Distress and spousal support in women with breast cancer
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INTRODUCTION

The present thesis focuses on psychological distress in women with breast cancer and their partners and on the influence of partner support on adaptation. In this introduction we will first pay attention to the prevalence of breast cancer as well as to possible treatment regiments and side effects followed by a short description of adaptation to cancer as a dyadic process. Next, we will review the literature on distress and spousal support in cancer patients and describe the background and aim of the different studies that make up this thesis.

PREVALENCE OFbreast cancer, TREATMENT REGIMENT AND SIDE EFFECTS

In the Netherlands approximately 37,500 men and 35,500 women receive a cancer diagnosis every year. Of these women approximately 11,500 (32%) receive a breast cancer diagnosis which makes breast cancer the most frequently occurring type of cancer among women. One in every ten women receive a breast cancer diagnosis before the age of 75. On average women have an 80% chance of surviving breast cancer the first five years. Fifty years ago the five year survival rate was 52% (Dutch Cancer Association).

Most women will receive an operation after the diagnosis, such as lumpectomy or mastectomy with or without reconstruction. After and sometimes before the surgery, women may receive radiotherapy to kill cancer cells and shrink the tumor. Typically, women receive treatment five days a week for several consecutive weeks. Women often feel quite tired towards the end of this treatment and breast tissue may become sore. In some women the problems may be more serious, including arm swelling, damage to the lungs, heart and nerves, or a change in the appearance and consistency of breast tissue. A relatively small percentage of women will receive chemotherapy when there is a chance that cancer cells have spread to tissue outside the breast. The side effects of chemotherapy may be quite severe, including loss of hair, nausea, vomiting, fatigue and cognitive impairments such as memory loss and word finding problems. As an adjuvant treatment (i.e., aimed at reducing the chance of recurrence) women with an estrogen receptor positive type of cancer may receive hormonal therapy which may go hand in hand with vaginal itch, hot-flashes and night sweating.

ADAPTATION TO BREAST CANCER AS A DYADIC PROCESS

With the improvements in medical treatment and increase in survival rate, the number of women that have to deal with the changes imposed by the illness increases. Being ill and receiving treatment threatens peoples’ daily routines, physical functioning and social life which are recognized to provoke emotional distress in patients. However, a breast cancer diagnosis may not only impact the lives of patients but also the lives of their intimates, especially partners. Even when prognosis for survival is relatively good partners also have to deal with interruptions in daily routines and with uncertainty regarding the effectiveness of the treatment. To a large degree coping with the changed reality is a dyadic process in which both partners of a couple not only have to deal with their own distress and the changes in their own lives but also with the emotional and instrumental needs of the other person. Depending on situational, personal and relational factors partners may provide support in a positive (e.g., showing empathy and interest) or negative (e.g., withdrawal and dismissal) way (O’Brien & DeLongis, 1996). This task of dealing with the needs of the other person is referred to as relationship focused coping or ways of providing support.
Few studies have investigated adaptation to a life-event such as cancer as a dyadic process in which support provided by a partner is central. In this study we will on the one hand investigate the impact of breast cancer on patients and partners emotional distress and on the other hand we will investigate determinants and outcomes of different ways of spousal support. Before presenting the studies in more detail we will elaborate on what currently is known about these topics.

**Course and Level of Distress**

A vast amount of studies have investigated distress levels in people confronted with cancer in general (e.g., Zabora, Brintzenhofeszoc, Curbow, Hooker, & Piantadosi, 2001; Honda & Goodwin, 2004; Pitceathly & Maguire, 2003) and with breast cancer in particular (e.g., Koopman et al., 2002; Groenvold et al., 1999). Most of these studies have, however, a cross-sectional design and lack a comparison group from the general population. The few studies that do follow women with breast cancer over time and include comparison-controls offer mixed results. Andersen, Anderson and deProesse (1989) found that while women with early stage breast cancer reported more anxiety, depressive feelings and confusion pre-treatment than healthy comparison-controls, six months post-treatment no differences were observed. In contrast, Northouse and colleagues (1998), observed markedly different patterns of distress in patients and partners facing benign and malignant breast disease. Couples facing malignant breast cancer reported higher levels of emotional stress, relationship problems and uncertainty than couples facing benign breast cancer. These differences persisted till one year after diagnosis. From these results it is not clear whether breast cancer is an ongoing or transitory stressor. Moreover, these and other studies (1) generally do not include non-cancer related factors that may explain the course and level of distress in patients and comparison-controls (2), use a limited number of assessment points, which limits the insight in the dynamic course of distress, and (3) analyze the data using less than optimal statistical techniques.

In the first study of this thesis (Chapter 2) we will fill this gap in the literature by investigating the level and course of distress in women with breast cancer and their partners in comparison to matched control couples from the general population, taking neuroticism into account and we will make use of multiple assessments in a twelve month period as well as a more sophisticated statistical technique.

Moreover, we will use the longitudinal data of patients, partners and comparison-controls to conduct sample size calculations for hypothetical intervention studies with a randomized control trial design. There is currently a growing body of literature reporting weak and null results for psychological interventions aimed at alleviating distress in cancer patients (Coyne & Lepore, 2006). This state of affairs may reflect more on the design of the trials in which interventions are being tested, than on their potential efficacy with appropriately chosen populations and appropriately timed follow-up assessments. The present study offers the opportunity to calculate the appropriate sample size for a hypothetical intervention study taking several key factors into account such as the initial distress level of those included in the intervention study, the distress trajectory of those receiving no formal intervention, and the level of distress present in matched comparison-controls from the general population. Therefore, the second aim of the first study was to offer provisional estimates of the number of people needed to ensure enough power to detect a realistic treatment by time effect for an intervention study aimed at alleviating distress in women with breast cancer and their partners.

**Spousal Support**

A central tenet in research on life-stress in general and oncology in particular is
to identify factors that may explain why some people fare better than others when confronted with cancer. Information about determinants of adaptation may help to develop interventions tailored to the individual needs and abilities of patients. One of the most widely used theories to explain individual differences in adaptation to stressful life events is the stress-coping theory (Lazarus & Folkman, 1984). Coping refers to constantly changing cognitive and behavioral efforts to manage a stressor. If an event is perceived as disrupting and demanding, coping responses are set off to manage the stressor (problem focused coping) and the emotional consequences of the stressor (emotional coping). Despite its merits, this theory has been criticized for its individualistic nature. More recently scholars have expanded coping to include relationship focused coping strategies (or ways of providing support) which refers to support that is aimed at dealing with the other person’s emotional and functional needs (DeLongis & O’Brien, 1990; Coyne & Smith, 1991; Coyne & Racioppo, 2000). Although most empirical studies have focused on perceived availability of support and support satisfaction we focused on supportive behavior by partners. Moreover, we addressed different ways in which partners may provide support rather than on different types of support (e.g., emotional, instrumental). In our view different types of support can be provide in more than one way (Hagedoorn et al., 2000). For example, a partner may try to provide emotional support by asking how the patient feels and by discussing fears and worries or alternatively by avoiding negative experiences while dismissing fears and worries.

Two broad ways of providing support have been identified in the literature; active engagement and protective buffering (Coyne et al., 1991; Hagedoorn et al., 2000; Kuijer et al., 2000). Active engagement is characterized by involving ones partner in discussions, asking how the other feels and other problem- and emotion focused strategies. Active engagement is generally perceived as supportive and helpful by the recipient. Protective buffering, on the other hand, is characterized by denying fears and worries and by avoiding negative experiences which is generally perceived as unsupportive and unhelpful. Both active engagement and protective buffering have been associated with emotional and relationship distress in chronically ill people. Specifically, active engagement has been found to be associated with more relationship satisfaction (Hagedoorn et al., 2000) while protective buffering has been found to be associated with more distress (De Ridder, Schreurs, & Kuijer, 2005; Kuijer et al., 2000; Coyne et al., 1991) and with less relationship satisfaction (Hagedoorn et al., 2000).

In the present study we were interested in determinants of active engagement and protective buffering and in the outcome of these strategies by taking potential moderators into account. This is import for understanding the outcome of these strategies which, in turn, may help the development of interventions for cancer patients aimed at improving social resources and reducing social obstacles.

**Determinants of the way in which partners provide support**

The extent to which a partner is actively engaged or uses more protective buffering strategies may depend on the appraisal of the other person’s needs and abilities. Put differently, partners may provide support in a way they feel is most supportive for their ill partners’ adaptation. For example, partners may avoid discussing fears and worries as they feel it would hinder patients’ adjustment (Lichtman, Taylor, & Wood, 1987) or partners may invite the other in discussions as they are confident about the ill partners’ coping abilities (Kuijer et al., 2000). However, partners may also use specific support strategies not because they feel it
is most appropriate for their partner but as a way to cope with their own fears and worries (Coyne et al., 1991; Thompson & Bolger, 1999). For example, partners may dismiss concerns and worries of their ill partner as they themselves feel unable to deal with the negative emotions.

In the second study of this thesis (Chapter 3) we investigated whether partner characteristics (i.e., emotional distress and level of neuroticism) explained the use of active engagement and protective buffering strategies. Both distress and neuroticism can be viewed as risk factors for becoming overly involved in one's own fears and worries, which might become manifest in the use of less active engagement and more protective buffering strategies. Moreover, this study also seeks to assess whether time since diagnosis has an effect on support behavior. As time passes and adaptation occurs, the need to discuss or, conversely, avoid illness-related fears and worries may diminish, which will be reflected in the use of less protective buffering and active engagement strategies over time.

The outcome of spousal support

It is often assumed that if only partners were more supportive and helpful patients’ adaptation would improve and distress would be alleviated. This may, however, be an oversimplification of reality. The outcome of partner support may depend on several factors. We will describe three factors that may impact the effectiveness of the way in which partners provide support followed by the description of two articles in which these factors are tested.

First, the effectiveness of active engagement and protective buffering may be idiosyncratic. That is, what is effective for one person may not be effective for someone else or, conversely, what is deleterious for one person may not be deleterious for someone else (Bolger & Zuckerman, 1995). Some individual characteristics may protect people from negative effects of support that is considered unhelpful. For example, people who are less inclined to express personal thoughts and feelings may be much less hampered by partners who try to avoid and minimize fears and worries than people who are more inclined to confide in others. Two potentially powerful individual characteristics that may moderate the outcome of spousal support are a patient’s assertiveness and a patient’s sense of mastery. Personal assertiveness is the ability to communicate personal thoughts and feelings effectively (Wolpe & Lazarus, 1966) and can be conceptualized as a two dimensional construct (Arrindell, Sanderman, & Ranchor, 1990; Arrindell et al., 1999; Arrindell et al., 2005). The two dimensions are (a) the frequency of interpersonal behaviors, such as expressing personal thoughts and feelings, and (b) the tension experienced when engaging in such behaviors. Mastery is a developmentally based mental representation about one's ability to control life and resolve problems (Pearlin & Schooler, 1978; Edwards, 2002; Edwards, 2002).

Secondly, the effectiveness of the way in which partners provide support may depend on the time frame adopted. Support that is effective on the short term may not be effective over time and visa versa (DeLongis & Holtzman, 2005). For example, DeLongis (2005) reported that while empathic responding did not always have an immediate beneficial effect, over time, such behaviors were found to be associated with favorable outcomes, such as a decrease in marital tension. Similarly, the outcome of active engagement and protective buffering may vary as a function of the time frame adopted (i.e., cross-sectional or longitudinal).

Thirdly, patients' awareness of the support received may impact the effectiveness of support. Bolger and colleagues (2000) have argued that support that occurs outside recipients' awareness is most effective. That is, receiving support may be ineffective as it makes salient to recipients that they need
help and are unable to cope with a stressor themselves. In contrast, support that occurs outside recipients’ awareness would buffer the negative effects of stressors without undermining personal resources such as self-esteem or self-efficacy. This possibility has not been investigated in cancer patients before.

The impact of these factors on the outcome of active engagement and protective buffering was tested in the third and fourth study of this thesis. In the third study (Chapter 4), we investigated the outcome of active engagement and protective buffering on relationship satisfaction taking patients’ personal assertiveness and time into account. The aim of the study was to investigate the extent to which the association between perceived active engagement and protective buffering on the one hand and relationship satisfaction on the other hand was moderated by personal assertiveness. These associations were investigated both cross-sectionally and over time. Furthermore, we were also interested in the association between personal assertiveness and relationship satisfaction in women with cancer and in control women from the general population to investigate whether assertiveness was differently associated with relationship satisfaction in women with and without cancer.

In the fourth study (Chapter 5), we investigated the outcome of active engagement and protective buffering on distress taking patients’ sense of mastery, patients’ awareness of the support provided and time into account. In this study we relied not only on patients’ accounts of active engagement and protective buffering but also on reports of their partner. By combining accounts of patients and partners we were able to investigate whether the effectiveness of partner support varied when perceived by patients or when only reported by partners. Moreover, we investigated the extent to which the association between relationship focused coping and distress was moderated by mastery and whether the time frame adopted (i.e., cross-sectional or longitudinal) impacted the outcome.

**Summary**

In sum, in this thesis we investigated the impact of breast cancer on psychological distress as well as the determinants and effectiveness of spousal support strategies on relationship satisfaction and emotional distress. The presented studies have some methodological strengths such as a longitudinal design, the inclusion of comparison-controls from the general population and reports of patients and partners.


