Université de Montréal

Predicting distress and benefit finding in breast cancer survivors at six-year follow-up

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Thèse présentée à la Faculté des études supérieures
en vue de l'obtention du grade de Philosophiæ Doctor (Ph.D.)
en psychologie recherche/intervention
option clinique

Juillet, 2004

Université de Montréal

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Université de Montréal
Faculté des études supérieures

Cette thèse intitulée :

Predicting distress and benefit finding in breast cancer survivors at six-year follow-up

présentée par :
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Résumé

Même plusieurs années après la fin de leur traitement oncologique, beaucoup de survivantes du cancer du sein ressentent toujours des symptômes de détresse liés à leur maladie, tels que des sentiments dépressifs, de l'anxiété ainsi que des symptômes d' intrusion et d'évitement qui suggèrent la manifestation d'un trouble de stress post-traumatique (PTSD). Néanmoins, plusieurs de ces patientes affirment aussi avoir retiré des bénéfices de leur expérience du cancer. Présentement, la relation entre la perception de bénéfices et la détresse psychologique chez les survivantes d'un cancer du sein n'est pas connue.

Cette thèse se compose de deux articles explorant la relation entre la détresse psychologique, les symptômes de PTSD et la perception de bénéfices chez les survivantes du cancer du sein. Le premier se propose de quantifier et de décrire les changements longitudinaux des niveaux de détresse psychologique et des symptômes de PTSD chez 86 survivantes du cancer du sein, six ans post-diagnostic. Des facteurs de risque potentiels de la détresse psychologique et des symptômes de PTSD ont également été examinés. Le second article étudie la relation entre la perception de bénéfices, la détresse psychologique, les symptômes d'intrusion et d'évitement auprès des survivantes du cancer du sein.

Les résultats de l'article 1 montre que près de 25% des survivantes d'un cancer du sein rapportent un niveau modéré de détresse psychologique et de symptômes de PTSD 6 ans après leur diagnostic. Les analyses transversales suggèrent que la peur du futur, la perception d'un mauvais état de santé, moins d'optimisme et l'occurrence d'une seconde expérience de cancer sont des facteurs de risque de la détresse et des symptômes de PSTD à 6 ans. Les analyses longitudinales montrent que, durant la première année suivant le diagnostic, le niveau de détresse psychologique, un pauvre soutien social et l'utilisation de stratégie de coping de résolution de problèmes axée sur les aspects positifs sont des facteurs de risque prospectifs de la détresse psychologique rapportée à 6 ans.

Les résultats de l'article 2 indiquent que, chez les survivantes d'un cancer du sein, il n'existe pas de relation entre la détresse psychologique et la perception de bénéfice, mais que cette dernière est positivement corrélée avec la fréquence des pensées intrusives. L'occurrence d'une seconde expérience de cancer, la perception d'un mauvais état de santé et l'utilisation de stratégie de coping de résolution de problèmes axée sur les aspects positifs prédisent une perception accrue de bénéfices liés à l'expérience du cancer.

Les résultats de ces articles mettent en évidence l'importance d'évaluer la peur du futur, l'évaluation cognitive de l'expérience du cancer ainsi que les préoccupations somatiques des survivantes d'un cancer du sein. Par ailleurs, la perception de bénéfices semble être un des processus cognitif permettant aux femmes souffrant d'un cancer du sein d'intégrer les conséquences négatives de leur maladie. Malgré cela, le fait d'encourager les patientes à rechercher les aspects positifs de leur expérience du cancer peut être nuisible à long terme, du moins pour celles qui ont fréquemment recours, durant la première année suivant le diagnostic de cancer, à des stratégies de résolution de problèmes axées sur les aspects positifs.

Mots-clés : cancer du sein, survivantes en rémission, détresse psychologique, intrusion et évitement, perception des bénéfices, coping, devis longitudinal

Abstract

Many long-term breast cancer survivors experience illness-related distress, e.g., symptoms of depression, anxiety, and intrusion or avoidance (suggestive of Posttraumatic Stress Disorder (PTSD) symptoms). Yet many breast cancer patients also report deriving benefits from their experience. We currently do not know what is the relationship between benefit finding and distress in breast cancer survivors. Few predictive, longitudinal studies have used baseline data (at time of diagnosis or treatment) to predict distress or benefit finding during the survivorship period in this population.

This dissertation consists of two articles designed to further our understanding of the relationships among distress, PTSD-like symptoms, and benefit finding in long-term breast cancer survivors. The first article proposed to quantify the levels of distress and PTSD-like symptoms found in (n = 86) breast cancer survivors at 6 years and described changes in these levels longitudinally. It also examined a number of variables as potential risk factors of distress and PTSD-like symptoms during the survivorship period. The second article examined the relationship between benefit finding, distress, and avoidance and intrusion among long-term breast cancer survivors (n = 86). This article studied the relationships between social, personality and coping variables with benefit finding at 6 years both cross-sectionally and longitudinally.

The results of article 1 indicated that about 25% of long-term breast cancer survivors displayed moderate levels of distress and PTSD-like symptoms at 6 years. Distress levels did not change over time while PTSD-like symptoms declined significantly from 3 months to 1 year but showed no further change at 6 years. Cross-sectional analyses revealed that fear of the future, poor perceived health, being less optimistic, and having had a second cancer experience were risk factors of distress and PTSD-like symptoms during the survivorship period. Longitudinal analyses revealed that distress, poor social support and positive problem solving coping during the first year following diagnosis were prospective risk factors of distress during survivorship.

The results of article 2 indicated that benefit finding was unrelated to distress, but was positively correlated with intrusive thoughts among breast cancer survivors. Having a second cancer experience, poorer perceived health, and using positive-problem solving coping predicted greater benefit finding. Benefit finding was positively associated with distress, intrusive thoughts, and worse perceived health assessed at the baseline interview and was generally unrelated to greater psychological resources during the first year following diagnosis.

These results highlight the importance of assessing illness worry, appraisals, fear of the future, and somatic preoccupation among breast cancer survivors. Benefit finding may be one possible way for breast cancer patients who are experiencing more current suffering to process cognitively the negative consequences of the illness. Encouraging patients to search for a 'silver lining' in their experience of breast cancer may, in fact, be detrimental in the long run, at least for those who rely extensively on positive problem solving coping during the first year after diagnosis.

Keywords : breast cancer, long-term survivors, distress, intrusive and avoidant thoughts, benefit finding, coping, longitudinal design

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List of abbreviations

ANCOVA: Analysis of covariance

ANOVA: Analysis of variance

DV: Dependent variable

ESC: Escape – Avoidance coping

FACT: Functional Assessment of Cancer Therapy

IES: Impact of Events Scale

IV: Independent variable

LOT: Life Orientation Test

POMS: Profile of Mood States

PPS: Positive Problem Solving coping

PTSD: Posttraumatic Stress Disorder

SSQ: Social Support Questionnaire

SSS: Seeking Social Support coping

SWB: Social Well Being Scale

WOC: Ways of Coping scale

WOC-CA: Ways of Coping scale- Cancer version

Je dédie cette thèse à la mémoire de ma mère, Francine Couture-Lebel et à mon grand-père Maurice qui ont tous deux transcendé leurs origines humbles grâce à l'étude et qui m'ont transmis la passion de la connaissance. Chère maman, cette thèse est pour moi une façon de donner un sens à ta maladie et à tes questionnements qui ont influencé mon choix de carrière et la femme que je suis devenue. Voici mon chapitre, dans le livre de notre histoire commune...

Acknowledgements

J'aimerais tout particulièrement remercier mon père pour son soutien moral, spirituel, et financier (vive la fondation Lebel!) et son accueil dans mes moments difficiles. Merci papa de m'avoir montré la voie du monde universitaire et de m'avoir enseigné l'amour de la justice. À ma très chère sœur Anne pour son amour et ses encouragements constants, mille fois mercis. Ténacité, grâce et résilience te caractérisent, tu es une grande source d'inspiration pour moi. Merci à Michelle Provost de m'avoir soutenue et encouragée pendant les 28 dernières années; tes conseils, ta réflexion et ta générosité me sont très précieux. Merci également à mon grand-père pour m'avoir financé, interrogé, s'être intéressé à la psychologie et à tout ce qui me touche, et avoir fait circuler mes articles et faits et exploits à toute la famille élargie!

J'aimerais souligner l'homme extraordinaire et exemplaire qu'est mon directeur de thèse, Dr. Zeev Rosberger. In the last 6 years, you have given me so much, I hardly know where to begin to express my gratitude. Thank you for sharing with me your passion for psychosocial oncology and your love for carefully thought out science and thoughtfully executed studies. Thank you for steering me early on towards existential issues by lending me *Man's search for meaning* and then for encouraging me gently along the way, pushing when you needed to, supporting me in my moments of doubts, opening so many professional doors for me and sharing my joys. You are a role model as an ethical, humane researcher and your example will no doubt inspire me greatly, when I myself one day become a mentor. PS : I enjoyed the stories too.

J'aimerais remercier toute l'équipe de recherche, dont particulièrement Johanne, qui est la source des sources et l'appui solide et solidaire sur lequel j'ai toujours pu compter. Merci à Marie, Peter, Lina, Roxane, Lorraine, Jean-Philippe et Amélie pour leur soutien, leurs commentaires très utiles pour l'avancement de cette thèse et leur amitié. Merci également à Chris Kupka qui a recruté les participantes pour les entrevues de suivi et au Dr. Linda Edgar pour son soutien.

À mes très, très chères amies du F-405, Caroline, Marie-Pierre et Rima, surtout pour le don extraordinaire de votre amitié qui a changé ma vie et qui m'a accompagné tout le long de ces études. Je trouve qu'on a fait une bonne ''job'' les filles, je suis fière de nous! Je remercie également Stéphanie, ma très grande amie de toujours et Brigitte, la complice de l'internat pour son infatigable écoute. Un merci tout spécial pour le Centre Étudiant Benoît-Lacroix qui a été mon tuteur de résilience. Maurice, Michel, Rick, Hélène, tante Diane, Karine, Myriam, Sybille, Eddy, Wendyam, Simon, Christine, Paul, Jean-Philippe et toutes les autres personnes extraordinaires que j'ai eu la chance de côtoyer, vous m'avez fait tellement grandir dans la Foi et l'Amour. Je vous aime profondément.

Aucune thèse n'est possible sans le soutien de nombreux professeurs qui montrent la voie. J'aimerai donc remercier les Drs. Norman White et Vivian Sziklas de l'Université McGill et les Drs. Luc Granger et Marcelle Cossette-Ricard de l'Université de Montréal. Merci aussi au Dr. Margaret Kiely qui m'a initié au processus dans son cours *Psychologie de la mort* et qui m'a beaucoup touché par sa générosité, son écoute et son souci des étudiants et aidé avec ses conseils précieux. Je tiens également à remercier M. Miguel Chagnon du Département de statistiques de ses conseils précieux pour l'analyse de mes données.

J'aimerai remercier le Fond de Recherche en Santé du Québec - Fond pour la Formation Des Chercheurs et l'Aide à la Recherche ainsi que l'Institut National du Cancer du Canada qui ont subventionné les travaux de la présente thèse.

Merci à toutes les participantes de cette étude qui ont généreusement accepté de livrer leurs expériences.

Introduction

Since breast cancer patients are living longer, distress and benefit finding have become important issues in long term survivorship. We define long-term survivorship and discuss prevalence of long-term breast cancer survivors. Some of the negative sequelae frequently encountered by breast cancer survivors will be briefly described and the literature on psychological distress in this population will be reviewed in detail. We will also review the literature on the phenomenon of positive changes following trauma such as breast cancer known as benefit finding. Next, we will examine the relationship between distress and benefit finding and attempt to explain some of the discrepancies in the literature. We will review psychological and medical variables that are predictive of distress and benefit finding and outline the importance of using longitudinal designs to investigate distress and benefit finding among long-term breast cancer survivors. Last, we will present the goals and hypotheses, as well as a brief review of the methodology employed in the two articles.

1. Breast cancer: definition of long-term survivorship and prevalence

Breast cancer will affect one out of nine women (National Cancer Institute of Canada, 2004). When diagnosed at the localized stage, the five-year survival rate is 94 % (National Cancer Institute of Canada, 2004). Using the American Cancer Society's definition of a long-term survivor as someone who is alive five years beyond cancer diagnosis, it is estimated that there are over two million long-term breast cancer survivors in North America (National Cancer Institute, 2000; National Cancer Institute of Canada, 2004).

2. Surviving breast cancer: Negative sequelae

The current literature suggests that a significant proportion of breast cancer survivors are affected by residual problems due to their illness and/or its treatments. The most frequently reported problems are fear of recurrence (Cella & Tross, 1986; Maher, 1982; Northouse, Dorris, & Charron-Moore, 1995a; Polinsky, 1994), alterations in social support (Bush, Haberman, Donaldson, & Sullivan, 1995; Fredette, 1993; Maher, 1982), residual physical side effects of the illness and the treatment such as numbness, swelling, conditioned nausea and vomiting, and fatigue (Bower, Ganz, Desmond, Rowland, Meyerowitz, & Belin, 2000; Dorval, Maunsell, Deschênes, Brisson, & Massé, 1998; Woods & Earp, 1978), decreased sexual well-being (Meyerowitz, Desmond, Rowland, Wyatt, & Ganz, 1999), and distress (Dow, Ferrell, Leigh, Ly, & Gulasekaram, 1996; Polinsky, 1994).

2.1 Surviving breast cancer: Distress

Few longitudinal psychosocial studies have followed breast cancer patients over several years. While studies have indicated that psychological recovery is optimal after one or two years (Ganz, Coscarelli, Fred, Kahn, Polinsky, & Petersen, 1996; Heim, Valach, & Schaffner, 1997; Helgeson, Snyder, & Seltman, 2004; Morris, Greer, & White, 1977), there currently is no agreement about adjustment beyond the first two years following diagnosis. Some studies have indicated that quality of life continued to improve during long-term survivorship and that 5-year survivors displayed better adjustment than women diagnosed less than five years ago (Dow et al., 1996; Heim et al., 1997). Other studies found that quality of life decreased at three years post-diagnosis (Ganz et al., 1996) or five years post-treatment (Holzner, Kemmler, Kopp, Moschen, Schweigkofler, Dunser et al., 2001) and that survivors showed worse limitations in overall quality of life than women one or two years beyond diagnosis.

Quantitative studies that have addressed the issue of psychological morbidity among long-term breast cancer survivors have found low rates of clinical psychiatric disorders in this population (Polinsky, 1994; Saleeba, Witzner, & Meyers, 1996). However, there is evidence that subclinical, yet elevated symptoms of distress, consisting mostly of depression and anxiety symptoms, will persist in a significant number of breast cancer survivors (Amir & Ramati, 2002; Andersen, 1992; Polinsky, 1994). Saleeba et al. (1996) reported that mild emotional distress (depression and anxiety) persisted in close to 30% of women who had been disease-free for at least five years after diagnosis of breast cancer compared to only 10 % of women that had been screened for cancer. Self-reported anxiety and depression, especially around follow-up visits, have been found in 38 to 70% of breast cancer survivors in some studies, while fear of recurrence and uncertainty over the future affected more than 80% of survivors (Dow et al., 1996; Ganz et al., 1996; Polinsky, 1994). Furthermore, recent studies have indicated that about 10 to 20 % of survivors will experience intrusive and avoidant thoughts about the cancer and its treatment severe enough to suggest that they might meet a diagnosis of Posttraumatic Stress Disorder (PTSD) and that many more will experience sub-clinical levels of such PTSD symptoms

(Andrykowski & Cordova, 1998; Amir & Ramati, 2002; Cella & Tross, 1986; Cordova, Andrykowski, Redd, Kenady, McGrath, & Sloan, 1995).

2.2 Surviving breast cancer: Benefit finding

Focusing only on the potentially negative sequelae of surviving breast cancer may lead to an incomplete picture. Some studies have found that cancer patients report more positive changes than negative ones and consider themselves to be better adjusted than before their diagnosis (Collins, Taylor, & Skokan, 1990; Fromm, Andrykowski, & Hunt, 1996; Katz, Flasher, Cacciapaglia, & Nelson, 2001; Sears, Stanton, & Danoff-Burg, 2003; Taylor, 1983). The phenomenon of perception of benefits following a traumatic event such as cancer is referred to as benefit finding (Affleck & Tennen, 1996).

A study of 90 bone-marrow transplant survivors found that the most common benefits reported were a new philosophy of life, changes in personal attributes, improved family relationships, and greater appreciation of life (Fromm et al., 1996). Similar benefits have also been reported in low-income HIV-positive women, and patients with lupus, multiple sclerosis, and heart disease (Katz et al., 2001; Mohr, Dick, Russo, Likosky, Pinn, Boudewyn et al.,1999; Thornton, 2002; Updergraff, Taylor, Kemeny, & Wyatt, 2002). Benefit finding has also been found in non-medical populations that have undergone trauma such as natural disasters, plane crashes, or bereavement (McMillen, Smith, & Fisher, 1997; Nolen-Hoeksema & Davis, 2002).

2.1.1. Surviving breast cancer: Distress

Psychological distress is defined as mental suffering and discomfort resulting from a perceived or actual stressor that causes harm to the individual (Ridner, 2004). Psychological distress may manifest itself by a change in emotional status from baseline (i.e levels found in the normal population) to anxiety or depression, amongst others (Ridner, 2004).

The majority of articles that examine distress in cancer patients measure it with a global mood state indicator, that is an ensemble of positive and negative emotions (Bloom,1982; Ell et al. 1989; Felton et Revenson, 1984; Filipp et al., 1990; Hoskins et al., 1996; Northouse, 1988) or a global psychiatric adjustment score (Moyer et Salovey, 1999; Northouse, 1988). Others distinguish between specific emotions (Carver et al., 1993; Epping-Jordan et al., 1999; Komproe et al., 1997; Neuling and Winefield, 1988) or specific psychiatric disorders (Parle et al., 1996). In each of these studies, anxious and depressed mood or symptoms were measured.

Based on the previous literature, we chose to operationalize distress in long-term breast cancer survivors by measuring anxiety and depression symptoms as well as Post Traumatic Stress Disorder symptoms of intrusion and avoidance.

2.2 Surviving breast cancer: Benefit finding

Benefit finding is defined as a pursuit for the silver lining to adversity. “Deriving benefit from loss or trauma is a key means of assigning positive value or significance to the event for one's own life. Learning about one's strengths…. May help to mitigate the feelings of loss or helplessness… Such perceptions may restore the notion that one's own life has purpose, value, and worth “(Davis, Nolen-Hoeksema, & Larson, 1998).

The above definition highlight some of the possible functions of benefit finding: to restore one’s shattered assumptions about the self and the world (Affleck & Tennen, 1996; McMillen, Smith, & Fisher, 1997), to decrease distress and to generate positive mood.

Benefit finding has been conceptualized as an outcome (i.e. healthy personal growth) (Brennan, 2001; Lechner et al., 2003; Updergraff, Taylor, Kemeny, & Wyatt, 2002), positive beliefs that can restore one’s shattered assumptions (Affleck & Tennen, 1996), or as a personal resource (Helgeson, Snyder, & Seltman, 2004). Benefit finding is usually measured by asking participants in an open-ended question if there have been any positive aspects to their traumatic experience and tallying up the number of benefits (Davis et al., 1998; Updergraff et al., 2002) or with self-report questionnaires where patients are asked to rate how much they agree that the illness has brought changes in themselves, their priorities, or their relationships with others (Katz, Flasher, Cacciapaglia, & Nelson, 2001; Mohr et al., 1999; Park et al., 1996).

Such remarkable similarity in benefit finding among various traumatized populations leads to the following question: are the benefits reported by cancer patients qualitatively or quantitatively different from benefits reported by individuals who have undergone other traumas? To our knowledge, no study has compared cancer patients to victims of other traumas. However, two recent studies have compared breast cancer survivors and healthy controls (who were asked to think of a recent difficult event, which received a stressfulness rating similar to the survivors' rating of their experience with cancer) (Cordova, Cunningham, Carlson, & Andrykowski, 2001a; Tomich & Helgeson, 2002). Both studies concluded that survivors are distinguishable from the general population in terms of the frequency, magnitude, and types of benefits they report.

While reports of benefits following a traumatic event such as cancer are well documented, there is considerable debate about their nature. Theories of stress-related growth like the Assumptive Worlds (Janoff-Bulman, 1992) and Cognitive Adaptation theories (Collins et al., 1990; Taylor, 1983) argue that a traumatic event such as cancer shatters certain views a person has about herself, the world, and others. Benefit finding is one form of positive evaluation, among others, that allows a victim of trauma to restore their worldviews and to continue believing that life has worth and meaning. These evaluations have been labeled "positive illusions" by Taylor (1983) and are believed to be adaptive and related to well being. Positive illusions, however, do not entail denial of the negative aspects of the trauma. When asked about both positive and negative changes following having had cancer, the majority of patients report both types of changes (Collins et al., 1990; Weiss, 2002). Nolen-Hoeksema and Davis (2002) and Tedeschi and Calhoun (1996) argue that the benefits reported may be a reflection of defensiveness or self-esteem preservation but that, at least for some people, they reflect true growth or positive transformation. Davis, Nolen-Hoeksema, & Larson, (1998) found that benefit finding was related to better adjustment 6, 13, and 18 months after the death of a loved one from a terminal illness. Those who found something positive about the death became somewhat more optimistic throughout the course of the study, perhaps indicating true growth.

3. The relationship between distress and benefit finding

Benefit finding has been inconsistently linked to distress in cross-sectional studies. Some studies of cancer patients have found no relationship between benefit finding and various measures of adjustment such as mood, depression, intrusive and avoidant thoughts, quality of life, perceived physical health, illness-related dysfunction, and self-esteem (Cordova et al., 2001a; Fromm et al., 1996; Tomich & Helgeson, 2002). In contrast, Mohr et al. (1999) found that multiple sclerosis patients who reported greater benefit finding had elevated levels of anxiety and anger, while a later study that attempted to replicate Mohr et al.'s findings, using the same benefit finding and emotional distress questionnaires found that benefit finding was negatively related to distress (Katz et al., 2001).

Longitudinal studies of men who experienced a first heart attack, bereaved individuals, and victims of disasters have all found that being able to identify at least one benefit early in the adjustment process was predictive of less distress a few years after the trauma occurred (McMillen et al., 1997; Nolen-Hoeksema & Davis, 2002; Tennen & Affleck, 2002). To our knowledge, there has been only one longitudinal study of the role of benefit finding with cancer patients (Sears et al., 2003). The authors interviewed 92 newly diagnosed breast-cancer patients after completion of treatment and again three months and one year later. Identifying benefits at the first interview was not predictive of subsequent distress or quality of life in this study.

The contradictory results could be explained by the different time points (early after the trauma in the longitudinal studies vs. years after completing treatment in most cross-sectional studies) at which benefit finding was assessed in these studies. It can be argued that a psychological 'cure' includes a return to normal life, and this might mean a tapering off of benefit finding as cancer patients become cancer-free survivors (Fromm et al., 1996). That is, finding benefits may be useful for a period of time after diagnosis but is eventually no longer needed which could explain the lack of relationship between benefit finding and distress found in some studies that examined patients years after diagnosis. Bone marrow transplant survivors who reported more benefits tended to have had a transplant more recently (12-30 months vs. 30-120 months) (Fromm et al., 1996). However, two studies found that longer time since diagnosis was associated with benefit finding in breast cancer survivors ranging from 2 to 58 months after diagnosis (Cordova et al., 2001a; Sears et al., 2003). Clearly, more studies are needed that examine how the relationship between benefit finding and distress evolves over the long-term trajectory of the illness.

4. Predictors of distress and benefit finding

The present dissertation focuses on the following predictors of distress, PTSD symptoms of intrusive and avoidant thoughts and benefit finding: external and internal resources (social support, optimism, perceived health), appraisal variables (stress appraisal and fear of the future), coping strategies (Escape-Avoidance, Positive Problem Solving and Seeking Social Support), and medical characteristics (having a second cancer experience).

Social support

Social support is defined as functions performed by significant others such as family members, friends, co-workers, relatives, and neighbors to provide assistance to an individual (House, 1981; Turner, 1983). Cross-sectional and longitudinal studies of women with breast cancer have repeatedly shown that patients who enjoy higher levels of social support around the diagnosis or surgery phase report less distress and PTSD symptoms measured from a few weeks up to two years later (Cordova, Cunningham, Carlson, & Andrykowski, 2001b; Ell, Nishimoto, Morvay, Mantell, & Hamovitch, 1989; Funch & Mettlin, 1982; Hoskins, Baker, Sherman, Bohlander, Bookbinder, Budin et al., 1996; Moyer & Salovey, 1999; Northouse, 1988; Zenmore & Shepel, 1989). We currently do not know if social support shortly after diagnosis would have an impact in long-term (i.e. beyond five years after diagnosis) breast cancer survivors.

The relationship between social support and benefit finding is unclear. Some studies have found no relationship between social support and benefit finding (McMillen et al., 1997; Sears et al., 2003; Updergraff et al., 2002). However, one study found that breast

Theoretical framework

In 1984, Folkman and Lazarus proposed the transactional theory of stress and coping to explain the relationship between a specific stressful situation and long-term outcomes, mostly negative adjustment. In recognition of a growing body of evidence that suggests that both positive and negative states are present during a difficult event such as taking care of a dying loved one (Folkman & Moskowitz, 2000), the model was later refined to include positive outcomes. Folkman and her colleagues (Folkman, 1997; Folkman & Moskowitz, 2000) suggested that positive affect was generated and sustained in the midst of difficult events by the following coping strategies: positive reappraisal, problem solving, and infusing ordinary events with positive meaning, strategies that all involve creating or reinforcing meaning. Folkman & Moskowitz (2000) describe situational meaning as the personal significance of a stressful situation (also known as primary appraisal in the original transactional stress model of Lazarus and Folkman, 1984) and distinguish it from global meaning (people's fundamental assumptions about the world and the self and the world).

Within this model, benefit finding could be understood as an outcome, as a coping strategy, as part of the appraisal process and even as a resource if we think of this phenomenon as a set of positive illusions. The coping model does not address the issue of a time frame for coping efforts, therefore not specifying whether these are immediate responses or if they can persist over a longer period of time (De Ridder, 1997). It may well be that benefit finding is a process that evolves over such a long period of time that it is not captured by the coping model of adjustment.

cancer patients who had talked more about their illness with others reported more benefits (Cordova et al., 2001b).

Optimism

Optimism, defined as the tendency to believe that one will generally experience good versus bad outcomes in life, has been linked to greater psychological and physical well being (Scheier & Carver, 1985). Two prospective, longitudinal studies of women with breast cancer have shown optimism to be a predictor of more active coping strategies as well as of less anxiety and depression symptoms at three and six months after diagnosis (Epping-Jordan, Compas, Osowiecki, Oppedisano, Gerhardt, Primo et al., 1999), and at a 12-month follow-up (Carver, Pozo, Harris, Noriega, Scheier, Robinson et al., 1993). We currently do not know the impact of optimism on distress among longer-term breast cancer survivors.

Optimism has also been linked to greater benefit finding among college students (Park, Cohen, & Murch, 1996; Tedeschi & Calhoun, 1996) and HIV-positive women (Updergraff et al., 2002). It has also been associated with a greater perception of benefit finding among bereaved individuals (Nolen-Hoeksema & Davis, 2002). This study showed individuals who were optimistic used more positive reappraisal coping, and the more reappraisal coping they used, the more likely they were to find something positive in their loss.

Perceived health

Perceived health status as measured with a one-item index where participants are asked to rate their overall physical health status can discriminate among breast cancer patients at different phases of the illness (i.e. newly diagnosed, treatment, stable disease, and recurrent cancer) (Frost, Suman, Rummans, Dose, Taylor, Novotny et al., 2000) and is highly correlated with the presence and evolution of major illnesses in the general population (Goldberg, Guéguen, Schmaus, Nakache, & Goldberg, 2001) and with physician's assessments of patients' health (Conill, Verger, & Salamero, 1990).

Poor perceived health has been found to predict lower psychosocial adjustment among cancer patients on average two (Schnoll & Harlow, 2001) and five years after diagnosis (Schnoll, Knowles, & Harlow, 2002). It has seldom been examined in relation to benefit finding and thus far has been found to be uncorrelated with benefits (Sears et al., 2003; Updergraff et al., 2002).

Coping

Coping is defined as "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus and Folkman, 1984, p. 141). Research on coping in general and coping with cancer in particular, has received substantial criticism (Coyne & Gottlieb, 1996; Coyne & Racioppo, 2000; Lazarus, 2000; Somerfield & Curbow, 1992; Somerfield & McCrae, 2000). Several problems exist in this field of cancer research: 1) a paucity of studies using longitudinal designs; 2) the use of heterogeneous samples of cancer patients both in terms of cancer site and time since diagnosis; 3) the inappropriate use of general coping checklists with cancer patients; 4) asking patients how they globally cope with "their cancer"; 5) not considering positive outcomes of stress; and 6) a limited applicability for intervention studies.

The present dissertation attempts to address some of these methodological concerns. First, we investigated the impact of coping on distress in a cohort of breast cancer patients followed shortly after diagnosis until long-term survival using a prospective, longitudinal design. Second, we used a modified version of the Ways of Coping Scale (WOC) that was designed for cancer patients (Dunkel-Schetter, Feinstein, Taylor, & Falke, 1992). Factor analysis of this version of the WOC in a sample of 250 cancer patients resulted in three scales: Escape-Avoidance (consisting of items that suggest avoiding the problem or people all together as well as items that suggest wishful thinking), Positive Problem Solving (composed of active problem solving items and positive reframing items), and Seeking Social Support (SSS) (items cover seeking advice, professional help, practical support, as well as emotional support) (Rosberger, Edgar, Collet, & Fournier, 2002).Third, we asked breast cancer patients to appraise their illness specifically rather than globally, with such choices as, e.g., fear of the future, disruption of social support, and physical limitations. Fourth, we aimed to identify coping strategies that predict less distress and more benefit finding among breast cancer survivors. These findings may contribute to the development of intervention programs designed to improve coping among survivors.

Despite these limitations, previous research on coping and cancer patients has yielded interesting results. Coping strategies that are active and directed towards the stressor (e.g. problem solving, positive reframing, and seeking social support) have usually been associated with better adjustment while strategies that are geared towards avoiding the stressor (e.g. escape or avoidance) usually predict poorer adjustment (Carver et al., 1993; Dunkel-Schetter et al., 1992; Epping-Jordan et al., 1999; Stanton & Snider, 1993).

Coping strategies may vary in their effectiveness in mitigating distress over time, depending on the phase of the illness (Heim et al., 1997; Stanton & Snider, 1993). The longitudinal studies that have examined how coping and distress associated to cancer evolved over time have typically ended their assessments at six months (Epping-Jordan et al., 1999) or twelve months (Carver et al., 1993) in spite of the fact, as reviewed above, that a significant proportion of breast cancer survivors will continue to experience distress perhaps long afterwards. As a result, we know little about what constitutes the most adaptive strategies for coping during long-term survival of breast cancer.

Among breast cancer survivors, suppression has been identified as a coping strategy leading to more PTSD symptoms (Amir & Ramati, 2002) and acceptance/resignation used at six months after diagnosis has been reported as a coping strategy that predicted more distress three years later (Hack & Degner, 2004).

Several studies have reported a positive association between coping strategies and benefit finding. Among bereaved individuals, benefit finding was related to active problem solving, seeking social support, and engaging in constructive expression of emotions but was unrelated to avoidance coping (Davis et al., 1998). Benefit finding was found to be related to seeking social support and positive reappraisal in multiple sclerosis patients (Mohr et al., 1999) while among patients with various cancers, positive changes were related to many coping strategies such as problem-focused coping, cognitive escape/avoidance, positive focus, and behavioral escape/avoidance (Collins et al., 1990) (Sears et al., 2003).

Stress appraisal

According to the transactional model of coping of Lazarus and Folkman (1984), coping efforts are influenced by a preceding cognitive appraisal process that evaluates the threat or challenge of an event and, if a threat is perceived, the resources and coping options that are available. Although identified as an important precursor of coping by Folkman and Lazarus, the influence of stress appraisal has been largely ignored in the cancer patient population (Brennan, 2001; Parle, Jones, & Maguire, 1996). Cancer patients who perceived their illness to be stressful reported higher levels of distress and greater use of coping strategies (Dunkel-Schetter et al., 1992; Marks, Richardson, Graham, & Levine, 1986; Parle et al., 1996; Stanton & Snider, 1993). We currently have little evidence regarding the role of stress appraisal in long-term cancer survivors.

In the field of benefit finding, stress appraisal of the traumatic situation is often referred to as perceived stressfulness (Cordova et al., 2001a; Sears et al., 2003). It appears that more severe and thus potentially more stressful events elicit more benefit finding. For example, bone-marrow transplant survivors who had a transplant associated with greater risk reported greater benefit finding (Fromm et al., 1996). Perceived stressfulness and not objective measures such as cancer stage was predictive of benefit finding in two studies of breast cancer patients (Cordova et al., 2001a; Sears et al., 2003).

Fear of the future

A major concern for breast cancer survivors is learning how to live with the uncertainty of their disease worsening or returning (Northouse, 1981). Fear or uncertainty about the future was considered as the most stressful aspect of having cancer among a heterogeneous group of cancer patients that were diagnosed a few months to several years prior (Dunkel-Schetter et al., 1992). Fear of the future has been found to be a predictor of lower quality of life in breast cancer survivors on average six years beyond diagnosis (Dow et al., 1996).

Having a second cancer experience

A frequently encountered limitation in studies of long-term breast cancer survivors is the lack of accounting for a second cancer experience (i.e. new primary, recurrence, or metastases) during survivorship and therefore not being able to examine the proportion of variance in adjustment scores accounted for by recurrence status (Dow et al., 1996; Ganz et al., 1996; Hack & Degner, 2004). Since very few studies have distinguished between having a recurrence, metastases, or second cancer and their respective impact on distress, it is unclear if these events should be studied together. Evidence for considering recurrence, metastases, and new primaries together comes from Dow et al. (1996) who asked breast cancer survivors how distressing each of these three events would be and found that they were rated as equally disturbing.

Patients have described experiencing a recurrence as being more stressful than the initial diagnosis, possibly because one of its implications is shorter survival time (Mahon, Cella, & Donovan, 1990; Northouse, Laten, & Reddy, 1995b). Women who had a second cancer experience during an 8-year follow-up had lower physical, psychological, and functional quality of life than women who had remained disease-free (Dorval et al., 1998).

It appears that "for stressors to elicit positive change, they must be of sufficient magnitude to challenge one's assumptions" (Cordova et al., 2001a, p. 182). Having had a second cancer could certainly be considered a stressor of sufficient magnitude but studies have yet to examine the impact of a second cancer experience on benefit finding.

To address this shortcoming, the present dissertation examined the relationship between having a second cancer experience, distress and PTSD symptoms, and benefit finding.

5. Importance of longitudinal design

Clearly, not every breast cancer patients will suffer from distress and PTSD symptoms. The few studies that have used a longitudinal design with long-term breast cancer survivors have not used baseline data (at time of diagnosis or treatment) to predict distress during survivorship (Dorval et al., 1998; Heim et al., 1997; Helgeson et al., 2004; Omne-Pontén, Holmberg, & Sjödén, 1994). While identifying risk factors that co-occur with distress and PTSD symptoms during survivorship is an essential step in the identification of survivors that may require further monitoring, identifying predictors early on in the disease trajectory would allow for early detection and possibly intervention with women at risk of long-term distress. In the context of limited psychosocial resources that cannot be offered to all patients, early identification is clearly important for preventive purposes.

Studies of benefit finding suffer from the same shortcoming: as the majority of studies have been cross-sectional, there is a paucity of information on the role of psychological variables occurring early in the illness trajectory and impacting on the subsequent development of 'personal growth'. As benefit finding may lead to less distress among cancer survivors, it is important to identify prospective factors that can discriminate survivors who experience high levels of benefit finding from survivors who derive few benefits from their illness. Some have hypothesized that participants with greater resources (psychological, physical, and socioeconomic) will fare better (Updergraff et al., 2002). This hypothesis has been found true among individuals experiencing the death of a loved one: younger age, optimism, and education were found to prospectively predict more benefit finding at six months post-loss (Davis et al., 1998). Only one study identified prospective predictors of benefit finding in cancer patients and found that breast cancer patients who, after completion of treatment, used more positive reappraisal coping, had more intrusive and avoidant thoughts and had a higher stress appraisal of their cancer experience reported more positive growth (Sears et al., 2003).

6. Goals of the dissertation

This thesis aims to further our understanding of distress, PTSD symptoms of intrusion and avoidance, and benefit finding in long-term breast cancer survivors, their relationship with each other, and their respective predictors. By using a longitudinal design, it also aims to overcome one of the limitations found in the majority of previous studies of distress and benefit finding in cancer survivors.

6.1. Goals and hypotheses of the first article

The first article aimed to quantify the levels of distress and PTSD symptoms found in long-term breast cancer survivors and to describe changes of these levels over time. The main objective of this article was to identify risk factors of distress and PTSD symptoms in long-term breast cancer survivors interviewed within 3 months after diagnosis (Time 1), and followed 1 year later (i.e. approximately 15 months after diagnosis; Time 2) and 6 years later (Time 3). The following potential predictors of distress and PTSD symptoms at six years were examined: social support, optimism, perceived health, coping strategies, stress appraisal, fear of the future, Time 1 and Time 2 levels of distress and PTSD symptoms, and having had a second cancer experience. These potential predictors and their relationships with distress and PTSD symptoms in long-term breast cancer survivors (Time 3) were examined at Time 1, Time 2, and Time 3.

It was hypothesized that a significant proportion of breast cancer survivors would experience heightened levels of distress and PTSD symptoms. It was also hypothesized that distress and PTSD symptoms would improve between Time 1 and Time 2. Based on the inconsistent findings reviewed above, no specific hypothesis was made about changes in levels of distress and PTSD symptoms between Time 2 and Time 3. It was hypothesized that poor perceived health, fear of the future, high stress appraisal of the cancer, avoidant coping, higher Time 1 and Time 2 levels of distress and PTSD symptoms, and having had a second cancer experience would predict more distress and PTSD symptoms in women 6 years beyond cancer diagnosis, while optimism, social support, and active coping would predict less distress and PTSD symptoms.

6.2. Goals and hypotheses of the second article

The first objective of the second article was to examine the relationship between benefit finding, distress, and avoidant and intrusive thoughts among a cohort of long-term breast cancer survivors interviewed four times during the first year after their diagnosis. Second, this article aimed to identify characteristics of the stressor that predict benefit finding. It was expected that some of the long-term breast cancer survivors might have experienced a recurrence during the 6-year follow-up, allowing the possibility of comparing reports of benefit finding among women who underwent a second cancer experience and those who remained disease-free.

Finally, the second article examined the relationship of social support, optimism, coping and perceived health with benefit finding in long-term breast cancer survivors. We also examined the relationship between first-year psychological resources and benefit finding during survivorship to see if breast cancer patients who displayed more resources early during the disease trajectory would report more benefit finding, as they became survivors.

It was hypothesized that breast cancer survivors who perceived more benefits from having had breast cancer would experience less distress and intrusive and avoidant thoughts. It was also hypothesized that breast cancer survivors who had a second cancer experience since their diagnosis would perceive more benefits, as would those who perceived their cancer to be more stressful, reported greater use of coping strategies, were more optimistic, and had more social support. Last, we predicted that breast cancer survivors who displayed more psychological resources during the first year following diagnosis would report more benefit finding.

Brief Overview of Methods

In order to minimize redundancy, we will limit the method section of the present dissertation to a brief overview of the design, participants, measures, and procedure. The reader will find a more detailed method section in each of the two articles.

Design

This dissertation used a longitudinal design to investigate the relations between sociodemographic and medical variables, social support, optimism, perceived health, fear of the future and stress appraisal, coping strategies, PTSD symptoms of intrusion and avoidance, distress, and benefit finding at the following time points: 3, 7, 11, 15 months, and 6 years after diagnosis. All variables were collected at each of these five time points except for benefit finding, which was measured only 6 years after diagnosis.

We did not use all time points in each article. The first article (focusing on predicting distress and PTSD symptoms in long-term breast cancer patients) used three time points: baseline-up to a mean of 3 months; 15 months; and 6 years. Our rational for using only these three time points was to compare variables collected as soon as possible after diagnosis (a time known to generate a substantial amount of distress) and a year later during remission (a time many studies have found corresponds to maximal adjustment for the majority of patients- see the first article for more details) for their predictive efficacy of distress and PTSD symptoms at 6 years. The second article (focusing on predicting benefit finding and examining its relationship with distress and PTSD symptoms) used all five time points.

Participants

Participants were 86 women diagnosed with breast cancer approximately six years previously who had participated in an intervention study [Nucare II study, (Edgar, Rosberger, & Collet, 2001)]. At baseline (3 months from diagnosis and prior to the intervention), 146 breast cancer patients were enrolled in the original study. Subsequently, patients were interviewed after each interval of four months up to one year (on average, 7, 11, and 15 months after diagnosis). A total of 128 breast cancer patients completed the 15-month interview. There were no significant differences in demographics between participants and dropouts at 15 months. Causes of attrition and differences between participants who completed the 6-year follow-up are discussed in details in the articles.

Measures

All the measures that were used in this dissertation were presented in the two articles and can be found in Appendix A. However, a table summarizing the variables of interest and their measures as they appeared in each article is provided following the method section to facilitate the reading of the present dissertation.

Procedure

Participants from the original Nucare study (Edgar et al., 2001) were located and asked if they were interested in completing the 6-year follow-up. Subjects who provided informed consent (see Appendix B) were interviewed individually for about one hour at the location of their choosing. A trained interviewer administered the questionnaires.

Ethics

The proposal of the present dissertation was reviewed and consent forms were approved by the Research Ethics Committee at the Sir Mortimer B. Davis - Jewish General Hospital. Permission to review hospital records was also obtained from the Committee.

Measures

The Ways of Coping (WOC) was created by Lazarus and Folkman (1984) and is the most widely used coping instrument. It has, however, received numerous criticisms for some of its psychometric shortcomings. Specifically, test-retest validity and convergent validity have not been established (the authors have claimed this is justifiable because coping is supposed to be situation-specific and therefore highly fluctuating and because other coping measures to compare the WOC to also suffer from psychometric shortcomings). By far, the most concerning problem of the WOC is that the original factor solution of eight ways of coping (confrontive coping, distancing, self-control, seek social support, accept responsibility, escape-avoidance, planful problem solving, positive reappraisal) is unstable. Authors who have used an exploratory factor analysis to confirm the factor structure of the WOC have reported between 3 and 10 factors, and have found that some items load on multiple factors. To palliate this problem, Folkman and Dunkel-Schetter (who factor analyzed the WOC with a sample of cancer patients) have recommend that researchers conduct their own factor analysis of the WOC with their sample of interest. Our own factor analysis of the WOC in two different cancer patients samples resulted in three scales: Positive Problem Solving, Escape-Avoidance, and Seeking Social Support which are listed in Appendix C.

Originally, coping strategies of the WOC fell into two broad functional categories: problem-focused (strategies that change the situation) and emotion-focused coping (strategies that alleviate negative emotional states). In a series of studies, Lazarus and Folkman demonstrated that most people use both kinds of strategies when confronting a stressor and that certain strategies such as seeking social support could serve both functions. This distinction was also criticized for its narrow sampling of emotion-focused strategies that tend to include only 'negative' strategies such as letting ones emotions out instead of actively processing and expressing ones emotions in a constructive way (Stanton, Persa, & Austenfeld, 2002).

There are many existing classifications of coping strategies, for example active vs. passive, cognitive vs. behavioral, and approach vs. avoidance. These classifications all have been criticized for not being conceptually clear, nor mutually exclusive, nor exhaustive, nor functionally homogeneous within a given category (Skinner, Edge, Altman, & Sherwood, 2003). It is safe to say that there currently is no agreement on the optimal way to classify coping strategies.

Table I. Variables of interest and measures used in the two articles of the present dissertation

Variable	**Measure**	**Article (s) in which the variable appeared**
Distress	Profile of Mood States (POMS)- Anxiety and Depression subscales only	1 and 2
PTSD symptoms of intrusive and avoidant thoughts	Impact of Events Scale(IES)- total score was used for article 1 while scores of each the two subscales of intrusive and avoidant thoughts were used for article 2	1 and 2
Benefit finding	Benefit Finding	2
Social support	Social Well-Being scale (SWB) of the Functional Assessment of Cancer Therapy (FACT)	1 and 2
Optimism	Life Orientation Test (LOT)	1 and 2
Perceived health	One-item index where participants were asked to rate their overall health status	1 and 2
Fear of the future	Ways of Coping Scale (WOC)	1
Stress appraisal	Ways of Coping Scale (WOC) (this variable is labeled perceived stressfulness in article 2)	1 and 2
Coping	Ways of Coping Scale (WOC) A previous factor analysis revealed the following factors: Escape-Avoidance	1 and 2

	(ESC) coping, Positive Problem Solving (PPS) coping, and Seeking Social Support (SSS) coping	

Chapter 1 : First article

Increased risk of distress and PTSD-like symptoms in long-term breast cancer survivors

Short title: DISTRESS IN LONG-TERM BREAST CANCER SURVIVORS

Increased risk of distress and PTSD-like symptoms in long-term breast cancer survivors

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This study was supported by Research Studentships to Sophie Lebel from the National Cancer Institute of Canada with support from the Canadian Cancer Society and from the Fond de Recherche en Santé du Québec -Fond pour la Formation Des Chercheurs et l'Aide à la Recherche; and an operating grant from the Canadian Breast Cancer Research Initiative to Zeev Rosberger and Linda Edgar. It forms part of the Ph.D. studies of Sophie Lebel

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The authors would like to thank Roxane Robitaille and Marie Achille for comments on earlier drafts and Miguel Chagnon for statistical advice. We are very grateful to all the women who participated in this study.

Abstract

Longitudinal studies on the psychosocial and medical variables that might influence distress and Posttraumatic Stress Disorder (PTSD)-like symptoms (intrusion and avoidance) among long-term breast cancer survivors are few. The purpose of the present study was to identify risk factors of distress and PTSD-like symptoms in long-term breast cancer survivors (n = 86) interviewed within 3 months after diagnosis, and followed 1 year later and 6 years later. A number of potential predictors were examined: social support, optimism, perceived health, active and avoidant coping strategies, stress appraisal, fear of the future, and having had a second cancer experience. Multiple hierarchical regressions including these predictors were performed at each time point to assess their relative contributions to distress and PTSD-like symptoms at 6 years. Results of these analyses showed that breast cancer survivors who have experienced a second cancer, are concerned about their future, have poor physical health, and are less optimistic, are at increased risk of distress and PTSD-like symptoms. Patients who, during the first year following diagnosis, are more distressed, have poor social support and rely extensively on active coping and focusing on the positive, may be at risk of distress during long-term survivorship and should be monitored closely.

It is estimated that there are over two million long-term breast cancer survivors in North America (National Cancer Institute, 2000; National Cancer Institute of Canada, 2004). Quantitative studies that have addressed the issue of psychological morbidity among long-term breast cancer survivors have found low rates of clinical psychiatric disorders in this population (Dorval *et al.*, 1998; Ganz *et al.*, 1996; Polinsky, 1994; Tomich and Helgeson, 2002). However, there is evidence that subclinical, yet elevated symptoms of distress, consisting mostly of depression and anxiety symptoms, will persist in a significant number of breast cancer survivors (Amir and Ramati, 2002; Andersen, 1992; Polinsky, 1994). Saleeba *et al.* (1996) reported that mild emotional distress (depression and anxiety) persisted in close to 30% of women who had been disease-free for at least five years after diagnosis of breast cancer compared to only 10 % of women who had been screened for cancer in the community. Self-reported anxiety and depression, especially around follow-up visits, have been found in 38 to 70% of breast cancer survivors in some studies, while fear of recurrence and uncertainty over the future affected more than 80% of survivors (Dow *et al.*, 1996; Ganz *et al.*, 1996; Polinsky, 1994). Recent studies have further indicated that about 5 to 20 % of breast cancer patients experience intrusion and avoidance symptoms (cognitive and/or behavioral) about the cancer and its treatment severe enough to suggest that they may meet a diagnosis of Posttraumatic Stress Disorder (PTSD) and that many more experience sub-clinical levels of such symptoms (Cella and Tross, 1986; Cordova *et al.*, 1995; Kornblith, 1998). Few studies have examined the prevalence of intrusion and avoidance or PTSD in long term breast cancer survivors. One study compared 39 long term breast cancer survivors to 39 matched women and found that survivors had significantly higher rates of full (18% vs. 3%) and partial diagnoses of PTSD (56% vs. 18%) than controls (Amir and Ramati, 2002).

No longitudinal study of intrusion and avoidance and only a few studies of distress in breast cancer patients have followed patients unto long tem survivorship to understand how they adjust to the experience and who may be at risk of developing anxiety, depression, and PTSD-like symptoms of intrusion and avoidance (Dorval *et al.*, 1998; Heim *et al.*, 1997; Helgeson *et al.*, 2004; Omne-Pontén *et al.*, 1994). As a result, the course of psychosocial adjustment to breast cancer from diagnosis to long term survival is still largely unknown. An optimal methodological design to accomplish this goal would be to follow a cohort of breast cancer patients prospectively until long-term survivorship and use baseline psychosocial variables to predict long-term distress. The few studies that have used a longitudinal design with long-term breast cancer survivors have not used baseline data (at time of diagnosis or treatment) to predict distress during survivorship (Dorval *et al.*, 1998; Heim *et al.*, 1997; Helgeson *et al.*, 2004; Omne-Pontén *et al.*, 1994).

Although there is evidence from cross-sectional studies that longer time since diagnosis is associated with less PTSD-like symptoms (Cella and Tross, 1986; Cordova et al., 1995), because of the paucity of longitudinal studies, we currently do not know if there is a time point after which these symptoms tend to become stable. Distress, on the other hand, has been found to be heightened during the diagnosis/ treatment period and usually returns to pre-diagnosis levels, for the majority of patients, within one or two years (Ganz *et al.*, 1996; Heim *et al.*, 1997). It is possible that those who have not recovered at one year are more at risk of distress during long-term survivorship. Therefore, it would be important to use psychosocial variables assessed at diagnosis/treatment and 1 year later to predict long-term distress. Identifying predictors of long term distress and PTSD-like symptoms early in the disease trajectory would allow for timely detection and intervention with women at risk for distress during long term survivorship. In the current context of limited psychosocial resources, early identification of at-risk patients is clearly important for preventive purposes.

An important variable that may affect how a woman recovers from breast cancer is whether she remains disease-free after her original diagnosis. A frequent limitation of studies of long-term breast cancer survivors is that many have not controlled for a second cancer experience (i.e. new primary, recurrence, or metastases) during survivorship therefore limiting the ability to examine the proportion of variance in adjustment scores accounted for by recurrence status (Dow *et al.*, 1996; Ganz *et al.*, 1996; Hack and Degner, 2004). Evidence for considering recurrence, metastases, and new primaries as possibly equivalent comes from Dow *et al.* (1996) who asked breast cancer survivors to rate the distress associated with each of these three events and found that they were rated as equally distressing.

While it is safe to say that not every breast cancer patient will suffer from distress and PTSD-like symptoms, evidence to date suggests that some women are indeed at risk of poor psychological adjustment during the survivorship period. Fear of the future has been found to be a predictor of lower quality of life in breast cancer survivors on average six years beyond diagnosis (Dow *et al.*, 1996). Poor perceived health has also been found to predict lower psychosocial adjustment among cancer patients on average two (Schnoll and Harlow, 2001) and five years after diagnosis (Schnoll *et al.*, 2002). Coping strategies that are active and directed towards the stressor (e.g. problem solving, positive reframing, seeking social support) have usually been associated with better adjustment to cancer while strategies that are geared towards avoiding the stressor (e.g. escape or avoidance) usually predict poorer adjustment (Carver *et al.*, 1993; Epping-Jordan *et al.*, 1999; Stanton and Snider, 1993). Among breast cancer survivors, suppression has been identified as a coping strategy leading to more PTSD symptoms (Amir and Ramati, 2002) and acceptance/resignation used at six months after diagnosis was a coping strategy that predicted more distress three years later (Hack and Degner, 2004).

Other likely candidates of distress and PTSD-like symptoms during survivorship are social support, low initial distress levels, low stress appraisal (i.e. individuals' cognitive appraisal of the threat of cancer), and optimism which have been linked to experiencing less distress and PTSD-like symptoms in the first two year following diagnosis (Carver *et al.*, 1993; Epping-Jordan *et al.*, 1999; Ell *et al.*, 1989; Hack and Degner, 2004; Hoskins *et al.*, 1996; Morris *et al.*, 1977; Moyer and Salovey, 1999; Parle *et al.*, 1996).

To address some of the shortcomings of the previous research, the present study attempted to identify risk factors of distress and PTSD-like symptoms of intrusion and avoidance in long-term breast cancer survivors interviewed within 3 months after diagnosis

(Time 1), 1 year later (i.e. approximately 15 months after diagnosis; Time 2) and 6 years later (Time 3), while controlling for a second cancer experience. The following potential predictors of distress and PTSD-like symptoms at six years were examined: optimism, social support, perceived health, fear of the future, stress appraisal, coping, and Time 1 and Time 2 levels of distress and PTSD-like symptoms. These potential predictors and their relationships with distress and PTSD symptoms in long-term breast cancer survivors (Time 3) were examined at Time 1, Time 2, and Time 3.

It was hypothesized that a significant proportion of breast cancer survivors would experience heightened levels of distress and PTSD-like symptoms. It was hypothesized that distress and PTSD-like symptoms would decrease over time. It was hypothesized that poor perceived health, fear of the future, high stress appraisal of the cancer, avoidant coping, higher Time 1 and Time 2 levels of distress and PTSD-like symptoms, and having had a second cancer experience would predict more distress and PTSD-like symptoms in women 6 years beyond cancer diagnosis, while optimism, social support, and active coping would predict less distress and PTSD-like symptoms.

Method

Participants

At Time 1, 146 recently diagnosed breast cancer patients were enrolled in an intervention study in which they had randomly been assigned to 1 of 4 groups [Nucare study, (Edgar *et al.*, 2001)]. Patients were subsequently followed at 3-month intervals up to one year (Time 2). A total of 128 patients completed the Time 2 interview. There were no significant differences in demographics between participants and dropouts at this point. Results from the Nucare study revealed that there were no main effects of the intervention on distress and quality of life but that patients who received the coping skills intervention (either in an individual or group administration) and who were highly distressed (1 SD above mean) became significantly more optimistic and reported greater physical well-being over time than patients who received a supportive group intervention or standard care (unpublished data). We did not anticipate that the intervention would have any effect on distress and PTSD symptoms at the 6-year follow-up as it did not during the first year following diagnosis but nonetheless verified statistically that there were no delayed effects before analyzing participants together.

Among the original 146 breast cancer patients, 86 agreed to complete the Time 3 interview, 31 had died, 9 could not be located, and 20 refused to be interviewed [including participants whose access was denied by the physician because of poor mental health (n = 1), or the family because the patient was too sick (n = 4), or by the researcher because of language problems (n = 1)]. Our accrual rate was 81.1 % (86 completers/ 20 refusals + 86 completers). Participants at the Time 3 follow-up differed from the original sample in that, at Time 1, they were more likely to be working ($\chi^2(1, N = 146) = 4.59, p < .05$) and had fewer sites affected by cancer ($\chi^2(1, N = 146) = 6.12, p < .05$), and thus were probably healthier. Women who refused to complete the Time 3 follow-up differed from participants in that they were older ($t(104) = -2.44, p < .05$) and less likely to be working ($\chi^2(1, N =$

106) = 4.59, $p < .05$), but more importantly, did not differ on medical variables nor on any of the Time 1 psychological variables.

Sociodemographics and medical characteristics of the present sample of 86 women diagnosed with breast cancer six years previously are presented in Table 1. Participants' ages ranged from 37 to 88. The majority of women had been diagnosed with stage I breast cancer. All 86 participants had undergone surgery: 60 had a segmental mastectomy, 6 had a lumpectomy, 4 had a total mastectomy, and the rest had other procedures. The most frequent treatment was a combination of surgery, radiotherapy, and chemotherapy ($n = 62$); while surgery and radiotherapy ($n = 15$), surgery and chemotherapy ($n = 7$), or surgery alone ($n = 2$) were less frequent combinations. Most women ($n = 56$) had taken or were finishing a course of Tamoxifen. During the six-year follow-up, 21 women had a second cancer experience (4 participants had a recurrence, 9 had a new primary, and 8 were diagnosed with metastases). We collected this information from the participants and verified it in their medical chart.

-- insert Table 1 about here ----------------------------------

Measures

Distress was assessed using the Profile of Mood States (POMS; McNair *et al.*, 1971). The POMS consists of 65 adjectives which are rated on a 5-point scale ranging from not at all (0) to extremely (4). The POMS contains six subscales: Anxiety, Depression, Anger, Vigor, Fatigue and Confusion. For the purpose of the present study, only the Anxiety and Depression subscales were used and were combined to create a distress indicator. Internal consistency of this combined indicator was between .89 and .95 throughout the study.

PTSD-like symptoms of cancer-related intrusion and avoidance were assessed using the Impact of Events Scale (IES; Horowitz *et al.*, 1979). The IES has been used before to assess the presence of PTSD symptoms in samples of breast cancer survivors (Cordova *et al.*, 1995; Cordova *et al.*, 2001). It consists of 15 items that are rated on a 4-point scale from not at all (1) to often (4), 7 of which measure intrusion (intrusive thoughts, nightmares, intrusive feelings and imagery) and 8 measure avoidance (avoidance of feelings, situations, ideas). In the present study, the total score of the IES was used with an internal consistency ranging between .87 and .90.

Coping was measured with the version of the Ways of Coping Scale (WOC; Lazarus and Folkman, 1984) adapted for cancer patients by Dunkel-Schetter *et al.*, (1992). Participants were first asked to rate the stressfulness of the following five aspects of their illness in the past six months: fear and uncertainty about the future; limitations in physical ability, appearance, or life style; acute pain, symptoms, or discomfort; problems with family or friends; any other problem. Each of the five concerns was rated on a 5-point scale ranging from not at all stressful (1) to extremely stressful (5) and the highest score was considered the stress appraisal (Dunkel-Schetter *et al.*, 1992). The concern with the highest stress appraisal rating was considered the primary concern. As suggested by Dunkel-Schetter *et al.* (1992), primary concern was dichotomized as (1) fear and uncertainty about the future or (0) all other concerns. Next, participants rated the degree with which they have used each of the 51 coping strategies in response to their primary concern. Each coping strategy was rated on a 5-point scale from not at all (1) to extremely (5). Factor analysis of the WOC in a sample of 250 cancer patients resulted in three scales: Escape-Avoidance (ESC) (consisting of items that suggest avoiding the problem or people all together i.e. "refused to believe it would happen" as well as items that suggest wishful thinking i.e. "wished the situation would go away"), Positive Problem Solving (PPS) (composed of active problem solving items such as "made a plan of action and followed it" and positive reframing items such as "rediscovered what is important in life"), and Seeking Social Support (SSS) (items cover seeking advice, professional help, practical support, as well as emotional support) (Cronbach's Alphas = 0.81, 0.88, and 0.82, respectively) (see Rosberger *et al.*, 2002 for details of this study).

Optimism was measured with the Life Orientation Test (LOT; Scheier and Carver, 1985). The LOT is a 12-item questionnaire that measures general expectancies of favorable future outcomes and is answered a 5-point scale, ranging from strongly disagree (0) to strongly agree (4). In the present study, internal consistency of the LOT ranged between .77 and .82.

Social support was measured with the Social Well-Being scale (SWB) of the Functional Assessment of Cancer Therapy (FACT), a well-known instrument designed to measure a number of dimensions of quality of life of cancer patients (Cella *et al.*, 1993). The SWB consists of seven items rated on a 5-point scale ranging from not at all (0) to very much (4) that measure support available from partner, friends and family. In the present study, internal consistency ranged between .69 and .73. Since the SWB is seldom used alone as a measure of social support (Yellen and Cella, 1995), we administered the Social Support Questionnaire (SSQ; Northouse, 1988) at the six-year follow-up in order to confirm convergent validity. The SSQ is a well validated scale where subjects rate the degree of support they perceive from five sources (spouse or significant other, family member, friend, nurse, physician). For purpose of the present study, only the spouse, friend, and family subscales were used. In the present study, an alpha of .91 was found for the SSQ. The correlation between the SWB subscale of the FACT and the SSQ was ($r = .75$, $p < .001$) indicating moderately strong convergent validity.

Perceived health status was measured with a one-item index where participants were asked to rate their overall health status on a five-point indicator ranging from very poor (1) to excellent (5). Past research has shown this measure to correlate highly with physician's assessments (Conill *et al.*, 1990).

Procedure

Participants from the original Nucare study (Edgar *et al.*, 2001) were located and asked if they were interested in completing the 6-year follow-up. Subjects who provided informed consent were interviewed individually for about one hour at the location of their choosing. The questionnaires were administered orally by a trained interviewer.

Results

Overview of statistical analyses

In consideration of potential covariates that might contribute significantly to the prediction of distress and IES at Time 3, independent sample t tests and Pearson correlations were performed with medical and sociodemographic variables. Significant covariates were entered in the final regression models. Second, independent sample t tests were used to compare participants who had a second cancer experience during the follow-up to participants who had remained disease-free on distress, IES, and potential predictors (i.e. optimism, perceived health, fear of the future, stress appraisal, ESC coping, PPS coping, and SSS coping) at Time 3. Third, descriptive analyses of distress, IES, and potential predictors at Time 1, Time 2, and Time 3 were performed and paired sampled t tests were used to compare means of variables for the 3 time points. Fourth, Pearson correlations were computed to examine the relationships among distress and IES at Time 3 and potential predictors measured at Time 1, Time 2, and Time 3. Fifth, based on theoretical assumptions and significance of correlations, potential predictors at Time 1, Time 2, and Time 3 were separately entered in hierarchical multiple regressions to identify the best predictors of distress and IES at Time 3.

Potential covariates

Intervention. We verified the effect of the Nucare intervention on distress, IES, and potential predictors at Time 3 by conducting one-way ANOVAs with intervention group as the between factor and each psychological variable as the dependent variable. There was no significant main or interaction effect of the intervention on any of the psychological variables.

Medical variables. A number of medical variables were available about the original diagnosis: nuclear grade, stage, and number of other sites affected. Despite our best efforts to find stage data through oncology charts and medical records reviews, complete staging information was available for only 59 of our 86 follow-up participants. Therefore, we used 'other sites affected at diagnosis' (other than breast), a variable available for all patients, as a measure of disease severity in our analyses. For the purpose of the present study, we defined other sites as 0 (no other sites affected/localized tumor) or 1 (1 or more sites affected at diagnosis/regional tumor). As expected, stage and other sites affected at diagnosis showed a strong correlation $r = .57$ ($p < .001$). Independent sample t-tests were conducted to test for differences on distress, IES, and potential predictors grouped by nuclear grade (1 vs. 2 and 3), stage (I vs. II and III), and number of other sites affected (0 vs. 1) for all three time points. The only significant differences that emerged were that women who had other sites affected at diagnosis reported better health at Time 1 ($t(144) = -2.10$, $p < .05$), used more PPS coping at Time 1 ($t(139) = -3.43$, $p < .001$) and Time 2 ($t(103) = -2.82$, $p < .01$), and more SSS coping at Time 1 ($t(139) = -2.45$, $p < .05$), Time 2 ($t(102) = -2.03$, $p < .05$), and Time 3 ($t(69) = -3.58$, $p < .001$). Number of sites affected at diagnosis was retained in the subsequent regression models.

The relationships between previous medical treatments and distress, IES, and potential predictors were examined by both number of treatments received (none, 1, or 2 treatments) and by type (chemo alone or in combo vs. no chemotherapy) at Time 1 and 2 and did not reveal any significant differences. Ten participants were currently in treatment at Time 3 (radiotherapy and/or chemotherapy) and did not differ on any sociodemographic or psychological variables from women not in treatment and were therefore included in the analysis.

Sociodemographic variables. Age and education were significantly correlated with numerous psychological variables at all three time points. Specifically, younger women reported more IES at Time 1 ($r = -.20$, $p < .05$) and higher stress appraisal at Times 1, 2, and 3 (rs = -.20, -.22, -.31, respectively, all ps < .05). Furthermore, younger women also reported using more ESC coping at Time 1 ($r = -.20$ $p < .05$), more PPS coping at Times 1, 2, and 3 (rs = -.20, -.22, -.31, respectively, all ps < .05) and using more SSS coping at Times 1, 2, and 3 (rs = -.40, -.36, -.43, respectively, all ps < .001).

More educated women reported more SSS coping at Time 1 and 2 (rs = .18, .25, respectively, all ps < .05). At Time 2, they had higher stress appraisal ($r = .23$, $p < .01$) and reported less social support ($r = -.18$, $p < .05$). At Time 3, they reported higher levels of IES ($r = .22$, $p < .05$) and being more concerned with fear of the future ($r = .35$, $p < 01$). We retained age and education in all subsequent regression models.

Having a second cancer experience

We verified the effect of having a second cancer experience on distress, IES, and potential predictors at Time 3 by conducting independent sample t tests. Women who had a second cancer experience during the 6-year follow-up appraised their cancer as more stressful ($t(84) = -2.22$, $p < .05$), used more SSS coping ($t(69) = -3.17$, $p < .01$), and reported higher levels of IES ($t(84) = -2.34$, $p < .05$), but were not more distressed ($t(84) = .16$, $p > .05$) than disease free survivors at Time 3. In order to account for the proportion of variance explained by having a second cancer experience in distress and IES scores at Time 3, it was retained in all subsequent regression models.

Changes over time in descriptive results of psychological variables

We opted to compare means of psychological variables at the three interviews with paired sample t tests instead of repeated measures ANOVA's because: 1) 8 of the 86 participants had not completed the Time 2 interview and 2) at each interview, some participants did not endorse any stressful aspect of cancer and therefore did not fill out the coping measure. The number of participants who did not appraise their cancer as stressful at Time 1, 2, and 3 were 5 (3.4%), 23 (18%), and 15 (17.4%), respectively.[1] In order to minimize loss of participants when looking at changes over time of psychological variables, and because these data cannot be considered to be missing randomly, we used paired sample t tests with Bonferroni corrections.

As shown in Table 2, there were no changes in distress levels over time (POMS anxiety and depression subscales). IES levels decreased significantly from baseline to a year later and did not further decrease 6 years later. Overall, analyses of changes in psychological variables over time reveal that improvements took place between Time 1 and Time 2. There were usually no significant further changes from Time 2 to Time 3, indicating that improvements maintained themselves over time, except for perceived health and ESC coping at Time 3 which were undistinguishable from Time 1, suggesting deterioration in these two variables during long-term survivorship.

We further examined distress and IES levels among participants at Time 3. Overall mean distress and mean levels of IES were low. However, when examining the range of response, 22.1% of the sample reported a moderate level of distress (≥ 1) and 25% of the sample experienced moderate levels of PTSD-like symptoms (≥ 2). Compared to POMS norms available on newly diagnosed female cancer patients, participants in the present study reported lower levels of depression and anxiety (Cella *et al.*, 1989). Compared to a more appropriate sample of breast cancer patients three years after diagnosis, participants in the present study displayed comparable levels of depression and somewhat higher levels of anxiety (Hack and Degner, 2004). Our IES total score was lower than scores found in breast cancer survivors on average 2-3 years after diagnosis (Cordova *et al.*, 1995; Cordova *et al.*, 2001) but comparable to a sample of long-term breast cancer survivors on average 7.5 years after diagnosis (Vickberg *et al.*, 2000).

-- insert Table 2 about here ----------------------------------

Correlational analyses between potential predictors and distress and IES at Time 3

Longitudinal analyses. As shown in table 3, both at Time 1 and Time 2, breast cancer patients who perceived having less social support and used more PPS coping reported being more distressed at the 6-year follow-up. Furthermore, breast cancer patients who were more distressed and used more ESC coping at Time 2 reported more distress at the 6-year follow-up.

At Time 1, breast cancer patients who perceived their health as poorer, were less optimistic, had high stress appraisal, used more ESC coping, and had higher IES scores reported more IES at the 6-year follow-up. At Time 2, similar relations emerged between potential predictors and IES at Time 3, except for perceived health which was no longer significant.

Cross-sectional analyses. Breast cancer survivors who, at the 6-year follow-up, had high stress appraisal, identified fear of the future as their primary concern with cancer, and used ESC coping reported more distress and higher levels of IES. There were trends with SSS coping ($r = .22, p = .06$) and PPS coping ($r = .23, p = .06$) being associated with more distress. Breast cancer survivors who benefited from good perceived health, optimism, and social support reported less distress and IES.

Correlational analyses between distress and IES

Distress and IES were moderately correlated throughout the study suggesting they are related but likely tap different dimensions: at Time 1, $r = .48$, $p < .001$, Time 2, $r = .43$, $p < .001$, and Time 3, $r = .32$, $p < .01$.

Hierarchical regressions

A total of six hierarchical regressions were performed to predict distress and IES at Time 3 using potential predictors at Time 1, Time 2, and Time 3. For each regression, age, education, other sites affected at diagnosis, and having a second cancer experience were entered in the first step. In the regressions that used Time 1 and Time 2 variables, distress or IES at the corresponding time was also entered in the first block. This way, we controlled for within subjects' Time 1 or Time 2 distress and IES and identified variables that made an independent contribution to the prediction of long-term distress and IES. Psychological resources (perceived health, optimism, and social support) were entered in the second step, appraisal variables (stress appraisal and primary concern) in the third, and last, coping variables (ESC, SSS, and PPS). For each regression, only variables that were significantly correlated to the dependent variable were entered in steps 2, 3, and 4. Final models are shown in Table 4, showing only the variables that explained a significant proportion of the variance of distress or IES.

Using Time 1 potential predictors, distress at Time 3 was best explained by social support and PPS coping, together accounting for 11% of the variance, $F(2, 81) = 5.20$, $p < .01$. Social support made an independent contribution when it was first entered but was no longer significant after PPS coping was entered in the last step. IES at Time 3 was only predicted by levels of IES at Time 1, which explained 28.3% of the variance $F(1, 82) = 32.41, p < .001$.

Using Time 2 potential predictors, distress at Time 3 was best predicted by distress levels at Time 2, social support, and PPS coping, together accounting for 23% of the variance $F(3, 59) = 5.94, p < .001$. IES at Time 3 was again only predicted by levels of IES at Time 2, which explained 20% of the variance, $F(1, 61) = 15.16, p < .001$.

Using Time 3 variables, poor perceived health and fear of the future as the primary concern were significant predictors of distress, together accounting for 35% of the variance, $F(2, 68) = 18.09$, $p < .001$. Having had a second cancer experience during the six-year follow-up, optimism, and fear of the future as the primary concern with cancer were significant predictors of IES, together accounting for 28.7 % of the variance, $F(3,67) = 8.99$, $p < .001$. Stress appraisal was almost a significant predictor ($p = .052$) but did not enter the final model.

Discussion

The present study attempted to identify risk factors of distress and PTSD-like symptoms in breast cancer survivors assessed within 3 months after diagnosis, one year later and again after 6 years. Surprisingly, distress levels at 15 months and 6 years after diagnosis were not different from baseline levels. This absence of difference in distress levels across time cannot be explained by the inclusion of women who reported a second cancer experience at the 6-year follow-up as they did not show more distress than women who had remained disease free. It has been suggested that cancer specific measures might be better at identifying cancer patients at risk for distress than general measures such as the POMS (Polinski *et al.*, 1994; Schag *et al.*, 1993). Perhaps this finding was caused by the variability of distress scores (as indicated by the large standard deviations) or by a floor effect, since baseline levels were generally low at baseline, a finding corroborated by other studies (Ganz *et al.*, 1996).

Cross-sectional analyses

Among 6-year predictors, fear of the future as the primary concern and poor perceived health made significant contributions to the prediction of distress. Dunkel-Schetter *et al.* (1992) had found that fear or uncertainty about the future was the most commonly identified problem in a heterogeneous sample of cancer patients. We found that the proportion of breast cancer patients who identified fear or uncertainty about the future as their main concern with cancer did not diminish over the 6 years of this study, suggesting that having had cancer may produce some indelible worries in some breast cancer patients. Thus, heightened fear of the future could serve as an indicator of survivors' overall long-term adjustment (Dow *et al.*, 1996; Kornblith, 1998). The finding that breast cancer survivors who perceived their health to be poorer experienced more distress suggests the importance of studying the psychosocial impact of physical health in this population. Residual physical symptoms have been found in well-over a third of long-term breast cancer survivors (Ganz *et al.*, 1996; Polinsky, 1994) and have been found to be related to more depressive symptoms (Woods and Earp, 1978). However, we cannot attribute the relationship between distress and perceived health only to breast cancer, as this measure was a general indicator of health that could have been influenced by co-morbid illnesses.

Among 6-year predictors, fear of the future as the primary concern, having had a second cancer experience and optimism significantly predicted PTSD-like symptoms. Some have argued that what distinguishes PTSD symptoms among cancer patients from symptoms found in other traumatized population is that most of the worries are about future threats (i.e. fear of recurrence) (Brennan, 2001). Our finding that women who had experienced a second cancer reported more intrusion and avoidance confirms the importance of accounting for recurrence status in studies of long-term adjustment to cancer (Dorval *et al.*, 1998). Having a second cancer may be linked to intrusion and avoidance through the patient's search for meaning. Experiencing cancer a second time is considered a traumatic event by most breast cancer patients. It shatters assumptions about the world as a just and benevolent place and raises concerns about why one is incurring such a fate (Brennan, 2001; Taylor, 1983). The existential crisis triggered by this event can start a process of "constructive rumination" that results in heightened intrusive symptoms (Lebel *et al.*, under review; Park *et al.*, 1996; Sears *et al.* 2003).

One way breast cancer survivors may have been protected from PTSD-like symptoms in this study is by higher levels of optimism. It has been suggested that cancer patients who are more optimistic experience less distress than more pessimistic patients because they tend to confront the stressor and use less avoidant coping (Carver *et al.*, 1993). However, coping variables did not explain distress or PTSD symptoms among long-term breast cancer survivors in the present study. Rather, perception of the stressfulness of the cancer and fear of the future, two appraisal variables, were better predictors. Our findings point to the importance of studying appraisal variables which have been neglected in the study of coping and cancer (Brennan, 2001).

Longitudinal analyses

This is one of the first studies that followed patients prospectively into long-term survivorship (i.e. beyond 5 years after diagnosis) and was able to compare the long-term predictive efficacy of psychological variables shortly after diagnosis and 1 year later. An important finding that emerged from these analyses was that levels of PTSD-like symptoms at 3 months after diagnosis could explain 28% of the variance in IES levels 6 years later. This finding and the fact that there were no changes in IES levels from 15 months to 6 years reflect the persistence of PTSD-like symptoms over time. In a closer examination of predictors of change in IES levels over 4 time points during the first year following diagnosis, we found that previous levels of IES explained more of the variance in current IES and that other psycholosocial factors explained progressively less variance of current IES over time (Robitaille *et al.*, 2004). Based on these findings, PTSD symptoms should be monitored carefully after diagnosis and interventions should be offered to mitigate these symptoms in the long term.

Women who reported less support from their family, friends and partner during their treatment and one year later when they were considered in remission were more distressed at the 6-year follow-up. Although the mechanism that links the support breast cancer patients report around diagnosis to distress during survivorship is unclear, one possible explanation is that patients who have more social support during the first year following diagnosis are able to process the traumatic elements of their illness more efficiently (through opportunities to ventilate and to reframe), leading to less distress and a greater sense of well-being (Cordova *et al.*, 2001).

Interestingly, distress at Time 2 (15 months after diagnosis), a time point by which patients' adjustment is often considered to have returned to normal (Ganz *et al.*, 1996; Heim *et al.*, 1997; Helgeson *et al.*, 2004; Morris *et al.*, 1977) was a predictor of distress at the 6-year follow-up unlike distress at 3 months after diagnosis, a time point which corresponds to active treatment and is known to generate a substantial amount of anxiety and depression (Epping-Jordan *et al.*, 1999). Previous level of distress was the most important predictor of 6-year distress among variables at Time 2, explaining 12% of the variance. This finding suggests that perhaps residual distress observable a year after diagnosis is a better predictor of distress during survivorship than the acute distress observed at the time of treatments. Previous research has found chronic levels of depression during the first year to be an important predictor of survival among a heterogeneous group of cancer patients over a 10-year follow-up (Brown *et al.*, 2003). An alternative explanation to this finding is that identifying psychological predictors of distress at 3 months is difficult because the impact of treatments may overwhelm all other psychological influences (Carver *et al.*, 1993; Epping-Jordan *et al.*, 1999).

One of the most intriguing findings of the present study is that positive problem solving both at Time 1 and Time 2 was associated with more distress in long-term breast cancer survivors. We had hypothesized that breast cancer patients who responded to their illness during the first year by doing something active and positive would be better adjusted as survivors. Our study suggests that maintaining this positive attitude during the first year may have a cost in the long run. Patients often feel the pressure to "think positive", a phenomenon that has been labeled the "tyranny of positive thinking" (Holland, 2000). A recent study investigating quality of life in 5-year breast cancer survivors and healthy controls found that, in both groups of women, those who were still searching for meaning of the traumatic event had impaired quality of life (Tomich and Helgeson, 2002). Studies of bereavement indicated that individuals who did not make sense of the death early on almost never did and when they did, it did not relate to better adjustment (Nolen-Hoeksema and Davis, 2002).

Taken together, these findings suggest that a prolonged, continuous search for meaning may be detrimental. What other coping strategy might be beneficial in the long run? Once treatments have ended, the main concerns survivors have are fear of recurrence and uncertainty about their future, for which problem solving or active coping might be ineffective coping strategies. Acceptance might be a potentially helpful coping in mitigating the distress raised by these concerns. Breast cancer patients who used more acceptance coping shortly after diagnosis reported less distress during the following year while the early use of positive reframing and active coping was either unrelated to or predictive of more distress (Carver *et al.*, 1993; Stanton *et al.*, 2002). The prospective role of early use of acceptance on distress during long-term survivorship needs to be investigated in future studies.

Clinical implications

This article highlights the importance of assessing rumination, appraisals, worries (especially about future threat), and somatic preoccupations among breast cancer survivors, and perhaps utilizing well-established cognitive behavioral therapy interventions to reduce distress and worry. Asking survivors to rate the stressfulness of their cancer could be a useful way to discriminate among survivors who are more at risk of distress. In addition asking which aspect of their illness they find stressful (since fear of the future was a strong predictor of both distress and PTSD symptoms) would also be useful.

Patients who, during the first year following diagnosis, have poor social support, rely extensively on active coping and focusing on the positive and suffer from residual distress may be at risk of distress during long-term survivorship and need to be monitored closely.

Limitations

Since our measures of psychological adjustment (POMS and IES) do not have cut-off scores for clinical levels, we attempted to compare our participants to available norms or scores found in other studies of long-term breast cancer survivors. Another way to determine if the survivors in the present study were more distressed than the general population would have been to use a control group. However, it has been suggested that comparing cancer survivors to healthy controls may be problematic because of the phenomenon of cognitive shift that seems to occur in evaluating quality of life after cancer (Holzner *et al.*, 2001). It is possible that life events occurring between 15 months and 6 years affected distress in long-term breast cancer survivors. We also did not screen for previous history of mental illness, particularly depression. The breast cancer survivors we interviewed in the present study are a select group of more highly educated, Caucasian, high SES women that were in better health at the start of the study. Furthermore, since they had originally agreed to take part in an intervention study they may have been more distressed at baseline than women who choose not to participate. The number of women who had a second cancer experience during the 6-year follow-up is small and an even smaller number were currently in treatment, which may have resulted in lack of power to detect some differences between these two groups and survivors who were disease-free.

Future studies and conclusion

The course of recovery from breast cancer is still largely unknown, especially after the first two years. The present study was able to identify some important clinical risk factors of distress and IES in long-term breast cancer survivors and suggests the importance of monitoring patients more than once over the first year, since the adjustment seen during the time point of treatments might not be the best predictor of long-term distress.

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Footnotes

[1] We further examined participants who did not appraise their cancer as stressful by conducting independent sample t tests to test for differences on distress, IES, and potential predictors grouped by cancer being appraised as stressful or not (dichotomized as 0 or 1) at Time 2 and Time 3. Significant differences at Time 2 revealed that participants who did not appraise their cancer as stressful had lower levels of distress ($t(126) = -2.36$, $p < .05$) and IES ($t(126) = -4.72$, $p < .001$), were older ($t(126) = 2.24$, $p < .05$), and less educated ($t(126) = -2.36$, $p < .05$) than participants who appraised their illness as stressful. Significant differences at Time 3 also revealed that participants who did not appraise their cancer as stressful had lower levels of distress ($t(84) = -2.27$, $p < .05$) and IES ($t(84) = -2.90$, $p < .01$), were older ($t(84) = 2.31$, $p < .05$), less educated ($t(84) = -3.09$, $p < .01$), and more optimistic ($t(84) = 2.87$. $p < .01$) than participants who appraised their illness as stressful. These results indicate that women who do not perceive their cancer to be stressful may be better adjusted than women who appraise their illness as stressful. These results should be seen as tentative given the small number of women who reported not being stressed about their cancer.

Table I. *Demographic and medical characteristics of breast cancer survivors sample (N=86)*

Characteristic	N	%	M	SD
Age	86		61.7	10.8
Years of education	86		13.3	3.4
Number of children	86		2.1	1.2
Number work hrs/week	86		12.1	16.6
Marital status				
Married	53	61.6		
Separated/Divorced	12	14.0		
Widowed	14	16.3		
Never married	7	8.1		
Second cancer experience				
Yes	21	24.4		
No	65	75.6		
Religion				
Jewish	31	36.0		
Catholic	26	30.2		
Protestant	13	15.1		
Other	10	11.6		
None	6	7.0		

Working status		
Not working	48	55.8
Working	38	44.2
Stage		
I	36	61.0
II	22	37.3
III	1	1.7
Income		
< 30 000$	19	25.7
30 000-60 000$	21	28.4
> 60 000$	34	45.9

Table II. *Descriptive statistics of psychological variables at Time 1, Time 2, and Time 3*

Psychological variable	Time 1		Time 2		Time 3		*P**		
(possible range)	M	(SD)	M	(SD)	M	(SD)	1 vs. 2	1 vs. 3	2 vs. 3
Distress (0-4)	.91	.70	.81	.68	.77	.56	NS	NS	NS
IES (1-4)	1.97	.65	1.82	.62	1.62	.58	.009	.003	NS
Optimism (0-4)	2.69	.61	2.73	.57	2.82	.59	NS	NS	NS
Perceived health (0-5)	3.71	.94	4.07	.90	3.94	.99	.003	NS	NS
Social support (0-4)	3.14	.79	3.23	.69	3.10	.71	NS	NS	NS
Stress appraisal (1-5)	3.58	1.09	2.63	1.15	2.88	1.32	.003	.003	NS
PPS (1-5)	2.77	.60	2.53	.65	2.55	.72	.003	.003	NS
ESC (1-5)	2.64	.66	2.35	.65	2.44	.66	.003	NS	NS
SSS (1-5)	2.68	.89	2.20	.84	2.24	.88	.003	.003	NS
Fear of the future (% yes)	48.9		60		43.7		NS	NS	NS

Note. Item mean scores presented for all variables.

Distress = combined Anxiety and Depression subscales of the POMS

* All tests were performed using paired sample t tests with Bonferroni corrections

Table III. *Correlations of distress and IES at Time 3 with potential predictors*

Predictors	Time 1/ Time 3 distress	Time 1/ Time 3 IES	Time 2/ Time 3 distress	Time 2/ Time 3 IES	Time 3/ Time 3 distress	Time 3/ Time 3 IES
Perceived health	-.19	-.25*	-.03	.16	-.56***	-.13
Optimism	.06	-.24*	-.22	-.35**	-.29**	-.29**
Social Support	-.23*	-.13	-.34*	-.15	-.24*	-.22*
Perceived Stress	.11	.25*	.12	.24*	.24*	.42***
Primary Concern	-.13	.19	.07	.11	.26*	.34**
Positive Problem Solving	.28**	.02	.28*	.15	.23	.06
Seeking Social Support	.07	.08	.13	.06	.22	.13
Escape-Avoidance	.13	.31**	.29*	.31**	.30*	.38**
Distress	.21	.37***	.33*	.03	—	.32**
IES	.11	.54***	.28*	.49***	.32**	—

Table IV. *Hierarchical regression of predictors at Times 1, 2, and 3 on distress and IES scores at Time 3*

Dependent variable Predictor variable	ΔR^2	Cumulative R^2	Beta weight	p
Time 1 Predictors				
Distress				
Social support	0.05	0.05	-0.18	0.045
PPS	0.06	0.11	0.26	0.017
IES				
IES	0.28	0.28	0.53	<0.001
Time 2 Predictors				
Distress				
Distress	0.12	0.12	0.25	0.006
Social support	0.06	0.18	-0.26	0.035
PPS	0.05	0.23	0.23	0.048
IES				
IES	0.20	0.20	0.45	<0.001
Time 3 Predictors				
Distress				
Perceived Health	0.30	0.30	-0.30	<0.001
Primary appraisal	0.05	0.35	0.25	0.028

IES				
Second cancer experience	0.08	0.08	0.35	0.016
Optimism	0.07	0.15	-0.25	0.018
Primary appraisal	0.13	0.28	0.37	0.001

Note. Second cancer experience was coded as 0 = no 1 = yes. Primary appraisal was coded as 0 = all other concerns 1 = fear or uncertainty about the future.

Chapter 2 : Second article

Distress and Benefit Finding in Long-Term Breast Cancer Survivors

Running head: DISTRESS AND BENEFIT FINDING IN CANCER SURVIVORS

Submitted on March 29, 2004

Distress and Benefit Finding in Long-Term Breast Cancer Survivors

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This study was supported by Research Studentships to Sophie Lebel from the National Cancer Institute of Canada with support from the Canadian Cancer Society and from the Fond de Recherche en Santé du Québec -Fond pour la Formation Des Chercheurs et l'Aide à la Recherche; and an operating grant from the Canadian Breast Cancer Research Initiative to Zeev Rosberger and Linda Edgar. It forms part of the Ph.D. studies of Sophie Lebel

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The authors would like to thank Mrs. Rima Azar, Brigitte Masse, Dr. Lina Didio and Dr. Marie Achille for comments on earlier drafts and Mr. Miguel Chagnon for statistical advice. We are very grateful to all the women who participated in this study.

Abstract

The relations between benefit finding, adjustment, social support, optimism, coping, perceived health, and having a second cancer experience were examined in 6-year breast cancer survivors (n = 86) that we had interviewed four times during the first year after their diagnosis. Having a second cancer experience during the 6 year following their diagnosis, poorer perceived health, and using the coping strategy of positive-problem solving predicted greater benefit finding and together accounted for 42.2% of its variance. Benefit finding was unrelated to distress (Profile of Mood States) but was positively correlated to intrusive thoughts (Impact of Event Scale). These results suggest that women who are experiencing more current suffering are the ones who report more benefits from having breast cancer.

Key words: adjustment to breast cancer, long-term survivors, benefit finding, coping

Submitted on March 29, 2004

Distress and Benefit Finding in Long-Term Breast Cancer Survivors

Using the American Cancer Society's definition of a survivor as someone who lives five years beyond cancer diagnosis, it is estimated that there are over two million women in North America currently living with breast cancer (National Cancer Institute, 2000; National Cancer Institute of Canada, 2003). While living with this chronic illness, patients are regularly monitored for signs of recurrence and must continue to face potential psychological and physical vulnerabilities for years after completion of treatment (Fredette, 1995; Woods & Earp, 1978). Distress, consisting mostly of depression and anxiety symptoms and intrusive and avoidant thoughts, will persist in 10 to 30% of breast cancer survivors (Andersen, 1992; Cella & Tross, 1986; Cordova, Andrykowski, Redd, Kenady, McGrath, & Sloan, 1995; Polinsky, 1994; Saleeba, Weitzner, & Meyers, 1996).

However, focusing only on the potentially negative sequelae of surviving breast cancer may lead to an incomplete picture. Some studies have found that cancer patients report more positive changes than negative ones (Collins, Taylor, & Skokan, 1990; Katz, Flasher, Cacciapaglia, & Nelson, 2001; Taylor, 1983). Many patients report benefits from having experienced their illness and consider themselves to be better adjusted than before their diagnosis (Fromm, Andrykowski, & Hunt, 1996; Sears, Stanton, Danoff-Burg, 2003; Taylor, 1983). A study of 90 bone-marrow transplant survivors found that the most common benefits reported were a new philosophy of life, changes in personal attributes, improved family relationships, and greater appreciation of life (Fromm et al., 1996).

The types of benefits reported among different populations are remarkably similar, but no studies have focused specifically on the changes reported by long-term survivors (i.e. past the 5-year indicator of survival) of breast cancer. A change of one's view of self and one's priorities in life, an increased sense of spirituality, and improved relationships have been found not only in cancer patients but also low-income HIV-positive women, and patients with lupus, multiple sclerosis, and heart disease (Katz et al., 2001; Mohr, Dick, Russo, Likosky, Pinn, Boudewyn, & Goodkin, 1999; Thornton, 2002; Upergraff, Taylor, Kemeny, & Wyatt, 2002). Similar benefits have also been reported in non-medical populations that have undergone trauma such as natural disasters, plane crashes, or bereavement (McMillen, Smith, & Fisher, 1997; Nolen-Hoeksema & Davis, 2002).

Benefit finding has been inconsistently linked to distress in cross-sectional studies. Some studies of cancer patients have found no relationship between benefit finding and various measures of adjustment such as mood, depression, intrusive and avoidant thoughts, quality of life, perceived physical health, illness-related dysfunction, and self-esteem (Cordova et al., 2001; Fromm et al., 1996). In contrast, Mohr et al. (1999) found that multiple sclerosis patients who reported greater benefit finding had elevated levels of anxiety and anger, while a later study that attempted to replicate Mohr et al.'s findings, using the same benefit finding and emotional distress questionnaires found that benefit finding was negatively related to distress (Katz et al., 2001).

Longitudinal studies of men who experience a first heart attack, bereaved individuals, and victims of disasters have all found that being able to identify at least one benefit early in the adjustment process was predictive of less distress a few years after the trauma occurred (McMillen et al., 1997; Nolen-Hoeksema & Davis, 2002; Tennen & Affleck, 2002). To our knowledge, there has been only one longitudinal study of the role of benefit finding with cancer patients (Sears et al., 2003). The authors interviewed 92 newly diagnosed breast-cancer patients after completion of treatment and again three months and one year later. Identifying benefits at the first interview was not predictive of subsequent distress, quality of life, and posttraumatic growth at one-year. Posttraumatic growth, defined as the experience of significant positive changes following trauma, was examined only at 12 months and was not related to distress, quality of life, physical health, but was related to greater positive mood.

The contradictory results can be explained by the different time points (early after the trauma in the longitudinal studies vs. years after completing treatment in most cross-sectional studies) at which benefit finding was assessed in these studies. It can be argued that a psychological cure includes a return to normal life, and this would mean a tapering off of benefit finding as cancer patients become cancer-free survivors (Fromm et al., 1996). That is, finding benefits may be useful for a period of time after diagnosis but is eventually no longer needed which could explain the lack of relationship between benefit finding and distress found in some studies that examined patients years after diagnosis. Bone-marrow transplant survivors who reported more benefits tended to have had a transplant more recently (12-30 months vs. 30-120 months) (Fromm et al., 1996). However, two studies found that longer time since diagnosis was associated with greater posttraumatic growth in breast cancer survivors ranging from 2 to 58 months after diagnosis (Cordova et al., 2001; Sears et al., 2003). Clearly, more studies are needed that examine how benefit finding evolves over the long term trajectory of the illness.

The impacts of characteristics of the stressor on benefit finding are not well-known. College students who had undergone a severe trauma in the past year reported more growth than those who did not (Tedeschi & Calhoun, 1996). Severity of illness, defined as having had a transplant associated with greater risk, was found to be related to greater benefit finding in the Fromm et al.'s study (1996). Both Cordova et al. (2001) and Sears et al. (2003) found that subjective severity of the trauma and not objective measures such as cancer stage was predictive of benefit finding in breast cancer survivors. Whether benefit finding correlates more with subjective or objective measures of the severity of the threat is still open to debate.

It appears that "for stressors to elicit positive change, they must be of sufficient magnitude to challenge one's assumptions" (Cordova et al., 2001, p. 182). One such challenge is experiencing a recurrence. Experiencing a recurrence has been described by patients as being more stressful and more distressing than the initial diagnosis, possibly because of the implications for survival (Mahon, Cella, & Donovan, 1990; Northouse, Laten, & Reddy, 1995; Silberfarb, Maurer, & Crouthamel, 1980). However, studies have yet to examine the impact of a second cancer experience on benefit finding.

A number of predictors of benefit finding have been investigated, such as social support, optimism, coping, and perceived health. Supportive partners, family and friends may help the woman with cancer come up with benefits from having the illness or may get closer to her (one of the most frequently cited benefits) (Cordova et al., 2001). Optimism has also been linked to greater benefit finding among college students (Tedeschi & Calhoun, 1996) and HIV-positive women (Updergraff et al., 2002). Dispositional optimism has been associated to perceiving more benefits among bereaved individuals and this relationship was explained by the greater use of reappraisal coping (Nolen-Hoeksema & Davis, 2002). Several studies have reported a positive association between coping strategies and benefit finding. Among bereaved individuals, benefit finding was related to active problem solving, seeking social support, and engaging in constructive expression of emotions but was unrelated to avoidance coping (Davis, Nolen-Hoeksema, & Larson, 1998). Benefit finding was found to be related to seeking social support and positive reappraisal in multiple sclerosis patients (Mohr et al., 1999) while among patients with various cancers, positive changes were related to many coping strategies: problem-focused coping, cognitive escape/avoidance, positive focus, and behavioral escape/avoidance (Collins et al., 1990). Perceived health status, an important predictor of distress, has seldom been examined in relation to benefit finding (Sears et al., 2003; Updergraff et al., 2002).

As the majority of studies on benefit finding have been cross-sectional, there is a paucity of information on the role of psychological variables early in the traumatic event in the development of subsequent personal growth. Being more optimistic, more educated and younger before experiencing the death of a loved one were found to be related to more benefit finding at six months post-loss (Davis et al., 1998). Some have hypothesised that participants with greater resources (psychological, physical, and socioeconomical) will fare better (Updergraff et al., 2002) but this remains to be examined prospectively in cancer patients.

The present study was designed to expand on the existing literature in several ways. First, this study examined the relationship between benefit finding, distress, and avoidant and intrusive thoughts among a cohort of long-term breast cancer survivors we had interviewed four times during the first year after their diagnosis. Second, this study also aimed to identify characteristics of the stressor that predict benefit finding. It was expected that some of the long-term breast cancer survivors may have experienced a recurrence during the follow-up.

The present study offered the possibility of comparing reports of benefit finding among women who underwent a second cancer experience and those who remained disease-free.

Last, this study examined the relations of social support, optimism, coping and perceived health with benefit finding in long-term breast cancer survivors. We also examined the relationship between first-year psychological resources and benefit finding during survivorship to see if breast cancer patients who displayed more resources early during the disease trajectory would report more benefit finding as they became survivors.

Hypotheses

It was hypothesized that: 1) Breast cancer survivors who perceived more benefits from having had breast cancer would experience less distress and intrusive and avoidant thoughts; 2) breast cancer survivors who had faced a second cancer experience since their diagnosis would perceive more benefits, as would those who perceived their cancer to be more stressful, reported greater use of coping strategies, were more optimistic, and had more social support; and 3) breast cancer survivors who displayed more psychological resources during the first year following diagnosis would report more benefit finding. Since the relationship between perceived health and benefit finding had seldom been examined, we did not make specific predictions.

Method

Design

This study used a longitudinal design to investigate the relations between sociodemographic and medical variables, social support, optimism, perceived health, coping, intrusive and avoidant thoughts, and distress at the following time points: 3, 7, 11, 15 months, and 6 years after diagnosis. The relationship between benefit finding, its predictors, intrusive and avoidant thoughts, and distress was assessed at 6 years.

Participants

Participants were 86 women diagnosed with breast cancer approximately six years previously who had participated in an intervention study [Nucare II study, (Edgar, Rosberger, & Collet, 2001)]. See Table 1 for sociodemographics and medical characteristics of the present sample. Participants' ages ranged from 37 to 88. The majority of women had been diagnosed with stage I breast cancer. All 86 participants had undergone surgery: 60 had a segmental mastectomy, 6 had a lumpectomy, 4 had a total mastectomy, and the rest had other procedures. The most frequent treatment was a combination of surgery, radiotherapy, and chemotherapy (n = 62), surgery and radiotherapy (n = 15), surgery and chemotherapy (n = 7) or surgery alone (n = 2). Most women (n =56) had taken or were finishing a course of Tamoxifen. During the six-year follow-up, 4 participants had a recurrence, 9 had a new primary, and 8 were diagnosed with metastases for a total of 21 women who had to face a second cancer experience.

The original sample consisted of 146 patients. At the follow-up, 31 had died, 9 could not be located, and 20 refused to be interviewed [including participants whose access was denied by the physician because of poor mental health (n = 1), or the family because the patient was too sick (n = 4), or by the researcher because of language problems (n = 1)]. Our refusal rate is thus 18.9 % (20 refusals /86 completers + 20 refusals). Participants at the six year follow-up differed from the original sample in that, at baseline, they were more likely to be working ($\chi^2(1, N = 146) = 4.59, p < .05$) and had fewer sites affected by cancer ($\chi^2(1, N = 146) = 6.12, p < .05$), and thus were probably healthier. Women who refused to complete the follow-up differed from participants in that they were older ($t(104) = -2.44, p < .05$) and less likely to be working ($\chi^2(1, N = 106) = 4.59, p < .05$), but did not differ on number of sites affected nor on any of the baseline psychological variables.

-- insert Table 1 about here -----------------------------------

Measures

Mood was assessed using the Profile of Mood States (POMS; McNair, Lorr, & Droppleman, 1971). The POMS consists of 65 adjectives which are rated on a 5-point scale ranging from not at all (0) to extremely (4). The POMS contains six subscales: Anxiety, Depression, Anger, Vigor, Fatigue and Confusion. For the purpose of the present study, the Anxiety and Depression subscales were combined to create a distress indicator. Internal consistency of this combined indicator was between .89 and .95 throughout the study.

Intrusive and avoidant thoughts were assessed using the Intrusion and Avoidant subscales of the Impact of Events Scale (IES; Horowitz, Wilner, & Alvarez, 1979). The IES is a measure of subjectively experienced stress related to an adverse life event and has been used to assess the presence of PTSD symptoms in a sample of breast cancer survivors (Cordova et al., 1995). It consists of 15 items that are rated on a 4-point scale from not at all (1) to often (4). Seven items of this scale form an Intrusion subscale and eight items form an Avoidance subscale. In the present study, internal consistency of the Intrusion subscale ranged between .83 and .87 and between .75 and .83 for the Avoidance subscale. Average correlation between the two subscales was .64.

Coping was measured with the version of the Ways of Coping Scale (WOC; Lazarus & Folkman, 1984) adapted for cancer patients by Dunkel-Schetter, Feinstein, Taylor, & Falke (1992). Patients were asked to rate the degree with which they have used any of the 52 coping strategies in response to five aspects of their illness in the past six months (fear and uncertainty about the future; limitations in physical ability, appearance, or life style; acute pain, symptoms, or discomfort; problems with family or friends; any other problem). Each coping strategy was answered on a 5-point scale from not at all (1) to extremely (5). Factor analysis of WOC-CA in a sample of 250 cancer patients resulted in three scales: Escape-Avoidance (consisting of items that suggest avoiding the problem or people all together i.e. "refused to believe it would happen" as well items that suggest wishful thinking i.e. "wished the situation would go away"), Positive Problem Solving (made of active problem solving items such as "made a plan of action and followed it" and positive reframing items such as "rediscovered what is important in life"), and Seeking Social Support (items cover seeking advice, professional help, practical support, as well as emotional support) (Cronbach's Alphas = 0.81, 0.88, and 0.82, respectively) (see Rosberger, Edgar, Collet, & Fournier, 2002 for details of this study).

Perceived stressfulness of the cancer was measured by asking respondents to choose the most stressful problem they had to face in the past six months out of the five aspects of their illness identified in the Ways of Coping scale. Each aspect was rated on a 5-point scale ranging from not at all stressful (1) to extremely stressful (5) (Dunkel-Schetter et al, 1992).

Optimism was measured with the Life Orientation Test (LOT; Scheier & Carver, 1985). The LOT is a 12-item questionnaire which measures general expectancies of favorable future outcomes and is answered a 5-point scale, ranging from strongly disagree (0) to strongly agree (4). In the present study, internal consistency of the LOT ranged between .77 and .82.

Social support was measured with the Social Well-Being scale (SWB) of the Functional Assessment of Cancer Therapy (FACT), a well-known instrument designed to measure a number of dimensions of quality of life of cancer patients (Cella, Tulsky, Gray, Sarafian, Linn, Bonomi, et al., 1993). The SWB consists of seven items rated on a 5-point scale ranging from not at all (0) to very much (4) that measure support available from partner, friends and family. In the present study, internal consistency ranged between .69 and .73. Since the SWB is seldom used alone as a measure of social support (Yellen & Cella, 1995), we administered the Social Support Questionnaire (SSQ; Northouse, 1988) at the six-year follow-up in order to confirm its convergent validity. The SSQ is a well validated scale where subjects rate the degree of support they perceive from five sources (spouse or significant other, family member, friend, nurse, physician). For purpose of the present study, only the spouse, friend, and family subscales were used. This shorter form of the SSQ may be useful for individuals who have little contact with nurses and physicians such as breast cancer survivors (Northouse, personal communication, 1999). In the present study, an alpha of .91 was found. The correlation between the SWB subscale of the FACT and the SSQ was (r = .75, p <.001) indicating that the SWB likely taps the construct of social support.

Perceived health status was measured with a one-item index that was answered with a five-point indicator ranging from very poor (1) to excellent (5). Past research has shown this measure to correlate highly with physician's assessments (Conill, Verger, & Salamero, 1990).

Benefit finding was measured with the Benefit Finding scale (Antoni, Lehman, Kilbourn, Boyers, Culver, Alferi, et al., 2001). This 17-item instrument was designed to assess perceived benefits that breast cancer patients may endorse after having had the illness. It covers domains such as developing a sense of purpose in life or relationships with others. Responses are made on a 5-point scale from 1 (not at all) to 5 (extremely). In a sample of a 100 newly treated women with breast cancer, Benefit Finding showed an average reliability of .95 and was relatively stable across the duration of the study (9 months) (Antoni et al., 2001). In the present study, internal consistency was .94.

Procedure

Participants from the original study were located and asked if they were interested in completing the follow-up study. Subjects who provided informed consent were interviewed individually at the location of their choosing. The interview took about one hour.

Results

Overview of analyses

Data were analysed in several steps in the present study. First, data were checked for missing items and outliers and distributions were examined to determine normalcy. Second, descriptive analyses of benefit finding and psychological variables were performed. Third, independent sample t-tests and Pearson correlations were computed to examine the relationships between medical and sociodemographic variables and benefit finding and psychological variables. Fourth, Pearson correlations were computed to examine the relationship among benefit finding, distress, intrusive and avoidant thoughts, and psychological variables at the six-year follow-up. Fifth, based on theoretical assumptions and significance of correlations, medical and psychological variables were entered in a hierarchical multiple regression to identify predictors of benefit finding. Sixth, we report correlations among first year psychological resources and benefit finding.

Descriptive results

As shown in Table 2, overall mean benefit finding scores were within the moderate to high range. Very few women (2.3%) endorsed no benefit at all and only 16.3 % of the sample had a score between not at all and a little (< 2).

Overall, mean distress (combined index of anxiety and depression subscales of the POMS) and mean levels of intrusive and avoidant thoughts were low. However, when examining the range of response, 22.1% of the sample reported a moderate level of distress (≥ 1) and 25% of the sample experienced moderate levels of intrusive and avoidant thoughts (≥ 2).

On average, respondents found their cancer somewhat stressful. Fear of the future was identified as the primary concern with having cancer by 43.7 % of the sample. Coping strategies of positive problem solving, escape-avoidance, and seeking social support were used rarely to sometimes. Women in this sample tended to optimistic, perceived themselves to be in reasonably good health, and to have quite a bit of support from their family, friends, and spouses.

--- insert Table 2 about here -----------------------------------

Medical and sociodemographic variables

A number of medical variables were available about the original diagnosis: nuclear grade, stage, and number of sites affected. Despite our best efforts to find stage data through oncology charts and medical records, staging information was available for only 59 of our 86 participants. Therefore, we used 'number of other sites affected at diagnosis' (other than breast), a variable available for all patients, as a measure of disease severity in our analyses. Number of sites was coded as 0 (no other sites affected/localised tumor) or 1 (1 or more sites affected at diagnosis/regional tumor). Stage and number of sites affected at diagnosis showed a strong correlation $r = .57$ ($p < .001$). Independent sample t-tests were conducted to test for differences on benefit finding, distress, intrusive and avoidant thoughts grouped by nuclear grade (1 vs. 2 and 3), stage (I vs. II), and number of other sites affected (0 or 1). No significant differences emerged. Ten participants were currently in treatment (radiotherapy and/or chemotherapy) and did not differ on any sociodemographic or psychological variables from women not in treatment and were therefore analysed together.

Women who had a second cancer experience showed higher levels of benefit finding ($t(84) = -2.11$, $p < .05$), perceived their cancer as more stressful ($t(84) = -2.22$, $p < .05$), reported using more seeking social support ($t(69) = -3.17$, $p < .01$) and having more intrusive ($t(84) = -2.08$, $p < .05$) and avoidant thoughts ($t(84) = -2.08$, $p < .05$), but did not report more distress ($t(84) = .16$, $p > .05$) than disease free survivors.

Sociodemographic variables were also examined for correlations with psychological variables. Benefit finding was not correlated with age (r = -.18, p > .05), education (r = -.01, $p > .05$), or income (r = -.03, $p > .05$).

Correlational analyses

Pearson correlations were conducted among benefit finding, distress, intrusive and avoidant thoughts, and psychological variables. As shown in Table 3, benefit finding was positively correlated with intrusive thoughts, perceived stressfulness of the cancer, and coping strategies of seeking social support, and positive problem solving. There was also a trend in women with worse perceived physical health to report greater benefit finding ($r = -.19$, $p = .08$). Benefit finding was unrelated to distress, social support, optimism, and the coping strategy of escape-avoidance.

Since correlational analyses indicated that benefit finding and intrusive thoughts were positively correlated and t-tests had revealed that women with a second cancer experience perceived both more benefits and more intrusive thoughts, we decided to further explore the relations between these three variables. A 2-way analysis of covariance (disease-free vs. second cancer experience) was performed with benefit finding as the dependent variable and using the Intrusion subscale as a covariate. In this analysis, there is no difference in benefit finding between the two groups ($F(1, 85) = 2.86$, $p > .05$). This result suggests that women who have had a second cancer experience report more benefit finding likely through the fact they also experience more intrusive thoughts.

-- insert table 3 about here ---------------------------------

Regression analysis

Based on the analyses presented above, we suspected that we may have two distinct groups of participants: those who have experienced cancer a second time and those who have remained disease-free. Before incorporating the variable of second cancer experience in our regression model, we verified if the relations between benefit finding and its predictors were the same in both groups, that is, the dependent variable (DV)-covariates slopes are the same for both groups and that there are no interactions between independent variable (IV) and covariates (Tabachnick & Fidell, 1996). This was done by testing the assumption of homogeneity of regression in an ANCOVA (disease-free vs. second cancer experience) with benefit finding as the dependent variable and distress, avoidant and intrusive thoughts, optimism, social support, perceived health, perceived stressfulness of the cancer and the coping strategies of positive problem solving, escape-avoidance, and seeking social support each examined as separate covariates. Homogeneity of regression was found for all independent variables except escape-avoidance ($F(1, 67) = 4.78, p = .03$) and seeking social support ($F(1, 67) = 4.31, p = .04$) which showed modest heterogeneity. This indicates that the relations between benefit finding and escape-avoidance and seeking social support may be different for women who have had a second cancer experience than for women who have not. We therefore computed interaction terms between having a second cancer experience and both escape-avoidance and seeking social support. When entered in our regression model, these two interactions terms were non-significant and were therefore not retained in the final model showed in Table 4.

A hierarchical multiple regression was performed to predict benefit finding. Predictors that showed a significant correlation with benefit finding (or trend in the case of perceived health) were entered in the following order: medical variables, psychological resources, and coping variables. Having had a second cancer experience was entered in the first step, perceived health in the second step, and perceived stressfulness of the cancer, positive problem solving and seeking social support in the last step. As shown in Table 4, having had a second cancer experience, poor perceived health status, and positive problem solving each made significant independent contributions to the prediction of benefit finding. Together, these 3 factors accounted for 42.2 % of the variance in benefit finding. The final model was highly significant ($F(5, 65) = 9.48, p < .001$).

-- insert table 4 about here---------------------------------

Correlational analyses between psychological variables measured during the first year after diagnosis and benefit finding

Pearson correlations were performed to examine the relationships between psychological variables that had been measured four times after diagnosis (3, 7, 11, and 15 months) and benefit finding in survivors at the six-year follow-up to test the hypothesis that greater psychological resources early during the disease trajectory are related to greater personal growth during survivorship.

At baseline, distress ($r = .24, p < .05$), intrusive thoughts ($r = .31, p < .01$), and poorer perceived health ($r = -.31, p < .01$) were correlated with benefit finding at the six-year follow-up. However, distress, intrusive thoughts, and perceived health at 7, 11, and 15 months following diagnosis were not related to benefit finding. Positive problem solving was consistently positively correlated with benefit finding both at baseline ($r = .31, p = .005$) and at every other time point (rs between .31 and .49, all ps $< .05$). Seeking social support was also significantly correlated with benefit finding at 7 months ($r = .24, p < .05$) and 11 months ($r = .31, p < .05$) and marginally significantly at 3 months. Avoidant thoughts, the coping strategy of escape-avoidance, social support, and optimism were unrelated to benefit finding across all time points. These results suggest that poorer adjustment at baseline was related to benefit finding. Greater resources, on the other hand, with the exception of positive problem solving and to a lesser extent seeking social support, were not related to benefit finding.

Discussion

The present investigation examined the relationship between benefit finding and distress, and the medical, sociodemographic and psychological predictors of benefit finding in long-term breast cancer survivors. We found that reports of benefits following breast cancer were prevalent in this sample, with close to 85% of respondents reporting at least some sense of personal growth. Our first hypothesis that women who reported more benefit finding would experience less distress was not supported. Women who reported more benefit finding did not experience less anxious and depressed mood, or avoidant thoughts, but experienced greater levels of intrusive thoughts.

Our second hypothesis about predictors of benefit finding was partially confirmed. Perceived stressfulness, a subjective indicator of the severity of the illness was related to benefit finding, contrary to objective indicators such as stage and other sites affected by cancer. An interesting result from this study is that participants who had been diagnosed with a recurrence, metastases, or a new primary during the six-year follow-up reported more of a sense of personal growth. Having had a second cancer experience accounted for 8 % of the variance in benefit finding. Also as predicted, correlational analyses indicated that breast cancer survivors who coped with their illness through seeking social support and positive problem solving reported more benefit finding. Positive problem solving was the strongest predictor of benefit finding accounting for 28% of its variance. Poorer perceived health added another 6% to the prediction of benefit finding. Contrary to predictions, optimism and social support were unrelated to benefit finding.

Our third hypothesis about first year psychological resources leading to more benefit finding was partially disconfirmed. Participants who, during the first year reported using positive problem solving and, to a lesser extent, seeking social support, reported more benefit finding at the six-year follow-up. However, optimism, social support, better adjustment or health status over the course of the first year after diagnosis were not associated with more benefit finding. On the contrary, benefit finding six years after diagnosis was positively associated with distress, intrusive thoughts, and worse perceived health assessed at the first interview that was done within three months after diagnosis.

In the present study, nearly 25% of women interviewed reported a moderate amount of distress and intrusive and avoidant thoughts. Our study did not replicate the finding that reporting at least one benefit is protective of distress (Tedeschi et Calhoun, 1996). Instead, women who reported more benefits also reported more intrusive thoughts about their illness. Results of this study contradict the hypothesis postulated by Davis et al., (1998) that the relationship between benefit finding and distress may be explained by the fact that depressed people are more likely to have a negative thinking style that prevents them from finding meaning in their adversity. Our results are consistent with other studies that concluded that benefit finding and negative adjustment may best be viewed as a two-dimensional construct rather than a continuous one (Fromm et al, 1996; Sears et al, 2003). A cautious note is that distress levels in our sample were low yet comparable to sub-clinical levels of distress found in other studies of long-term breast cancer survivors (Andersen, 1992; Cordova et al., 1995; Polinsky, 1994; Saleeba et al., 1996).

Our findings that breast cancer survivors who report more benefit finding are also experiencing more intrusive thoughts about their cancer is in line with Calhoun and Tedeschi's model that suggests that the existential crisis triggered by the illness starts a process of "constructive rumination". They postulate that the more somebody engages in constructive rumination, the more one will report growth. A few other studies have reported this result as well using the same intrusive thoughts measure (Impact of Events Scale) (Park, Cohen, & Murch, 1996; Sears et al. 2003).

Perceived stressfulness of a trauma has been found to be related to increased benefit finding in previous work (Cordova et al, 2001; Lechner, Zakowski, Antoni, Greenhawt, Block, & Block, 2003; Park et al., 1996; Sears et al., 2003). In the present study, while respondents identified many stressful aspects about having had cancer, fear or uncertainty about the future was chosen by more than 40% of our sample as their main preoccupation with cancer. Cancer survivors often report not knowing for sure if they are cured and fearing the cancer may come back (Cella & Tross, 1986; Maher, 1982; Northouse, Dorris,

& Charron-Moore, 1995; Polinsky, 1994). One possible explanation for the lack of relationship between stage and benefit finding comes from Lechner et al. (2003) who reported that only a third of the patients they interviewed were able to provide staging information and that, of those, 78% gave accurate information. Given that patients in the Lechner et al.'s study (who had cancer ranging across stages I-IV) could not recall staging information, it would not be surprising if most patients in the present study did not remember whether they were diagnosed with a stage I or II 6 years ago (assuming they were told). How patients construe the severity of their illness is not well understood. Like previous studies (Cordova et al., 2001), we found that perceived subjective severity of the threat may be a better predictor of growth than medical indicators of severity.

The finding that participants who had cancer a second time reported more benefit finding suggests that greater current suffering leads to more personal growth. Additional analyses revealed that this relationship could be explained by the fact that women who experienced cancer a second time experienced more intrusive thoughts. As these results are based on cross-sectional data, causality cannot be inferred. However, intrusive thoughts three months after diagnosis were also positively associated with benefit finding in survivorship, adding to the idea that greater suffering may trigger more growth.

Other studies have found coping strategies, particularly positive reframing to be predictive of greater benefit finding (Mohr et al., 1999; Nolen-Hoeksema & Davis, 2002; Sears et al., 2003). Positive Problem Solving contains items that may be similar in content to our measure of benefit finding such as "Changed or grew as a person in a good way" or

"Rediscovered what is important about life". However, it can be argued that benefit finding is an end state, an evaluation, while a coping strategy such as positive reframing is a process (Calhoun, Cann, Tedeschi, & McMillen, 2000). Affleck & Tennen (1996) have argued that benefit finding is not a coping strategy. Reporting benefits (i.e. benefit finding) does not mean that one will use the coping strategy of reminding herself that having gone through the illness has changed her life for the better (benefit reminding) (Tennen and Affleck, 2002). While the two concepts are intuitively similar, previous studies have shown that they have different predictors (Affleck and Tennen, 1996; Sears et al., 2003). Seeking social support was related to increased benefit finding in college students (Park et al., 1996), multiple sclerosis patients (Mohr et al., 1999), and bereaved individuals (Davis et al., 1998). Because coping by seeking social support can serve many functions, it is unclear how it can enhance benefit finding. For example, seeking social support can be considered an active problem-focused strategy when one seeks information, an emotional-focused coping strategy when one talks out one's worries, or a means of distraction (Skinner, Edge, Altman, & Sherwood, 2003). By sharing with significant supportive others, one may be more likely to cognitively process the consequences of the illness, come up with a different perspective or have friends reflect back the growth process.

The result that women who perceived their physical health to be poorer also reported greater growth also suggests that greater suffering leads to increased reporting of benefit finding.

The finding that social support or optimism were not related to benefit finding in our sample contradicts most studies (Davis et al., 1998; Nolen-Hoeksema & Davis, 2002; Park et al., 1996; Tedeschi & Calhoun, 1996; Updergraff et al., 2002) but with some exceptions (Sears et al., 2003). Of note, we also found that optimism was uncorrelated with positive problem solving. In this study benefit finding was not related to age, education, or income, contrary to Updergraff et al. (2002) who found that HIV positive women with more resources reported more benefits and to Cordova et al. (2001) who found that breast cancer survivors with higher income reported more growth. It could be that the women we interviewed have predominantly high resources and that there is not enough diversity in our sample. The positive relationship between distress, intrusive thoughts, and poorer health status at three months indicates that perhaps the women who suffered most initially are the ones who had the most incentive to find benefits and were more likely to report increased personal growth. Again, this supports the idea that greater suffering may trigger more benefit finding.

Limitations and future directions

While our refusal rate was moderate, many of our participants had died before the six-year follow-up. The breast cancer survivors we interviewed in the present study are a select group of highly educated, Caucasian, high SES women that were in better health at the start of the study. One of the most important limitations of this study is that, while we had a longitudinal design, we did not measure benefit finding across time. It will be of great importance to investigate the role of benefit finding across the disease trajectory in longitudinal studies, including long-term survivorship and recurrence. Because of our design, we do not know if women who remained disease-free would have reported more benefits in the first year or two following diagnosis. For example, five-year survivors of bone marrow transplant reported less positive sequelae than short-term and middle-term survivors (Fromm et al., 1996). However, mean benefit finding in our study was similar to that found in Antoni et al.'s (2001) sample of 100 women with breast cancer 6-8 weeks post-surgery who were waiting for a psychological intervention, which makes one wonder if there in fact was a tapering off of benefit finding over time. Benefit finding may be one possible way for breast cancer patients to cognitively deal with the negative consequences of the illness. It may eventually no longer be needed as patients become cancer-free survivors and may become reactivated with a second cancer experience.

Conclusions

Numerous avenues are left to explore about the role of benefit finding in cancer patients. An understanding of how this process unfolds remains unclear: questions regarding duration and relapses have yet to be addressed. Definitional issues and whether the reported benefits are true growth or positive illusions have to be investigated further (Nolen-Hoeksema & Davis, 2002; Taylor, 1983; Tedeschi & Calhoun, 1996). We need more studies of benefit finding and cancer patients that include reports of significant others. Benefits have so far been assessed mostly in breast cancer patients with good prognoses. How one restores one's world views when the trauma being faced is an illness with a much lower survival rate such as lung cancer would be of great interest in understanding the stability of the benefit finding phenomenon.

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Table I. Demographic and medical characteristics of breast cancer survivors sample (N =86).

Characteristic	N	%	M	SD
Age	86		61.7	10.8
Years of education	86		13.3	3.4
Number of children	86		2.1	1.2
Number work hrs/week	86		12.1	16.6
Marital status				
Married	53	61.6		
Separated/Divorced	12	14.0		
Widowed	14	16.3		
Never married	7	8.1		
Second cancer experience				
Yes	21	24.4		
No	65	75.6		
Religion				
Jewish	31	36.0		
Catholic	26	30.2		
Protestant	13	15.1		
Other	10	11.6		
None	6	7.0		

Working status		
Not working	48	55.8
Working	38	44.2
Stage		
I	36	61.0
II	22	37.3
III	1	1.7
Income		
< 30 000$	19	25.7
30 000-60 000$	21	28.4
> 60 000$	34	45.9

Table II. Means and standard deviations of psychological variables at six-year follow-up

Psychological variable (possible range)	M	SD
Optimism (0-4)	2.82	.59
Perceived Health (0-5)	3.94	.99
Social Support (0-4)	3.1	.71
Perceived stressfulness (1-5)	2.88	1.3
Positive Problem Solving (1-5)	2.55	.72
Escape-Avoidance (1-5)	2.44	.66
Seeking Social Support (1-5)	2.24	.78
Distress (0-4)	0.77	.56
Intrusive Thoughts (1-4)	1.59	.65
Avoidant Thoughts (1-4)	1.64	1.00
Benefit Finding (1-5)	3.03	1.05

Table III. Correlations among benefit finding and psychological variables at the six-year follow-up.

Measure	1	2	3	4	5	6	7	8	9	10	11
1. Benefit finding											
2. Intrusive Thoughts	.23*										
3. Avoidant Thoughts	.15	.60***									
4. Distress	.14	.36**	.21*								
5. Perceived health	-.19	-.12	-.12	-.56***							
6. Optimism	.003	-.21	-.30**	-.29**	.19						
7. Social Support	-.09	-.08	-.32**	-.24*	.29**	.50***					
8. Perceived Stress	.22*	.45***	.30**	.24*	-.09	-.41***	-.21				
9. Positive Problem Solving	.55***	.11	.01	.22	-.09	-.01	-.06	.23			
10. Escape-Avoidance	.20	.36**	.31**	.30*	-.13	-.35**	-.16	.38***	.42***		
11. Seeking Social Support	.29*	.25*	-.003	.28	-.13	.04	-.02	.31**	.58***	.36***	

* $p < .05$. ** $p < .01$. *** $p < .001$.

Table IV. Hierarchical regression of predictor variables on benefit finding scores

Predictors	β	R	R^2	Adj R^2	R^2 change
Step 1. Second cancer experience	$.28^{*}$	.28	.08	.06	$.08^{*}$
Step 2. Perceived health	$-.25^{*}$	.38	.14	.12	$.06^{*}$
Step 3. Perceived stress	-.07	.65	.42	.38	$.28^{***}$
Seeking Social Support	-.18				
Positive Problem Solving	$.62^{***}$				

Note. Age and education were not correlated with benefit finding. However, age was negatively associated with perceived stress ($r = -.27$, $p < .01$), Positive Problem Solving ($r = -.34$, $p < .01$), and Seeking Social Support ($r = -.43$, $p < .001$) while education was positively correlated with intrusive thoughts ($r = .23$, $p < .05$). Age and education were entered in the first step of the regression model. Since they did not make a significant contribution, they were not kept in the final model.

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

Conclusion

The present discussion summarizes the main findings of the dissertation and highlights their theoretical and clinical implications. The strengths and limits of this research will also be presented, as well as suggestions for future studies.

Main findings

Study 1. We found that levels of distress and PTSD symptoms at the 6-year follow-up were low yet comparable to sub-clinical levels of distress found in other studies of long-term breast cancer survivors (Andersen, 1992; Cordova et al., 1995; Polinsky, 1994; Saleeba et al., 1996). Our first hypothesis was supported: when examining the distribution of distress and IES scores, 25% of the participants were found to report a moderate amount of distress and intrusive and avoidant thoughts.

Our second hypothesis about changes of distress and PTSD symptoms over time was partially supported. Examining changes over the course of the study, we found that improvements in PTSD symptoms occurred between 3 months and 15 months and that there were no further improvements at 6 years. Distress, however, did not change over time. Similarly, participants reported lower stress appraisal of the cancer, better perceived health, and decreased use of escape-avoidance, seeking social support, and positive problem solving coping between 3 months and 15 months. There were no further improvements at 6 years, except for perceived health and escape-avoidance coping which were no longer different from baseline.

We identified a number of potential predictors of distress and PTSD symptoms in long-term breast cancer survivors. In general, cross-sectional analyses supported our hypothesis: at the 6-year follow-up, breast cancer survivors who reported poor perceived health and fear of the future because of their illness were significantly more distressed. Survivors who had a second cancer experience during the six-year follow-up, and who reported being less optimistic and being concerned about their future because of their illness had significantly more PTSD symptoms. Our attempt at identifying longitudinal predictors, in particular of intrusion and avoidance symptoms at six years, was less successful. None of the potential predictors at baseline and at the 1-year follow-up attained statistical significance in the final regression models, once previous levels of PTSD symptoms were controlled. Longitudinal predictors of distress at 6 years after diagnosis were social support (both at baseline and one year later), distress one year later, and positive problem solving coping (both at baseline and one year later).

Article 2. We found that reports of benefits following breast cancer were prevalent, with close to 85% of respondents reporting at least some personal growth. Our first hypothesis that women who reported more benefit finding would experience less distress was not supported. Benefit finding was unrelated to distress, but was positively correlated with intrusive thoughts among breast cancer survivors. Our second hypothesis about predictors of benefit finding was partially confirmed. Participants who had a second cancer experience during the six-year follow-up reported more growth. Having had a second cancer experience accounted for 8 % of the variance in benefit finding. Positive problem solving was the strongest predictor of benefit finding accounting for 28% of its variance.

Poorer perceived health added another 6% to the prediction of benefit finding. Contrary to predictions, optimism and social support were unrelated to benefit finding.

Our third hypothesis that first year psychological resources would lead to more benefit finding was, for the most part, not supported. Participants who reported using positive problem solving and, to a lesser extent, seeking social support during the first year reported more benefit finding at the six-year follow-up. However, optimism, social support, better adjustment or health status over the course of the first year after diagnosis were not associated with more benefit finding. On the contrary, benefit finding six years after diagnosis was positively associated with distress, intrusive thoughts, and worse perceived health assessed at the first interview that was done within three months after diagnosis.

Theoretical implications

Reports of finding benefits such as improved relationships, deeper sense of self and life priorities, or increased spirituality are prevalent amongst cancer patients. While self-reported distress is considered a valid indicator of negative adjustment, self-reported benefits are sometimes considered with skepticism. There is debate about the theoretical nature of benefit finding: some argue that it reflects denial or defensiveness, while others consider it to be positive illusions, and some to indicate true growth (Nolen-Hoeksema & Davis, 2002; Taylor, 1983; Tedeschi & Calhoun, 1996).

What have we learnt about the nature of benefit finding based on the results of the present dissertation? Insights on the nature of benefit finding come from its relationship with distress and intrusive thoughts as well as from its predictors. First, the fact that the avoidance subscale of the Impact of Events Scale and that the coping strategy of escape-avoidance did not correlate with benefit finding suggests that benefit finding is not a by-product of defensiveness or denial. The present dissertation did not replicate the finding that reporting at least one benefit is protective of distress (Tedeschi & Calhoun, 1996). Instead, survivors who reported more benefits also reported more intrusive thoughts about the illness. Results of this study contradict a hypothesis put forward by Davis et al. (1998) that the relationship between benefit finding and distress may be explained by the fact that depressed people are more likely to have a negative thinking style that prevents them from finding meaning in their adversity. Our results are consistent with other studies that concluded that benefit finding and negative adjustment may best be viewed as a two-dimensional construct rather than a continuous one (Fromm et al, 1996; Sears et al, 2003). The present dissertation suggests that a breast cancer survivor will not necessarily experience less distress because she derived benefits from her illness.

Our finding that breast cancer survivors who report more benefit finding are also experiencing more intrusive thoughts about their cancer is in line with Calhoun and Tedeschi's model that suggests that the existential crisis triggered by the illness starts a process of "constructive rumination"(Calhoun, Cann, Tedeschi, & McMillen, 2000). They postulate that the more somebody engages in constructive rumination, the more one will report growth. A few other studies have found this as well using the same intrusive thoughts measure (Impact of Events Scale) (Park et al., 1996; Sears et al. 2003).

One would assume that those who suffer most are more likely to experience a greater existential crisis. Our results support this hypothesis: breast cancer survivors with poor perceived health and a high stress appraisal of their cancer reported more benefit finding. Furthermore, survivors who had cancer a second time reported more benefit finding. Additional analyses revealed that this relationship could be explained by the fact that women who experienced cancer a second time experienced more intrusive thoughts. As these results are based on cross-sectional data, causality cannot be inferred. However, intrusive thoughts, distress, and poorer health status three months after diagnosis were also positively associated with benefit finding in survivorship, indicating that breast cancer patients who suffered more initially may be the ones who had the most incentive to find benefits and thus report increased personal growth during survivorship.

Based on these results, we argue that benefit finding may be one possible way for breast cancer patients to cognitively process the negative consequences of the illness. It may eventually no longer be needed as patients become cancer-free survivors and may become reactivated with a second cancer experience. Such an understanding of benefit finding leads to the following question: could benefit finding be conceptualized as a coping strategy? The strongest predictor of benefit finding was the coping strategy of Positive Problem Solving which contains items that may be similar in content to our measure of benefit finding such as "Changed or grew as a person in a good way", or "Rediscovered what is important about life". However, we removed these items (in further analyses after submitting our second article) and found that the correlation between benefit finding and positive problem solving coping remained virtually unchanged. Other studies have also found coping strategies, particularly positive reframing to be predictive of greater benefit finding (Mohr et al., 1999; Nolen-Hoeksema & Davis, 2002; Sears et al., 2003). However, it can be argued that benefit finding is an end state, an evaluation, while a coping strategy such as positive reframing is a process (Calhoun et al., 2000). Affleck & Tennen (1996) have also argued that benefit finding is not a coping strategy. Reporting benefits (i.e. benefit finding) does not mean that one will use the coping strategy of reminding herself that having gone through the illness has changed her life for the better (benefit reminding) (Affleck and Tennen, 2002). While the two concepts are intuitively similar, previous studies have shown that they have different predictors (Affleck and Tennen, 1996; Sears et al., 2003).

We think benefit finding may best be viewed as part of the appraisal process, an attempt at reducing the threat of the cancer by injecting positive aspects into the perception of the illness experience. The present dissertation does not permit us to answer whether benefit finding reflects positive illusions (Taylor, 1983) or true growth (Nolen-Hoeksema & Davis, 2002; Tedeschi & Calhoun, 1996). Perhaps benefit finding, like other appraisal processes, is a combination of objective reality and subjective representation of the world based on past experiences and dominant cultural views.

Our popular culture does indeed suggest that a "positive attitude" is very important in coping with breast cancer and may even play a role in cure and survival from this illness. Many cancer patients report feeling pressured to maintain a positive attitude and feeling guilty when they fail to do so, a phenomenon that has been labeled the ‘tyranny of positive thinking’ (Holland, 2000). One of the most intriguing findings of the present study is that positive problem solving both at 3 months after diagnosis and a year later was associated with more distress in long-term breast cancer survivors. We had hypothesized that breast cancer patients who responded to their illness during the first year by doing something active and positive would be better adjusted as survivors. This finding suggests that, at least for some patients, maintaining a positive attitude during the first year may have a cost in the long run.

A recent study investigating quality of life in 5-year breast cancer survivors and healthy controls found that, in both groups of women, those who were still searching for meaning of the traumatic event had impaired quality of life (searching for meaning was measured with the following two items which seem to tap into coping effort: “In the past month, how much energy have you spent trying to figure out why (the event) happened to you?” and “In the past month, how much have you found yourself searching to make some sense or find meaning in your experience?”) (Tomich & Helgeson, 2002). Studies of bereaved individuals indicated that individuals who did not make sense of the death early on almost never did and when they did, it did not relate to better adjustment (Nolen-Hoeksema & Davis, 2002). Taken together, these findings suggest that a prolonged, continuous search for meaning may be detrimental. There may be alternative coping strategies that could be beneficial in the long run. Once treatments have ended, the main concerns survivors have are fear of recurrence and uncertainty about their future, for which problem solving or active coping might be ineffective coping strategies. Breast cancer patients who used more acceptance coping shortly after diagnosis reported less distress during the following year (Carver et al., 1993; Stanton, Danoff-Burg, & Huggins, 2002). These same studies found that early use of positive reframing and active coping was either unrelated to or predictive of more distress over the first year following diagnosis. The prospective role of early use of acceptance on distress during long-term survivorship needs to be investigated in future studies.

Clinical implications

The present dissertation was able to identify some important clinical risk factors of distress and PTSD symptoms in long-term breast cancer survivors such as residual distress, poor social support, extensive use of the coping strategy of positive problem solving, having had a second cancer experience, optimism, stress appraisal and fear of the future.

This dissertation highlighted the importance of assessing illness worries, appraisals, concerns about the future, and somatic preoccupations among breast cancer survivors, and perhaps utilizing well-established cognitive behavioral therapy interventions to reduce distress and worry. Stress appraisal of the cancer was a better predictor of distress, PTSD symptoms, and benefit finding than objective indicators of the severity of the illness such as stage and other sites affected by cancer or treatment variables. In the light of the finding that women who did not perceive their cancer to be stressful at 15 months and at 6 years reported less distress and PTSD symptoms, asking women to rate the stressfulness of their cancer could be a useful way to discriminate among survivors who are more at risk of distress. While respondents identified many stressful aspects about having had cancer, fear or uncertainty about the future was chosen by more than 40% of our sample as their main preoccupation with cancer. We found that the proportion of breast cancer patients who identified fear of the future as their main concern did not diminish throughout the 6 years of this study. This indicates that having had cancer may produce some indelible worries in some patients. That fear of the future was found to be an important predictor of both distress and PTSD symptoms in long-term breast cancer survivors suggests that it could serve as an indicator of survivors' overall adjustment (Dow et al., 1996; Kornblith, 1998).

Based on the findings that 25% of long-term breast cancer survivors still experienced moderate levels of intrusive and avoidant thoughts and that these symptoms were greatly explained by previous levels of PTSD symptoms, patients who display high levels of PTSD symptoms shortly after diagnosis should be offered an intervention because these symptoms may tend to persist over many years. Patients who experience a second cancer also constitute a population of cancer survivors who are at risk of more PTSD-like symptoms of intrusion and avoidance and should be monitored closely, as well as those who have poor social support and rely extensively on active coping and focusing on the positive over the first year following diagnosis. We recommend that patients be monitored for risk factors more than once over the first year, until we can identify the time point during the disease trajectory that best predicts distress during the survivorship period.

We should address identification of benefits in cancer survivors in a sensitive way, so that survivors do not feel forced to engage in positive thinking and downplay their distress. We should keep in mind that not every patient will report benefits. One participant in this study expressed this well: “I am surprised I did not change so much. I had heard having breast cancer can change somebody a lot; maybe it is because I did not get so sick”. Benefit finding can be encouraged through cognitive-emotional processing such as positive problem solving coping, which this study showed was a very important predictor of growth. But with the finding that relying extensively on the coping strategy of positive problem solving in the first year can lead to more distress long-term, it would be important to reflect to patients that sometimes thinking negatively or feeling discouraged is normal and that one does not always have to maintain a positive attitude. Interventions focusing on benefit finding should not yet be offered to cancer patients until a better theoretical understanding of benefit finding, for whom it works, and how best to measure it is developed (Tennen & Affleck, 2002).

Strengths

The present dissertation attempted to reconcile distress and benefit finding, two important clinical phenomena of breast cancer survivorship while overcoming a number of methodological flaws that have clouded these issues. Particular attention was given to overcome some of the flaws of previous research on coping with cancer.

Important strengths of our research are the use of a prospective, longitudinal design covering many phases of the illness: treatments, recovery, and long-term survivorship and accounting for a second cancer experience. To our knowledge, the present dissertation is the first study that identified prospective predictors of distress in long-term breast cancer survivors (i.e. 5 years beyond diagnosis). A novel element of our study is the use of more than one time point (3 months and 1 year later) to identify risk factors of distress and PTSD symptoms in breast cancer survivors. The present dissertation is also amongst the first to identify prospective predictors of benefit finding and to examine the impact of having a second cancer experience on personal growth.

A number of measures were taken to increase internal validity: an attempt to re-interview all the original participants and a face to face interview in which a trained interviewer reviewed the questionnaires with the patient to ensure comprehension instead of a mailed out survey. The low refusal rate at the 6-year follow-up also increased the internal validity of the present dissertation.

In the statistical analyses, we controlled for numerous medical and sociodemographic covariates and used multivariate statistics to identify the most important predictors of distress, PTSD-like symptoms and benefit finding.

Limits

Like many studies in the field of psycho-oncology, the breast cancer survivors we interviewed at 6 years are a select group of highly educated, Caucasian, high SES women that were in better health at the start of the study, which somewhat limits the generalizability of our findings. While our refusal rate was low, many of our participants had died before the six-year follow-up. Furthermore, since participants had originally agreed to take part in an intervention study they may have been more distressed at baseline than women who chose not to participate. Another limitation is that we did not assess life events that may have occurred between 15 months and 6 years and could have contributed to distress in long-term breast cancer survivors. We also did not screen for previous history of mental illness, particularly of depression, which could explain the prolonged distress reported by some survivors.

It will be of great importance to investigate the role of benefit finding across the disease trajectory in longitudinal studies, including long-term survivorship and recurrence. Because of our design, we do not know if women who remained disease-free would have reported more benefits in the first year or two following diagnosis. For example, five-year survivors of bone marrow transplant reported less benefits than short-term and middle-term survivors (Fromm et al., 1996). However, mean benefit finding in our study was similar to that found in a sample of 100 women with breast cancer 6-8 weeks post-surgery who were waiting for a psychological intervention, which makes one wonder if there in fact was a tapering off of benefit finding over time (Antoni, Lehman, Kilbourn, Boyers, Culver, Alferi et al., 2001).

In the present dissertation, we found that breast cancer survivors who reported more benefits did not report less distress. A cautious note is that distress levels in our sample were low yet comparable to sub-clinical levels of distress found in other studies of long-term breast cancer survivors (Andersen, 1992; Cordova et al, 1995; Polinsky, 1994; Saleeba et al, 1996). Whether this result would be replicated in breast cancer patients who experience more distress is unknown. Distress is only one potential negative consequence of cancer. In the past few years, methodologically sound studies have revealed that a number of survivors will be affected by body image problems, decreased sexual satisfaction, fatigue, and specific residual physical symptoms (Bower et al., 2000; Dorval et al., 1998; Meyerowitz et al., 1999). Studies have yet to examine the relationship between benefit finding and some of these other negative sequelae. Last, in order to limit respondents' burden and keep an adequate statistical power, we were careful not to add too many measures at the 6-year follow-up, and chose not to include a measure of positive mood which as been found to be positively correlated with benefit finding (Katz et al., 2001; Park et al., 1996; Sears et al., 2003; Tomich & Helgeson, 2002).

Although the measures used in the present dissertation have good psychometric properties and had been used previously with cancer populations, some had limitations. The Benefit Finding scale we used did not allow us to distinguish amongst types of benefits. Previous studies have found that individuals that have survived disasters (McMillen et al., 1996) or cancer (Collins et al., 1990; Cordova et al., 2001a) do not report benefits in all aspects of their lives and that some types of benefits may be more related to well-being then others. We could not collect cancer staging information for all participants and therefore had to use the proxy measure of number of sites affected. Our measures of distress (anxiety and depression subscales of the POMS) and of perceived health are not keyed specifically for cancer. Furthermore, the POMS and the IES do not have clinical cut-off scores and we did not have a control group, which makes it difficult to say if the present survivors experience more distress than the general population. It has been suggested that comparing cancer survivors to healthy controls may be problematic because of the phenomenon of cognitive shift that seems to occur in evaluating quality of life after cancer (Holzner et al., 2001). We tried to remedy this limitation by using available norms on the POMS for female cancer patients and comparing participants in the present research to other samples of breast cancer survivors. Our measure of coping was composed of three distinct strategies: escape-avoidance, seeking social support, and positive problem solving. There are many more coping strategies we did not measure. A recent review of empirical studies and theoretical driven models listed over 400 coping strategies (Skinner, Edge, Altman, & Sherwood, 2003). Skinner et al. suggest that five categories of coping make up the core of coping: problem solving, support seeking, avoidance, distraction, and positive cognitive restructuring, four of which are measured in the present dissertation (with the exception of distraction).

We had originally estimated we needed a sample of 91 participants, based on a power analysis for multiple regression analysis with 9 independent variables using an alpha of 0.05, power of 0.80, and a moderate effect size (Cohen & Cohen, 1983). Since we interviewed 86 breast cancer survivors and used between 5 and 9 independent predictors in the regressions presented in the two articles, we had the statistical power to identify predictors of distress, PTSD symptoms, and benefit finding. However, some of our secondary analyses were performed on smaller numbers of participants such as those who had a second cancer experience (n = 21) or were currently in treatment at the 6-year interview (n = 10) and should be considered as tentative.

Future directions

The course of recovery from breast cancer is still unknown, especially after the first two years. A recent study examining recovery trajectories over 4 years in women diagnosed with breast cancer suggested that, while some patients recover well from their illness, others do not recover at all, and yet others may not maintain their adjustment during long-term survivorship (Helgeson et al., 2004). It is therefore very important to identify those breast cancer survivors at risk of poor psychological functioning and to investigate what distinguishes them from women who recover their psychological functioning.

Numerous avenues are left to explore about the role of benefit finding in cancer patients. An understanding of how this process unfolds remains unclear: questions regarding duration and relapses have yet to be addressed. It would be of great interest to further investigate benefit finding in cancer patients who experience a recurrence and thus see one of their worst fears come true to discover how they restore their world views after they have been challenged a second time.

Definition and measurement of benefit finding have to be further investigated. A recent study of newly diagnosed breast cancer patients demonstrated that asking patients to name any benefits that have resulted from having the illness yielded very different results from asking patients to fill a posttraumatic growth inventory (Sears et al., 2003). Identified benefits were not related to posttraumatic growth or to mood, quality of life, or perceived health while posttraumatic growth was correlated with higher positive mood. These results lead us to wonder if the existing inventories of benefit finding adequately capture patients' experience of personal growth.

Clarifying whether the reported benefits are true growth or positive illusions would be beneficial to the study of benefit finding and cancer. In order to do this, we need more studies of benefit finding that include reports of cancer patients' significant others to corroborate the patients' perception of positive changes.

Benefits have so far been assessed mostly in breast cancer patients with good prognoses who live in North America or Europe. How one restores one's world views when the trauma being faced is an illness with a much lower survival rate such as lung cancer would be of great interest in understanding the stability of the benefit finding phenomenon. Investigating the cultural specificity of benefit finding and adjustment would further our understanding of universality of the phenomenon of growth through adversity. In cultures where myths of personal triumph over life' hurdles are less prevalent, would cancer patients derive benefits as frequently and strongly as they do in North America?

Theoretical implications

The current findings support the social cognitive theories of Janoff-Bulman (1992) and Tedeschi and Calhoun (1996) that postulate that individuals who perceive greater trauma are more likely to have their assumptions shattered, to suffer from intrusive thoughts and to derive benefits from their experience. However, these theories do not specify whether benefit finding represents veritable personal growth or positive illusions (i.e. a set of appraisals that can lead to better mental health, Taylor (1983)). A major claim of these theories is that one of the functions of benefit finding is to restore world assumptions; however, this relationship has yet to be empirically demonstrated. Last, social cognitive theories do not adequately explain why some cancer survivors remain affected by distress while others seem to recover after the first year or two following diagnosis (Brennan, 2001).

Coping theories (Brennan, 2001; Folkman & Moskowitz, 2000) on the other hand, have yielded interesting results that explain why some cancer patients are more distressed by their illness than others. Coping theories, however, were until recently, focused only on the negative consequences of difficult events. Folkman and her colleagues (Folkman & Moskowitz, 2000) recognized the need to include positive processes and outcome in coping models. They did so by describing a series of coping strategies that involve meaning-making such as positive reappraisal and by stating that the appraisal process also takes on positive personal significance. This conceptualization of benefit finding suffers from two shortcomings. The first one is that benefit finding is not a coping strategy and thus should be distinguished from benefit reminding (Tennen & Affleck, 2002). Second, the term ‘meaning’ carries a great deal of ambiguity because it has a long standing tradition in the field of psychology and refers to attributional and exploratory processes and existential sense of purpose in life as well as referring to benefit finding (Thornton, 2002).

It appears the current state of theoretical and empirical work of adjustment to traumatic events such as cancer do not fully explain both the significant distress and the potential for post traumatic growth that are generated, for some individuals, by the illness. The present dissertation highlighted the importance of investigating appraisal processes among breast cancer survivors. We echo Parle and his colleagues (1996, p. 737) by concluding that « the first step in adaptive coping with cancer may be with appraisal that minimizes the perceived threat » and that in such appraisal may lie the nature of benefit finding.

Limits

Multiple statistical comparisons were computed to identify predictors of distress and benefit finding across time in the present dissertation. Care was taken to ensure that the regression models presented on the two articles had a participant/variable ratio that allowed sufficient statistical power. Care was also taken to lower the probability of type I error in the pairwise t-tests performed in the first article to compare the evolution of distress and potential predictors from 3 to 15 months and to 6 years by using Bonferroni corrections (these were computed by multiplying the p value obtained for each pairwise comparison by the number of comparisons per variable, i.e., 3, and declaring as significant only those that had a new p value < .05). These Bonferroni corrections allow us to keep the type I error at .05 for *each* variable, however, the overall type I error for the entire set of comparisons is higher. Given also the number of correlations that were performed prior to computing the final regression models, results of the present dissertation should be considered exploratory and will need to be replicated.

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Annexe A

_II

ID#
Int#

Now I have some questions about how you approach things in your life. Please tell me to what extent you agree with each of the following items according to card A. Be as accurate and honest as you can be and try not to let your answer to one question influence your answer to another question. There are no correct or incorrect answers.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1. In uncertain times, I usually expect the best.	1	2	3	4	5
2. It's easy for me to relax.	1	2	3	4	5
3. If something can go wrong for me, it will.	1	2	3	4	5
4. I always look on the bright side of things.	1	2	3	4	5
5. I'm always optimistic about my future.	1	2	3	4	5
6. I enjoy my friends a lot.	1	2	3	4	
7. It's important for me to keep busy.	1	2	3	4	
8. I hardly ever expect things to go my way.	1	2	3	4	
9. Things never work out the way I want them to.	1	2	3	4	
10. I don't get upset too easily.	1	2	3	4	
11. I'm a believer in the idea that "every cloud has a silver lining".	1	2	3		
12. I rarely count on good things happening to me.	1	2	3		

Social Support Questionnaire

INSTRUCTIONS: People frequently experience different amounts of support from various people in coping with a life stress. The following questions ask about your relationships with various people in your life, such as your spouse (or significant other), relatives, and friends and the amount of support you perceive from them in regard to your illness.

PLEASE INDICATE THE EXTENT TO WHICH YOU AGREE OR DISAGREE WITH EACH OF THE STATEMENTS.

If you strongly agree with the statement, check the box under the Strongly Agree column. If you agree with the statement but not to a strong degree, check the box under the word Agree. If you equally agree and disagree with the statement, check the Neutral box. If you disagree check the Disagree box and if you disagree strongly check the box marked strongly Disagree.

There are no right or wrong answers. This questionnaire is asking for your first impressions to the statements.

The following eight statements ask about your relationship with your spouse (or significant other) regarding your illness.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1. My spouse is willing to listen to me when I just need to talk..............................					
2. I feel comfortable discussing my concerns about this situation with my spouse					
3. Sometimes my spouse ignores or makes light of my concerns.....					
4. My spouse seems to understand what I am going through					
5. I often feel as if I should put up a front around my spouse and pretend that things are going better than they actually are					
6. I am feeling a great deal of affection and warmth from my spouse..............................					
7. I often receive credit from my spouse for my attempts to cope with this situation.......					
8. My spouse helps me put this experience into perspective....					

_V

The following eight statements ask about your relationship with a <u>family member</u> regarding your illness. Think about one family member or relative (other than your spouse) who is important to you as you respond to these statements.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
9. My family member is willing to listen to me when I just need to talk.................................					
10. I feel comfortable discussing my concerns about this situation with my family member....					
11. Sometimes my family member ignores or makes light of my concerns..........................					
12. My family member seems to understand what <u>I</u> am going through............................					
13. I often feel as if I should put up a front around my family member and pretend that things are going better than they actually are.................					
14. I am feeling a great deal of affection and warmth from my family member.....................					
15. I often receive credit from my family member for my attempts to cope with this situation......					
16. My family member helps me put this experience into perspective..............................					

The following eight statements ask about your relationships with other people such as a friend (neighbor, work associate, etc.) regarding your illness. Think about one friend who is important to you as you respond to these statements.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
17. My friend is willing to listen to me when I just need to talk......					
18. I feel comfortable discussing my concerns about this situation with my friend............................					
19. Sometimes my friend ignores or makes light of my concerns..					
20. My friend seems to understand what I am going through............					
21. I often feel as if I should put up a front around my friend and pretend that things are going better than they actually are.....					
22. I am feeling a great deal of affection and warmth from my friend................................					
23. I often receive credit from my friend for my attempts to cope with this situation....................					
24. My friend helps me put this experience into perspective.....					

Health Status

Please circle the number which best describes how you have been feeling physically during the PAST SEVEN DAYS.

Well, healthy, strong, most of the time	5
In fairly good spirits, reasonably well	4
Lacking energy, not entirely "up to par"	3
Weak, "washed out", used up	2
Very ill, "lousy"	1
Extremely ill most of the time	0

VIII

POMS ID#__________

CARD B

0	1	2	3	4
NOT AT ALL	A LITTLE	MODERATELY	QUITE A BIT	EXTREMELY

Next I will read a list of words that describe feelings people have. Using this card please tell me HOW YOU HAVE BEEN FEELING DURING THE PAST WEEK INCLUDING TODAY.

1. Tense………0 1 2 3 4	9. Hopeless…..0 1 2 3 4	17. Miserable…0 1 2 3 4
2. Unhappy….. 0 1 2 3 4	10. Relaxed……0 1 2 3 4	18. Anxious……0 1 2 3 4
3. Sorry for….. 0 1 2 3 4 things done	11. Unworthy…0 1 2 3 4	19. Gloomy……0 1 2 3 4
4. Shaky ……0 1 2 3 4	12. Uneasy……0 1 2 3 4	20. Desperate…0 1 2 3 4
5. Sad…………0 1 2 3 4	13. Restless…..0 1 2 3 4	21. Helpless…..0 1 2 3 4
6. On edge……0 1 2 3 4	14. Discouraged..0 1 2 3 4	22. Worthless…0 1 2 3 4
7. Blue…………0 1 2 3	15. Nervous…..0 1 2 3 4	23. Terrified…..0 1 2 3 4
8. Panicky……0 1 2 3 4	16. Lonely……0 1 2 3 4	24. Guilty……..0 1 2 3 4

IX

BENEFIT FINDING

CARD B

0	1	2	3	4
NOT AT ALL	A LITTLE	MODERATELY	QUITE A BIT	EXTREMELY

Having had breast cancer has...

1. has led me to be more accepting of things.................................0 1 2 3 4
2. has taught me how to adjust to things I cannot change.....................0 1 2 3 4
3. has helped me take things as they come.....................................0 1 2 3 4
4. has brought my family closer together.......................................0 1 2 3 4
5. has made me more sensitive to family issues................................0 1 2 3 4
6. has taught me that everyone has a purpose in life..........................0 1 2 3 4
7. has shown me that all people need to be loved..............................0 1 2 3 4
8. has made me realize the importance of planning for my family's future..0 1 2 3 4
9. has made me more aware and concerned for the future of all human beings..0 1 2 3 4
10. has taught me to be patient...0 1 2 3 4
11. has led me to deal better with stress and problems.........................0 1 2 3 4
12. has led to meet people who have become some of my best friends...0 1 2 3 4
13. has contributed to my overall spiritual and emotional growth..0 1 2 3 4
14. has helped me become more aware of the love and support available from other people......................................0 1 2 3 4
15. has helped me realize who my real friends are..............................0 1 2 3 4
16. has helped me become more focused on priorities, with a deeper sense of purpose in life.......................................0 1 2 3 4
17. has helped me become a stronger person, more able to cope effectively with future life challenges...............................0 1 2 3 4

_X

FACT-B

ID#PT.: ____________ 1

ID#INTERV.: ________

Now I have a list of statements that other people with your illness have said are important. Please indicate how true each statement has been for you during the past seven (7) days according to CARD C.

CARD C

NOT AT ALL	A LITTLE BIT	SOMEWHAT	QUITE A BIT	VERY MUCH
1	2	3	4	5
NA	LB	S	QB	VM

During the past 7 days:

SOCIAL/FAMILY WELL-BEING	NA	LB	S	QB	VM
1. I feel distant from my friends	1	2	3	4	5
2. I get emotional support from my family	1	2	3	4	5
3. I get support from my friends and neighbors	1	2	3	4	5
4. My family has accepted my illness	1	2	3	4	5
5. Family communication about my illness is poor	1	2	3	4	5
If you have a spouse/partner, or are sexually active, please answer questions #6 and #7. Otherwise, go to question #8.					
6. I feel close to my partner (or main support)	1	2	3	4	5
7. I am satisfied with my sex life	1	2	3	4	5

8. How much does your SOCIAL/FAMILY WELL-BEING affect your quality of life?

Not at all 0 1 2 3 4 5 6 7 8 9 10 Very much so

XI

ID#
Int#

Now I shall read a list of items about your illness. Please tell me how frequently, if at all, each was true of you during the PAST SEVEN DAYS according to card D.

	Not at All	Rarely	Sometimes	Often
1. I thought about it when I didn't mean to.	1	2	3	4
2. I avoided letting myself get upset when I thought about it or was reminded of it.	1	2	3	4
3. I tried to remove it from memory.	1	2	3	4
4. I had trouble falling asleep, or staying asleep, because of pictures or thoughts that came into my mind.	1	2	3	4
5. I had waves of strong feelings about it.	1	2	3	4
6. I had dreams about it.	1	2	3	4
7. I stayed away from reminders of it.	1	2	3	4
8. I felt as if it hadn't happened or wasn't real.	1	2	3	4
9. I tried not to talk about it.	1	2	3	4
10. Pictures about it popped into my mind.	1	2	3	4
11. Other things kept making me think about it.	1	2	3	4
12. I was aware that I still had a lot of feelings about it, but I didn't deal with them.	1	2	3	4
13. I tried not think about it.	1	2	3	4
14. Any reminder brought back feelings about it.	1	2	3	4
15. My feelings about it were kind of numb.	1	2	3	4

XII

ID#
Int#

Next I shall read a list of problems people sometimes have in dealing their illness and treatment. Please tell me how stressful, according rd E, if at all, each of these problems have been for you in the PAST

a. Fear and uncertainty about the future due to cancer.

b. Limitations in physical ability, appearance, or lifestyle due to cancer.

c. Acute pain, symptoms, or discomfort from illness or treatment.

d. Problems with family or friends related to cancer.

	Not at All	A Little	Somewhat	Quite a Bit	Extremely
a. Fear...	1	2	3	4	5
b. Limitations...	1	2	3	4	5
c. Acute pain...	1	2	3	4	5
d. Problems...	1	2	3	4	5

Have you had any other problems dealing with your illness or treatment he past month?

____

____

How stressful has this problem been in the PAST MONTH?

e. Other...	1	2	3	4	5

to Interviewers:

Continue to probe and clarify if there are 2 or more problems of equal stress intensity until the <u>most</u> stressful problem is established. e.g., So you have mentioned (_____ and _____) have been stressful for you. Which of these problems has been <u>most</u> stressful for you in the past month?

So _____ has been the most stressful for you in the past month?

When people experience stress in their lives, they usually try to manage : by trying out different ways of coping. The next set of items is on the ays of coping you may have used in trying to manage your problem with _____ n the past month. Please tell me how often you have used each of the ollowing coping strategies to deal with _____ in the past month according to ARD F.

	Does not Apply	Rarely	Sometimes	Often	Very Often
. Concentrated on the next step	1	2	3	4	5
. The only thing to do was wait	1	2	3	4	5
. Did something just to do something	1	2	3	4	5
. Talked to someone to find out more	1	2	3	4	5
. Criticized or lectured myself	1	2	3	4	5
. Tried not to close off options	1	2	3	4	5
. Hoped a miracle would happen	1	2	3	4	5
. Went along with fate	1	2	3	4	5
. Went on as if it were not happening	1	2	3	4	5
). Tried to keep my feelings to myself	1	2	3	4	5
'. Looked for a silver lining; looked on the bright side	1	2	3	4	5

	Does not Apply	Rarely	Sometimes	Often	Very Often
2. Slept more than usual	1	2	3	4	5
3. Looked for sympathy	1	2	3	4	5
4. Was inspired to be creative	1	2	3	4	5
5. Tried to forget the whole thing	1	2	3	4	5
6. Tried to get professional help	1	2	3	4	5
7. Changed or grew as a person in a good way	1	2	3	4	5
8. Waited to see what would happen before acting	1	2	3	4	5
9. Made a plan of action and followed it	1	2	3	4	5
0. Let my feelings out somehow	1	2	3	4	5
1. Came out of the experience better than before	1	2	3	4	5
2. Talked to someone who could do something	1	2	3	4	5
3. Tried to make myself feel better by eating, drinking, smoking or drug use	1	2	3	4	5

	Does not Apply	Rarely	Sometimes	Often	Very Often
4. Took a big chance and did something risky	1	2	3	4	5
5. Tried not to act too hastily	1	2	3	4	5
6. Found new faith	1	2	3	4	5
7. Rediscovered what is important in life	1	2	3	4	5
8. Changed something so things turn out	1	2	3	4	5
9. Avoided being with people	1	2	3	4	5
0. Didn't let it get to me; refused to think about it	1	2	3	4	5
1. Asked a friend or relative for advice	1	2	3	4	5
2. Kept others from knowing how bad things were	1	2	3	4	5
3. Made light of it; refused to get too serious	1	2	3	4	5
4. Talked to someone about how I was feeling	1	2	3	4	5
5. Took it out on other people	1	2	3	4	5

	Does not Apply	Rarely	Sometimes	Often	Very Often
Drew on past experiences from similar situations	1	2	3	4	5
Knew what had to be done, so I increased my efforts	1	2	3	4	5
Refused to believe it would happen	1	2	3	4	5
Came up with different solutions	1	2	3	4	5
Tried to keep my feelings from interfering	1	2	3	4	5
Changed something about myself	1	2	3	4	5
Wished the situation would go away or be over	1	2	3	4	5
Had fantasies/wishes about how it might turn out	1	2	3	4	5
Prayed	1	2	3	4	5
Prepared for the worst	1	2	3	4	5
Went over in my mind what I would say or do	1	2	3	4	5

	Does not Apply	Rarely	Sometimes	Often	Very Often
7. Thought of how a person I admire would act	1	2	3	4	5
Reminded myself how much worse things could be	1	2	3	4	5
Tried to find out as much as I could	1	2	3	4	5
Treated the illness as a challenge	1	2	3	4	5
Depended mostly on others to handle things	1	2	3	4	5
Lived one day at a time/took one step at a time	1	2	3	4	5

Did you use any other particular coping strategy besides those mentioned?

YES_____ NO_____

If so, describe: ______________________________

____

____

How often did you use this strategy? 1 2 3 4 5

ID____________

INFORMATIONS SOCIO-DÉMOGRAPHIQUES

NOM :________________________________

Je vais débuter en vous demandant votre adresse à la maison et votre numéro de téléphone.

1. Quelle est votre adresse?

ADRESSE : ____

____

VILLE :________________ CODE POSTAL :_________

TEL DOM :____________ TEL TRAV :____________

2. Êtes-vous présentement mariée?

Mariée____________	1
Séparée___________	2
Divorcée__________	3
Veuve_____________	4
Jamais mariée_______	5

3. Combien d'enfants avez-vous?

	1-9
#______________	=9 si >9

4. Quelle est votre religion?

Catholique_________	1
Protestante_________	2
Juive______________	3
Autre______________	4
Aucune____________	5

5. Quelle est votre date de naissance?

__________/__________/__________

jour mois année

Finally, I have a few more questions about your backround. .ID________

6. How many years of schooling have you completed?

0, 1, 2, 3, 4, 5, 6, 7	8,9,10,11	12,13	14,15,16,17,18,19,20+_
ELEMENTARY	HIGH SCHOOL	COLLEGE	UNIVERSITY

7. Are you presently working at a job for pay?

no	1
yes	2

8. How many hours are you working per week right now?
#hrs________

9. Which of the following best describes your situation?
Choose only one.

Employed full time	1
Employed part time	2
Employed but on leave - full time	3
part time	4
Unemployed but looking for work	5
Unemployed because of illness or disability	6
Unemployed and not looking for work	7
Homemaker	8
Retired	9
Student - full time	10
part time	11

10. What is your occupation?

____

11. In what kind of business, industry or service do you work?

____

12. Spouse/partner's occupation

____

XX

13. Just roughly, show me the letter that corresponds to your total household income in the last year.

A. Under $3,000
B. $3,000 - $5,999
C. $6,000 - $8,999
D. $9,000 - $11,999
E. $12,000 - $19,999
F. $20,000 - $29,000
G. $30,000 - $39,999
H. $40,000 - $49,999
I. $50,000 - $59,999
J. $60,000 - $69,999
K. $70,000 -$79,999
L. $80,000 - $99,999
M. $100,000 -$119,999
N. $120,000 - $139,999
O. $140,000 +

A=1
B=2
C=3
D=4
E=5
F=6
G=7
H=8
I=9
J=10
K=11
L=12
M=13
N=14
O=15

Now to finish, one or two questions about your current medical status.

MEDICAL HISTORY

ID________

Name ________________________________
(maiden) married first

Family Doctor____________________________

Primary Diagnosis__________________________ Date_______

____

Would you bring me up to date on your current medical status since the last time we interviewed you?

Sites affected	Date Dx at this site d m y	Metastasis Yes/No

Current or most recent Treatment:

	Treatments	Code	Dates d m y
To date			

Code for Treatments:

None……………1	surgery………………..2	Chemo…………………3
Radiotherapy…...4	surg, chemo, radio……5	surg, chemo…………..6
Surg, radio……...7	Chemo, radio…...8	

ID________

MEDICAL HISTORY
Other than treatments

Hospitalizations
Complications
Unrelated medical events
Etc.

Events	Dates d m y
Since last interview ______________________________	__________
______________________________	__________
______________________________	__________
______________________________	__________

Annexe 2

Sir Mortimer B. Davis Jewish General Hospital
Institute of Community and Family Psychiatry
"A longitudinal study of adjustment
to breast cancer: a six-year follow-up"
Zeev Rosberger, Ph.D.

Patient stamp

CONSENT FORM

I agree to participate in a follow-up study examining coping and psychological well being in women with breast cancer who participated in the original Nucare project in 1993-96.

I understand that if I agree to participate, I will fill out questionnaires about coping and my psychological well-being and answer some questions about my background. This will take about an hour and will take place once- either at my home or in another convenient place that I choose. While I am encouraged to answer all questions, I am not obliged to do so. I am free to withdraw my consent and to discontinue my participation in the study at any time without giving any reason and without it affecting my medical care. If I agree to participate, I also authorize the investigators of this study to retrieve my medical file in order to verify my current medical status for the length of this study. The information that I give will be treated with strictest confidentiality. My name or my responses will not be used in any report on the project. Only the average data for the whole group of patients will be reported. No medical procedures are involved in this research.

Sir Mortimer B. Davis Jewish General Hospital

Institute of Community and Family Psychiatry
"A longitudinal study of adjustment
to breast cancer: a six-year follow-up"
Zeev Rosberger, Ph.D.

Information that I provide will help health professionals understand the experiences of breast cancer survivors. There is no expected benefit to me but I will receive a brief report of the results, if I wish. A possible risk regarding my participation is that some of the questions may be potentially upsetting. If this happens and I want to speak to someone (e.g., a counsellor), then I will be directed to the appropriate resources for this.

The research project has been explained to me and any questions that I have about the study have been answered. The study will be conducted by Sophie Lebel, a Ph.D. candidate at Université de Montréal. She may be contacted at (514) 343-5706. The Principal Investigators of this study are Drs. Zeev Rosberger and Linda Edgar. They may be contacted at (514) 340-8210, ext. 4215. If you have any questions regarding your rights as a research participant, you may contact the Jewish General Hospital Patients Representative, Ms. Lianne Brown at (514) 340-8222, ext. 5833.

Based on the above statements, I voluntarily agree to take part in this research study. A copy of the consent form has been given to me.

Patient/date: ____________________________________

Witness/date: ____________________________________

Annexe C

Factor 1 : Positive Problem Solving :

WOC27 : Rediscovered what is important in life
WOC17 : Changed or grew in a good way
WOC21 : Came out of the experience better than before
WOC50 : Treated the illness as a challenge
WOC41 : Changed something about myself
WOC26 : Found new faith
WOC37 : Knew what had to be done, so I increased my efforts
WOC52 : Lived one day at a time/took one step at a time
WOC28 : Changed something so things turn out
WOC39 : Came up with different solutions
WOC11 : Looked for a silver lining; looked on the bright side
WOC49 : Tried to find out as much as I could
WOC47 : Thought of how a person I admire would act
WOC36 : Drew on past experiences from similar situations
WOC19 : Made a plan of action and followed it
WOC40 : Tried to keep my feelings from interfering
WOC01 : Concentrated on the next step

Factor 2 : Escape-Avoidance :

WOC38 : Refused to believe it would happen
WOC42 : Wished the situation would go away or be over
WOC15 : Tried to forget the whole thing
WOC43 : Had fantasies/wishes about how it might turn out
WOC18 : Waited to see what would happen before acting
WOC33 : Made light of it; refused to get too serious
WOC07 : Hoped a miracle would happen
WOC32 : Talked to someone who could do something
WOC29 : Avoided being with people
WOC05 : Criticized or lectured myself

WOC08 : Went along with fate

WOC10 : Tried to keep my feelings to myself

Seeking Social Support :

WOC04 : Talked to someone to find out more

WOC34 : Talked to someone about how I was feeling

WOC20 : Let my feelings out somehow

WOC13 : Looked for sympathy

WOC22 : Talked to someone who could do something

WOC31 : Asked a friend or relative for advice