other than cancer. For partners, morbidity was coded as present if partners indicated they had at least one chronic medical condition.

Reference List

Aiken, L. S., & West, S. G. (1991). *Multiple regression: Testing and interpreting interactions*. Thousand Oaks, CA US: Sage Publications, Inc

Badger, T. A. (2001). Depression, psychological resources, and health-related quality of life. *Journal of Clinical Geropsychology, 7,* 189-200. doi:10.1023/A:1011339111515

Badr, H., Carmack, C. L., Kashy, D. A., Cristofanilli, M., & Revenson, T. A. (2010). Dyadic coping in metastatic breast cancer. *Health Psychology, 29,* 169-180. doi:10.1037/a0018165

Ben-Zur, H. (2002). Coping, affect and aging: The roles of mastery and self-esteem. *Personality and Individual Differences, 32,* 357-372. doi:10.1016/S0191-8869(01)00031-9

Berg, C. A., & Upchurch, R. (2007). A developmental-contextual model of couples coping with chronic illness across the adult life span. *Psychological Bulletin, 133,* 920-954. doi:10.1037/0033-2909.133.6.920

Blaney, N. T., Goodkin, K., Feaster, D., Morgan, R., Millon, C., Szapocznik, J. et al. (1997). A psychosocial model of distress over time in early HIV-1 infection: The role of life stressors, social support and coping. *Psychology & Health, 12,* 633-653. doi:10.1080/08870449708407411

Bouma, J., Ranchor, A. V., Sanderman, R., & van Sonderen, E. (1995). *Het meten van symptomen van depressie met de CES-D [The measurement of symptoms of depression with the CES-D]*. Groningen: Northern Centre for Healthcare Research, University of Groningen, The Netherlands

Coyne, J. C., & DeLongis, A. (1986). Going beyond social support: The role of social relationships in adaptation. *Journal of Consulting and Clinical Psychology, 54,* 454-460. doi:10.1037/0022-006X.54.4.454

Dalgard, O. S., BjØrk, S., & Tambs, K. (1995). Social support, negative life events and mental health. *British Journal of Psychiatry, 166,* 29-34. doi:10.1192/bjp.166.1.29

Demange, V., Guillemin, F., Baumann, M., Suurmeijer, T. P. B. M., Moum, T., Doeglas, D. et al. (2004). Are there more than cross-sectional relationships of social support and support networks with functional limitations and psychological distress in early rheumatoid athritis? The european research on incapacitating diseases and social support longitudinal study. *Arthritis & Rheumatism: Arthritis Care & Research, 51,* 782-791. doi:10.1002/art.20694

Elfström, M. L., & Kreuter, M. (2006). Relationships between locus of control, coping strategies and emotional well-being in persons with spinal cord. *Journal of Clinical Psychology in Medical Settings, 13,* 93-103.

Elliott, D. J., Trief, P. M., & Stein, N. (1986). Mastery, stress, and coping in marriage among chronic pain patients. *Journal of Behavioral Medicine, 9,* 549-558. doi:10.1007/BF00845284

Frazier, P. A., Tix, A. P., & Barnett, C. L. (2003). The relational context of social support: Relationship satisfaction moderates the relations between enacted support and distress. *Personality and Social Psychology Bulletin, 29,* 1133-1146. doi:10.1177/0146167203254545

Hagedoorn, M., Buunk, B. P., Kuijer, R. G., Wobbes, T., & Sanderman, R. (2000). Couples dealing with cancer: Role and gender differences regarding psychological distress and quality of life. *Psycho-Oncology, 9,* 232-242. doi:10.1002/1099-1611(200005/06)9:3<232::AID-PON458>3.0.CO;2-J

Hagedoorn, M., Dagan, M., Puterman, E., Hoff, C., Meijerink, W. J., Delongis, A. et al. (2011). Relationship satisfaction in couples confronted with colorectal cancer: the interplay of past and current spousal support. *J.Behav.Med.* doi:10.1007/s10865-010-9311-7

Hagedoorn, M., Kuijer, R. G., Buunk, B. P., DeJong, G. M., Wobbes, T., & Sanderman, R. (2000). Marital satisfaction in patients with cancer: Does support from intimate partners benefit those who need it most? *Health Psychology, 19,* 274-282. doi:10.1037/0278-6133.19.3.274

Hagedoorn, M., Sanderman, R., Bolks, H. N., Tuinstra, J., & Coyne, J. C. (2008). Distress in couples coping with cancer: A meta-analysis and critical review of role and gender effects. *Psychological Bulletin, 134,* 1-30. doi:10.1037/0033-2909.134.1.1

Hagedoorn, M., Sanderman, R., Buunk, B. P., & Wobbes, T. (2002). Failing in spousal caregiving: The 'identity-relevant stress' hypothesis to explain sex differences in caregiver distress. *British Journal of Health Psychology, 7,* 481-494. doi:10.1348/135910702320645435

Helgeson, V. S., & Cohen, S. (1996). Social support and adjustment to cancer: Reconciling descriptive, correlational, and intervention research. *Health Psychology, 15,* 135-148. doi:10.1037/0278-6133.15.2.135

Henselmans, I., Fleer, J., de Vries, J., Baas, P. C., Sanderman, R., & Ranchor, A. V. (2010). The adaptive effect of personal control when facing breast cancer: Cognitive and behavioural mediators. *Psychology & Health, 25,* 1023-1040.

Hinnen, C., Ranchor, A. V., Baas, P. C., Sanderman, R., & Hagedoorn, M. t. (2009). Partner support and distress in women with breast cancer: The role of patient awareness of support and level of mastery. *Psychology & Health, 24,* 439-455. doi:10.1080/08870440801919513

Jopp, D. S., & Schmitt, M. (2010). Dealing with negative life events: Differential effects of personal resources, coping strategies, and control beliefs. *European Journal of Ageing, 7,* 167-180. doi:10.1007/s10433-010-0160-6

Kempen, G. I. J. M., & Van Eijk, L. M. (1995). The psychometric properties of he SSL12-I, a short scale for measuring social support in the elderly. *Social Indicators Research, 35,* 303-312. doi:10.1007/BF01079163

Kenny, D. A., Kashy, D. A., & Cook, W. L. (2006). *Dyadic data analysis*. Methodology in the social sciences. New York, NY US: Guilford Press

Kuijer, R. G., Buunk, B. P., De Jong, G. M., Ybema, J. F., & Sanderman, R. (2004). Effects of a brief intervention program for patients with cancer and their partners on feelings of inequity, relationship quality and psychological distress. *Psycho-Oncology, 13,* 321-334. doi:10.1002/pon.749

Kuijer, R. G., Ybema, J. F., Buunk, B. P., De Jong, G. M., Thijs-Boer, F., & Sanderman, R. (2000, Sum). Active engagement, protective buffering, and overprotection: Three ways of giving support by intimate partners of patients with cancer. *Journal of Social & Clinical Psychology, 19,* 256-275.

Manne, S. L. (1999). Intrusive thoughts and psychological distress among cancer patients: The role of spouse avoidance and criticism. *Journal of Consulting and Clinical Psychology, 67,* 539-546. doi:10.1037/0022-006X.67.4.539

Manne, S., & Badr, H. (2008). Intimacy and relationship processes in couples' psychosocial adaptation to cancer. *Cancer, 112,* 2541-2555. doi:10.1002/cncr.23450

Manne, S. L., Taylor, K. L., Dougherty, J., & Kemeny, N. (1997). Supportive and negative responses in the partner relationship: Their association with psychological adjustment among individuals with cancer. *Journal of Behavioral Medicine, 20,* 101-125. doi:10.1023/A:1025574626454

Martire, L. M., Stephens, M. A. P., Druley, J. A., & Wojno, W. C. (2002). Negative reactions to received spousal care: Predictors and consequences of miscarried support. *Health Psychology, 21,* 167-176. doi:10.1037/0278-6133.21.2.167

Martire, L. M., Stephens, M. A. P., & Townsend, A. L. (1998). Emotional support and well-being of midlife women: Role-specific mastery as a mediational mechanism. *Psychology and Aging, 13,* 396-404. doi:10.1037/0882-7974.13.3.396

Pearlin, L. I., Menaghan, E. G., Lieberman, M. A., & Mullan, J. T. (1981). The stress process. *Journal of Health and Social Behavior, 22,* 337-356. doi:10.2307/2136676

Pearlin, L. I., & Pioli, M. F. (2003). Personal control: Some conceptual turf and future directions. In S.H. Zarit, L. I. Pearlin, K. W. Schaie, S. H. Zarit, L. I. Pearlin, & K. W. Schaie (Eds.), *Personal control in social and life course contexts* (pp. 1-21). Societal impact on aging. New York, NY US: Springer Publishing Co.

Peterson, C., & Stunkard, A. J. (1989). Personal control and health promotion. *Social Science & Medicine, 28,* 819-828. doi:10.1016/0277-9536(89)90111-1

Preacher, K. J., Rucker, D. D., & Hayes, A. F. (2007). Addressing moderated mediation hypotheses: Theory, methods, and prescriptions. *Multivariate Behavioral Research, 42,* 185-227.

Radloff, L. S. (1977, Sum). The CES-D Scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement, 1,* 385-401. doi:10.1177/014662167700100306

Ranchor, A. V., Wardle, J., Steptoe, A., Henselmans, I., Ormel, J., & Sanderman, R. (2010). The adaptive role of perceived control before and after cancer diagnosis: A prospective study. *Social Science & Medicine, 70,* 1825-1831. doi:10.1016/j.socscimed.2009.10.069

Rasbash, J., Charlton, C., Browne, W. J., & Healy, M. (2010). MLwiN Version 2.16 Centre for Multilevel Modelling, University of Bristol.

Rauktis, M. E., Koeske, G. F., & Tereshko, O. (1995). Negative social interactions, distress, and depression among those caring for a seriously and persistently mentally ill relative. *American Journal of Community Psychology, 23,* 279-299. doi:10.1007/BF02506939

Reich, J. W., & Zautra, A. J. (1991). Experimental and measurement approaches to internal control in at-risk older adults. *Journal of Social Issues, 47,* 143-158. doi:10.1111/j.1540-4560.1991.tb01839.x

Rotter, J. B. (1966). Generalized expectancies for internal versus external control of reinforcement. *Psychological Monographs: General & Applied, 80,* 1-28.

Schokker, M. C., Links, T. P., Luttik, M. L., & Hagedoorn, M. t. (2010). The association between regulatory focus and distress in patients with a chronic disease: The moderating role of partner support. *British Journal of Health Psychology, 15,* 63-78. doi:10.1348/135910709X429091

Stiegelis, H. E., Hagedoorn, M. t., Sander-man, R., van der Zee, K. I., Buunk, B. P., & van den Bergh, A. C. M. (2003). Cognitive adaptation: A comparison of cancer patients and healthy references. *British Journal of Health Psychology, 8,* 303-318. doi:10.1348/135910703322370879

Tuinstra, J., Hagedoorn, M. t., van Sonderen, E., Ranchor, A. V., Van den Bos, G. A. M., Nijboer, C. et al. (2004). Psychological distress in couples dealing with colorectal cancer: Gender and role differences and intracouple correspondence. *British Journal of Health Psychology, 9,* 465-478. doi:10.1348/1359107042304588

van Sonderen, E. (1993). *Het meten van sociale steun met de Sociale Steun Lijst – Interacties (SSL-I) en Sociale Steun Lijst – Discrepancies (SSL-D): Een handleiding [The measurement of social support with the Social Support List – Interactions (SSL-I) and Social Support List (SSL-D): A manual]* Northern Centre for Healthcare Research, University of Groningen, The Netherlands

VanderZee, K. I., Buunk, B. P., & Sanderman, R. (1997). Social support, locus of control, and psychological well-being. *Journal of Applied Social Psychology, 27,* 1842-1859. doi:10.1111/j.1559-1816.1997.tb01628.x

Vinokur, A. D., & Van Ryn, M. (1993). Social support and undermining in close relationships: Their independent effects on the mental health of unemployed persons. *Journal of Personality and Social Psychology, 65,* 350-359. doi:10.1037/0022-3514.65.2.350

Wolinsky, F. D., Wyrwich, K. W., Babu, A. N., Kroenke, K., & Tierney, W. M. (2003). Age, aging, and the sense of control among older adults: A longitudinal reconsideration. *The Journals of Gerontology: Series B: Psychological Sciences and Social Sciences, 58B,* S212-S220.

Chapter 4

The Interplay Between Partners' Responsiveness and Patients' Need for Emotional Expression in Couples Coping with Cancer

Meirav Dagan
Robbert Sanderman
Christiaan Hoff
Jeroen Meijerink
Peter C. Baas
Michiel van Haastert
Mariët Hagedoorn

Journal of Behavioral Medicine (2013),

I promise to support you in times of sickness and in times of health

Cancer diagnosis and its treatment are stressful and may elicit a great deal of negative emotions and concerns. Accordingly, many researchers suggest that it is beneficial for cancer patients not to hold back but openly disclose their emotions and concerns to their partner (cf., Figueiredo, Fries, & Ingram, 2004; Lepore, 2001). Although disclosure is considered to be a critical aspect of successful interactions between intimate partners, having a responsive partner is equally important (Maisel, Gable, & Strachman, 2008). In the current paper, we examined whether partners' actual responsive behaviors (i.e., showing understanding, validation, and caring towards the patient) that "match" patients' support needs are beneficial in terms of reducing patients' depressive symptoms.

According to the interpersonal process model of intimacy, the degree to which people feel understood, validated and cared for by their intimate partner (i.e., perceived partner responsiveness) plays a central role in relational and emotional well-being (Reis & Shaver, 1988). In line with this, many studies have consistently demonstrated perceived partner responsiveness to be positively associated with intimacy (e.g., Laurenceau , Barrett, & Pietromonaco, 1998; Laurenceau , Barrett , & Rovine , 2005; Shelton, Trail, West, & Bergsieker, 2010) and relationship quality (e.g., Canevello & Crocker, 2010; Fekete, Stephens, Mickelson, & Druley, 2007; Kubacka, Finkenauer, Rusbult, & Keijsers, 2011; Maisel et al., 2008), also in the context of couples coping with cancer (Manne et al., 2004a). Less is known about the role of perceived partner responsiveness in promoting individuals' emotional well-being, but the few existing empirical studies did find weak to moderate associations with depressive symptoms (e.g., Fekete et al., 2007; Khan et al., 2009).

An interesting question is what partners need to do to be perceived as responsive. The optimal matching model of social support posits that support (cf. responsive behavior) is most beneficial when it matches the specific needs of the stressed individual (Cutrona, 1990). Accordingly, it was found that following emotional disclosure, support receivers perceived their spouse as responsive when they received emotional support that matched their needs, whereas unmatched support, such as providing information, produced negative partner evaluations (Cutrona, Shaffer, Wesner, & Gardner, 2007). Moreover, unmatched support (i.e., discrepancy in preferred vs. perceived emotional support) was found to be associated with higher levels of depressive symptoms (Cho, Zunin, Chao, Heiby, & McKoy, 2012).

In general cancer patients are encouraged not to hold back and to openly express their emotions and concerns to their partners (cf., Cordova, Cunningham, Carlson, & Andrykowski, 2001; Figueiredo et al., 2004; Iwamitsu et al., 2003) despite the fact that different people have different needs to express their emotions. Some have a high need for emotional expression and therefore want to share their emotions with people close to them while others do not. As a consequence, different types of support or responses may have different effects on individuals high versus low in need for emotional expression. For example, following emotional disclosure, securely attached people were rated as more calmed after their partners showed emotional support rather than instrumental support. However, avoidantly attached people, who are likely to be low in need for emotional expression, were rated as being more calmed after their partners showed instrumental support, which is less emotionally threatening for these individuals (Simpson, Winterheld, Rholes, & Oriña, 2007).

The vulnerability hypothesis adds to the optimal matching model of social support in that it focuses on individual differences with a specific aim to identify sub-groups of patients who depend on others for support and therefore are at higher risk for depressive symptoms (i.e., vulnerable). Accordingly, previous studies have shown that patients with a poor physical condition or who perceived little personal control can be classified as vulnerable sub-groups of patients in that they appeared to benefit from a supportive partner and to be harmed by an unsupportive partner more than patients with a relatively good physical condition and high personal control (e.g., Dagan et al., 2011; Hagedoorn et al., 2000). In line with this hypothesis, we argue that, similarly as other vulnerable subgroups, patients with a relatively high need for emotional expression heavily depend on others to deal with stressful events. Consequently, they are more susceptible to their partners' actual behavior and, thus, may benefit more from a responsive partner or alternately may be more adversely affected by an unresponsive partner than patients with a relatively low need for emotional expression. Put differently, showing understanding, validation and caring matches especially the needs of the vulnerable sub-group of patients high in need for emotional expression.

The current longitudinal study seeks to identify a subgroup of patients (i.e., support receivers) who are sensitive to their healthy partners' (i.e., support providers) *actual* responsive behavior when disclosing cancer-related concerns. More specifically, we examine the unique contribution of the three components of partner responsiveness, namely understanding, validation and caring in predicting patients' depressive symptoms over time.

Maisel and her colleagues (2008) have examined how responsiveness in conversations should be defined and identified specific behaviors in which the support provider conveys understanding, validation and caring toward the support receiver or discloser. The first component *understanding* refers to the extent to which the partner takes on the other partner's perspective and elaborates this point of view in a way that shows accurate recognition of the patient’s concerns and needs. This may include behaviors such as asking questions in order to “get the facts right”. The second component, *validation*, refers to partner’s ability to use the patient’s disclosure as an opportunity to reinforce his or her self -view and make the patient feel valued and respected. This may include behavior such as communicating acceptance and respect for the patients’ position. The third component, *caring*, refers to the extent to which the partner communicates feelings of affection towards the patient. This may include behavior such as emphasizing that the partner shares in the outcomes of the patient’s event. Comments like “we will go through this together” convey caring (for the full manual see Maisel et al., 2008).

In studies examining the vulnerability hypothesis as well as in studies examining partner responsiveness, researchers often do not explicitly observe actual supportive behaviors, but predominately rely on self-reported perceptions of those behaviors in cross-sectional designs. The current study is the first to examine the responsiveness-depressive symptoms association longitudinally among couples coping with cancer. We expect partners’ responsiveness to be negatively associated with patients’ depressive symptoms at follow-up especially in patients with a relatively high need for emotional expression.

Methods

Procedure

This investigation is part of a larger study examining support processes in couples coping with colorectal cancer (Dagan et al., 2011; Hagedoorn et al., 2011a; Hagedoorn et al., 2011b). The study includes three assessment time points: three (T1), five (T2) and nine (T3) months after cancer diagnosis. The current paper focuses on 58 couples who took part in a support interaction task (T2) and who also provided complete self-report data for the other two measurement points. Estimated time for participation was 3-4 hours and couples did not get any compensation for their participation. This procedure was approved by the Medical Ethical Committees of all hospitals involved.

We recruited couples using a *couples approach (through patients),* as described in a systematic review paper (Dagan & Hagedoorn, 2013). More specifically, all patients who were deemed eligible based on medical records were consecutively approached by their physician or nurse during a visit at the hospital and were given a letter inviting both patients and spouses to participate in a couples-based study.

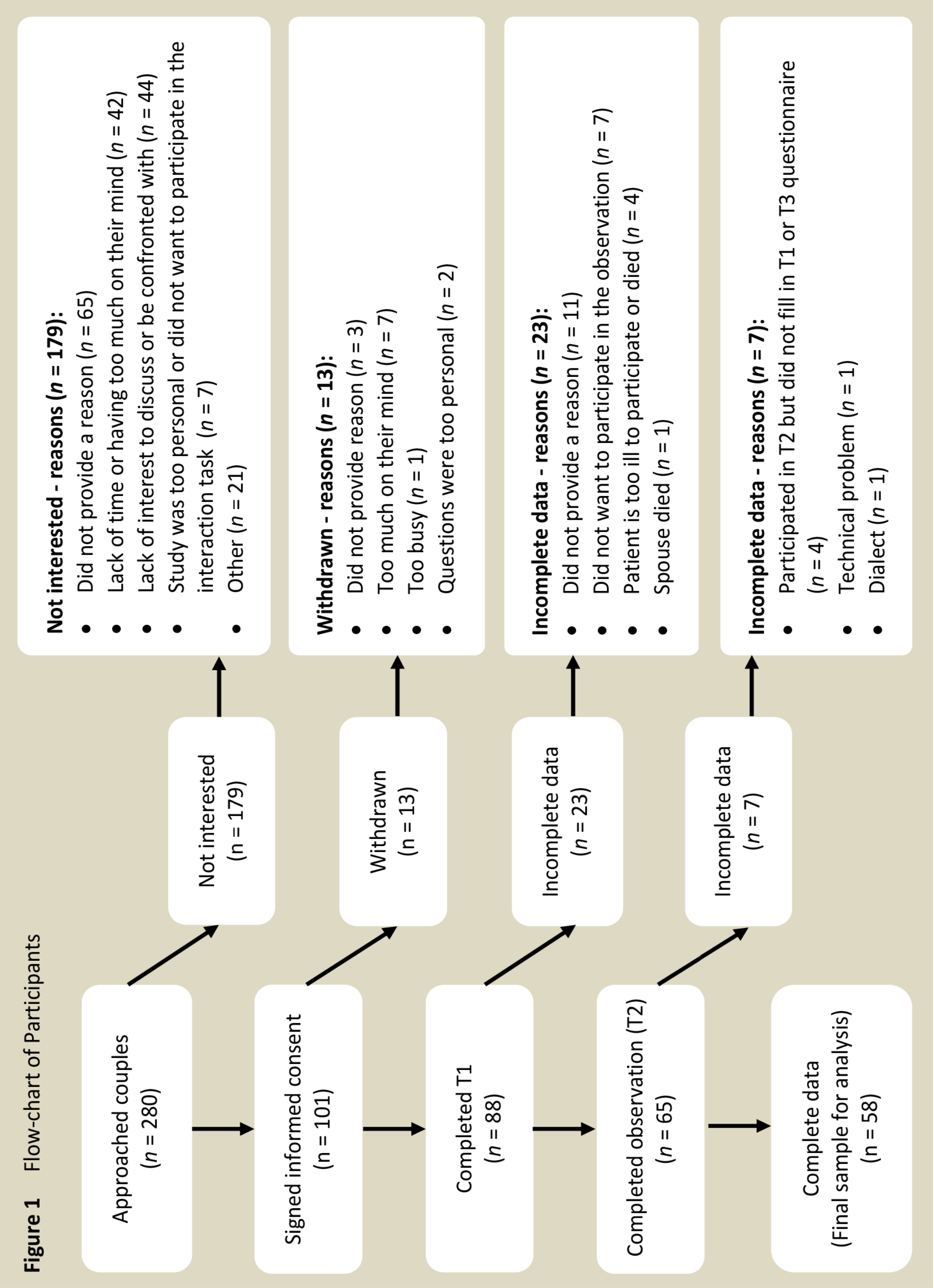
After both partners had given their informed consent, baseline questionnaires (T1) were sent separately to patients and spouses including return envelopes. At the second assessment (T2) couples engaged in a videotaped support interaction task. This task consisted of a semi-structured communication task in which patients presented a personal cancer-related concern to their partners. This procedure was used in previous marital interaction studies (e.g., Manne et al., 2004b; Pasch & Bradbury, 1998). Specifically, in the current study, patients were asked to list their cancer-related concerns and to select one that caused them considerable distress. Next, they were invited to discuss it with their partner for about 10 minutes. The most common cancer-related concerns were fear of recurrence, uncertainty about the future, concerns about their stoma and treatment, and concerns about their partner and children. Partners were instructed to be involved in the discussion and to respond in whatever way felt natural to them. The conversation was later coded for partner responsiveness and patients' self-disclosure.

The interaction task took place in couples' homes. Compared with conducting such an interaction task in a laboratory setting, filming couples in their homes was suggested to facilitate more spontaneous and realistic conversations (e.g., Gottman & Notarius, 2000). In addition, the interaction was preceded by a 5-min warm-up conversation about how they met, allowing the couple to get used to the taping procedure. The task was guided by a psychologist who left the room during the interaction. The underlying idea was that this interaction task captures how couples talk about cancer-related issues when the patient brings up a concern in everyday life. After completing the conversation about the patients' cancer-related concern, participants rated the discussion in terms of the degree to which the discussion had been typical of their discussions outside the study. The mean rating was 3.94 (*SD* = 0.82) for patients and 4.14 (*SD* = 0.71) for partners on a scale ranging from 1 (not at all) to 5 (very much). There were no gender differences with respect to these ratings. Finally, four months later participants fill in questionnaires (T3).

Participants

Participants were newly diagnosed patients and their intimate partners, recruited from oncology clinics at eight hospitals in the Northern Netherlands. Eligibility criteria were: patients with a diagnosis of colorectal cancer who were waiting for treatment or recently underwent surgery, with no documented hearing or cognitive impairments. The exclusion criteria were being older than 75 years of age (47%), insufficient knowledge of the Dutch language (1%), and not having a partner (28%). Out of 280 partnered patients approached who met all criteria, 88 heterosexual couples consented to participate and filled in the baseline questionnaire. We compared patients who declined participation and patients who participated at baseline and found no gender, or age differences (Hagedoorn et al., 2011b). Out of the 88 couples who completed questionnaires at T1, 65 couples also completed the interaction task (T2), but seven couples had to be excluded (for details see Figure 1). Finally, participants completed questionnaires 4 months later (T3). No differences were found between couples who completed all assessments and those who were lost to follow-up in any of the baseline variables.

Figure 1 Flow-chart of Participants



Not interested - reasons (*n* = 179):
- Did not provide a reason (*n* = 65)
- Lack of time or having too much on their mind (*n* = 42)
- Lack of interest to discuss or be confronted with (*n* = 44)
- Study was too personal or did not want to participate in the interaction task (*n* = 7)
- Other (*n* = 21)

Withdrawn - reasons (*n* = 13):
- Did not provide reason (*n* = 3)
- Too much on their mind (*n* = 7)
- Too busy (*n* = 1)
- Questions were too personal (*n* = 2)

Incomplete data - reasons (*n* = 23):
- Did not provide a reason (*n* = 11)
- Did not want to participate in the observation (*n* = 7)
- Patient is too ill to participate or died (*n* = 4)
- Spouse died (*n* = 1)

Incomplete data - reasons (*n* = 7):
- Participated in T2 but did not fill in T1 or T3 questionnaire (*n* = 4)
- Technical problem (*n* = 1)
- Dialect (*n* = 1)

The final sample for analysis included 58 couples out of 280 approached (couples' response rate; CRR = 21%) including 44 male patients and 14 female patients. Most couples were married (88%) and the mean length of their relationship was 33 years (*SD* = 14; range 2-56). Participants had a mean age of 61 years (*SD* = 9.5 years). Participants' level of education varied from completed elementary school to university degree: 9% finished elementary school only, 62% received secondary education, and 28% received higher vocational education or a university degree. About 16% of the participants had a paid job. Most of the men were retired (52% of the patients, 62% of the partners), whereas the modal occupation for women was homemaker (37% of the patients, 36% of the partners).

Forty-seven percent of the patients were diagnosed with colon cancer and the rest with rectal cancer. The stage of the cancer varied: 18% stage I, 34% stage II, 43% stage III and 4% stage IV. The majority (*n* = 39, 67%) of the patients had received surgery. Twelve patients (21%) had a colostomy and another 9 (14%) were scheduled to receive one in the near future. At the initial assessment about 34% of the patients received chemotherapy (n = 6), preoperative radiotherapy (*n* = 13), or chemoradiation (*n* = 1). By the time of the follow up, the majority of the patients had finished their treatment. Most of the participants (patients as well as partners) indicated co-morbidities (67%) such as hypertension, chronic back pain, or arthritis.

Measures

Partner responsiveness was coded using the coding system developed by Maisel and her colleagues (2008). Two trained coders (who were not involved in coding patients' behavior) rated the healthy partners' behavior during the videotaped interactions. They assigned a global score for understanding, validation, and caring (representing three different aspects of partner responsiveness) using a 7-point Likert scale (1 = *not at all* and 7 = *a great deal*). Saying "I understand you" and questions like "What happened after that?" were considered as signs of understanding. The more often a (healthy) partner endorsed such strategies the higher the rating (s)he would get. Sentences like "I know how important it is to you" or "that probably makes you really sad" were considered to reflect validation. Finally, simply saying "I love you" or "I'll always be here for you" were considered to be signs of caring. Following Maisel and her colleagues' (2008) suggestion, we examined the three codes separately. Two coders were trained to use the coding system by the first author. Coders met with the first and the last authors several times to discuss the ratings and to reach consensus on the coding. After reaching a reasonable reliability between the coders, one coder rated all interactions and the second coder rated a random sample of 25%.

Patient disclosure was defined as the disclosure of a personal feeling, wish, thought or need with respect to the concern discussed. We used an adjusted version of Bradbury and Pasch's (1994) coding system, with subdivided categories based on the Rapid Marital Interaction Coding System (RMICS; Heyman & Vivian, 1997) to allow for the coding of disclosures on each speaker turn. Because couples varied in the number of speech turns, the number of times a patient discloses a personal concern was divided by the patient's total number of speech turns. Three coders (who were not involved in coding partners' responsiveness) were trained by the last author. After reaching a reasonable reliability between the coders, videotapes were randomly assigned to coders, with 25% assigned to two coders for reliability checks.

Need for emotional expression was assessed at baseline with three items from the Emotional Inhibition scale developed by Roger et al. (2001). These three items were: "When something upsets me I prefer to talk to someone about it than to bottle it up", "I seldom show how I feel about things" (reversed scoring), and "I don't feel embarrassed about expressing my feelings". In addition, we added two items: "I like to talk about my problems to vent my emotions" and "Some people feel the need to confide in someone, but I prefer to solve my problems by myself" (reversed scoring). All items were completed on a dichotomy scale 1 *(agree)* and 2 *(disagree)*. A higher average score reflects a higher need for emotional expression.

Depressive symptoms was assessed two times, approximately three months (T1), and nine months (T3) after diagnosis, by using the Center of Epidemiologic Studies Depression Scale (CES-D; Dutch translation by Bouma, Ranchor, Sanderman, & van Sonderen, 1995; Radloff, 1977). The CES-D consists of twenty self-report items measuring the frequency of depressive symptoms, has good psychometric properties, and is widely used in studies of distress in cancer patients and their partners (for an overview see a meta-analysis by Hagedoorn et al., 2008). All 20 items were completed on a 4-point scale ranging from 0 *(rarely or never)* to 3 *(almost always)*. Item scores were summed into a single index, with a higher score indicating higher levels of depressive symptoms.

Relationship satisfaction was assessed at baseline with 10 items from the marital quality subscale of the Maudsley Marital Questionnaire (MMQ; Arrindell, Boelens, & Lambert, 1983; Crowe, 1978). Items were answered on 9-point scales (ranging from 0 to 8); a higher average score indicates higher levels of satisfaction.

Data analysis

To test our hypothesis, that is, partners' responsiveness (i.e., understanding, validation and caring) will be negatively associated with depressive symptoms at follow-up especially for patients with a relatively high need for emotional expression, we conducted three hierarchical regression analyses for each component of responsiveness separately. For each analysis, patients' CES-D at T3 was entered as the dependent variable. Specifically, in the first analysis to examine partners' understanding, we first included all the covariates (i.e., patients' baseline CES-D and relationship satisfaction as well as their self-disclosure during the interaction at T2)[1]. Next, we included the predictors of interest (i.e., partners' understanding and patients' need for emotional expression), and finally the interaction effect was included. All predictors were centered around the sample mean before analysis, and we used these scores to calculate the interactions. In the second regression analysis, we replaced the main and interaction effects of partners' understanding with partners' validation and in the third we replaced it with partners' caring. Significant interactions were plotted to interpret whether the effects were consistent with our hypothesis. More specifically, we calculated and plotted the regression slopes for patients at two levels of need for emotional expression; high (+ 1 *SD*) and low (- 1 *SD*).

Results

Table 1 presents the correlations and descriptive for the variables used in this study. Overall the three components of partner responsiveness were moderately associated with each other. In addition, the more patients reported having a need to express their emotions at baseline, the more they actually engaged in disclosure behavior during the interaction, two months later. Notably, neither patients' need for emotional expression nor their actual disclosure behavior was found to be related to any of the partner responsiveness components.

Testing the hypotheses

In line with our hypothesis, two out of three interactions between partner responsiveness (i.e., understanding and validation) and patients' need for emotional expression did indeed predict depressive symptoms four months later[2]. As can be seen in Figure 2, the negative association between understanding and depressive symptoms at follow-up was significant for patients with a high need for emotional expression (*B* = -2.425, *p* = .01), but not in patients with a low need for emotional expression (*B* = .74, *p* = .34). Additional simple slope analyses showed that the positive association between levels of need for emotional expression and depressive symptoms at follow-up was significant when partner understanding was low (*B* = 11.234, *p* = .01), but not when partner understanding was high (*B* = -3.800, *p* = .34). Similar findings were observed for validation behaviors. Validating was negatively associated with depressive symptoms at follow-up, but only for patients high in need for emotional expression (*B* = -2.063, *p* = .01). The association was not significant for patients low in need for emotional expression (*B* = .556, *p* = .53).

Table 1 Means and standard deviations, reliability, and pearson's correlations between patients and partners, for all variables under study

Variables	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
1. (P) Need for Emotional Expression T1	–	-.12	-.22	-.08	.32*	.09	-.07	.06
2. (S) Understanding T2		–	.37**	.32*	-.18	.12	-.21	-.26
3. (S) Validation T2			–	.75**	.15	-.12	.01	-.15
4. (S) Caring T2				–	.09	-.08	-.03	-.05
5. (P) Disclosure T2					–	-.06	.30*	.13
6. (P) Relationship Satisfaction T1						–	-.30*	-.41**
7. (P) Depressive Symptoms T1							–	.58**
8. (P) Depressive Symptoms T3								-
M	1.55	3.77	4.27	3.19	0.30	7.01	14.17	10.45
SD	.34	1.63	1.55	1.95	.16	1.00	9.41	8.45
Reliability	.77	.73	.76	.86	.74	.90	.87	.87

Note. *(P) = Patient / (S) = Spouse*

$^{*}p < .05$, $^{**}p < .01$

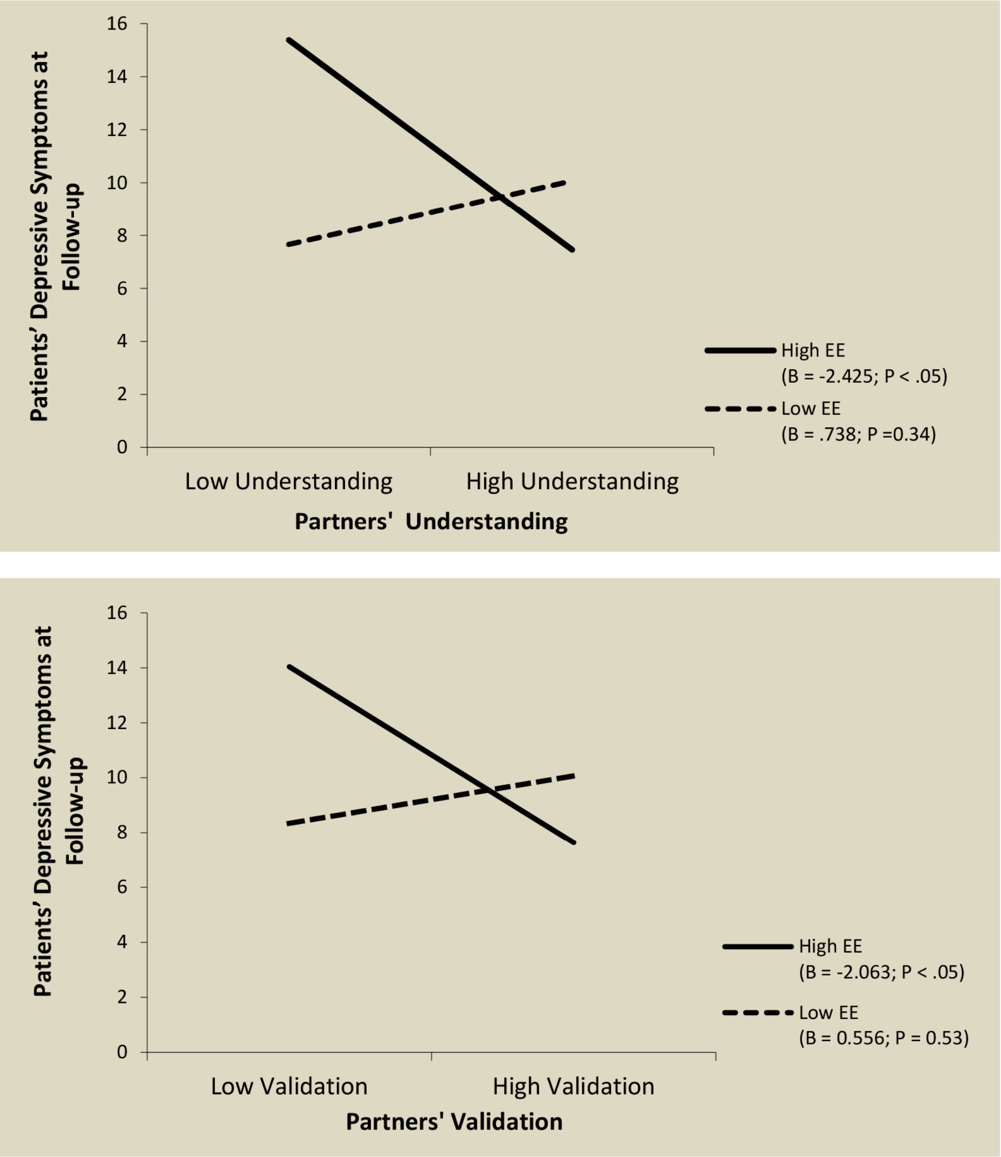
Table 2 Hierarchical linear model 1: associations between partners' responsiveness and patients' depressive symptoms at follow-Up

	Depressive Symptoms at T3				
	B	***SE***	***Δ R^2***	***ΔF***	***P***
Spouse Understanding					
Step 1			.40	11.82	**< .01**
(P) Depressive Symptoms at T1	.51	.10			**< .01**
(P) Disclosure at T2	-7.04	5.92			.24
(P) Relationship Satisfaction at T1	-2.13	.88			**.02**
Step 2			.03	1.62	.21
(S) Understanding	-.86	.62			.17
(P) Emotional Expression	-.84	.54			.12
Step 3			.06	6.44	**.01**
Understanding x Emotional Expression	-4.60	1.81			**.01**
Spouse Validation					
Step 1			.40	11.82	**< .01**
(P) Depressive Symptoms at T1	.52	.10			**< .01**
(P) Disclosure at T2	-3.00	6.14			.63
(P) Relationship Satisfaction at T1	-1.91	.92			**.04**
Step 2			.04	1.98	.15
(S) Validation	-.75	.58			.20
(P) Emotional Expression	2.37	2.78			.40
Step 3			.05	4.61	**.04**
Validation x Emotional Expression	-3.81	1.78			**.04**
Spouse Caring					
Step 1			.40	11.82	**< .01**
(P) Depressive Symptoms at T1	.50	.11			**< .01**
(P) Disclosure at T2	-4.25	6.25			.50
(P) Relationship Satisfaction at T1	-2.22	.93			**.02**
Step 2			.02	1.03	.36
(S) Caring	-.17	.46			.72
(P) Emotional Expression	3.57	2.79			.21
Step 3			.02	2.14	.15
Caring x Emotional Expression	1.92	1.31			.15

Note. P-values < .05 are in boldface. (P) = Patient / (S) = Spouse

Additionally, need for emotional expression was positively associated with depressive symptoms at follow-up, but only when partner validation was low (*B* = 8.296, *p* = .03), and not when partner validation was high (*B* = -3.546, *p* = .38). Finally, we did not find a significant interaction between partner's caring and patients' need for emotional expression when predicting patients' depressive symptoms at follow-up (Table 2).

Figure 2 Association between partners' responsiveness (understanding, validation) and patients' depressive symptoms at follow-up moderated by patients' need for emotional expression (EE), controlling for baseline depressive symptoms



Discussion

This longitudinal observational study was conducted to extend our knowledge of the role of partner's actual responsive behavior in alleviating cancer patients' depressive symptoms over time. Specifically, our central aim was to identify a subgroup of patients who are sensitive to their partners' responsiveness, and therefore at risk for developing depressive symptoms if such responsiveness is withheld. This study adds to the small but growing observational literature that examines actual supportive behaviors within couples coping with cancer (e.g., Hagedoorn et al., 2011a; Manne et al., 2004b). We found some support for our hypothesis that partners' responsiveness is negatively associated with depressive symptoms over time, above and beyond the effect of relationship satisfaction, especially in patients with a relatively high need for emotional expression. Specifically, the current study revealed differences between the three unique components of partner responsiveness. That is, partners' understanding and validation were more important in explaining patients' depressive symptoms than partners' caring behavior.

Main findings in the context of the broader literature

Although prior research has documented the beneficial effects of perceived social support, and especially perceived responsiveness (e.g., Canevello & Crocker, 2010; Kubacka et al., 2011) the findings for support that is actually provided have been more inconsistent (Cutrona et al., 2007; Simpson et al., 2007). Following the optimal matching model of social support which posits that for support to be beneficial it needs to meet the needs of recipients (Cutrona, 1990), our findings suggest that patients with a relatively high need for emotional expression need partners who show high levels of understanding and validation. Our results are also in line with a previous observational study reporting that spousal support that does not meet the patients' needs (i.e., providing solutions or advice in response to patients' self-disclosure) was associated with more distress in patients coping with cancer (Manne et al., 2004a,b). Moreover, it is in line with studies supporting the vulnerability hypothesis (e.g., Dagan et al., 2011; Hagedoorn et al., 2000) by showing that the absence of understanding and validation for a vulnerable sub-group of patients who depend on others for support, namely patients with a relatively high in need for emotional expression, is very costly. Specifically, patients with a relatively high need for emotional expression appear to be harmed more by low responsive partners over time compared to patients with a relatively low need for emotional expression.

Another important finding is the unique contribution of each component of responsiveness (i.e., understanding, validation and caring). Although the three components of partner responsiveness were moderately associated, allowing us to compute an aggregated construct, we followed the advice given by Maisel and her colleagues (2008) and examined also the effect of each component separately. As expected, the *aggregated* construct of partner responsiveness did predict changes in depressive symptoms over time for patients with a high need for emotional expression[2]. A closer examination of the data confirmed this finding for both understanding and validation behaviors, but not for caring behavior. This suggests that it is not enough for partners to show only how much they care for the patients in order to help the patients reduce their level of depressive symptoms.

One explanation for the different effects found for understanding and validation versus caring maybe related to the potential function of these behaviors. Understanding and validation include behaviors such as asking questions, summarizing, paraphrasing, and offering elaboration of the patients' concerns, while reinforcing the patients' self-view (Maisel et al., 2008). Perhaps these behaviors support and promote cognitive processing that reduces the cognitive load and the emotional impact of the concern. This, in turn, may lead to a decrease in patients' depressive symptoms over time. This explanation is in line with previous suggestions that the expression of emotions may be beneficial in terms of reducing levels of distress only if it allows one to re-evaluate the event (Zech & Rimé, 2005). In addition, it is in line with previous findings showing that a cognitive mechanism (i.e., positive reappraisal) mediated the effect of a communication-enhancing intervention on depressive symptoms in female cancer patients (Manne et al., 2008). When partners show caring they express love, affection, empathy and demonstrate their involvement. These behaviors may create the feeling that the couple is "in it together", which in turn may contribute to feelings of intimacy and relational well-being, but not necessarily leads to a decrease in patients' depressive symptoms.

Strengths and limitations

The current study has a number of strengths. First, the longitudinal design of this study allowed us to predict lower levels of depressive symptoms at follow-up in patients who had a relatively high need for emotional expression. Second, the observational method (i.e., the support interactional task) and the rating of concrete behaviors allowed us to examine actual couples' behavior and avoid problems that might have affected previous findings, such as same-method variance, social desirability, and memory distortions. Additionally, we believe that an observational method can better capture how couples actually behave when engaged in a conversation in which patients disclose cancer-related concern, than would a self-report method. Nonetheless, we also recognize that an observational method may be somewhat artificial. Therefore, to enable spontaneous and realistic conversations, the interaction took place in couples' homes (e.g., Gottman & Notarius, 2000). Accordingly, couples indicated they behaved in a natural way and that the conversation reflected the way they usually talked with each other.

Several limitations should also be noted. First, our coding system is predominantly focused on verbal cues, and thus, not capturing all non-verbal aspects of responsiveness. Accordingly, an alternative explanation for not finding an effect for caring is that caring is expressed by more subtle non-verbal behaviors that an objective observer would have missed. This may have had some influence on the findings. Second, the study has a relatively low coupes' response rate (21%). This rate reflects the burden of the intensive design of the study as couples were asked to voluntarily invest the time and complete a broad range of questionnaires at three time points and to participate in an interaction in which they were asked to discuss their cancer-related concerns in front of a camera. Additionally, this rate may reflect the less expressive culture in the northern part of the Netherlands. More than a third of the non-responders mentioned lack of interest to discuss or be confronted with this issue, at this moment. This may have biased our sample. We may appear to have recruited a sample of couples with well-functioning relationships. However, we could not find a strong indication of bias in the sample with respect to the central variables of the study. In fact, when comparing the overall levels of depressive symptoms with a more representative sample of couples coping with colorectal cancer (Tuinstra et al., 2004; M = 12.14), we found overall somewhat higher but comparable levels of depressive symptoms in our sample (M = 14.15). Since our study is the first to examine actual responsive behavior in couples coping with cancer, no data were available for comparison. Nonetheless, partner responsiveness as well as patients' need for emotional expression scores were around the midpoint of the scale and exhibited reasonable variance. Moreover, as suggested by a recent review paper (Dagan & Hagedoorn, 2013) a comparison between responders and non-responders was performed and revealed no differences in terms of gender and age.

Future directions

The current study might inspire future studies to examine further the responsiveness-depressive symptoms association in patients. A promising avenue for future studies would be to examine the underling mechanisms that are involved in these processes. For example, factors such as cognitive processing or re-evaluation of the patients' cancer-related concerns could be examined as mediators through which partners' understanding and validations might affect patients' emotional well-being, especially in patients who have a high need for emotional expression. In addition, the caring component of partner responsiveness, might affect patients' well-being through its effect on intimacy. As outlined in the introduction many studies have consistently demonstrated a positive association between perceived partner responsiveness and intimacy. In addition, based on self-report data, it has been previously suggested that intimacy is an important mechanism that may help explaining how couples' communication patterns influence patients' well-being (Manne, Badr, Zaider, Nelson, & Kissane, 2010). Unfortunately, we did not measure cognitive processing factors and intimacy in the current study. Finally, future studies are also encouraged to examine the unique contribution of the different components of partners' responsiveness on relationship outcomes, such as intimacy.

Clinical implications

Although interventions that promote particular types of support (e.g., partner responsiveness) for less functional couples should adopt our findings with some caution, the findings of the current study have some important clinical implications. First, it has often been reported that interventions aiming to facilitate psychosocial well-being of cancer patients are not as beneficial for everyone to the same degree. A recent review paper provided support for this notion and encouraged personalizing psychosocial interventions for cancer patients by identifying who would benefit from them the most (Tamagawa, Garland, Vaska, & Carlson, 2012). Our findings contribute to these efforts by identifying a subgroup of patients with a high need for emotional expression who are at risk for depressive symptoms if partner responsiveness is withheld. Second, our findings suggest that a module to improve partners' skills of showing understanding and validation might be valuable to increase the efficacy of existing couples interventions (e.g., Kuijer, Buunk, De Jong, Ybema, & Sanderman, 2004).

Conclusions

The findings from the current study contribute to the existing literature on supportive behavior by demonstrating the importance of partners' actual responsive behavior for patients' emotional well-being especially for those with a relatively high need for emotional expression. Based on the observational design of the study and the examination of the unique contribution of the three components of partner responsiveness, we could tease apart specific actual behaviors that interventions aiming to reduce depressive symptoms could potentially focus on. Finally, couples in which patients have a high need for emotional expression that is not met by their partner appear to be especially good candidates for couples' interventions.

Footnotes

[1] We also examined the models including gender, and morbidity as covariates because of their correlation with patients' depressive symptoms. Patients' were asked to indicate whether they had additional health complaints or not on a checklist of 26 chronic medical condition. Morbidity was coded as present if patients indicated one or more medical conditions other than cancer. Including these covariates did not change the results. Therefore, we excluded them from the final model to assure enough power for testing our hypotheses. We further examined the associations between depressive symptoms and several other demographic, and medical variables but none of these variables showed a significant correlation with depressive symptoms. Therefore they were not included in the final analysis. Finally, we have examined the association between several patient behaviors during the interaction (i.e., self-disclosure, frequency of speech turns, and total duration of patients' speech) and other variables included in the models. Except for patient's self-disclosure that was found to be related with patients' need for emotional expression, none of the other behaviors were related to any of the predictors or outcome and therefore only patient's self-disclosure was included in the final models.

[2] We also conducted one hierarchical regression analysis for the aggregated component of partners' responsiveness (i.e., the average score of understanding, validation, and caring) and found similar results as for the models of understanding and validation R^2 = .34 for step 1; ΔR^2 = .10 for step 2 (p = .08); ΔR^2 = .06 for step 3 ($p < 0.05$).

Reference List

Arrindell, W. A., Boelens, W., & Lambert, H. (1983). On the psychometric properties of the maudsley marital questionnaire (MMQ): Evaluation of self-ratings in distressed and 'normal' volunteer couples based on the dutch version. *Personality and Individual Differences, 4*, 293-306.

Bouma, J., Ranchor, A. V., Sanderman, R., & van Sonderen, E. (1995). *Het meten van symptomen van depressie met de CES-D [the measurement of symptoms of depression with the CES-D]*. Groningen: Northern Centre for Healthcare Research, University of Groningen, The Netherlands.

Bradbury, T. N., & Pasch, L. A. (1994). *The social support interaction coding system (SSICS). Unpublished coding manual.* Los Angeles: University of California.

Canevello, A., & Crocker, J. (2010). Creating good relationships: Responsiveness, relationship quality, and interpersonal goals. *Journal of Personality and Social Psychology, 99*, 78-106. doi:10.1037/a0018186

Cho, S., Zunin, I. D., Chao, P. J., Heiby, E. M., & McKoy, J. (2012). Effects of pain controllability and discrepancy in social support on depressed mood among patients with chronic pain. *International Journal of Behavioral Medicine, 19*, 270-279. doi:10.1007/s12529-011-9175-4

Cordova, M. J., Cunningham, L. L. C., Carlson, C. R., & Andrykowski, M. A. (2001). Social constraints, cognitive processing, and adjustment to breast cancer. *Journal of Consulting and Clinical Psychology, 69*, 706-711. doi:10.1037/0022-006X.69.4.706

Crowe, M. J. (1978). Conjoint marital therapy: A controlled outcome study. *Psychological Medicine, 8*, 623-636. doi:10.1017/S0033291700018833

Cutrona, C. E. (1990). Stress and social support: In search of optimal matching. *Journal of Social and Clinical Psychology, 9*, 3-14.

Cutrona, C. E., Shaffer, P. A., Wesner, K. A., & Gardner, K. A. (2007). Optimally matching support and perceived spousal sensitivity. *Journal of Family Psychology, 21*, 754-758. doi:10.1037/0893-3200.21.4.754

Dagan, M., & Hagedoorn, M. (2013, November 25). Response rates in studies of couples coping with cancer: A systematic review. *Health Psychology,* Advance online publication. doi: 10.1037/hea0000013

Dagan, M., Sanderman, R., Schokker, M. C., Wiggers, T., Baas, P. C., van Haastert, M., & Hagedoorn, M. (2011). Spousal support and changes in distress over time in couples coping with cancer: The role of personal control. *Journal of Family Psychology, 25*, 310-318. doi:10.1037/a0022887

Fekete, E. M., Stephens, M.,Ann Parris, Mickelson, K. D., & Druley, J. A. (2007). Couples' support provision during illness: The role of perceived emotional responsiveness. *Families, Systems, & Health, 25*, 204-217. doi:10.1037/1091-7527.25.2.204

Figueiredo, M. I., Fries, E., & Ingram, K. M. (2004). The role of disclosure patterns and unsupportive social interactions in the well-being of breast cancer patients. *Psycho-Oncology, 13*, 96-105. doi:10.1002/pon.717

Gottman, J. M., & Notarius, C. I. (2000). Decade review: Observing marital interaction. *Journal of Marriage & the Family, 62*, 927-947. doi:10.1111/j.1741-3737.2000.00927

Hagedoorn, M., Dagan, M., Puterman, E., Hoff, C., Meijerink, W. J., Delongis, A., & Sanderman, R. (2011a). Relationship satisfaction in couples confronted with colorectal cancer: The interplay of past and current spousal support. *Journal of Behavioral Medicine, 34*, 288-297. doi:10.1007/s10865-010-9311-7

Hagedoorn, M., Kuijer, R. G., Buunk, B. P., DeJong, G. M., Wobbes, T., & Sanderman, R. (2000). Marital satisfaction in patients with cancer: Does support from intimate partners benefit those who need it most? *Health Psychology, 19*, 274-282. doi:10.1037/0278-6133.19.3.274

Hagedoorn, M., Puterman, E., Sanderman, R., Wiggers, T., Baas, P. C., van Haastert, M., & DeLongis, A. (2011b). Is self-disclosure in couples coping with cancer associated with improvement in depressive symptoms? *Health Psychology, 30*, 753-762. doi:10.1037/a0024374

Hagedoorn, M., Sanderman, R., Bolks, H. N., Tuinstra, J., & Coyne, J. C. (2008). Distress in couples coping with cancer: A meta-analysis and critical review of role and gender effects. *Psychological Bulletin*, 134(1), 1-30. doi:10.1037/0033-2909.134.1.1

Heyman, R. E., & Vivian, D. (1997). *RMICS: Rapid marital Interaction Coding system: Training manual for coders. Unpublished manuscript.* State University of New York at Stony Brook.

Iwamitsu, Y., Shimoda, K., Abe, H., Tani, T., Kodama, M., & Okawa, M. (2003). Differences in emotional distress between breast tumor patients with emotional inhibition and those with emotional expression. *Psychiatry and Clinical Neurosciences, 57*, 289-294. doi:10.1046/j.1440-1819.2003.01119.x

Khan, C. M., Iida, M., Stephens, M. A. P., Fekete, E. M., Druley, J. A., & Greene, K. A. (2009). Spousal support following knee surgery: Roles of self-efficacy and perceived emotional responsiveness. *Rehabilitation Psychology, 54*, 28-32. doi:10.1037/a0014753

Kubacka, K. E., Finkenauer, C., Rusbult, C. E., & Keijsers, L. (2011). Maintaining close relationships: Gratitude as a motivator and a detector of maintenance behavior. *Personality and Social Psychology Bulletin, 37*, 1362-1375. doi:10.1177/0146167211412196

Kuijer, R. G., Buunk, B. P., De Jong, G. M., Ybema, J. F., & Sanderman, R. (2004). Effects of a brief intervention program for patients with cancer and their partners on feelings of inequity, relationship quality and psychological distress. *Psycho-Oncology, 13*, 321-334. doi:10.1002/pon.749

Laurenceau , J. P., Barrett , L. F., & Rovine , M. J. (2005). The interpersonal process model of intimacy in marriage: A daily-diary and multilevel modeling approach. *Journal of Family Psychology, 19*, 314-323. doi:10.1037/0893-3200.19.2.314

Laurenceau , J. P., Barrett, L. F., & Pietromonaco, P. R. (1998). Intimacy as an interpersonal process: The importance of self-disclosure, partner disclosure, and perceived partner responsiveness in interpersonal exchanges. *Journal of Personality and Social Psychology, 74*, 1238-1251. doi:10.1037/0022-3514.74.5.1238

Lepore, S. J. (2001). A social–cognitive processing model of emotional adjustment to cancer. In B. L. Andersen (Ed.), *Psychosocial interventions for cancer.* (pp. 99-116). Washington, DC US: American Psychological Association. doi:10.1037/10402-006

Maisel, N. C., Gable, S. L., & Strachman, A. (2008). Responsive behaviors in good times and in bad. *Personal Relationships, 15*, 317-338. doi:10.1111/j.1475-6811.2008.00201.x

Manne, S. L., Winkel, G., Rubin, S., Edelson, M., Rosenblum, N., Bergman, C., . . . Rocereto, T. (2008). Mediators of a coping and communication-enhancing intervention and a supportive counseling intervention among women diagnosed with gynecological cancers. *Journal of Consulting and Clinical Psychology, 76*, 1034-1045. doi:10.1037/a0014071

Manne, S., Ostroff, J., Rini, C., Fox, K., Goldstein, L., & Grana, G. (2004). The interpersonal process model of intimacy: The role of self-disclosure, partner disclosure, and partner responsiveness in interactions between breast cancer patients and their partners. *Journal of Family Psychology, 18*, 589-599. doi:10.1037/0893-3200.18.4.589

Manne, S., Badr, H., Zaider, T., Nelson, C., & Kissane, D. (2010). Cancer-related communication, relationship intimacy, and psychological distress among couples coping with localized prostate cancer. *Journal of Cancer Survivorship, 4*, 74-85. doi:10.1007/s11764-009-0109-y

Manne, S., Sherman, M., Ross, S., Ostroff, J., Heyman, R. E., & Fox, K. (2004). Couples' support-related communication, psychological distress, and relationship satisfaction among women with early stage breast cancer. *Journal of Consulting and Clinical Psychology, 72*, 660-670. doi:10.1037/0022-006X.72.4.660

Pasch, L. A., & Bradbury, T. N. (1998). Social support, conflict, and the development of marital dysfunction. *Journal of Consulting and Clinical Psychology, 66*, 219-230. doi:10.1037/0022-006X.66.2.219

Radloff, L. S. (1977). The CES-D scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement, 1*, 385-401. doi:10.1177/014662167700100306

Reis, H. T., & Shaver, P. (1988). Intimacy as an interpersonal process. In S. Duck, D. F. Hay., S. E. Hobfoll., W. Ickes. & B. M. Montgomery (Eds.), *Handbook of personal relationships: Theory, research and interventions.* (pp. 367-389). Oxford England: John Wiley & Sons.

Roger, D., Garcia de, l. B., Lee, H. S., & Olason, D. T. (2001). A factor-analytic study of cross-cultural differences in emotional rumination and emotional inhibition. *Personality and Individual Differences, 31*, 227-238. doi:10.1016/S0191-8869(00)00131-8

Shelton, J. N., Trail, T. E., West, T. V., & Bergsieker, H. B. (2010). From strangers to friends: The interpersonal process model of intimacy in developing interracial friendships. *Journal of Social and Personal Relationships, 27*, 71-90. doi:10.1177/0265407509346422

Simpson, J. A., Winterheld, H. A., Rholes, W. S., & Oriña, M. M. (2007). Working models of attachment and reactions to different forms of caregiving from romantic partners. *Journal of Personality and Social Psychology, 93*, 466-477.

Tamagawa, R., Garland, S., Vaska, M., & Carlson, L. E. (2012). Who benefits from psychosocial interventions in oncology? A systematic review of psychological moderators of treatment outcome. *Journal of Behavioral Medicine, 35*, 658-673. doi:10.1007/s10865-012-9398-0

Tuinstra, J., Hagedoorn, M., Van Sonderen, E., Ranchor, A. V., Van, d. B., Nijboer, C., & Sanderman, R. (2004). Psychological distress in couples dealing with colorectal cancer: Gender and role differences and intracouple correspondence. *British Journal of Health Psychology, 9*, 465-478. doi:10.1348/1359107042304588

Zech, E., & Rimé, B. (2005). Is talking about an emotional experience helpful? effects on emotional recovery and perceived benefits. *Clinical Psychology & Psychotherapy, 12*, 270-287. doi:10.1002/cpp.460

Part 2

Methodological Issues in Couples-Based Studies

Chapter 5

Response Rates in Studies of Couples Coping with Cancer - A Systematic Review

Meirav Dagan
Mariët Hagedoorn

Health psychology, (2013), Advance online publication.

I promise to support you in times of sickness and in times of health

There is a growing recognition that cancer is a dyadic stressor that affects both patients and their partners. Although information from both members of the dyad is important for our understanding of how to help them and other couples alike, participating in research may not have high priority for these couples. Therefore, situations in which all individuals approached agreed to participate are extremely rare in couples-based research, particularly in the context of cancer. There are two main reasons. First, in couples-based research, “it takes two to tango”. Thus, even if only one of the partners decides not to participate, both subjects are lost. Second, the indirect recruitment conditions often imposed by the Ethical Review Board (following the HIPAA privacy rule) allow researchers only to ask the patients to invite their spouse to participate. The result of this unique recruitment procedure may be reflected in relatively low response rates that are sometimes reported in couples-based studies (e.g., couples' response rates reported in Garos, Kluck, & Aronoff, 2007; Hinnen et al., 2008 are 32% and 38%, respectively) in comparison to response rates reported in patients only studies (e.g., patients' response rates reported in Biedrzycki, 2010; Higginson & Sen-Gupta, 2000 are 73% and 80%, respectively). While researchers agree that recruiting couples to participate in an observational study (i.e., a non-intervention study) is challenging (Hagedoorn et al., 2011), no study until now has examined this issue systematically.

Importantly, the inability to successfully obtain and retain research participants may have a profound effect on the study's validity and ability to generalize findings. It is often assumed —correctly or not— that the lower the response rate, the less valid the generalizations of the study results from the sample to the target population. Basically, response rates are the proportion of people deemed eligible and approached for a study that actually complete all measurements (Aday & Llewellyn, 2006). Although response rate information alone is not sufficient to determine how much non-response bias exists in a study, or even whether it exists, calculating this rate is a critical first step. Therefore, the first aim of the current paper is to examine the average couples’ response rate (CRR; all analyzed couples divided by the number of eligible partnered patients/couples approached) in observational studies of couples coping with cancer.

One factor that may affect the ability to calculate and interpret CRR is the way couples were approached. There are many ways to recruit couples and each has its limitations (for details about the different approaches, strengths, limitations, and recommendations, see supplemental material A). Besides convenience sampling, the so-called *un-partnered patients approach,* in which researchers ask patients (either single or partnered) to participate with their spouse if applicable, often precludes the calculation of the CRR. Although this approach might be practical since it allows approaching large groups more easily, in most cases, information about relationship status of patients is only known for those who were willing to participate. It is important to note that other procedures in which only partnered individuals are approached should also be used with caution. For example, in a *true couples approach*, researchers make a pre-selection of the population. That is, partnered patients who visit the clinic alone are not invited. It might be that patients and partners who come together to the clinic are significantly different from couples of which only the patient is present. If many partnered patients were *not* approached because they came without their partner, CRR may be biased.

Even though there is no official minimum response rate for publication, a 60% response rate is sometimes presented as a minimum golden standard (Fincham, 2008). Johnson and Owens (2003) asked 18 editors of a convenience sample of journals in social and health sciences about their journals' policies regarding response rates of survey studies. Although none of the editors reported having an established minimal response rate standard, one editor did report that 60% is a minimum response rate for publication with rare exceptions. Another editor added that the response rate does contribute to a decision on publication. These practices create pressure to present other favorable figures when the response rate is lower than 60%. This pressure may also affect researchers in our area of interest as many studies currently present rates other than the CRR (e.g., expressed interest rate, agreement rate; for a detailed description of the rates, see Figure 1). Nonetheless, CRR is the most relevant when discussing generalizability and should be presented, if possible. Therefore, our second goal is to establish how many researchers report the CRR and how many report other more favorable rates instead of CRR.

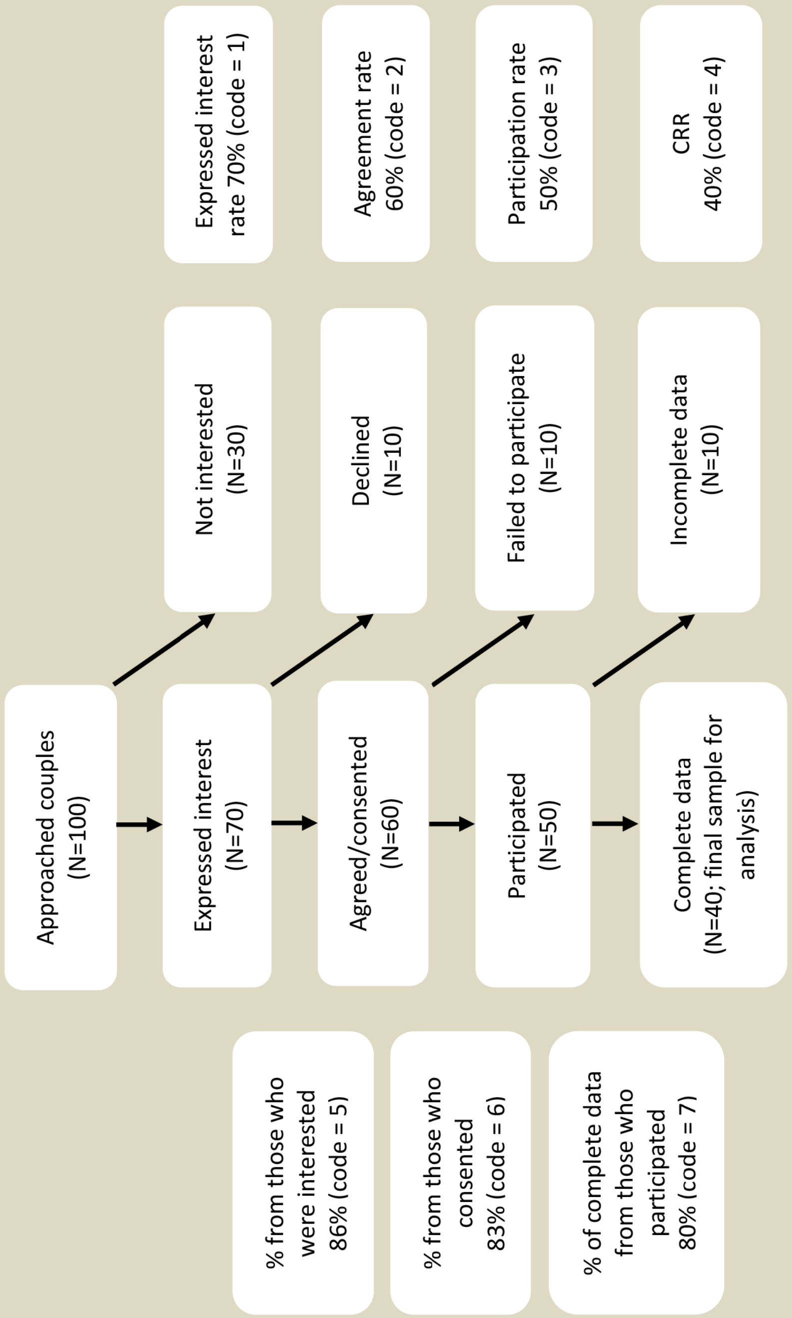
Methods

Design and Search Strategy

A systematic review of response rates in studies about couples coping with cancer was conducted, using when applicable the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA statement 2009). The search strategy used was identical to the one described in a previous meta-analysis that examined studies dealing with distress in couples coping with cancer (Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008). Research papers published between January 1980 and May 2011 were identified in MEDLINE, PsycINFO, EMBASE, and CINAHL. The search terms included: (Neoplasms or Cancer) and (Spouse$ or Partner$ or Caregiver$ or Couple$ or Husband$ or Wife$ or Family or Marriage or Interpersonal-relations, or Human-relation$) and (Quality-of-Life or Well-Being or Distress or Psychological-Stress or Depression or Adjustment or Adaptation). For the full electronic search strategy see Supplemental material B. An extra effort was made to also capture publications that had not yet been indexed with

Mesh-headings, by adding the following terms Spouses (ti) OR couples (ti) only between January 1st and May 1st 2011.

Figure 1 Flow-chart depicting how every rate has been calculated



Note. Flow chart depicting how every rate has been calculated. This figure depicts a fictional study in which 100 couples were approached. This example demonstrates the different rates. On the right hand side, you see rates in which the number of couples included in each step is divided by the number of couples approached.

Selection Process and selection Criteria

Abstracts of all identified articles were screened by the first author of this paper based on defined eligibility criteria. A random selection of 25% of the abstracts was independently assessed by the second author to check inter-rater reliability. A four percent disagreement was the result of a more conservative screening by the first author; these studies were selected for the full text reading. Based on Hagedoorn et al. (2008), the following criteria were formulated:

1. Published in a scientific journal.
2. Full text articles were available in Dutch, German, or English.
3. Patients were in active treatment or remission including patients with advanced or end-stage disease.
4. Data came from a cross-sectional or longitudinal design. We only included studies that examined some aspect of well-being in the absence of an intervention, because couples may be more motivated to volunteer for studies that offer an intervention versus studies that only seek information from them.
5. The initial sample included at least 20 couples at T1.
6. Partners were distinguishable (already in the recruitment procedure) from other family members or caregivers that might be included in the same sample.
7. Studies were oriented toward couples, meaning that the focus of the article is couples' adjustment. When the analyses were not done for patients and partners together in one model (multi-level analysis) then at least both patients' and partners' adjustment should be presented.

Studies were excluded based on the following criteria:

1. Articles in which the focus of the study was merely on one of the partners (patients or partners), even if both filled in questionnaires. Motivations to take part in a study that focuses on couples' adaptation might differ significantly from a study that focuses on patients' QOL, caregiver burden, or cancer impact on children. Therefore, proxy studies, caregiver studies and family studies were excluded.
2. Studies that are the immediate or later spin-off of patient only or partner only studies, when one of the partners started his/her participation before the other was approached (e.g., partners entered as part of follow-up). Patients or partners who already participate in a related study may differ from participants with no such experience.

3. Studies in which patients (who had a partner) could nominate another significant person than their partner. This was done because the focus of the study was not the couple.

Care was taken to ensure as best as possible that two papers concerning the same or overlapping samples were not included. Hence, after studies were selected based on the inclusion criteria, it was checked whether multiple reports from one research group came from independent samples by comparing the descriptions of the procedure and demographic data of participants. We checked with the authors when there was doubt whether or not samples were independent. In case of dependent samples, one of the papers was selected based on the following criteria (in order of importance): (1) largest sample size (e.g., largest approach), and (2) first publication on couples' data.

Selection results and characteristics of the selected studies

The electronic literature search yielded a total of 1,165 unique titles, of which 214 studies were included for full text screening (for more details see Figure 2). Our final selection included 83 publications of original studies that described 86 unique samples.

Mixed diagnosis samples were most frequently examined (33), followed by couples dealing with breast cancer (23), prostate (14) and other specific types (16). The majority (n=53) of the samples had a cross-sectional design, 33 were longitudinal, of them three included videotaped observations. The time since diagnosis varied considerably, with 21 samples approaching couples within the first six months after diagnosis, 34 samples more than six months after diagnosis, and in nine samples the time since diagnosis was varied. For nine samples, couples were approached within the first six months after surgery or treatment and for 13 samples no information about timing was available. Similarly, there was significant variation in stages of cancer across studies: 12 samples consisted of patients with a relatively good prognosis (stage I/II, no metastases), six samples included stage 3 or 4 or both, whereas 20 included patients with varied stages of disease. For 48 samples, information about the stage was not available.

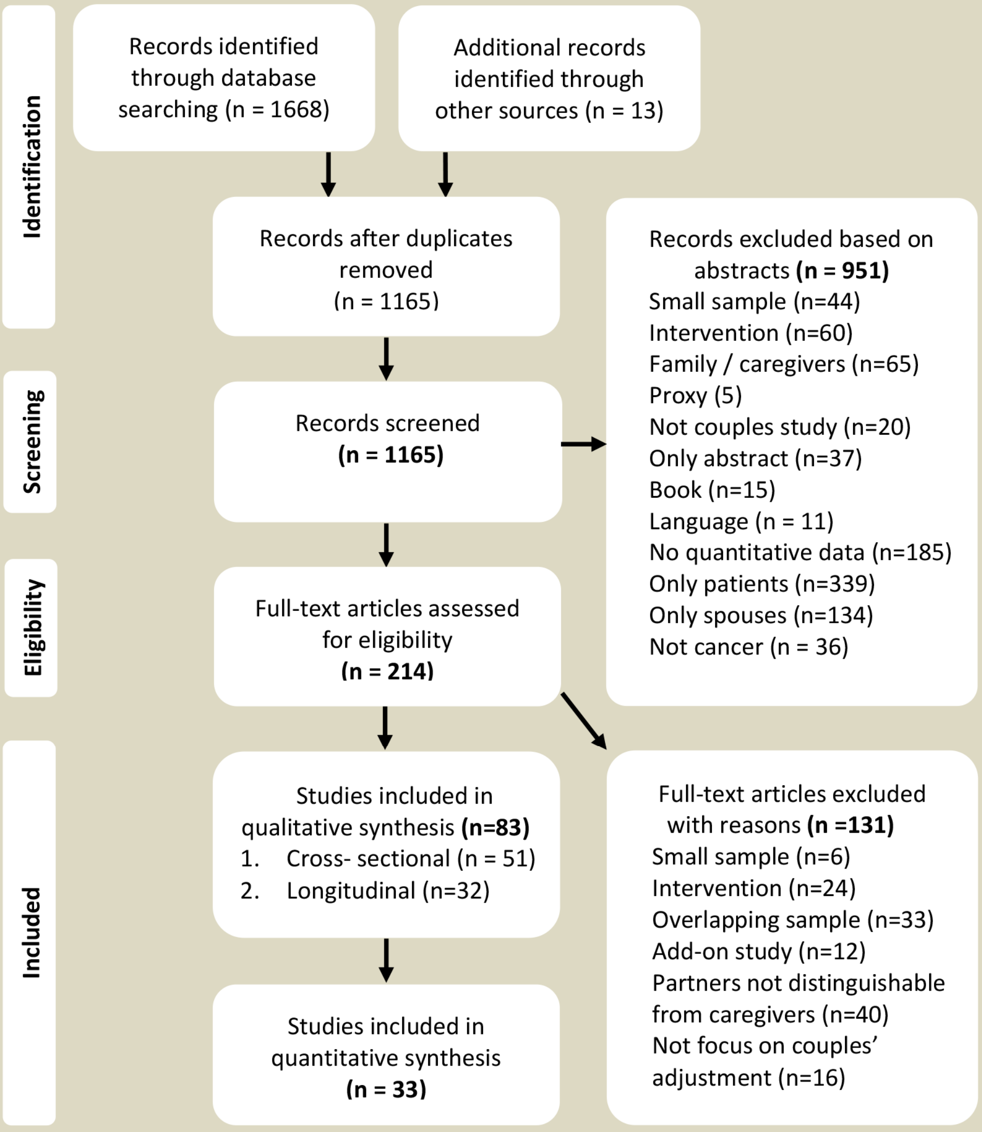


Figure 2 PRISMA Flow Diagram

Results

The CRR: How many studies reported it and what is the average?

Of the 86 samples, 31 (36%) used a sampling technique that did not allow the calculation of CRR. This concerned studies using convenience sampling (n=13) and studies using a recruitment procedure in which the number of eligible patients approached who have a partner was not known (n=18). Additionally, 22 (25%) samples were excluded because of poor reporting (i.e., information needed for calculating CRR was not given although potentially could have been provided). Thus, the CRR could be calculated for 33 (38%) out of 86 samples (the characteristics of the final sample are presented in supplemental material C). For each sample, CRR was calculated as the number of couples included in the final analysis divided by the initial eligible partnered patients / couples that were approached. Based on the final 33 samples, we found an average CRR of 58% (*SD* = 17%) with a considerable range of 25% to 90%.

How many studies reported other more favorable rates instead of CRR

For the second research goal, we retrieved rates regarding recruitment that were reported. Seven different rates to describe the proportion of eligible and included participants in different phases of recruitment were identified (e.g. expressed interest rate, agreement rate, participation rate, CRR). For a detailed description of the rates, see Figure 1. In cases where more than one rate was reported, the rate closer to the CRR was registered. Eight studies reported CRR accurately (CRR_M= 58%), 10 did not report any rate at all. The remaining 15 reported various alternative rates. Some presented the percentage of those approached who expressed interest (*N*=1, 71%), who agreed (*N*=6, *M*=66%), or who participated (*N*=3, *M*=69%). Others presented the percentage of those who agreed to participate that actually participated (*N*=4, *M*=74%) and the percentage of those who participated that have complete data (*N*=1, *M*=73%). We calculated the CRRs and compared them with the rates reported in the papers (*N*=23). A paired sample t-test revealed that CRRs for these studies were significantly lower than the alternative rates that were actually reported in the papers (*M*=57% vs. 65%, *t*(23) =3.743 *p*=0.001, *r*=0.816).

Discussion

The results might give the impression that, overall, samples of couples in cancer research are approaching the unofficial golden rule of a minimum response rate of 60%. However, one should be cautious to draw this conclusion. First, a definite answer to “What is the CRR in cancer studies?” cannot be provided since the final sample for calculating CRR was only 38% of the samples included in this systematic review. Second, a huge range was found between studies with the highest CRR of 90% and lowest of 25%. Furthermore, it has to be noted that the calculation of CRR is based on the assumption that the samples were nonselective, that is, that either a random sample or a consecutive number of eligible couples were invited. Unfortunately, authors were not always explicit about the way of sampling and we had to assume that the sampling was essentially nonselective unless it could be proven otherwise. Speculating that selective samples usually have higher response rates, this may have resulted in an overestimation of the average CRR.

Some may argue that a relatively low response rate may be enough for rejection. Support for this belief can be seen in our finding that in most studies, the CRR was not reported transparently. That is, authors provided higher rates that were less indicative of their studies' generalizability. For example, one paper (Ming, 2002) reported a 100% consent rate, meaning all patients that were approached agreed to participate in the study. Although not incorrect, a closer look revealed that only 53% of those who had been approached actually participated and were analyzed in the final analysis (thus CRR is 53%). Unfortunately, this point was not discussed in this and other articles.

At least seven rates can be reported for describing the number of participants included in the different phases of recruitment. In the current literature, authors used the labels of these rates interchangeably or used different labels for the same rate, and in some cases the label "response rate" was being used when it should not (e.g., Ptacek, Ptacek, & Dodge, 1994). Our paper is the first to discuss the issue of response rate in the context of couples-based research. We provide clear definitions of the different rates in Figure 1.

Limitations

First, this paper reviewed only published studies. If unpublished work has somewhat lower CRRs than published work, lower CRRs are underrepresented in this review. Second, couples research in other contexts is likely to have similar response rate issues, but we focused our review on research in psycho-oncology since this is one of the largest research literatures on couples facing illness. Third, we examined only one criterion of generalizability namely CRR. CRR is only one and not a sufficient indicator to determine the generalizability of findings from a particular study. Many more participant and procedural details are needed to provide sufficient information so that a reader is able to determine the generalizability**.**

Recommendations

Although there is a tension between complete reporting and available space, authors should provide the necessary information to calculate CRR and other information to evaluate the external validity of the sample. First of all, the calculation of the CRR presented in this review paper (i.e., the number of couples in the final analysis divided by eligible partnered patients or couples approached) is recommended as a standard in future publications. Any decision to use other rates should be justified, transparent, and critically discussed. Furthermore, there are several reporting standards and checklist (e.g., Journal article reporting standards - JARS, 2008) available that should be applied also in couples-based studies. In addition, one reporting issue that was not specifically addressed in previous reporting standards but that may affect the ability to calculate the CRR is the way couples were approached. Unfortunately, researchers often did not describe clearly the approach they used. We recommend using the labels presented in supplemental material A to describe the recruitment procedure.

The CRR should be evaluated and discussed. A low CRR may be indicative of a biased sample. When there is a concern about the representativeness of the sample or a suspicion regarding non-response bias, attempts should be made to estimate the potential bias (e.g., Was non-response selective?) and evaluate its consequences (e.g., Might it have affected the score distribution on core variables?). For example, the consequences of bias could be evaluated by comparing findings with results of other studies that used a more representative sample (e.g., Hagedoorn, Buunk, Kuijer, Wobbes, & Sanderman, 2000). Furthermore, researchers should provide a meaningful discussion of these issues. Finally, information about relatively high CRRs is also very important; especially information about how it was achieved may help other researchers to improve their response rates. It also has to be noted that a very high response rate does not automatically mean that one can generalize the findings to all couples dealing with cancer. For example, findings from a study with a high response rate in an area with a specific ethnic make-up may not be generalized to a population with a different ethnic make-up.

Conclusions

This review encourages future publications to provide appropriate, transparent descriptions of their samples so that readers can make informed decisions regarding the generalizability of the findings. Authors as well as journal editors should strive to achieve this goal. CRR is only one indicator of the findings' potential generalizability and not a sufficient indicator to determine the quality of a manuscript. Some of the findings presented in a paper might not be affected by a relatively low CRR while others are. If the representativeness of a sample is biased, for example if there is an overrepresentation of more functional relationships, the results might still be interesting and relevant for this specific group. Nonetheless, the next step should be to increase efforts regarding the recruitment and understanding of underrepresented couples. Finally, we hope that this review paper will raise awareness for the challenges couples-based researchers, in psycho-oncology and other illness contexts, are facing when trying to achieve a high CRR.

Supplemental materials:

- **Supplemental material A:** Ways of approaching couples
- **Supplemental material B:** Full electronic search strategy
- **Supplemental material C:** Summary of the studies that CRR could be calculated

Supplemental material A Ways of approaching couples

Name	Description	Strengths and limitations	Recommendations
True couples approach[1]	Partnered patients and their partners are approached together and asked to participate as a couple, for example during consultation visits when both partners are present.	**Strength**: CRR can be calculated. Using this approach researchers are assured that both partners have received the invitation to participate in the study. This promotes a couples' decision to participate in the study. **Limitation**: A pre-selection is made. Instead of approaching all partnered patients, researchers approach only patients who come together with their partner. It might be that patients and partners who come together to the clinic are significantly different from patients and couples of which only the patient is present.	Register how many patients (that had a partner) were not approached because they came without their partner. When this number is unknown, acknowledge it as a limitation. Indicate clearly in the discussion section that the results can only be applied to patients and partners that were approached together.
Couples approach (through patients)[2]	Partnered patients are approached, but only couples can participate. Patients are the link to the partner, but the decision is made by the couple as a unit. A classic example is sending a letter to patients inviting both patients and partners to participate in a couples-based study.	**Strength**: CRR can be calculated. **Limitation**: The initiative is mainly in the hands of the patients. In some cases, patients may have already decided for the partner that he or she does not want to participate.	Register as clearly as possible the reasons for refusal.

Supplemental material A (continued) Ways of approaching couples

Name	Description	Strengths and limitations	Recommendations
Partnered patients approach (stepped procedure)[3]	Partnered patients and partners are approached sequentially, but only couples can participate. Utilizing this approach consenting patients approve of the research team approaching their partners separately.	**Strength**: CRR can be calculated. More information about partners' refusal can be obtained. The research team has a direct contact with the partners. Meaning that the research team shares the responsibility of recruitment with the patients. **Limitation**: Patients may not approve contacting the partner or decide for the partner that he/she is not interested.	Register as clearly as possible the reasons for refusal.
Individual decision approach[4]	Partnered patients and partners are approached separately, with the aim of recruiting the couple but allowing participation as individuals. An example is contacting partners through support groups.	**Strength**: CRR can be calculated. Including individuals that will not participate in a couple-based study (due to partner refusal). This may help researchers to gain more information about non-response bias. **Limitation**: Because the possibility to participate in the study as an individual is open perhaps some potential couples will be lost.	In the initial approach invite the couple as a unit to participate in the study. Provide the option to participate as an individual based on refusal.
Un-partnered patients' approach[5]	Patients (either single or partnered) are approached and asked to participate with their partner if applicable. An example is sending a letter to all patients in a clinic (without knowing if they are partnered or not).	**Strength**: Large groups can be contacted more easily, for example by using registries. **Limitation:** In most of the cases, researchers that utilize this approach are only able to collect information about relationship status of patients who were willing to participate; hence the number of eligible partnered patients approached is unknown and CRR cannot be calculated.	(1) Researchers may ask patients whether they have a partner, regardless of whether or not the patient is interested in participation (2) Make a special attempt to estimate how many partnered patients were approached (e.g., based on hospital registration). (3) Acknowledge that the sample's representativeness is unknown.

Supplemental material B Full electronic search strategy

03052011	**Cinahl**	**PsycINFO**	**Pubmed**	**Embase**
Cancer	(MM "Neoplasms+") or TI cancer or AB cancer	Explode the term Neoplasms: DE "Neoplasms" OR DE "Benign Neoplasms" OR DE "Breast Neoplasms" OR DE "Endocrine Neoplasms" OR DE "Leukemias" OR DE "Nervous System Neoplasms" OR DE "Terminal Cancer" OR DE "Nervous System Neoplasms" OR DE "Brain Neoplasms" OR DE "Glioma" OR TI cancer OR AB cancer	"Neoplasms"[Majr] OR cancer[tiab]	'neoplasm'/exp/mj OR cancer.ti,ab
Couples	(MM "Interpersonal Relations" or MM "Caregivers") AND TI (spouse* OR wife OR wives OR husband* OR marriage OR marital OR partner*) or AB (spouse* OR wife OR wives OR husband* OR marriage OR marital OR partner*) OR MH "Spouses" or MH "Marriage" OR MH "Sexual Partners" OR TI spouses OR couples (only when added to the database between 01/01/2011 and 01/05/2011 to capture publications that had not yet been indexed with Mesh-headings	(MM "Caregivers" OR MM "Interpersonal Relationships") AND TI (spouse* or wife or wives or husband* or marriage or marital or partner*) or AB (spouse* or wife or wives or husband* or marriage or marital or partner*) or KW (spouse* or wife or wives or husband* or marriage or marital or partner*) OR DE "Couples" OR DE "Spouses" OR DE "Husbands" OR DE "Wives" OR DE "Marital Relations" OR DE "Sexual Partners" OR TI spouses OR couples (only when added to the database between 01/01/2011 and 01/05/2011 to capture publications that had not yet been indexed with Mesh-headings	("Caregivers"[Majr] OR "Interpersonal Relations"[Majr:NoExp]) AND (spouse*[tiab] or wife[tiab] or wives[tiab] or husband*[tiab] or marriage[tiab] or marital[tiab] or partner*[tiab]) OR "Spouses"[Mesh] OR "Sexual Partners"[Mesh] OR "Marriage"[Mesh] OR spouses[ti] OR couples[ti] (only when added to the database between 01/01/2011 and 01/05/2011 to capture publications that had not yet been indexed with Mesh-headings	(('sexuality'/exp/mj OR 'caregiver'/exp/mj OR 'human relation'/exp/mj AND (spouse* OR wife OR wives OR husband* OR marriage OR marital OR partner*)) OR 'spouse'/exp OR 'marriage'/exp OR spouses:ti OR couples:ti (only when added to the database between 01/01/2011 and 01/05/2011 to capture publications that had not yet been indexed with Mesh-headings

Supplemental material B (continued) Full electronic search strategy

03052011	**Cinahl**	**PsycINFO**	**Pubmed**	**Embase**
Depression / distress / QoL	MH "Social Adjustment" OR MH "Adaptation, Psychological" OR MH "Stress, Psychological" OR MH "Psychological Well-Being" OR MH "Depression") OR MM "Quality of Life" OR TI distress or AB distress	DE "Major Depression" OR DE "Depression (Emotion)" OR DE "Distress" OR DE "Psychological Stress" OR DE "Social Adjustment" OR DE "Well Being" OR MM "Quality of Life" OR DE "Life Satisfaction" OR DE "Coping Behavior" or TI distress or AB distress or KW distress	"Quality of Life"[Majr] OR "Depression"[Mesh] OR "Depressive Disorder"[Mesh] OR "Stress, Psychological"[Mesh] OR "Adaptation, Psychological"[Mesh] OR "Social Adjustment"[Mesh] OR distress[tiab]	'coping behavior'/de OR 'mental stress'/exp OR 'depression'/exp OR 'major depression'/exp OR 'wellbeing'/exp OR 'quality of life'/mj OR distress:ab,ti

Supplemental material C: Summary of the studies that CRR could be calculated

Citation	**Cancer diagnosis**	**Study design**	**No. of couples approached**	**No. of couples in T1**	**CRR**	**Hierarchy code**	**Rate reported**	**Name of the rate reported**
Axelsson et al., 1998	Mix	L	53	37	70%	4	69%	Patients enrolment
Badr et al., 2008	Lung	L	344	158	46%	6	66%	-
Badr et al., 2009	Prostate	CS	245	116	47%	1	71%	Express interest
Badr et al., 2010	Breast	L	343	191	56%	7	73%	Passive refusal (recode)
Ben-Zur et al., 2001	Breast	CS	81	73	90%	N.A	-	-
Campbell et al., 2004	Prostate	CS	157	40	25%	2	29%	Refusal rate (recode)
Couper et al., 2006	Prostate	L	141	103	73%	4	73%	-
Dagan, et al., 2011	Colorectal	L	280	88	31%	N.A	-	Relatively low RR
Dorval et al., 2005	Breast	L	399	308	77%	3	87%	Patients participation
Ezer et al., 2011	Prostate	L	188	81	43%	N.A	-	-
Garos et al., 2007	Prostate	CS	150	57	38%	N.A	-	-
Gilbar et al., 2007	Breast	CS	71	57	80%	N.A	-	-
Goebel et al., 2010	H&N	CS	47	26	55%	N.A	-	-

* CS – cross-sectional study / L – Longitudinal / H&N – Head and Neck diagnosis.

Supplemental material C (continued) Summary of the studies that CRR could be calculated

Citation	**Cancer diagnosis**	**Study design**	**No. of couples approached**	**No. of couples in T1**	**CRR**	**Hierarchy code**	**Rate reported**	**Name of the rate reported**
Goldzweig et al., 2009	Colorectal	CS	258	231	89%	2	94%	Refusal (recode)
Hagedoorn et al., 2000	Mixed	CS	110	68	62%	N.A	-	-
Hinnen et al., 2008	Breast	L	284	92	32%	4	32%	-
Jenewein et al., 2008	Oral	CS	60	31	52%	4	52%	Couples' response rate
Langer et al., 2007	Mixed	CS	66	42	64%	N.A	-	-
Langer et al., 2009	Mixed	L	136	80	59%	2	76%	Agreement rate
Ming et al., 2002	Breast	CS	86	46	53%	2	100%	Patients consent rate
Manne et al., 2007	Breast	L	630	235	37%	2	41%	Consented
Manne et al., 2010	Mixed	CS	370	109	29%	4	29%	-
Mantani et al., 2007	Breast	CS	67	46	69%	4	69%	Rate of data available
Northouse et al., 1987	Breast	L	73	50	68%	3	71%	-
Northouse et al., 1995	Breast	CS	108	74	68%	4	68%	Patients’ response rate

* CS – cross-sectional study / L – Longitudinal / H&N – Head and Neck diagnosis.

Supplemental material C (continued) Summary of the studies that CRR could be calculated

Citation	**Cancer diagnosis**	**Study design**	**No. of couples approached**	**No. of couples in T1**	**CRR**	**Hierarchy code**	**Rate reported**	**Name of the rate reported**
Norton et al., 2007	Mixed	L	792	377	48%	6	66%	Provide informed consent but did not return any questionnaires
Peleg-Oren et al., 2001	Mixed	CS	54	38	70%	N.A	-	-
Porter et al., 2005	Mixed	CS	68	45	66%	N.A	-	-
Ptacek et al., 1994	Breast	CS	48	36	75%	6	86%	Response rate
Tuinman et al., 2007	Testicular	L	30	21	70%	4	70%	-
Tuinstra et al., 2004	Colorectal	L	263	179	68%	6	77%	From the one who agree
Vickery et al., 2003	H&N	CS	87	44	51%	2	59%	Refusal (recode)
Walker et al., 1997	Breast	CS	135	58	43%	3	49%	Participation rate

* CS – cross-sectional study / L – Longitudinal / H&N – Head and Neck diagnosis.

Footnotes

[1] Example of a publication using true couples approach: Barnoy et al., 2006
[2] Example of a publication using couples approach (through patients): Hagedoorn et al., 2000
[3] Example of a publication using partnered patients approach (stepped procedure): Badr et al., 2010
[4] Example of a publication using individual decision approach: Garos et al., 2007
[5] Example of a publication using un-partnered patients' approach: Silver-Aylaian & Cohen, 2001

Reference List

Aday, L. A., & Llewellyn, J., Cornelius. (2006). *Designing and conducting health surveys* (3rd ed.) San Francisco: Jossey-Bass.

* Axelsson, B., & Sjoden, P. O. (1998). Quality of life of cancer patients and their spouses in palliative home care. *Palliative Medicine, 12*(1), 29-39. doi:10.1191/026921698676629560

* Badr, H., Acitelli, L. K., & Carmack Taylor, C. L. (2008). Does talking about their relationship affect couples' marital and psychological adjustment to lung cancer? *Journal of Cancer Survivorship, 2* (1), 53-64. doi:10.1002/pon.3200

* Badr, H., Carmack, C. L., Kashy, D. A., Cristofanilli, M., & Revenson, T. A. (2010). Dyadic coping in metastatic breast cancer. *Health Psychology, 29*(2), 169-180. doi:10.1037/a0018165

* Badr, H., & Carmack Taylor, C. L. (2009). Sexual dysfunction and spousal communication in couples coping with prostate cancer. *Psycho-Oncology, 18*(7), 735-746.

* Baider, L., & Bengel, J. (2001). Cancer and the spouse: Gender-related differences in dealing with health care and illness. *Critical Reviews in Oncology/Hematology, 40*, 115-123. doi:10.1016/S1040-8428(01)00137-8

* Baider, L., & Denour, A. K. (1999). Psychological distress of cancer couples: A levelling effect. *New Trends in Experimental & Clinical Psychiatry, 15*(4), 197-203.

* Baider, L., & Kaplan De-Nour, A. (1988). Adjustment to cancer: Who is the patient--the husband or the wife? *Israel Journal of Medical Sciences, 24*(9-10), 631-636.

* Baider, L., Koch, U., Esacson, R., & De-Nour, A. K. (1998). Prospective study of cancer patients and their spouses: The weakness of marital strength. *Psycho-Oncology, 7*(1), 49-56.

* Barnoy, S., Bar-Tal, Y., & Zisser, B. (2006). Correspondence in informational coping styles: How important is it for cancer patients and their spouses? *Personality and Individual Differences, 41* (1), 105-115. doi:10.1016/j.paid.2005.12.013

* Ben-Zur, H., Gilbar, O., & Lev, S. (2001). Coping with breast cancer: Patient, spouse, and dyad models. *Psychosomatic Medicine, 63*(1), 32-39.

* Berg, C. A., Wiebe, D. J., Butner, J., Bloor, L., Bradstreet, C., Upchurch, R., . . . Patton, G. (2008). Collaborative coping and daily mood in couples dealing with prostate cancer. *Psychology & Aging, 23*(3), 505-516.

* Campbell, L. C., Keefe, F. J., McKee, D. C., Edwards, C. L., Herman, S. H., Johnson, L. E., . . . Donattuci, C. F. (2004). Prostate cancer in african americans: Relationship of patient and partner self-efficacy to quality of life. *Journal of Pain and Symptom Management, 28*(5), 433-444.

Biedrzycki, B. A. (2010). Decision making for cancer clinical trial participation: A systematic review. *Oncology Nursing Forum, 37*(6), E387-E399. doi:10.1188/10.ONF.E387-E399

* Carter, R. E., & Carter, C. A. (1993). Individual and marital adjustment in spouse pairs subsequent to mastectomy. *American Journal of Family Therapy, 21*, 291-300. doi:10.1080/01926189308251000

* Chen, M. L., Chu, L., & Chen, H. C. (2004). Impact of cancer patients' quality of life on that of spouse caregivers. *Supportive Care in Cancer : Official Journal of the Multinational Association of Supportive Care in Cancer, 12*(7), 469-475.

* Cliff, A. M., & MacDonagh, R. P. (2000). Psychosocial morbidity in prostate cancer: II. A comparison of patients and partners. *BJU International, 86*(7), 834-839. doi:10.1046/j.1464-410x.2000.00914.x

* Couper, J. W., Bloch, S., Love, A., Duchesne, G., Macvean, M., & Kissane, D. W. (2006). The psychosocial impact of prostate cancer on patients and their partners. *Medical Journal of Australia, 185*(8), 428-432.

* Dagan, M., Sanderman, R., Schokker, M. C., Wiggers, T., Baas, P. C., van Haastert, M., & Hagedoorn, M. (2011). Spousal support and changes in distress over time in couples coping with cancer: The role of personal control. *Journal of Family Psychology, 25*(2), 310-318. doi:10.1037/a0022887

* Dalton, W. T.,III, Nelson, D. V., Brobst, J. B., Lindsay, J. E., & Friedman, L. C. (2007). Psychosocial variables associated with husbands' adjustment three months following wives' diagnosis of breast cancer. *Journal of Cancer Education, 22*(4), 245-249.

* Dar, R., Beach, C. M., Barden, P. L., & Cleeland, C. S. (1992). Cancer pain in the marital system: A study of patients and their spouses. *Journal of Pain and Symptom Management, 7*(2), 87-93. doi:10.1016/0885-3924(92)90119-3

* Dorval, M., Guay, S., Mondor, M., Masse, B., Falardeau, M., Robidoux, A., . . . Maunsell, E. (2005). Couples who get closer after breast cancer: Frequency and predictors in a prospective investigation. *Journal of Clinical Oncology : Official Journal of the American Society of Clinical Oncology, 23*(15), 3588-3596.

* Douglass, L. G. (1997). Reciprocal support in the context of cancer: Perspectives of the patient and spouse. *Oncology Nursing Forum, 24*(9), 1529-1536.

* Ey, S., Compas, B. E., Epping-Jordan, J., & Worsham, N. (1998). Stress responses and psychological adjustment in patients with cancer and their spouses. *Journal of Psychosocial Oncology, 16*(2), 59-77. doi:10.1300/J077V16N02_04

* Ezer, H., Chachamovich, J. L. R., & Chachamovich, E. (2011). Do men and their wives see it the same way? congruence within couples during the first year of prostate cancer. *Psycho-Oncology, 20*(2), 155-164. doi:http://dx.doi.org/10.1002/pon.1724

Fincham, J. E. (2008). Response rates and responsiveness for surveys, standards, and the *journal*. *American Journal of Pharmaceutical Education, 72*(2), 43. doi:10.5688/aj720243

* Fuller, S., & Swensen, C. H. (1992). Marital quality and quality of life among cancer patients and their spouses. *Journal of Psychosocial Oncology, 10*(3), 41-56.

* Galbraith, M. E., Pedro, L. W., Jaffe, A. R., & Allen, T. L. (2008). Describing health-related outcomes for couples experiencing prostate cancer: Differences and similarities. *Oncology Nursing Forum, 35*(5), 794-801. doi:10.1188/08.ONF.794-801

* Garos, S., Kluck, A., & Aronoff, D. (2007). Prostate cancer patients and their partners: Differences in satisfaction indices and psychological variables. *Journal of Sexual Medicine, 4*(5), 1394-1403. doi:10.1111/j.1743-6109.2007.00545.x

* Gilbar, O., & Zusman, A. (2007). The correlation between coping strategies, doctor-patient/spouse relationships and psychological distress among women cancer patients and their spouses. *Psycho-Oncology, 16*(11), 1010-1018.

* Goebel, S., von Harscher, M., & Mehdorn, H. M. (2011). Comorbid mental disorders and psychosocial distress in patients with brain tumours and their spouses in the early treatment phase. *Supportive Care in Cancer, 19*(11), 1797-1805.

* Goldzweig, G., Hubert, A., Walach, N., Brenner, B., Perry, S., Andritsch, E., & Baider, L. (2009). Gender and psychological distress among middle- and older-aged colorectal cancer patients and their spouses: An unexpected outcome. [review] [63 refs]. *Critical Reviews in Oncology-Hematology, 70*(1), 71-82.

* Gotay, C. C. (1984). The experience of cancer during early and advanced stages: The views of patients and their mates. *Social Science & Medicine, 18*(7), 605-613.

* Green, H. J., Wells, D. J. N., & Laakso, L. (2011). Coping in men with prostate cancer and their partners: A quantitative and qualitative study. *European Journal of Cancer Care, 20*(2), 237-247. doi:10.1111/j.1365-2354.2010.01225.x

* Gritz, E. R., Wellisch, D. K., Siau, J., & Wang, H. (1990). Long-term effects of testicular cancer on marital relationships. *Psychosomatics, 31*(3), 301-312. doi:10.1016/S0033-3182(90)72168-8

* Hagedoorn, M., Buunk, B. P., Kuijer, R. G., Wobbes, T., & Sanderman, R. (2000). Couples dealing with cancer: Role and gender differences regarding psychological distress and quality of life. *Psycho-Oncology, 9*(3), 232-242. doi:10.1002/1099-1611(200005/06)9:3<232::AID-PON458>3.0.CO;2-J

Hagedoorn, M., Dagan, M., Puterman, E., Hoff, C., Meijerink, W. J., Delongis, A., & Sanderman, R. (2011). Relationship satisfaction in couples confronted with colorectal cancer: The interplay of past and current spousal support. *Journal of Behavioral Medicine, 34*(4), 288-297. doi:10.1007/s10865-010-9311-7; 10.1007/s10865-010-9311-7

Hagedoorn, M., Sanderman, R., Bolks, H. N., Tuinstra, J., & Coyne, J. C. (2008). Distress in couples coping with cancer: A meta-analysis and critical review of role and gender effects. *Psychological Bulletin, 134*(1), 1-30. doi:10.1037/0033-2909.134.1.1

* Hannum, J. W., Giese-Davis, J., Harding, K., & Hatfield, A. K. (1991). Effects of individual and marital variables on coping with cancer. *Journal of Psychosocial Oncology, 9*(2), 1-20. doi:10.1300/J077v09n02_01

* Hasson-Ohayon, I., Goldzweig, G., Braun, M., & Galinsky, D. (2010). Women with advanced breast cancer and their spouses: Diversity of support and psychological distress. *Psycho-Oncology, 19*(11), 1195-1204. doi:10.1002/pon.1678

Higginson, I. J., & Sen-Gupta, G. (2000). Place of care in advanced cancer: A qualitative systematic literature review of patient preferences. *Journal of Palliative Medicine, 3*(3), 287-300. doi:10.1089/jpm.2000.3.287

* Hinnen, C., Ranchor, A. V., Sanderman, R., Snijders, T. A., Hagedoorn, M., & Coyne, J. C. (2008). Course of distress in breast cancer patients, their partners, and matched control couples. *Annals of Behavioral Medicine, 36*(2), 141-148. doi:10.1007/s12160-008-9061-8

* Hoskins, C. N. (1995). Adjustment to breast cancer in couples. *Psychological Reports, 77*(2), 435-454. doi:10.2466/pr0.1995.77.2.435

JARS. (2008). Reporting standards for research in psychology: Why do we need them? what might they be? *American Psychologist, 63*(9), 839-851. doi:10.1037/0003-066X.63.9.839

* Jenewein, J., Zwahlen, R. A., Zwahlen, D., Drabe, N., Moergeli, H., & Buchi, S. (2008). Quality of life and dyadic adjustment in oral cancer patients and their female partners. *European Journal of Cancer Care, 17*(2), 127-135. doi:10.1111/j.1365-2354.2007.00817.x

Johnson, T., & Owens, L. (2003). Survey response rate reporting in the professional literature. *Annual Meeting of the American Association for Public Opinion Research,* Sheraton Music City, Nashville, TN. 127-133.

* Keitel, M. A., Zevon, M. A., Rounds, J. B., Petrelli, N. J., & Karakousis, C. (1990). Spouse adjustment to cancer surgery: Distress and coping responses. *Journal of Surgical Oncology, 43*, 148-153. doi:10.1002/jso.2930430305

* Keller, M., Henrich, G., Beutel, M., & Sellschopp, A. (1998). Wechselseitige belastung und unterstetzung bei paaren mit einem krebskranken. / mutuality of distress and support in couples including a cancer patient. *Psychotherapie Psychosomatik Medizinische Psychologie, 48*(9-10), 358-368.

* Knoll, N., Burkert, S., Rosemeier, H. P., Roigas, J., & Gralla, O. (2007). Predictors of spouses' provided support for patients receiving laparoscopic radical prostatectomy peri-surgery. *Psycho-Oncology, 16*(4), 312-319. doi:10.1002/pon.1061

* Kornblith, A. B., Regan, M. M., Kim, Y., Greer, G., Parker, B., Bennett, S., & Winer, E. (2006). Cancer -related communication between female patients and male partners scale: A pilot study. *Psycho-Oncology, 15*(9), 780-794.

* Kuenzler, A., Hodgkinson, K., Zindel, A., Bargetzi, M., & Znoj, H. (2011). Who cares, who bears, who benefits? female spouses vicariously carry the burden after cancer diagnosis. *Psychology & Health, 26*(3), 337-352. doi:10.1080/08870440903418877

* Lalos, A., & Eisemann, M. (1999). Social interaction and support related to mood and locus of control in cervical and endometrial cancer patients and their spouses. *Supportive Care in Cancer, 7* (2), 75-78. doi:10.1007/s005200050230

* Langer, S. L., Brown, J. D., & Syrjala, K. L. (2009). Intrapersonal and interpersonal consequences of protective buffering among cancer patients and caregivers. *Cancer, 115*(18), Suppl-25.

* Langer, S. L., Rudd, M. E., & Syrjala, K. L. (2007). Protective buffering and emotional desynchrony among spousal caregivers of cancer patients. *Health Psychology, 26*(5), 635-643. doi:10.1037/0278-6133.26.5.635

* Manne, S., & Badr, H. (2010). Intimacy processes and psychological distress among couples coping with head and neck or lung cancers. *Psycho-Oncology, 19*(9), 941-954. doi:10.1002/pon.1645

* Manne, S. L., Norton, T. R., Ostroff, J. S., Winkel, G., Fox, K., & Grana, G. (2007). Protective buffering and psychological distress among couples coping with breast cancer: The moderating role of relationship satisfaction. *Journal of Family Psychology, 21*(3), 380-388. doi:10.1037/0893-3200.21.3.380

* Mantani, T., Saeki, T., Inoue, S., Okamura, H., Daino, M., Kataoka, T., & Yamawaki, S. (2007). Factors related to anxiety and depression in women with breast cancer and their husbands: Role of alexithymia and family functioning. *Supportive Care in Cancer, 15*(7), 859-868.

* Ming, V. M. W. (2002). Psychological predictors of marital adjustment in breast cancer patients. *Psychology, Health & Medicine, 7*(1), 37-51. doi:10.1080/13548500120101540

Moher, D., Liberati, A., Tetzlaff, J., Altman, D., & The PRISMA Group. (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *Plos Med, 6*(6), e1000097. doi:10.1371/journal.pmed1000097

* Molassiotis, A., Wilson, B., Blair, S., Howe, T., & Cavet, J. (2011). Unmet supportive care needs, psychological well-being and quality of life of patients living with multiple myeloma and their partners. *Psycho-Oncology, 20*(1), 88-97. doi:10.1002/pon.1710

* Nordin, K., Wasteson, E., Hoffman, K., Glimelius, B., & Sjoden, P. O. (2001). Discrepancies between attainment and importance of life values and anxiety and depression in gastrointestinal cancer patients and their spouses. *Psycho-Oncology, 10*(6), 479-489. doi:10.1002/pon.536

* Northouse, L. L., Mood, D., Templin, T., Mellon, S., & George, T. (2000). Couples' patterns of adjustment to colon cancer. *Social Science & Medicine, 50*(2), 271-284. doi:10.1016/S0277-9536 (99)00281-6

* Northouse, L. L., & Swain, M. A. (1987). Adjustment of patients and husbands to the initial impact of breast cancer. *Nursing Research, 36*(4), 221-225. doi:10.1097/00006199-198707000-00009

* Northouse, L. L., Laten, D., & Reddy, P. (1995). Adjustment of women and their husbands to recurrent breast cancer. *Research in Nursing & Health, 18*(6), 515-524. doi:10.1002/nur.4770180607

* Norton, T. R., & Manne, S. L. (2007). Support concordance among couples coping with cancer: Relationship, individual, and situational factors. *Journal of Social and Personal Relationships, 24* (5), 675-692. doi:10.1177/0265407507081454

* Oberst, M. T., & Scott, D. W. (1988). Postdischarge distress in surgically treated cancer patients and their spouses. *Research in Nursing & Health, 11*(4), 223-233. doi:10.1002/nur.4770110404

* Offerman, M. P. J., Schroevers, M. J., L, de Boer, M. F., & Pruyn, J. F. A. (2010). Goal processes & self-efficacy related to psychological distress in head & neck cancer patients and their partners. *European Journal of Oncology Nursing, 14*(3), 231-237. doi:10.1016/j.ejon.2010.01.022

* Omne-ponten, M., Holmberg, L., Sjoden, P. O., & Bergstrom, R. (1995). The married couple's assesment of the experience of early breast cancer: A longitudinal interview study. *Psycho-Oncology, 4*, 183-190. doi:10.1002/pon.2960040303

* Passik, S. D., & Kirsh, K. L. (2005). A pilot examination of the impact of cancer patients' fatigue on their spousal caregivers. *Palliative & Supportive Care, 3*(4), 273-279.

* Peleg-Oren, N., & Sherer, M. (2001). Cancer patients and their spouses: Gender and its effect on psychological and social adjustment. *Journal of Health Psychology, 6*(3), 329-338. doi:10.1177/135910530100600306

* Perez, M. A., Skinner, E. C., & Meyerowitz, B. E. (2002). Sexuality and intimacy following radical prostatectomy: Patient and partner perspectives. *Health Psychology, 21*(3), 288-293. doi:10.1037/0278-6133.21.3.288

* Porter, L. S., Keefe, F. J., Hurwitz, H., & Faber, M. (2005). Disclosure between patients with gastrointestinal cancer and their spouses. *Psycho-Oncology, 14*(12), 1030-1042. doi:10.1002/pon.915

* Ptacek, J. T., Pierce, G. R., Ptacek, J. J., & Nogel, C. (1999). Stress and coping processes in men with prostate cancer: The divergent views of husbands and wives. *Journal of Social and Clinical Psychology, 18*(3), 299-324. doi:10.1521/jscp.1999.18.3.299

* Ptacek, J. T., Ptacek, J. J., & Dodge, K. L. (1994). Coping with breast cancer from the perspectives of husbands and wives. *Journal of Psychosocial Oncology, 12*(3), 47-72. doi:10.1300/J077V12N03_04

* Quinn, M. E., Fontana, A. F., & Reznikoff, M. (1986). Psychological distress in reaction to lung cancer as a function of spousal support and coping strategy. *Journal of Psychosocial Oncology, 4* (4), 79-90. doi:10.1300/J077v04n04_07

* Rabin, E. G., Heldt, E., Hirakata, V. N., Bittelbrunn, A. C., Chachamovich, E., & Fleck, M. P. (2009). Depression and perceptions of quality of life of breast cancer survivors and their male partners. *Oncology Nursing Forum, 36*(3), E153-E158.

* Rodrigue, J. R., & Hoffmann, R. G. (1994). Caregivers of adults with cancer: Multidimensional correlates of psychological distress. *Journal of Clinical Psychology in Medical Settings, 1*(3), 231-244. doi:10.1007/BF01989624

* Shields, C. G., Travis, L. A., & Rousseau, S. L. (2000). Marital attachment and adjustment in older couples coping with cancer. *Aging and Mental Health, 4*, 223-233. doi:10.1080/713649921

* Silver-Aylaian, M., & Cohen, L. H. (2001). Role of major lifetime stressors in patients' and spouses' reactions to cancer. *Journal of Traumatic Stress, 14*(2), 405-412. doi:10.1023/A:1011129321431

* Soloway, C. T., Soloway, M. S., Kim, S. S., & Kava, B. R. (2005). Sexual, psychological and dyadic qualities of the prostate cancer 'couple'. *BJU International, 95*(6), 780-785.

* Tuinman, M. A., Fleer, J., Sleijfer, D. T., Hoekstra, H. J., & Hoekstra-Weebers, J. E. (2005). Marital and sexual satisfaction in testicular cancer survivors and their spouses. *Supportive Care in Cancer :*

Official Journal of the Multinational Association of Supportive Care in Cancer, 13(7), 540-548. doi:10.1007/s00520-004-0758-3

* Tuinman, M. A., Hoekstra, H. J., Sleijfer, D. T., Fleer, J., Vidrine, D. J., Gritz, E. R., & Hoekstra-Weebers, J. E. (2007). Testicular cancer: A longitudinal pilot study on stress response symptoms and quality of life in couples before and after chemotherapy. *Supportive Care in Cancer, 15*(3), 279-286.

* Tuinstra, J., Hagedoorn, M., Van Sonderen, E., Ranchor, A. V., Van, d. B., Nijboer, C., & Sanderman, R. (2004). Psychological distress in couples dealing with colorectal cancer: Gender and role differences and intracouple correspondence. *British Journal of Health Psychology, 9*(4), 465-478. doi:10.1348/1359107042304588

* Verdonck-de, L.,I, Eerenstein, S. E., Van, d. L., Kuik, D. J., de, B. R., & Leemans, C. R. (2007). Distress in spouses and patients after treatment for head and neck cancer. *Laryngoscope, 117*(2), 238-241.

* Vess, J. D., Moreland, J. R., & Schwebel, A. I. (1985). A follow-up study of role functioning and the psychological environment of families of cancer patients. *Journal of Psychosocial Oncology, 3* (2), 1-14. doi:10.1300/J077v03n02_01

* Vickery, L. E., Latchford, G., Hewison, J., Bellew, M., & Feber, T. (2003). The impact of head and neck cancer and facial disfigurement on the quality of life of patients and their partners. *Head and Neck, 25*(4), 289-296. doi:10.1002/hed.10206

* Volk, R. J., Cantor, S. B., Cass, A. R., Spann, S. J., Weller, S. C., & Krahn, M. D. (2004). Preferences of husbands and wives for outcomes of prostate cancer screening and treatment. *Journal of General Internal Medicine, 19*, 4-348. doi:10.1111/j.1525-1497.2004.30046.x

* Walker, B. L. (1997). Adjustment of husbands and wives to breast cancer. *Cancer Practice, 5*(2), 92-98.

* Weiss, T. (2002). Posttraumatic growth in women with breast cancer and their husbands: An intersubjective validation study. *Journal of Psychosocial Oncology, 20*(2), 65-80. doi:10.1300/J077v20n02_04

* Wenzel, L. B., Berkowitz, R. S., Robinson, S., Goldstein, D. P., & Bernstein, M. R. (1994). Psychological, social and sexual effects of gestational trophoblastic disease on patients and their partners. *Journal of Reproductive Medicine, 39*(3), 163-167.

* Yeo, W., Kwan, W. H., Teo, P. M., Nip, S., Wong, E., Hin, L. Y., & Johnson, P. J. (2004). Psychosocial impact of breast cancer surgeries in chinese patients and their spouses. *Psycho-Oncology, 13* (2), 132-139.

* Zacharias, D. R., Gilg, C. A., & Foxall, M. J. (1994). Quality of life and coping in patients with gynecologic cancer and their spouses. *Oncology Nursing Forum, 21*(10), 1699-1706.

Chapter 6

Potential Determinants of Response Rates in Studies on Couples Coping with Cancer.

Meirav Dagan
Robbert Sanderman
Mariët Hagedoorn

(to be submitted)

I promise to support you in times of sickness and in times of health

Cancer is increasingly recognized as a disease that affects both patients and their partners. As more studies examine the psychosocial adjustment among couples facing cancer, the challenges of recruiting couples to studies are becoming apparent. In a recent systematic review (Dagan & Hagedoorn, in press), we examined the average response rate of couples coping with cancer to couples-based studies. For this we have calculated Couples' Response Rates (CRR) for each study by dividing all analyzed couples by the number of eligible partnered patients/couples approached. Our review revealed that ostensibly samples of couples in cancer research are approaching the unofficial golden rule of a minimum response rate of 60% (CRR_M = 58%, *SD* = 17%). However, this finding should be interpreted with caution because overall reporting on couples' recruitment to observational studies in the context of caner was unsatisfactory and CRR could not be calculated for more than half of the included studies (53 samples out of 86). Moreover, we found a considerable variance of CRR across studies, ranging from 25% to 90%. This indicates that some studies succeeded more than others to include couples in their studies.

Previous publications identified a number of barriers to recruitment of couples to Intervention studies. Although detailed descriptions of the barriers to enrolling couples were not routinely provided by empirical papers describing couples-based interventions, those that did provide this information have identified that both characteristics of potential participants and the research design can affect the likelihood of participation (e.g., Fredman et al., 2009; Motzer, Moseley, & Lewis, 1997; Northouse et al., 2006). Specifically, a recent review of psychosocial interventions for couples coping with cancer indicated that across intervention studies, timing of recruitment, scheduling issues, distance from intervention center and age of the participants (i.e., younger couples are more likely to enroll than older couples) are frequently reported as barriers to recruitment (Badr & Krebs, 2013).

Despite the importance of identifying factors associated with participation, this issue has received little attention in couples-based observational studies. Except for the obvious generalizability challenge of low CRR, examining these factors is valuable because a significant portion of the budget for conducting a study is usually spent on recruitment (e.g., Motzer et al., 1997; Northouse et al., 2006). Moreover, it is not uncommon to underestimate the amount of time, planning, and organization necessary to recruit the desired number of couples into a study (e.g., Goodwina et al., 2000; Motzer et al., 1997; Northouse et al., 2006). Finally, identifying these factors may ultimately aid investigators in adapting their recruitment procedures to maximize the number of eligible couples enrolled in their studies.

The present paper represents an effort to help address this gap in the existing literature. Our goal is to describe and empirically assess facilitating and impeding factors to enrollment of couples coping with cancer into observational couples-based studies, with a focus on demographic variables and methods of approaching eligible participants. The current paper is a follow-up of the findings published in our recent systematic review (Dagan & Hagedoorn, in press). Specifically, we examined a sub-sample of papers included in the systematic review namely studies that allowed calculating CRR (n = 33) and related their CRR to different study and participants' characteristics. The current paper examined the following six factors (i.e., study design, approach size, ways of approaching participants, who approach couples, incentives, cancer diagnosis), reflect on their potential effect on CRR and provide preliminary data and examples from the literature when possible. These factors have not been studied systematically before in couples-based observational studies.

Study design. It was previously suggested, that individuals' decisions to take part in a study are influenced by the time they are asked to invest in a study, ease of participation, and data collection procedures, including the time lag between assessments (e.g., Corder & Manton, 1991; Neumark, Stommel, Given, & Given, 2001). A common perception is that in comparison to single assessment, repeated assessments introduce a greater burden on participants and therefore result in low CRRs. Nonetheless, acknowledging the importance of longitudinal evidence, there is a need to estimate the price researchers have to pay for collecting this type of data.

Approach size (and **actual participation**). An inherent part of every research proposal is a calculation of the number of couples that need to be approached to include a sufficient number of couples in the study. One may assume that approaching more couples will result in a bigger sample for analysis. However, it was previously suggested that an extended recruitment phase with more people to contact and ask for informed consent might even hinder recruitment for example, because some eligible couples become ineligible by the time that they are finally reached (Northouse et al., 2006).

Ways of approaching participants. There are many ways to recruit couples and each has its strengths and limitations. While reviewing the papers, we identified five types of approach procedures in the literature, namely: true couples approach, couples approach through patients, partnered patients approach (stepped procedure), individual decision approach, un-partnered patients approach (for details about the different approaches, see chapter 5 pages 74-76). In our review, we concluded that the way couples were approached affects the ability to calculate CRR and, therefore, it should be clearly described in a paper. The next step, which will be addressed in the current paper, is to evaluate whether the way couples were approached affected couples' willingness to participate in a study. The effort to standardize the way couples were approached is novel and unique to couples-based studies. As part of these efforts, it is important to be aware of the strengths and the limitations of each approach regarding possible effects on the CRR.

Who approach couples. Several intervention studies reported the importance of involving oncologists or other key medical staff in the referral procedure to increase participants' response rates (e.g., Goodwina et al., 2000). Nonetheless, physicians and nurses differ in their priorities to recruit participants into psychosocial studies in both clinical and research situations (e.g., Del Giudice, Leszcz, Pritchard, Vincent, & Goodwin, 1997).

Incentives. A substantial amount of literature demonstrates that monetary incentives are likely to be effective in increasing response rates to mailed surveys (e.g., Edwards et al., 2002; King & Vaughan, 2004; Szelényi, Bryant, & Lindholm, 2005). Accordingly, one reason that is often used when explaining a relatively low response rate is not compensating couples for their participation (e.g., S. Manne & Badr, 2010).

Cancer diagnosis. In most cases, little is known about couples who refused to participate in a study besides the fact that they met eligibility criteria for a specific study. Nonetheless, one clear demographic characteristic that is often known for all eligible couples is the cancer diagnosis. Some cancer types may have unique characteristics that might make the recruitment procedure more challenging than other types of cancer. For example, it was previously proposed that patients with head and neck cancers have preexisting medical and addictive issues that may reduce their interest in psychosocial studies (Manne & Badr, 2010). Although some types of cancer diagnoses may be confounded with gender and age, such as breast and prostate cancer, examining this factor is an important step in estimating the determinants of CRR.

To sum, the current paper will perform an empirical evaluation of the six factors mentioned above that might account for variability in enrollment rates for couples into studies. Our paper is the first to examine systematically this important issue in couples-based observational studies in the context of adaptation to cancer.

Methods

A systematic review of response rates in studies about couples coping with cancer was conducted. Research papers published between January 1980 and May 2011 were identified in MEDLINE, PsycINFO, EMBASE, and CINAHL. The search included: cancer, couple, distress as well as their related terms. For the full electronic search strategy see chapter 5 page 77.

Selection results and characteristics of the selected studies

Abstracts of all identified articles were screened by the first author of this paper based on defined eligibility criteria. A random selection of 25% of the abstracts was independently assessed by the last author to check inter-rater reliability. The electronic literature search yielded a total of 1,165 unique titles, of which 214 studies were included for full text screening (for more details see Figure 2 chapter 5 page 61). Studies included in the current paper are identical to the studies included in the final sample for the quantitative synthesis reported in our systematic review. This sample included 33 publications of original studies out of 86 samples originally included in the review paper.

Eligibility criteria included: Full text papers in Dutch, German, or English published in a scientific journal; Patients were in active treatment or remission; Data came from a cross-sectional or longitudinal design; The initial sample included at least 20 couples at T1; Partners were distinguishable (already in the recruitment procedure) from other family members or caregivers that might be included in the same sample; Studies were oriented toward couples, meaning that the focus of the article is couples' adjustment. For full description of inclusion and exclusion criteria see chapter 5 page 59.

Couples dealing with breast cancer were most frequently examined (12), followed by samples of couples coping with mixed cancer diagnoses (8), prostate (5), and other specific types (8). Out of 33 studies 19 had a cross-sectional design, 14 were longitudinal, and of them three included videotaped observations. The time since diagnosis varied, with 8 samples approaching couples within the first six months after diagnosis, 13 samples more than six months after diagnosis, and in three samples the time since diagnosis was varied. For four samples, couples were approached within the first six months after surgery or treatment and for 5 samples no information about timing was available. Similarly, there was variation in stages of cancer across studies: four samples consisted of patients with a relatively good prognosis (stage I/II, no metastases), two samples included stage 3 or 4 or both, whereas 11 included patients with varied stages of disease. For 16 samples, information about the stage was not available.

Data analysis

First, only studies that provided information necessary to calculate CRR were included in the final analysis. Based on this information, for each sample CRR was calculated as the number of couples included in the final analysis divided by the initial eligible partnered patients / couples that were approached. Thereafter, based on the final 33 samples, we found an average CRR of 58% (*SD* = 17%). Next, we have examined the six potential factors summarized in the introduction that may affect CRR, namely study design, approach size (and actual participation), ways of approaching participants, incentives, cancer diagnosis, and year of publication. When possible, correlations or group comparisons were made. When data did not allow for statistical tests, we use descriptive statistics.

Results

Study design. A t-test revealed no significant differences in CRR between cross-sectional and longitudinal study designs. On average, CRR in cross-sectional studies was slightly higher (M_{CRR} = 59%, *SD* = 0.18; *n*= 19) than in longitudinal studies (M_{CRR} = 55%, *SD* = 0.16; n=14), but this difference was not significant *t*(31) =.607 *p* =.548.

Approach size (and **actual participation**). CRR was negatively associated with approach size (*r* = -.38 *p* = .031), meaning that studies with a bigger approach size had a lower CRR. However, this was not the case for the correlation between CRR and number of couples actually participating in the study (*r* = -.001 *p* = .994). To examine the different magnitudes of CRRs between studies with a big and small approach size, we have split the sample into two groups based on the sample median (*M*dn = 136) and performed an independent t-test. On average, the CRR was 65% (*SD* = 12%) for a small approach (≤ 136) and 50% (*SD* = 19%) for a large approach (≤ 136). Thus, CRR was significantly higher for a small approach than the CRR of studies with a large approach (*t*(25) = -2.743 *p* = 0.01).

Ways of approaching participants. As indicated in our systematic review (Dagan & Hagedoorn, in press), researchers often failed to clearly describe the approach they used to recruit participants. Therefore, the manner in which couples were recruited could not be determined unambiguously. Consequently, we could not systematically examine this factor and we examined only samples in which we could clearly identify the way in which participants were approached (n = 24). Based on descriptive statistics, we found some indications that the *partnered* patients *approach (stepped procedure)* in which consenting patients approved of the research team approaching their partners separately, reached the highest CRR (M_{CRR} = 74%, *SD* = 14%; n = 4) whereas the *couples approach (inviting partners through patients)*, which is the most common approach, reached the lowest CRR (M_{CRR} = 54%, *SD* = 15%; n = 20).

Who approach couples. Only 11 studies reported who approached participants, therefore, we could not perform any statistical test to compare CRRs between the different referral agencies' groups. Based on descriptive statistics we found that the eight studies in which physicians approached couples either in person or by letter reached a higher CRR (M_{CRR} = 64%, *SD* = 18%) than the two studies reported that research staff approached couples (M_{CRR} = 33%, *SD* = 6%). Finally, one study that reached a high CRR (75%) reported approaching 48 couples by the office staff. Unfortunately this study did not provide more specific information that clarifies who was considered to be office staff.

Incentives. Ten studies reported whether or not they provided participants with incentives. Of them, three studies clearly mentioned that they did not provide incentives (M_{CRR} = 43%, *SD* = 28%) and seven reported that they did but only for two of them CRR could be calculated (M_{CRR} = 61%, *SD* = 7%). This may illustrate that studies giving incentives had a higher CRR.

Cancer diagnosis. Although all studies provided the information regarding the cancer diagnosis as can be seen in Table 1, the sample distribution with respect to cancer diagnosis varied. Therefore, a group comparison test could not be performed. Based on descriptive statistics we found that on average studies of couples coping with colorectal or breast cancer reached the highest CRRs and studies of couples coping with prostate cancer had the lowest CRR. However, it is important to note that there is a considerable variation with respect to CRR between the studies within the same cancer diagnosis.

Table 1 Couples' response rates according to the cancer diagnosis

	Number of studies	Mean	SD	min	max
Colorectal	3	63%	28%	31%	90%
Breast	12	62%	18%	32%	90%
Mix diagnosis	8	58%	14%	29%	70%
Other (lung, testicular and oral)	3	56%	12%	46%	70%
Head and Neck	2	52%	3%	51%	55%
Prostate	5	42%	18%	25%	73%

Discussion

The current paper examined potential determinants of couples' response rates in studies of couples coping with cancer. Our goal was to describe and empirically assess facilitating and impeding factors to enrollment of couples coping with cancer into couples-based studies. With too few published empirical reports providing information specifically on variables that might be associated with couples' enrollment, it is difficult to draw substantive conclusions regarding the usefulness of a specific recruitment strategy and to guide researchers. Therefore, the aim of the current discussion is not to answer the question but to provide some clues, generate new questions (e.g., what are the mechanism that can explain a specific determinant?), and set this issue on the agenda for further research. Nonetheless, this discussion eventually may contribute to more efficient recruitment of couples.

We found some indications for recruitment strategies that might be more efficient than others in recruiting couples into couples-based studies. Two factors (i.e., study design and approach size) out of six could have been examined empirically. Therefore, for the other factors we utilized a descriptive approach. Additionally, to put the findings in broader perspective we compared the CRRs found using the descriptive approach with the average CRR reported in the review paper (M_{CRR} = 58%). In the next few paragraphs we elaborate on the different findings.

Study design. The first encouraging finding of the current investigation is that CRR was not affected to a significant level by longitudinal study designs. Given the added value of prospective data, it seems worthwhile to continue designing longitudinal studies. Nonetheless, the reader should bear in mind that CRR could be calculated for only 33 out of 86 samples and therefore the finding could be obscuring negative consequences of repeated measures. Additionally, longitudinal studies varied with respect to the number of assessments and participation burden. In the future when reporting will improve, it will useful to examine the threshold of number of assessments after which CRR is dropping. For example, one study that reported a CRR (32%) that was significantly lower than the average CRR (58%) had a longitudinal design with nine assessments (Hinnen et al., 2008).

However, when an extra demanding task was introduced we found some evidence that it negatively affected CRR. For example, one longitudinal study (Dagan et al., 2013; Dagan et al., 2011) with videotaped conversations approached 280 couples of which 88 couples filled out baseline questionnaires at home but only 64 of the couples participated in the videotaped observation while somewhat more couples (n = 70) completed follow-up questionnaires at home. In another study (Hodgson et al., 2003 (ref 1181 overlap with ref 30 Shields et al., 2000) 28 couples completed questionnaires of which only 20 couples participated in the more demanding assignment of completing a Rorschach task while being videotaped. These two examples indicate that fewer couples were willing to participate in the more intensive task.

Approach size (and **actual participation**). As pointed out by previous research, we found that the CRR was higher when researchers had approached fewer eligible couples (65%) than when they approached more eligible couples (50%). It is important to note that the factor that affects levels of CRR was the number of eligible couples that were approached and not the number of couples that actually participate. One mechanism that can explain the finding regarding the approach size is that when approaching more couples researchers run the risk of having a less personal approach whereas when approaching a small number of couples, researchers may know the potential couples in advance or may have more resources to invest (e.g., time and effort) in recruitment of each couple. It was suggested that in-person, on-site recruitment is more effective and cost-efficient than mail and phone recruitment (Sears et al., 2003). An alternative explanation is that those researchers that already faced a low response rate have tried to include more participants into their study and therefore approached more people. One longitudinal study with multiple publications (Manne, Taylor, Dougherty, & Kemeny, 1997; Norton & Manne, 2007) allowed us to compare CRR of two publications from different years. For this study data was collected for a period of five years (between 1992 and 1997). The earliest publication (Manne et al., 1997) reported approaching 260 couples with 61% CRR while the latest publication (Norton & Manne, 2007) reported approaching 792 couples and the CRR dropped to 48%. This example seems to be consistent with our first explanation.

Ways of approaching participants. We found indication that a *partnered patients approach (stepped procedure)* - in which researchers ask patients for permission to contact their partner separately and by that establish a direct link between the research team and the partners - might be especially efficient. Specifically, the four studies that utilized this approach reported, on average, a higher CRR than the *couples approach (inviting partners through patients)*, which is the most common approach. Additionally, the stepped procedure approach had a considerably higher CRR (74%) than the average CRR (58%) estimated for observational couples-based studies. One mechanism that may explain this finding is situated in the different roles researchers and patients may play as recruiters. For example, compared to patients, researchers are likely to be more motivated to convince the partners plus they have more knowledge about the study and therefore may provide better answers to potential worries partners may have. Additionally, patients might be reluctant to bother their partners with participation in a study, or it might be difficult for them to ask their partners. For example, in one study on low-income married couples, it took the research staff fewer phone calls to get the couple to attend the first intake conversation when the husband was contacted directly (Carlson et al., 2012).

Who approach couples. In line with previous studies (e.g., Goodwina et al., 2000), we found that when physicians approached couples, CRR (64%) was higher than the average CRR estimated for observational couples-based studies. This indication, suggests that the involvement of physicians in the recruitment procedure might be very beneficial. It is interesting to note that even a small involvement of the physician, such as by signing the research invitation letter, appears beneficial.

Incentives. In line with previous studies (e.g., King & Vaughan, 2004; Szelényi et al., 2005), we found that the three studies that indicated explicitly that an incentive to participants was not provided had much lower CRRs than the average CRR estimated for observational couples-based studies. Although this finding is in line with the literature, it is important to note that only ten studies provided us the information about incentives. It is plausible that the three studies that reported not providing incentives did so as part of their efforts to understand the relatively low CRR to their study. Although we did not examine the value of the incentives, in accordance to previous studies indicating that even small incentives are beneficial (e.g., Shaw, Beebe, Jensen, & Adlis, 2001) researchers should consider this option.

Cancer diagnosis. Our finding revealed that colorectal and breast cancer studies had the highest CRRs. Moreover, prostate cancer studies had the lowest CRRs, considerably lower than on average (58%) estimated for observational couples-based studies. One possible explanation is that older couples are less willing to participate in psychological studies. Indeed prostate cancer is usually diagnosed at a somewhat old age. Accordingly, and as outline in the introduction, it was found that younger couples were more likely to enroll to interventions than older couples (Badr & Krebs, 2013).

Another possible explanation is related to the patients' gender. It was suggested that females (patients) are more willing to participate in psychological studies but sometimes are prevented because of the husbands' refusal (cf. Carlson et al., 2012). Accordingly, one couples-based intervention study (Northouse et al., 2006) reported that refusals were somewhat greater among the (male) patients than their spouses. However, because all patients were males and nearly all spouses were female it was hard to determine if the number of refusals was more a function of role (i.e., patients vs. spouse) or gender (male vs. female). It is interesting to note that the three colorectal studies included in our sample had on average the highest CRR and even though typically the prevalence of colorectal cancer is distributed equally between men and women, these three studies included more male patient couples than female patient couples. Following the gender explanation, and based on this finding one might speculate that recruiting male partners (e.g., husbands of female patients) are the most challenging population for recruitment to couples-based research. However, without knowing the gender/role distribution in the original sample of couples that were approached it is difficult to draw definitive conclusions. In the future, researchers are encouraged to examine the refusal rates by gender and role. Based on this knowledge researchers may develop gender specific strategies to recruitment.

Limitations

First, because of poor reporting our sample size was small (33 samples out of 86) and for most factors it was underpowered. Therefore, our findings should be replicated and adopted with some caution. Second, this paper focused on six factors that may affect CRR. However, when reporting will improve other factors that are related to other characteristics of potential participants and the research design are important to investigate in the future. For example, it was suggested that training, personal contact, and reimbursement for referral staff may affect couples enrollment (Motzer et al., 1997; Northouse et al., 2006).

Recommendations and conclusions:

We found some indications for factors that potentially affect CRR with some even encouraging message. With some caution researchers could consider the following recommendations when writing their next research proposal. Depending on the research questions, consider collecting longitudinal data above cross-sectional. Approaching smaller numbers of couples and personal and direct recruitment (*partnered patients approach (stepped procedure)* may be more efficient. Involve physicians in the recruitment procedure. Finally, budget money for providing incentives to couples; even a small amount may help.

Our paper is the first to examine barriers to recruitment in couples-based observational studies. We hope that this paper will raise the awareness of the need for more detailed descriptions of recruitment efforts and the relative success of the strategies that were employed so others can benefit from these efforts. Recognition of the barriers to recruit couples to couples-based studies is the critical first step in efforts to overcome them, improve CRRs, and facilitate a realistic prediction of benefits, costs, and response rate to their study.

Reference List

Badr, H., & Krebs, P. (2013). A systematic review and meta-analysis of psychosocial interventions for couples coping with cancer. *Psycho-Oncology, 22*(8), 1688-1704. doi:10.1002/pon.3200

Carlson, R. G., Daire, A. P., Munyon, M. D., Soto, D., Bennett, A., Marshall, D., & McKinzie, C. (2012). Examining recruitment follow-up phone calls and their influence on attendance for husbands and wives in a marriage and relationship education program. *Marriage & Family Review, 48*(1), 82-95. doi:10.1080/01494929.2011.627493

Corder, L., S., & Manton, K., G. (1991). National surveys and the health and functioning of the elderly - the effects of design and content. *Journal of the American Statistical Association, 86*(414), 513-525. doi:10.2307/2290603

Dagan, M., & Hagedoorn, M. (in press). Response rates in studies of couples coping with cancer - A systematic review. *Health Psychology,*

Dagan, M., Sanderman, R., Hoff, C., Meijerink, W. J., Baas, P. C., van Haastert, M., & Hagedoorn, M. (2013). The interplay between partners' responsiveness and patients' need for emotional expression in couples coping with cancer. *Journal of Behavioral Medicine,* doi:10.1007/s10865-013-9543-4

Dagan, M., Sanderman, R., Schokker, M. C., Wiggers, T., Baas, P. C., van Haastert, M., & Hagedoorn, M. (2011). Spousal support and changes in distress over time in couples coping with cancer: The role of personal control. *Journal of Family Psychology, 25*(2), 310-318. doi:10.1037/a0022887

Del Giudice, M. E., Leszcz, M., Pritchard, K. I., Vincent, L., & Goodwin, P. (1997). Attitudes of canadian oncology practitioners toward psychosocial interventions in clinical and research settings in women with breast cancer. *Psycho-Oncology, 6*(3), 178-189. doi:2-O

Edwards, P., Roberts, I., Clarke, M., DiGuiseppi, C., Pratap, S., Wentz, R., & Kwan, I. (2002). Increasing response rates to postal questionnaires: Systematic review. *BMJ: British Medical Journal, 324* (7347), 1183-1185. doi:10.1136/bmj.324.7347.1183

Fredman, S. J., Baucom, D. H., Gremore, T. M., Castellani, A. M., Kallman, T. A., Porter, L. S., . . . Carey, L. A. (2009). Quantifying the recruitment challenges with couple-based interventions for cancer: Applications to early-stage breast cancer. *Psycho-Oncology, 18*(6), 667-673. doi:10.1002/pon.1477

Goodwina, P.,J., Leszczb, M., Quirtc, G., Koopmansd, J., Arnolde, A., Dohanf, E., . . . Navarroi, M. (2000). Lessons learned from enrolment in the BEST study - a multicenter randomized controlled trial of group psychosocial support in metastatic breast cancer. *Journal of Clinical Epidemiology, 53*, 47-55.

Hinnen, C., Ranchor, A. V., Sanderman, R., Snijders, T. A. B., Hagedoorn, M., & Coyne, J. C. (2008). Course of distress in breast cancer patients, their partners, and matched control couples. *Annals of Behavioral Medicine, 36*(2), 141-148.

King, K. A., & Vaughan, J. L. (2004). Influence of paper color and a monetary incentive on response rate. *Psychological Reports, 95*(2), 432-434. doi:10.2466/PR0.95.6.432-434

Manne, S. L., Taylor, K. L., Dougherty, J., & Kemeny, N. (1997). Supportive and negative responses in the partner relationship: Their association with psychological adjustment among individuals with cancer. *Journal of Behavioral Medicine, 20*(2), 101-125.

Manne, S., & Badr, H. (2010). Intimacy processes and psychological distress among couples coping with head and neck or lung cancers. *Psycho-Oncology, 19*(9), 941-954. doi:10.1002/pon.1645

Motzer, S., A., Moseley, J., R., & Lewis, F. M. (1997). Recruitment and retention of families in clinical trials with longitudinal designs. *Western Journal of Nursing Research, 19*, 314-333.

Neumark, D.,E., Stommel, M., Given, C., W., & Given, B., A. (2001). Research design and subject characteristics predicting nonparticipation in a panel survey of older families with cancer. *Nursing Research, 50*, 363-368.

Northouse, L. L., Rosset, T., Phillips, L., Mood, D., Schafenacker, A., & Kershaw, T. (2006). Research with families facing cancer: The challenges of accrual and retention. *Research in Nursing & Health, 29*(3), 199-211. doi:10.1002/nur.20128

Norton, T. R., & Manne, S. L. (2007). Support concordance among couples coping with cancer: Relationship, individual, and situational factors. *Journal of Social and Personal Relationships, 24*(5), 675-692.

Sears, S., Stanton, A., Kwan, L., Krupnick, J., Rowland, J., Meyerowitz, B., & Ganz, P. (2003). Recruitment and retention challenges in breast cancer survivorship research: Results from a multisite, randomized intervention trial in women with early stage breast cancer. *Cancer Epidemiology Biomarkers & Prevention, 12*(10), 1087-1090.

Shaw, M., Beebe, T., Jensen, H., & Adlis, S. (2001). The use of monetary incentives in a community survey: Impact on response rates, data quality, and cost. *Health Services Research, 35*(6), 1339-1346.

Szelényi, K., Bryant, A. N., & Lindholm, J. A. (2005). What money can buy: Examining the effects of prepaid monetary incentives on survey response rates among college students. *Educational Research and Evaluation, 11*(4), 385-404. doi:10.1080/13803610500110174

Chapter 7

General discussion

I promise to support you in times of sickness and in times of health

The overall aim of the thesis was to expand the knowledge on under what condition spousal support affects the emotional and relational wellbeing of couples coping with colorectal cancer. In this last chapter, I will discuss a couple of main conclusions; a complete overview of the results and conclusions can be found in the summary. In the first part, I will discuss the main conclusion derived from the *empirical data* (part 1), pointing out the theoretical and clinical implications. Next, I will outline the methodological strengths and limitations of the study design and sample. In the second part, I will focus on the conclusions derived from the *review of the literature* regarding recruitment issues in couples coping with cancer studies and list our recommendations for future research (part 2). Finally, I will end with some *personal reflections* on one issue that was not included in the body of this thesis but may serve as a valuable lesson for future researchers.

Part 1 – Empirical Studies

Overall people who perceived their partner to be supportive in the past, had a high sense of personal control and/or had a low need for emotional expression were less affected by their partners' current behavior compared to people who perceived their partners not to be supportive in the past, had a low sense of personal control and/or had a high need for emotional expression. Several explanations for these findings (e.g., making benign attribution to current behavior) were already proposed in the different chapters. In the next paragraph I will provide an additional theoretical perspective that may also describe the findings.

While writing the empirical papers for this thesis, we have developed and tested a new theoretical perspective, which we called the **vulnerability hypothesis**. The vulnerability hypothesis posits that spousal support has more impact on some people than others. This perspective focuses on sub-groups of vulnerable people (patients and/or partners) who are at higher risk for poor adaptation because they depend on others for support. To be precise: this perspective predicts that if vulnerable people receive no support or the wrong type, they will adjust less well than people who do not depend on others for support. When testing this hypothesis in our sample, we found indications for two vulnerable groups: (1) those low in personal control and (2) those with a high need for emotional expression.

This perspective is currently under development and it is presented as a starting point for further discussion and research. Although we found some prospective evidence for our model (i.e., predicted changes in depressive symptoms over time) there are still some empirical questions that should be examined in future research. *First*, although we do not expect the general process suggested by the vulnerability hypothesis to differ for different cancer diagnoses it will be reassuring to see a replication in samples of couples coping with other types of cancer or other types of illness. For example, one cross-sectional study provided support for the model in a small sample that included different types of cancer (Hagedoorn et al., 2000). This study suggested that patients with a poor physical condition might also be identified as a vulnerable group of patients who depend on their partners for support. *A second* important task for future research is identifying other vulnerable groups. In order to refine the description of the term *vulnerability* it is important to identify more factors that make people vulnerable (i.e., rely on the support of others). It would be worthwhile to examine factors such as attachment style. For example, people with a preoccupied attachment style have low confidence in their ability to take care of themselves, and therefore turn to others for support. They need constant reassurance to feel safe and therefore might be more affected by spousal support. Another interesting avenue is examining personality characteristics such as extraversion. People high on extraversion tend to view their problems optimistically, might see them as manageable through the use of social support. Indeed extraversion was found to be positively associated with seeking support (Amirkhan, Risinger, & Swickert, 1995). It will be interesting to examine whether people with a preoccupied attachment and/or high score on extraversion can be identify as vulnerable subgroups because they depend on others for support. *Third*, a promising avenue for future studies would be to examine directly the underlying mechanism involved in our model. For example, in our research we identified characteristics that suggest dependence but did not measure directly whether people actually depend on spousal support. Future studies could examine a model in which support-dependency is mediating the association between a specific vulnerable characteristic and adjustment. This could be done by measuring support seeking behavior during couples' interactions. *Finally*, for a greater understanding of the theoretical foundations of our model it will be valuable to answer the question why people with a particular type of vulnerability characteristic will benefit more from a certain type of support then others. For example, we have demonstrated that patients and partners low in personal control who perceived more spousal support reported less depressive symptoms over time. This was done by using a global measurement of spousal support which includes both emotional and instrumental support. Future studies could examine whether people low on personal control rely on others for support in general or rely more on a specific type of support. For example, people low in personal control may especially benefit from esteem support which communicates a belief in the individual's ability and competence.

Clinical implications.

Overall couples coping with cancer seem to adjust well to their experience with cancer. Also in our sample of couples coping with colorectal cancer, we found on average a decrease in depressive symptoms nine months after diagnosis. However, about 16% of patients and 25% of partners, in our sample, reported experiencing high levels of depressive symptoms nine months after cancer diagnosis, and might benefit from psychological interventions. Although, couples' interventions for less functioning couples than our sample should adopt our findings with some caution, the findings from our three empirical studies have some important recommendations for couples' interventions targeted at improving spousal support. *First*, interventions should reflect the important role of the patients as providers of support to their intimate partners and not only as support receivers. *Second*, interventions should encourage spouses not only to pay attention to the positive support they might provide but also to the amount of negative supportive behaviors such as disapproval, hostility, enmity, that they might engaged in. *Third*, couples with at least one partner who is low in personal control, high in need for emotional expression, and/or who perceived the other as relatively unsupportive before the diagnosis might be especially good candidates for this type of couples' interventions. A greater match between the interventions and the participants' characteristics and needs with respect to the stressor may result in a more efficacious treatment. *Finally*, a promising direction to increase the efficacy of existing couples interventions that are targeted on the exchange of support (e.g., Kuijer, Buunk, De Jong, Ybema, & Sanderman, 2004) is including a module to improve partners' skills of showing responsiveness, particularly behaviors that convey understanding and validation.

Methodological strengths and limitations.

The design. The design of the current study has several strengths (i.e., dyadic approach, multi-method approach, and longitudinal study design that includes an observational task). To start with, we utilized a dyadic approach. That is, when possible we included both patients and partners as one unit (i.e., couple) in our research question, study design, and the choice to use a dyadic-level statistical approach to analyze the data. This approached enabled us to take into account the interdependency between spouses.

A second strength is that we utilized a multi-method approach. We examined support processes using self-report questionnaires as well as observational methods. The use of this multi-method approach enabled us to capture the interactional nature of support processes from different perspectives.

A third strength is a longitudinal study design that included an observational task in which spouses were asked to present (each in a separate conversation) a personal cancer-related concern to their partners. Although this procedure was used in previous marital interaction studies (e.g., Manne et al., 2004; Pasch & Bradbury, 1998), the combination of an observational task embedded in a longitudinal study design in the context of cancer is novel. This procedure enabled us to examine supportive behaviors in a naturalistic setting (i.e., couples' homes) and to predict their effect on the couples' wellbeing over time. Additionally, the observational method and the rating of concrete behaviors allowed us to examine couples' actual supportive behavior and avoid problems that might have affected previous findings, such as same-method variance, social desirability, and memory distortions. Finally, we believe that an observational method can better capture how couples actually behave when engaged in a conversation in which they disclose cancer-related concerns than would a self-report method.

Nonetheless, several aspects of this observational task warrant discussion. *First*, we recognize that an observational method may be somewhat artificial. Therefore, to enable spontaneous and realistic conversations, we followed Gottman's (2000) recommendation and filmed the couples in their homes. Accordingly, couples indicated they behaved in a natural way and that the conversation reflected the way they usually talked with each other. *Second*, following the idea that a conversation is a two-way stream and that both spouses should be considered as support providers as well as support receivers, we have recorded two supportive conversations. One conversation (patients' conversations) in which patients were asked to disclose a cancer-related concern and the healthy partners were assigned to the support provider role and another conversation (partners' conversations) in which the healthy partners were asked to disclose a cancer-related concern and patients were assigned to the support provider role. However, the data allowed us to examine only the patients' conversations. Already while coding, coders reported difficulties to accurately code patients' supportive behavior (i.e., responsiveness) in the partners' conversation. Typically, the partners' conversations were less structured then the patients' conversations. That is, patients and partners would switch roles (discloser vs. support provider) frequently during the conversation. This was not the case during the patients' conversations. Accordingly, this affects the reliability of the measurement of patients' responsiveness behavior ($\alpha = 0.49$). In turn, the question arose whether it was measurement error or whether we actually captured a reality in which it is very difficult for patients to support their healthy partner when discussing cancer-related concerns. If the latter is true it is an important issue to examine in future research for two reasons. First, many patients report a wish to return to "life as it used to be" which includes also supporting their partner when needed. Helping them accomplishing this wish may promote better adjustment. Second, the pattern in which partners are not receiving adequate spousal support may hamper their adjustment in the long run.

***The sample*.** Recruiting couples for psychological studies can be challenging, especially when the burden of participation is rather high. Namely, couples were asked to discuss their cancer related concerns in front of a camera and it is likely that these interactions are confronting to some couples. Accordingly, the study has a relatively low coupes' response rate (CRR ≤ 31%) However, it is important to note that dropouts were also relatively low. Specifically, out of 280 eligible partnered patients approached, 88 heterosexual couples filled in the baseline questionnaires (T1) and 77 couples filled in follow-up questionnaires (T3); so only 11 couples dropped-out of the study. Twelve couples decided not to participate in the interaction, but only to complete the questionnaires. This may reflect the less expressive culture in the northern part of the Netherlands. Perhaps the combination of having to talk and doing it in front a camera was especially difficult for this population. More than a third of the non-responders mentioned lack of interest to discuss or be confronted with this issue, at this moment.

A relatively low couples' response rate may have biased our sample. Although a comparison between responders and non-responders revealed no differences in terms of gender and age, it may appear that our sample over-represents couples with well-functioning relationships and low levels of depressive symptoms. We could not find a strong indication of bias in the sample with respect to levels of depressive symptoms. Overall levels of depressive symptoms were somewhat higher but comparable to the levels of depressive symptoms reported in a more representative sample of couples coping with colorectal cancer (Tuinstra et al., 2004).

Finally, as we concluded in our systematic review, couples' response rate (CRR) is only one indicator of the findings' generalizability. Additionally, even if the representativeness of a sample is somewhat biased, for example, if there is an overrepresentation of more functional relationships, the results are still interesting and relevant for this specific group (see chapter 5).

Part 2 – literature reviews on recruitment issues in couples coping with cancer studies

There is a growing recognition that cancer is a dyadic stressor that affects both patients and their partners. As more studies examine the psychosocial adjustment among couples facing cancer, the challenges of recruiting both members of the dyad to studies are becoming apparent. Nonetheless, the inability to successfully obtain and retain research participants may have a profound effect on the study's validity and ability to generalize findings and therefore, clear reporting about recruitments couples into studies is important. Chapters 5 and 6 provide evidence that overall reporting of recruitment was unsatisfactory in more than half of the included studies. As a consequence, the couples' response rate (CRR) could be calculated for only 33 samples out of 86. Therefore, it cannot be firmly concluded that the average CRR reported (58%) is representative for all studies on couples coping with cancer. Additionally, the rates reported in the papers that are often more favorable than the CRR may create the impression that the sample is more representative of the target population than it actually is.

Finally, with too few published empirical reports providing information specifically on variables that might be associated with couples' enrollment, no substantive conclusions can be drawn regarding the usefulness of specific recruitment strategies. In the next paragraph I will list the most important recommendations for future research derived from both reviews.

Recommendations for future research:

1. Couples' response rate should be clearly presented. We recommend using the calculation of presented in chapter 5 (i.e., the number of couples in the final analysis divided by the number of eligible partnered patients or couples approached).
2. The couples' response rate should be evaluated and discussed (e.g., attempts should be made to estimate the potential bias of the sample and evaluate its consequences).
3. The recruitment procedure should be clearly presented (e.g., who approached participants, in what way, were incentives offered). Any insight regarding factors that may affect couples' response rate (for good or bad) should be addressed.
4. How couples' were approached should be clearly presented. We recommend using the labels presented in chapter 5 (pages 74-76). Namely: true couples approach, couples approach through patients, partnered patients approach (stepped procedure), individual decision approach, un-partnered patients approach.
5. With some caution researchers could consider the following recommendations in order to increase couples' response rate: Approaching smaller numbers of couples and personal, and direct recruitment (e.g., using *partnered patients approach (stepped procedure)*, involving physicians in the recruitment procedure, budget money for providing incentives to couples (even a small amount may help).

Outtakes – Personal Reflection

Non-verbal communication, the unspoken word. Originally, the aim of the current project was to examine both verbal and non-verbal aspects of spousal supportive communication. With respect to the non-verbal aspect, our original goal was to focus on *non-verbal conversation involvement* - "*the degree to which participants in a communication exchange are cognitively and behaviorally engaged in the topic, relationship, and/or situation*" (Coker & Burgoon, 1987, p.463) and to examine its role during couples' discussion of cancer-related concerns in predicting adjustment to cancer. We followed Bouhuys and colleagues' work in which they found non-verbal conversation involvement to be related to several positive outcomes in samples of depressed patients. For example, they found that non-verbal conversation involvement was related with more satisfaction and favorable prognosis of depression (Bos, Geerts, & Bouhuys, 2002). Bouhuys and colleagues have developed and tested a very detailed coding system at the UMCG, the department of psychiatry. To adopt their coding system I first set up a team that included three M.A students and myself. We received an intensive training by the late Erwin Geerts and each coder had coded a different behavior (i.e., vocal back channeling, head and hand movement, and gaze, respectively). Next, when coders reached 80% occurrence agreement, coders began coding the actual interactions. Finally, after all the coding was completed, I computed a confirmatory factor analysis to replicate the factors that were found by Bouhuys and colleagues (Bouhuys & Van, 1991; Bouhuys, Jansen, & Van, 1991). This was necessary to be done because till now the coding system had been tested mainly in a specific setting of conversations between depressed patients and their therapists. Our setting of couples coping with cancer was significantly different. Unfortunately, we not only failed to replicate the factors reported previously (Bouhuys & Van, 1991; Bouhuys et al., 1991) but also could not find other reliable factors that we could work with. After investing significant efforts, we had to conclude that at this point we do not trust the data and we decided to drop this line of research.

So what did I learn from this intensive experience that might help future researchers? *First*, coding non-verbal behavior is a very time consuming task. The training takes a long time; actually for us it took longer than we anticipated. The coding itself often demands watching the clips multiple times, because coding several behaviors and/or two partners simultaneously may not be possible. *Second*, coding nonverbal behaviors is a complicated task and many decisions need to be taken about the filming condition before starting the data collection. Finding the balance between desirable and feasible conditions is very difficult. For example, for the current study, we have decided to film the couples at their homes using only one camera that was situated in front of the couple capturing both couples in one frame. This was done in order to encourage natural discussions between the partners while minimizing the influence of the filming procedure. The drawback of this decision was the increased likelihood of missing data. Specifically, in many clips one camera could not capture all body parts of both partners and coding gaze from a profile angle was problematic. The preferable configuration is to have two cameras, one for each partner, each placed directly facing the subject. *Third*, one should consider the program and the coding devices in advance. Each program and devices has its advantage and disadvantage and one should consider the best option for the type of coding system that is being used. *Finally*, consider in advance the necessity for a very detailed coding system. From my experience, although observational data can be very rich and very detailed aspects of the human behavior could be coded, one should consider “not seeing the forest for the trees”. Behaviors may have little meaning in isolation, but rather receive their meaning in combination with other behaviors. Also in real life conversations, people typically do not divide their attention to the different parts of non-verbal behavior but usually compose a more global evaluation of the conversation. Some behaviors might be important to examine separately while others should perhaps already during coding receive a more global code. After dropping the very detailed coding system, we choose to work with a global assessment of partner responsiveness, which turned out to be more reliable and predictive.

To conclude, this experience gave me the opportunity to develop new skills and gain experience that otherwise I could not gain during my PhD. Although it was not productive in terms of publication it was defiantly valuable.

General Conclusions

The present thesis has shown that individuals’ characteristics as well as spouses’ supportive behaviors conjointly affect couples’ adjustment to colorectal cancer. The results add to the existing literature that examines the role of spousal support within couples coping with cancer. As mentioned in chapter 1 (i.e., the introduction to this thesis) cancer is indeed a dyadic stressor that affects both patients and their partners, and cancer patients (and not only partners) should be motivated to continue their role as supportive partners even in the midst of recovering from illness. This was demonstrated for both supportive as well as unsupportive behaviors. Finally, it was shown that reporting on recruitment of couples into couples-based observational studies in the context of cancer is insufficient. Future improvement in reporting is a critical first step to overcome challenges to recruitment and increase Couples Response Rate.

Reference List

Amirkhan, J. H., Risinger, R. T., & Swickert, R. J. (1995). Extraversion: A 'hidden' personality factor in coping? *Journal of Personality, 63*(2), 189-212. doi:10.1111/j.1467-6494.1995.tb00807.x

Bos, E. H., Geerts, E., & Bouhuys, A. L. (2002). Non-verbal interaction involvement as an indicator of prognosis in remitted depressed subjects. *Psychiatry Research, 113*(3), 269-277.

Bouhuys, A. L., Jansen, C. J., & Van, d. H. (1991). Analysis of observed behaviors displayed by depressed patients during a clinical interview: Relationships between behavioral factors and clinical concepts of activation. *Journal of Affective Disorders, 21*(2), 79-88.

Bouhuys, A. L., & Van, d. H. (1991). The interrelatedness of observed behavior of depressed patients and of a psychiatrist: An ethological study on mutual influence. *Journal of Affective Disorders, 23*(2), 63-74.

Coker, D. A., & Burgoon, J. K. (1987). The nature of conversational involvement and nonverbal encoding patterns. *Human Communication Research, 13*(4), 463-494.

Gottman, J. M., & Notarius, C. I. (2000). Decade review: Observing marital interaction. *Journal of Marriage & the Family, 62*(4), 927-947. doi:10.1111/j.1741-3737.2000.00927

Hagedoorn, M., Kuijer, R. G., Buunk, B. P., DeJong, G. M., Wobbes, T., & Sanderman, R. (2000). Marital satisfaction in patients with cancer: Does support from intimate partners benefit those who need it most? *Health Psychology, 19*(3), 274-282. doi:10.1037/0278-6133.19.3.274

Kuijer, R. G., Buunk, B. P., De Jong, G. M., Ybema, J. F., & Sanderman, R. (2004). Effects of a brief intervention program for patients with cancer and their partners on feelings of inequity, relationship quality and psychological distress. *Psycho-Oncology, 13*(5), 321-334. doi:10.1002/pon.749

Manne, S., Sherman, M., Ross, S., Ostroff, J., Heyman, R. E., & Fox, K. (2004). Couples' support-related communication, psychological distress, and relationship satisfaction among women with early stage breast cancer. *Journal of Consulting and Clinical Psychology, 72*(4), 660-670. doi:10.1037/0022-006X.72.4.660

Pasch, L. A., & Bradbury, T. N. (1998). Social support, conflict, and the development of marital dysfunction. *Journal of Consulting and Clinical Psychology, 66*(2), 219-230. doi:10.1037/0022-006X.66.2.219

Tuinstra, J., Hagedoorn, M., Van Sonderen, E., Ranchor, A. V., Van, d. B., Nijboer, C., & Sanderman, R. (2004). Psychological distress in couples dealing with colorectal cancer: Gender and role differences and intracouple correspondence. *British Journal of Health Psychology, 9*(4), 465-478. doi:10.1348/1359107042304588

Chapter 8

Summary

I promise to support you in times of sickness and in times of health

A cancer diagnosis can be stressful and upsetting for patients as well as their partners. Many studies have demonstrated the important role of intimate partners in adaptation. The goal of the current thesis was to expand the knowledge on the conditions under which spousal support affects the emotional and relational well-being of couples coping with colorectal cancer.

In the introductory **chapter 1,** we provide a short overview of the importance of spousal support in couples' adaptation to cancer, and present the framework of the current thesis. We describe three issues that are important to consider when examining spousal support in couples coping with cancer: (1) cancer as a dyadic process, (2) patients and their partners as support receivers as well as support providers, and (3) supportive versus unsupportive spousal behavior. Thereafter, we provide theoretical background on three inter- and intrapersonal factors that were empirically tested in the first part of this thesis. Finally, we describe a common methodological issue that was examined in the second part of the thesis; namely, couples recruitment to psycho-oncological studies.

Part 1: Spousal Supportive Behaviors - Empirical Examination

One may assume that if only partners were more supportive and helpful, couples' levels of well-being would increase. However, this is an oversimplification of reality. The first part of the current investigation (i.e., chapters 2, 3, and 4) focuses on how the behavior of one partner helps or hinders the other partner's adaptation to cancer. We examined the role of different inter- and intrapersonal factors in the relationship between spousal supportive behaviors and well-being. Specifically, **chapter 2** examines the role of past spousal support (an interpersonal factor) in the relationship between spousal supportive behaviors and relational well-being (i.e., relationship satisfaction). **Chapters 3 and 4** examine the roles of sense of personal control, and need for emotional expression (intrapersonal factors) in the relationship between spousal supportive behaviors and emotional well-being (i.e., depressive symptoms). This part of the thesis reports data collected in a longitudinal observational study design (3, 5, and 9 months after being diagnosed with colorectal cancer). Participants were newly diagnosed patients and their partners, recruited from oncology clinics at eight hospitals in the northern Netherlands. Couples were asked to complete self-report measures at T1, engage in a videotaped interaction task in which they discussed cancer-related concerns at T2, and complete follow-up measures at T3.

Chapter 2 addresses how the association between current spousal supportive behavior and relationship satisfaction depends on past spousal supportiveness; i.e., the degree to which the spouse was generally responsive to the other's needs before the couple was confronted with cancer. Specifically, this chapter focuses on two spousal supportive behaviors: *active engagement* (e.g., discussing feelings and engaging in joint problem solving) and *protective buffering* (e.g., hiding worries and fears and avoiding talking about the disease). In this chapter, we adopted the perspective of attribution theory within close relationships. According to this theory, individuals who have a positive global perception of their relationship have a tendency to make benign attributions about their partner's behavior, probably to maintain their satisfaction with the relationship. Therefore, we proposed a mitigating effect of past spousal supportiveness. We argued that one partner's behavior will be related to the other partner's relationship satisfaction, only when he or she did not feel supported in the past. Overall, the results supported our short-term hypotheses. That is, in the context of low past spousal supportiveness individuals reported low levels of relationship satisfaction if current active engagement was low and/or current spousal protective buffering was high. In other words, our results demonstrated that, if past spousal supportiveness was high, both partners rated the quality of the relationship relatively high, regardless of their spouses' current supportive behavior. These results seem to indicate that patients who perceived their partner to be supportive before the cancer diagnosis are more forgiving towards their partners' current unsupportive behavior (such as protective buffering). Possibly, they make benign attributions about their partner's negative behavior, ascribing the protective buffering behavior to external causes. Patients who did not perceive their spouse to be supportive in the past were more affected by his / her negative current behaviors. However, in the long run, the findings seem to suggest that there are limits to individuals' tendency to use benign attributions and forgiveness of their partners' current unsupportive behavior. The findings presented in the current chapter contribute to the existing literature on supportive behavior by demonstrating the importance of examining dyadic coping processes in the interpersonal context in which these occur.

Individual characteristics as well as spousal supportive behaviors may separately affect patients' and their partners' level of depressive symptoms, nonetheless, it is also conceivable that they conjointly affect well-being. In **chapter 3,** we examined how the association between support and depressive symptoms depends on individuals' sense of *personal control*; i.e., the belief that life is not ruled by fate, but that one is personally able to influence the outcomes of important events or situations in life. This chapter focuses on perceptions of both supportive and unsupportive spousal behavior and examines the associations for both patients and partners. We argued that, individuals low in control need spousal support the most (i.e., rely heavily on their intimates for support), and therefore, are at higher risk for depressive symptoms if their partner is not forthcoming with support. Overall the results showed that individuals relatively low in control are more responsive to perceived spousal supportive behavior than people relatively high in control. Specifically, individuals who perceived more spousal supportive behavior reported fewer depressive symptoms over time, but only those relatively low in control. Additionally, partners' perceptions of patients' unsupportive behavior were associated with more depressive symptoms over time, but only for partners relatively low in control. Put differently, our results demonstrated that, individuals (both patients and partners) relatively high in control reported relatively low levels of depressive symptoms regardless of their perceptions of their spouses' behavior. These results seem to indicate that, in the long run, people low in personal control may benefit more from supportive behaviors but may also be more adversely affected by unsupportive behaviors (criticism, disapproval) than people high in personal control. Thus, people low in personal control might be identified as a vulnerable subgroup. These findings highlight the importance of utilizing a dyadic perspective that considers both the patients and their partners as recipients as well as providers of support and the need to examine both supportive and unsupportive spousal behaviors.

In **chapter 4,** we adopted *the optimal matching model of social support*, which posits that support is most beneficial when it matches the specific needs of the stressed individual (Cutrona, 1990). This evokes an interesting question: What do partners need to do for their support to be most beneficial? Hence, this chapter focuses on spousal actual supportive behavior (i.e. partner responsiveness such as understanding, validation, and caring towards the patients).We aimed to test whether partners' actual responsive behaviors (as shown during the interaction task) that "match" patients' support needs (i.e., need for emotional expression) are beneficial in terms of reducing patients' depressive symptoms. Many studies have demonstrated the beneficial role of perceived partner responsiveness in eliciting intimacy, trust, and relationship satisfaction. Less is known about the role of partners' actual responsive behavior in promoting emotional well-being. Overall, our results showed that individuals with a relatively high need for emotional expression are more sensitive to their partner responsive behaviors than individuals with a relatively low need for emotional expression. Specifically, we revealed differences between the three unique components of partner responsiveness. That is, partners' understanding and validation were more important than partners' caring behavior in explaining patients' depressive symptoms. One explanation for the different effects found for understanding and validation versus caring may be related to the potential function of these behaviors. Perhaps understanding and caring promote cognitive processing that reduces the cognitive load and the emotional impact of the concern. This, in turn, may lead to decreased depressive symptoms in patients over time. On the other hand, when partners show caring they express love and affection, thereby demonstrating their involvement.

This may create the feeling that the couple is "in it together", which in turn may contribute to a greater feeling of intimacy but not necessarily leads to a decrease in patients' depressive symptoms. The findings presented in this chapter contribute to the existing literature on supportive behavior by demonstrating the importance of partners' actual responsive behavior for patients' emotional well-being especially for those with a relatively high need for emotional expression. Moreover, we could identify specific actual behaviors which might be used in interventions to reduce depressive symptoms.

Part 2: Recruitment couples to psycho-oncological studies

The first part of this thesis demonstrated the importance of examining cancer from a dyadic perspective, as it is a dyadic stressor affecting both patients and their partners. As more studies examine the psychosocial adjustment among couples facing cancer, the challenges of recruiting both members of the dyad to studies are becoming apparent. Hence, the second part of this thesis (i.e. chapters 5 and 6) focuses on a common methodological problem in observational studies of couples coping with cancer; that is couples' recruitment. This part of the thesis presents a systematic review including studies of couples coping with cancer published between January 1980 and May 2011 (**chapters 5 and 6**).

While researchers agree that recruiting couples to participate in an observational study is challenging, no study until now has examined this issue systematically. The first goal of **chapter 5** is to examine the average Couples' Response Rate (CRR; all analyzed couples divided by the number of eligible partnered patients/couples approached) in observational studies of couples coping with cancer. The second goal is to systematically review the quality of reporting couples' response rates in these studies. Overall, reporting was unsatisfactory in more than half of the included studies. As a consequence, the couples' response rate could be calculated for only 33 samples (out of 88). This CRR varied considerably across studies from 25% to 90% (CRR_M =58%, SD=17%). Moreover, this review showed that the reported response rates in the studies were often higher than the CRRs of these samples. It seems that studies present more favorable figures, potentially creating the impression that their sample is more representative of the target population than it actually is. In order to improve reporting, we provided specific recommendations for future reporting. We pled for appropriate and transparent descriptions of recruitment and samples, so that readers can make informed decisions about the generalizability of the findings.

Recruiting couples for psychological studies can be challenging but apparently some studies succeeded more than others. In **Chapter 6,** we examined potential barriers to recruitment in studies of couples coping with cancer. The goal of this chapter is to describe and empirically assess factors which may facilitate enrollment of couples coping with cancer into observational studies. Thereby, we focused on demographic variables and methods of approaching eligible participants. We examined a sub-sample of papers included in chapter 5 namely, studies that allowed calculating CRR (n = 33) and related their CRR to different study and participant characteristics: study design, approach size, ways of approaching participants, who approach couples, incentives, cancer diagnosis. Thereafter, we reflected on their potential effect on CRR and provide preliminary data and examples from the literature when possible. We concluded that the recognition of the barriers to recruitment is the first critical step in efforts to overcome them, improve CRRs, and facilitate a realistic prediction of benefits and costs of recruitment of couples into couples-based studies. However, drawing substantive conclusions regarding the usefulness of a specific recruitment strategy was difficult, due to incomplete reporting of recruitment.

Finally, **chapter 7** starts with a discussion of the main conclusion derived from the empirical data, that is, patients' as well as their partners' relationship satisfaction and depressive symptoms are affected by the other partner's supportive behavior. However, these effects seem to depend on the vulnerability or need of the receiver. Next, we point out the theoretical and clinical implications. We explicitly reflect upon a new theoretical perspective (i.e., *vulnerability hypothesis*) that was developed and tested while writing the empirical papers of this thesis. Specifically, the vulnerability hypothesis posits that spousal support has more impact on some people than others. This perspective focuses on subgroups of people (patients and/or partners) who are at risk for poor adaptation because they depend on others for support. Hence it is predicted that vulnerable people will adjust less well than people who do not depend on others for support, if they receive no support or the wrong type of support. Subsequently, we discuss strengths and limitations of our own study. Thereafter, we discuss the conclusions derived from our review. We give recommendations about recruitment and reporting for future couples' studies.

I promise to support you in times of sickness and in times of health

Chapter 9

Samenvatting

Translated and edited by:
drs. Moniek Janse
drs. Evelien Snippe
Prof. M. Hagedoorn

De diagnose kanker kan een stressvolle en verontrustende ervaring zijn voor zowel patiënten als hun partners. Veel studies hebben de belangrijke rol van intieme partners in het adaptatieproces aangetoond. Het doel van dit proefschrift was om meer kennis te verkrijgen over de condities waaronder partnersteun het emotioneel en relationeel welbevinden van paren met darmkanker beïnvloedt.

In het inleidende **hoofdstuk 1** presenteren we een kort overzicht van de belangrijke rol van partnersteun in de adaptatie van paren aan kanker en het theoretische raamwerk van dit proefschrift. We beschrijven drie aspecten die belangrijk zijn om in acht te nemen wanneer men partnersteun in paren die omgaan met kanker onderzoekt: (1) kanker als een dyadisch proces, (2) patiënten en hun partners als ontvangers alsook gevers van steun en (3) ondersteunend versus niet-ondersteunend partnergedrag. Daarna presenteren we een theoretische achtergrond betreffende de drie inter- en intrapersoonlijke factoren die empirisch onderzocht zijn in het eerste deel van dit proefschrift. Tenslotte beschrijven we een veelvoorkomend methodologisch probleem dat werd onderzocht in het tweede deel van het proefschrift, namelijk de werving van paren in psycho-oncologische studies.

Deel 1: Ondersteunend gedrag van partners – Empirische onderbouwing

Men zou kunnen veronderstellen dat het welbevinden van paren zou verbeteren als partners maar meer steun en hulp zouden bieden. Echter, dit is een oversimplificatie van de werkelijkheid. Het eerste deel van het huidige onderzoek (hoofdstukken 2, 3 en 4) richt zich op hoe het gedrag van de ene partner, de adaptatie aan kanker van de andere partner helpt of hindert. We onderzochten de rol van verschillende inter- en intrapersoonlijke factoren in de relatie tussen ondersteunend gedrag van de ene partner en het welbevinden van de andere partner. Meer specifiek, **hoofdstuk 2** onderzoekt de rol van ondersteunend gedrag van de partner in het verleden (een interpersoonlijke factor) in de relatie tussen het huidig ondersteunend partnergedrag en het welbevinden binnen de relatie (tevredenheid met de relatie). **Hoofdstukken 3 en 4** onderzoeken de rol van persoonlijke controle en de behoefte aan emotionele expressie (i.e., intrapersoonlijke factoren) in het verband tussen ondersteunend partnergedrag en het emotioneel welbevinden (i.e., symptomen van depressie). Dit deel van het proefschrift bevat observationele data verzameld in een longitudinale opzet (3, 5 en 9 maanden na de diagnose darmkanker). Deelnemers waren nieuw gediagnosticeerde patiënten en hun partners die werden benaderd via de oncologie afdelingen van acht ziekenhuizen in noord Nederland. Paren werden op T1 en T3 gevraagd om een vragenlijst in te vullen. Op T2 namen ze deel aan een interactietaak waarin patiënten en partners kanker gerelateerde zorgen met elkaar bespraken. Dit gesprek werd opgenomen op video en het gedrag werd later door onafhankelijke beoordelaars gecodeerd.

Hoofdstuk 2 richt zich op de vraag hoe de relatie tussen huidig ondersteunend partnergedrag en tevredenheid met de relatie afhangt van eerdere steunervaringen; i.e., de mate waarin de partner in het algemeen meelevend reageerde op de behoeftes van de ander voordat het paar werd geconfronteerd met kanker. Meer specifiek richt dit hoofdstuk zich op twee ondersteunende gedragingen van de partner: *actieve betrokkenheid* (gevoelens bespreken en samen actief problemen oplossen) en *beschermend bufferen* (zorgen en angsten verbergen en vermijden om over de ziekte te praten). In dit hoofdstuk hebben we het perspectief van attributietheorie toegepast binnen intieme relaties. Het idee is dat personen die over het algemeen een positief beeld hebben van hun relatie, de neiging hebben om positief gedrag van hun partner toe te schrijven aan stabiele persoonlijke kenmerken van de partner en negatief gedrag aan externe factoren en omstandigheden, waarschijnlijk om hun tevredenheid met de relatie in stand te houden. Met andere woorden, de verwachting was dat eerder ondersteunend partnergedrag het effect van huidig negatief partnergedrag zou verzachten. Over het algemeen ondersteunden de resultaten onze hypothesen op de korte termijn. In de context van weinig ondersteunend gedrag van de partner in het verleden, rapporteerden respondenten een lage relatietevredenheid als de partner nu weinig actieve betrokkenheid en/of veel beschermend bufferen toonde. Met andere woorden, onze resultaten toonden aan dat wanneer de partner in het verleden veel ondersteuning heeft geboden, beide partners de kwaliteit van de relatie relatief hoog waardeerden, zonder dat het huidige ondersteunende gedrag van hun partner een rol speelde. Deze resultaten lijken erop te wijzen dat patiënten die vonden dat hun partners ondersteunend waren vòòr de diagnose kanker, meer vergevend waren tegenover het huidige niet ondersteunende gedrag van hun partner (zoals beschermend bufferen). Een mogelijke verklaring is dat zij hun partners’ negatieve gedrag toeschreven aan externe oorzaken en niet aan negatieve eigenschappen van de partner zelf.

Individuen bleken meer beïnvloed door de huidige negatieve gedragingen van hun partner als ze vonden dat hun partners ook in het verleden weinig ondersteunend gedrag hadden vertoond. Op de lange termijn wijzen de resultaten er echter op dat er een grens is aan positieve attributies en de vergevingsgezindheid van patiënten voor het huidige niet ondersteunende gedrag van hun partners. Het huidige hoofdstuk toont aan dat het van belang is in onderzoek naar dyadische coping processen rekening te houden met de interpersoonlijke context waarin deze processen plaatsvinden.

Zowel individuele kenmerken als ondersteunend partnergedrag zouden afzonderlijk de mate van depressieve symptomen in patiënten en partners kunnen beïnvloeden, maar het kan ook worden verwacht dat een combinatie van invloed is op het welbevinden. In **hoofdstuk 3** onderzochten wij hoe het verband tussen steun en depressieve symptomen afhangt van het gevoel van persoonlijke controle van de persoon, i.e., het geloof dat het leven niet wordt bepaald door het lot, maar dat men persoonlijk is staat is om de uitkomsten van belangrijke gebeurtenissen en situaties in het leven te beïnvloeden. Dit hoofdstuk richt zich op de percepties van zowel ondersteunend (bv. een luisterend oor bieden of concrete hulp) als niet-ondersteunend (bv. afkeurende opmerkingen maken) partnergedrag en onderzoekt de verbanden voor patiënten en partners. Wij beredeneren dat personen met weinig controle meer partnersteun nodig hebben (i.e., zij zijn meer afhankelijk van hun partners voor steun) en daarom meer kwetsbaar zijn voor het ontwikkelen van depressieve symptomen als hun partners deze steun niet geven. Over het algemeen laten onze resultaten zien dat individuen die relatief weinig controle ervaren, meer gevoelig zijn voor ondersteunend partnergedrag dan individuen die veel controle ervaren. Meer specifiek vonden wij dat personen die meer ondersteunend partnergedrag ervoeren, minder depressieve symptomen over tijd rapporteerden, maar dit gold alleen voor degenen die relatief weinig controle ervoeren. Daarnaast rapporteerden partners ook meer depressieve symptomen over de tijd wanneer zij meer niet-ondersteunend gedrag van patiënten waarnamen, maar dit gold ook alleen voor partners die relatief weinig controle ervoeren. Anders gezegd toonden onze resultaten aan dat individuen (zowel partners als patiënten) die relatief veel controle hadden, relatief weinig depressieve symptomen rapporteerden, ongeacht het ondersteunend gedrag van hun partner. Deze resultaten lijken erop te wijzen dat, op lange termijn, personen laag in persoonlijke controle meer voordeel zouden kunnen hebben van ondersteunend gedrag, maar ook dat zij meer nadeel zouden kunnen hebben van niet ondersteunend gedrag (bv. kritiek, afkeuring) dan personen hoog in persoonlijke controle. Daarom zouden personen laag in persoonlijke controle kunnen worden geïdentificeerd als een kwetsbare subgroep. Deze bevindingen onderstrepen de noodzaak van het gebruik van een dyadisch perspectief dat rekening houdt met zowel de patiënten als hun partners als ontvangers maar ook als gevers van steun, en de behoefte aan het bestuderen van zowel ondersteunende als niet ondersteunde partnergedragingen.

In **hoofdstuk 4** gebruikten we het *optimal matching model of social support*, welke er vanuit gaat dat steun het meest heilzaam is wanneer deze overeenkomt met de specifieke behoeften van degene die steun ontvangt (Cutrona, 1990). Dit model roept een interessante vraag op: "Hoe kunnen partners op de beste manier steun geven?" Dit hoofdstuk gaat over de manier waarop partners feitelijk steun bieden (d.w.z. hoe meelevend de partner reageert op de patiënt, bijvoorbeeld door te valideren, begrip of warmte te tonen). Ons doel was om te onderzoeken of steun (gedurende een interactietaak) die overeenkomt met de behoeften van de patiënt (namelijk emotionele expressie) bijdraagt aan het verminderen van depressieve klachten van de patiënt. Veel studies hebben aangetoond dat meelevend reageren positief bijdraagt aan intimiteit, vertrouwen en tevredenheid met de relatie. We weten minder over de rol van meelevende reacties in het verbeteren van het emotioneel welbevinden van patiënten. Uit de resultaten van ons onderzoek blijkt dat partners meer gevoelig zijn voor of hun partner meelevend reageert als ze veel behoefte hebben aan emotionele expressie. Ook waren er verschillen tussen de drie unieke componenten van meelevende reacties. We vonden namelijk dat valideren en het tonen van begrip betere voorspellers waren voor de depressieve klachten van de patiënt dan de mate waarin de partner warmte toonde. De verschillende effecten van valideren, begrip tonen en warmte tonen kunnen wellicht verklaard worden door de verschillende functies van deze gedragingen. Misschien is het zo dat valideren en het krijgen van begrip cognitieve verwerkingsprocessen bevorderen en dat daardoor de emotionele lading van de zorgen van de patiënt vermindert. Dit kan dan weer leiden tot een afname van depressieve klachten van patiënten op de lange termijn. Aan de andere kant kan het zo zijn dat partners hun liefde en affectie uitdrukken door warmte te tonen en daarmee hun betrokkenheid laten zien. Dit kan een gevoel van saamhorigheid en intimiteit teweeg brengen, terwijl het niet noodzakelijkerwijs leidt tot een afname van de depressieve klachten van de patiënt. De bevindingen uit dit hoofdstuk dragen bij aan bestaande literatuur over ondersteunend gedrag. We vonden namelijk dat meelevende reacties van partners een belangrijke rol spelen in het emotioneel welbevinden van patiënten, met name voor patiënten die veel behoefte hebben aan emotionele expressie. Daarnaast hebben we specifieke feitelijke gedragingen geïdentificeerd die bevorderd kunnen worden in interventies gericht of het verminderen van depressieve klachten.

Deel 2: Het rekruteren van paren voor psycho-oncologische onderzoeken

In het eerste deel van dit proefschrift hebben we aangetoond dat het belangrijk is om omgaan met kanker te onderzoeken vanuit een dyadisch perspectief. Kanker is immers een stress-veroorzakende factor die invloed heeft op zowel patiënten als hun partners. Omdat er steeds meer onderzoek wordt gedaan naar psychosociale aanpassing onder paren met kanker, wordt het steeds uitdagender om zowel patiënten als partners te werven voor onderzoek. Daarom richt het tweede deel van dit proefschrift (d.w.z. **hoofdstuk 5 en 6**) zich op dit veel voorkomende methodologische probleem in observationeel onderzoek naar het omgaan met kanker binnen intieme relaties, namelijk, de werving van paren. In dit deel van het proefschrift wordt een systematisch overzicht van de literatuur gegeven. In dit overzicht zijn onderzoeken opgenomen die gaan over hoe paren omgaan kanker en die gepubliceerd zijn tussen januari 1980 en mei 2011 (hoofdstuk 5 en 6).

Ondanks dat onderzoekers het er over eens zijn dat het werven van paren voor observationeel onderzoek een uitdaging is, zijn er geen onderzoeken bekend die dit probleem systematisch in kaart hebben gebracht. Het doel van **hoofdstuk 5** is om de gemiddelde 'Couples' Response Rate' te onderzoeken (CCR: alle deelnemende paren gedeeld door het aantal benaderde geschikte patiënten met een partner of benaderde paren) in observationeel onderzoek naar hoe paren omgaan met kanker. Het tweede doel is om een systematisch overzicht te geven van de wijze waarop de CRR gerapporteerd wordt in deze onderzoeken en de kwaliteit van de rapportages. In de helft van de onderzoeken werd er onvoldoende informatie gegeven over de CRR. Daardoor kon de response rate van paren enkel berekend worden voor 33 onderzoeken (van de 88). De hoogte van de CRR varieerde aanzienlijk tussen onderzoeken, namelijk tussen 25% en 90% (CRR_M =58%, SD=17%). Bovendien toonde ons systematisch onderzoek aan dat de gerapporteerde reponse rates in de artikelen vaak hoger waren dan de door ons berekende CRRs. Het lijkt erop dat de onderzoeken cijfers presenteren die gunstiger zijn dan de CRR waardoor de indruk wordt gewekt dat hun steekproef een meer representatieve afspiegeling van de populatie is dan de steekproef in werkelijkheid is. We hebben daarom specifieke aanbevelingen gedaan om de rapportage van CRRs te verbeteren in toekomstig onderzoek. We pleiten voor een accurate en transparante beschrijving van de werving en de steekproef, zodat de lezers beter de generaliseerbaarheid van de bevindingen kunnen inschatten.

Het werven van paren voor psychologisch onderzoek kan dus uitdagend zijn. Toch slagen sommige onderzoeken hier blijkbaar beter in dan andere. In **hoofdstuk 6** onderzochten we potentiele barrières bij het werven van paren voor onderzoeken gericht op het omgaan met kanker binnen intieme relaties. Het doel van dit hoofdstuk is om factoren te beschrijven en vast te stellen hoe die de deelname van paren aan onderzoek naar omgaan met kanker bevorderen. In dit onderzoek richten we ons op demografische variabelen en verschillende methoden om geschikte deelnemers te benaderen. We onderzochten een steekproef van de artikelen uit hoofdstuk 5, namelijk die onderzoeken waarvoor we de CRR konden berekenen (n=33). De CRRs relateerden we aan de verschillende karakteristieken van de onderzoeken en de deelnemers, waaronder de opzet van het onderzoek, de grootte van de groep die benaderd werd, de manieren waarop deelnemers werden benaderd, door wie de paren werden benaderd, beloningen en de vorm van kanker. Daarna reflecteerden we op het mogelijke effect van deze variabelen op de CRR, waarbij we daar waar mogelijk ook analyses en voorbeelden uit de literatuur presenteerden. We concludeerden dat het herkennen van barrières bij het werven van paren een eerste cruciale stap is om dergelijke barrières te overkomen, om CRRs te verbeteren en om een realistische inschatting mogelijk te maken van de kosten en baten van het werven van paren in onderzoek. We konden geen specifieke wijze van werven aanbevelen daar de informatie over de gebruikte wervingsmethoden in veel onderzoeken te beperkt was.

Tenslotte bevat **hoofdstuk 7** een bespreking van de belangrijkste conclusie die we kunnen trekken uit het empirisch onderzoek, namelijk, dat depressieve klachten en tevredenheid met de relatie van zowel de patiënt als de partner beïnvloed worden door de manier waarop de partner steun geeft. Daarbij moet vermeld worden dat deze effecten afhangen van de kwetsbaarheid en de behoeften van degene die steun ontvangt. Vervolgens bespreken we de theoretische en klinische implicaties. We reflecteren uitvoerig op een nieuw theoretisch perspectief (d.w.z. *de kwetsbaarheid hypothese*) die we hebben ontwikkeld en onderzocht in het empirische deel van dit proefschrift. Volgens de *kwetsbaarheid hypothese* heeft steun van partners meer invloed op sommigen dan op anderen. Deze hypothese gaat in het bijzonder over subgroepen van mensen (patiënten en/of partners) die depressieve klachten ervaren omdat ze afhankelijk zijn van de steun van anderen. Vandaar dat er verwacht wordt dat kwetsbare mensen zich minder goed aanpassen dan mensen die niet afhankelijk zijn van de steun van anderen wanneer ze geen steun of de verkeerde vorm van steun ontvangen. Vervolgens bespreken we de sterke punten en de beperkingen van ons eigen onderzoek. Daarna bespreken we de conclusies die getrokken kunnen worden op basis van ons systematische review. We doen daarbij aanbevelingen voor het werven van paren en het rapporteren hierover ten bate van toekomstig onderzoek.

Acknowledgments

After five years of reading, writing, coding, designing, debating, analyzing, puzzling, understanding, validating, and caring, it is time to thank all the amazing people who supported me professionally and personally throughout this project. With a great pleasure I am writing these words, remembering the people and the anecdotes that made this journey complete.

First of all, I would like to thank the **couples** who participated in the study. Thank you for the time that you invested in this study and for opening your heart and your house to us. I know that discussing your concerns in front of a camera was not an easy task but it helped a lot to further our understanding of the complex nature of spousal support in the face of illness. Without your cooperation this project would have never existed.

I would like to thank my promoters Professor Mariët Hagedorrn and Professor Robbert Sanderman. **Mariët,** thank you for being a great mentor to me, providing the perfect environment to grow, keeping a balance between freedom and guidance. Thank you for passionate but constructive discussions, giving space to my enthusiasm and creativity while keeping my "feet on the ground". And most of all, thank you for keeping your door, ears and heart wide open. I will always cherish our heart to heart talks during conferences trips. **Robbert**, thank you for supporting, inspiring and encouraging me along the way. I admire your skill of thinking outside the box, thank you for inspiring me to do the same. Thank you for your tip about Philips, it made our integration in the Netherlands faster and nicer. Also, thank you for pushing me to submit my thesis before my due date, it made the transition to parenthood smoother. Special thanks to the members of the reading committee**, Prof. dr. C. Finkenauer**, **Prof. dr. A.J Oldehinkel**, and **Prof. dr. K.MG Schreurs** thank you so much for reading and approving the manuscript.

Now, I would like to thank co-authors, collaborators, and other colleagues who supported me in this journey: **Prof. Rebecca Jacoby** and **Prof. Yael Benyamini,** thank you for encouraging me to take this opportunity. **Dr. Erwin Geerts**: I wish I could thank you face to face. Your death was shocking and shaking both for me personally as well as for the project. Erwin invest a lot of time and efforts opening the non-verbal world to me, training me and my students and making sense of the unspoken words. May he rest in peace. **Prof. Nico van Yperen**, thank you for willing to think along, providing useful feedback and sharing your great expertise with experimental design. Special thanks to the ***Wenckebach Skills Center UMCG***, **Sip**, **Ingrid**, and **Camiel** for being flexible, creative and kind while helping the experiment go through. And to the students: **Melchior**, **Elsie-Marie**, **Rohan**, **Ester**, **Nils**, **Marlon**. Thank you for your contribution, by hours of translating, recruiting, and coding.

To all my wonderful **colleagues of the 5th floor** for the gezelligheid and good working atmosphere. Especially I would like to thank our dedicated secretaries: **Renate Kroese**, **Tineke van der Wees**, and **Annemieke Brouwers**, for taking care of all the administrative issues with so much patience and efficiency. Also I would like to thank: **Prof. Adelita Ranchor** for your tips, prompt and helpful feedback and for always willing to think along. **Prof. James Coyne** for your inspiring, fascinating, and remarkable stories that add flavor to science. **Ans Smink** for always willing to help, and for your assistance with the coding of *responsiveness*. **Truus van Ittersum**, for your caring, and for being so helpful, fast, and approachable. For keeping your door always open, and approaching each problem with a smile. **Dr. Eric van Sonderen**, for great and inspiring discussions and for making statistic and methodology such a lively topic. **Dr. Joke Fleer,** for being such a supportive listener, especially with handling pregnancy, new born, and becoming a mother.

PhD fellows: Adriana, Annika, Corina, Daphne, Evelin, Inge, Fabiola, Gemma, Lei, Lihua, Marike, Moniek, Somayhe, Vicky, Yvette, Franziska, Ying. Thank you all for being part of the special moments during my PhD trajectory. I cherish our countless lunch breaks, and laughter moments which colored my workdays. I wish you all the best with your projects and your future careers. Especially I would like to thank **Vicky** (**Pedia**) for being such a great friend, always offer to help and so good in shortening my long texts! Thank you for being such a precious listener and a coffee and tea supplier ☺. **Marike Alferink**, for understanding my heart and sharing yours, and for dog-sitting our precious Lia. Thank you for lots of chatting and endless laughter moments. **Somayeh,** for your kind heart, for caring so much and for sharing your delicious Persian food (especially Dolmeh). Thank you for hosting and organizing the amazing baby shower. **Marike Schokker** for teaching me the wonder of MLwiN software and introducing me to the Elfstedentocht. **Gemma** (and of course **Marcel**) for your warm welcome and help with finding the way in Groningen, for the successful connection to Philips. **Inge**, special thanks for being an inspiration to me in many situations and for sharing with me your hobby, the beauty of rowing. Also special thanks for **Evelien** and **Moniek** for your great help with the Dutch translation of the summary. And of course to my second **officemates**: Katerina**,** Moniek, Marrit and Vicky thank you for always keeping a chair, and your heart available for me when I needed support of a real friend.

My dear friends, in the Netherlands, Israel, and around the globe. Thank you for your support and encouragement, for sharing with us all our holiday dinners and being our global family. Thank you for your visits that made our home full of joy. Thank you for bringing the sunshine, the love, and the flavor of Israel. Especially I would like to thank, **Matan** for many years of unconditional friendship, for always being there for me, cheer me up and giving me a good advice, for reading lots of my drafts, doing English editing, and being THE frequent visitor! **Katerina** and **Manolis,** for being our family in Groiningen. Katerina, since the first time you entered our house you entered our hearts. Thank you for sharing with us all those magical moments of Friday dinners, cooking, playing, hiking, traveling, canoeing, talking, arguing and finally, making our life in Groningen so enjoyable. My dear rowing team **“Ladies first”: Ana, Irene, Mariken, Sistske, Wemke** for being there in these relaxing moments of sanity and for keeping my place in the boat and in your heart for such a long time. **Nico Wiegersma**, for your patient and dedication to show us the beauty of the Dutch language in our weekly meetings.

My dearest paranymphs Dr. Marrit Tuinman and Mirjam Heersmink. **Marrit,** thank you for endless clever jokes, sharps feedbacks and heart to heart discussions advices and tips. And simply thank you so much for being there! **Mirjam**, thank you for being my best friend, for making me smile, for being there in ups and downs. For unconditioned and non-judgmental friendship, thank you for all the laugher moments and the warm hugs.

To our family who, despite the distance made us feel close with visits, calls, and packages from the holy land. To my parents **Michael** and **Talma Dagan**, thank you for your love, encouragements and for having faith in me along the way. Daddy (אבא) thank you for insisting on issuing a polish citizenship for me, it made our relocation much smoother. Mommy (אמא) thank you for our talks and for endless treats. My sister **Eynav**, thank you for challenging me and for making me laugh. **Shaked** my dear son, thank you for your patience, for letting me submit my dissertation just before joining the family. Thank you for your sweet smiles and for teaching me to become your mother. **Ishay** my life partner and my best friend. Thank you for sharing this amazing journey with me. Thank you for all your love, support, and for knowing me so well. Thank you for being there for me in times of joy and sorrow the last five years (and many years before). Thank you for the endless cooking (also with special delivery to the UMCG) that kept my spirit high and my smile big. Thank you for being so involved, thinking along with me on my project and for inspiring me to think "in solutions" (which stimulate writing a review). Thank you for responsive spousal support and for reminding me about the important things in life.

About the author,

Meirav Dagan was born on November 12th, 1980 in Jerusalem, Israel. In 1998, she graduated from the Thelma Yellin High School of the Arts with a Theater major. Between 1991 and 2001 she served in the Israeli Defense Force as an operations control supervisor at the Air Force Operational Unit, and was awarded Outstanding Soldier Award for Exceptional Service. Following her honorary discharge in 2002, she started her academic career in psychology. In 2007, she has earned an M.A in Health Psychology from The Academic College of Tel Aviv-Yaffo. The title of her M.A thesis was "*Pregnant Woman and Fetus Physical Reaction Accompanied Stress and Relaxation*". She was also the co-chair of the Ethic Research Committee at The Academic College of Tel Aviv-Yaffo and served as database supervisor of the Health Psychology Website.

As part of her M.A studies she had gained practical training as a health psychologist in Kaplan Hospital, Israel. She worked with children and their parents applying cognitive behavioral protocols and a systematic approach and instructed personal strengthening workshops. Additionally, she provided long-term therapies at the mental health clinic. In 2008, she received her psychologies license, and was further trained in the Developmental Individual Differences Relationship Model (D.I.R). Between 2004 and 2008 she worked part -time with young children who suffer from autistic spectrum disorders and applied the D.I.R model when assisting them to integrate into their class environment.

In 2009, she was accepted for a four-year PhD position under the supervision of Professor Mariët Hagedorrn and Professor Robbert Sanderman at the Health Psychology Section, Department of Health Sciences, University Medical Center Groningen, the Netherlands. During her PhD she published four papers in top-30 Journals. In addition, she presented her work in several national and international conferences and was invited to present at Columbia University, USA and at Fribourg University, Switzerland. Her research interests include intimate relationships, spousal support, dyadic coping with chronic illness, and sexuality in the face of illness. She balances her life by hiking, rowing, and photography.

For more information please contact the author: Mervdagan@gmail.com

Institute for Health Research SHARE

This thesis is published within the **Research Institute SHARE** of the University Medical Center Groningen / University of Groningen.
Further information regarding the institute and its research can be obtained from our internetsite: www.rug.nl/share.

More recent theses can be found in the list below.
((co-) supervisors are between brackets)

2014

Lakke AE. *Work capacity of patients with chronic musculoskeletal pain*
(prof JHB Geertzen, prof MF Reneman, prof CP van der Schans)

Bodde MI. *Complex-Regional Pain Syndrome type I & ampuatation*
(prof JHB Geertzen, prof PU Dijkstra, dr WFA den Dunnen)

Tiessen AH. *Cardiovascular risk management in general practice*
(prof K van der Meer, prof AJ Smit, dr J Broer)

Jong LD de. *Contractures and hypertonia of the arm after stroke*
(prof K Postema, prof PU Dijkstra)

Krieke JAJ van der. *Patients in the driver's seat. A role for e-mental health?*
(prof P de Jonge, prof M Aiello, dr S Sytema, dr A Wunderink)

Silarova B. *Unraveling the role of sense of coherence in coronary heart disease patients*
(prof SA Reijneveld, dr JP van Dijk, dr I Rajnicova-Nagyova)

Weening-Dijksterhuis E. *Physical exercise to improve or maintain Activities of Daily Living performance in frail institutionalized older persons*
(prof CP van der Schans, prof JPJ Slaets, dr MHG de Greef, dr W Krijnen)

Koolhaas W. *Sustainable employability of ageing workers; the development of an intervention*
(prof JJL van der Klink, prof JW Groothoff, dr S Brouwer)

Flach PA. *Sick leave management beyond return to work*
(prof JW Groothoff, prof U Bültmann)

2013

Bosker BH. *Pitfalls in traditional and innovative hip replacement surgery*
(prof SK Bulstra, dr CCPM Verheyen, dr HB Ettema)

Holwerda A. *Work outcome in young adults with disabilities*
(prof JJL van der Klink, prof JW Groothoff)

Mohseninejad L. *Uncertainty in economic evaluations: implications for healthcare decisions*
(prof E Buskens, dr TL Feenstra)

Flach LR. *A view beyond the horizon; a prospective cohort study on mental health and long-term disability*
(prof JJL van der Klink, prof JW Groothoff, dr S Brouwer)

Sobhani S. *Rocker shoes for ankle and foot overuse injuries: a biomechanical and physiological evaluation*
)prof K Postema, prof ER van den Heuvel)

Pitel L. *Sociocultural determinants, gender and health-related behaviour in adolescence*
(prof SA Reijneveld, dr JP van Dijk, dr A Madarasova-Geckova)

Majerníková M. *Sef-rated health and mortality after kidney transplantation*
(prof JW Groothoff, dr JP van Dijk, dr J Rosenberger, dr R Roland)

Verschuren J. *Sexuality and limb amputation: perspectives of patients, partners and professionals*
(prof JHB Geertzen, prof PU Dijkstra, prof P Enzlin)

Riphagen-Dalhuisen J. *Influenza vaccination of health care workers*
(prof E Hak)

Hasselt FM van. *Improving the physical health of people with severe mental illness; the need for tailor made care and uniform evaluation of interventions*
(prof AJM Loonen, prof MJ Postma, dr MJT Oud, dr PFM Krabbe)

Piening S. *Communicating risk effectively*
(prof FM Haaijer-Ruskamp, prof PA de Graeff, dr PGM Mol, dr SMJM Straus)

Siebelink MJ. *The child as a donor; a multidisciplinary approach*
(prof HBM van de Wiel, prof PF Roodbol)

Sidorenkov G. *Predictive value of treatment quality indicators on outcomes in patients with diabetes*
(prof FM Haaijer-Ruskamp, prof D de Zeeuw)

Vu DH. *Clinical pharmacology of tuberculosis drugs and tuberculosis control in developing world; the involvement of private pharmacy and the individualization of treatment using dried blood spot*
)prof JRBJ Brouwers, prof DRA Uges, prof VH Le, prof DH Nguyen, dr JWC Alffenaar)

Sijtsma A. *Physical activity and overweight in young children*
(prof PJJ Sauer, prof RP Stolk, dr E Corpeleijn)

Rosicova K. *Regional mortality in Slovakia: socioeconomic indicators and ethnicity*
)prof JW Groothoff, dr JP van Dijk, dr A Madarasova-Geckova)

Bobakova D. *Youth subcultures and problem behaviours in Slovakia: hip-hop, techno-scene, metal, punk,skinheads and Roma*
)prof SA Reijneveld, dr JP van Dijk, dr A Madarasova-Geckova)

Arends I. *Prevention of recurrent sickness absence in workers with common mental disorders*
(prof JJL van der Klink, prof U Bültmann)

Theunissen MHC. *The early detection of psychosocial problems in children aged 0 to 6 years by Dutch preventive child healthcare; professionals and their tools*
)prof SA Reijneveld, dr AGC Vogels)

Bragaru M. *Sports and amputation*
(prof JHB Geertzen, prof PU Dijkstra, dr R Dekker)

Broesamle TC. *Designing health care services using systems thinking; a theory, a method and their application in the Dutch community pharmacy*
)prof JJ de Gier, prof JJ van der Werf)

Jong J de. *Antibiotics use in children; pharmacoepidemiological, practical and environmental perpectives in the Netherlands*
(prof LTW de Jong-van den Berg, dr TW de Vries)

Laat FAJ de. *Measuring mobility in persons with a lower-limb amputation*
(prof JHB Geertzen, dr LD Roorda, dr GM Rommers)

Rettke HG & Geschwindner HM. *Long-term outcomes in stroke rehabilitation patients and informal caregivers*
(prof WJA van den Heuvel)

Fortington LV. *Enabling the elderly person with lower limb amputation through surgery, rehabilitation and long term care*
(prof JHB Geertzen, prof PU Dijkstra, dr GM Rommers)

Lako IM. *Depressive symptoms in patients with schizophrenia; count symptoms that count*
(prof K Taxis, prof D Wiersma)

Arnardottir AH. *Regulatory benefit-risk assessment; different perspectives*
(prof FM Haaijer-Ruskamp, prof PA de Graeff, dr PGM Mol, SMJM Straus)

Meijer A. *The forest trough the trees; investigating depression in patients with cancer and patients with myocardial infarction using systematic reviews and meta-analytic techniques*
)prof P de Jonge, dr HJ Conradi, dr BD Thombs)

Kuchenbecker WKH. *Obesity and female infertility*
(prof JA Land, prof BHR Wolffenbuttel, dr A Hoek, dr H Groen)

Rozenbaum MH. *Costs and effectiveness of extended vaccination strategies against pertussis and pneumococcal disease*
(prof MJ Postma, prof E Hak)

For more 2013 and earlier theses visit our website