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Living in the shadow: a personal construct model of adjustment to breast cancer survival and tests of its clinical usefulness

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LIVING IN THE SHADOW:
A PERSONAL CONSTRUCT MODEL OF ADJUSTMENT
TO BREAST CANCER SURVIVAL
AND TESTS OF ITS CLINICAL USEFULNESS

A thesis submitted in fulfilment of the requirements
for the award of the degree

DOCTOR OF PHILOSOPHY

from

UNIVERSITY OF WOLLONGONG

by

Lisbeth Geralyn Lane

B.A. (Hons), B. Ed

Department of Psychology

2002

DECLARATION

I, Lisbeth Lane, declare that this thesis, submitted in fulfilment of the requirements for the award of Doctor of Philosophy, in the Department of Psychology, University of Wollongong, is wholly my own work unless otherwise referenced or acknowledged. The document has not been submitted for qualifications at any other academic institution.

Lisbeth Geralyn Lane

29th April, 2002

**LIVING IN THE SHADOW: A PERSONAL CONSTRUCT MODEL OF
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¹ Throughout this report I have changed the participants' names to maintain confidentiality.

ABSTRACT

This research demonstrated the contribution that personal construct theory makes to understanding women's experiences of breast cancer, and based on this understanding, showed how to effectively support these women as they adjust to the ongoing task of living as breast cancer survivors. To achieve this aim a personal construct model of women's adjustment to breast cancer survival was developed.

Study 1, a qualitative study, was conducted with focus groups and individual interviews to elicit from the participants ($n = 59$) their major concerns. The findings showed that breast cancer survivors live with threat to their core understandings about themselves, their relationships, and their ways of being in the world. Study 2 (the Retreat study) examined the role of validation of current meanings, and Study 3 (the group therapy study) evaluated validation and elaboration of new meanings on women's levels of emotions. Study 2, with 40 breast cancer survivors, showed that validation of current meanings alone is not enough to effect lasting improvement in women's levels of threat to their physical and psychological integrity, threat to existence, dislocation, or in levels of hope.

Study 3 evaluated personal construct group therapy with 42 breast cancer survivors. The findings showed that the group therapy, providing opportunities for women to have their current meanings confirmed, and to elaborate new and more helpful meanings, resulted in significant initial decreases in threat, threat to existence and dislocation, and gains in levels of hope, which were maintained at the three month follow-up.

The limitation of this series of studies, suggestions for future research on the mediational processes of adjustment to breast cancer survival, the usefulness of the personal construct model, and the clinical implications of the research, are discussed.

CHAPTER 1

THIS RESEARCH ON ADJUSTMENTS TO BREAST CANCER: AN INTRODUCTION

“Being a survivor for me didn’t feel like there was a guarantee that you were not going to die. I felt like a survivor when I decided that I was going to live. So that even if I die from the breast cancer, I intend to LIVE till then” (Leonie, aged 48 years).

My research focuses on women diagnosed with breast cancer and examines the psychological processes that assist or impede their adjustment to being breast cancer survivors. In this chapter, the context of the research is described, and the theoretical approach chosen through which to explore these processes of adjustment is then discussed. Finally, I provide an account of the chapters that follow.

This is a necessarily academic account of what was, for me, an extremely rewarding three years of work. In this time, I came to know many women courageously facing the challenge of being breast cancer survivors. Some of these women, since participating in this research, now face the daunting challenge of meeting their deaths as their disease has recurred or metastasised¹. I am deeply honoured that these women allowed me the opportunity to hear their changing stories of their breast cancer experiences. Others, the majority, continue to live with the fear of recurrence, or spread of the disease. In the face of this uncertainty, these women must daily confront the challenge of living with cancer. All the women volunteered to participate, a testimony of their enormous generosity. Their commitment to the research over the three years was astonishing, and I hope that what follows will do justice to their faith in me.

Consistent with a personal construct approach, because I cannot consider myself a neutral observer in the enterprise (Viney, 1988, 1998), and to reflect my own journey, I will use the first person report in this account. I will argue that, to understand the problems faced by breast cancer survivors, not only the actual manifestations of the disease but the meanings people attach to it must be taken into account (Holland & Zittoun, 1990; Postone, 1998). These meanings affect both women's responses to their breast cancer diagnosis (Cassileth, 1979), and the

responses of those involved in their care (Mathieson & Stam, 1991). These meanings also colour the interpersonal context in which women strive to adapt to their changed circumstances. Crucial to an understanding of the processes involved in adjusting to being a breast cancer survivor, therefore, is the social context in which these processes take place.

1.1 The Context: The Impact of Breast Cancer

The International Agency for Research on Cancer has reported breast cancer to be by far the most frequently occurring cancer in women worldwide, apart from non-melanocytic skin cancer, and the leading cause of death from cancer in women. Breast cancer accounts for approximately 16% of all deaths due to cancer in women (Pisani, Parkin & Ferlay, 1993). In the United States of America (USA), more than 180,000 new cases of breast cancer and 46,000 breast cancer-related deaths were expected in 2001, and in the United Kingdom (UK) 34 deaths per 100,000 females were reported for 1996 (Great Britain Office for National Statistics, 2001). In America, before the age of forty, a woman has a 1 out of 257 chance of being diagnosed with breast cancer. The risk increases dramatically with age, so that for women between the ages of 40 to 59 years the risk of being diagnosed with breast cancer is 1 out of 67; from 50 to 59 years, 1 out of 36; from 60 to 69 years, 1 out of 28; and from 70 to 79 years, 1 out of 24 (Reis, Kosary, Hankey, Miller, Clegg & Edwards, 1999).

In Australia, approximately 10,000 women are diagnosed with breast cancer each year and one in 11 will be diagnosed by the age of 74 (Australian Institute of Health & Welfare [AIHW], 1998). Although the disease can and does affect a small number of men, females are 148 times more likely to develop breast cancer than

¹ The spread of a cancer from the part of the body where it originally appeared, the primary site, to another part, the metastatic site (Mayer, 1998).

males and 104 times more likely to die from it in Australia (AIHW, 1999). In 1992, the latest date for which comprehensive Australian epidemiological statistics are available, deaths from breast cancer accounted for some 27,000 woman-years of life lost before 75 years of age. In 1990-1992, on average, 2,458 women in Australia died each year of breast cancer (Kricker & Jelfs, 1996).

Between 1982-1986 and 1992-1996, breast cancer incidence rates increased by 37% in women aged 50 years and over in Australia. There was also a 7% increase in the rate for women aged 15 to 39 years and a 23% increase in the rate for women aged 40-49 years. However, while breast cancer remains the most common cause of cancer death for women in Australia, a fall in mortality rates of 4% in 1995 and 3% in 1996 was noted (AIHW, 1999). In the light of a now growing population of women survivors of breast cancer, in this research I address their psychological needs.

1.2 The Approach Chosen for this Psychological Research: Personal Construct Theory

It is important to remember that women diagnosed with breast cancer have roles beyond the role of "a cancer patient". These women have roles in relation to others (mother, wife, daughter, friend, and colleague). They also have needs (for example companionship and intimacy) and interests that will be unrelated to their sick role (Rainey, 1984). It was essential that the theory chosen could describe the processes involved in facing the every day task of living in health and in illness. Furthermore, adjustment to breast cancer consists of dynamic and complex processes that take place in social contexts and are mediated by the unique meanings people place on their experiences. To examine these processes of adjustment it was important to adopt an approach that allowed for an understanding of both the personal and the relational. I also needed a theoretical stance that recognised and acknowledged the

immense courage of these women, which enabled them to voice their issues from their own perspectives, and valued their attempts to make sense of their experiences.

I chose personal construct psychology. According to Kelly (1955/1991)², the founder of personal construct psychology, people live in two basic worlds: firstly, the world that exists outside of human understanding, and secondly, the ways in which people interpret this world in the form of representations or constructs. The main implication of this philosophical position is that all constructions of reality, being human interpretations, must be relative rather than absolute, and therefore may be subject to eventual revision or replacement (Kenny, 1984). In taking this position, Kelly emphasised the uniquely personal ways in which people make sense of experience. However, unlike many approaches, personal construct psychology, while recognising the uniqueness of people's meanings, also recognizes the interpersonal context in which these meanings are formed. In the past four years I have been fortunate to be associated with the Personal Construct Research Group at the University of Wollongong, first as an Honours student and now as a Doctoral student. Personal construct theory has guided my research and my clinical work. This approach has provided the framework in which I could formulate the processes of adjustment to breast cancer.

1.3 The Experience of Being a Breast Cancer Survivor

Women diagnosed with breast cancer face two major challenges. The first challenge is met at the time of diagnosis when they confront the fact of their own mortality (Weisman & Worden, 1976). Little, Jordens, Paul, Montgomery and Philipson (1998, p.1486) describe this phenomenon as "mortality rendered visible". A

² George Kelly's two volume "Psychology of Personal Constructs" was first published in New York by Norton in 1955. This work was republished in 1991 in London by Routledge. The citation Kelly (1955/1991) will be used throughout. Page numbers refer to the 1991 Routledge volumes unless otherwise indicated.

breast cancer diagnosis challenges women's assumptions about themselves and their worlds (Baum & Poluszny, 2001). Following such a diagnosis, prior assumptions become inadequate, and core constructs, the constructs by which these women define themselves, may need to be revised to include: "self as ill", "self as vulnerable", and "self as threatened with death".

Once initial treatment of the disease is complete, these women face a second challenge, the challenge of being breast cancer survivors. Improved treatment regimens, the introduction of routine mammographic screening programmes that can detect breast cancer in its early stages, and greater awareness in the community of detection procedures have greatly contributed to an increase in survival rates in recent years. Relative Survival is the term given to the ratio of the survival observed in women with breast cancer to the survival expected if they were subject to the same overall mortality rates, by age and calendar period, as the general population. This ratio indicates the rate of survival from breast cancer, if having a diagnosis of breast cancer was the only difference between the breast cancer population and the general population. The five-year Relative Survival for women diagnosed with breast cancer in the state of New South Wales, Australia, where this study was conducted, increased from 73% in the period 1973-77 to 82% in the period 1988-95 (Supramaniam, Smith, Coates, Hayes & Armstrong, 1998). While this increase in survival rates is reassuring, the state of breast cancer survival is not, of course, without its own difficulties. Because of the inherent unpredictability of cancer, survivors remain in a state of vulnerability and uncertainty about their future (Zampini & Ostroff, 1993).

Survivors can range from those living with persistent but controlled disease to those who are disease free (Mullan, 1985). Frank (1998) refers to a stage that he terms "deep illness". Deep illness may be critical or chronic, immediately life threatening or long-term. What is important, according to Frank (1998), is people's own perceptions

of illness as affecting all life choices and decisions, and as altering their identity. “The essence of deep illness is to be always there for the ill person, and the person believes it will always be there. If the illness moves temporarily to the background of awareness, that shift is only provisional” (Frank, 1998, p 197). This is the state in which some see themselves as living ‘with’ cancer. They are not yet, or are not ever, in the realm of the cured. They are not women who ‘had’ cancer. This is the “shadow” in which breast cancer survivors live, to which I refer in the title of this report, and the definition of survivor adopted for this research.

1.4 This Research on Breast Cancer: Three Studies

My own challenge in this research is to demonstrate the contribution that personal construct psychology can make to the understanding of women’s experience of breast cancer and, based on this understanding, show how most effectively to help women adjust to the ongoing task of being breast cancer survivors. I have conducted three studies to achieve these objectives, and they will be reported in the chapters that follow. I first review the existing literature in Chapter 2, to evaluate current understandings of the psychological impact of a breast cancer diagnosis, and the long-term psychological effects linked with the disease. In Chapter 3, I review the literature on psychological interventions provided by professionals for women diagnosed with breast cancer. In Chapter 4, a set of personal construct concepts that inform these understandings are explored. In Chapter 5, building on these theoretical conceptualisations, a personal construct model of adjustment to breast cancer is presented. The model focuses on the meaning-making processes involved in adjusting to a breast cancer diagnosis and the social context in which these meanings are created.

I test this model in the three studies. In Study 1, a qualitative study, I explore the recurrent themes identified by the participants through transcriptions of their

accounts of their experiences of being breast cancer survivors. In Chapter 6, a description of this study, and a discussion of the findings in terms of the usefulness of the personal construct model of adjustment to breast cancer survival, is presented. The women who participated in Study 1 confirmed repeatedly that having someone who understood their experience was crucial to their successful adjustment from the acute stage of breast cancer diagnosis to the ongoing stage of being a breast cancer survivor. However, few women felt that family and friends could give them the support they needed. Most commonly the greatest support they reported receiving came from other breast cancer survivors who had gone through similar experiences. As one woman told me: "I needed something beyond what family and friends could give."

I conducted Study 2 to examine whether being able to share meanings in common with others is enough to facilitate successful adjustment to being a breast cancer survivor. Each year the local Cancer Carers Group organises a residential retreat for cancer survivors. At the retreat women diagnosed with breast cancer have the opportunity to spend five days in the company of other women who have been similarly diagnosed. As one attendee said: "The retreat is the ultimate week, free of any family distractions, worries, problems, no TV, no radio, just lots of hugs from friends who have been there, done that". Kelly (1955/1991) suggests that when people share meanings they will tend to expect the same things. It follows from this that the expectations that are common to women diagnosed with breast cancer will act as validators against which they will verify the predictive efficiency of their own meanings. The second study, the Retreat Study, was conceptualised, then, as an evaluation of the beneficial effect of "validation of current meanings". A fundamental aspect of the retreat was the opportunity it provided for the confirmation of a shared reality. The results of this study are presented in Chapter 7.

Although I expected that attending the retreat would be helpful in defining women's current meanings, support that only offers understanding of these meanings can serve to entrench unhelpful stories, with a risk that they become a meaningful way of life (Winter, 1997). I expected, therefore, in Study 3, that greater long-term benefits would be gained from personal construct therapy, which provides opportunities not only to define current meanings, but also to elaborate new and more helpful meanings. In Chapter 8, I describe a personal construct group therapy developed to help women living as survivors of breast cancer adjust to their changing circumstances. In Chapter 9, the methods used to evaluate the benefits of the personal construct group therapy and the findings of Study 3, conceptualised as the confirmation of current meanings and elaboration of new meanings study, are presented.

In Chapter 10, I look beyond the quantitative analysis to examine the processes involved in this personal construct group therapy with breast cancer survivors. The therapeutic factors the participants identify as being helpful to them are described. An evaluation of the group processes experienced by the participants is reported from their own perspective. My perspective on group processes experienced by the participants is also provided.

In the final chapter, Chapter 11, I describe the overall finding of this body of research. The report concludes with an evaluation of the contribution personal construct psychology can make to understanding the psychological and social effects of a breast cancer diagnosis, and the role of therapeutic support in women's adjustment to breast cancer survival.

CHAPTER 2
THE PSYCHOLOGY OF SURVIVING BREAST CANCER:
THE LITERATURE

“I feel like everyone thinks I am back to normal. They have no idea that this is so far from the truth” (Melanie, aged 41 years).

Advances in the treatment and early detection of cancer have transformed the disease from one that was inevitably fatal to one that now offers increasing rates of survival, opening up the relatively new discipline of psycho-oncology. This discipline describes, monitors, and tries to improve, the psychological reactions of people who have come close to their death through a cancer diagnosis (Bloch & Kissane, 2000; Massie & Holland, 1984; Tross & Holland, 1989). In this chapter the research literature on psychological reactions to a cancer diagnosis is briefly presented. This research is included because a diagnosis of any cancer is likely to be daunting. This is followed by a review of the research literature specific to breast cancer. It will be evident from the following reviews that anxiety and depression are the most frequently diagnosed disorders in adults living with cancer, and that the experience of these emotions contributes greatly to the overall psychological distress of women diagnosed with cancer.

There are two ways in which anxiety and depression are approached in the literature. In the first, researchers are interested in the prevalence of anxiety and depression as psychiatric disorders. The second approach deals with the emotions triggered by the diagnosis, the subjective experience of anxiety and depression. In this approach it is levels of intensity that are of interest to the researchers. In the reviews that follow I deal first with studies that report on the prevalence of psychological disorder, as these studies reflect the “objective” impact of a cancer diagnosis on women, much valued by the majority of researchers. I then examine studies that report on people’s experience of emotion, the approach more valued by personal construct theorists. The literature reporting the long-term psychological and social effects of breast cancer on breast cancer survivors is then presented. Following this review, I discuss the literature on factors linked with poor adjustment to living as a breast cancer survivor.

2.1 The Literature on Psychological Reactions to a Cancer Diagnosis

Because of the belief of medical teams that being diagnosed with cancer is understandably depressing (Massie & Holland, 1984), that anxiety and depression are “normal” reactions given the circumstances and, therefore, not treatable (Endicott, 1983), psychological disorders associated with a cancer diagnosis are often under-diagnosed and under-treated (Bloch & Kissane, 2000; Holland, Romano, Heiligenstein, Tepner & Wilson, 1998; McDaniel, Musselman, Porter, Reed & Nemeroff, 1995; Maguire, 1985). Nevertheless, the prevalence of psychological disorders in cancer populations is well documented.

In an early study conducted by Massie and Holland (1984) the authors found that 47% of adults diagnosed with cancer met the criteria defining a psychiatric disorder. Of these, 68% were found to be suffering from an Adjustment Disorder, characterized by anxiety or depression, and a further 13% met the criteria for major depression. More recently, this finding has been replicated by Grassi & Rosti (1996).

In a major study, representing the findings from the largest sample of adults diagnosed with cancer to date, and conducted to determine the differential prevalence of distress among adults diagnosed with a range of cancers ($n = 4,496$), Zabora (Zabora, Brintzenhofeszoc, Curbow, Hooker & Piantadosi, 2001) reported an overall prevalence rate of distress of 35% for the sample, ranging from 43% for lung cancer to 30% for gynecological cancer. These researchers were dealing with overall global distress, including somatic factors (loss of appetite, difficulty falling asleep, physical discomfort and tiredness). Anxiety was found to account for 30% of distressed cases, and depression for 19% of all cases reporting high levels of distress (Zabora et al., 2001). The prevalence of anxiety and depressive disorders in the general population is estimated to be approximately 9% in the United States (U.S. Department of Health & Human Services, 1999), the United Kingdom (Singleton, 2001) and Australia

(Australian Bureau of Statistics [ABS], 1999). The studies reported above indicate that a diagnosis of cancer places people at a far greater risk of psychological disorder than for the general population.

Worldwide, women are known to be at greater risk of experiencing anxiety and depressive disorders than men. Prevalence rates for women in the general populace reported by the epidemiological sources cited range from 12% to 14% (ABS, 1999; Singleton, 2001; U.S. Department of Health & Human Services, 1999). This increased risk of anxiety and depressive disorders in women probably reflects the multiple roles that they fulfil in society (World Health Organization [WHO], 2001). Women bear the burden of responsibility associated with being wives, mothers and carers of others. Women are also an essential part of the labour force, and in one-quarter to one-third of households they are the prime source of income (WHO, 2001). It is in the context of this trend towards a greater prevalence of anxiety and depressive disorders in women, that women diagnosed with breast cancer face the added burden of their disease.

Clearly a cancer diagnosis is linked to an increased prevalence of anxiety and depressive disorders, however, the focus of my research is on women's experience of these emotions. A diagnosis of cancer is a threat to life itself, generating fear and turmoil in the lives of women diagnosed with the disease (Massie & Holland, 1984; Zabora et al., 2001), as they, and their families, struggle to define and resolve the series of meanings and decisions that confront them (Parle, Jones & Maguire, 1996; Parle & Maguire, 1995; Weisman & Worden, 1976). Cancer conjures up images of loneliness, abandonment and painful death (Holland & Zittoun, 1990). Striking often without warning, and appearing to come from nowhere, cancer is not an external threat; the enemy resides within the body itself. Cancer represents at a global level, therefore, both our tenuous hold on life, and the fragile reality of our control over that

life (Hersh, 1979). Those fateful words: “I’m afraid it’s cancer”, raise the question, “Why me?” (Holland & Lewis, 2000), challenging, at existential and spiritual levels, women’s beliefs about the nature of their worlds (Baum & Posluszny, 2001; Weisman & Worden, 1976).

The diagnosis may also impact on their psychological health and their ability to continue in their roles at home and at work (Zampini & Ostroff, 1993). Liang, Dunn, Gorman and Stuart-Harris (1990) asked 188 adults diagnosed with cancer (129 women, 59 men) to prioritize their psychological and social needs by ranking, in order of impact on their well-being, their concerns following diagnosis. The participants ranked their concerns in the following order: dealing with family issues, psychological distress, getting information, dealing with work issues, having a social life, sustaining a sex life, and dealing with medical personnel. A diagnosis of cancer represents, therefore, a broad and diverse range of illness demands (Parle & Maguire, 1995) as illustrated in Figure 1.

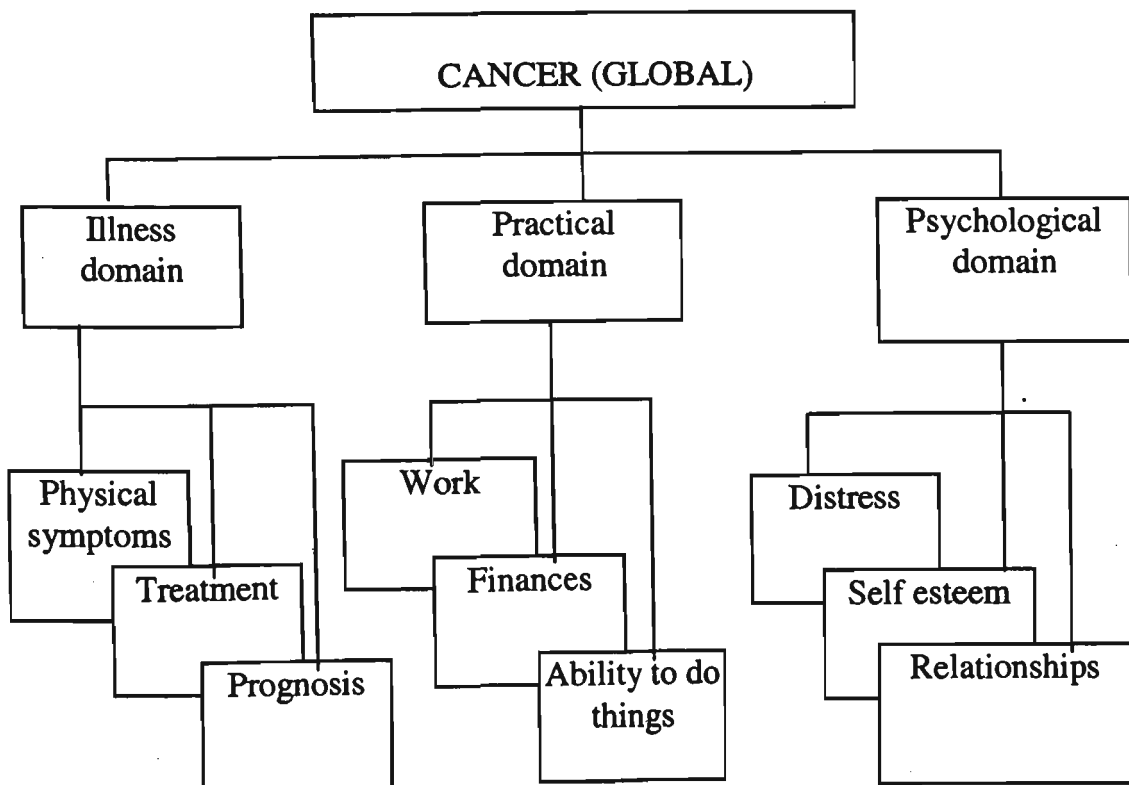


Figure 1. An example of how cancer demands can be represented at global and more specific levels (Parle & Maguire, 1995, p. 33).

In contrast to the view of a cancer diagnosis as traumatic with uniformly negative effects, is the view that the event has the potential to elicit perceptions of psychological growth, of finding a new purpose in life (Calhoun & Tedeschi, 2001; Goodare, 1996; Lane & Marlow, 1999; Parkes, 1971; Tedeschi, Park & Calhoun, 1998), and that neither state is exclusive of the other (Antoni, Lehman, Klibourn, Boyers, Culver, Alferi, et al., 2001; Folkman, 1977). These findings suggest that future research should describe both positive and negative experiences (Gotay, and Muraoka, 1998). To date, only a few studies have incorporated experiences of positive emotion.

2.2 The Literature on Psychological Reactions to a Breast Cancer Diagnosis

In this section the literature dealing specifically with the prevalence of psychiatric disorders in women faced with a breast cancer diagnosis is reported, followed by a review of the literature on women's experience of psychological distress. Overall the literature suggests that at the time of diagnosis, 40-50% of women diagnosed with breast cancer will experience severe anxiety and/or depression (Hall, A'Hern & Fallowfield, 1999), and although this incidence appears to decrease in the first 12 months, 25-35% of women treated for breast cancer will continue to experience problems in adjusting to being breast cancer survivors (Fallowfield, Hall, Maguire & Baum, 1990). As for cancer in general (Breitbart, 1995), the most common DSM-IV (American Psychiatric Association, 1994) diagnoses for these women are adjustment disorders, characterised by depressed and anxious mood (Royak-Schaler, 1991).

An Australian study conducted by Kissane and his colleagues (Kissane, Clarke, Ikin, Bloch, Smith, Vitetta & McKenzie, 1998) found that 135/303 (45%) women had a psychiatric disorder of whom 127/303 (42%) were diagnosed with depression or anxiety, or both. This finding suggests that psychological disorder associated with

women diagnosed with breast cancer in Australia rates two to three times higher than in the general community (Kissane et al., 1998). Studies reporting the prevalence of anxiety and depression disorders in the United States (Ganz, Hirji, Sim, Schag, Fred & Polinsky, 1993) and in the United Kingdom (Hall et al., 1999; Woods, Tobin & Mortimer, 1995) reach similar conclusions. While the disorders linked with breast cancer diagnosis are most commonly characterised by anxious and depressed mood, other reactions reported in the literature include phobic reactions (Kissane et al., 1998), and posttraumatic stress (Alter, Axelrod, Harris & Gobois, 1996; Andrykowski, Cordova, McGrath, Sloan & Kenady, 2000; Cordova, Andrykowski, Kenady, McGrath, Sloan & Redd, 1995; Tjemmland, Soreide & Malt, 1996a, 1996b).

A large body of research has examined women's experiences of distress in response to breast cancer in the months following diagnosis and treatment (Bloom & Kessler, 1994; Cassileth, Walsh & Lusk, 1986; Dean, 1987; Hughson, Cooper, McArdle & Smith, 1987; Omne-Ponten, Holmberg, Burns, Adami & Bergstrom, 1992; Ward, Viergutz, Tormey, de Muth & Paulen, 1992). Studies of the effect of diagnosis and treatment of the disease on women are first presented, followed by studies dealing with the impact of a breast cancer diagnosis on women in their social context. Overall this literature suggests that women diagnosed with breast cancer may experience a range of negative emotions, and while some emotions may be transitory, the experience of distress can be long-standing. The distress linked with breast cancer diagnosis is again most commonly experienced as the emotions of anxiety and depression; however, high levels of anger and hostility (Gottschalk & Hoigaard-Martin, 1986a; Sneed, Edlund & Dias, 1992; Viney, Walker, Robertson, Lilley & Ewan, 1994), hopelessness (Bloom, 1987) and helplessness (Morris, 1979; Watson, Greer, Rowden, Gorman, Robertson, Bliss et al., 1991) are also reported. A few studies also note that a breast cancer diagnosis has the potential to trigger positive

experiences in some women. These include the expression of positive affect (Viney et al., 1994), a sense of having a life purpose (Dow, Ferrell, Leigh, Ly & Gulasekaram, 1996) and hopefulness (Heszen-Niejodek, Gottschalk & Januszek, 1999).

Examining the effect on psychological well-being of differences in surgical treatments, MacArdle (McArdle, Hughson & McArdle, 1990) found women treated by mastectomy reported higher levels of depression than women treated by breast conserving lumpectomy. In contrast to this finding two studies report little difference in levels of anxiety and depression in women treated by these surgical procedures (Fallowfield et al., 1990; Maunsell, Brisson & Deschenes, 1989). Fallowfield and her colleagues (Fallowfield, Baum & Maguire, 1986; Fallowfield et al., 1990) assessed 269 women for anxiety and depression, two weeks, three months, and 12 months after surgery, to examine the psychological outcome of different treatment policies in women with early breast cancer. Although no significant differences in the incidence of anxiety or depression between women who underwent mastectomy and those who underwent lumpectomy were observed, overall levels of anxiety and depression were found to be high. The earlier study, conducted by Maunsell, Brisson and Deschenes (1989) similarly examined differential levels of anxiety and depression in newly diagnosed women following surgical treatment. They studied the relationship between type of mastectomy and psychological distress. Three months following surgery, 39% of women treated with a partial (breast conserving) mastectomy had higher scores for anxiety and depression compared to 26% of women treated by total mastectomy. However, fifteen months later, percentages with high scores were identical at 35%, in the two samples. These findings suggest that a fear of cancer itself, rather than fear of losing a breast, may underlie the high levels of anxiety and depression noted in women following surgery.

In recent years women may be given the choice between modified radical mastectomy (MRM) or lumpectomy plus radiation therapy (LRT). Margolis, Goodman, Rubin and Pajac (1989) investigated the impact of breast cancer on women who chose between these treatment options. In the year following surgery and treatment, participants who had a mastectomy felt less attractive, less sexually desirable, and more ashamed of their breasts. Women who had a breast-conserving lumpectomy followed by radiation therapy experienced no changes in these areas. Half of the women treated by mastectomy regretted not choosing the breast-conserving alternative. Similarly, Schain, d'Angelo, Dunn, Lichter and Pierce (1994) found that six months after surgery, women who had undergone mastectomy reported significantly less control over events in their lives and more problems with sexual relations than those conservatively treated.

Following surgery, many women undergo invasive adjuvant treatment, most usually chemotherapy and/or radiation treatment given as part of the initial treatment (Holland & Lewis, 2000). A study conducted by Campora (Campora, Naso, Vitulli, Giudici, Camoirano, Repetto et al., 1992) found that levels of anxiety reported by women undergoing chemotherapy for primary breast cancer were as high as for women undergoing chemotherapy for advanced breast cancer and who could, therefore, expect a much poorer prognosis. Other studies have similarly found the psychological impact of breast cancer diagnosis, both at the time of initial diagnosis, and in the years following diagnosis, to be unrelated to prognosis (Carter, 1993; Ferans, 1994; Polinsky, 1994). These findings suggest that it is unwise to assume that women who are given a good prognosis at the time of diagnosis will necessarily experience less distress, and be in need of less support, than women with poorer prognoses.

Examining the impact of a breast cancer diagnosis on women in their social contexts, Schag, Ganz, Polinsky, Fred, Hirji and Petersen (1993) found that, while physical problems linked with the disease and its treatment tended to subside over the 12 months following diagnosis, communication problems with husbands remained persistent. Examining the differential effects of breast cancer on women and their husbands, Northouse and Swain (1987) compared their psychosocial adjustment immediately post surgery and one month later. Interestingly, the women and their husbands were found to differ only on the adjustment measure that assessed problems in carrying out various psychosocial roles, with the women reporting more role adjustment problems than the men.

In a review of the literature assessing the impact of breast cancer and its treatment on marital functioning in breast cancer survivors and their spouses, by O' Mahoney and Carroll (1997), psychological distress was found to be high for both partners, as evidenced by increased anxiety, depression, and psychosomatic complaints. These researchers also reported an interesting aspect of the impact of breast cancer on relationships: that it can, paradoxically, have both positive and/or negative effects. They conclude that lack of a conceptual model with which to understand these processes limits current assessment, and intervention in this area.

Examining satisfaction with levels of support from family members, close friends and medical professionals, Neuling & Winefield (1988) found that quite different patterns emerged in support needs for women with a breast cancer diagnosis from professional and non-professional sources. Empathic support was required from all sources, while informational support was desired from medical professionals, rather than from family and friends. Furthermore, these women were found to be more discriminating about support from family and friends. It was more likely for these sources to give unwanted support than it was for professional sources, from

whom many women also reported inadequate support. Satisfaction with social support was matched with measures of adjustment, and it was found post-surgery, anxiety and depression levels were significantly related to satisfaction with support from surgeons; and at three months post-surgery, anxiety and depression levels were significantly related to satisfaction with support from both family members and surgeons.

Examining the effects of a breast cancer diagnosis on women with children, Lewis and Hammond (1992) collected data from 111 child-rearing mothers with breast cancer on three occasions at four-monthly intervals, using standardized measures of psychosocial adjustment. Results revealed that over time the families experienced significantly lower levels of illness-related demands and the marriages became better adjusted. Levels of depressive mood in the women, however, remained stable. This negative mood reduced the quality of the marriage, which, in turn, caused the family to cope less well with its problems. A further study by this team of researchers (Lewis, Hammond & Woods, 1993), obtained data from mothers diagnosed with breast cancer and from their husbands. More frequently experienced illness demands were linked with higher levels of depressed mood, and with reduced quality of the marriage relationship.

In recognition of the need to make the subjective experience of illness more intelligible (Allbrook, 1997; Broyard, 1992; Toombs, 1992; Viney, 1983a), there has recently been a surge of interest, within qualitative medical research, in narrative accounts of illness, and in methods of narrative and thematic analysis (Frank, 1995; Kleinman, 1988; Little et al., 1998; Viney & Bousfield, 1992). Such qualitative studies have helped to identify the concerns of women diagnosed with breast cancer that underlie the emotions experienced. Predominantly these issues relate to the threat breast cancer poses to their physical and psychological integrity (Deadman, Dewey,

Owens & Leinster, 1989; Steginga, Occhipinti, Wilson, & Dunn, 1998), their fear of the cancer recurring (Ferrell, Grant, Funk, Otis-Green, & Garcia, 1997a), uncertainty about their prognosis (Hilton, 1989), and concerns about the effect of their illness on their relationships with people close to them (Pistrang and Barker, 1992).

Loveys and Klaich (1991) examined the qualitative experience of illness demands on women diagnosed with breast cancer by asking: "What is the impact of breast cancer on the daily lives of women of childbearing age?" Semi structured interviews with 79 women newly diagnosed with breast cancer were transcribed and analyzed. Content analysis yielded 14 domains of illness demands: treatment issues, change in life context or perspective, acceptance of the illness, social interaction or support, physical changes, reconstructing the self, uncertainty, loss, making comparisons, acquiring new knowledge, making choices, mortality issues, financial or occupational concerns, and making a contribution. Illness demands were experienced in every aspect of the lives of the women, including their identity, daily routines, family and social experiences, and their perceptions of the past, present, and future. While this study was conducted in the U.S., the findings reflect similar issues identified in an Australian study conducted by Steginga, Occhipinti, Wilson and Dunn (1998), who found that fear of recurrence, decisional uncertainty, and problems with self-image, social relationships, sexual functioning and social isolation ranked highly in the participants' responses.

Clearly, these concerns place an enormous emotional burden on women as they, and their families, respond to the initial diagnosis and treatment. However, after treatment is completed, and following the one year 'check-up', many women continue to find it hard to put the experience behind them, even when reassured by doctors that no further evidence of cancer has been found (Holland & Lewis, 2000). It is at this point that women often feel that they "should" be able to "get on with their lives"

(Lane & Viney, 2000a, 2000b). In the following section, evidence of the long-lasting experiences of distress in women living as breast cancer survivors is reported.

2.3 Evidence of Long-Term Psychological Distress for Survivors of Breast Cancer

A small but growing body of research has examined the long-term psychosocial impact on survivors of their initial disease experience (Bleiker, Pouwer, van der Ploeg, Leer & Ader, 2000; Ellman & Thomas, 1995; Northouse, 1990; Vinokur, Threath, Caplan & Zimmerman, 1989). Examining the prevalence of psychological disorder in women more than five years post surgery, Saleeba, Weitzner and Meyers (1996) administered the Beck Depression Inventory and the State-Trait Anxiety Inventory to 52 women who had no history of a psychiatric diagnosis, and had been disease-free for at least five years. They found the incidence of depression to be significantly higher in the survivors than in the control sample of 88 women who underwent low-risk breast cancer screening. The incidence of mild anxiety was also higher in the survivor group.

Studies that included measures of anxiety and depression in the adjustment of breast cancer survivors more than one-year post surgery generally showed that living as survivors of breast cancer involves ongoing psychological distress. An early study by Morris (1979) found that a substantial 33% reported feelings of helplessness, anxiety and depression, and, up to two years after surgery, 25% of the women in the study had depression severe enough to require treatment. Reduced quality of life, especially in the areas of emotional, social, and sexual functioning, has been found, not only after initial treatment (1 - 2 years), but also several years post-treatment (> 5 years) (Holzner, Kemmler, Kopp & Moschen, 2001; Schover, Yetman, Tuason, Meisler, Esselstyn, Hermann et al., 1995).

Studies that set out to identify the specific underlying issues that give rise to this ongoing psychological distress reported that many women continue to fear a

recurrence of their cancer. Carter (1993), examining women's perceptions of living with a cancer diagnosis interviewed 25 women identified as being between 5 years and 26 years from their initial diagnosis of breast cancer and found that these women never seemed to free themselves from their cancer experience. Fear of recurrence, a sense of vulnerability, isolation and uncertainty of prognosis were commonly identified concerns for long-term survivors (Dunkel-Schetter, Feinstein, Taylor & Falke, 1992; Hilton, 1989; Lane & Viney, 2000a; Loveys & Klaich, 1991; Spiegel, Morrow, Classen, Raubertas, Stott, Mudaliar et al., 1999). Polinsky (1994) showed that the chronic nature of breast cancer disease was demonstrated by many respondents' continued pain, numbness, swelling and other physical effects of the surgery, continued thoughts about recurrence and nervousness associated with medical follow-up, fearing that the cancer would be found to have re-occurred or spread to other body parts, and concerns about the willingness of others to discuss the cancer and its long-term effects. More than 70% of the women reported thoughts of recurrence, the experience of anxiety, and negative feelings about their body. In a further study that included measures of satisfaction with body image (Omne-Ponten, Holmberg & Sjoden, 1994), 60% of the women studied reported being unwilling to show themselves naked, and 22% felt that they had become less attractive because of the surgical treatment.

Finally, a descriptive study conducted by Dow (Dow et al., 1996) evaluated the quality of life of 294 breast cancer survivors, and reviewed the continuum of positive and negative quality of life outcomes in this population. Results indicated that: a. fatigue, aches and pains, and sleep problems were persistent after treatment ended; b. psychological distress from cancer diagnosis and treatment, and fear of recurrent, or metastatic disease were problematic over time; c. family distress, sexuality, and family burden issues were of greatest social concern; and d. uncertainty

over the future, plagued breast cancer survivors long-term. However, breast cancer survivors also reported good outcomes in hopefulness, experiencing a greater sense of purpose in life after the treatment.

In the light of the findings presented, while many women undoubtedly do adjust to their breast cancer survivor status, and some women experience positive outcomes, the weight of the above evidence suggests that many survivors continue to experience distress, and that the uncertainty of their prognosis, and persistent fears of recurrence continue to trouble them long after their initial diagnosis. These findings suggest that besides recovering from the acute consequences of cancer treatment, long-term survivors of breast cancer may continue to have special needs for psychological support (Holzner et al., 2001; Welch-McCaffrey, Hoffman, Leigh, Loescher & Meyskens, 1989).

2.4 Predictors of the Survival of Women Diagnosed with Breast Cancer

A number of studies have examined the link between psychological well-being and extended survival with breast cancer. Longer survival has been linked to closer relationships (Spiegel, Bloom, Kraemer & Gottheil, 1989) and social support (Waxler-Morrison, Hislop, Mears & Kahn, 1991). Although, in general, being married has been linked to longer survival in adults diagnosed with cancer (Goodwin, Hunt, Key & Samet, 1987), studies of women with breast cancer show that this link between being married and longer survival is not straightforward. Forsen (1991) found no effect, or negative effects, of being married on survival, and two studies have reported increased survival time for unmarried women, when compared with married women (Ell, Nishimoto, Mediansky, Mantell & Hamovitch, 1992; Waxler-Morrison et al., 1991). In comparison to widows, however, married women with breast cancer appear to be at an advantage in survival (Neale, Tilley & Vernon, 1986). It seems likely, therefore, that the quality of the relationship, rather than the fact of the relationship,

may be a better indicator of the effect of marital status on breast cancer survival (Weihs & Reiss, 1996).

Levy and colleagues (Levy, Herberman, Whiteside, Schlien & Lippman, 1990) examined the roles of perceived social support and tumor estrogen/progesterone receptor status as predictors of natural killer cell activity in women diagnosed with breast cancer and found that significant variance in natural killer cell activity was accounted for by the extent of perceived social support from the women's intimate partner. However, Linn, Linn and Harris (1982) and Cassileth, Walsh and Lusk (1985) have shown no link between psychological well-being and survival.

2.5 Predictors of Psychological Distress in Women Diagnosed with Breast Cancer

Psychological well-being for breast cancer survivors, may be linked to age at diagnosis. Bloom and Kessler (1994) found that being younger, and having more children under the age of 21, was linked with poor psychological adjustment. Tjemsland, Soreide and Malt (1996a, 1996b) have also noted a statistically significant effect for age on psychological distress.

Support from the interpersonal environment has been shown to be an important factor in adaptation to a breast cancer diagnosis (Bloom, 1996; Bloom, Stewart, Johnston & Banks, 1998; Dunkel-Schetter, 1984; Dunkel-Schetter & Wortman, 1982; Ell, Mantell, Hamovitch & Nishimoto, 1989; Zemore & Shepel, 1989). Yet, despite the important role of social support in the lives of women living with breast cancer (Royak-Schaler, 1991), up to 33% report that they do not have adequate support (Peters-Golden, 1982; Welch-McCaffrey et al., 1989). Bolger, Foster, Vinokur and Ng (1996) found support to be forthcoming in response to women's physical needs. However, when they looked at women's emotional needs they found the opposite to be true. This may result from both the women diagnosed

with breast cancer and their supporters feeling better able to define physical needs, and more clearly perceive a path towards fulfilling those needs.

A further study (Stanton, Danoff-Burg, Cameron, Bishop, Collins, Kirk et al., 2000) found that women who considered their social contexts to be receptive to emotional disclosure reported better quality of life than women who considered themselves unable to express their fears and share their concerns. These researchers tested the hypothesis that actively processing and expressing emotions enhances psychological adjustment and health status. They found that women ($n = 92$) who, within 20 weeks following medical treatment for breast cancer, coped through expressing their emotions surrounding cancer had fewer professional appointments for cancer-related distress. These women also reported enhanced physical health and vigour, and decreased distress during the next three months, compared with those low in emotional expression

Other studies have examined the attributes the women themselves bring to their cancer experience as predictors of their psychological adjustment. With accumulating evidence that hopeful thinking is associated with a better medical outcome (Everson, Goldberg, Kaplan, Cohen, Pukkala, Tuomilehto & Salonen, 1996; Pettingale, Morris, Greer and Haybrittle, 1985), a small, but growing body of research has examined the role of hopeful thinking in women's psychological adjustment to breast cancer. There is, as yet, only limited evidence to support this hypothesis, although there is reason to believe that a link between hopefulness, a sense of purpose in life and successful adjustment to breast cancer may exist (Levy et al., 1985; Spiegel et al., 1989; Waxler-Morrison et al., 1991), and it is clearly an area that deserves further research.

Examining the possibility that women's sense of global meaning (i.e., the existential belief that their lives have purpose and order) may moderate the

relationship between intrusive thoughts and psychological distress in breast cancer survivors, Vickberg, Johnson, Bovberg, DuHamel, Currie and Redd (2000) conducted telephone assessments of 61 women. Results confirmed that the frequency of intrusive thoughts was positively related to psychological distress. Global purpose, moreover, moderated the relationship between intrusive thoughts and psychological distress. Nelson (1996) also found that an ability to put the diagnosis into a broader and meaningful life perspective was helpful in dealing with uncertainty in the participants she studied.

The relationship of hope to better adjustment has been proposed to be, in part, based on underlying coping styles (Taylor, 2000). Much of the research on hope, therefore, is subsumed within the larger body of literature on coping styles and adjustment to breast cancer, with hopeful thinking linked to a more active and future-oriented style of adjusting to breast cancer. Burgess, Morris and Pettingale (1988) studied the cognitive responses to the diagnosis of 178 newly diagnosed adults with breast cancer and non-Hodgkin's or Hodgkin's lymphoma. Analysis revealed that four broad coping styles could be delineated: positive/confronting, hopeless/helpless, fatalistic, and denial/avoidance. Lower psychological distress was linked with a positive/confronting response, while higher anxiety and depression scores were linked with a hopeless-helpless response. The role of hopelessness on adherence to medical regimens has also been examined. Rowland (1998) found that women with less hope diagnosed with breast cancer were more likely to discontinue their adjuvant treatment (chemotherapy and/or radiation treatment) in the face of adverse treatment side effects than women who were more hopeful.

In a study of 70 women having surgery for early stage breast cancer, women rated as optimists at the time of diagnosis, i.e. they had a generalised expectation that good things will happen (Scheier and Carver, 1987), reported greater feelings of well-

being and less upsetting thought intrusion during their post surgery year (Carver, Pozo, Harris, Noriego & Scheier, 1993; Carver, Pozo, Kaderman, Harris, Noriego, Scheier et al., 1994). Pessimistic women, in contrast, were found to be at increased risk of poor adjustment to their diagnosis and treatment.

2.6 A Summary of the Literature on Psychosocial Reactions to a Breast Cancer Diagnosis

Social support has been identified as an important correlate of the adjustment of women to their breast cancer status, both to their initial diagnoses and the ongoing tasks of living as women who have breast cancer. In the literature the direction of causality is not addressed, most studies examining social support being retrospective. The extent, therefore, to which psychological distress alienates actual support and perceptions of the support, or lack of support increases psychological distress, remains unclear (Turner, Wooding & Neil, 1998). What is clear, however, is that many breast cancer survivors face a paradox: social support is a potentially strong resource in enabling them to adjust well to their diagnoses, yet reaction to the disease, both by the women themselves and their support networks, can interfere with the effective provision of support (Dunkel-Shetter, 1984; Silver, Wortman & Crofton, 1990).

Breast cancer survivors, therefore, can live in a state of subjective alienation from the people in their lives, expressed as an inability to communicate the nature of the experience of the illness to them (Little et al., 1998). Having confronted their own mortality, breast cancer survivors find themselves reassessing life and wanting to discuss issues that may have no meaning for their families and friends. Concerns about the recurrence of the cancer and about death may be less talked about than other concerns, because they are emotionally more threatening and less socially acceptable (Pistrang & Barker, 1992; Spiegel, Bloom & Yalom, 1981; Spiegel, 1990). Studies of

attitudes of healthy adults to breast cancer suggest a prevailing view that breast cancer survivors who do not discuss their disease are healthier and better adjusted than those who speak about it (Pistrang & Barker, 1995; Peters-Golden, 1982; Wortman & Dunkel-Schetter, 1979). These attitudes may result in a disinclination to encourage discussion of ongoing fears and problems.

The direction of causality in the relationship between hope and better adjustment is also unclear. It seems just as likely that poor adjustment results in women perceiving their situation to be hopeless as it is that a hopeless orientation causes high levels of negative affect. Furthermore, the assumption that a particular coping style in response to breast cancer is representative of the coping responses of the women to other stressors in their life, is unfounded (Parle & Maguire, 1996; Spiegel, 1995). Women's coping response style in relation to chemotherapy, for instance, may be very different from their response to other illness related physical, psychological and social demands.

As I review the literature on women's psychological reactions and adjustment to being a breast cancer survivor, a number of questions remain unanswered by the current literature. As increasing numbers of women diagnosed with breast cancer continue to live without a recurrence of the disease, why do some women continue to experience problems in adjusting to their changed condition years after their original diagnosis? Although an ongoing fear of recurrence may explain these findings to some degree, it appears that some women experience a sense of personal growth following a breast cancer diagnosis, yet there is no evidence to suggest that these women no longer fear a recurrence of their disease.

Brennan (2001) notes that the term 'adjustment' is widely used within the psycho-oncology literature and, although it is a topic of central importance to the lived experience of people with cancer, the psychological mechanisms of adjustment

have rarely been described. He suggests that rather than seeing it as the absence of psychopathology or the end-point of coping with the global threat of cancer, adjustment should refer to the psychological processes that occur over time as the individual, and those in their social world, manage, learn from and adapt to the multitude of changes which have been precipitated by the illness and its treatment. Brennan argues, therefore, that it is only from explicit theories of adjustment that progress can be made in understanding how and why psychological disorders so frequently develop in cancer, and what steps may be taken to prevent them. To date, the majority of the studies are not grounded in such a theory. Finally, although social support has been linked with better outcomes, the mechanisms by which this outcome is achieved, and the nature of effective support, is not addressed in the literature. The personal construct model I have developed in Chapter 5 in response to these unanswered questions, and the three studies conducted, and reported, in Chapters 6, 7, 9 and 10, test the usefulness of the model in addressing these questions. These questions are summarised in Table 2.1.

Table 2.1

A Summary of Questions That Need to be Addressed for Breast Cancer Survivors

1. How can we explain the long lasting negative emotions in some women?
 2. How can we explain the apparent paradox of outcomes observed: both the high degree of distress linked with the disease and the potential for positive experiences of self-discovery, personal growth and life change?
 3. What is the underlying process that results in some women experiencing greater negative affect than others?
 4. What is effective interpersonal support?
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My literature review has illustrated the psychological and social challenges faced by breast cancer survivors. While psychological distress is higher immediately after diagnosis and during treatment, there is overwhelming evidence that many women continue to suffer ongoing distress in the years following diagnosis. This literature review has shown that both the intrapersonal and interpersonal domains affect psychological adjustment to breast cancer, as women attempt to create and restructure their meanings following their breast cancer diagnosis. The interaction between these domains is clearly seen in the studies reviewed in the following chapter. A summary of the literature reviewed in this chapter on psychological reactions to a breast cancer diagnosis can be found in Appendix A. In Chapter 3, I review the literature on psychological interventions aimed at helping women adjust to life as breast cancer survivors. Reflecting a diverse range of theoretical frameworks and practices, the review provides evidence of the psychological benefits experienced by women who have the opportunity to receive support in the form of both individual and group psychotherapy.

CHAPTER THREE
INDIVIDUAL AND GROUP PSYCHOLOGICAL INTERVENTIONS
FOR WOMEN WITH BREAST CANCER BY PROFESSIONALS
AND THEIR EFFECTIVENESS

“I needed some one to unload on. Everything that I felt, exactly what I felt, without having to worry about how it might affect others” (Christine, aged 47 years).

In this chapter, I present the literature on psychological interventions provided by health professionals for women with breast cancer. First, I briefly outline both the general approach to interventions, and the rationale behind these interventions. Secondly I describe three approaches to psychological intervention for women diagnosed with breast cancer: cognitive-behavioural, psycho-educational, and supportive/existential. I then present the findings of the evaluation studies for each of these approaches, followed by my conclusions. The focus of this review is on women diagnosed with breast cancer. However, some studies that demonstrate significant findings for oncology in general, or provide models of care for women with cancer, have been selectively included and are identified in the text.

3.1 The Psychological Interventions in the Breast Cancer Literature

In general, psychological interventions for women with early breast cancer have aimed at facilitating adjustment, and reducing mood disturbance brought about by a breast cancer diagnosis (Burke & Kissane, 1998a). The variety of concerns facing newly diagnosed women offers a daunting set of threats to overcome or modify (Baum & Andersen, 2001). At the time of diagnosis, existential concerns may be of greatest importance. During surgery and chemotherapy or radiation treatments, specific fears about the effects of treatment and the physical consequences of these therapies (anorexia, hair loss, fatigue, nausea, diarrhoea and mouth sores, to name but a few), may extract a further toll on women's psychological well-being. A number of studies have aimed to provide psychological support for women newly diagnosed with breast cancer. To date, few interventions have been specifically targeted at survivors of breast cancer.

The interventions reported have been provided in both individual and group forms. Although many therapeutic strategies used to help clients can be adapted for both forms, each has particular advantages. In the individual form, the clients'

particular needs can be addressed, and the therapy adapted to meet their changing circumstances. In the group form, while the goals of the therapy may be more global, addressing issues the participants have in common, women participating in this form of therapy have the opportunity to develop a network of supportive relationships. The dual benefits of receiving and giving support also provide women living with breast cancer opportunities to both learn from others, and gain a sense of accomplishment, as the sharing of their experiences or knowledge is seen to help others (Spiegel & Diamond, 2001). As will be seen when I review the outcome literature, therapies delivered in a group form appear to be at least as effective in reducing psychological distress as individual therapies. Group therapy has also been shown to be up to four times more cost-effective than individual therapy (Yalom & Yalom, 1990), so it allows for greater utilization of scarce resources. For these reasons, the majority of psychological interventions provided for women diagnosed with breast cancer are group therapies. The length of the interventions reported varies enormously, ranging from one session only, to weekly sessions lasting for one year and more. In general though, interventions for women with early breast cancer tend to be relatively brief, with weekly sessions of one to two hours lasting between six and twelve weeks.

Within the large body of outcome research literature three primary approaches are distinguishable: the cognitive-behavioural, educational, and existential or supportive interventions, though many interventions tend to be eclectic (Burke & Kissane, 1998a; Owen, Klapow, Hicken & Tucker, 2001), borrowing techniques from across a range of therapeutic approaches. The studies reviewed in section 3.2 have been grouped under these headings according to the predominant component of the intervention. These three approaches are now described.

3.1.1 The Cognitive Behavioural Therapies

The cognitive behaviour therapies (CBT), from the work of Ellis (1962) and Beck (1976), have emerged as the most often used treatment for psychological distress, and an increasingly large body of empirical data supports its efficacy in treating anxiety and depression in adults in the general population (Clarke & Fairburn, 1997). In the breast cancer literature, interventions with a predominantly cognitive-behavioural content focus on changing specific thoughts and behaviours, and on teaching coping skills. They usually include a combination of problem solving, lifestyle management, identification of dysfunctional attitudes, behaviour modification and reinforcement, with the teaching of relaxation techniques. An underlying assumption of the CBT approach to intervention is that: “people do not get disturbed by their early or later environments but that they have strong innate predispositions to disturb themselves consciously and unconsciously” (Ellis, 1992, p. 63). People are thought to do this by producing dysfunctional thoughts, feelings and behaviours. The goal of therapy is to change unhelpful cognitions to more helpful thoughts, feelings and actions. The therapy is, therefore, oriented towards the content of people’s meanings, as opposed to the process of meaning-making.

Few interventions use a ‘pure’ cognitive behavioural model. They tend, instead, to borrow from the approach particular techniques thought to be applicable to the task of adjusting to breast cancer (Burke & Kissane, 1998a). Relaxation, problem solving, and goal setting techniques have been incorporated into a number of interventions (Edgar, Rosberger & Nowlis, 1992; Fawzy, Cousins, Fawzy, Kemeny, Elashoff, Morton et al., 1990; Telch & Telch, 1986; Worden & Weisman, 1984). The first study to apply a complete CBT model (Greer, et al., 1992; Moorey, Greer, Watson, Baruch, Mason, Rowden, et al., 1994), evaluated the effects of a brief, focused individual therapy for adults living with cancer (Moorey & Greer, 1989).

Two studies have applied this approach to group therapy (Edelman, Bell & Kidman, 1999; Watson, Fenlon, McVey, & Fernandez-Marcos, 1996). The tasks of the group CBT therapy, developed for women newly diagnosed with early breast cancer (Edelman et al., 1999) are as follows:

1. Introducing the concepts of self-talk and thought-monitoring;
2. Recognizing the beliefs that underlie negative self-talk;
3. Identifying irrational thinking;
4. Disputing negative self-talk;
5. Teaching of relaxation skills;
6. Teaching of communication skills;
7. Assertiveness training; and
8. Problem solving.

3.1.2 The Psycho-Educational Therapies

Psycho-educational interventions can be critically important to people with cancer at the time of diagnosis and during treatment. The clarification of information given by the medical team, and an explanation of the side-effects of adjuvant chemotherapy and radiation treatments, can all assist in de-mystifying the breast cancer experience for women at this time. Psycho-educational interventions (Berglund, Boland, Gustavsson & Sjoden, 1994; Ferlic, Goldman & Kennedy, 1979; Johnson, 1982), both increase women's understanding of the disease of breast cancer and its treatment, and engender their sense of mastery over a situation that has the potential to rob them of a sense of control over their circumstances (Fawzy, Fawzy, Arndt & Pasnau, 1995). In addition to providing information, psycho-educational therapies often include elements from the other forms of therapy such as specific coping skills and relaxation techniques. An early American study by Johnson (1982), examining the effects of eight one and a half hour sessions of a structured group 'I

Can Cope' study program over a four week period, has been instrumental in the development of informational programs developed to assist newly diagnosed adults with a range of cancers. Topics covered in the study program were:

1. Learning about the disease;
2. Coping with daily health problems;
3. Communicating with others;
4. Liking yourself;
5. Living with limits; and
6. Accessing resources.

3.1.3 The Supportive/Existential Therapies

Supportive therapies consist of those based on existential (Spira, 1997a, 1997b), supportive-existential (Spiegel et al., 1981; Spiegel et al., 1989; Spiegel, et al., 1999), crisis intervention (Gilbar, 1991) and psychodynamic models of therapy (Straker, 1998), and generally focus on the expression of emotions linked with the breast cancer experience. Most of the supportive interventions described in the general cancer literature are formulated on existential principles. In contrast to cognitive-behavioural and educational therapies, these therapies are frequently of longer duration, examining underlying conflicts, and applied most often to people facing advanced disease (Straker, 1998). Spira (1997a, p. 193) proposes the following general principles of existential group therapy:

1. Achieving a state of safety and comfort within themselves from the group;
2. Recognizing their distress and avoidance of it;
3. Exploring and expressing their problems and concerns without fear of social appropriateness;
4. Interacting openly, honestly, and meaningfully with others, offering and receiving support;

5. Exploring their core beliefs in the light of their 'shattered assumptions' of themselves and their world;
6. Determining what brings them the greatest meaning, purpose, and value in life now; and
7. Showing their understanding by committed action.

Adapting the existential model of group therapy (Yalom, 1980, 1995) to work with women with breast cancer, two further group forms are identified in the literature: supportive-expressive (Spiegel et al., 1981, 1989, 1999) and cognitive-existential (Kissane, Bloch, Miach, Smith, Seddon & Keks, 1997). The supportive therapy developed by Spiegel and his colleagues (1981, 1989) focused initially on addressing the problems of terminal breast cancer, improving relationships with family, friends and physicians, and living as fully as possible in the face of death. The underlying premise of the intervention is that sympathetic and direct confrontation with life-and-death issues results in mastery rather than demoralization, and that the group setting provides emotional support through the facilitation of Yalom's (1975, 1995) therapeutic factors. These factors consist of eleven primary factors: instillation of hope, universality, imparting information, altruism, the corrective recapitulation of the primary family group, development of socialising techniques, imitative behaviour, interpersonal learning, group cohesiveness, catharsis and existential factors (Yalom, 1995). These factors refer to the complex processes that occur through interpersonal experiences in group therapy (Yalom & Yalom, 1990). Spiegel and his research team have now developed a brief supportive-expressive therapy of 12 weeks duration for women recently diagnosed with breast cancer (Spiegel et al., 1999). Their group therapy, based on Yalom's therapeutic factors, was developed to increase the participants' self understanding, self acceptance, and universality (the sense of

belonging), that enhance women's repertoire of coping strategies and diminishes their sense of isolation, hopelessness and worthlessness (Spiegel et al., 1981, 1989).

Kissane and his colleagues (Bloch & Kissane, 2000; Kissane et al., 1997) have developed a therapy they term cognitive-existential therapy designed to be provided over six months for women diagnosed with early breast cancer. This therapy aims to bring together the supportive aspects of existential therapy with the problem solving and cognitive reframing approach of cognitive-behavioural therapy. It draws largely on Moorey & Greer's (1989) cognitive behavioural approach (Adjuvant Psychological Therapy), as they applied it in individual therapy, Yalom's (1995) existential concepts of group therapy, and Bowlby's (1969) work on loss and grief. The broad therapy goals for the women include:

1. Developing their supportive networks;
2. Working through their grief over losses;
3. Improving their problem solving; and
4. Developing their cognitive strategies to maximize coping, enhance a sense of mastery over life, and re-evaluate priorities for the future.

Specific group themes include: death anxiety, fear of recurrence, living with uncertainty, understanding treatment with chemotherapy, radiotherapy and hormone regimens, the collaborative doctor-patient relationship, body and self image, sexuality, relationships with partners, friends and family, surgical reconstruction, life style effects and future goals. Active coping skills are developed for the women through teaching formal problem solving and cognitive restructuring of automatic negative thoughts.

One of the major contributions of the supportive therapists is their assumption that the processes of adjustment are essentially interpersonal. The major difference between therapies based on a supportive/existential model of therapy and those based

on cognitive-behavioural or educational models, is in their honouring of the lived experiences of the women. Rather than viewing distressing thoughts, feelings and actions as dysfunctional, they are acknowledged, and the women's meanings are explored rather than eradicated. This overarching view of people as creative makers of meaning is crucial to an understanding of how best to support women diagnosed with breast cancer. This view will be developed in the next chapter that describes some useful personal construct concepts, and in Chapter 5, when I describe the personal construct model of adjustment to breast cancer survival.

Three meta-analytic studies (Devine & Westlake, 1995; Meyer & Mark, 1995; Sheard & Maguire, 1999), on the effects of psychological interventions with adults diagnosed with a range of cancers, provide strong evidence for the beneficial effect of intervention on psychological well-being. The meta-analysis conducted by Devine and Westlake (1995) examined 98 studies, representing data from a total of 5,326 adults diagnosed with cancer. Of these 98 studies, 18 involved only women, 69 included more women than men, and in nearly one third of the studies the majority of participants were women with breast cancer. Examining the effect of intervention on levels of both anxiety and depression for each therapeutic approach (cognitive-behavioural, educational and existential or supportive interventions), Devine & Westlake (1995) found statistically significant beneficial effects in relation to both these outcomes for each of the treatment subgroups, with no statistically significant differences in effect size for type of treatment.

In the following section, I review the outcome literature on psychological interventions. The review examines the outcomes of cognitive-behavioural, psycho-educational, and the supportive interventions. Some studies report on interventions provided in an individual format, while others report on the findings of group

interventions. I describe them separately here. A summary of these findings is provided in Appendix B.

3.2 A Review of the Literature on Evaluations of Psychological Interventions for Women Diagnosed with Breast Cancer

In this section of the report, studies that have evaluated the effects of professionally led psychological interventions for women diagnosed with breast cancer are described. Two types of support can be identified; self-help/peer support, serving to provide mutual support and advocacy; and support/intervention provided by health professionals. Only the latter are the focus of this report. Most frequently, the interventions I review were led by psychologists/counsellors, social workers or oncology nurses. As was noted earlier, many studies use an eclectic approach. In these cases, the studies have been categorized according to the predominant approach. Some studies that evaluated outcomes of intervention in adults diagnosed with other cancers are included, if the findings seem transferable to a breast cancer sample, (Fawzy, Fawzy & Wheeler, 1996; Jacobs, Ross, Walker & Stockdale, 1983). The participants in some studies had been diagnosed with a range of cancers (see Appendix B), including breast cancer (Edgar et al., 1992; Greer et al., 1992; Moorey et al., 1994; Telch & Telch, 1986; Worden & Weisman, 1984).

Studies examining individual cognitive-behavioural interventions reported improved levels of psychological adjustment following therapy for women diagnosed with breast cancer (Bindeman, Soukop & Kaye, 1991; Edgar et al., 1992; Greer et al., 1992; Moorey et al., 1994; Worden & Weisman, 1984). For example, in the British study conducted by Greer and his colleagues (Greer et al., 1992; Moorey et al., 1994), adults who showed elevated levels of anxiety and depression on a screening instrument (Greer et al., 1992) pre-therapy, were randomly assigned to either a treatment or control sample. Assessments two and four months after therapy revealed

a more significant improvement for the therapy sample than the controls. Twelve months later, the treatment sample continued to report significantly lower levels of anxiety and depression than the control (Moorey et al., 1994).

Group therapies with major cognitive-behavioural components generally also report beneficial treatment effects. Improvement in levels of affect was reported in six studies (Antoni et al., 2001; Cunningham & Tocco, 1989; Edelman & Kidman, 1999; Samarel, Fawcett & Tulman, 1997; Telch & Telch, 1986). In two studies, group therapy with a major cognitive-behavioural content was found to be more effective than a contrast supportive therapy group in improving psychological adjustment (Cunningham & Tocco, 1989; Telch & Telch, 1986). In contrast, Edelman and Kidman (1999) found no long-term differences between cognitive-behavioural and supportive therapy. Sixty women newly diagnosed with primary breast cancer were randomised to attend either 12 sessions of group cognitive-behaviour therapy or of supportive therapy. Self-report psychological assessments were completed before and after therapy, and at four months follow-up. In the period following therapy, women in both groups showed significant reductions in depression, and improvements in quality of life and self-esteem, relative to their baseline scores. Although women in the cognitive-behaviour therapy group showed significant improvements in their quality of life and self-esteem compared to those in the supportive therapy group, these differences were no longer apparent at the four-month follow-up.

Information about their disease and its treatment is usually given to women by medical teams (Burke & Kissane, 1998b), though a number of studies have included additional educational components in the programs reported. The role of information alone in reducing levels of anxiety and depression at the time of treatment, and in the early stages of adjustment, has been clearly shown in an outcome study of individual educational intervention conducted by Jacobs, Ross, Walker and Stockdale (1983).

Participants in the intervention, adults diagnosed with Hodgkin's Disease, were given an educational booklet with information about advances in treatments for the disease and a question and answer section. One month after receiving the booklet the participants were found to be less depressed and anxious than those in the control group.

Comparing the effectiveness of a psycho-educational intervention delivered in group versus individual form, Fawzy and his colleagues (1996) found both to be effective in decreasing affective distress in their participants diagnosed with metastatic melanoma. Hosaka (1996) modified the therapy developed by Fawzy to implement a programme with Japanese women, all of whom had been diagnosed with breast cancer. Again, both group and individual forms were found to be effective in decreasing psychological distress, with no differential improvement between individual and group form at follow-up. These findings support the earlier finding that group and individual forms of an educational and informational program were equally effective in decreasing levels of anxiety and depression in women diagnosed with cancer (Cain, Kohorn, Quinlan, Latimer & Schwartz, 1986). While the interventions were provided to women diagnosed with gynaecological cancer, the authors suggest that it is easily adaptable to meet the needs of women diagnosed with breast cancer.

Examining the differential outcomes for information-based educational groups compared with peer discussion groups for 230 women with breast cancer Helgeson, Cohen, Schulz and Yasko (2000) found that participating in the educational groups resulted in greater benefits for the physical functioning of women, especially for those who started the study with more difficulties (e.g., they lacked support or personal resources), compared with those with fewer difficulties. Consistently positive effects on adjustment were seen in the educational groups both immediately following and six months after the therapy. The researchers concluded that education-based group

therapies aided the initial psychological adjustment of women diagnosed with early stage breast cancer, while there was no evidence of benefits from peer discussion groups.

Few studies include or target the women's "significant other". One such study, examining the effects of psycho-educational groups for partners of women diagnosed with early stage breast cancer, conducted by Bultz, Speca, Brasher, Geggie and Page (2000) found that, following the intervention and three months later, partners in the therapy sample had less mood disturbance than did partners in the no treatment control sample. Women whose partners received the therapy also reported less mood disturbance, and greater marital satisfaction.

Examining the effects of an early supportive group intervention on adjustment for women with advanced breast cancer, Spiegel and his colleagues (1981, 1989) found the intervention significantly reduced phobic responses, fatigue and pain, while also improving vigour and coping responses. Recently adapting this therapy to women newly diagnosed with breast cancer, favourable outcomes have also been reported (Spiegel et al., 1999). In this study 111 women with breast cancer, within one year of diagnosis, were recruited from ten geographically diverse sites of the U.S. National Cancer Institute's Community Clinical Oncology Program and two academic medical centres. The supportive-expressive groups met for 12 weekly sessions lasting 90 minutes. Results indicated a significant decrease in negative emotions as measured by the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983) over the six-month period that these women were evaluated. Evaluation, also recent, of an Australian cognitive-existential intervention (Kissane et al., 1997) showed decreases in anxiety and depression in the intervention sample compared to the control sample.

3.3 Conclusions from the Review of the Evaluation Research for Individual and Group Psychological Interventions

The outcome studies reviewed here have consistently shown improvements in emotional adjustment. Based upon this literature, psychotherapy is now considered to be a necessary part of comprehensive care for women with breast cancer (Burke and Kissane, 1998a; Spiegel, 1995). In this section I draw together the findings from the above studies. The limitations of these existing studies are then discussed.

The push in the late 1980's and throughout the 1990s to identify effective psychological interventions and select strategies for training therapists in "empirically validated" treatments (Chambless, 1999; Chambless & Hollon, 1998; Chambless & Ollendick, 2000) is evidenced in the growing shift towards standardizing treatment. This is based on a belief that techniques, as opposed to interpersonal processes, are the most important contributors to the success of psychological intervention (Miller, Duncan, & Hubble, 1997). The review of the current literature presented above, however, provides little support for this view.

Although the findings of outcome studies provide strong evidence for the integration of psychological interventions into the care of women living with breast cancer, what is less clear is which model of therapy is indicated for which women (Burke & Kissane, 1998a). Meyer & Mark (1995) suggest that it is now an inefficient use of research resources to ask the simple question: Is there an effect of psychotherapy on the emotional adjustment, functional adjustment, and treatment and disease related symptoms in adults diagnosed with cancer? They suggest that important future research directions include the study of mediational processes in adjustment to cancer.

While both group and individual forms of therapy have been shown to be effective in reducing levels of distress in breast cancer survivors, the group form

appears to have particular advantages over individual interventions in terms of the support network developed during the course of the therapy. Group psychotherapy provides a social network with the common bond of confronting similar problems (Spiegel, 1993) at a time when the participants may be feeling isolated from other people who may retreat out of fear or awkwardness (Spiegel & Diamond, 2001). Both universality and acceptance (Yalom & Yalom, 1990) will help participants feel a sense of belonging in the group, promoting feelings of being cared for, comforted, supported, understood and valued. This perception may well be pivotal to participant's well-being (Bloch & Kissane, 2000; House, Landis & Umberson, 1988). The group process also allows for the instillation of hope as participants see the progress of others (Yalom & Yalom, 1990). Groups also have the practical advantage of being more cost effective than individual therapies (Spira, 1997b).

These findings suggest, therefore, that as well as it being an inefficient use of resources to ask only the question: "Is there an effect for intervention?" it is now no longer an effective use of resources to compare outcomes of group and individual interventions. What research should now concentrate on is achieving a better understanding of therapeutic factors, and how these processes may be specifically incorporated into future interventions.

Most studies randomly assigned the participants into either the treatment or control arms, and used inventories and questionnaires with known reliability and validity. Most studies also provided sufficient information at baseline on psychological and medical variabilities to evaluate comparability between control and treatment arms, or reported on the statistical measures used to control for baseline differences. It should be noted, however, that there is growing evidence that many measures developed originally for populations other than cancer populations may not be sensitive enough for measuring outcomes for women diagnosed with breast cancer.

For example, Hall (Hall et al., 1999) found that the Hospital Anxiety and Depression [HADS] Scale (Zigmond & Snaith, 1983), commonly used in outcome studies, was less effective in detecting psychological distress in women diagnosed with early breast cancer than a clinical interview.

In the studies reviewed, measures of positive psychological well-being were conspicuously rare. Yet, as reported in Chapter 2, a number of studies have noted the potential for the breast cancer experience to elicit perceptions of personal growth and a gratitude for life as well as distress (Brennan, 2001; Carter, 1993; Cordova, Cunningham, Carlson & Andrykowski, 2001; Lane & Viney, 2000a). Harvey (1995) suggests that a certain kind of fearless authenticity often comes from a confrontation of one's mortality, consistent with Carter's (1993) finding that many women in her study also described the emergence of a more authentic self as a result of their breast cancer experiences.

It also appears from my review of the literature, that most interventions for women diagnosed with breast cancer are aimed either at those who have advanced cancer or are newly diagnosed. To date few studies focus specifically on providing therapy for breast cancer survivors (Spiegel et al., 1999), addressing their long-term issues of living as a survivor. There is now sufficient evidence that ongoing psychological distress is experienced by many, as evidenced in the earlier review of the literature on the long-term psychological effects of a breast cancer diagnosis presented in Chapter 2, to warrant the development of psychological interventions focussing specifically on this population.

In a review of the current literature on psychosocial interventions for cancer, Owen (Owen, Klapow, Hicken & Tucker, 2001) notes the "cloudiness" of the collective results of current studies. Measures of depression and anxiety appear to be the most frequent outcomes assessed, however, outcome measures and target

populations vary widely among studies, and there appears to be little consistency regarding the stated objectives for providing the therapy. This observation holds true, too, for the breast cancer outcome literature. Many of the psychosocial interventions reported incorporate components of cognitive-behavioural therapy, existential therapy, educational strategies, relaxation training and social support. This eclectic or “kitchen-sink” approach (Owen et al., 2001, p. 226) to clinical intervention makes it difficult to determine which components of the intervention contribute to an improvement in outcomes. Owen (Owen et al., 2001) proposes that greater benefits to individuals diagnosed with cancer could be derived through the use of a clinical intervention firmly grounded in its parent theory.

In summary, the current literature has served to show, without doubt, that psychological intervention can assist in women’s adjustment to breast cancer survival. Issues that need to be addressed in future outcome research are presented in Table 3.1.

Table 3.1

A Summary of Issues to be Addressed in Intervention Outcome Studies for Breast
Cancer Survivors

1. All aspects of the outcome should be firmly based in sound psychological theory of human processes;
 2. It should address the needs of women more than one year post-diagnosis to evaluate the benefits of psychological interventions with this population;
 3. It should include measures of positive affect in addition to negative affect;
 4. It should include measures that overcome the difficulties of conventional measures noted above;
-

Table 3.1 (continued)

A Summary of Issues to be Addressed in Intervention Outcome Studies for Breast
Cancer Survivors

5. It should include qualitative as well as quantitative measures to enhance our understanding of the mediational processes in adjustment to cancer; and
 6. It should add to an understanding of the therapeutic factors that may contribute to improvement in well-being.
-

In Chapter 4, I will present a range of personal construct concepts, on which my model of psychological adjustment to breast cancer survival is based. In Chapter 5, I will present the model.

CHAPTER 4
PERSONAL CONSTRUCT THEORY

“Some people become a beacon of hope in our lives. They help us to discover that the sharing of feelings connects us all, and they give us reason to believe. Some come into our lives by chance, or maybe not really by chance. Perhaps, in destiny’s grand design, these are no random meetings, all is meant to be” (Winifred, 80 years).

In this chapter, I describe personal construct concepts relevant to an understanding of the psychological processes set in motion by breast cancer diagnosis and the challenge of adjustment to living as a breast cancer survivor. I provide an overview of the theory. I then describe personal construct concepts that are particularly useful in understanding women's experiences of breast cancer diagnosis. These are the concepts of the Experience Cycle, Validation/Invalidation, Transition and Dislocation. I also describe concepts relevant to understanding the interpersonal processes of adjustment to breast cancer survival. These concepts add to an understanding of the social context in which women must formulate their new meanings about themselves as breast cancer survivors. The theoretical concepts introduced in this chapter provide the framework for the personal construct model of adjustment to breast cancer survival described in Chapter 5.

4.1 An Overview of Personal Construct Theory

Central to personal construct theory (Kelly, 1991/1955) is the underlying philosophical assumption that there are innumerable possible alternative views of reality. Kelly (1986) defined this philosophical stance as constructive alternativism.

He states:

Like other theories, the psychology of personal constructs is the implementation of a philosophical assumption. In this case the assumption is, that whatever nature may be, or howsoever the quest for truth will turn out in the end, the events we face today are subject to as great a variety of constructions as our wits will enable us to contrive. This is not to say that one construction is as good as any other, nor is it to deny that at some infinite point in time human vision will behold reality out to the utmost reaches of existence (Kelly, 1986, p.1).

Personal construct theory consists of a Fundamental Postulate and eleven corollaries. Kelly's (1955/1991) Fundamental Postulate states that people are primarily concerned with the anticipation of their worlds, as they actively engage in defining their personal realities. Specifically Kelly states: "a person's processes are

psychologically channelized by the ways in which he anticipates events” (Kelly, 1991, p. 32).

An important implication of the Fundamental Postulate is that action flows from the ways people choose to test their beliefs about the future, given the limitations imposed by their current understandings. Neither past nor future events, in themselves, are regarded as basic determinants of a course of action. It is the interpretations of events, in terms of their potential for future anticipations, which form the basis for the human process of living within this theory (Fransella & Dalton, 1990). The eleven corollaries elaborate on this proposition.

A helpful way to both conceptualise and order the eleven corollaries is in terms of their foci. The first four corollaries describe the structure of the construct system (the organisation of meanings); the next four describe the processes of construing (implicit or explicit theories about the world); and the final three describe the social context of construing.

Personal construct theory holds that people experience the world through bipolar dimensions termed constructs (the Dichotomy Corollary). Unlike concepts, constructs specifically represent the distinctions that people make, for example, between self and non-self; good and bad; ill and healthy. The construct of “self with cancer”, therefore, takes on meaning when this understanding is contrasted with “self without cancer”. People, the theory further proposes, will place relative value on one pole of their dichotomous constructs, for example, they may prefer to be healthy rather than unhealthy (the Choice Corollary). Some of these values may be quite transient, while others may be stable and represent guiding principles (Kelly, 1977). The essence of this corollary is that people will always choose the alternative in a dichotomised construct through which they anticipate the greater possibility for definition and/or extension of their construct systems (Winter, 1992).

People's understanding of their worlds is a direct function of the organization and content of their "personal" construct systems (the Construction Corollary). These complex and often idiosyncratic systems of constructs, developed over a lifetime, are the "matrix of meaning" through which they filter their experiences, define their personal realities, and act in the world (Neimeyer, Epting & Krieger, 1983 p. 90). These systems are organized hierarchically (the Organization Corollary), with relationships of superordination and subordination among their interconnected constructs. Superordinate (abstract and central) constructs subsume subordinate (specific and peripheral) constructs (Hinkle, 1965). Constructs about self are termed core constructs, and the most superordinate of these constructs concern people's values and beliefs, their assumptions about the world and their places within it. These assumptions are fundamental to meaning-making, in that they help to make events appear predictable (Kelly, 1991). Core constructs dealing with interpersonal relations are termed core role constructs. The most influential and superordinate of people's values are crucial in defining their relationships with others (Landfield & Leitner, 1980).

Within these systems of constructs are subsystems of constructs for different realms, which may be inferentially incompatible with each other (the Fragmentation Corollary). For example, a mother, who generally condemns capital punishment, may argue strongly for the death penalty for child abusers. The ability of the construct to include new events into its range of applicability will vary (the Modulation Corollary), depending upon the permeability of the superordinate constructs. Permeability defines whether or not constructs will admit to their range of convenience new events that are yet to be construed within their framework. When superordinate constructs are relatively permeable, they provide a thread of consistency throughout the system as a whole so that subsystems that are functionally

differentiated at lower levels of abstraction may be reintegrated at higher levels of abstraction (Adams-Webber, 1979).

Experience is viewed as the successive construing of events, rather than the succession of events themselves. Events may precipitate change if construed as ambiguous within the context of current construct systems (the Experience Corollary). Kelly (1955/1991) states that people's construct systems vary as they successively construe the replication of events. Every construct also has limited applicability, its range of convenience (the Range Corollary), and a context in which it fits best, its focus of convenience. People's behaviours, based on their constructs, are not a reflection of forces beyond their control, that can be "treated" with the acquisition of skills, or the correction of "distorted thoughts", but are their attempts to make meaning.

Although constructs are essentially unique (the Individuality Corollary), they will, in part, be similar to those of another (the Commonality Corollary). Finally, the Sociality Corollary states that, to the extent that people construe the construction processes of another, they may play a role in a social process involving the other person. Kelly's definition of role, unlike traditional concepts of role as a behavioural description, states that role behaviour is based both on attempts to understand other people's construct systems, and actions based on these understandings. This statement of sociality provides the framework for understanding interpersonal relationships. In formulating this corollary, Kelly emphasised the concepts of content and process, distinguishing between construing things in the same manner (the Commonality Corollary), akin to seeing "eye to eye", and trying to construe the other's process of construing (the Sociality Corollary), to "see from where the other is standing" (Leitner & Faidley, 1995).

4.2 The Experience Cycle

In the manner in which scientists aim at better control of reality by predicting events, people, the theory proposes, try to predict the course of events in their lives in order to control their outcomes (Scheer, 1996). While the attempt to live predictably is a quest for stability, constructs are constantly subject to change (Kelly, 1955/1991). Experience is conceptualised, therefore, as a cycle embracing five phases: anticipation, investment, encounter, confirmation or disconfirmation, and constructive revision. The Experience Cycle is illustrated in Figure 2.

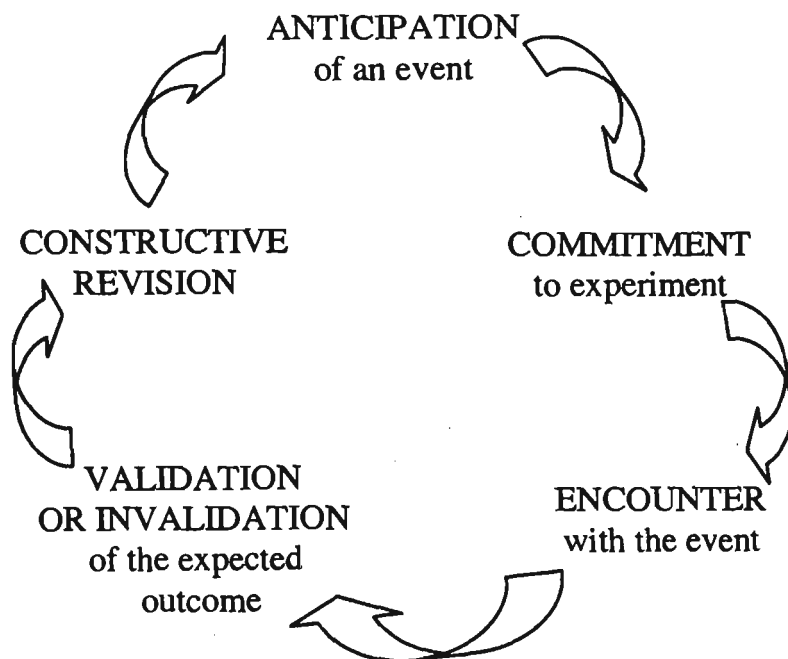


Figure 2. The Experience Cycle

The first stage in the cycle is Anticipation. By construing past recurring themes, people are facilitated in their anticipation of future events. The second stage of the cycle is Commitment, a combination of anticipation and self-involvement. The extent to which people are committed to particular outcomes will determine the degree of risk they encounter. The Encounter stage is conceptualised, not simply as a collision of people with an event, but: “as an active knowledge of what one has met which lets that knowledge make a difference” (Epting & Amerikaner, (1980, p. 58).

The fourth stage is Validation (Confirmation) and Invalidation (Disconfirmation). In this stage people make assessments of the commitments made during the encounter and the resulting evidence, which either confirms or disconfirms their construing of the encountered experience. In the final stage of this cycle, Constructive Revision, people face the implications of the event. It should be noted that the term “constructive” is not meant to imply a value, the term relates solely to the nature of the element to which it is applied, i.e. that it has been constructed. The subjective assessment of the outcome of their anticipation in the Confirmation/Disconfirmation stage determines the degree of revision deemed necessary, preparing for fresh anticipations and further Experience Cycles (Winter, 1992). Epting and Amerikaner (1980) describe this crucial phase as follows:

On the one hand is the possibility that some areas of the person's life are more compatible than before, aspects that were discrete or in opposition may move towards integration. Previously inaccessible material (not clearly understood experiences) may become more fully synchronized with the rest of the person's life. It is in constructive revision that all of the greater moments of life, which are often recognized and labelled as “growth experiences”, take place. From these we are enlivened and invigorated, and feel more fully-grown. On the other hand, the person may now realize that certain beliefs or life stances cannot be maintained, and drastic, painful changes are needed. . . . The recognition of the need to change, to relinquish old constructions, and the subsequent actuality of revision are, of course, what were risked at the outset of the cycle (Epting & Amerikaner, 1980, pp. 58-59).

The completion of the full Experience Cycle to Constructive Revision is essential for optimal functioning (Winter, 1992). This completion is characterized by openness to interaction with the environment, and an orientation towards movement into the future (Epting & Amerikaner, 1980). Optimal functioning represents the contrast pole of construing that typifies psychological disorder (Winter, 1992). From this it follows that, in personal construct terms, experience is not marked by years, or the accumulation of events, but by the revisions made (Kelly, 1980). Furthermore,

the completion of the full cycle of experience is not merely cognitive, but an active, constructive orientation of the person to their world (Epting & Amerikaner, 1980).

4.3 Validation/Invalidation

The concept of validation is critical to a personal construct understanding of experience. From the Latin *validus-valere* (to be strong), validation is about the strengthening of people's theories (Button, 1996). Conversely, invalidation is defined as the incompatibility, subjectively construed, of people's predictions and the outcomes observed (Kelly, 1955/1991). Button (1996) made four useful observations. Firstly, validation/invalidation, when viewed as a process of strengthening or weakening a construct, is not an absolute truth to be believed completely or abandoned completely, but a matter of degree. Secondly, validation/invalidation is not a reality but a subjective judgement that a construct has been validated or invalidated. Thirdly, validation/invalidation may be actively sought or can come unexpectedly. Finally, validation/invalidation is not just an intra-individual process but also goes on between persons.

4.4 Personal Construct Concepts of Transition

In personal construct theory, psychological disorder is seen as the continued use of constructs that have been invalidated. Kelly felt that it was unhelpful to think in terms of diagnostic labels such as "schizophrenia". He rejected these labels, which implied static disease entities presumed to reside within people, preferring to think in terms of transitive diagnoses, that carry pragmatic implications for change and transition in the people's lives (Johnson, Pfenninger & Klion, 2000). The term "transitive diagnoses" implies that personal construct theory focuses on "the bridges between the person's present and future", (Kelly, 1991: Vol. 2, p. 153). Although Kelly dispensed with the traditional diagnostic entities, personal construct theory has been successfully applied to traditional categories of diagnosis including "Anxiety

Disorders” and “Depression” (Drysdale, 1991; Neimeyer, 1985a; Rowe, 1983; Sanz, Avia & Sanchez-Bernados, 1996), “Eating Disorders” (Button, 1987) and “Schizophrenia” (Bannister, 1963; Bannister, Adams-Webber, Penn & Radley, 1975; Pierce, Sewell & Cromwell, 1992).

Kelly integrated emotional experience within his theory by defining negative emotion as people’s awareness that their systems of constructs, evolved to anticipate and predict the world of events, are inadequate for construing the events with which they are now confronted (Fransella & Dalton, 1990). In personal construct terms, emotions are people’s experience of, or resistance to, change (Bannister & Fransella, 1980). Emotions serve as signals of the state of people’s meaning-making attempts, in the wake of challenges to the adequacy of their constructions (Neimeyer, 1998).

One dimension of transition on which my model for this research is formulated is threat. Threat is the process that underlies and sustains the symptoms of distress many breast cancer survivors experience. In personal construct terms, threat is defined as: “the awareness of imminent comprehensive change in one’s core structures” (Kelly, 1991 p. 391). Threat will occur when these women recognise that their most influential meanings are seriously inconsistent with their cancer diagnosis and they find themselves on the threshold of deep changes that have far-reaching implications. Kelly recognized that death, or possible death, represents the paradigmatic threatening event to most people.

The construct “anxiety”, as used in the cancer literature reviewed in Chapters 2 and 3, has a meaning quite different from the personal construct meaning of anxiety. Threat and anxiety, in personal construct theory, are two parallel, but different transitional reactions to an event. In personal construct theory, anxiety has a very specific meaning. As defined by Kelly (1955/1991), anxiety is the experience that events lie outside the range of convenience of the construct system. Similarly, the

construct “depression”, as used in the cancer literature reviewed in Chapters 2 and 3, has a meaning quite different from the personal construct meaning of depression. Depression is associated with constriction of construing (Neimeyer, 1984), whereby people reduce their perceptual fields to minimize apparent incompatibilities (Kelly, 1955/1991). In comparing the transitional reactions, threat, anxiety and depression, threat clearly is best fitted to women’s experience of a breast cancer diagnosis. Although women speak of the uncertainty of their diagnoses, this uncertainty concerns whether or not particular undesired outcomes (recurrence of the disease, metastases, or death) will actually occur. Their uncertainty is not due to an inability to construe these undesired but potential outcomes because they do not have the constructs available to them. The distress these women experience is also not due a reduction in their perceptual fields. These women experience threat; threat to their lives, threat to their physical integrity, threat to their important relationships; and threat to their constructions of the future. Therefore, throughout my report, the distress women experience following a breast cancer diagnosis is conceptualised, theoretically, as threat.

Other constructs of transition concern people’s interactions with others. These constructs of transition, including hostility, guilt and shame, are similarly elaborated as aspects of construct systems in a state of change. Hostility is defined as: “the continued effort to extort validation evidence in favour of a type of social prediction, which has already proved itself a failure” (Kelly, 1955/1991, p. 375). According to Bannister and Fransella: “We cease to be hostile only when we can find alternative ways of interpreting ourselves and our situation” (Bannister and Fransella, 1980, p. 22). Kelly defines guilt as: the awareness of dislodgement of the self from one’s core role structure (Kelly, 1955/1991, p.391). Conversely, shame has been defined as: “awareness of dislodgement of the self from another’s construing of your own role”

(McCoy, 1977, p. 113). It should be noted that these constructs of transition refer to underlying processes and people's attempts to maintain the integrity of their construct systems, and do not imply necessarily "good" or "bad" behaviours.

In 1977, McCoy extended Kelly's concepts of the dimensions of transition to include the elaboration of positive affect within a personal construct framework. Positive affect is associated with people's recognition that the system of constructs they have evolved to anticipate and predict the world of events successfully allows them to construe the events with which they are now confronted. Hope is another dimension of transition that is central in my model. Hope is characterised by a readiness to engage in encounter, "to affect and be affected" (Epting & Amerikaner, 1980, p.60). It implies willingness to interact with the environment, and an orientation towards movement into the future. These are all features of optimal functioning (Epting & Amerikana, 1980).

4.5 Threat

Kelly states that the most important condition unfavourable to the revision of meanings "is that in which the elements out of which the new construct is to be formed involves threat" (Kelly, 1963, p.166). The construct 'breast cancer' is threatening, when it is an element in a next-higher-order construct, which is, in turn, incompatible with other higher-order constructs that women depend upon for the maintenance of their identities. Breast cancer in relation to other people may not be a major threat, unless it is an element in women's construing of their loved ones. Their own diagnosis of breast cancer, however, is likely to be a major source of threat to their meanings. When breast cancer is an element in their construing of themselves, their most superordinate constructs are threatened. One mediating factor in this process may be the degree to which they see breast cancer as synonymous with death.

Their belief systems of the hereafter will also mediate in the degree of threat they experience.

4.6 Dislocation

While threat refers to incompatibility with core constructs, dislocation refers to incompatibility with non-core constructs. The personal construct concept of dislocation has been examined by Viney (1990) in the context of bereavement. In developing a personal construct model of bereavement, Viney notes that the death of loved ones can bring about major changes in the lives of those who are bereaved, that may also require changes to their construct systems (Epting & Neimeyer, 1983). Death of a loved one, however, is not the only event people may experience as loss. To more fully understand the nature of loss, Neimeyer (1998) observes the universality of loss in human life. "In a sense, we lose something at each step of life's journey, the loss of people, places and objects we have come to cherish as we confront life's hard realities (Neimeyer, 1998, p.4)". Women diagnosed with breast cancer lose their previous sense of invulnerability; they can no longer anticipate their future with the same sense of certainty they experienced prior to their diagnosis. The grief triggered by such loss may be compounded by the misunderstanding or inattention of other people: "adding to the burden of private anguish, . . . for those whose mourning is disallowed, trivialized or unrecognised by those around them (Neimeyer, 1998, p.4). Dislocation, from non-core meanings, therefore, is unlikely to occur without emotional distress (Viney, 1990).

4.7 Personal Construct Concepts of the Interpersonal

Kelly (1955/1991) argues that people define their constructs about themselves in relation to others. He referred to these important self-images as "core role" constructs, describing these constructs as dimensions that operate to define people's personal identities, their complex and unique senses of phenomenological continuance

(Kelly, 1991). Relationships with others, based on an intention to understand their meanings, and engaging in interpersonal actions based on these attempts are termed role relationships. The personal construct concept of understanding goes beyond understanding the content of another's construct system to encompass understanding the other person's processes of construing. Understanding another's processes of construing involves understanding their core role constructs. These constructs provide us with: "our sense of who we are, who we would like to be, and who we feel we are becoming" (Leitner & Dill-Standiford, 1993, p.137). Role relationships, therefore, provide a primary source of validation and invalidation (Leitner, 1985) and, potentially, afford the experience of richness and meaning in life (Leitner, 1985; Leitner & Dill-Standiford, 1993).

A major assumption of personal construct theory is that people's construction processes are psychologically channelized by the ways in which they anticipate events (the Fundamental Postulate), and those ways present themselves in dichotomous form (the Dichotomy Corollary). The choice of one pole over another is essentially elaborative and functionally integral to the anticipation of events. Personal construct theory suggests that role relationships provide the context for this elaboration. Firstly they provide for the validation/invalidation of core construing, leading potentially to definition, and to internal consistency that makes the construct systems clearer and more explicit (Winter, 1992). Secondly, role relationships allow for extension of core construing. Extension serves to make constructs more comprehensive, by increasing their range of convenience, "making more of life's experiences meaningful" (Kelly, 1991, p. 47). When role relationships are reciprocal, they provide the context in which people can collaborate in supporting one another's "critical life investments" (Neimeyer & Neimeyer, 1985, p. 197). Stringer suggests that many role-based activities: "have the characteristic of attempting to move forward another's

construction processes” (Stringer, 1979, p. 107). These elaborations of role relationships help make clear the supportive potential of role relationships.

4.8 Personal Construct Concepts of Social Support

Kelly states that when people cannot take an unexpected event in their stride, or when they cannot handle all modes of their reality, support minimizes the negative results of their experimentations (Kelly, 1955/1991, Vol. II p.74). Support is defined as a broad-based response pattern that permits receivers to experiment widely and successfully. Kelly elaborates this definition of support by saying that support, unlike reassurance, does not trap people in their own construct systems. Support is about confirming the others’ processes of construing. Supporters, in attempting to see things from the others’ points of view, are not responding in terms of certainties or outcomes, but are accepting and acknowledging their processes of construing, and their exploratory attempt to communicate their meanings. This definition of support implies that the mechanism of support lies in validation of people as construers of meaning.

Supportive role relationships are a subset of role relationships that have particular characteristics that may differ from other role relationships in which people are engaged. The intention in role relationships will always be, primarily, in terms of moving people’s own construing processes towards optimum anticipation of future events, with a possible secondary intention to move the other’s construing processes forward. Supportive role relationships, on the other hand, have the primary intention of moving the other’s processes further. The intended direction of movement in supportive relationships will be towards optimal functioning in terms of the receivers’ successive engagement in elaborating helpful ongoing cycles of experience.

Support can be derived from sharing common constructs for interpreting experiences (Duck, 1973, 1979), and meanings (Neimeyer & Hudson, 1985;

Neimeyer & Neimeyer, 1983). Duck (1973) suggests that when people find others share a similar view, they may subjectively construe this similarity as evidence for the merit of their own construct systems. The more constructs are shared with others, the more the constructs will seem to be well formed and justified. Similarity helps, therefore, to define people's meanings, by confirming the viability of their existing constructs. It follows from this, that the success of supportive relationships will be determined, in part, by the extent to which people are able to help others define their existing meanings.

Although some level of similarity in construing may be necessary to conduct supportive role relationships, from Kelly's account of role relationships, understanding is also necessary. So important to him was the notion of understanding, as acknowledgment of another person's construction processes, and engaging in a role based on that understanding, that he suggested that Social Psychology should be the psychology of interpersonal understandings rather than common understandings (Kelly, 1991). Role relationships require people to acknowledge the others' ways of seeing the world (Leitner & Faidley, 1995). Supportive role relationships imply, therefore, 'understanding' of others' processes of construing and their exploratory attempts to communicate their meanings. As Fran said of the women she met at her local support group: "We've walked in each other's shoes. In different ways we've all been touched and that's our bond".

4.9 When Things Go Wrong in a Relationship

An essential aspect of relationships is that they are dynamic. Partners and close friends must, therefore, be both willing and able to revise their constructs about each other (Duck, 1979). Neimeyer and Neimeyer (1985) suggest that a failure to do so denies the dynamic reality of the relational process and of each partner as a construer of meaning. For example, when women are confronted with a breast cancer

diagnosis, constructs of themselves in relation to breast cancer, and breast cancer in relation to themselves, are likely to be new. The new constructs that women are now forced to include in their systems of meanings are also likely to be outside the range of convenience of their relational others. In supporting them, partners, relatives and friends must encompass their new construing within their own. If they are unable to do this, original levels of similarity and support may not be maintained (Duck, 1979). As Mary, 54 years of age and two years from her diagnosis said: "I get very frustrated with my husband, and I realize it is because he doesn't always understand. Sometimes I can talk to him and sometimes I can't. It's them not understanding or not knowing, so they don't want to talk about it". According to Neimeyer and Neimeyer (1985), the inability to maintain levels of similarity can: "... set the stage for the *disruption* of a once satisfactory relationship that previously offered validation and extension to both partners" (Neimeyer & Neimeyer, 1985, p. 199). This need not imply that these relationships are no longer supporting other systems of construing. Women's existing relationships may be inadequate only in supporting them to elaborate new meanings in relation to themselves as recipients of a diagnosis of breast cancer. However, the implications of this absence of support may have ramifications throughout their entire systems of meaning (Hinkle, 1965).

4.10 A Summary of the Relevant Personal Construct Concepts

From my description of the personal construct concepts, it should be clear that personal construct theorists view human beings as construers of meaning, striving to organize and anticipate their engagement with the world. People's idiosyncratically structured meanings will be organized around a set of superordinate core constructs that encompass their core assumptions, which both govern their perceptions of events and channel their behaviour in relation to them. One implication of this position, according to Neimeyer (Neimeyer, 1998): "is that the concept of psychological

“disorder” becomes relativized, insofar as different individuals and communities may adopt quite different criteria for judging a particular construction of events to be valid or invalid, functional or dysfunctional” (Neimeyer, 1998, p. 86). Similarly, theorists may conceptualise emotions quite differently.

Personal construct concepts can help us make sense of women’s experiences of breast cancer diagnosis and survival. Central to women’s sense of ‘being in the world’ are their assumptions, beliefs and values, their superordinate core constructs. The enormous potential of a breast cancer diagnosis to create an “emotional abyss” in their lives, despite the evidence that it is not, necessarily, a deadly disease, is understandable when their superordinate core constructs are invalidated and placed under threat. How then, in the face of threat to their sense of being in the world, can these women elaborate new meanings? Personal construct theory suggests that this will take place in the context of their role relationships. But the breast cancer diagnosis is likely to disrupt their relationships as evidenced in the literature review presented in Chapter 2. Personal construct concepts about relationships help us understand the nature of this phenomenon and explain why, at a time when some women most need support, they find this support to be unavailable to them.

As completion of the Experience Cycle is necessary for optimal functioning, women must revise their current meanings in the light of their breast cancer diagnosis. Unless they can do this, they remain dislocated from their meanings about the world of events, and stuck in unhelpful cycles of experience. This understanding helps to explain the ongoing emotional distress many breast cancer survivors experience.

Finally, and to my mind most importantly, personal construct concepts point to ways I, and others, can support these women. Support, according to the theory, requires both acknowledgement of their current meanings and their attempts to express them. When they communicate their fears, these must be acknowledged. To

pacify or reassure them that what they fear is unlikely to happen serves only to invalidate them as construers of meaning. In the face of this invalidation, some women may feel unable to express their fears again, so they have no opportunity to define their current meanings. Support also provides opportunities to experiment with new meanings. Only by allowing women to clarify their current meanings and experiment with new meanings can women be supported in the challenges they face as breast cancer survivors. In the next chapter, building on the theoretical concepts presented in this chapter, I describe the personal construct model of adjustment to breast cancer survival.

CHAPTER 5
MODELS, INCLUDING THE PERSONAL CONSTRUCT MODEL,
OF ADJUSTMENT TO BREAST CANCER SURVIVAL

“Life for me right now is pretty messy. Everyone I know thinks that I have coped so well and have such a positive attitude – and this impression has served to isolate me incredibly” (Jan, 41 years).

In this chapter I bring together the personal construct concepts introduced in Chapter 4, and present them as a model of women's adjustment to breast cancer survival. To begin, I briefly describe three models of adjustment to unwanted and potentially distressing events. Whilst these models were not developed specifically for a breast cancer population, they currently exert a major influence on the field of psycho-oncology, and inform many of the therapies for women living with a breast cancer diagnosis reviewed in Chapter 3. The personal construct model of adjustment to breast cancer survival is then presented and similarly evaluated.

5.1 Two Coping Models of Adjustment to Breast Cancer Survival

In the body of research on coping I described in Chapter 2, two models can be identified. One model has examined how people characteristically approach and appraise demands and experiences like breast cancer, based on an assumption that coping will reflect relatively enduring emotional/behavioural styles of coping. Studies using this model (Burgess et al., 1988; Carver et al., 1993; Carver et al., 1994; Watson et al., 1991) have traditionally examined the link between different coping styles and levels of anxiety and depression (see Chapter 2). The second model views coping as more situation-specific than an enduring trait. Within this model, coping is defined as: "constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman, 1984, p.114).

The model of stress and coping processes proposed by Lazarus and Folkman (1984), and elaborated by Folkman (1997), has served as a conceptual frame in research on coping-related adjustment to breast cancer (Heim, Valach & Schaffner, 1997; Stanton & Snider, 1993). One proposition of the model is that adjustment can be understood in terms of two processes: appraisal and coping. Appraisal consists of people's evaluations of the personal significance of events and the adequacy of their

perceived resources for coping. Coping consists of the thoughts and behaviours people use to regulate their distress. Lazarus and Folkman (1984) originally formulated two general coping strategies: emotion-focused and problem-focused. When people appraise situations to be beyond their control, emotion-focused coping reduces their emotional distress by using specific coping strategies such as denial, distraction and avoidance. Perceptions of control are associated with more problem-focused coping, involving strategies to solve or reconceptualise the event, such as direct action and information seeking.

In the context of a breast cancer diagnosis, the level of psychological distress experienced is thought to be dependent upon the women's appraisal of their change in health status as personally threatening harm or loss (primary appraisal). Following this appraisal, women will then appraise the extent to which they can control or change the situation (secondary appraisal). At this level of appraisal, women will determine the degree of control they have over the situation, and the resources available to them to deal with the implications of their diagnosis. Women who view their diagnosis as a challenge to be overcome are thought to adopt a problem-focused coping style. The teaching of problem-focused strategies is the focus of many of the cognitive-behavioural and psycho-educational interventions I reviewed in Chapter 3. Conversely, women who view the diagnosis as beyond their control, or above and beyond the resources available to them, are proposed to be more likely to adopt emotion-focused coping strategies such as avoiding thinking about the consequences of their diagnosis, keeping busy to avoid having time to think about it, and denial. A number of women in my studies reported denying the possibility of cancer as a delaying tactic. Women may discover a lump in their breast, but push the thought of cancer from their minds, thus avoiding going to a doctor and receiving an actual diagnosis. As one 54 year old woman said: "I was nursing my father, and that was a

full-time job. I just couldn't think about my own health". Unfortunately, while this strategy may diminish distress in the short-term, the chances of the cancer spreading are great, with women who have delayed in seeking mammograms being significantly over-represented in the population of women diagnosed with advanced disease (Baum & Andersen, 2001).

A favourable resolution is thought to lead to the experience of positive emotions. For example, after women have "come through their ordeal", they may well feel more confident of their abilities to face other challenges in the future. In 1997, Folkman elaborated this model to include a third coping style, meaning-based coping. In the event of an unfavourable resolution, or when no resolution is available, people may use meaning-based coping, in which old and untenable goals are relinquished and new ones are formulated. Thus, in the face of continuing uncertainty, many women "make sense" of their cancer experiences by attributing "a reason". Many women look to God, or their spiritual sense of "a meaning to life", by construing their diagnoses as "messages that they needed to slow down", or as "lessons they needed to learn". Others attribute the cause of their cancer to previous stressors. By adopting this reasoning, women may feel that they can take measures to reduce further risk. This places them, seemingly, back in control. In these ways, women can place their diagnosis in a context of meaning. It is the meaning-based process of coping that can account for the finding in the literature that positive affect can co-occur with negative affect in the face of adversity (Folkman, 1997). Folkman's (1997) model of the coping processes of adjustment is now illustrated diagrammatically in Figure 3.

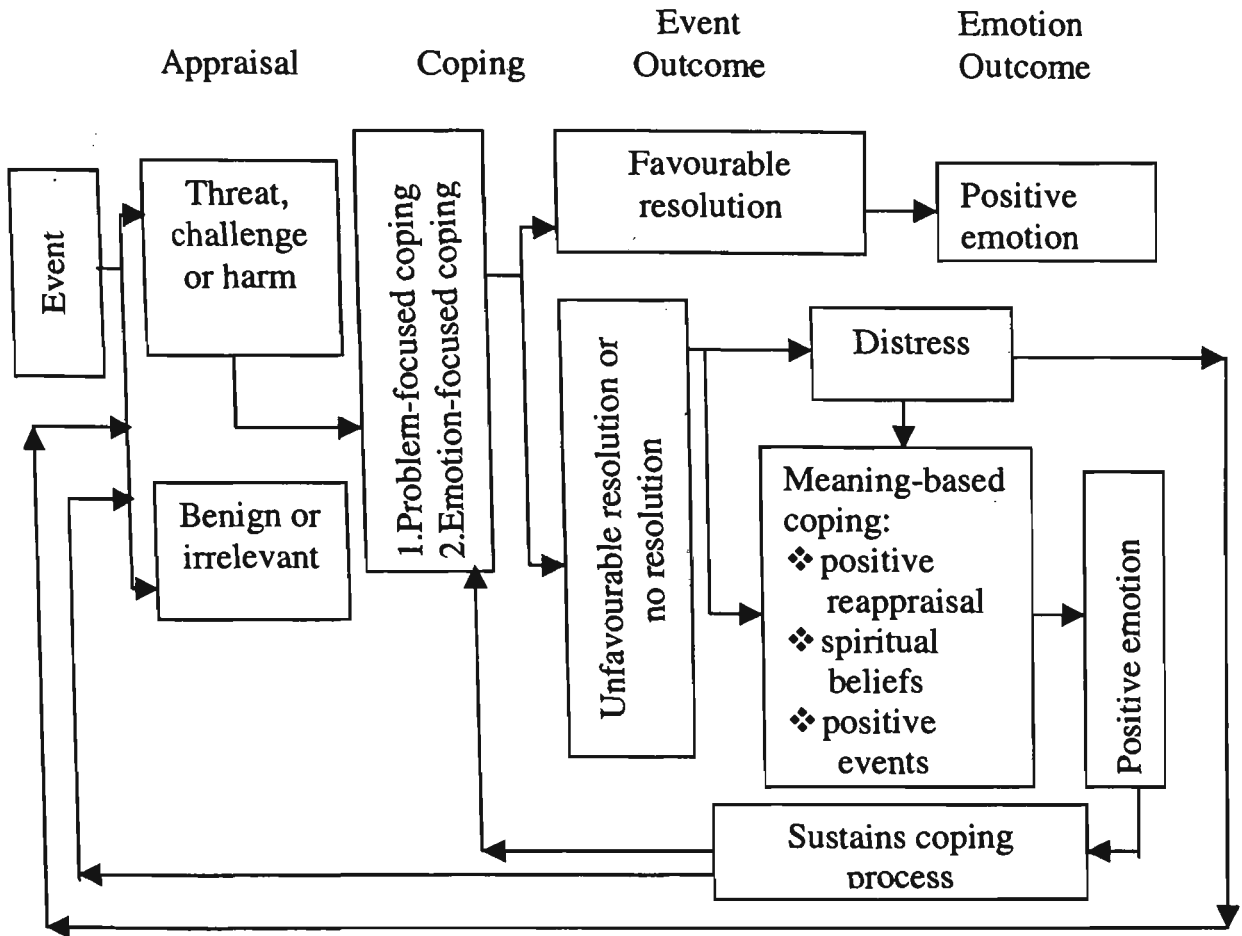


Figure 3. The modified theoretical model of the coping process (Folkman, 1997)

In applying the coping process model to therapy Folkman and Greer (2000) make the following recommendations:

1. Create an opportunity for challenge by:
 - a. Finding out what matters to each of the clients;
 - b. Identifying relevant and attainable goals for them;
2. Reinforce their sense of personal control;
3. Encourage behaviours to attain their goals; and
4. Maintain background positive mood through the recounting of positive events (Folkman, 1997) and the scheduling of activities that give a sense of pleasure and achievement (Greer et al., 1992).

Perhaps the most helpful influence of these coping models, in the field of psycho-oncology, is their emphasis on adjustment as a *process*. Both coping models

described recognise that the degree to which women perceive themselves to be “threatened” (not in the specific personal construct sense here, but as perceiving it as potentially fatal, damaging or harmful) by their breast cancer diagnoses will play a major role in their experience of psychological distress. Furthermore, the addition of meaning-making coping strategies in the second model helps explain the positive emotions experienced by some women diagnosed with breast cancer.

The “appraisal” process carries with it an implication that part of the primary appraisal of the threat of harm or loss may include appraisal of the effect of the event on people’s relationships and their social roles. However, how the social context both modulates adjustment and is subjected to it, the interpersonal dimension, is not clearly articulated (Brennan, 2001). Many women also find the term “coping” to be a major understatement of the challenges they face when confronted with a breast cancer diagnosis. Leonie, 48 years old, reported that she felt the conceptualisation of the process of adjustment as coping failed to capture the depth of her experience. She said: “I don’t like the word “coping”, surviving is a better word. It does at least acknowledge what we have been through”. Other women suggested that the term “coping” implied “minimal functioning”, preferring, instead, the term “living as breast cancer survivors”. It is also unclear how coping differs from behaviour in general. As noted by Zeidner & Endler (1996), coping may be nothing more than behaviour under adverse conditions. For example, many women remarked on how angry they felt when family and friends tried to make them feel better by saying: “You have coped so well”. Almost unanimously the women felt this to be a silly, and somewhat patronising statement. As they said: “What choice did we have, you just do the best you can”.

5.2 The Self-Regulation Model of Adjustment to Breast Cancer Survival

The third model to be described is the self-regulation model of adjustment. Based on expectancy-value models of motivation (Atkinson, 1964; Feather, 1982; Shah & Higgins, 1997; Vroom, 1964), the self-regulation model is based on the assumption that people's goals provide the structures that define their lives (Scheier & Carver, 2001). Central to this model is the notion that people live by the goals they identify for themselves, and that these goals provide meaning and a purpose for living. Within this framework a diagnosis of breast cancer is believed to explicitly and directly undermine ongoing goal pursuits.

Processes such as hope (Snyder, 1994a; 1994b; 1998), optimism (Scheier & Carver, 1985, 1987) and self-efficacy (Bandura, 1986), are integral to contemporary theories of self-regulation as they are proposed to be the mechanisms that underlie people's attainment, or inability to attain, or pursue, their goals. In developing a cognitive theory of hope, Snyder (1994a, 1994b, 1998; Snyder, Scott & Cheavens, 1999) defines it as goal-directed thinking, in which people appraise their ability to produce workable routes to their goals (pathways thinking). People also have the potential to initiate and sustain movement along a pathway (agency thinking). Negative emotions and difficulties in coping are the result of people being unable to envisage a pathway, or make movement toward a desired goal (Scheier & Carver, 2001). Hope and purpose are seen by Carver and Scheier (1998) to go hand in hand. The extent to which people's goals seem attainable (hope), serves as guiding points for action (purpose). Carver and Scheier's (1998) self-regulation model is presented in Figure 4.

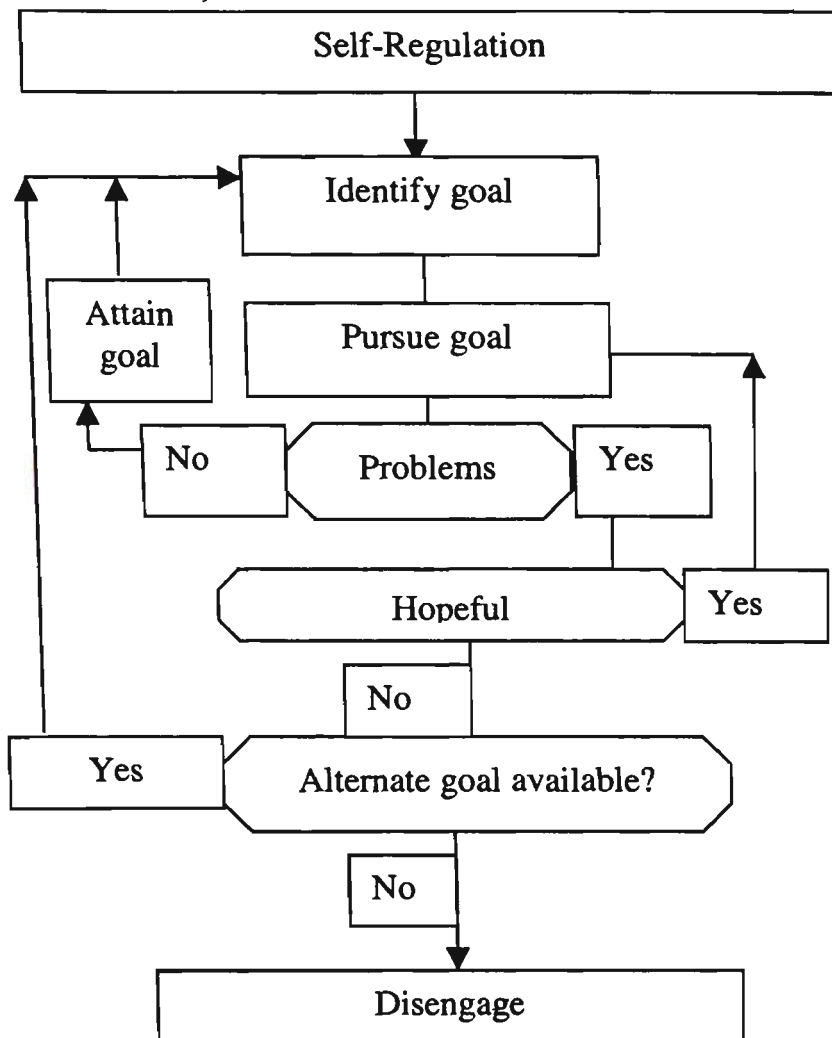


Figure 4. A model for Self-Regulation (Carver & Scheier, 1998)

The role of the therapist within the self-regulation model is to help clients define their goals, determine how they *can* achieve them (agency thinking) and how they *will* achieve them (pathway thinking). Therapies are essentially eclectic, sharing/borrowing concepts from the cognitive-behavioural and educational/informational models of intervention (Scheier & Carver, 2001). Explicit training in coping and problem-solving techniques is thought to enhance women's confidence in their ability to deal effectively with the consequences of breast cancer so that the disease seems more manageable and less likely to disrupt ongoing life plans. Similarly, informational and educational interventions are thought to bolster their confidence in dealing effectively with uncertainty.

The self-regulation model implies that women who experience ongoing psychological distress will be those unable to clarify and pursue alternative goals. Proponents of the model argue that prime tasks of therapists are to help clients define their goals, and decide that they *can* achieve them and how they *will* achieve them. However, my experience with women living with breast cancer is that they have no shortage of goals. Yet how can they effect achievement of these goals? There is, as yet, no known path to ensuring the cancer will not recur. While the pursuit of goals and hopeful engagement in life is clearly to be encouraged, it is also hard to see how women can give up some goals, and to imagine what alternatives may adequately replace those they must abandon. How do women give up the goal of living long enough to see their children grow up, being well enough to help a daughter with a new baby, being well enough to keep on working so that they can pay off a mortgage, and living long enough to grow old? These goals are central to their roles in their relationships with others. Certainly many women have recounted to me that they now live “one day at a time”. This does not, however, mean that they have given up their goals of living to a healthy old age. Statements such as these reflect, instead, their awareness of living in the moment, of valuing their life each day, now they have been made painfully aware of the fragility of their hold on their personal destiny. This emphasis on goals and goal directed behaviours, therefore, fails to aid in understanding how to support breast cancer survivors.

The self-regulation model largely ignores the interpersonal context, as do the coping models. These models do little, therefore, to add to our understanding of the role of social support in adjustment to breast cancer. Furthermore, both models imply that psychological distress results from women’s inability to cope effectively with their present situation, as in the coping process model; or to define future goals, as in the self-regulation model. Essentially, these models are deficit models of adjustment,

with an underlying assumption that women experiencing negative emotions are failing to meet the tasks with which they are faced.

Each of the models described has served to aid present understanding of the processes involved in adjusting to life as a breast cancer survivor: the coping models, in their emphasis on processes and meanings, and the self-regulation model, in identifying hope as an important factor in women's adjustment to breast cancer survival. However, the application of these models to therapy has served to continue the drift towards eclectic interventions, employing a mixture of cognitive-behavioural and psycho-educational techniques to support women facing the ongoing challenge of living as breast cancer survivors. Neither are these models helpful in explaining the success of supportive-expressive, psychodynamic, and existential interventions for example, which are based on quite different underlying philosophical assumptions of what it is to be human. These models for intervention were described in Chapter 3. In the following section, a personal construct model of adjustment to the breast cancer experience is presented. This model, based on the concepts of Chapter 4, informs the studies I have undertaken and described in Chapters 6, 7, 9 and 10.

5.3 The Personal Construct Model of Women's Adjustment to Breast Cancer Survival

The personal construct model I have developed (Lane & Viney, 2000a, 2000c) begins with one general proposition about the nature of construing. This is followed by two propositions about the diagnosis of breast cancer as validation or invalidation of women's constructs about themselves (Propositions 2 and 3). Two propositions (Propositions 4 and 5) then describe the processes set in motion when a breast cancer diagnosis invalidates these anticipations, and six propositions (Propositions 6, 7, 8, 9, 10, and 11) are about women's attempts to restore these meanings in the context of their role relationships. Clearly, any new model of adjustment to breast cancer

survival, should aim to provide answers to the unanswered questions raised in my review of the literature on the psychology of surviving breast cancer (Chapter 2). This was my *Aim* in applying personal construct concepts to the context of adjustment to breast cancer survival. The propositions of the model I developed are:

A General Proposition

Proposition 1

Women's constructs are the paths by which they make sense of their experiences and along which they anticipate their future.

Propositions about two Forms of Reaction to the Breast Cancer Diagnosis

Proposition 2

A diagnosis of breast cancer will either validate or invalidate women's constructs about themselves, their relationships and the nature of their worlds.

Proposition 3

Women for whom the diagnosis of cancer validates their anticipations, will be able to 'make sense' of the event and continue to engage in ongoing Cycles of Experience.

Kelly (1955/1991) describes psychological health as: "the facts against which the individual must validate the pattern of their daily living, and the implements with which they must explore their world" (p.142). While it would generally be imagined that a diagnosis of breast cancer would be experienced as invalidating, women whose anticipations are: "Everything bad always happens to me"; "I deserve to get cancer"; or, "I will probably get breast cancer, because it runs in the family" may be better able to accommodate the diagnosis into their ongoing anticipations, i.e. the event will be consistent with their predictions. Similarly, women diagnosed with breast cancer in their seventies and eighties may accept their diagnosis more readily, feeling that they

have already lived a long life, and that eventually we all must die of something. This may account for the finding in the literature that younger women, who are more likely to have anticipated good health for many years to come, experience higher levels of distress than older women (Bloom & Kessler, 1994).

Propositions about the Breast Cancer Diagnosis as Invalidation

Proposition 4

Women for whom the diagnosis of breast cancer invalidates their most influential constructs will experience threat to their meaning-making about themselves.

Proposition 5

Women for whom the diagnosis of breast cancer invalidates their core constructs may choose to suspend an element from their construing.

Studies of life change as a predictor of psychological distress, suggest that the most distressing life changes are those that require people to undertake a major revision of their assumptions about themselves and their worlds (Parkes, 1993). From a personal construct perspective, a diagnosis of breast cancer has the potential seriously to threaten women's most superordinate core constructs, those concerning their values and beliefs, their assumptions about the world and their places within it. These assumptions are fundamental to meaning-making, in that they help to make events appear predictable (Kelly, 1991). A diagnosis of breast cancer may present a serious risk to life, challenging not only the assumptions and expectations of these women about their worlds, but also how long they may have to live in it (Baum & Posluszny, 2001). Following a breast cancer diagnosis, core constructs may need to be revised to include "self as having cancer", "self as vulnerable", and "self as potentially threatened with death". The world and events within it may also now seem

unpredictable, and the previous sense of invulnerability, of denial of one's own mortality, may be gone forever. Little and his colleagues (1998) describe this phenomenon as: "mortality rendered visible".

In response to threat to their most superordinate core constructs, women may choose to suspend an element. By suspending, or holding in abeyance, an element, they can avoid the threat. For example: suspending the element "self" from the context of the construct "cancer" as in: "I don't believe I really had cancer" or the element "cancer" from the context of the construct "future self" as in: "I know it's not going to come back". This process can be seen as denial, and is often considered to be unhelpful by medical practitioners, friends and family alike. However, Kelly (1991) suggests that ideas are not suspended because of their intrinsic nature, but because their implications are intolerable. In this way suspension/denial can be seen as the valiant attempts of women diagnosed with breast cancer to maintain the integrity of their meanings about themselves. As Miller Mair (1979) poetically describes this state: "There are some things too painful for me to know. There are places too frightening for me to go. There is knowing that is too burdensome for me to seek" (Mair, 1979, p. 35). When threat challenges these women's core meanings, suspension allows them to maintain their assumptions and continue to engage in ongoing Experience Cycles. Suspension/denial is an attempt, on the part of these women, to maintain the integrity of their "assumptive worlds" (Janoff-Bulman, 1989, 1992), the loss of which may be as threatening as loss to life itself.

Propositions about the Breast Cancer Survivors' Attempts to Restore Meaning Within the Context of their Role Relationships

Proposition 6

In the face of threat to their physical and psychological integrity, as construers of meanings, women living with a breast cancer diagnosis will anticipate opportunities to develop and test their meanings about themselves in the context of their role relationships.

Proposition 7

In the face of invalidation of themselves as construers of meanings, women will experience threat to their superordinate core role constructs.

Proposition 8

When women are unable to maintain their old and preferred meanings about non-core events they also experience dislocation.

Proposition 9

In the face of threat to their superordinate core role constructs, and dislocation from their non-core meanings, women will be unable to elaborate new meanings.

Proposition 10

Women whose role relationships validate their processes of construing will be able to elaborate new meanings.

Proposition 11

When women elaborate new meanings they will experience hope as they contemplate and invest in ongoing positive Cycles of Experience.

Relationships provide the context in which women test their construing processes and develop workable predictive systems to anticipate their ever-changing approximations of reality (Walker, 1990). The most influential

relationships are role relationships. Core role constructs define people's values and ways of relating to others. Women's sense of who they are, therefore, will be inextricably bound with the role relationships in which they engage (Walker, 1996).

Kelly (1955/1991) states that when people are faced with unexpected events, or when they cannot handle all modes of their reality, support minimizes the negative results growing out of their experimentations. Investigators now almost unanimously agree that social support is linked with physical and psychological health (House et al., 1988; Sarason, Sarason & Pierce, 1990). There is, however, less agreement about the conceptualisation of this phenomenon (Pierce, 1994). Definitions of social support vary (Bloom, 1996). Cobb (1976) sees "support" as information that leads people to believe that they are cared for and loved, are esteemed and valued, and belong to a network of communication and mutual obligation. Similarly, Kaplan and his colleagues (Kaplan, Cassel & Gore, 1977) define "social support" as the degree to which people's needs for affection, approval, belonging, and security are met by significant others.

Some concepts of support focus on people's perceptions of the social environment and the extent to which global or specific social resources are perceived to be available (Cutrona & Russell, 1987; Sarason, Levine, Bashman & Sarason, 1983). Other concepts emphasize quantitative properties of the social network, including its size, and the interconnectedness of network members (Stokes, 1985; Vaux & Harrison, 1985). Perceptions of support may be influenced, however, more by people's understanding of the nature of their relationships, their working models of their relationships, than the actual features of their social networks (Pierce, 1994). In personal construct terms, perceptions of support will depend upon women's anticipations of support, and the extent to which these anticipations are validated or invalidated.

In Chapter 4, I suggested that support requires supporters to respond, not in terms of certainties or outcomes, but to accept and acknowledge others' processes of construing, and their exploratory attempts to communicate their meanings. An example will help to differentiate between validation of breast cancer survivors' construing processes, i.e. themselves as construers of meaning, and validation of the content of their construing in terms of outcomes or certainties. When a woman expressed her fear, for example, that she may not be alive to attend her daughter's graduation ceremony in five years time, and her husband or friends responded "of course you will", they have effectively cut off her means of experimentation, and in doing so have also invalidated her prediction that she would be afforded the opportunity to experiment. They have responded to the communication as if only the content of the construct was of import. Yet for such a survivor, her future will remain uncertain, and only time will tell whether she will in fact be alive at the time of her daughter's graduation. Had they responded, "Is that what worries you?" they would be validating her processes of construing, acknowledging her as a construer of meaning. Women offer themselves as makers of meaning in their communications, and to have this invalidated can be severely damaging (Leitner & Guthrie, 1992).

As women living with breast cancer attempt to make the unreal, real, opportunities to elaborate their meanings, and to experiment with alternative meanings that help to restore a sense of coherence to their frameworks of meaning, their ongoing stories, will be essential (Lane & Viney, 2001b, 2000c). In the face of invalidation of core role constructs, women may experience dislocation, a sense of being cut off from the non-core meanings they used to make sense of the world. Without opportunities for constructive revision of their meanings women living with breast cancer will be unable to successfully adjust to their new circumstances, finding

themselves stuck in unhelpful Cycles of Experience, without the means to elaborate and enter into new, and more rewarding Experience Cycles.

In contrast to invalidation, validation, in the context of supportive role relationships, involves being confirmed as real in the eyes of someone else (Mair, 1979). When women have the opportunity to develop new meanings they are able to envisage a future that accommodates their changed circumstance. They can again anticipate some positive outcomes of their future-oriented predictions. Christine, a woman of 49, who has had two breast cancer diagnoses in the past five years, told me: “ I suppose now, looking back on it, it’s changed my life. You can’t say it’s better than it was, because you never would want to get sick in the first place. But now, I have a new meaning of life. I think I’ve come to terms with having cancer.” Clearly, this woman senses that she has developed new meanings, and, having tested these new meanings, she has established a bridge between her past and present meanings. The re-establishment of a sense of coherence in her life story allows her to look to the future. Even in the face of recurring breast cancer this woman dares to hope.

In summary, the diagnosis of breast cancer may invalidate these women’s central assumptions about themselves, conceptualised as threat to their superordinate core constructs. This invalidation accounts for the initial experience of psychological distress at the time of diagnosis. In order to elaborate new meanings, following their diagnosis, women will turn to their role relationships for validation of themselves as constructors of meaning. Invalidation of women’s constructs about their supportive role relationships results in a second threat to their construct system, threat to their superordinate core role constructs. This invalidation of constructs at the very centre of their being results in the experience of ongoing distress, and keeps women in a loop of negative emotion, with little opportunity to elaborate new meanings.

It is in the context of role relationships that support them as construers of meaning, that women with a diagnosis of breast cancer will first define their current meanings, and then elaborate new and more helpful meanings. Elaboration of new meanings, in the context of supportive role relationships, allows these women to re-establish coherence in their life stories, and envisage their future with hope. Hope that does not deny the uncertainty of their futures but reflects, as Leonie expressed it: "That I was going to have a full life, however long it was".

A major advantage of personal construct models is their heuristic value, in that they necessarily provide implications about processes rather than being purely descriptive (Winter, 1992). Personal construct models have been developed to define and inform understanding of a range of phenomena including psychological reactions to illness and injury (Viney, 1990), young women's constructions of trust in their relationships (Lane & Viney, 2002 in press) and crisis intervention counselling (Viney, 1995). The personal construct model of women's adjustment to breast cancer survival informs understanding of the process that underlies women's initial experience of psychological distress at the time of diagnosis, and explains why some breast cancer survivors continue to experience ongoing distress. The model also points to factors that may indicate women who are at greater risk of ongoing distress than others. These will be women who lack supportive role relationships that provide the context to define and elaborate their meanings.

The model also illustrates the mechanism that underlies the process of support. Support must validate women as construers of meaning, providing women with the context in which they can define and elaborate their new meanings. Finally, the model accounts for the paradox of findings that a diagnosis of breast cancer may be linked to both positive and negative responses. A diagrammatic illustration of the model is presented in Figure 5.

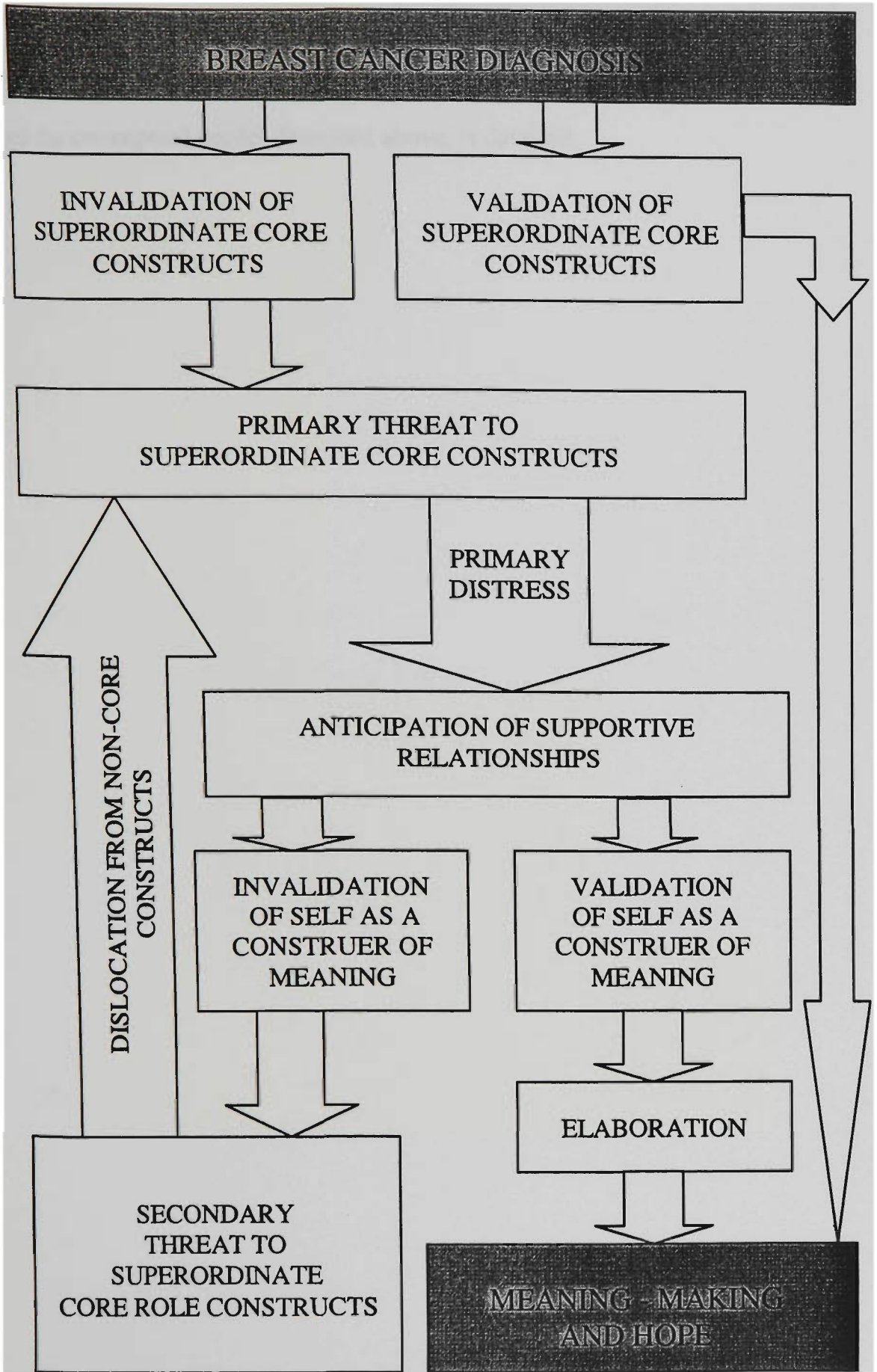


Figure 5. The personal construct model of the psychological processes of adjustment to breast cancer survival

In the following chapter, the first study, which investigated the ways in which the experiences of fifty-nine women “living with breast cancer” either confirmed or challenged the conceptual model described above, is detailed.

CHAPTER 6

STUDY 1: EXAMINING THE USEFULNESS OF THE MODEL IN UNDERSTANDING WOMEN'S EXPERIENCES OF BREAST CANCER SURVIVAL

“Every now and then it’s like a monster in the cupboard, or something, and he sneaks out and says: “Huh, I’m really here”. And you know, what if it comes back? You can live positively a lot of the time, but, when the cracks come, they are really deep”. (Catherine, 45 years).

In this chapter, Study 1, which was conducted to explore the usefulness of this personal construct model with women's experiences of breast cancer survival, is described. I first present my reasons for examining women's subjective experiences of living as survivors of breast cancer, and describe the two methods used in this qualitative study: focus groups and individual interviews. I introduce the participants and the manner of their recruitment to the study. The findings of the study are then reported (Lane & Viney, 2000b). In the discussion section I evaluate the helpfulness of these findings to breast cancer survivors and those involved in their care. I then discuss the fit of the personal construct model to the findings. I consider how the information generated by this study may inform the development of interventions to work therapeutically with breast cancer survivors. The limitations of the study with recommendations for future studies and a summary of the findings of Study 1 are then presented.

6.1 The Subjective Experience

In recognition of the need to make the subjective experience of illness more intelligible (Allbrook, 1997; Broyard, 1992; Toombs, 1992; Viney, 1983a), there has recently, within qualitative medical research, been a surge of interest in narrative accounts of illness, and in methods of narrative and thematic analysis (Little et al., 1998; Kleinman, 1988; Frank, 1995; Viney & Bousfield, 1992). In 1998, the NHMRC National Breast Cancer Centre (Turner, Wooding & Neil, 1998) in Australia published their report on the psychological and social impact of breast cancer as part of a larger project aimed at developing guidelines for the provision of psychological interventions for women diagnosed with breast cancer. Of several recommendations, one has particular relevance to this study:

The existing literature on the psychosocial impact of breast cancer, overall, focuses on 'end points', using measures of anxiety and depression. There is a need for high quality research, which elucidates the particular aspects of the disease, management and course, which contribute to adverse psychological outcome, including specific concerns of women and their families.

Qualitative research methods provide researchers with opportunities to '*listen*' to the experiences of their participants. The methods used in qualitative research are founded on the belief that they can provide a deeper understanding of psychological and social phenomena than would otherwise be obtained from purely quantitative data (Silverman, 2000). The *Aims* of this qualitative study were to:

1. Undertake research that is useful for breast cancer survivors, as well as health workers and consumer groups;
2. Examine the fit of the personal construct model described in Chapter 5; and
3. Generate information about how to work therapeutically with breast cancer survivors.

Research Questions for this study were:

1. What are the issues that breast cancer survivors identify?
2. What can the personal construct model add to current understanding of the ongoing issues faced by these women?
3. What can the personal construct model add to current understanding of working therapeutically with these women?

6.2 The Methods Used to Explore the Usefulness of the Personal Construct Model in Understanding Women's Subjective Experiences of Breast Cancer Survival

In Study 1, my methodology is both interpretive and deductive. I did not set out to test hypotheses. I started with the view that the participants themselves were the experts on their breast cancer experiences. These methods, allowed me the opportunity

to meet with my participants, to hear their narratives, and gain a deeper understanding of their experiences. In this section I describe the two methods used in this study: focus groups and individual interviews.

6.2.1 Focus Groups

A useful technique for exploring the subjective psychological issues of a cancer population is the focus group method (Boehmer & Clarke, 2001; Ferrell, Grant, Funk, Otis-Green & Garcia, 1997a; Weitzman, Zapka, Estabrook & Goins, 2001; Wilkinson, 1998, 2000; Wyatt, Kurtz & Liken, 1993). A focus group is a group discussion in which a number of people with identified “expertise”, or information, are brought together to talk about a specified group of topics in an organized manner to address a particular issue or research question. The purpose of the focus group is to gain understanding rather than to make generalizations.

Focus group methods have been used in market research since the 1920s (Kitzinger, 1994) and are now gaining acceptance in both clinical and research fields, particularly as a method of collecting data to inform improvement in practice and quality of care through consumer input (Ferrell et al., 1997). Focus group methods have been used to examine a wide range of issues related to breast cancer diagnosis in the past five years, including quality of life issues for breast cancer survivors (Ferrell et al., 1997), the information needs of well, long-term survivors (Gray, Fitch, Greenberg, Hampson, Doherty & Labrecque, 1998), understanding the breast cancer experiences of African-American women (Ashing-Giwa, & Ganz, 1997) and women’s use of mammography (Bailey, Erwin & Belin, 2000). Phan and Fitzgerald (1996) identify a number of advantages that the focus group has over more structured methods of data collection. These are presented in Table 6.1.

Table 6.1

Advantages of the Focus Group Method (Phan & Fitzgerald, 1996)

1. It places participants in a natural real-life situation as opposed to controlled experimental conditions.
 2. Participants provide an audience for one another that encourages discussion and greater variety of communication than may be found in other methods of data collection.
 3. It provides the opportunity to explore the reasoning behind the participants' meanings (and vice versa).
 4. It allows facilitators to explore issues that arise spontaneously, which is not possible with many other structured questioning sequences and surveys.
 5. Data collected have high face validity with opportunities to check immediately on the validity of people's meanings.
 6. It is relatively low in cost and in time.
 7. It provides a means for the generation of research hypotheses.
 8. It provides information about appropriate ways to conduct future research on the topic.
-

6.2.2 Individual Interviews

Interviews are also an important source of information, and can be either open-ended or structured. The purpose of open-ended interviews is to gain an understanding of an event from the participants' accounts of it. The participants can also be asked to propose their own understandings of the event, the meanings they have ascribed to the event. In this way the participants take on the role of "informants" rather than respondents (Yin, 1994). A second type of interview is the

focused interview (Merton, Fiske & Kendall, 1990), in which the researcher follows a certain set of pre-determined questions. In Study 1, I used a combination of these forms, to both listen to the individuals' accounts of their breast cancer experiences, and to corroborate the focus group findings. The interview participants were first asked to talk freely about their own breast cancer experiences. I then reported on the issues raised by the women who had participated in the focus groups, and asked each participant in the individual interviews to comment on these issues by responding to the following three questions:

1. In what ways do you consider your own experiences were similar to these women's?
2. In what ways do you consider your experiences were different from these women's?
3. What do you think might account for any differences in your experiences to those of the women in the focus groups?

The individual interviews served, therefore, not only to allow for the participation of women who were unavailable to attend a focus group due to other commitments, but also as a check on my understanding of the issues raised by the women in the focus groups.

The Study was conducted in November 1999 in the Illawarra region of New South Wales, Australia. The conceptual framework on which this study was based was the personal construct model of the breast cancer experience described in Chapter 5. Ethics approval for the study was granted by the University of Wollongong, in conjunction with Illawarra Area Health Service, a part of the State Department of Health.

6.3 The Participants

Women who attend the Illawarra Breast Cancer Support Group meetings, were invited to participate in a focus group to identify the issues of concern to breast cancer survivors. A total of 34 women (approximately 68%) said they would participate in the study. These support group members were also asked to invite women from within their social network who were also breast cancer survivors, but chose not to attend a support group. In this way a further 25 women were recruited. The use of a convenience sample is consistent with established qualitative methodology, the sample being representative of the phenomenon of interest (Patton, 1990).

In recruiting participants for the study, I gave no definition of the term “survivor”. The research participants were, then, women with breast cancer who identified themselves as being “survivors”. The sampling framework relied on self-selection as the unit of inclusion and no exclusion criteria were employed. All 59 women who volunteered, irrespective of age, time since diagnosis, and disease stage, were included in the study, the only two criteria were: they had been treated for breast cancer and considered themselves to be “survivor”.

6.3.1 A Description of the Participants

The mean age of the participants was 55 years (SD = 10 years, median = 53 years). The youngest participant was 38 years and the oldest, 78 years. Time since diagnosis ranged from 2 months to 24 years (median = 4 years). Twenty-four women (41%) were less than 45 years at time of diagnosis. Thirty-two women (54%) were between the ages of 45 and 64 years at time of diagnosis. Only three women (5%) were older than 65 years at the time of diagnosis. Twelve women (20%) had completed adjuvant chemotherapy or radiation treatment in the previous twelve months. Twenty-one women (37%) were currently on adjuvant hormone treatments, most commonly Tamoxifen, a drug that blocks oestrogen pathways to inhibit cancer

cell growth. Adverse effects from this drug are common, and include menopausal symptoms and weight gain (Aiken, 1996). Thirty-four women (58%) regularly attended support group meetings and twenty-five women (42%) had either never attended a support group meeting, or had not done so in the past year.

6.3.2 The Approach to the Participants

All of the 59 women volunteers were contacted by phone and their availability to attend the focus groups established. Information and consent forms for consideration and signature (see Appendix C) were mailed to the participants in the week prior to attendance. Six focus groups were scheduled, two morning groups, two afternoon groups and two evening groups, at community health centres in various locations within the Illawarra. The women chose the place and time that was most convenient to them. Of the 59 women who volunteered to participate, 41 (70%) were available to attend a focus group. Eighteen women were interviewed individually in their own homes. The most common reasons these women gave for not attending a group were: childcare difficulties, work commitments, or the demands of caring for a dependent adult. I conducted the focus groups for two hours and provided the participants with refreshments following the discussions. Individual interviews ran for approximately one hour in the homes of the women. At the time of these interviews, I had completed four years of study in psychology and was conditionally registered with the New South Wales Psychologists' Registration Board, while undertaking two further years of supervised clinical experience. The participants were informed that much of the literature on breast cancer survivors suggests that issues of loss and uncertainty are frequently found to be ongoing concerns. The prompt questions were, however, framed to be more general, so that other issues would not be excluded. The open ended prompt format allows considerable freedom to participants to give accounts that highlight the experience not afforded when responding to an order of

importance imposed by the researcher (Boehmer & Clarke, 2001). The three prompts were identical for all groups and interviews and are shown below. Women interviewed in their own homes were also asked, after responding to these prompt questions, to comment on the focus group findings, in terms of how their own experience fitted with these. The three prompt questions were asked of all participants:

1. From your personal experience, what issues are of specific concern to breast cancer survivors?
2. What, if anything, has been unhelpful to you?
3. What has been most helpful to you?

With the participants' permission, field notes and audio tape recordings of the focus group discussions and the individual interviews were made. I subsequently transcribed these verbatim. During group and interview sessions, participants were asked to elaborate on any contributions that I did not clearly understand. These transcripts formed the data source for the analysis process.

The guiding framework of the model directed my initial thematic analyses (Miles & Huberman, 1994). I first immersed myself in the responses by reading the transcripts in their entirety. Participants' comments about validation and invalidation of their anticipations were identified and extracted. These comments were then grouped into clusters, using a 'cut and paste' method (Robson, 1993). The clusters were arranged into tables with direct quotations from the discussions and interviews inserted to illustrate the different categories of validation and invalidation. I returned to the original complete data set to explore the themes that underlie these women's accounts of the meaning of being a breast cancer survivor.

To enhance the trustworthiness of my findings, meetings were arranged with the participants, to report on the themes identified, and to confirm that my

understandings captured the participants' meanings. This method of confirmation of the interpretations from the informants themselves has been recommended for researchers using personal construct theory (Kelly, 1965; Nagy & Viney, 1994; Viney, 1987), and serves as a source of "phenomenological validity" (Miles & Huberman, 1994). My view is that researchers also have an ethical responsibility to report to their participants the conclusions drawn from their responses. Overwhelmingly the research participants reported that the themes identified captured the underlying processes that give rise to the distress they experienced. Every one of the 59 women indicated that she had experienced some aspects of these processes.

Miles and Huberman (1994) suggest that qualitative definitions may become sharper when two researchers examine the same material. Disagreements can highlight definitions that need to be expanded or amended. A three year trained psychology graduate, blind to the model, undertook a second analysis of the transcripts. Her instructions were: "Group the data extracts into thematic clusters". Comparisons were then made of our groupings. Cohen's Kappa statistic (Cohen, 1960) of inter-judge reliability was used to overcome the shortcomings of the simple proportion of agreement. Cohen's Kappa statistic explicitly recognizes the likelihood of chance agreement between judges and removes it from consideration. Inter-rater reliability was considered adequate (86%) and, following discussion, all differences of interpretation were resolved. Table 6.2 summarizes the methodological processes of Study 1 and is presented below.

Table 6.2

Methodological Processes of Study 1

Research method			Outcome
Review of the breast cancer literature	Development of a theoretical model of breast cancer	Focus group discussions (n = 41)	Interpretation of findings within the framework of the model
Review of the personal construct literature		Individual interviews (n = 18)	
		Check by participants	
		Check by second thematic coder	Development of a theoretical intervention

6.4 The Findings

The focus groups and individual interviews resulted in over 26 hours of audio taped data that was transcribed and then analysed into thematic patterns. The themes identified, themes of validation and invalidation, relationship themes, themes of survival, and themes of change, are now presented. Due to the interactive nature of focus groups it is not possible to identify individuals from the transcripts of the discussions. For many of the examples, then, in the following section, age and time since diagnosis of the women is not reported. Descriptive information is included in examples taken from the individual interviews. The themes raised by the women in the individual interviews did not differ from those raised in the focus groups, nor were there differences between focus groups. I selected examples in this section according to their representativeness of the major issues raised by the participants.

6.4.1 Themes of Validation and Invalidation

The experience of their diagnosis with breast cancer as invalidation of prior anticipations was common to all the participants. For many, their initial reaction was

anger, and a search for an answer to the question: "Why me?" Jan, a 55-year-old woman, now only two years post diagnosis said: "For about a month after surgery, I walked along the beach writing WHY ME". She went on to say: "but then it slowly got to me, why not me? There's no one else you would wish it on, not even your worst enemy".

The experience of threat, a deeply personal experience of profound changes required in themselves and their ways in the world, that has far-reaching implications (Kelly, 1955/1991), was a recurring theme for the women in this study. They expressed their sense of loss as they were forced to let go of their old and preferred ways of being in the world. "And then to find out that I wasn't this invincible person", was how one woman expressed how her cancer diagnosis threatened her previous sense of self. The world and events within it now seemed unpredictable to these women. For many, this was expressed as a sense of vulnerability. Marie, six years since her diagnosis, remembered vividly the impact of her diagnosis on her most fundamental beliefs. She said: "You thought you were safe, and suddenly you realise that you are at the mercy of the fates." Helen echoed this sense of threat to her prior meanings: "You go along thinking that you are immortal and thinking you know everything will go according to some sort of plan, and then you realise there isn't a plan, or there might be a plan, but you don't know it," she said.

For many women, their breast cancer diagnosis also threatened the meanings they had constructed about themselves as mothers. Women with daughters, both young and old, were concerned that they may have passed on the disease, and those with young children were fearful of not being alive to see them into adulthood. As Christine recounted: "I used to get really angry at the doctors when they would talk about the five year life expectancy as if it was a gold medal at the Olympics. And I said to him: 'a five year plan, I need a 15 year one'. I mean I've got little kids".

Most of the women recounted how their diagnosis came “out of the blue”. Strikingly, all the women remembered the exact day and date of their diagnosis. For these women, from that day on, everything changed. Their sense of loss, of having to let go of their preferred meanings was expressed succinctly by Bella, now two years since her diagnosis: “I wish I could be like I was before. You can’t ever have that sense again. You feel like that has been taken away from you, that sense of I’m OK”.

While not all women who underwent a mastectomy were distressed by the loss of a breast, the impact for some women was intense. For these women, their breast cancer diagnosis invalidated their anticipations about their physical ways of being in the world. Sue, a woman of 52 years, reported that it was not any easier for her to accept the loss of her breast now than it had been five years earlier: “You’ve got a constant reminder. I mean you forget about it and then you get in the shower and your breast is gone”. The following examples of threat in response to invalidation of prior meanings, presented in Table 6.3 below, illustrate some of the ways threat may manifest itself in women living as breast cancer survivors.

Table 6.3

Breast Cancer Diagnoses as Invalidation of Prior Meanings Leading to Threat

Invalidation of prior meanings about themselves (threat)

- I never thought that I was the sort of person to get breast cancer, there wasn’t any history of it or anything, and I have always been healthy and never thought of myself as a cancer candidate.
 - I’d been doing all the right things, swimming, exercising and eating right.
 - You always feel you are not a full woman. You have lost that part of your body.
 - I think you lose confidence both as a person and as a woman because you didn’t choose breast cancer.
 - When you are dealing with what you might feel at the time is a death sentence it’s pretty hard not to feel vulnerable.
-

Table 6.3 (continued)

Breast Cancer Diagnoses as Invalidation of Prior Meanings Leading to Threat

Invalidation of prior meanings about their ways of being in the world (threat)

- It's your own self-esteem. I didn't like him seeing me. I'd go into the bathroom to get dressed.
 - I would like to dress femininely or provocatively, but I don't like to go there anymore.
 - I feel a real sense of loss because I was only 28 and that was very difficult. I mean. I used to go to the beach a lot. Well, I don't set foot on the beach these days.
 - I felt a lot better after my reconstruction. It was for me, not for my husband, for me. To try to put back what had been taken away.
 - There is a loss of sexuality to the extent that I did not want my husband to touch me
 - You do lose your confidence. I think chemo does it. Chemo, and losing your hair, you just lose so much confidence in yourself.
-

Many women feared a recurrence of the disease, and felt distressed by their inability to anticipate positive future outcomes. As Frances, a 73 year-old woman who said, "I mean, you don't know if you are completely free". Viney (1983b) has examined how hospitalised women with severe and chronic illnesses like cancer may construct images of helplessness. Characterized by an inability to commit to the future, these images lead to withdrawal and passivity. Breast cancer survivors, however, are relatively well. The challenge they face is to hope for positive outcomes, in the face of their uncertain futures.

In Chapter 4, hope was defined as the awareness of a commitment to the outcome of positive future events. In contrast to this dimension of transition, hopelessness is characterised by an inability to anticipate positive future outcomes. As Sheila observed: "I mean, there are nine of us sitting here, you're doing research, how many of us are going to be here in five years time?" Further examples of the hopelessness experienced by these breast cancer survivors are presented in Table 6.4.

Table 6.4

Invalidation of Breast Cancer Survivors' Prior Meanings (Threat), Leading to an
Inability to Anticipate Positive Future Outcomes

- I feel as if I am in no man's land at the moment, you know, waiting to get up to the magic five years then I'll know I'm past that, which of course is no guarantee.
 - I'm nine years down the track now, but I must say that every time I get something wrong with me, even nine years later it's still there. I still think the cancer will come back. And I don't think that ever leaves you.
 - You try not to, but you get an ache somewhere, or a lump somewhere or other, and you look at it and say 'is it?'
 - I just don't believe you ever beat it; you're not ever cured.
-

Grouping the issues raised by the participants into thematic clusters, helped to conceptualise the factors that contributed to the threat these women experienced. The themes reflect the nature of threat for breast cancer survivors. The unexpected nature of their diagnosis was a major theme for these women. Coming “out of the blue”, and without warning, the women were unprepared to face the challenge of breast cancer. Once diagnosed, these women felt a sense of loss as they were forced to let go of their old meanings. This loss was experienced as grieving. Val, a 51-year-old woman revealed: “I was diagnosed with breast cancer, and it's nearly ten years, but they took the whole breast off. I feel like this beautiful tree that has had its branch lopped off.” A summary of all of the themes identified by the participants is presented in Table 6.5.

Table 6.5

A Summary of the Themes Identified by Breast Cancer Survivors

Threat to their current meanings:

It was random (“Why me?”);
 It was unexpected (“It came out of the blue”);
 It made no sense (“No one in my family has cancer”);
 It challenged their view of themselves; and
 It challenged their view of their roles in relation to others.

Threat to their ways of being in the world:

Loss of confidence as a result of losing their breast;
 Loss of confidence after losing their hair during chemotherapy treatment;
 Loss of sexuality; and
 Not being able to do things they previously enjoyed.

Threat to positive future anticipations (hopelessness):

Fear of death;
 Fear of recurrence; and
 Uncertainty of their prognosis (“Never knowing if you are cured”).

6.4.2 Relationship Themes

Having identified the major issues faced by women diagnosed with breast cancer, I then wanted to understand the factors that had been most helpful or unhelpful to these women, as they struggled with these issues. Unanimously, the women reported that their relationships with others had been the most instrumental factor in their adjustment to their diagnosis. The women spoke at length of their expectations about their partners' and friends' responses to their diagnosis. For some women, these anticipations were validated, as Sylvie, a 69-year-old woman, twelve months post surgery recounts: “Actually I had no problems whatsoever, I have a good husband, three good children, five grandchildren, . . . I feel like I haven't got a problem in the world, at the moment anyway. We go out square dancing and live our

life to the full. All the time. And he's very supportive, I mean I'm spoilt rotten, I really am. And that's what makes it easy".

For many women, however, their anticipations about their relationships with husbands/partners, family and friends, were invalidated. Some women, though disappointed, expressed an understanding of the difficulties people may experience when someone they love is diagnosed with cancer. Others felt angry and hurt. As they tried to articulate and make sense of their experience, they found that others actively discouraged, or cut off, opportunities for such discussions. Some women also felt inhibited in expressing their anxieties to family members, because they wanted to protect them from their fears. Examples of invalidation of their anticipations concerning their relationships, particularly with husbands and family, were sadly common. Kathy, two years after her surgery, continued to feel distressed by her family's inability to "hear" her. "I mean you can tell other people things, but they (family) can't understand. They can only think that you are going to be all right. They never think that you are not going to be here", she said. Kathy's experience of invalidation of herself as a construer of meaning was echoed in many of these women's stories. Julie, a 52-year-old woman who was diagnosed with breast cancer 3 years ago, said: "If I said to him (her husband) that I hope I'll be alive in 5 years time, I mean, I would like to be able to say that but, until you are faced with your own mortality, I don't think people can understand. They just want to think that it (the cancer) has gone forever."

Not only did the women report being unable to discuss their feelings, they also found it difficult to talk about the ongoing physical discomforts they were experiencing. Betty, a 65 year old woman, 22 months post diagnosis said: "I'm scared to talk about it, even on the phone they (her adult children) say: 'How are you Mum'"

and I say, "Oh, I'm pretty good". I don't say, " Oh, I think I've got lymphoedema³ because my arm's hurting". And I don't like to say it because they will say: "Oh, you're dwelling on it". And I am not. You just want to talk to someone".

The inability of others to understand their support needs was, therefore, a recurring theme in the transcripts of these women's accounts of their struggles to adjust to being breast cancer survivors. Support requires the supporter to accept and acknowledge the other's processes of construing, and their exploratory attempts to communicate their meanings. I argued in Chapter 4 that the mechanism of support lies in validation of people as construers of meaning. Even women five or more years after their treatment for breast cancer wished they could express their continuing concerns to someone who would listen without judgement. This need to have their meaning-making processes validated was clearly expressed by Jean who said: "I think it would be great if there could be some form of counselling. People could talk more frankly and not have to hold back like it is in front of family. To admit I'm scared, I think that would be a wonderful thing" (63 years, eight years since diagnosis). Like Jean, many of the women felt that counselling would be helpful to them, most particularly so that they could express their anxieties and fears with someone who was not family. Margaret, a 48 year-old woman said: "Everybody needs help because things you want to say to your family you can't without getting them upset". Further examples of invalidation of the participants' meaning-making processes are provided in Table 6.6.

³ Lymphoedema occurs in approximately 10% of women treated for breast cancer. Characterized by swelling and pain in the arm, it results from dissection of axillary lymph nodes and or the effects of chemotherapy and radiation treatments (Dow et al., 1996).

Table 6.6

Examples of Invalidation of their Meaning-Making (Construing) Processes Identified
by Breast Cancer survivors

Invalidation of their meaning-making processes from husbands/partners and family

- He (husband) was sick of my being sick. So that really hurt that he said that.
- I get frustrated (with husband) and I realize that it is because he doesn't always understand. Sometimes I can talk to him and sometimes I can't. It's them not understanding or not knowing, so they don't want to talk about it.
- He (husband) couldn't support me because he didn't have it in him. He'd lost his first wife and he lost his father to cancer so he's got no belief in it being cured.
- I would feel angry about it because I would rather that I could talk to him. I felt that he didn't understand and that was why he got cross with me and got angry because he would just say "Well if you've got no pain and you've not got this, what's wrong with you?"
- I'm not that sort of person (to keep thinking about death), it's not that I dwell on it, but I find these unwanted thoughts. If I said that to my husband, he'd have a fit.

Invalidation of their meaning-making processes from friends

- Sometimes female friends would cross to the other side of the street or duck into the nearest shop because they couldn't face the fact. They feel guilty because they think 'I'm glad it's her and not me'.
 - Another woman (friend) put a basket of flowers in my hands and just ran off. Couldn't speak, just threw them in my hands and went. Couldn't handle it I suppose.
 - I lost 10 kilos and I had no hair and everyone was saying to me, 'oh you look great'. People can't be honest with you, they say this and that, but you know deep down they are not telling you the truth. That's the hard part.
 - It's like your friends are there and they say they understand and everything. But they don't understand. They haven't been through it.
-

Support from other breast cancer survivors was perceived by many to be very helpful. Many spoke of the bond they experienced between women who had similarly been diagnosed with breast cancer. The bond they described was connected to their sense of being understood. As Sylvia said: "You become part of a club and nobody else can understand". Talking to someone who had been through a similar experience helped re-establish these women's connection to others. The thirty-four women who

attended the local support groups spoke enthusiastically about the benefits of attending the groups. Most particularly they believed it afforded them the opportunity to talk to other women who had been through the experience of breast cancer, and express their fears without worrying their families. The support group provided these women with validation of the content of their construing. The benefits they identified are presented in Table 6.7.

Table 6.7

The Benefits of Validation of the Content of their Meanings Identified by Breast

Cancer Survivors who Attend a Support Group

- I think you need to get on with your life and that's why the support group is so good. You don't want to upset your families and that. I like to protect them.
- I've always tried not to bother them (daughters), and that's why I've found so much support from the support group.
- I think I am initially over the scare because I've been going to the support group.
- But when you talk to other women with breast cancer they know exactly, everybody has experienced those feelings. And I think that is why the bond is there.
- Going to the support group made me feel that I was not alone.

Many women identified the period when treatment first finished as a time when they felt highly distressed. The following two examples from the women reflect the challenge survivors of breast cancer face at the end of treatment. Ellen said: "You're glad to get rid of it (treatment), but also you think, I'm not going to get any more. You feel abandoned, because they (doctors) don't want to see you anymore". Clair said: "After chemo or radiation, it's like a death, a lot of people manage to hold it together until after the funeral and then they fall." She went on to say: "And it is so easy to sink when you are in that dreadful state, as well I know. I almost did, I mean, as I said, I even prayed to die". For many, this was also a time when they felt enormously pressured by others to "put it all behind them", with an expectation from

others that they should return to their former selves. As Ellen said: “I had a lot of sympathy with the breast being taken off, you know, but then I had a breakdown, well, all I got was: ‘snap out of it’”.

6.4.3 Themes of Survival

The task for breast cancer survivors is to reconstruct their meanings in the face of an apparently random and frequently unexpected event. Adjustment, for survivors of breast cancer, therefore, involves the reformulation of coherent self-stories or theories that become the bridges between the past, present and future. Many of the women, irrespective of time since their diagnosis, felt they had not fully adjusted to being a cancer survivor. Sheila, a 52 year old woman reported: “Well it’s been six years since I had my mastectomy and the cancer has left me more of a stressed person. Parts of me, my body and my brain are distressed”. Others, however, felt they had “emerged” from the experience with new meanings. Although they were not glad to have been through the trauma of the disease, they reported being grateful for the lessons they felt they had learned. Their themes of survival as meaning restructuring are summarized in Table 6.8.

Table 6.8.

Themes of Survival as Meaning Restructuring Identified by Breast Cancer Survivors

Themes of new meaning

- I think you tend to respect life more and to enjoy life more.
 - You don’t tend to worry so much about the big things. The little things still throw you, but anything big happens, you just face it and get over it. It’s just those tiny little things that sort of mount up.
 - I think having cancer made me stop and have a look at the whole, my surroundings, the way I lived, and everything like that, and what I really wanted out of my life.
 - I think you try to fit more into your life, you don’t know how long you’ve got so you think, and I’m going on this holiday or whatever, things like that.
-

Table 6.8 (continued)

Themes of Survival as Meaning Restructuring Identified by Breast Cancer Survivors

Themes of gratitude

- I think we've all been given prime time because you could get run over and never get to tell your family that you love them or anything. We've had time to enjoy them and we've been given that chance where other people might not get that.
 - You thank God you're here for another day.
 - It makes you appreciate each day because you don't know how long you've got.
-

6.5 Themes of Change

The model of women's adjustment to breast cancer described in Chapter 5 proposes that women who recognise that their most influential meanings of themselves are seriously inconsistent with their cancer diagnosis will experience threat. In Chapter 4, threat was defined as: "the awareness of imminent comprehensive change in one's core structures" (Kelly, 1991 p. 391). The opportunity to return to the participants allowed for feedback on the themes of change that had been identified. The participants were presented with a range of issues raised in the focus group discussions and individual interviews. The degree to which they endorsed these issues is now presented. Overall endorsement was judged to occur when the participants expressed their ability to identify with the issue raised. Many women offered similar experiences, or if not a part of their own experience, they could think of others to whom the issue had been a concern and was, therefore, important to a study on the challenges faced by breast cancer survivors. Areas of change unanimously endorsed by the women as crucial to an understanding of the challenge of a breast cancer diagnosis are summarised below in Table 6.9.

Table 6.9

Themes of Change Identified as Important by all the Participants in the Process of Adjustment to Breast Cancer Survival

Self in relation to others	Self in relation to the wider world
Change in their prior anticipations about self	Change in their prior anticipations about the world
Change in their support needs	Change in their physical being
Change in their levels of communication with others	Change in their ability to anticipate a positive future
Change in others' levels of understanding	
Change in their patterns of friendship	

Of the 72 issues raised by the participants that concerned change, 46% involved change in their interpersonal world. For a few women these changes were for the good. As Jane reported: "I'm a lot stronger now. The changes have been incredible within myself and in my relationships with people in general". For many, sadly, changes in their relationships brought about by their breast cancer diagnoses were not helpful. The type of relationships that proved problematic for these participants are summarized below in Figure 6.

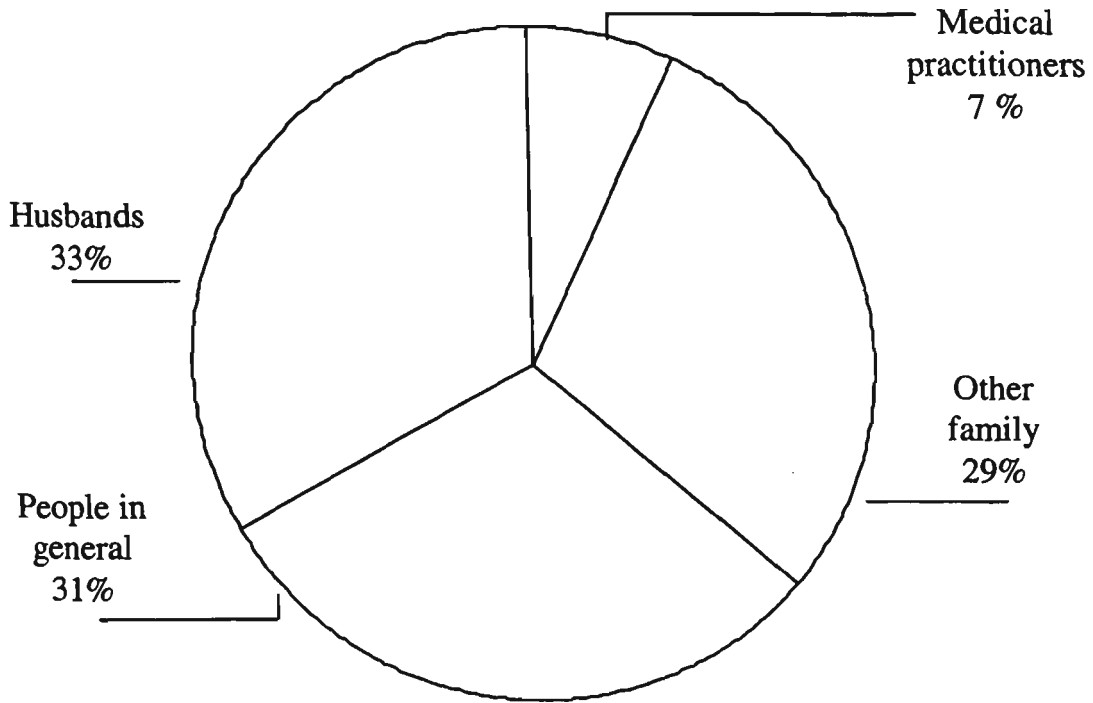


Figure 6. Types of relationships that proved problematic for breast cancer survivors

All the women felt their breast cancer diagnosis had forced them to change their beliefs about the world. Change in response to invalidation of their “assumptive worlds” (Janoff-Bulman, 1989, 1992) was often expressed as a sense of vulnerability, of being “at the mercy of the fates”. Allied to this sense was a change in their ability to predict their future outcomes with what they now recognized as an erroneous previous sense of confidence. As Mary expressed this understanding: “People say that anyone could be hit by a bus tomorrow, but in our case, the bus has already left the depot”. A further 17% of their issues concerned change to their physical being in the world. The impact of these changes was felt both on their understanding of themselves as women, and on their sense of themselves in relation to others. The identified changes as proportions of the issues raised by the participants are presented below in Figure 7.

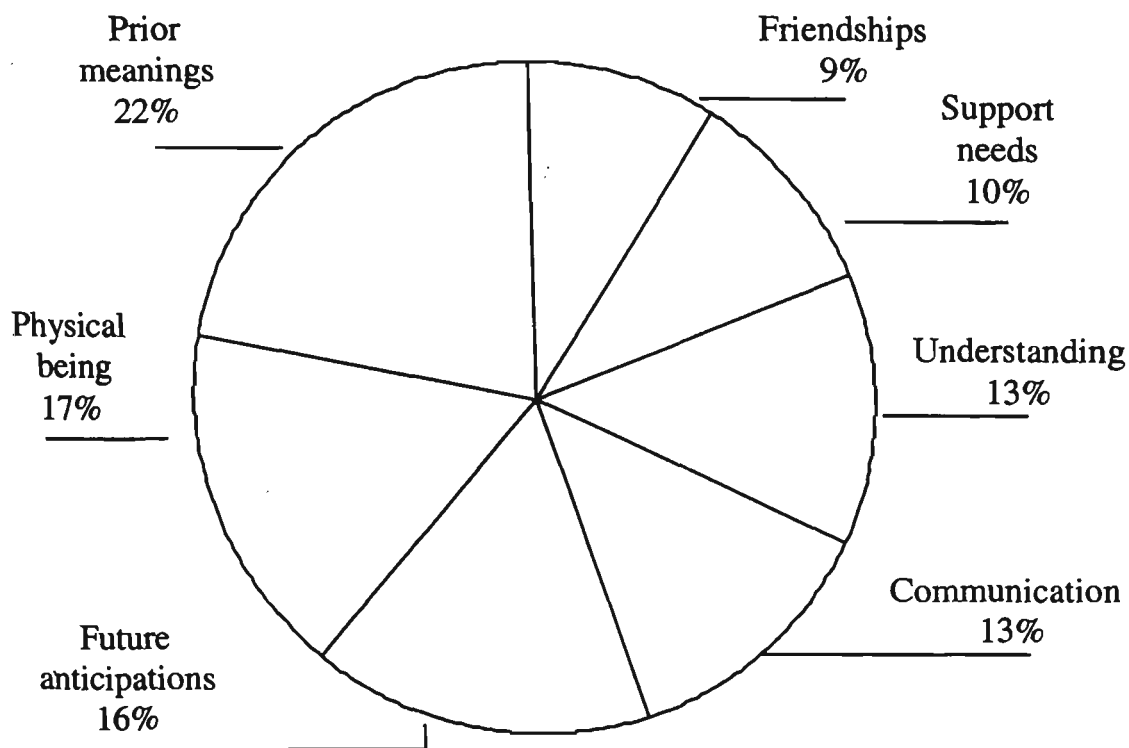


Figure 7. The proportions of issues linked with the changes required in breast cancer survivors as a percentage of all the issues raised

6.6 Discussion

I will now address the aims of this study. Its first *Aim* was to undertake research that was useful to the participants as breast cancer survivors, as well as to health workers and consumer groups. In terms of the usefulness of the study to the participants, the women in this study reported that it had been very helpful to them to conceptualise their experiences in terms of the processes identified. To them it “made sense” of their experiences of distress, and confirmed that they were not “crazy” or “silly”, or “failing to stay positive”. Many of the women were also hopeful that the disclosure of their issues would result in a better understanding of the issues women with a breast cancer diagnosis may face. To achieve this aim, a summary of these findings was distributed to medical oncologists within the Illawarra region. I also met with a number of these oncologists to discuss how the psychological needs of women with breast cancer may best be met. For many women, the sense that they were

participating in a project that may benefit women with breast cancer in the future was also seen to be valuable. They were pleased to have the opportunity to pay back some of the support they had received, and to redress some of the problems they themselves had encountered, so that the breast cancer experience may be easier in the future for women diagnosed with the disease. Most importantly, they reported that the realisation that others shared similar issues made them feel less isolated by their diagnosis.

In terms of the helpfulness of the study to health workers and consumer groups, the women in this study made clear the nature of the support they require. While they may seek reassurance from some relationships, what is clearly needed is a context in which to articulate their deepest fears, to receive acknowledgement of their concerns, untroubled by concerns about upsetting those who hear them, and in a non-judgemental and accepting environment. The findings show that these breast cancer survivors would welcome greater understanding of their own attempts to articulate their processes of construing their experiences, and opportunities to relate to others who could offer this understanding because they had similarly experienced a breast cancer diagnosis.

The second *Aim* of this study was to examine the fit of the personal construct model developed and described in Chapter 5. The model served as a framework for identifying the issues of concern for the women living as breast cancer survivors in the study. The theoretical concept of threat, upon which the model was based, also provided an alternative means to define the issues they raised.

Having established the model's usefulness in aiding the conceptualisation of the psychological processes precipitated by a breast cancer diagnosis, this study served to confirm the processes of adjustment to being a breast cancer survivor proposed by the model. Overwhelmingly, the participants in this study perceived the

degree of support they received, or failed to receive, played a major role in their ongoing adjustment to being a breast cancer survivor. The role of the interpersonal environment as a factor in psychological adjustment to breast cancer has been identified in the breast cancer literature (Bloom, 1996; Bloom et al., 1998; Dunkel-Schetter, 1984; Dunkel-Schetter & Wortman, 1982; Ell et al., 1989), although the mechanisms of support from others has remained unclear (see Chapter 2). The personal construct model proposes that it is within these social contexts that breast cancer survivors anticipate opportunities to define their current meanings, and elaborate new meanings. Invalidation of this anticipation is proposed to result in a secondary threat to the women's meanings, accounting for the ongoing distress noted in the literature on breast cancer survivors (see Chapter 2), and the finding of this study. The model, supported by the findings of this study, may help those involved in these women's care understand how central to the processes of adjustment is the social context in which breast cancer survivors face the challenge of adjusting to their new circumstances.

The third *Aim* of this study was to generate information about how to work therapeutically with breast cancer survivors. Many women reported feeling "unheard" and unable to "voice" their fears and concerns to family members. The primary goal of therapy with survivors of breast cancer, therefore, should be to aid the development of supportive relationships that validate their meanings and strengthen their connectedness to others. For many women, their preferred avenue of support was women who had also experienced breast cancer. This finding supports the view that a breast cancer diagnosis often precipitates a realignment of interactions (Rowland & Holland, 1989), and suggests that group interventions may be most effective for breast cancer survivors, as these interventions provide opportunities to develop a supportive network of women who have their cancer diagnoses in common. Finally, the finding

that, for so many women in this study, invalidation of their processes of meaning-making by family and friends was experienced as highly distressing, suggests that interventions should be structured to include ample opportunities for the disclosure of breast cancer survivors' meanings, for validation of their role in construing these meanings, and the elaboration of new meanings. The group therapy that I developed based both on the information generated from this study and on personal construct concepts, will be described in Chapter 8.

6.7 The Limitations of the Study

In terms of the representativeness of the sample of 59 "survivors", only 5% were older than 65 years at the time of diagnosis, whereas approximately 18% of women diagnosed with breast cancer in NSW fall into this older age category (Kricker & Jelfs, 1996). Women beyond the age of 65 years at time of diagnosis were under represented in this study. The proportion of women in this sample attending the local support group (68%) is large (Taylor, Falke, Shoptaw & Lichtman, 1986). Non-support group members were, therefore, also under represented in this sample. The method of recruitment no doubt partly accounts for this. The tireless efforts of the Area Health Oncology Nurse Consultant for the Illawarra may further account for the overall positive attitudes women living in the region have towards support group attendance. These two limitations suggest that the findings of this study may be generalizable, only with care, to other breast cancer survivors. A third limitation concerns the use of a volunteer sample. Random selection of participants was not possible, given the nature of the study, which required participants to either attend a focus group, or allow me to visit them in their own homes. Rosnow & Rosenthal (1998) list a number of volunteer characteristics that may bias the outcomes of non-randomly selected studies. These include a tendency towards being more sociable, and more approval seeking. Both of these characteristics may have resulted in the

under-identification of issues of concern. If the women in this sample were more sociable than other women with breast cancer, given the link between social support and psychological well-being (Chapter 2), it is possible that these women had adjusted more successfully to breast cancer survival than non-volunteers. A tendency to seek social approval may also have influenced the women's responses. In attempting to "say the right thing", the volunteer sample may have felt uncomfortable voicing some issues. This characteristic may also have influenced the participants' endorsement of the issues raised.

However, many studies, as identified in the literature review presented in Chapter 2, have reported on the ongoing impact on breast cancer survivors of their initial disease experience (Bleiker et al., 2000; Carter, 1993; Ferrans, 1994; Ganz et al., 1993; Holzner, et al., 2001; Polinsky, 1994), a finding confirmed by the participants of this study. This finding supports earlier studies (Peters-Golden, 1982; Welch-McCaffrey et al., 1989) in that many women reported an inability to gain the support they needed from close family and friends, and a disinclination of others to discuss death-related issues (Pistrang & Barker, 1992; Spiegel et al, 1981; Spiegel, 1990). The women in this study were concerned about the uncertainty of recurrence and the effect of their illness on people close to them, as were the women reported by Pistrang and Barker (1992) and others (Dunkell-Schetter et al., 1992; Hilton, 1989; Loveys & Klaich, 1991). It is likely, therefore, that the issues identified in this study reflect issues that are generalizable to the wider population of breast cancer survivors. Further studies, with more representative samples, should confirm this.

The focus group format in which the majority of women were interviewed does not allow for easy identification of the individual participants. Differences in subgroups of participants were, therefore, not identified. It would have been valuable to determine whether the issues raised by younger women really reflected those of

older women, and to what extent time since diagnosis eases the burden of the initial trauma of diagnosis. The impression I gained was that although younger women expressed greater concerns for their children, the nature of the themes expressed was similar.

6.8 Future Research Directions

The women identified that talking about their concerns to others was helpful. The focus group discussions, individual interviews, and follow-up report back sessions gave the participants opportunities to share their issues with others in a supportive environment. It is likely therefore, that being a participant in this study was, in itself, of therapeutic benefit. As 'expert informants', their personal meanings received validation. As Sylvie said: "You have given us a sense of control. You have listened to us, you have heard us, and made us feel that we have something to say about what has happened to us". Another woman said: "The way you put it up in a diagram made it easier for me to understand, and see that that is exactly what is happening to me". In retrospect, measures of their levels of distress both before and after participation would have been useful. Although the role of validation of their meanings in adjustment to being breast cancer survivors is addressed in Study 2 and reported in the next chapter, future studies might usefully evaluate the benefits of being "informants" in qualitative research.

Finally, a woman who accompanied her sister to the report back session said: "Well, what you said. I have kidney cancer, I am here from Queensland, visiting my sister, and that is just what I felt". Future studies to evaluate the usefulness of the personal construct model that include participants with a range of cancers would help to identify the issues that are common to people living as cancer survivors.

6.9 Summary

In summary, the focus group and individual interview methods provided rich sources of information, allowing the breast cancer survivors to voice their personal understandings of the effects of breast cancer diagnosis. The findings of Study 1 support my model's conceptualisation of a breast cancer diagnosis as threat to the systems of meaning of these women, resulting in massive invalidation of their core assumptions, about themselves, their relationships, and their ways of being in the world.

For many of the women who participated in Study 1, their anticipations that their need for support would be met within the context of their social network, particularly by spouses and family members, were also invalidated. The participants linked this invalidation to the ongoing distress they experienced. This finding supports previous research findings (Chapter 2). However, although previous research has identified the beneficial role of support from the interpersonal environment, the message from these participants was that it was not merely *a* factor, but *the* factor that helps or hinders their adjustment.

Having established the usefulness of my model in adding to understanding of the mediating processes involved in adjustment to breast cancer survival, I then conducted two further studies of the role of interpersonal support in women's adjustment to breast cancer survival. In the following chapter, I describe Study 2, in which I use both quantitative and qualitative methodologies to evaluate the role of validation of women's understandings of their breast cancer experiences by others who have had similar experiences.

CHAPTER 7

STUDY 2: THE VALIDATION STUDY FOR BREAST CANCER SURVIVORS.

AN EXPLORATION OF THE BENEFITS OF THE RETREAT

“I remember thinking how dare anything invade me without my permission, which my husband still thinks that’s a funny thing to say. He says: ‘I don’t think cancer knocks on the door and asks if it can come in’. That was my thought. How dare you invade me?” (Robyn, 48 years)

Study 2, explored the effects on emotion of one process of support, validation of current breast cancer-related meanings through participation in the Retreat. In this chapter, the study is described and the findings are reported. I first present a summary of the key elements of the personal construct model that I explored in this study. The Retreat is then described. The evaluating concepts, aims, research questions, method, and approach to the participants are provided. I then describe the measures I used, with evidence of their appropriateness for the research I am conducting. These measures, the Content Analysis Scales (Gottschalk & Gleser, 1969; Gottschalk, 1979), and the Derogatis Affects Balance Scale (Derogatis, 1996), are used in both Study 2 and Study 3 (Chapter 9). They will be described in this chapter, with evidence of their reliability and validity. The results of Study 2 are then presented, followed by a discussion of the findings, with the limitations of this study and recommendations for future research.

7.1 A Summary of the Key Elements of the Model to be Explored

The personal construct model of adjustment to breast cancer survival proposes that the distress women experience following their diagnosis results from threat to their most important constructions of themselves. This proposition was supported by the findings of Study 1. The model proposes that when women find they must let go of old and preferred meanings about the world of events, they experience dislocation from their non-core meanings. This was also confirmed in Study 1. The model also proposes that women diagnosed with breast cancer will turn to their important relationships for support. Invalidation of their anticipations of support compounds the initial threat to their systems of meaning, making adjustment to their diagnoses and their ongoing living as survivors of breast cancer problematic. The accounts of the women who participated in Study 1 supported this proposition.

Within a personal construct framework, support is defined as a broad based response pattern that permits receivers to experiment widely and successfully (Kelly, 1955/1991). In Chapter 6, I reported that many women felt they could talk more freely about their breast cancer-related issues with other women who had similarly been diagnosed with breast cancer. This aspect of support is proposed to stem from women's search for validation of their existing meanings. The more meanings are shared with others, the more they will seem to be justified (Neimeyer & Hudson, 1985; Neimeyer & Neimeyer, 1983). However, as Rimé (1995) observed, many social situations are unlikely to offer people opportunities to express, in depth and at length, their feelings, leaving their attempts to process emotional information incomplete. This observation was also supported by the accounts of breast cancer survivors I presented in Study 1.

7.2 The Retreat

In the Illawarra, there are very few services addressing the psychological needs of women living as breast cancer survivors. To date, due largely to a failure of many Australian health authorities to prioritise psychological support for these women, both at the time of diagnosis, and in their adjustment to breast cancer survival, the services of even one psychologist experienced in oncology, is unavailable. Peer support, available in support groups, and the annual Retreat are the only supports available. Even these are largely dependent on; external funding, the women's own fund-raising initiatives, and the commitment and energy of the Oncology Nurse Consultant. The annual five-day/four-night residential Retreat for women living with breast cancer is organised, and in part funded, by Adcare Lifestyles Programmes, and the Illawarra Cancer Care Centre in New South Wales, Australia. The participants meet their own accommodation costs. Activities at the Retreat are predominantly planned to encourage physical well-being, and include

walking, swimming, gentle aerobics, tennis, yoga and massage. An educational component is also included, with classes in nutrition and simple relaxation techniques. Participants have opportunities to interact with each other informally over meals, games of cards and board games in the evenings. I have assumed that the Retreat would offer breast cancer survivors a social context in which to talk about their breast cancer-related meanings, and to have these meanings validated.

Although women may “hear” alternative meanings of others’ breast cancer experiences, no specific activities providing for the elaboration of new meanings, are structured into the Retreat programme. The primary aim of the organisers is to provide women with opportunities to share their common meanings, with activities structured towards this end. The success of the Retreat organisers in achieving this outcome is reflected in a remark made by Jean in Study 1, who had attended the Retreat in previous years. She said: “The retreat is the ultimate week, free of worries, just lots of hugs from friends who have been there, done that”. The Retreat should offer a social situation conducive to the sharing of the participants’ breast cancer-related meanings, that is, validation of their existing meanings without elaboration.

7.3 The Evaluating Concepts

The evaluating concepts of interest, deriving from the personal construct model of adjustment to breast cancer (Chapter 5) and the findings of Study 1 (Chapter 6) are now described. Study 1 confirmed that a breast cancer diagnosis threatens women’s super-ordinate core and core role constructs. Many breast cancer survivors experienced ongoing breast cancer-related concerns and felt overwhelmed by the changes they were forced to contemplate. Many feared they had passed on a breast cancer gene to their daughters. Some were ashamed of their new body image. All of these processes relate to threat to women’s sense of themselves. *Threat*, therefore was

an evaluating concept of interest. Many breast cancer survivors also fear a recurrence of their disease, or a spread of their disease, resulting in an early death. As uncertainty of prognosis is inherent to cancer, *Threat to existence* was a further evaluating concept of interest.

In Chapter 4, I argued that the interpretation of events, in terms of their potential for future anticipations, forms a basis for the human processes of living (Fransella & Dalton, 1990). However, when breast cancer survivors are unable to find meaning in their changed circumstances, they may experience a sense of loss or dislocation (Viney, 1990a). Breast cancer survivors mourn the loss of their non-core meanings, their sense of coherence in their stories about the world of events, which previously allowed them to successfully anticipate events. The third evaluating concept of interest, therefore, was *dislocation*.

In addition to these three evaluating concepts, with a decrease in levels of these being indicative of an increase in psychological well-being, *hope* was also included as an evaluating concept. Epting and Amerikaner (1980) suggest that the optimally functioning person is characterised by both openness to interaction with the environment and an orientation towards movement into the future. Kelly (1977) states that such a person is able to “transcend the obvious” (p. 4), “in arriving at fresh hopes never before envisioned” (p.9). If levels of hope increased as the participants became aware of their commitment to new and more rewarding cycles of experience, this too would indicate that the Retreat was beneficial to their psychological well-being.

Two further evaluating concepts were included. The rationale for their inclusion is now presented. To date personal construct concepts have not been applied to the study of women’s adjustment to breast cancer. The aim of the series of studies I conducted was to explore how these concepts may add to current understandings of the processes of adjustment to breast cancer. It was, therefore, important to evaluate

personal construct concepts, and anxiety and depression as they are more commonly conceptualised. In this way, the outcomes of Studies 2 and 3 can be compared to the general literature on adjustment to breast cancer (Chapters 2 and 3). In Chapter 2, I reported that the most common outcomes measured in the breast cancer literature were anxiety and depression. The concept of anxiety, in its common usage, is characterised by nervousness, tension and hyper-vigilance, with a strong cognitive component exemplified by worry and dread (Carver et al., 1993; Hall et al., 1999). Depression is characterised by feelings of sadness and melancholy, with a characteristic cognitive pattern involving feelings of worthlessness and discouragement (Antoni et al., 2001; Hall et al., 1999). It can be seen from these descriptions that these concepts refer to the expression of the psychological processes, rather than their underlying mechanisms. Personal construct formulations of these concepts refer to the processes of construing. In Chapter 4, I described the processes involved in the experience of anxiety as: “the recognition that the events with which one is confronted lie outside the range of convenience of one’s construct system (Kelly, 1955/1991, p. 366)”. Similarly, depression is linked with constriction of construing (Neimeyer, 1984), whereby people reduce their perceptual fields to minimize apparent incompatibilities (Kelly, 1991). The variables of anxiety and depression included in Studies 2 and 3 refer to the common (non personal construct) formulations of these concepts.

7.4 Aims and Research Questions

Personal construct theory suggests that validation of existing meanings only is not enough to bring about lasting reductions in psychological distress. Support also requires the provision of opportunities to experiment with new meanings. The personal construct concept of support, therefore, implies that it is only by allowing women diagnosed with breast cancer to define their current meanings

(validation of current meanings), and experiment with new meanings (elaboration of meanings), that women can be supported in facing the challenges of threat and dislocation as breast cancer survivors.

To examine these two processes of support, validation of current meanings and elaboration of meanings, I first needed to explore the effect of validation of current meanings alone. However, given that I anticipated any improvement in psychological distress would be short-lived, and that greater improvement would be achieved by opportunities to also elaborate new meanings, it would have been ethically questionable to conduct an experimental study that evaluated the results of an intervention that may not offer women the best possible outcome. As an established event in the Illawarra breast cancer community, the Retreat provided the solution to this dilemma, and this exploratory “natural experiment” became possible.

My *Aim* in conducting Study 2 was to learn more about one process of support, validation of current meanings. Because it was an exploratory, rather than empirical study, no hypotheses were formulated. Because construing and reconstruing are ongoing processes, the Research Questions were framed in terms of benefits both immediate and more long-term. The Research Questions were as follows:

1. Do women who attend the Retreat show significant decreases in levels of threat to construing of their physical and psychological selves, as a result of attending the Retreat and three months after the Retreat?
2. Do women who attend the Retreat show significant decreases in levels of threat to existence (death threat), as a result of attending the Retreat and three months after the Retreat?

3. Do women who attend the Retreat show significant decreases in levels of dislocation, as a result of attending the Retreat and three months after the Retreat?
4. Do women who attend the Retreat show significant increases in levels of hope, as a result of attending the Retreat and three months after the Retreat?
5. Do women who attend the Retreat show significant decreases in levels of (non personal construct) anxiety and depression, as a result of attending the Retreat and three months after the Retreat?

7.5 Method

As the study was examining the effects of a natural experiment, randomised sampling was not possible. Instead, purposeful, multiple case sampling was used. Purposive sampling allows for the selection of participants on the basis of their potential manifestation of theoretical constructs (Patton, 1990). The population of interest, breast cancer survivors, was defined as women having been diagnosed with breast cancer a minimum of six months prior to entry into the study, as the study is of women's adjustment to breast cancer survival, rather than the effect of diagnosis and treatment. As the physical effects of chemotherapy and/or radiation treatments, including, nausea, hair loss and fatigue, are known to affect women's psychological well-being (Chapter 2), completion of these treatments a minimum of two months prior to entry into the study was also deemed necessary.

Inclusion criteria were as follows:

1. First occurrence biopsy-proven breast cancer; and
2. Diagnosis more than six months prior to participation.

Exclusion criteria were as follows:

1. Metastases beyond adjacent lymph nodes;

2. Recurrence in breast or other tissue; and
3. Other cancers or illnesses thought to be life threatening.

Ethics approval for the study was granted by the University of Wollongong, in collaboration with Illawarra Area Health Service, and it was conducted by the researcher between January and July, 2000.

7.5.1.1 Recruitment and Sampling

In January 2000, 25 women living with breast cancer enrolled to attend the Retreat. I contacted these women and invited them to participate in this study. Of these 25 women, 23 chose to participate. Two had been diagnosed with metastatic cancer and one was currently receiving adjuvant chemotherapy. This resulted in a total of 20 women in the Retreat treatment group.

To examine the effects of attending the Retreat, I needed a population pool of similarly self-selected participants from which to draw a matched control sample. In February 2000, a call to participate in research examining the role of relationships, and support from others, in women's experience of breast cancer was placed in the Illawarra Breast Cancer Newsletter. Whilst this monthly newsletter is predominantly distributed to women with breast cancer who live in the Illawarra, it is circulated to a small number of Area Health Regions outside the Illawarra, including Shoalhaven, Wagga Wagga, and Albury/Wodonga on the New South Wales/Victoria border. Current circulation is 320. The aim of the newsletter is to provide a forum in which women can access and share news and information relevant to their experience of living with a diagnosis of breast cancer. This method of recruitment was preferred to referrals from oncologists and general practitioners; a method that can run the risk of inferring that the individual *should* take part. Willing research participants were invited to telephone me for further details of the study.

A total of 123 women (39%) responded to the request for participants. They were each sent the consent and information form, and the data collection set (see Appendices D and E), with a stamped addressed envelope for data return. Sadly, one woman died two weeks after returning her data, from a heart attack. On examination of their demographic information, two women were found to be less than six months post diagnosis. Four women had been diagnosed with metastases and five were currently undergoing adjuvant chemotherapy treatment. This resulted in a total population pool of 111 participants (for the demographic characteristics of these women see Appendix G). The twenty women enrolled to attend the Retreat in March were matched on age and time since diagnosis variables to a control sample drawn from this population pool of participants. Based on the research findings (Chapter 2) that age may be a significant predictor of distress, age was considered an important demographic variable on which to match the two samples. Time since diagnosis was also an important demographic variable on which to match the two samples, to control for any differences in emotions as a result of the passage of time from their original diagnoses. Current understanding suggests that quality of marital relationship, rather than marital status alone is likely to influence well-being in women with breast cancer (Chapter 2). Marital status of the participants is reported, therefore, but the samples were not matched on this variable. Table 7.1 summarises the recruitment and data collection processes for the Retreat and matched control samples.

Table 7.1

Methodological Processes of Study 2

Research Plan						
January	February	March	April	May	June	July
Retreat sample		Time 1 data collection Retreat sample (n = 20)				Time 3 data collection Retreat sample
25 women enrol in the Retreat		Retreat				
		Time 2 data collection Retreat sample				
Control sample	Call to participate	Time 1 data collection sampling Pool (n = 111)	20 women selected as matched control			Time 3 data collection matched control sample (n = 20)

7.5.1.2 The Participants

The mean age of the women at Time 1 was 60.7 years (SD = 9.65), and their median age = 62 years. Time since their breast cancer diagnoses ranged from one to ten years. Comparing the two samples, the 20 women who attended the Retreat were successfully matched on age and time since diagnosis categories. Five women in each sample were between the ages of 40 and 54 years, 12 in each sample were between the ages of 55 and 69 years, and three women in each sample were more than 70 years of age. Four women in each sample had been diagnosed more than one year, but less than two years ago. Nine women in each sample were more than two years, but less than five years from their diagnosis. Six women in each sample were more than five

years, but less than ten years from their diagnosis, and one woman in each sample had been diagnosed with breast cancer more than ten years earlier. As intended, the two samples were well matched. Although not matched for marital status the two samples were very similar. Fourteen women in the Retreat sample were married, while thirteen women in the control sample were married, and one was living in a defacto relationship. Six women in each sample were living alone, either as a result of being widowed, separated, divorced or never married. Table 7.2 details the demographic characteristics of the participants.

Table 7.2

Frequencies of Age, Time Since Diagnosis, and Marital Status of Participants by

Sample

Variable	Category	Retreat (n = 20)	Control (n = 20)	Percentage of total sample
Age	40-54	5	5	25
	55-69	12	12	60
	70+	3	3	15
Time since diagnosis	1 - 2 years	4	4	20
	2 - 5 years	9	9	45
	5 - 10 years	6	6	30
	10+ years	1	1	5
Marital status	married	14	13	68
	de facto	0	1	2
	widowed	3	4	18
	separated	0	1	2
	divorced	1	1	5
	single	2	0	5

7.5.1.3 The Representativeness of the Sample

To examine the representativeness of the samples, the age of these women at the time of their diagnoses were compared to the ages of women at time of diagnosis in NSW in 1999, the most recent statistics currently available (New South Wales

Cancer Council, 2001). In NSW, 40% of women diagnosed with breast cancer were under the age of 54 years at the time of their diagnosis, compared to 45% of the women in these samples. The over representation of women diagnosed between the ages of 55-84 years may be due to the general appeal of the Retreat to older women, who may also have fewer family and work commitments to make easier their attendance.

A further criterion on which to view the representativeness of the samples was marital status. Seventy seven per cent of women in Australia are likely to marry (Australian Bureau of Statistics [ABS], 2000). In these samples (see Table 7.2) 68% cent were in fact married, one woman was currently separated from her husband, and one woman was divorced. These samples are, then, representative of the marital status of women in Australia. As at June 1999, 10% of the Australian population over the age of 15 were widowed. For these samples, 17% reported widow status, which probably reflects the finding that this population is proportionately older than the general population (ABS, 2000).

7.5.2. Design

A 2 X 2 mixed between and within design was used with one between subjects variable, group, with two levels (Retreat sample and matched control sample), and one within subjects variable, time, with two levels (baseline Time 1, and Time 3, 13 weeks after the collection of Time 1 data). To further explore the data contributed by the Retreat sample only, a one-factor (time) within-subjects design with three levels, Time 1, Time 2 and Time 3 was also employed.

7.5.3 The Measures

A number of measures used in previous studies with breast cancer populations were considered, including the Psychological Adjustment to Cancer Scale (Dunn, Welch, Butow & Coates, 1997) and the Mental Adjustment to Cancer Scale (Watson,

Greer, Inayat, Burgess & Robertson, 1988). Some items in both these scales were considered to be likely to cause distress to the participants. Items that were problematic included: "Since getting cancer my body has felt unclean"; and "Since getting cancer I have felt like an exile from the human race". In selecting my measures, I wanted to allow the contributors to reflect on their personal experiences from the perspective of their own meanings rather than on instrument-provided constructs.

7.5.3.1 The Content Analysis Scales (CAS)

Although cancer may be "the night side of life" (Sontag, 1979), from the personal construct perspective, women living with breast cancer are expected to function psychologically just as healthy individuals do, that is, reacting with distress to that which is distressing because changes in their meanings are needed (Viney, 1985). Beyond their roles as breast cancer survivors, these women continue to perceive themselves in other roles (mother, daughter, friend, colleague, wife etc.), and to have other needs beyond those precipitated by their cancer status (companionship, intimacy, etc.), and other interests (Rainey, 1984). The measures chosen, therefore, needed to ask participants to evaluate their everyday experience of living.

Two further, and very important, criteria for selecting the measures were that the underlying assumptions of the scales are consistent with personal construct theory, and the conceptualisation of the variables of interest; and they have proven effectiveness in discriminating between groups of women living with breast cancer. The decision to use the Gottschalk-Gleser Content Analysis Scales (Gottschalk, 1979; Gottschalk & Gleser, 1969; Gottschalk & Bechtel, 1982) was based on the following reasons:

1. They allow for the interpretation of the participants' meanings;
2. They are sensitive to the participants' status as survivors of breast cancer; but also
3. They encompass aspects of the participants' lives beyond their breast cancer status;
4. They are consistent with personal construct theoretical assumptions;
5. They allow for the measurement of personal construct concepts;
6. They have previously been used with a breast cancer population; and proven effective in discriminating between groups.

The Gottschalk-Gleser Content Analysis Scales (Gottschalk, 1979, 1987; Gottschalk & Gleser, 1969) are a combination of qualitative and quantitative approaches. An advantage of content analyses over questionnaire type instruments is that it allows for the interpretation of the contributor's meanings (Viney, 1988). Furthermore, application of content analysis scales allows for quantitative summaries of a series of qualitative content analyses, making comparisons of the experiences of one person with another feasible (Viney & Caputi, 2001). The scales have been used in medical settings (Viney, Benjamin, Clarke & Bunn, 1985; Viney, Clarke, Bunn & Benjamin, 1986) and have been shown to be more sensitive to the status of the medically ill, including women with breast cancer, than other self-report affect scales (Lebovits and Holland, 1986). They are consistent with personal construct assumptions and concepts (Viney, Caputi & Webster, 2000), and they allow contributors to express their personal meanings. Further description of the scales, and the items scored on the scales used in this study, are provided in Appendix F.

7.5.3.2 The Total Anxiety Scale

To measure *threat*, the Gottschalk-Gleser Total Anxiety Scale (Gleser, Gottschalk & Springer, 1961; Gottschalk & Gleser, 1969) was used. The Total

Anxiety Scale is classified into six subtypes; three of these were proposed by Weekes (1998) to be conceptually consistent with the personal construct concept of threat. The three Subscales generally linked to threat are, Death Anxiety, Mutilation Anxiety and Separation Anxiety. These three subscales measure threat to both physical and psychological integrity. Death Anxiety measures threat to existence and will be discussed in detail below, as scores on this subscale will be reported separately. Examples of the women's meanings scored on this scale included: "A lot of people think cancer is a death sentence", "At least six friends from the group have died", and "I could be dead next year". Mutilation Anxiety refers to injury or physical damage ("You see the scar everyday as a constant reminder", "They cut off my breast"), while Separation Anxiety includes references to abandonment ("I felt very isolated", "He wouldn't come with me to the doctors"). Death and Mutilation Anxiety therefore, refer directly to physical threat to the individual, while Separation Anxiety, may refer to threat to physical and/or psychological integrity. Together they represent threat to women's core construing.

Guilt ("I feel so guilty because my daughter might get it"), and Shame (I don't like my husband to look at me now", "I feel unworthy of their love") are also subscales of the Total Anxiety Scale. Although not usually linked to threat, I believe these subscales can be conceptualised as threat to the individual's core role constructs. The diagnosis of breast cancer threatens women's core, and core role constructs. The personal construct model of women's adjustment to breast cancer survival proposes that these central and most important meanings, both about themselves and their relationship to others, are threatened by their cancer diagnosis. The findings of Study 1 supported this proposal. Diffuse Anxiety ("There is an ever present threat", "Sometimes I wake up in the morning feeling really scared, and I don't know why") is the sixth subscale in the Total Anxiety Scale, and refers to unspecified threat.

Therefore, for breast cancer populations, the CAS Total Anxiety Scale is the best assessor of threat.

7.5.3.3. The Death Anxiety Subscale

Fear of death was a recurrent theme for the women who participated in Study 1. Rigdon and Epting (1985) maintain that a positive resolution of the issue of personal mortality enables people to live more intense and meaningful lives. For this reason, women's scores on the Death Anxiety Subscale will be analysed separately as indicators of *threat to existence*. Items scored on the Death Anxiety Subscale include references to death, dying, threat of death, or anxiety about death experienced by or occurring to self or others.

7.5.3.4. The Depression Scale

As noted above, the personal construct conceptualisation of depression differs from general usage of the term. I have used the Depression Scale (Gottschalk & Hoigaard-Martin, 1986b) as a measure of the women's *dislocation* from non-core meanings. In looking for a measure of dislocation I sought an instrument that could detect women's sense of loss, their loss of coherent ongoing stories, and the loss of their previous sense of invulnerability. Items scored on this scale include: "There is so much violence in the world today", "I don't go out as much as I used to", and "No one really understands me anymore".

7.5.3.5. The Hope Scale

The Hope Scale (Gottschalk, 1974) was used as an indicator of women's *hope* or commitment to engage in ongoing and rewarding cycles of experience. The scale is designed to measure the intensity of optimism that a favourable outcome is likely to occur. Items scored on this scale include: references to feelings of optimism ("They are finding new treatments everyday", "I hope I'll live to be 100"), the preservation or enhancement of health ("I really look after myself now", "I'm going from strength

to strength”), and being the recipient of good fortune (“I have three wonderful grandchildren”, “I think God is looking after me”).

7.5.3.6 The Reliability and Validity of the Content Analysis Scales

Issues concerning the *reliability* of the Content Analysis Scales have largely centred on *inter-judge consistency*, that scores assigned to participants’ responses by two or more investigators are similar. The processing of the raw data of verbal samples, and the conversion of this data into scales measuring psychological dimensions, affords many points at which distortion of meanings may occur (Gottschalk & Bechtel, 1995). Care, warn Gottschalk and Bechtel (1995), must be taken to avoid making assumptions about contributors’ meanings. Furthermore, when research is viewed as a co-operative enterprise, then the personal meanings that the scorer brings to the task of scoring must be also considered. In this study of breast cancer survival, it was anticipated that many of the women’s meanings might evoke scorers’ personal fears of cancer. An example of this is the possible tendency to classify references to cancer as necessarily evidence of Death or Mutilation Anxiety. To overcome this problem, data was scored using the PCAD 2000 programme, developed by Gottschalk and Bechtel (1998).

The development of this reliable method of measuring a variety of psychological states from natural language was motivated by Gottschalk’s recognition that diagnosticians and therapists use their clients’ speech as the major source of information for their diagnostic formulations and therapeutic interventions. In doing so, they assess how and what is said in an impressionistic manner that may allow for a relatively high likelihood of distortion and/or error from potentially incorrect empathic responses and inferences during the process of evaluating the meanings and significance of their clients’ talk. How to minimize such error, and how to maximize the uniformity and consistency of the inferential evaluations concerning a speaker’s

subjective experience, and the relative magnitude of these psychological states, became a major aim in Gottschalk and Bechtel's development of a computerized method of measuring these states from natural language (Gottschalk, 2000). Interscorer reliability between automated and human scoring is satisfactory with reported correlations above .80 (Gottschalk and Bechtel, 1982, 1995, 1998).

The Content Analysis Scales are often applied to verbal samples. However, the personality of the interviewer and the situation in which the data is elicited, have been shown to influence the content of participants' communications (Gottschalk & Gleser, 1969). For this reason, the participants' written responses formed the data for analysis, written in my absence, and in the participants' own homes. The Content Analysis Scales have been applied to a range of written texts including newspaper accounts, literature, letters and suicide notes, and their reliability when applied to texts is well established (Viney, 1986).

The other main form of reliability, consistency over time (*test-retest reliability*) is incompatible with personal construct theory. Kelly (1955/1991) argues that people are constantly changing and in motion as they engage in successive experience cycles. The purpose of Studies 2 and 3 is to evaluate change in construing. It is anticipated that these measures will verify that change has occurred.

Validity refers to the extent to which these content analysis scales measure the states they purport to measure (Viney, 1981, 1983a). Reported evidence of the *validity* of these scales is plentiful. In an early study by Gottschalk and Gleser (1969), pre-treatment Hope Scale scores were found to be predictive of survival time of adults with metastatic cancer receiving partial or total body radiation from radioactive cobalt. Gottschalk and Hoigaard-Martin (1986a) used the Total Anxiety, Depression and Hope Scales to measure the emotional impact of mastectomy, and found that these scales successfully discriminated between women diagnosed with breast cancer

and women diagnosed with benign, non-cancerous tumours. More recently, Heszen-Niejodek, Gottschalk and Januszek (1999) explored emotional reactions to different kinds of illnesses and changes in these emotions over time. The Total Anxiety Scale and the Hope Scale were found to successfully discriminate between illnesses across time. The participants were 122 medical patients (aged 18-60 years) suffering from primary hypertension, myocardial infarction and cancer of the lungs or pharynx. Their emotional states were evaluated with the Gottschalk-Gleser Total Anxiety and Hope Content Analysis Scales, immediately after diagnosis, five weeks post diagnosis and six months post diagnosis. Significant effects of the kind of illness and of its interaction with the phase of the study were found. The myocardial infarction group exhibited a low level of these emotions in the first phase, an increase in the second phase and then a small decrease. Adults diagnosed with cancer manifested high anxiety and relatively low hope in the initial phase, then a decrease in anxiety and an increase in hope.

Viney and Manton established the validity of these content analysis scales with Australian samples in 1973 (Viney & Manton, 1973). Early Australian studies include the series of studies conducted by Viney and Westbrook (1981, 1982a, 1982b, 1986). In these studies, content analysis scales were proven useful in assessing the emotional status of medically ill adults, independent of age, sex and education level. Furthermore, the scales successfully discriminated the chronically ill from other people, and identified a pattern of reactions among chronically ill adults who were later to die. More recently, Viney, Walker, Robertson and Lilley (1994) found that these content analysis scales discriminated between the quality of life of terminal cancer patients in palliative care units from those in a general hospital. These content analysis scales were also found to successfully discriminate the quality of life of palliative care, burns and neo-natal nursing staff (Viney, Walker, Lilley & Tooth,

1993); and Rudd, Viney and Preston (1999) found the Content Analysis Scales [CAS] Total Anxiety and Depression successfully discriminated nursing home caregivers of adults diagnosed with Alzheimer's Disease from home caregivers, and caregiving wives from caregiving husbands. These content analysis scales have also been used to discriminate HIV positive men from men with other illnesses, and gay men socialising in multiple bereaved HIV/AIDS communities from gay men socialising in less bereaved communities (Viney, Henry, Walker & Crooks, 1989, 1991).

Viney and her team of researchers (Viney, Benjamin, Clarke & Bunn 1985; Viney, Clarke, Bunn & Benjamin, 1985, 1986) have also used the content analysis scales to evaluate the outcome of personal construct therapies. They evaluated the long- and short-term effects of crisis-intervention counselling with hospitalised adults for whom illness or injury constituted the crisis. Examining the emotional reactions of 389 medical and surgical patients (aged 18-60 yrs), they found that participants in the personal construct crisis-intervention showed a greater decrease in their CAS Total Anxiety Scale scores at discharge, than did the patients without counselling. This differential decrease was maintained at follow-up, one year after the intervention. Other studies include an evaluation of the impact of personal construct and psychodynamic group work on the psychosocial functioning of offender adolescents (Viney, Henry & Campbell, 2001; Viney & Henry, in press; Viney, Truneckova, Weekes & Oades, 1999).

A further series of studies conducted by Viney, Benjamin and Preston (1988a, 1988b, 1989) evaluated the beneficial effects of personal construct therapy with the elderly using both the CAS Total Anxiety Scale and the CAS Depression Scale to examine changes in the participants' emotional states following therapy. Most notably, these researchers found that the therapy sample improved in levels of anxiety, especially in terms of their anxieties about dying and disability as evidenced

by reduced scores on the CAS Death Anxiety and Mutilation Subscales. Improved scores on the CAS Depression Scale were also reported following the therapy, and at follow-up, three months later.

Examining the validity of computerized content analysis of speech, Gottschalk, Stein, and Shapiro, (1997) report significant intercorrelations of these content analysis measures with scores obtained from the MMPI-2, SCL90, and other measures, which confirm previously published construct validation findings. *Content validity* of the Content Analysis Scales is assumed because the meanings expressed, the verbalisation data, are the participant's own. In Table 7.3, I summarise a number of outcome studies that have used the Content Analysis Scales and provide further evidence of their validity.

Table 7.3

Outcome Studies that have Used the Content Analysis Scales Used in this Study

Study	Application
Australian studies	
Viney & Henry (in press) Viney, Henry & Campbell (2001)	Measured the impact of personal construct and psychodynamic group therapy on the psychosocial functioning of offender adolescents.
Viney, Crook & Walker (1995)	Measured changes in AIDS caregivers following personal construct therapy
Viney, Benjamin & Preston (1988a) Viney, Benjamin & Preston (1988b)	Measured changes in the elderly following personal construct therapy
Viney, Benjamin, Clarke & Bunn (1986) Viney, Benjamin, Clarke & Bunn (1985) Viney, Clarke, Benjamin & Bunn (1985)	Measured changes in medical and surgical clients following personal construct therapy

Table 7.3 (continued)

Outcome Studies that have Used the Content Analysis Scales Used in this Study

Study	Application
Non-Australian studies	
Heszen-Niejodek, Gottschalk & Januszek, (1999)	Explored emotional reactions to different kinds of illnesses and changes of these emotions over time
Gottschalk (1987) Gleser, Winget, Seligman & Rauh (1979)	Discerned the course of psychotherapy
Gottschalk, Fox & Bates (1973)	Predicted psychotherapeutic outcome
Gottschalk, Bates, Waskow, Katz, & Olson (1972)	Showed the effects of major tranquillisers
Gottschalk, Mayerson, & Gottlieb (1967)	Predicted psychotherapeutic outcome
Gottschalk, Winget, Gleser & Springer (1966)	Measured changes occurring in adults and children during therapy
Gleser, Gottschalk & Lippert, 1965)	The effects of a new anti-anxiety drug
Gottschalk, Gleser, Wylie & Kaplan (1965)	The effects of anti-depressant drugs
Gottschalk (1961)	Discerned the course of psychotherapy

7.5.3.7 The Derogatis Affects Balance Scale (DABS)

The Derogatis Affects Balance Scale was a secondary measure used in this study to measure the two non model-related variables. This scale is a 40-item, multidimensional, self-report emotions and moods inventory. The decision to include this measure was based on the following reasons:

1. It focuses on subjective experiences, which is consistent with personal construct theory;

2. It has published norms, and good internal consistency reliability coefficients (Derogatis, 1996); and
3. It has been used with breast cancer and other oncology populations to evaluate the emotional impact of cancer (Ayres, Hoon, Matheny, Cotanch & Takayangi, 1994; Carter, Carter & Prosen, 1992; Derogatis, Abeloff & Melisaratos, 1979; Northouse, 1988; Northouse & Swain, 1987), and therapy outcomes (Holland, Romano, Heiligenstein, Tepner & Wilson, 1991).

The scale also has the added advantages of being relatively non-intrusive, and easily administered and scored.

Although the measure asks participants to report on instrument-provided constructs, and, therefore, did not allow for an analysis of their meanings, the inclusion of this measure was considered important, as noted above, to assess the (non personal construct) concepts of anxiety and depression. For the purpose of this study, therefore, only the items making up the Anxiety and Depression Subscales were scored.

In addition, as reported in Chapter 2, there is some debate as to whether self-report questionnaires are sufficiently sensitive (Coyone & Gottlieb, 1996; Gottschalk & Hoigaard-Martin, 1986), especially when applied to cancer populations (Lebovits & Holland, 1986; Wilkinson, 2000). Hall and colleagues (1999) note the reluctance of many cancer patients to honestly disclose how they are feeling in self-reports. Women diagnosed with breast cancer are under immense pressure to “*stay positive*” (Holland & Lewis, 2000; Lane & Viney, 2000a). Consistent with the findings of Study 1, Wilkinson (2000) found that the women in her study spoke of the “*moral obligation*” they felt to “*stay positive*”. Family and friends often believe they are being helpful by encouraging positive thinking (Lane & Viney, 2000a), and, as Wilkinson (2000)

observes, the medical professionals who come into contact with breast cancer survivors are likely to encourage positive thinking as a coping strategy, not least because of the research of Moorey and Greer (Moorey & Greer, 1989), that has suggested an inverse relationship between positive thinking and cancer mortality. Self-report questionnaires, therefore, may under report the degree to which breast cancer survivors live with ongoing distress, as women feel they *must* present as positive. Their scores on self-report affects scales are perhaps more representative of the degree to which they are attempting to *appear positive*. Results on these scales, therefore, will be interpreted with caution. The opportunity to explore this issue further, to explore whether the participant's self-rated emotions were in line with the psychological states tapped through content analysis of their verbalisations, however, further led me to believe that the inclusion of a self-report questionnaire measuring non-personal construct anxiety and depression would be valuable.

7.5.3.8 The Reliability and Validity of the DABS Scale

Derogatis (1996) has established acceptable *internal consistency* for the Anxiety and Depression Subscales with coefficient alphas ranging from .78 to .85. Internal consistency reliability for the two subscales for each of the samples in Study 2, at each data collection time, ranged from .67 to .89 for Anxiety, and .68 to .94 for Depression. Ideally the Cronbach alpha coefficient of a scale, the measure of the homogeneity of the items that make up the scale, should be above .7. Cronbach alpha values are, however, quite sensitive to the number of items in a scale (Pallant, 2001). As only five items make up each of the subscales, the obtained alphas were considered adequate. To confirm this, inter-item correlations were run for the five items that make up the scale for each group where alphas below .7 were observed. Briggs and Cheek (1986) recommend an optimal range for the mean of the inter-item correlations of .2 to .4. The mean inter-item correlations fell within this range.

Examining concurrent validity of these measures with populations other than breast cancer, Wolfe, Elston and Kissling (1989) found significant correlations between DABS measures scores and scores on other measures of both health locus of control and self-esteem in first year medical students. Rabins and his associates (Rabins, Fetting, Eastham & Fetting, 1990) and Rudd, Viney and Preston (1999) have used the DABS in studies examining the impact of Alzheimer's Disease on caregivers.

Examining the predictive validity of these measures with breast cancer populations, Ayers and her colleagues (Ayers et al., 1994), working with women newly diagnosed with breast cancer, evaluated factors involved in predicting compliance to chemotherapy regimens. High scores on DABS measures of anxiety and depression were found to predict adherence to treatment compliance. Northouse and Swain (1987) applied the DABS to primary breast cancer patients and their spouses, immediately after mastectomy, and one-month post surgery. Both patients and spouses showed a significant decrease in positive affect immediately post-surgery, which returned to normative levels one month later. The scale has also been employed to examine the nature of the relationship between social support and psychosocial adjustment of mastectomy patients and their spouses (Northouse, 1988).

Treatment outcomes have been evaluated by a number of researchers using the DABS measure. Hoehn-Saric, Merchant, Keyser & Smith (1981) examined the effects of clonidine, an anti-hypertensive agent, on anxiety disorders, providing validation evidence for the use of these measures with participants experiencing a range of problems including chronic anxiety, mixed anxiety-depression, panic disorder and generalized anxiety disorder. Quinn and Strelkauskas (1993) also reported substantial reductions in negative affect as measured by the DABS following intervention in the recently bereaved, and Holland and her colleagues (Holland et al., 1991) reported

reductions in anxiety following intervention in anxious and depressed adults diagnosed with a range of cancers.

7.5.3.9 Procedure

Women in the Retreat sample were sent a data collection set (see Appendix E) one week prior to the Retreat in March 2000, for completion before attendance (Time 1). I collected this data on the first day of the Retreat. On the last day of the Retreat they were given a second data set, which they completed at home in the week following the Retreat (Time 2). A third set was posted to them 12 weeks after the Retreat, with a stamped addressed envelope for their return (Time 3). The data set included a demographic survey, together with the Derogatis Affects Balance Questionnaire and a sheet with the prompt (see below) for their written responses for content analysis. Examples of the data collection sets, and the information and consent forms sent to each participant at Time 1, can be found in Appendices D and E.

Data was collected from the matched control group on entering the study (Time 1). These women formed a subset of the total population pool who were each sent a data collection set on expressing an interest in participating in the study, with a stamped addressed envelope for data return. Demographic characteristics only of each of the 91 participants who were not attending the Retreat were examined on receipt, until all 20 women in the Retreat sample could be matched to women from this population pool. The twenty women who made up the matched control sample were sent a second data collection set 13 weeks after they had completed their first set (Time 3). Asking the control sample to complete a questionnaire only five days after their first, with no intervention provided for them was unreasonable, therefore no Time 2 data was collected from the matched control sample.

The four model-related dependent variables were CAS Total Anxiety Scale scores, CAS Death Anxiety Subscale scores, CAS Depression Scale scores, and CAS Hope Scale scores. The data analysed for these scales was the participants' written responses to the following request:

I would like you to write about your life right now, both the good and the bad. Write as much as you like in about fifteen minutes (Gottschalk & Gleser, 1969).

Anxiety and depression (non personal construct) were explored using the DABS Anxiety and Depression Subscales. Each of the 40 items comprising the Derogatis Affects Balance Scale is measured on a five-point scale of intensity ranging from 0 = "not at all" to 4 = "extremely". The instructions for data contributors were:

Below is a list of words that describe the way people sometimes feel. We would like you to tell us whether you have been having any of these feelings during the past *7 days including today*. Please indicate the degree to which you have felt each emotion by circling the number that best describes your experience. Circle only one number for each emotion and do not skip any items (Derogatis, 1996).

7.5.3.10 Statistical Analyses

To examine differences in the samples scores, multiple repeated measures ANOVAs were conducted on scores for each of the dependent variables. Where the interaction effects of time and group were found to be significant, further analyses were conducted. To examine between group differences within times, pairwise comparisons of group means at Times 1 and 3 were made, using the Bonferroni statistic to control for multiple comparisons. To examine differences for the Retreat sample between scores at Time 1 (baseline), Time 2 (immediately after the Retreat), and Time 3 (three months following the Retreat), one-way repeated measures ANOVA statistics were conducted.

The use of multivariate analysis (MANOVA) was considered. In MANOVA the question is whether the individual variable significantly affects an optimal linear

combination of the dependent variables (Tabachnick & Fidell, 1996). MANOVA therefore, tests a single statistical construct, which should reflect an underlying conceptual construct. However, the dependent variables of this study did not form a single conceptual construct. Multiple ANOVAs allowed for a comparison of means, on a number of separate dependent variables, to detect whether there were any reliable differences.

There are a number of assumptions underlying mixed between- and within-subjects analyses of variance. Those of simple analysis of variance (ANOVA), the assumption of normality, the assumption of homogeneity of variance and the assumption of independence of observation, must be met, with the additional assumption of homogeneity of intercorrelations, that for each of the levels of the between-subject variable the pattern of the intercorrelations among the levels of the within-subject variable should be the same. Examination of the data revealed that only the CAS Death Anxiety Subscale scores were not normally distributed. Pallant (2001) observes that ANOVA techniques are reasonably robust and tolerant of violations to the assumption of normality. The Wilcoxon Signed Rank statistic was performed on Death Anxiety Subscale scores, to confirm this. As no differences were found between the parametric and non-parametric statistics for Death Anxiety Subscale scores, and with a sample of 40, it was considered that violations of this assumption would not cause a problem (Gravetter & Wallnau, 2000; Stevens, 1996). As the Levene homogeneity-of-variance test is less dependent on the assumption of normality than most tests (Pallant, 2000) it was used to test for equality of variance. No violations of this assumption were found. Univariate statistics make the assumption of sphericity, that is, that the variance of the population difference scores for any two conditions are the same as the variance of the population scores for any other two conditions (Pallant, 2001). Maunchley's test of sphericity revealed that the

four model-related dependent variables violated this assumption. The Wilks Lambda statistic does not require sphericity, and is, therefore, the statistic reported.

7.6 Results

Sample means at Time 1, for CAS Total Anxiety Scale scores were within one standard deviation of the norm for the general population. Looking at individual scores, Gottschalk and Gleser (1969) suggest that a score of 2.2 or above on this scale is indicative of moderate anxiety, and a score above 3.0 is indicative of pathological anxiety. At Time 1, six women (30%) in the Retreat sample and seven women (35%) in the matched control sample had moderately elevated Total Anxiety Scale scores. One woman (5%) in the treatment sample and two (10%) in the control sample had scores indicating severe anxiety. At Time 2 for the Retreat sample, only three women (15%) had moderately elevated scores, with one additional woman scoring above 3.0. Three months later, four women (20%) in the Retreat sample now had moderately elevated scores, and two women had levels indicative of pathological anxiety (Gottschalk & Gleser, 1969). For the control sample, four women (20%) exhibited moderately elevated anxiety scores and three women (15%) were exhibiting pathological levels of anxiety.

Sample means at Time 1 for the dependent variable CAS Death Anxiety Subscale were found to be moderately elevated for both samples, scores being greater than one standard deviation from the norm for the general population (Gottschalk & Gleser, 1969). Normalising data for women experiencing illness or accident are available for the CAS Death Anxiety Subscale (Viney, 1980). Group means for both samples on this dependent variable fell within one standard deviation of these norms. Mean scores were also compared to those reported by Gottschalk and Hoigaard-Martin (1986a) for a mastectomy population one to three months post surgery, and one-year post surgery, and were found to be representative of a breast cancer sample.

CAS Depression Scale scores were more than one standard deviation above the norm for the general population for both samples. This level dropped to within one standard deviation of the norm immediately post the Retreat for the Retreat sample, but rose to pre-retreat levels three months post-retreat.

Sample means on the CAS Hope Scale were within published norms for a cancer population (Heszen-Neijodek et al., 1999). Again, looking at individual scores at Time 1, one woman in the Retreat sample scored more than two standard deviations below the published mean, and one woman's score was found to be more than three standard deviations below the normalising mean. At Time 2, immediately after the Retreat, all Hope Scale scores for the Retreat sample were within one standard deviation of the norm. Three months later, four women had scores more than one standard deviation below the normalising mean, and one woman scored more than three standard deviations below this mean. For the control sample at Time 1, one woman scored more than one standard deviation below the normalising mean, and three women scored more than three standard deviations below this mean. Three months later, no differences were observed.

Tests of differences between the scores of the Retreat and control samples at Time 1 were carried out. Kolmogorov-Smirnov (KS) and Shapiro-Wilk (SW) tests for normality indicated that only one dependent variable, CAS Death Anxiety, significantly differed from the normal distribution (KS, $p = .03$, SW, $p = .01$). Consequently, a non-parametric test was performed on this variable. The Mann-Whitney U test revealed no significant difference of means between the two samples for this variable. Paired samples t tests on Time 1 scores for all variables (excluding Death Anxiety) revealed that on the CAS Depression Scale, the Retreat sample showed significantly less distress than the control sample ($t(38) = -2.35$, $p = .02$). Paired samples t tests on Time 1 score means for the remaining dependent variables

showed no significant differences between group means for the Retreat and control samples at baseline. Means for the two groups on the dependent variables for Time 1, Time 2 and Time 3 for the Retreat sample and Times 1 and 3 (equivalent time frame) for the control sample are shown in Table 7.4.

Scores on both the Derogatis Affects Balance Subscales were within the norm for the general population. Given the difficulties associated with self-report questionnaire measures with their potential to under-estimate distress in women diagnosed with breast cancer, this is not surprising. This will be examined further in the discussion section of this chapter. The means and standard deviations for the two DABS Subscales are presented in Table 7.5.

Table 7.4

Mean, and Standard Deviations of Scores on CAS Total Anxiety, Death Anxiety, Depression and Hope by Samples

	CAS Total Anxiety		CAS Death Anxiety		CAS Depression		CAS Hope	
	Retreat sample	Control sample	Retreat sample	Control sample	Retreat sample	Control sample	Retreat sample	Control sample
Time 1	1.84 (0.64)	2.14 (0.62)	0.67 (0.34)	0.80 (0.32)	6.70 (1.40)	7.85 (1.40)	2.78 (2.07)	2.05 (3.06)
Time 2	1.50 (0.85)		0.74 (0.28)		6.38 (1.28)		3.70 (2.04)	
Time 3	1.91 (0.82)	2.14 (0.76)	0.59 (0.19)	0.82 (0.39)	7.06 (1.82)	7.68 (1.90)	2.36 (2.39)	1.89 (3.05)

Table 7.5

Means and standard deviations of DABS Anxiety and DABS Depression Subscale

Scores by Samples

	DABS Anxiety		DABS Depression	
	Retreat sample	Control sample	Retreat sample	Control sample
Time 1	8.25 (3.86)	8.20 (2.69)	5.74 (3.54)	5.25 (2.40)
Time 2	5.80 (3.81)		3.40 (3.93)	
Time 3	7.35 (3.65)	8.10 (2.31)	4.60 (4.10)	6.30 (2.68)

To examine differences between groups on the personal construct, model-related variables, 2 X 2 repeated measures ANOVAs were conducted on CAS Total Anxiety, CAS Death Anxiety, and CAS Hope Scale scores at Times 1 and 3, to examine both within- and between-subjects effects. Due to significant differences between the groups in Time 1 scores on the CAS Depression Subscale, as stated earlier, a repeated-measures ANCOVA, using Time 1 scores as the covariate, was conducted. These analyses showed no evidence of significant interaction effects for time by group, and no main effects for either time or group.

Examining differences between the groups on DABS Anxiety scores from Time 1 to Time 3, a 2 X 2 repeated measures ANOVA also showed no significant interaction effect for time by group. Using the same statistical analysis on DABS Depression Subscale scores, the analysis revealed a significant interaction effect of time by group ($F(1, 38) = 10.87, p = <.01, \eta^2 = .22$). Using the commonly used guidelines proposed by Cohen (1988) (.01 = small effect, .06 = moderate effect, .14 = large effect), examination of the effect size ($\eta^2 = .22$) for this variable indicated a

large interaction effect. Examining the simple effect of time on sample scores, using the Bonferroni procedure, multiple comparisons of means at Times 1 and 3 showed a significant decrease in scores for the Retreat sample (mean difference = -1.15 , $SE = .50$, $p = .05$). A significant increase in scores for the matched control sample was also noted in this time frame (mean difference = -1.05 , $SE = .52$, $p = .05$).

To examine differences in scores between Times 1, 2 and 3, on the model-related personal construct variables (CAS Total Anxiety, CAS Death Anxiety, CAS Depression & CAS Hope) for the Retreat sample only, a series of one-way repeated-measures ANOVAs was performed. The results of these, for each of the dependent variables, are now reported. With one factor, Retreat sample, a one-way repeated-measures ANOVA on CAS Total Anxiety Scale scores indicated that scores on this variable did not significantly differ from each other across time. The same analyses were conducted on CAS Death Anxiety, CAS Depression and CAS Hope Scale scores with similar non-significant results.

Analyses conducted on the DABS Anxiety and Depression Subscales scores, measuring (non personal construct) anxiety and depression are now reported. The effect of time for the Retreat sample on the dependent variable DABS Anxiety was first examined, again using the one-way repeated measures ANOVA statistic. A significant effect for time was revealed ($F(2,18) = 6.42$, $p < .01$, $\eta^2 = .42$). Again using the commonly used guidelines proposed by Cohen (1988), examination of the effect size ($\eta^2 = .42$) for this variable indicated a large effect for time. Using the Bonferroni procedure, multiple comparisons revealed a significant decrease in scores between Time 1 and Time 2 (mean difference = 2.45 , $SE = .67$, $p < .01$). This was followed by a significant increase in scores from Time 2 to Time 3 (mean difference =

-1.55, $SE = .57$, $p = < .01$). This resulted in a non-significant difference between scores at Times 1 and 3.

Examining differences in scores for the Retreat sample on DABS Depression scores, a significant effect for time was again observed ($F(2,18) = 8.03$, $p = < .01$, $\eta^2 = .47$). The size of the effect was also large. Further examination, again using the Bonferroni procedure for multiple comparisons, revealed a significant decrease in scores between Time 1 and Time 2 for this sample (mean difference = 2.35, $SE = .59$, $p = < .01$). Although scores increased between Time 2 and Time 3, this increase was not significant. At Time 3, scores on this variable remained significantly lower than at Time 1 (mean difference = 1.40, $SE = .49$, $p = < .05$).

In summary, on each of the model-related dependent variables, no evidence was found to conclude that attending the retreat had a beneficial effect for the participants. A significant time by group interaction effect was found only on the non-personal construct depression variable, as measured by the DABS Depression Subscale. Examination of the results of the pairwise comparisons revealed that although scores for the Retreat sample had significantly decreased between Time 1 and Time 3, scores for the matched control sample had significantly increased in this time frame. This finding suggests that results on this variable should be interpreted with caution.

7.7 Confirmation of the Retreat as Validation

Validation of current meanings was expected to occur when women experienced “commonality”. When women who are breast cancer survivors share their cancer-related meanings, they have the opportunity to both provide and receive validation. It was, therefore, important to ask myself the following question: Is there evidence that the women who attended the Retreat shared their meanings? The Retreat

participants' transcripts for content analysis at Time 2 suggest that they did. Rita wrote: "Sharing with all the ladies this past week has been a breath of fresh air to me. A much-needed break from the normal, everyday things we do. A time of happiness as I shared laughs (and there were plenty of them). It's a special kind of friendship that gladdens and warms the heart". Moira wrote: "I have just finished my retreat and have a great feeling of well-being having spent a week amongst friends. The love and support I have felt this week has given me a happier perspective and outlook on life". The feeling of having gained new friends, who understood their problems, was frequently mentioned. As Joyce wrote: "The friendships formed are precious". Clearly, the women felt that they had shared many of their common meanings.

Based on my personal construct model of support as involving validation of current meanings (commonality) and elaboration of meanings (sociality), I had anticipated that any gains in psychological well-being, as a result of validation alone, would be short-lived. A number of women expressed a fear that the "high" they felt immediately after the Retreat, would not last. This is best expressed in the words of Brenda who said: "I leave here into a promise for the future and there is a little hope that I don't lose it, and let it fade away. I hope it doesn't fade into the background, because we don't all see each other every week. I want to keep in touch with all this, to keep the memory and the atmosphere. I'm sad that it's finishing and I'm a bit feared that I will loose what I have got. But I'll try to think positively that I will keep things up". Subjectively, all the Retreat participants felt the Retreat had been beneficial to them.

7.8 Discussion

In this section I discuss the findings from this study on the effects of validation of current meanings on breast cancer survivors' emotions, through participation in the Retreat. I first examine the usefulness of the study in addressing

the Aim and Research Questions. I discuss the results of the analyses of the content analysis scales scores, then the self-report emotions questionnaire findings. I examine the implications of these findings. Finally, I identify the limitations of Study 2, before drawing conclusions about future research directions.

My *Aim* in conducting this study was to learn more about one process of support, that is, validation of their current meanings of breast cancer survivors. The Research Questions were framed in terms of decreases in levels of negative affect, and increases in positive affect for the Retreat sample as a result of attending the Retreat. Based on my personal construct model, I anticipated that validation of current meanings would result in initial feelings of well-being, but that without opportunities to elaborate new meanings, such benefits would be short-lived. Despite these women's subjective experiences of short-term gains after attending the Retreat, their scores on the measures of the personal construct variables did not show change. Levels of *threat* to core and core role meanings, and to existence, remained unchanged, both immediately after the Retreat and at the three-month follow-up. Levels of *dislocation* from non-core meanings were unchanged. Neither did there appear to be evidence to suggest that, following the Retreat, the participants were more hopeful, and able to engage in positive ongoing cycles of experience.

Levels of (non personal construct) anxiety were observed to decrease immediately following the Retreat, but this was not maintained at three-month follow-up. A significant decrease in scores for the Retreat sample between Time 1 and Time 2 was revealed, and although the Retreat samples scores were found to rise between Times 2 and 3, Time 3 scores remained significantly lower than at Time 1. Given that the control sample scores on this variable were also found to significantly differ at Time 3 from Time 1, unfortunately indicating an increase in depression, this finding is somewhat ambiguous. Two factors may have influenced these scores. The

questionnaire specifically asks whether the women were: nervous, timid, tense, anxious, or afraid in the past week, to measure anxiety. Items scored for depression were: sad, hopeless, worthless, miserable and bitter. Therefore, having spent five days in the company of others, with opportunities to talk and play together, they may not have experienced these negative feelings during the Retreat. As Mary said: "What a week I have had! I am still on a high. I have been talked to, I have had some enjoyable relaxation, some heavenly massages, eaten far too much, played some hilarious games, and had a good laugh". Secondly, the participants may have mistakenly felt that their responses would be considered as an evaluation of the Retreat. If so, they may well have chosen to say they had a good time, free from anxiety and depression. Ceiling and floor effects may also have been working here.

Interestingly, scores at Time 1 for both samples on measures of (non-personal construct) anxiety and depression were within one standard deviation of population norms. From this finding, it could be assumed that these women had already adjusted successfully to being breast cancer survivors. This, however, is in conflict with the findings for threat, dislocation and hope. At Time 1, six women (35%) in the Retreat sample and seven women (45%) in the matched control sample had elevated scores measuring threat, ranging from slightly elevated to severely elevated, in a population of women many of whom (35%) were more than five years post diagnosis. Scores measuring dislocation were more than one standard deviation above the norm for the general population for both samples. Looking at individual scores at Time 1, on CAS Hope Scale scores, one woman in the Retreat sample scored more than two standard deviations below the published mean, and one woman's score was found to be more than three standard deviations below the mean. For the control sample at Time 1, one woman scored more than one standard deviation below the normalising mean, and three women scored more than three standard deviations below this mean.

Earlier studies have suggested that between 20 and 35% of women diagnosed with breast cancer, irrespective of their stage of disease, experience measurable psychiatric morbidity (Maunsell, Brisson & Deschenes, 1989, 1992; Fallowfield et al., 1990). The findings for CAS-measured concepts from the model support the view that the percentage of women suffering ongoing distress is frequently underestimated (Bloch & Kissane, 2000; Holland et al., 1998; Parle & Maguire, 1995). Hall (Hall et al., 1999) points out that this is particularly the case when self-report questionnaire measures are used. These findings also suggest that the CAS scales are more sensitive to detecting the underlying distress of breast cancer survivors. From this a tentative conclusion can be drawn, that validation of current meanings (commonality) alone is not enough to effect change in breast cancer survivors' psychological well-being.

7.9 The Limitations of the Study

A major limitation of the present study relates to the generalizability of the findings. The present findings are not representative of all breast cancer survivors. They represent a small population of women living in the Illawarra Region, NSW, Australia. Even within this population, sampling bias must be assumed. The problems inherent in volunteer samples are important to consider. By asking participants to give 'informed consent' before participating, and assuring participants that they may refuse to participate or withdraw at any time, and that refusal or withdrawal will not affect their treatment or relationship with anyone connected to the study (see Appendix D), no information is gathered from those who choose not to participate. Therefore, while informed consent is a highly ethical method to use, the generalizability of the findings is necessarily limited. Although no one dropped out of this study after they had consented to participate, it must be remembered that in the original call to participate, only 39% of the women invited chose to participate, and of

the 25 women who attended the Retreat, while three did not meet the inclusion criteria, two chose not to participate.

As the women who attended the Retreat were self-selected, the very nature of women who choose to attend a Retreat compared to those who choose not to, or who cannot attend, may also have influenced the findings. Women who chose not to attend may have done so over and beyond the restraints of finances. They may be less socially oriented, or more restricted by family commitments or work requirements. Volunteers are typically more sociable than non-volunteers, and rate higher in need for social approval (Rosnow & Rosenthal, 1998). These characteristics are particularly likely to bias self-report questionnaire responses. The use of the content analysis scales, where the intent of the researcher is less obvious, may overcome this tendency to some degree, although what the contributors choose to disclose will, of course, be tempered by these influences. Sampling of a larger number of participants within the wider community would be needed to establish the reliability of the present findings.

The over representation of women between the ages of 45-64 years and the under-representation of older women (65-84 years) is also problematic when considering the generalizability of the findings. The women who elected to attend the Retreat set the population characteristics of the total sample. Women aged 45-65 years may have fewer family commitments and so are available to attend the Retreat, and older women (over 65 years) may feel uncomfortable sharing communal facilities or may be unable to be away from their partners, presumably also older.

As the women who attended the Retreat were self-selected, random allocation of the participants to one of the two treatment conditions was not an option. The lack of a Time 2 data collection for the control group also weakened the design of the study. Further studies would ideally overcome these problems. Comparisons might

usefully be made between a non-residential workshop that provided opportunities to share meanings, and a wait-listed control. In this way, participants could be randomly assigned to a sample with fewer obstacles to participating, expense, time away from family, and a dislike of sharing the company of others for 24 hours each day, for example. If the workshop were to run over a longer period than the residential Retreat, data could more appropriately be collected from the control sample, in the same time frames as the intervention sample.

Women's scores on the content analysis scales at Time 1 revealed that, despite non-elevated levels of (non personal construct) anxiety and depression, these women were distressed. However, as no change was noted on these scores after the Retreat, the question remains: Were these measures sensitive enough to detect change in these breast cancer survivors' construing? For this reason, conclusions drawn from these findings must be made tentatively. Further studies with survivors of breast cancer using these measures will confirm their validity. This will be addressed in Study 3.

The apparent face-validity of the Derogatis Affects Balance Scale is also considered to be problematic. A number of women reported to me that they delayed a little in writing their responses, as they were: "waiting to feel better". They said that if they had returned them immediately: "you would have thought I was crazy". As I observed earlier, women diagnosed with breast cancer face enormous pressure to "stay positive". Self-report measures of anxiety and depression with obvious face-validity, therefore, may reflect only women's attempts to "stay positive" rather than their underlying distress. Furthermore, the finding that, for the control sample, scores on depression significantly increased from Time 1 to Time 3, suggests that the validity of this scale, with this population, may be questionable.

7.10 Conclusions

As a purposeful multiple case study strategy was adopted, the findings are necessarily exploratory. They can, however, according to Patton (1990), be generalized to theoretical propositions. In considering my *Aim* in conducting this study, to learn more about the mediational process of validation of current meanings in breast cancer survivors' adjustment to breast cancer survival, the findings suggest that validation of their current meanings, for the women who attended the Retreat, was not enough to affect change in their levels of threat, threat to existence, dislocation and hope. Although these women reported "feeling better" following it, they were continuing to engage in unhelpful cycles of experience in response to unresolved threat to their most central meanings. My *Aim* was therefore achieved.

Although no long-term effects for the Retreat were found, except for non-personal construct depression, a finding that should be treated with caution due to the limitations discussed, women clearly enjoyed the Retreat. Just as holidays may not result in long-term benefits, it would be inappropriate to suggest that the Retreat, or holidays, be abandoned in the future. Whatever the statistical results, the women enjoyed themselves, and 18 (90%) of the 20 women who attended the Retreat in 2000 attended again in 2001.

Given the limitations of this study, further research could usefully explore whether the measures of model-derived evaluating concepts were sufficiently sensitive to detect changes. If found to be so, this would strengthen the conclusion that validation of breast cancer survivors' current meanings alone, in the face of threat to their core and core role constructs, is not enough to bring about change in their psychological well-being. The same measures of model-derived concepts and (non personal construct) anxiety and depression, therefore, will be used in Study 3.

In Chapter 8, I describe the group therapy I developed to provide breast cancer survivors with opportunities for both validation of their current meanings *and* elaboration of new meanings. This therapy is evaluated in Study 3, the final study, which I report in Chapters 9 and 10.

CHAPTER 8

WORKING WITH BREAST CANCER SURVIVORS:

PERSONAL CONSTRUCT GROUP THERAPY

“It (the group intervention) has shown us our diversity. I don’t think that you’d find many situations where women of all ages, and from all walks of life, come together in this way. There’s really a strange and fantastic bond between women in supporting each other – you feel comfortable, accepted and you feel affection. And it’s not morbid, or all clinging together”.
(Rose, 57 years).

In this chapter I first provide accounts, from a personal construct perspective, of therapy in general, and group therapy. The personal construct group therapy, I developed specifically to work therapeutically with breast cancer survivors, is described. I provide an outline of each session, and explain the underlying personal construct processes or themes that the tasks are structured to promote. Finally, I summarise these processes, and discuss the potential of the intervention for promoting supportive role relationships.

8.1 Personal Construct Therapy

The two overarching aims of personal construct therapy are to facilitate opportunities for clients to maximize their potential for confirmation of their interpretations (Epting, 1984), and to construct alternative understandings of their more problematic meanings (Fransella & Dalton, 1990; Neimeyer, 1985b). The central philosophical assumption underlying the theory on which personal construct therapy was developed is that there are innumerable possible alternative constructions of reality, and that “all of our present interpretations of the universe are subject to revision or replacement” (Kelly, 1955/1999, p.15). From this assumption it follows that all meanings can be revised or replaced by better understandings and predictions (Viney, 1996).

Viney suggests that the first goal of personal construct therapists is to make the meanings the clients place on their experiences explicit (Viney, 1996). In understanding their own construing processes clients can then realise their ability to write alternative stories (reconstrue) for themselves. From the ongoing process of story telling, clients can then be guided to an understanding of the possibility of alternative stories to tell themselves, that is, new and more satisfying stories about themselves. This telling of alternative stories is identified as the second goal of the personal construct therapist (Viney, 1996). These alternative stories provide clients

with an opportunity to change their actions to fit their new meanings, to test the viability of their alternative stories. This is the third goal of personal construct therapists as defined by Viney (1996).

In contrast to the cognitive behavioural and psycho-educational interventions described in Chapter 3, the focus of personal construct therapy is upon the journey, rather than the achievement of a specific destination (Epting, 1984). Unlike theorists who view human behaviour as determined, personal construct therapists regard peoples' actions as the means by which they test their beliefs about the future, given the limits imposed by their current understandings (Neimeyer, 1987a). Personal construct psychotherapy, therefore, is primarily concerned not to change the clients' behaviours, but to encourage experimentation: "aiming for creative and personal elaboration of meanings" (Winter, 1992, p.383).

8.2 Personal Construct Group Therapy

Given that the interpersonal context in which women must adjust to their breast cancer diagnosis was identified in the literature reviews in Chapters 2 and 3, and by the women participating in Study 1, as an important factor in their adjustment to living as a breast cancer survivor, I chose group over individual therapy for Study 3. Unlike many theoretical orientations, personal construct psychology offers a theoretical rationale for conducting therapy on a group basis (Winter, 1997). While many current schools of therapy derive their distinctiveness primarily from the techniques they employ (Neimeyer & Harter, 1988), personal construct therapy can be distinguished by its underlying theory of the person (Kelly 1955/1991) as outlined in Chapter 4. Two personal construct concepts, "commonality" and "sociality" are essential to an understanding of group processes. Kelly (1955/1991) proposes that the elaborative potential of a given relationship, and this includes the therapeutic relationship, is governed by:

1. The level of “commonality”, providing confirmation of important meanings; and
2. The level of understanding, or “sociality”, providing for elaboration of those meanings.

Kelly's (1991/1955) Commonality Corollary indicates that, while all group participants are unique, there is the potential for their sharing of common understandings. These understandings provide the experience of consensual validation of the individual view of each participant, offering some assurance of the workability of their current meanings. These understandings also provide a psychologically secure context in which to elaborate their new meanings (Koch, 1985). Implied in the Sociality Corollary is the implication that relationships are limited by the degree of understanding that is attempted. Koch (1985) has suggested that the ability to experience recurring cycles of commonality and sociality are key features of psychological well-being. The task of personal construct group therapists, therefore, is to foster the awareness of both commonality and sociality among the group members, with sessions specifically structured towards this objective.

As a base for experimentation, the group, with its range of personalities and experiences among the members, affords more scope for the development of new and more comprehensive roles than might individual therapy. A group format has further advantages as identified by Neimeyer (1988). Those of particular relevance, in that they specifically relate to commonality and sociality, are now listed:

1. A group format promotes rapid self-disclosure, by encouraging mutual sharing of personal meanings;
2. A group format encourages the development of empathic listening so that similarities and differences may be discovered;

3. A group format aids group cohesion in that each member has the opportunity to be known and to know every other member of the group;
4. A group format permits the participants to experience themselves in the roles of both supporter and supported;
5. A group format provides for a less threatening context in which to test reconstructions of meaning; and
6. A group format provides the opportunity for the elaboration of meanings in whole-group discussions where individual experiences can be viewed in the perspective of implicit group themes.

The therapeutic processes identified by Yalom (1975, 1995), and described in Chapter 3, as part of the supportive-expressive intervention developed by Spiegel and his team of researchers (Spiegel et al., 1981, 1999), are particularly useful to personal construct therapists when conducting group therapy. The most important of these processes are experiencing hope and other emotions and sharing or disclosure of information and meanings (Viney, 1996). These processes allow clients to engage in cycles of sharing, individuation, and elaboration of their meanings (Koch, 1985; Llewelyn & Dunnet, 1987; Viney, 1996).

8.3 The Personal Construct Group Therapy for Breast Cancer Survivors

In the cancer literature the term adjustment is often used to imply the absence of “psychological morbidity”, or the end point of “coping” with the global threat of cancer; the goal of psychotherapy being to reduce elevated levels of distress and return these to normatively derived levels (Brennan, 2001). Rarely, however, do people return to their pre-cancer diagnosis state of being in the world (Doka, 1997; Ferrell & Dow, 1996; Frank, 1995; Janoff-Bulman, 1992; Taylor, 1983; Wilkinson, 2000). The personal construct model of adjustment to breast cancer survival,

described in Chapter 5, suggests, instead, that a major task of psychological intervention with women facing the ongoing threat of breast cancer will be to help these women's adjustment to a new state of being (Lane & Viney, 2001b). This requires the revision of old meanings, and the elaboration of new meanings. Based on this model, the overall goal of this group intervention was:

To encourage interpersonal opportunities for group members to formulate, confirm, revise, elaborate, and test their meanings of living as breast cancer survivors.

In reviewing the literature on psychological interventions for breast cancer survivors, Burke and Kissane (1998a) found short interventions of between six to twelve weeks to be appropriate for women diagnosed with early breast cancer. I felt a total of eight sessions would be sufficient. Eight weeks is long enough for supportive role relationships to develop between group members. It also allows enough time for participants to elaborate new meanings. The sessions were held weekly, allowing time between sessions for group members to test their new meanings in the context of their daily lives.

The first step in establishing the "social context" in which women living as breast cancer survivors can experiment with new meanings is the establishment and maintenance of a cohesive group. Group cohesion engenders feelings of acceptance and belonging and is related to factors that contribute to positive outcomes, including being highly valued by the group members (Spiegel & Diamond, 2001), increased self-disclosure, and acceptance and openness to the views of others (Yalom, 1995). The role of the therapist, therefore, is to stimulate and encourage cohesive interaction between members of the group. To promote safe disclosure, the importance of non-judgemental responses and confidentiality should be agreed on as both the right, and the responsibility, of the group members.

Structure is fundamental to personal construct group work. The tasks that provide structure make possible the process of experimentation (Viney et al., 1999). Throughout the eight sessions the interpersonal transaction (IT) group format (Landfield & Rivers, 1975) was adopted. Developed as “a method of studying and improving social relationships (Landfield & Rivers, 1975, p.365), this format allows the members of a larger group to engage in rotating dyads for a series of brief exchanges on a designated topic, then reconvene as a group to process the experience. Topics chosen were broad enough to allow individual participants a degree of choice in the level of disclosure they felt able to risk. By offering repeated opportunities, this technique allowed the participants to take greater risks in their experimentations following initial validation. The processes and themes for each of the eight sessions are now presented. The specific tasks that provided the structure of the sessions, selected to optimise the process of experimentation, are detailed later in this Chapter.

Session 1

The theme of the first session is commonality. Activities in this session focus on exploring the experiences and meanings shared by the group members. As noted in Chapter 4, commonality helps to define people’s meanings, by confirming the viability of their existing constructs. The development of supportive role relationships within the group will depend, in part, on the extent to which group members are able to help each other define their existing meanings. Emphasising their commonality provides, therefore, the foundation on which group members can begin to develop a network of supportive relationships.

Although group members share a breast cancer diagnosis in common, and it is important that they be given ample opportunities to explore their common experience of cancer, it is equally important that the activities chosen allow group members to extend their focus beyond their roles as women with cancer. Other aspects of their

lives they have in common may include their roles as wives or partners, as mothers, as daughters, and as friends. They may also share values and beliefs in common, and even a love of pizza.

Session 2

The theme of this session is individuality. In this session group members examine how different their personal meanings may be from others'. Starting from simple, subordinate, therefore less threatening meanings, the group begin to explore their differences. For example, two women may both adore pizza, but one likes pineapple on hers, while the other may prefer olives. From this understanding, that although constructs may, in part, be similar to those of another (the Commonality Corollary), they are essentially unique (the Individuality Corollary), group members can begin to explore their different breast cancer experiences. Listening to others' interpretations of events clearly illustrates to the group members how people can experience "similar" events in different ways. Disclosure of their personal meanings allows group members to gain an understanding of each other's meanings and is a pre-requisite for the formation of role relationships (Koch, 1985).

Session 3

The theme for this session is self constructions. Here the group members begin to clarify the constructs by which they define themselves. Activities in this session are more individually focused, although the provision of ample opportunities for the group members to share their meanings remains important. A group guided imagery exercise takes the participants back in time. They then draw on these reminiscences to explore the constructs by which they define themselves, particularly focussing on the qualities they identify in themselves. The activity that provides the structure for this session is the "Self-Sort Activity" an adaptation of the dependable strengths process (Forster, 1991). This exercise (see Appendix I) also allows women to identify their

most important self constructs, those meanings that are central to their definition of themselves (superordinate core constructs), and examine how these may have changed over their lifetime. Dyadic and group discussions then provide opportunities to examine how the importance of certain core constructs may change, for instance, being fun-loving and carefree may be important core constructs at twenty, but being loving and responsible may become more important (superordinate) core constructs during child-bearing and caring years, illustrating how important self constructions are open to revision in the face of changing circumstances.

Homework is given in this session. Participants are asked to write a brief personal autobiography choosing from one of the following: the history of my family of origin; the history of the family I created; the history of my friendships; or the history of my loves (Botella, 1991; Botella & Feixas, 1993).

Session 4

Sociality is the theme for this session and builds on the foundations laid in Session 2. The activity that provides the structure for this session is the recounting of their written autobiographies. The process involves the sharing of experiences (meanings) within an atmosphere of acceptance and understanding (validation). This is the essence of being validated as a construer of meaning. Sharing of their core constructs provides the foundations for “sociality”. That is, it allows group members to relate to each other in ways that are based on their attempts to understand each other’s meanings.

In this session, as group members share the autobiographies they prepared as homework, their autobiographical writing acts as a form of reminiscence. Viney, Benjamin and Preston (1989, 1990) suggest that reminiscence and life review can be considered as a means to test one’s personal construct system. The generation of alternative constructions of these histories is also considered to be a core process in

the revision of the individual's system of construing (Botella, 1991). In the context of the supportive relationships, which are developing, group members can begin to experiment with new meanings, thus widening the range of choices available for action (Lovenfosse & Viney, 1999), and restoring a sense of coherence to their ongoing stories.

Session 5

The major theme of this session is alternative meanings. Again, as in Session 2, it is helpful to first explore alternative ways of making sense of experiences that are less threatening than their cancer experiences. "Stress", for example, is a construct that group members can all identify; yet it may have different meanings to them. Some women may feel "stressed" at the thought of standing up in front of a group of people; others may feel comfortable doing this, but get "stressed" at the thought driving in the city. The women are likely to have a wealth of "tricks and tips" to share on dealing with every day stresses. The sharing of these "tips" is anticipated to provide a range of alternative ways of approaching stressors which in themselves may be helpful, but, most importantly, it sets the context in which to explore alternative ways of making sense of other troublesome areas in their lives.

The challenge of living as survivors of breast cancer is being met in the face of other challenges in women's lives as noted in Chapter 1. Many of these women are also facing the burden of caring for aging parents; other women are dealing with the added strain their diagnosis places on their marriages; and all women are dealing with the myriad of stressors involved in being a woman living in the 21st century. This session allows the women opportunities to disclose their problems, including their difficulties in adjusting to living as survivors of breast cancer, and to fully experience the supportive potential of the group.

Session 6

This session's theme extends the work of the previous two sessions by examining alternative constructions of themselves and their relationships. Its activities are loosely based on Robert Neimeyer's (1999) life imprints exercise. First, participants discuss how people, figuratively, have left their footprints on their lives. Participants then examine who is helping them to view themselves positively, and who is not. This process allows group members to examine how the stories others have told them about themselves have shaped the stories they tell themselves. Opportunities are given to test alternative constructions of these "footprints" (Neimeyer, 1999) in dyads, small groups and whole group sharings. Care must be taken in this exercise to include a closing guided imagery of waves that can wash away the unhelpful "footprints".

Session 7

The theme for this session is elaboration. In this session the participants have the opportunity to elaborate their breast cancer stories. The recounting of past events is not about history making, but about meaning making (Neimeyer, 1998). It is important, therefore, that the group is given the opportunity to revisit their experiences. In the retelling they have the opportunity to elaborate their stories and test their new meanings in a group whose members have developed a deep understanding of each other. It is also an opportunity to clarify future anticipations in which they may now wish to engage.

Based on the deep understanding they have developed, group members are encouraged to assist in the elaboration of the story tellers' new meanings. This is the essence of supportive role relationships. It is also an opportunity to reflect on how the meanings attached to the experience may now be changing.

A homework task is given for the following session. Participants are asked to write a short letter to an unknown woman who might just now be getting a breast cancer diagnosis. What would you like to tell them? This exercise gives the participants an opportunity to record for themselves how far they have come from their diagnosis. This exercise also forms the basis of a wonderful resource for women newly diagnosed with breast cancer, and their families.

Session 8.

The theme for the final session is choice. A major assumption of personal construct theory is that women's construction processes are psychologically channelized by the ways in which they anticipate events (*the Fundamental Postulate*), and those ways present themselves in dichotomous form (*the Dichotomy Corollary*). It follows from this that women diagnosed with breast cancer will choose between the poles of their dichotomies in a manner that is predicted by their anticipations (*the Choice Corollary*). This choice is essentially elaborative and functionally integral to the anticipation of events. The major activity for the last session is the sharing of helpful messages they would like to give to those just starting their experience of a cancer diagnosis. The task of the group therapist in the final session is to aid the participants with the following:

1. Clarifying their new perspectives;
2. Recognising and clarifying the future choices now available to them; and
3. Ensuring that everyone has telephone numbers and contact details for group members, and arranging a social follow up meeting in three months.

8.4 A Summary of the Intervention: The Group Processes

In this section I summarise the group intervention described above by examining the intervention in terms of its potential to promote therapeutic group processes. The personal construct group intervention described here was developed to

specifically address the issues identified in Chapters 2 and 6. In seeking to establish a network of supportive role relationships, the goal was to create a social context in which group members could formulate, confirm, revise, elaborate, and test their meanings of living as breast cancer survivors.

The awareness of commonality among group members, the theme for Session 1, helps foster a sense of universality. Universality (Yalom, 1995) is an important therapeutic factor that operates when participants perceive that other group members have similar problems and feelings (Bloch, Reibstein, Crouch, Holroyd, & Hemen, 1979). Recognition that they are not alone with their feelings and problems reduces their sense of isolation. Discussion of their shared meanings also promotes clarification of each member's unique meanings, the theme for Session 2. In Session 3, clarification of important meanings is extended further to examine the women's superordinate core meanings, those meanings concerning their identity, values and beliefs.

Over the course of the first three sessions the women disclose these meanings to the group. Disclosure of meanings promotes sociality, the theme for Session 4. Sociality involves engaging in behaviours based on an attempt to understand another's construing processes. The concept of sociality is central to this support process. Supportive role relationships require the supporter to acknowledge the other as a construer of meanings. To facilitate these relationships, women must first formulate, and then recount their meanings. The process of sharing experiences (meanings) and having these meanings confirmed also promotes acceptance and understanding (group cohesiveness).

A cohesive group provides a safe and accepting environment for group members in which they can risk revising, elaborating and testing their new meanings, essential to their adjustment as breast cancer survivors. As in the early sessions, the

revision of current meanings is first attempted on less important meanings. This is the focus of the first part of Session 5. This is then extended in the session to include the initial revision of important meanings. Sessions 6 and 7 continue this process, providing structures that allow for the elaboration and testing of new meanings. In the final session, group participants are provided with opportunities to reflect on the group processes, and commit to future anticipations. An account of this group work is provided in Lane & Viney (2001a). Table 8.1 summarises the structures and processes of the personal construct therapy described here. Examples of Worksheets referred to in this summary are provided in Appendix I.

Table 8.1

The Structures and Processes of the Group Therapy

Structures

Processes

Session 1: Commonality

- | | |
|--|--|
| <ol style="list-style-type: none"> 1. Initial introduction of self with one detail about self to the whole group. 2. Start discussion with the aspects of themselves that they share with each other. "Things we as a group have in common". Breast cancer is an obvious one, but it is important that the group acknowledges that "they are not breast cancers" but women with a diversity of interests, talents, beliefs, strengths, likes and dislikes. Write up all the ways that we are the same on board. 3. Participants complete Worksheet 1 (shown in Appendix I) for themselves and then, mingle in the room to find at least one other person who has the same like or dislike. Participants place the name in the space provided. More than one name can be entered. 4. Return to group and discuss. | <p>Exploring the experiences and meanings shared by members of the group – the foundation on which to develop a support network of relationships based on an understanding of each other's construing.</p> |
|--|--|
-

Table 8.1 (continued)

 The Structures and Processes of the Personal Construct Intervention

Structures

Processes

 Session 2: Individuality

- | | |
|--|-------------------------------|
| <ol style="list-style-type: none"> 1. In dyads, discussing statements about self showing positive regard.
Who gives you these messages?
What do you tell yourself? 2. Come together as a group and discuss | Sharing of personal meanings. |
|--|-------------------------------|

Session 3: Self Constructions

- | | |
|--|--|
| <ol style="list-style-type: none"> 1. Discuss how important it is to clarify who we are, who we were, and who we wish to become. Clarification of current meanings is an important pre-requisite for future revision and elaboration of constructs concerning self. 2. Group members are taken back to earlier times in their lives in an imagery exercise. They may draw on these reminiscences for the self sort activity. This activity is an adaptation of the dependable strengths process (Forster, 1991). 3. Discussing the changes in their lives, in terms of their plans at the time. 4. Who was in their life then? 5. What qualities in themselves do they see as being evident when they look back at themselves over the years? 6. Participants are given 10 cards, each with one of ten elements (life stages). These life stages include: self when I was young; self in my twenties; self before I was diagnosed with breast cancer; and self at a time when I was very happy. The participants are asked to sort these cards into two groups; whereby all the life stages in one group are the same, and all the life stages in the other are not. Repeating this exercise a number of times allows group members to identify several self-constructs, and to see common threads through their histories. An example of a completed Self Sort is given in Appendix I. 7. Discuss unexpected findings. | Identifying the core constructs by which the individuals make meaning of their past, present and future. |
|--|--|

 HOMEWORK

Writing personal autobiography.
Choose from one of the following topics:

- The history of my family of origin
 - The history of the family I created
 - The history of my friendships
 - The history of my loves (Botella, 1991)
-

Table 8.1 (continued)

The Structures and Processes of the Personal Construct Intervention

Structures	Processes
Session 4: Sociality	
<ol style="list-style-type: none"> 1. Discuss how pre-diagnosis future stories might now need to be rewritten. To reconstrue the future we need to be sure of where we are right now and where we have been. 2. Group members recount their history to others and others will be given the opportunity to ask questions and comment on these accounts. 3. The therapist's task is to pick up on any recurring themes, identify the constructs by which the women make sense of these experiences. 4. Ask the women to think, after hearing everyone's story, of their own plans. Record future plans on the whiteboard. 	<p>The therapeutic process involves the sharing of experiences (stories) within an atmosphere of acceptance and understanding (validation). Sharing of their personal stories allows members of the group to make their own meanings explicit. In the context of the relationships formed, group members can experiment with new meanings, thus widening the range of choices available for action (Lovenfoss & Viney, 1999), and restoring a sense of coherence to their ongoing stories.</p> <p>The generation of alternative constructions of these histories is also considered to be a core process in the revision of the individual's construct system (Botella, 1991). Discussion of these reminiscences may facilitate a greater awareness of the meanings attached to the memories.</p>
Session 5: Alternative Meanings	
<p>Following an examination of the stressors in their lives, and the meanings they place on their experience of stress, participants work in dyads, before joining together as a group to identify other aspects of their life open to alternative construction.</p>	<p>The purpose of this session is to provide opportunities to explore alternative meanings. Stress is an experience that group members can all identify, although it may have different meanings to them. The sharing of these differences is intended to provide a range of alternative ways of approaching stressors but, most particularly, it provides the context in which to explore alternative constructions of other troublesome areas in their lives.</p>

Table 8.1 (continued)

 The Structures and Processes of the Personal Construct Intervention

Structures

Processes

 Session 6: Alternative Meanings About
Self and Relationships

1. Discussion about how people figuratively leave their footprints on us.
2. Who is currently helping you to view yourself positively? Who isn't?
3. In dyads group members help each other to complete worksheet 6 shown in Appendix I.
4. Opportunities should be given for group members to share their meanings with other group members in dyads first, then progressing to the whole group.
5. Closing guided imagery of waves washing away the footprints that may be unhelpful.

Following on from last week's work on alternative constructions, this concept is now examined in the context of relationships. The activities are loosely based on Neimeyer's (1999) life imprints exercise.

 Session 7: Elaborating the Breast Cancer
Story

Discussion in dyads and small group explores the following themes.

- 1 How is the story changing?
- 2 Why might it be changing?
- 3 What is the meaning of this change for you?
- 4 Share these meanings with the whole group.

At this point the group participants often need to go back and again tell their experiences of their diagnoses. It is important that they be given this opportunity to revisit their experiences. In the retelling, they have the opportunity to elaborate their stories and test their new meanings in a group that has developed a deep understanding of each other. It is also an opportunity to clarify future anticipations in which they may now wish to engage.

HOMEWORK

Writing a short letter to an unknown person who might just now be getting a breast cancer diagnosis. What would you like to tell them?

Table 8.1 (continued)

The Structures and Processes of the Personal Construct Intervention

Structures

Processes

Session 8: Elaborative Choice

The major activity for the last session is the sharing of the messages they would like to give to those just starting their experience of a cancer diagnosis. The task of the therapist is to help the participants with the following:

1. Identify what have they learnt;
2. Clarify their new perspectives;
3. In the light of personal core constructs identified in Session 4, and acknowledgment of the choices already made and now available to them, clarify their future goals.

The sharing of prior meanings and the testing of helpful new meanings, recognising the choices now available to them as they continue to elaborate new meanings (Lovenfosse & Viney, 1999).

Before leaving, make sure that everyone has telephone numbers and contact details for group members and arrange a social follow up session in three months.

In the next chapter, I report on the outcomes of Study 3, conceptualised as the validation/elaboration study. In this study the benefits of participating in the group intervention outlined above are evaluated.

CHAPTER 9

STUDY 3: THE VALIDATION/ELABORATION FOR BREAST CANCER

SURVIVORS EVALUATION STUDY:

THE GROUP THERAPY

“Imagine if we had never had breast cancer and we didn’t know one another. We’d just walk past each other in the street – wouldn’t it be awful. We’ve got such strong friendships now. I didn’t want to have breast cancer but I would hate to be without all these wonderful friends” (Rita, aged 47 years).

In this chapter I present the final study evaluating the effects of the group therapy on survivors of breast cancer, Study 3. I first provide the aims and hypotheses of the study and then introduce the participants. I briefly describe the measures used in this study, a fuller account of which was provided in Chapter 7. The design of the study and the forms of analysis of data are then described. The results of the statistical analyses of the data contributed by the women who participated in the personal construct group therapy and their controls is then presented, followed by a discussion of the findings and the limitations of the study. In Chapter 10 I will examine the group processes involved.

9.1 Aims and Hypotheses

In this study I evaluated a randomised trial to empirically validate the personal construct group therapy I developed, based on my personal construct model of adjustment to breast cancer survival. In providing a structure for the evaluation of treatments, Chambless and Hollon (1998) argue that treatment efficacy must be demonstrated in controlled research in which it is reasonable to conclude that benefits observed are due to the effects of the treatment and not to chance, or confounding factors such as the presence of different types of clients in the various treatment conditions. This was identified as a limitation of Study 2. Efficacy is best demonstrated in randomised clinical trials in which participants are randomly assigned to the treatment of interest or one or more comparison conditions (Chambless & Hollon, 1998, Chambless & Ollendick, 2000).

The *Aim* of Study 3 was to provide empirical evidence of the benefits of therapeutic support. Therapeutic support was defined as the provision of opportunities for the therapy participants to optimise both *commonality* and *sociality*. Commonality provided validation of the content of their current meanings, thereby helping them define their experiences. Sociality provided validation of their processes of

construing, allowing these women to elaborate new meanings that would be more helpful to their ongoing tasks of living as breast cancer survivors. As a test, then, of personal construct group work, based on the model of adjustment to breast cancer survival, this study set out to test a number of hypotheses. The hypotheses for Study 3 were as follows:

1. Women in the group therapy sample will show significant decreases in levels of threat to construing of their physical and psychological selves, compared to women in the control sample at Time 2, and this differential decrease will be maintained at Time 3;
2. Women in the group therapy sample will show significant decreases in levels of threat to their existence (death threat), compared to women in the control sample at Time 2, and this differential decrease will be maintained at Time 3;
3. Women in the group therapy sample will show significant decreases in levels of dislocation, compared to women in the control sample at Time 2, and this differential decrease will be maintained at Time 3;
4. Women in the group therapy sample will show significant increases in levels of hope, compared to women in the control sample at Time 2, and this differential decrease will be maintained at Time 3; and
5. Women in the group therapy sample will show significant decreases in levels of non-model based anxiety and depression, compared to women in the control sample across time, with the difference located between Time 1 and Time 2, but not between Time 2 and Time 3.

The University of Wollongong, in collaboration with Illawarra Area Health Service granted ethics approval for this study, and I conducted the group therapy sessions between September and December, 2000.

9.2 Recruitment and Sampling

The sample consisted of 42 women recruited from the original sampling pool of 111 breast cancer survivors. Of these 111 women (see Appendix G), 20 attended the Retreat and another 20 were matched to this group to act as the Retreat control sample. This resulted in a potential sampling pool of 83 participants. Inclusion and exclusion criteria for participation in this study were the same as for Study 2, with the addition of two inclusion criteria and one exclusion criterion. These were, being less than 70 years of age, to eliminate the confounding effect of age related illnesses, and being within ten years of diagnosis, in order to limit the study to women who were more likely to be still adjusting to their diagnoses. The additional exclusion criterion was to currently be receiving counselling or other psychotherapeutic support, as this would undoubtedly confound the effect of the personal construct group therapy. The inclusion and exclusion criteria for Study 3 were as follows:

Inclusion Criteria

1. First occurrence biopsy-proven breast cancer;
2. Diagnosis more than six months prior to participation;
3. Less than 70 years of age (to eliminate the confounding effects of age related illness);
4. Being within ten years of diagnosis.

Exclusion Criteria

1. Metastases beyond adjacent lymph nodes;
2. Recurrence in breast or other tissue;
3. Other cancers or illnesses thought to be life-threatening;
4. Currently receiving counseling or other psychotherapeutic support.

Of the 83 women remaining to be invited to participate in this study, 19 lived too far away from the location of the study to be available. Three women were

currently receiving counselling, and a further 19 women did not meet the inclusion criteria, being either beyond 70 years of age or more than 10 years since diagnosis. Forty-two participants met all of the inclusion criteria and none of the exclusion criteria. These volunteers were randomly assigned using a table of random numbers (Jaccard & Becker, 1997) to either the intervention ($n = 20$) or wait-list control samples ($n = 22$). The 22 women in the wait-list control sample were offered the opportunity to participate in the group therapy after their last data contribution. Data collection sets for participants in Study 3 were the same as for Study 2 participants, and can be viewed in Appendix E. Consent and information forms for Study 3 participants are shown in Appendix H.

9.2.1 The Participants

The mean age of the participants in the group therapy sample at the time of the study ($n = 20$) was 51.3 years (S.D. 8.82; median 51.5). Ages ranged from 33 years to 69 years. The mean age for the control sample ($n = 22$) was 56.5 years (S.D. 8.64; median 57.5). Ages ranged from 42 years to 69 years. Mean age at diagnosis was 48.2 years (S.D. 8.65; median 48) for the treatment group and 53.36 years (S.D. 8.31; median 54) for the controls. The participants in the two groups, although randomly assigned, were quite similar to each other in terms of time since diagnosis and marital status. In the therapy sample, 65% of the women were between the ages of 40 and 54 years, compared to only 41% in the control sample. More women in the control sample, therefore, were more than 55 years of age (59%) than women in the therapy sample (30%).

Compared to the participants in Study 2, 15% of the women in the Retreat Study were over the age of 70 years, while women over the age of 70 years were excluded

from this study⁴. In Study 3, more than half of the participants were younger than 55 years of age, compared to a quarter of the women in Study 2. Comparing marital status between the participants in Studies 2 and 3, 18% of the women in Study 2 were widowed, compared to only 7% in Study 3. It is likely that this was due to the older age of the women in Study 2. I summarise the demographic characteristics of the sample of breast cancer survivors who participated in Study 3 in Table 9.1.

Table 9.1

Frequencies of Age, Time Since Diagnosis, and Marital Status of Study 3 Participants

Variable	Category	Group		Percentage of total sample
		therapy (n = 20)	Control (n = 22)	
Age	30-39	1	0	2
	40-54	13	9	53
	55-69	6	13	45
Time since diagnosis	6m>1yr	2	3	12
	1 > 2 years	8	6	33
	2 > 5 years	5	7	29
	5 >10 years	5	6	26
Marital status	married	19	14	79
	de facto	1	2	7
	widowed	0	3	7
	divorced	0	1	2
	single	0	2	5

9.2.2. The Representativeness of the Sample

To examine the representativeness of the sample, the ages of the women at the time of their diagnoses were again compared to the ages of women at time of diagnosis in NSW in 1999 (New South Wales Cancer Council, 2001). In NSW, 40% of women diagnosed with breast cancer were under the age of 54 years at the time of

⁴ Women excluded because of age, or length of time since diagnosis, were given the opportunity to participate in the pilot study. Provision was made for women who lived too far away to participate in a half-day workshop in their local area. I travelled to their locale for this. In this way, they were not totally ignored.

their diagnosis, compared to 67% of the women in this sample. A further criterion on which to view the representativeness of the samples was marital status. In Chapter 7, I noted that 77% per cent of women in Australia are likely to marry (ABS, 2000). Seventy-nine percent of the participants in Study 3 were married. The samples are, then, representative of the marital status of women in Australia. As at June 1999, 10% of the Australian population over the age of 15 were widowed. For these samples, only 7% reported widow status, which probably reflects the finding that this population is younger than the general population (ABS, 2000).

9.3 The Group Therapy

Two personal construct therapy groups were conducted with the participants attending eight, two-hour sessions, weekly. The goal was to create a social context in which group members could formulate, confirm, revise, elaborate, and test their meanings about living as breast cancer survivors (Lane & Viney, 2001a, 2001b). The structure and processes of the group therapy were described in Chapter 8. Participants were allocated to either a day or evening group to suit their individual needs. The two therapy groups were run concurrently, with ten participants in each group.

I conducted the therapy sessions for the two groups, so was able to ensure that the same structure and processes were followed, and were offered in the same sequence. At the time of conducting the therapies I was registered with the New South Wales Psychologists' Registration Board as an intern psychologist. I had completed one year of the two year supervised probationary period required by the Board. Ideally a more experienced co-therapist would have been helpful (Yalom, 1995), but this was beyond the resources available for this research. Associate Professor Linda Viney who has 25 years of experience applying personal construct concepts and practices with clients supervised my clinical work.

9.4 The Procedure

Women in the therapy sample were sent, by mail, a data collection set one week before the commencement of the therapy, to be completed prior to starting. These instructions were the same as for the Retreat sample (see Chapter 7). The women brought their data collection sets to the first session, and these were collected as they arrived. Their second data collection set was given to the therapy participants at the end of the final session for completion at home within 7 days of finishing the therapy. These were returned to me in the stamped addressed envelope provided. The third data collection set was mailed to each participant 12 weeks after the therapy sessions ended.

Women in the control sample were posted data collection sets, with stamped addressed envelopes for their return, at the same time as the first data collection sets were sent to therapy participants. A second set was mailed to them eight weeks later, and the third set was sent 12 weeks later. Three months after these participants had contributed their Time 3 data they were invited to participate in a group therapy.

9.5 The Measures

As in Study 2, the CAS Total Anxiety Scale measured the evaluating concept of *threat*. The CAS Death Anxiety Subscale was used to measure *threat to existence* in the face of diagnosis with a life-threatening disease, and the CAS Depression Scale measured the evaluating concept of *dislocation*. *Hope* was measured using the CAS Hope Scale. Levels of anxiety and depression (non personal construct) were measured using the DABS Anxiety and Depression Subscales. A full description of all of these measures, with evidence of their reliability and validity, was provided in Chapter 7.

Internal-consistency for the two DABS Subscales for Study 3 participants at each data collection was considered adequate. Although Cronbach alpha values ranged from .71 to .87 for Anxiety and .65 to .9 for Depression, inter-item correlations were run again for the five items that make up each scale, for each group

where alphas below .7 were observed. The mean inter-item correlations fell within the recommended optimal range of .2 to .4 (Briggs and Cheek, 1986).

9.6 Design and Data Analysis

A randomised controlled trial was conducted with a 2 X 3 mixed between and within design with one between subjects variable, group with two levels (therapy sample and control sample), and one within subjects variable, time with three levels (baseline Time 1, Time 2 eight weeks later at the end of the group therapy, and Time 3 a further 12 weeks after Time 2). The six dependent variables were CAS Total Anxiety Scale scores, CAS Death Anxiety Subscale scores, CAS Depression Scale scores, CAS Hope Scale scores and DABS Anxiety and DABS Depression Subscale scores.

The scores were analysed using multiple univariate repeated measures analyses of variance. Where the interaction effects of time and group were found to be significant, further analyses were conducted. To examine between-group effects within times, pairwise comparisons of group means were made for each occasion. To examine within-group effects across time, one-way repeated measures ANOVAs were conducted.

The assumptions underlying mixed between- and within-subjects analyses of variance were reported in Chapter 7. Examination of the data revealed that only the CAS Anxiety Scale scores were not normally distributed. With a sample of 42, violation of this assumption was not anticipated to cause problems (Gravetter & Wallnau, 2000; Stevens, 1996). Levene tests for equality of variance revealed that variances for the therapy sample and the control sample on the CAS Death Anxiety subscale scores were not equal. As the size of the groups was reasonably similar ANOVA was considered to be sufficiently robust against violation of this assumption (Stevens, 1996). Maunchley's test of sphericity revealed that Death Anxiety Subscale

scores violated this assumption. As the Wilk's Lambda and Pillai's Trace statistics do not require sphericity, in the following examination of results these are reported.

A final assumption to be met was homogeneity of the inter-correlations, that, for each of the levels of the between-subject variable, the pattern of inter-correlations among the levels of the within-subjects variable should be the same. This was tested using Box's M statistic. Scores on the CAS Death Anxiety Subscale again violated this assumption ($F(6, 11289) = 3.727, p = .001$), all other dependent variables showing acceptable patterns of inter-correlation. Although the discrepancy in cell sample sizes was small, examination of the variances and covariances for the cells revealed that the smaller sample (the therapy sample) produced larger variances. In this case the significance test may be too liberal. Deletion of cases was not considered to be appropriate given the small sample size. Tabachnik and Fidell (1996) recommend that Pillai's criterion rather than Wilk's Lambda is used to evaluate significance when this assumption is violated. Results for Death Anxiety reported are, therefore, Pillai's Trace, all other reportings are Wilk's Lambda. The results of the statistical analyses of the data contributed by breast cancer survivors are now reported.

9.7 Results

Means and standard deviations for scores on the dependent variables were calculated for both samples and are presented in Table 9.2.

Table 9. 2

Means and Standard Deviations for Content Analysis Scales and Derogatis Affects

Balance Subscale Scores by Sample for Times 1, 2 and 3

Time	Variable	Variable	Variable
	CAS Total Anxiety	CAS Death Anxiety	CAS Depression
Therapy sample			
Time 1	2.33 (.54)	.84 (.51)	7.86 (1.94)
Time 2	1.72 (.68)	.56 (.19)	6.22 (1.45)
Time 3	1.53 (.44)	.57 (.16)	6.26 (0.98)
Control sample			
Time 1	2.03 (.63)	.70 (.27)	7.37 (1.85)
Time 2	2.08 (.82)	.66 (.23)	7.19 (1.78)
Time 3	1.85 (.75)	.78 (.37)	7.27 (1.67)
	CAS Hope	DABS Anxiety	DABS Depression
Therapy sample			
Time 1	1.72 (2.11)	8.45 (3.07)	6.30 (3.74)
Time 2	2.89 (1.88)	7.50 (2.40)	5.10 (3.37)
Time 3	3.10 (2.35)	7.90 (2.36)	5.60 (3.07)
Control sample			
Time 1	2.05 (2.38)	7.55 (3.31)	4.64 (2.34)
Time 2	1.97 (2.84)	7.05 (2.95)	5.41 (3.05)
Time 3	1.24 (2.41)	6.95 (2.70)	5.55 (2.82)

Gottschalk and Gleser (1969), as reported in Chapter 7, suggest that a Total Anxiety score above 2.2 is indicative of a moderate clinical disorder and a score of 3.0 or more is indicative of the presence of pathological disorder. At Time 1 the therapy sample mean indicated moderate threat. The group mean for the control sample was within the normal range. Examination of the individual data revealed that at Time 1, 11 women (55%) in the therapy sample had a Total Anxiety Scale score above 2.2, with four women (18%) in the control sample having similarly elevated scores. Two women in each sample were found to have scores above 3.0. At Time 3, six women in the control group continued to express moderately elevated threat, as

measured on the Total Anxiety Scale, with one score above 3.0. For the treatment group, no individual scores at Time 3 were above 2.2.

As might be expected from an oncology population, at Time 1, group means for the Death Anxiety Subscale were elevated compared to published norms for the general population (Gottschalk & Gleser, 1969). At Time 1, the therapy sample group mean was almost two standard deviations above the norm, while the control sample mean was one standard deviation above the mean for the general population. Within the therapy sample, five women's scores were found to be more than one standard deviation above the population norm, and six women's scores were more than two standard deviations above this norm. For the control sample, at Time 1, eleven women's scores were moderately elevated, and four women's scores were more than two standard deviations above the mean for the general population. At Time 3, for the therapy sample, only one woman's score remained more than two standard deviations above the norm, compared to six women in the control sample.

At Time 1, both samples also reported moderately elevated dislocation scores as measured by the Content Analysis Depression Scale. The group means for both groups were more than one standard deviation above published norms (Gottschalk & Hoigaard, 1986). Examination of the individual scores revealed that at Time 1, for the therapy sample, six women (30%) showed moderately elevated scores, and a further eight women (40%) had dislocation scores, as measured by the CAS Depression Scale, of more than two standard deviations above the normed mean. Similarly, for the control group, 8 women (36.4%) were found to have moderately elevated scores, while six women (27.3%) had scores more than two standard deviations above the population mean. At Time 3, five women continued to show moderately elevated levels of dislocation, though no participants now scored more than two standard

deviations above the mean in the treatment group, while scores for the control sample remained relatively unchanged from Time 1.

Comparing Hope Scale scores for both samples to published means for a cancer population (Heszen-Niejodek et al., 1999), at no time did sample means fall below one standard deviation from this mean. Again, looking at individual scores at Time 1, one woman in the therapy sample scored more than one standard deviation below the published mean. Two women were found to have scores more than two standard deviations below the mean, and one woman had a score more than three standard deviations below the population mean. For the control sample at Time 1, two women scored more than one standard deviation below the population mean, and two women scored more than three standard deviations below this mean. At Time 3, all women in the therapy sample were found to have Hope Scale scores within one standard deviation of the norm. For the control sample at Time 2, two women again scored more than one standard deviation below the norm, and three women scored more than three standard deviations below this mean. At Time 3, three women scored more than one standard deviation below the norm, two women scored more than two standard deviations below this mean, and two women had Hope Scale scores more than three standard deviations below the mean for a cancer population. As in Study 2, both sample means for the DABS Anxiety Subscale and for the DABS Depression Subscale scores fell within the normal range at Time 1.

I now compare these samples' means at Time 1, to those of the participants in Study 2. Although the two samples were drawn from the same sampling pool, they were allocated in different way, so their data are not strictly comparable. Examination of the individual data showed that, compared to eleven women in the therapy sample having scores on the Total Anxiety Scale more than one standard deviation above the population norm, only six women in the Retreat sample had similarly moderately

elevated scores. Two women in the therapy sample had scores more than two standard deviations above the norm, compared to one woman in the Retreat sample. While four women in the therapy control sample had moderately elevated scores at Time 1, compared to seven women in the Retreat control sample, two women in each of these samples had scores of more than two standard deviations above the population norm. It is possible that women in the therapy sample, at Time 1, perceived greater threat to their core constructs in anticipation of the group therapy. This may account for the finding that the women in the therapy sample scored higher on the Total Anxiety Scale than women in the other samples. Time 1 means for the therapy and therapy control samples on all other measures were similar to those of the participants in Study 2.

It was hypothesised that women in the group therapy sample would show significant decreases in scores on CAS Total Anxiety, compared to women in the control sample at Time 2, and this differential decrease would be maintained at Time 3. A significant interaction effect, $F(2,39) = 4.94$, $p = < .05$, ($\eta^2 = .20$) suggested that scores on this scale did change over time, and that this change in scores was not the same for the two samples. The size of this effect was large (Cohen, 1988).

To examine threat to women's existence, scores on the CAS Death Anxiety Subscale were analysed separately. It was hypothesised that women in the therapy sample would show significant decreases in scores on the CAS Death Anxiety Subscale, compared to women in the control sample at Time 2, and this differential decrease would be maintained at Time 3. A 2 X 3 repeated measures ANOVA on Death Anxiety Subscale scores resulted in a significant interaction effect for this dependent variable, $F(2,39) = 3.15$, $p = .05$ ($\eta^2 = .14$). The size of this effect was again large (Cohen, 1988).

To examine levels of women's dislocation from their important meanings about the world of events, scores on the CAS Depression Scale were analysed. It was hypothesised that women in the therapy sample would show significant decreases in scores on the CAS Depression Scale, compared to women in the control sample at Time 2, and this differential decrease would be maintained at Time 3. A 2 X 3 repeated measures ANOVA on CAS Depression Scale scores revealed a significant interaction effect for this dependent variable, $F(2,39) = 3.74$, $p < .05$, ($\eta^2 = .16$). The size of the effect was large (Cohen, 1988).

To examine levels of hope, scores on the CAS Hope Scale were analysed. It was hypothesised that women in the therapy sample would show significant increases in scores on this variable, compared to women in the control sample at Time 2, and this differential decrease would be maintained at Time 3. A 2 X 3 repeated measures ANOVA on CAS Hope Scale scores revealed a significant interaction effect, $F(2,39) = 3.91$, $p < .05$, ($\eta^2 = .17$). Again, the size of the effect was large (Cohen, 1988).

The plots of the interaction effects for scores on the CAS Scale measures of these model-related variables are provided in Figure 8. The plots show that at Time 2, the therapy sample's means had fallen on the measures of distress and increased on the measure of positive affect, compared to the control sample, whose scores remained relatively unchanged. The most notable gains for time can be seen for the therapy sample's levels of dislocation (CAS Depression) and hope (CAS Hope). Relatively low levels of dislocation were maintained at Time 3, while levels of hope continued to rise. Looking at the gains for threat to existence (CAS Death Anxiety), the decrease in scores at Time 2 was again maintained at Time 3. Levels of threat (CAS Total Anxiety) scores were continuing to decrease from Time 2 to Time 3 and may well have continued.

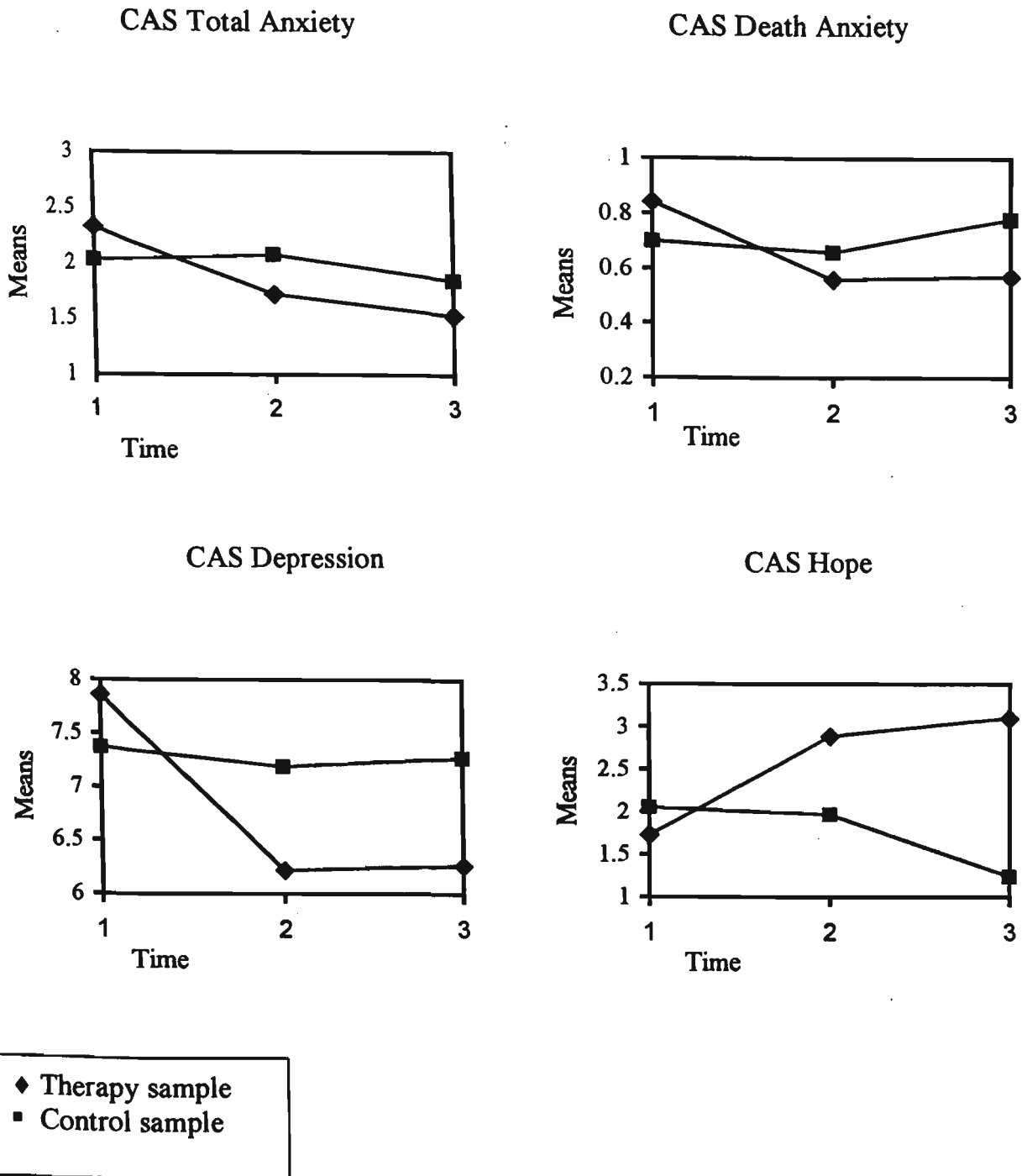


Figure 8 Plots of the interaction effects for scores on the measures of threat, threat to existence, dislocation and hope.

It was further hypothesised that women in the group therapy sample would show significant decreases across time in levels of (non personal construct) anxiety and depression, compared to women in the control sample, with the difference located between Time 1 and Time 2, but not between Time 2 and Time 3. Two further 2 x 3 ANOVAs were conducted, this time on DABS Depression and Anxiety Subscale scores. No significant interaction effects for time by group were found on these non-model-related variables.

Tests of the between-subjects effects on the model-related variables, threat, threat to existence, dislocation and hope, were not significant. Stevens (1996) observes that a non-significant result may be due to poor power in studies where sample sizes are small. One way of overcoming this problem is to set an alpha level of .15 or .25 in an attempt to overcome potential Type II errors (Stevens, 1996). For the purpose of this study, it was considered preferable to examine the data more closely. To protect against inflated Type I error, resulting from multiple comparisons, the Bonferroni procedure, with an alpha level .05 was used to examine between group differences on the four model-related variables. In this way, more fruitful understanding of treatment effects could be explored. The results of these pairwise comparisons are now reported.

Multiple comparisons revealed that the effect for group was not significant on CAS Total Anxiety Scale scores. To further examine the interaction effect of scores on this variable, a one-way repeated-measures ANOVA for the therapy sample was conducted. Results indicated that scores on this variable significantly differed from each other across time, $F(2,18) = 11.88$, $p < .01$, ($\eta^2 = .57$), and that the size of the effect was very large (Cohen, 1988). Using the Bonferroni statistic to control for multiple comparisons, pairwise comparisons were made to examine these differences.

Multiple comparisons of therapy sample means revealed a significant difference in therapy sample scores on the CAS Total Anxiety Scale from Time 1 to Time 2 (mean difference = .62, SE = .18, $p = < .01$), and between Times 1 and 3 (mean difference = .81, SE = .18, $p = < .01$). A non-significant difference between Time 2 and Time 3 scores showed the decrease in scores on this measure at Time 2 was maintained at Time 3.

The between-group differences across time on CAS Death Anxiety Subscale scores, CAS Depression Scale scores and CAS Hope Scale are now reported. A significant effect for group was found on scores on the CAS Death Anxiety Subscale at Time 3 (mean difference = -.21, SE = .09, $p = < .05$). A significant effect for group was found on scores on the CAS Depression Scale, again at Time 3 (mean difference = -1.01, SE = .49, $p = < .05$). A significant effect for group was also found on scores on the CAS Hope Scale at Time 3 (mean difference = -1.87, SE = .74, $p = < .05$).

Pairwise comparisons of therapy sample means revealed a significant difference in therapy sample scores on the CAS Death Anxiety Scale from Time 1 to Time 2 (mean difference = .28, SE = .09, $p = < .05$), and between Times 1 and 3 (mean difference = .27, SE = .10, $p = < .05$). Therapy sample scores on CAS Depression were also shown to differ across time from Time 1 to Time 2 (mean difference = 1.63, SE = .43, $p = < .01$), and between Times 1 and 3 (mean difference = 1.60, SE = .43, $p = < .01$). Pairwise comparisons of therapy sample means on CAS Hope across time failed to reach significance.

In summary, significant interaction effects were found for the overall measure of threat (CAS Anxiety Scale), and for the measure of threat to existence (CAS Death Anxiety Subscale). Significant interaction effects were also found for the measure of dislocation (CAS Depression), and for the measure of hope (CAS Hope). No interaction effects of time by group were found for scores on DABS Anxiety and

DABS Depression Subscales, used as measures of (non personal construct) anxiety and depression.

Pairwise comparisons, to examine between-group differences across time in scores on measures of threat, threat to existence, dislocation and hope, were then performed. These comparisons revealed significant differences between the therapy sample and the control sample's scores at Time 3 on the CAS Death Anxiety, CAS Depression and CAS Hope Scales. Although a non-significant effect for group was noted for CAS Total Anxiety Scale scores, pairwise comparisons of the therapy sample's means at Times 1, 2 and 3, revealed a significant decrease in scores from Time 1 to Time 2, which was maintained at Time 3. Significant decreases from Time 1 to Time 2 were also found in scores on the CAS Death Anxiety Subscale, and the CAS Depression Scale for the therapy sample. These differences were maintained at Time 3. Summaries of these findings are presented in Table 9.3, Table 9.4 and Table 9.5.

Table 9.3

Significant Interaction Effects for CAS Total Anxiety, CAS Death Anxiety, CAS Depression and CAS Hope Scores

Variable	Value	F	df	Sig.
CAS Total Anxiety	Wilks' Lambda .80	4.94	2,39	.01
CAS Death Anxiety	Pillai's Trace .14	3.15	2,39	.05
CAS Depression	Wilks' Lambda .79	3.74	2,39	.03
CAS Hope	Wilks' Lambda .83	3.91	2,39	.03

Table 9.4

Significant Pairwise Comparisons of Sample Means for CAS Death Anxiety, CAS Depression and CAS Hope Scale Scores with Mean Differences and 95% Confidence Intervals

Variable	Sample	Time	Mean Difference	95% Confidence Interval	
				Lower Bound	Upper Bound
CAS Death Anxiety	Therapy x control	3	-.20*	-.387	-.02
CAS Depression	Therapy x control	3	-1.01*	-1.87	-.14
CAS Hope	Therapy x control	3	1.86*	.374	3.35

* The mean difference is significant at the .05 level

Table 9.5

Significant Pairwise Comparisons Based on Sample Means at Times 1, 2 and 3, with Mean Differences and 95% Confidence Intervals

Sample	Variable	Time	Mean difference	95% Confidence Interval	
				Lower bound	Upper bound
Therapy	CAS Total Anxiety	1 and 2	.62**	.17	1.07
		1 3	.81**	.36	1.25
Therapy	CAS Death Anxiety	1 and 2	.28*	.04	.52
		1 3	.27*	.02	.52
Therapy	CAS Depression	1 and 2	1.63**	.55	2.72
		1 3	1.60**	.52	2.68

** The mean difference is significant at the .01 level

* The mean difference is significant at the .05 level

This completes the statistical analysis of the data. In the following section I discuss these findings in relation to the hypotheses. In discussing the findings of Study 3, I shall, in addition to addressing the hypotheses, address the appropriateness

of the measures used to operationalise the evaluating concepts. I then discuss the limitations of the study and the implications of the findings to clinical practice.

9.8 Discussion

My personal construct model of adjustment to breast cancer survival proposed that threat was the underlying process that gave rise to breast cancer survivors' experiences of psychological distress. The personal construct group therapy was developed, therefore, to provide opportunities to optimise both commonality and sociality, thereby allowing the participants to define their current meanings, and elaborate new and more helpful meanings, for their ongoing tasks of living as breast cancer survivors.

Hypothesis 1 stated that women in the group therapy sample would show significant decreases in levels of threat, compared to women in the control sample, at Time 2, and this differential decrease would be maintained at Time 3. This hypothesis was partly supported. No differential decreases between the therapy sample and the control sample's levels of threat were found at Time 2 or Time 3. However, the group therapy sample did show a significant decrease in their levels of threat at Time 2, and this was maintained at Time 3. Particularly striking is the fact that at Time 1, eleven women in this sample had levels of threat indicative of distress, and two had levels of threat suggestive of severe emotional disturbance. Three months after the therapy, the levels of threat of all women in the therapy sample were within the normal range of scores for women in the general population. Clearly the therapy was effective in reducing the levels of threat being experienced by these women.

Hypothesis 2, like the first, made predictions about the participants' levels of threat. The hypothesis was formulated to specifically examine women's levels of threat to their existence. The hypothesis stated that women in the group therapy sample would show significant decreases in levels of threat to their existence,

compared to women in the control sample at Time 2, and this differential decrease would be maintained at Time 3. The degree to which the therapy was successful was anticipated to be reflected in a reduction in the prevalence of death related meanings found in the women's communications about their lives. This hypothesis was partly supported. A differential decrease was found, however, it was located at Time 3, rather than Time 2.

From the Fundamental Postulate: "a person's processes are psychologically channelized by the ways in which he anticipates events" (Kelly, 1991, p. 32) we understand that breast cancer survivors' actions will flow from the ways they choose to test their beliefs about the future, given the limitations imposed by their current meanings. That a significant difference was found in the two samples' scores at Time 3, three months after the therapy sessions had ended, suggests that the meanings elaborated during the group therapy were tested and validated, not only in the context of the therapy group, but in the context of their role relationships beyond the group. This finding is important, as death-related concerns were identified in the review of the breast cancer literature (Chapter 2), and by the participants of Study 1 (Chapter 6), as a major factor in breast cancer survivors' experiences of ongoing distress.

Hypothesis 3 stated that women in the group therapy sample would show significant decreases in levels of dislocation from their non-core meanings, compared to women in the control sample at Time 2, and this differential decrease would be maintained at Time 3. As for Hypothesis 2, the differential decrease was observed at Time 3, rather than Time 2. As the women in the therapy sample experienced both commonality and sociality, they were able, in the context of their supportive network of group members, to define their current meanings, and elaborate new and more helpful meanings, for their ongoing tasks of living as breast cancer survivors. These processes were reflected in a decrease in their levels of dislocation at Time 2, which

was maintained at Time 3. If their new meanings had been invalidated in the context of their role relationships beyond the group it would be expected that decreases in dislocation would not be maintained at Time 3. As this did not occur, I suggest their new meanings allowed them to successfully anticipate events.

Hypothesis 4 stated that women in the group therapy sample would show significant increases in levels of hope, compared to women in the control sample at Time 2, and this differential decrease would be maintained at Time 3. This hypothesis tested the benefit of the group therapy on women's abilities to anticipate a positive future. It was anticipated that, as women elaborated new and more helpful meanings about themselves and their world of events, and received validation of these meanings, they would increasingly be able to envisage and commit to ongoing cycles of positive experience. This follows from Kelly's definition of a meaningful construct as: "one which is designed to embrace the future, rather than merely catalogue the past" (Kelly, 1955/1991, p, 240). The findings of the study again partly supported this hypothesis. A differential increase in levels of hope for the therapy sample was noted at Time 3, not Time 2. This finding suggests that these women's new meanings allowed them to successfully anticipate events. Over time, validation of their anticipations confirmed the viability of their meanings, allowing them to risk engaging in ongoing cycles of experience.

Hypothesis 5 stated that women in the group therapy sample would show significant decreases in levels of (non personal construct) anxiety and depression, across time, compared to women in the control sample, with the difference located between Time 1 and Time 2, but not between Time 2 and Time 3. Because (non personal construct) anxiety and depression levels were found to decrease immediately after the Retreat (Study 2), it was anticipated that the therapy group members would experience a similar decrease immediately after the group therapy. This hypothesis

was not supported. Levels of (non personal construct) anxiety and depression remained relatively unchanged across time for both samples.

In Chapter 7, I suggested that non personal construct conceptualisations of anxiety and depression referred to the expression of distress, rather than the process of distress. The process of distress, according to my model of adjustment, is threat to psychological and physical integrity, threat to existence, and dislocation. In Chapter 7, I also reported that the women who attended the Retreat felt that validation of their current meanings was helpful in decreasing their levels of distress. However, these perceived benefits were not reflected in their levels of threat to core and core role meanings, threat to existence, dislocation from non-core meanings, or hope. It was important first to confirm, therefore, that threat and dislocation are the underlying processes of breast cancer survivors' distress. The finding that, for women in the therapy sample, levels of these evaluating concepts significantly decreased following the therapy suggests that threat and dislocation are the underlying processes that give rise to, and maintain, their ongoing distress.

Secondly, the findings that levels of threat, dislocation and hope were found to change across time for the therapy sample, confirmed that the Content Analysis Scales used to measure these evaluating concepts were sufficiently sensitive to detect change in breast cancer survivors' meanings. From this, I must conclude that validation of current meanings alone is not enough to reduce levels of threat and dislocation (see Study 2). The findings of Study 3 show, that while validation of current meanings is an important element of support, validation of themselves as makers of meaning is essential to breast cancer survivors. Validation of their construing processes allows them to elaborate more helpful meanings when their current meanings no longer allow them to optimally anticipate their futures.

Overall, these findings support my personal construct model of the processes of adjustment to breast cancer survival. Clearly, at the beginning of the study, many women in both the therapy and control samples experienced elevated levels of threat to their core and core role meanings and dislocation from non-core meanings. As noted above, this finding supports my proposal that the underlying processes of breast cancer survivors' distress are threat and dislocation.

The model proposed that women would turn to their role relationships for support. A failure to obtain validation of their construing processes within the context of these relationships was proposed to keep women trapped in unhelpful cycles of experience. This was proposed to result from a failure of "others" to provide the social context in which breast cancer survivors can resolve threat and dislocation to their important meanings. It was anticipated therefore, that the provision of a network of supportive group members would allow women to define their current meanings and elaborate more helpful meanings. Following the group therapy, the group members' levels of threat and dislocation decreased, and their levels of hope increased. This finding supported my proposition that the social context in which these women attempt to adjust to breast cancer survival is a crucial factor in their ability or inability to elaborate more helpful meanings.

Most importantly, the study findings support my conceptualisation of breast cancer survivors' support needs. I defined supportive role relationships as those that provide breast cancer survivors with opportunities to experience commonality (validation of their current meanings) and sociality (validation of themselves as construers of meaning). That the experience of these in the social context of the therapy group resulted in decreases in levels of threat and dislocation, and an increase in hope, suggests the processes of commonality and sociality are crucial to our understanding of the support needs of breast cancer survivors. This finding suggests,

therefore, that clinically, therapy with women living as breast cancer survivors should specifically address their interpersonal issues, working towards helping breast cancer survivors develop supportive relationships that confirm their central meanings and allow for the elaboration and testing of their new meanings.

9.9 The Limitations of the Study

The major limitation of this study relates to the size of the sample. With such a small sample, generalization to the population of breast cancer survivors at large is limited. Furthermore, the younger age group at time of diagnosis (less than 55 years) was over represented in both treatment and control samples. Younger women have been found to experience greater distress (Bloom & Kessler, 1994; Mor, Malin & Allen, 1994) than older women. These women were also younger at the time of their diagnosis than the population of breast cancer survivors living in New South Wales, Australia (New South Wales Cancer Council, 2001). Future replication of this study should be undertaken with larger and more representative samples. Future studies, with larger samples, might also explore the contribution of age on treatment effects.

The problems stemming from the use of volunteer populations were discussed in Chapter 7. Volunteer bias will again affect the generalisability of these findings. While all participants in the therapy remained in the study, the original sampling pool from which the participants were drawn and then randomly allocated to either the therapy sample or the wait-list control sample volunteered to participate. As participation in the study was voluntary, it is likely that those women experiencing greater distress were more inclined to participate in research that offered support. This would result in bias in the original sampling pool. Furthermore, possibly, women experiencing less distress would have declined to participate in the group therapy. In this case, intent to treat analysis of both participants' and decliners' data would have shown a more conservative effect for the group therapy (Bland, 1990).

The design of Study 3 overcame some of the shortcomings of Study 2. The participants were randomly allocated, and data was collected from both samples over the same time frame. Larger samples would have increased the opportunity to use a greater range of statistical analyses that may have provided further understanding of the effects of the therapy. Comparison of personal construct group and individual therapy for breast cancer survivors, and of personal construct therapy with different therapies is suggested.

A further limitation of this study concerns my role as both researcher and therapist. Random allocation of the participants to treatment condition, and the use of a computer programme to score their data, limited the degree of bias this non-ideal situation may have created. Nevertheless, future studies would benefit greatly by separating these roles. In addition, the use of only one therapist is not ideal. Although no research has been conducted to determine the relative efficacy of co-therapists and sole therapist methods, group therapies are often conducted with two therapists working in collaboration with each other (Yalom, 1995). The primary goal of the therapy was to develop supportive relationships among the group members and therapist; the addition of a co-therapist would have been an added resource both for the participants and the therapist.

The Content Analysis Scales proved to be useful in tapping into the women's levels of threat, dislocation and hope. As the findings support the view that the interpersonal context is crucial to women's adjustment to breast cancer survival, future outcome studies would benefit from the addition of measures of interpersonal processes.

9.10 A Summary

The *Aim* of Study 3 was to provide evidence of the benefits of personal construct group therapy. Therapeutic support for breast cancer survivors was defined

as the provision of opportunities for the group participants to optimise both *commonality* and *sociality*. Commonality provided validation of the content of their current meanings, helping them to define their experiences. Sociality provided validation of their processes of construing, making it possible for them to elaborate meanings that would be more helpful to their ongoing tasks of living as breast cancer survivors. This aim was achieved. Personal construct group therapy was found to be effective in reducing levels of threat and dislocation and increasing levels of hope in breast cancer survivors.

The study, the first to use personal construct theory concepts and practices in group therapy specifically developed for this population, has further shown that personal construct concepts and practices have much to contribute to current understanding of breast cancer survivors. Personal change was facilitated by making the participants' meanings more explicit to them, and by promoting alternative stories, thus widening the choices of construing and behaviours available to them. Within a personal construct framework, research examining therapy outcomes also has a duty to ask the participants about their experience of therapy, and to deal with their meanings (Viney, 1988). It was important, therefore, to explore too, the participants' view of the changes brought about by their participation in the group therapy. In the following chapter I present the participants' perspectives on these processes of change. I also report on my own experiences of the processes of change as therapist, researcher and fellow-member of the groups.

CHAPTER 10

THE PROCESSES OF CHANGE IN THE GROUP THERAPY FOR BREAST CANCER SURVIVORS

“I found the other women so very inspirational. They showed me their quiet strength and ability to endure”
(Mary, 54 years).

In examining the processes of change, my first step was to evaluate whether change had occurred. This was the content of Chapter 9. Of equal importance to me was an experimental understanding of how this change occurred. In this chapter I examine the different ways in which this change took place, from the perspective of the participant, and from my own viewpoint. I first discuss why we need to understand the nature of therapeutic change from the participants' perspectives. I then present the method by which I examined group processes. Next, I examine the participants' perspectives of the impact on their therapy experience of the group therapeutic factors. I then examine the participants' evaluations of the group therapy. The first evaluation examines group therapeutic factors, from the perspective of the participants, on the nature of their therapy experiences. The second evaluation examines the participants' assessments of the effectiveness of the group therapy. I then give, as therapist and fellow-member of all of the groups, an account of the group processes from my perspective. Finally I discuss the overall findings and the implications of these findings for future therapeutic work with breast cancer survivors.

10.1 The Processes of Change from the Perspective of the Participants

In Chapter 3, I noted with concern, the eclectic approach currently adopted in providing therapeutic support to women with breast cancer. Many of the psychosocial interventions reported, incorporated components of cognitive-behavioural therapy, existential therapy, educational strategies, relaxation training and social support, thereby making it difficult to determine which components of the intervention contribute to an improvement in outcomes. The lack of differential effects for a variety of treatment formats developed to work therapeutically with breast cancer populations reflects the findings of the larger body of research examining differences in effectiveness among the various schools of psychotherapy in general (Lambert &

Bergin, 1994). Asay and Lambert (1999) point to three possible reasons for this. It is likely that different therapies reach the same goals but through different processes. Different outcomes may occur, but to date they have not been identified. Different therapies may also embody common factors that are curative.

In Australia, MacCormack and his colleagues (MacCormack, Simonian, Lim, Remond, Roets, Dunn et al., 2001) set out to examine common elements of therapy that adults living with metastatic cancer, who had been randomly assigned to two different forms of individual psychotherapy, found to be most helpful. Results indicated that participants offered cognitive behavioural therapy had similar experiences to those who received a type of relaxation therapy that included time for non-specific, patient-centred "talk". Central to the participants' experiences was the opportunity both therapies gave them to enter into a relationship in which they could *safely* share their thoughts and feelings with someone who they perceived was *genuinely* interested in understanding their cancer experience. This finding supports Leszcz's (1992) earlier observation that effective therapists, regardless of their psychotherapeutic orientation, share common attributes that include empathy and acceptance.

Two implications follow from this finding. Firstly, the outcome of studies that have focused on teaching particular skills and strategies to women with breast cancer may have overestimated the benefits of the acquisition of these skills. Secondly, and most importantly, if interpersonal factors are of the greatest benefit to clients, then the structure of therapies should be directed towards harnessing these factors. What follows are two examinations of the processes of the personal construct therapy detailed in Chapter 8. The first examines group therapeutic factors, from the perspective of the participants. The second examines the participants' evaluations of the group therapy.

10.2 The Method for the Study of Group Factors

To examine group processes, participants were asked to respond to the following two questions (Bloch et al., 1979) at the end of the session in Week 7.

1. The event/exercise/thing that has been the most important/helpful to me in the last seven sessions of the workshop was when
2. This was important/helpful because

This method has clear advantages for the study of therapeutic factors for three reasons. Firstly, it allows the participants to give their own interpretation of an important/helpful event in the group process, without restricting them to a structured questionnaire or implying how they could or should perceive their therapy. Secondly, it is based on an interpersonal model of therapy (Yalom, 1990). Thirdly, it has been used successfully to evaluate personal construct group work (Winter, 1997). The concept of group factors is founded on the assumption that the processes of group therapy embody a number of elements, distinguishable from each other by their specific effect on the group members (Bloch & Crouch, 1985). In group therapy, then, therapeutic factors are elements of therapy that contribute to improvement in a group member's condition as a function of the interaction of a group member with other members of the group, including the group therapist. The method used for the study of group therapeutic factors derives from the early work of Yalom (1975) and Bloch and his colleagues (Bloch et al., 1979). Yalom's (1975/1995) influential text on group psychotherapy identifies twelve therapeutic factors, and later studies, designed to evaluate the relative importance of therapeutic factors, have largely relied on these classifications. Bloch and his colleagues (1979) took as their model the minimally structured "most important event" questionnaire, which is then coded into a pre-determined classification of factors, derived from an extensive review of the literature (Berzon, Pious, & Farson, 1963). The ten therapeutic factors identified are as follows:

self-disclosure, learning from interpersonal action, universality, and the instillation of hope, acceptance, self-understanding, altruism, vicarious learning, guidance, and catharsis.

Winter (1997), evaluating personal construct group work with agoraphobics, found that universality was the therapeutic factor most highly rated by the group members, followed by self understanding. Other studies, that have evaluated women's experiences of group therapy, include a study of women with bulimia nervosa, who reported that universality and the instillation of hope had been important factors in their therapy experiences (Hobbs, Birtchnall, Harte & Lacey, 1989), and Liberman (1990) found that new mothers in self-help groups found interpersonal learning, self understanding, and the instillation of hope to be helpful.

Qualitative analysis of the understandings of the participants of group factors is now reported. In coding, the guiding question was: "How is this event important for this particular participant?" Further guidelines for coding the participants' responses are provided in Appendix J, with a full explanation of the ten factors defined by Bloch and colleagues (1979). Although all participants responded to both questions, their responses to Question 1 were considered in conjunction with their responses to Question 2, to arrive at one factor for each participant. Two independent raters (4 year trained psychology graduates) coded the participants' responses to these questions. Consistency of response allocation between the two raters was high at 90% (18/20). In consultation with the two raters, I assigned the only two responses that had been differently coded. By the end of this procedure we were satisfied that all responses were correctly coded.

10.3 Results of the Exploration of the Therapeutic Factors Identified by the Participants

Analysis of the responses to the two important event questions identified five factors the participants perceived to be helpful. What follows is a description of the factors identified, with examples to illustrate these factors taken from the responses of the participants.

10.3.1 Universality

Universality operates when participants recognise that they are not alone in their feelings and problems, and this reduces their sense of aloneness (Bloch et al., 1979). Five women felt universality to be the most helpful factor in their group experience. Catherine, a young woman with small children and a difficult marriage reported: "I was beginning to feel that I was the only one with a difficult life (other than having breast cancer). It (being part of the group) has given me some sort of balance of perspective. Recognising that we are women/wives/mothers first and the breast cancer is a separate, complicating issue, has been helpful to me". Leanne wrote: "It (being part of the group) reinforces the fact, that while we are all different people, in one way, breast cancer has made us: 'sisters under the skin'". Most often this sense of connection to others came about through the participants' sharing of their stories.

10.3.2 Self-Understanding

The basis of self-understanding is that participants learn something important about themselves as a result of feedback and interpretation from other group members (Bloch et al., 1979). Five women, too, considered this factor to be the most important to their therapy experiences. Sharing their histories allowed them to learn about themselves from the feedback of the group. As Hannah said: "It made me look at my self as a whole, my past and my future life and I know now that I am more stable and happy than in my early years". Nell said: "It made me focus on aspects back in my

childhood which have impacted on my self-esteem and family's acceptance". Feedback from group members and the group therapist was instrumental in promoting these new understandings.

10.3.3 Acceptance

During the course of the therapy, all women remarked on the high level of acceptance the groups had established. The participants felt safe to disclose their feelings, because they sensed that their meanings would be accepted and valued, even though they may be challenged. Four women regarded this level of acceptance to be the most important factor in their therapy experiences. Acceptance operates when participants feel a sense of belonging and comfort in the group; they feel cared for, supported, understood and valued (Bloch et. al., 1979). Sheila, describing her experience of disclosing her feelings about her problematic relationship with her sister said: "I felt someone listened and cared". Another reported an ongoing sense of connection to the other group members and found this helpful because: "It puts my own problems into a different context".

10.3.4 Learning from Interpersonal Action

This factor, though similar to self-understanding, deals with participants' efforts to relate to other group members, and their experience of these acts. Ways in which participants try their new ways of being in relation to others may include expressing themselves to achieve greater closeness with other group members, or trying out new ways of responding to other group members. Four women reported this factor to be the most important in their therapy experience. Rebecca reported that: "Here everyone has been able to speak freely, and I have learned to speak. Even though I have strong feelings, I am usually very shy". Susie said: "I've never been able to talk about it to anyone before".

10.3.5 Instillation of Hope

Instillation of hope occurs when participants gain a sense of optimism about their progress, or potential for progress, through their participation as group members (Bloch et. al., 1979). Two women's responses reflected the instillation of hope. Examples of the women's perception of an instillation of hope as a result of participating in the group are: "I found the other women very inspirational. They showed me their quiet strength and ability to endure", and "I found we have a lot of goals to head for".

10.3.6. A Summary of the Group Therapeutic Factors

The five group factors identified by the women as being most helpful to them were Universality, Acceptance, Self Understanding, Interpersonal Learning and the Instillation of Hope. The full range of the women's responses to the Most Important Event questions are shown in Table 10.1.

Table 10.1

The Full Sample of Women's Responses to the Important Event Questions of the Breast Cancer Survivors Group Members

Universality

1. I was beginning to feel that I was the only one with a difficult life (other than having breast cancer).
2. It (being part of the group) reinforces the fact that breast cancer has made us sisters under the skin.
3. It made me feel that my own emotions are OK and normal, and I didn't feel so isolated.
4. Just to know I'm normal.
5. It's so important to hear that others feel the same.

Self-Understanding

1. I know now that I am more stable and happy than in my early years.
 2. Feedback from Lis, surprising and challenging, has led me to stop and look, and I'm discovering new things about myself.
 3. I'd never realised before how much I have done.
 4. I'd never thought before about how important music is to my life, and how much I've missed it.
 5. I can see now where it all started.
-

Table 10.1 (continued)

The Full Sample of Women's Responses to the Important Event Questions of the
Breast Cancer Survivors Group Members

Acceptance

1. I felt someone listened and cared.
2. It puts my own problems into a different context.
3. It's so important to have that sense of belonging.
4. Although I have attended other groups I never felt I was a part of the group,
... we didn't have what we have here.

Learning from Interpersonal Action

1. Here everyone has been able to speak freely, and I have learned to speak.
2. I have learned so much from just listening and talking.
3. It was so good to be able to join in.
4. I've never been able to talk about it to anyone before.

Instillation of Hope

1. I found the other women very inspirational.
 2. I found we have a lot of goals to head for.
-

In Chapter 8, I argued that the elaborative potential of a relationship is governed both by the level of commonality, providing confirmation of important meanings, and by the level of understanding, or sociality, providing elaboration of important meanings. I anticipated sharing of common understandings during the group therapy would provide the experience of consensual validation of the participants' individual views, offering some assurance of the workability of their current meanings, and a psychologically secure context in which to elaborate new meanings (Koch, 1985). The distribution of percentages of responses to the important event questions is presented below in Figure 9.

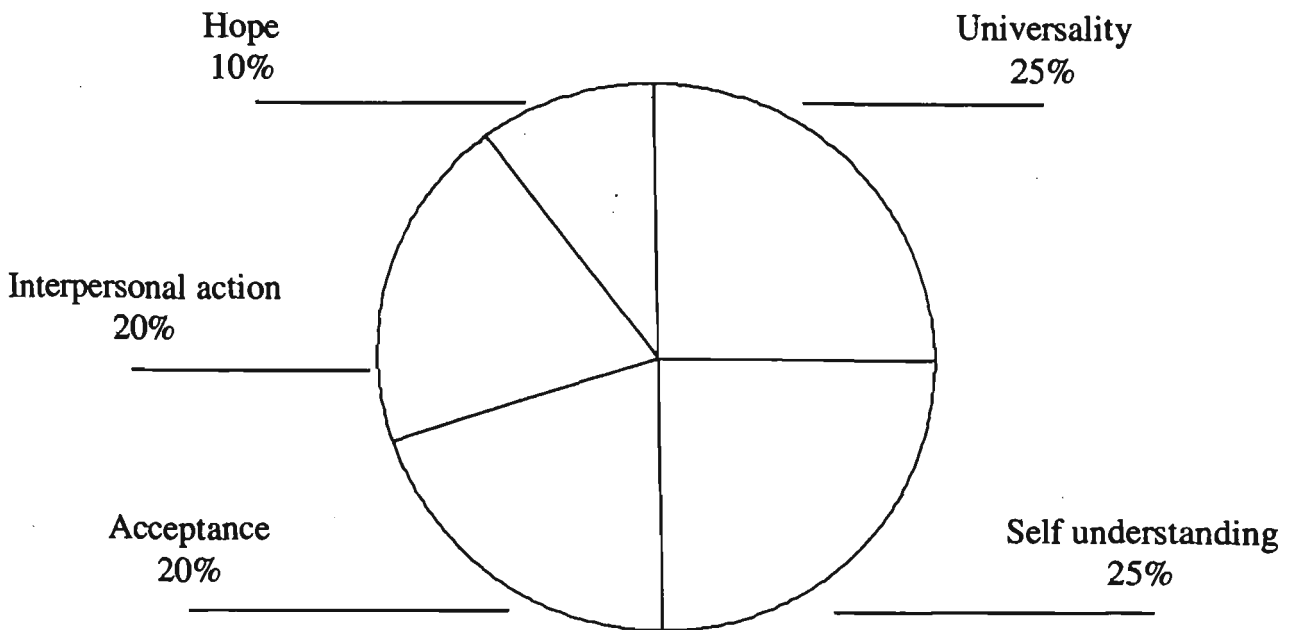


Figure 9. The group factors of therapeutic change identified by breast cancer survivors

From a personal construct perspective *Universality* might be described as “commonality”, since the reduction in participants’ sense of “aloneness” resulted from validation of their current meanings. Learning more about themselves from the feedback of others (*Self Understanding*) helped these women define their core meanings. The experience of *Acceptance* from the group members provided the context in which they could begin to risk testing new meanings (sociality). As they continued to test and elaborate their meanings, in the knowledge that they were valued as construers of meaning, group members could risk invalidation of some of these meanings (*Learning from interpersonal action*). Constructive revision of their meanings enabled them to envisage and engage in new and more helpful cycles of experience (*The Instillation of Hope*).

10.4 The Group Evaluation

In addition to the minimally structured “most important event” questionnaire (Bloch et al., 1979), the participants were asked to add (on a tear off portion of the response sheet) any comment they thought might be helpful. I now report these. The

purpose of this invitation was, firstly, to evaluate the therapy, secondly, to gain further insight into how changes took place for these women, and thirdly, to gain information on how this group therapy might be improved. The participants' responses to this question were not identifiable by name. Such anonymity was hoped to allow the women to respond truthfully, and without a concern for my feelings. All the women filled in a comment about the group. From their responses it was evident that the sharing of their stories was a central process of change for them. Of the twenty responses, eighteen referred to the interpersonal context in which their therapy took place. Some women commented on the opportunities the therapy had given them to disclose their meanings. Others commented on the levels of understanding they had received. As one woman said: "I would not change anything about this workshop. It was extremely helpful and everyone was so understanding". Two women spoke of the participants' common bonds. Another woman spoke of the value of the understanding she had gained into others' experiences: "The insight I obtained into other women's experiences, supported my belief that we, as women, can overcome most problems/concerns and are so very caring and supportive of each other". One woman reported being surprised that she had enjoyed herself so much, and one woman wished the group could continue for longer. The participants' responses are provided below in Table 10.2.

Table 10. 2

The Full Sample of Responses of the Group Participants to the Open Question

The Interpersonal Context of the Group Therapy

1. I've enjoyed the study. There were people younger than me, people older and with different personalities. It was a real bond.
2. Although we all share a breast cancer diagnosis that was not the focus of the group, which was great. Dealing with the rest of our lives, other important things, and sharing the experiences of our lives was very nurturing.
3. The opportunities made to share private things was so helpful, to be able to share.
4. It's always good for us to share and talk with others in similar circumstances. Thanks Lis for giving us the opportunity to become closer to others.
5. It was great to have a forum where we can say what we want without fear of upsetting people close to us, and to know that those who listen to us can empathise.
6. Being a member of the group has had a positive effect on the way I feel in myself. I find it easier to talk (express myself) within the group than I do otherwise. The size of the group was a real plus.
7. I have been able to talk to others about how I feel. This has been unusual as at home I find I worry more about my husband, and not myself.
8. Just talking about our experiences was so helpful.
9. I found this small group of very lovely women very easy to relate to about a lot of issues that we have in common.
10. I wasn't sure I wanted to join the group, because I'm not really a group person. But sharing our stories, I have had a lovely time.
11. I am a fairly private person and I'm not used to speaking in a group but you managed to draw us out and we surprised ourselves the way we opened up.
12. Being able to talk in the group and listening to others talking.
13. Thank you Lis. We have opened up about our feelings. I know I had bottled up my feelings and they have surfaced and I have let them go.
14. It's very important to be able to share with other women who have some understanding of the trauma involved with breast cancer.
15. The whole workshop was well worth attending, especially the sharing with each other, and to you Lis, for the way you presented it, putting us all at our ease, many, many thanks.
16. There's a really strange and fantastic bond between women in supporting each other – you feel comfortable, accepted and you feel affection. And it's not morbid or all clinging together.
17. I think since you have been doing the study, I personally feel that we have become more aware of one another.
18. The insight I obtained into other women's experiences supported my belief that we, as women, can overcome most problems/concerns and are so very caring and supportive of each other.

Other Issues

19. Even though we've moaned about doing the questionnaires, it has made us think about things with more clarity.
 20. I'm glad it is at least 8 weeks, as I would like it to continue. I think if it were any shorter it would be awful. I don't want it to end.
-

10.5 An Account of the Group Processes from my Perspective as Therapist, Researcher and Fellow-Member of the Groups

During all of the group therapy sessions I kept a diary, and I audiotaped each session. What follows are my reflections on these experiences. The opportunity to be therapist, researcher and fellow-member of the groups allowed me valuable insights into the processes of change that occurred in the participants, as a result of being in the group.

In looking back on my experience as therapist, the greatest sense I have is of the tremendous fun we all had. As I listened to the tapes of the sessions, while there were tears as women spoke of past hurts, what I found striking was the amount of laughter. I also continue to be astounded by the immense courage of these women. The level to which they disclosed their concerns, and talked about their lives, is a tribute, not only to their commitment to the group therapy, but to each member's contribution to the creation of a supportive context in which these issues could be disclosed.

In the beginning sessions, the women offered support to their fellow group members by showing their understanding and acceptance. At first, they felt compelled to offer comforting words to each other, and tissues. They offered each other reassurance. Very soon, with a little guidance, they came to understand that support is not only about giving comfort to others. There is a subtle distinction between showing support, and closing down others' ways of expressing their experiences. With this understanding, group members began to allow others to express their feelings freely and open themselves to the experiences of other group members. They also came to share my role as therapist in helping each other elaborate their new meanings.

Undoubtedly, the opportunity to share their experiences gave rise to a high level of cohesiveness in each group. In addition to sharing their experiences, they found the

opportunities to write their autobiographies very helpful. Gloria said: "I'm surprised at what I did write down. I won't be able to relate it all because it's too long, so I'll read a little. It was funny when I was writing this, it was just amazing, and I can see that a lot of healing came because I had two times when I really cried. You know, and I can see now where that's coming from, which I will probably share with you". Anne also found the writing homework helpful. She said: "I've never been able to say lots of things, but writing them, even writing this, I seem to have come full circle. And I see the bit in the middle that is still cloudy, where it is still cloudy and still not clear, but I see that in writing it down that its getting clearer, I'm getting clarity on who I am". This sense of clarity was a common theme in their discussions during the groups. Sometimes this understanding came about by the processes of writing and disclosing, at other times group members helped in the process of defining meanings.

In a quite different example of support from the group, Helen disclosed how "ragged" she felt at this particular time in her life. With young children and a full-time job she said: "I just have to go faster and faster". Then Elaine, whose children are now grown up, told of her experience of raising a family, and how now they are grown up she can do things for herself. "I can virtually do what I want to do", she said. Elaine was not telling Hazel how she should be, she was offering an alternative construction, her own. Hazel, who earlier had been feeling very distressed, took from this exchange a new construction. She said: " So I can hang on to the future, and know that I will get there, and this is just for the moment. Thank you for that".

Opportunities to talk about their fear of death and dying were also valuable for many of the participants. Interestingly, it was in these discussions that the women first recognised the choices they made. The following extracts illustrate how Sandra and Maureen came to reconstrue the choices they had made:

It's very hard to make sense of, I mean I am only 32, and I have always been fit, I never smoked. And how can you make sense of that. I have three small kids and a husband, and I am just starting my life. I've just moved into a new home, I'm just starting out in my life. I'm thinking no way, I am determined, I want to see my children grow up and graduate. So I have come to peace with whatever happens. I don't want my children to remember me as a miserable old hag. I want to enjoy everything I have with them and be a positive person in their life. I mean I hope I will be here, but if I am not, then they will remember me well. They are probably sick of me, but they see me 24 hours a day. I don't want to regret, and that is a choice that I have made (Sandra).

I remember when I got cancer I was very depressed, and I used to see people on TV with heart disease and they were fighting for life. And at the time I thought: "Well I will get off this ride thank you very much. If this is my way out I will take it". But now I've started to look at how I want people to remember me. And the cancer has given me a chance to do that (Maureen).

Transcribing the tapes allowed me to identify the numerous ways in which change occurred for the participants. As the women talked in general about their week between sessions a number of changes became apparent. Catherine, for example, had talked about her wish to get a job now that her children had grown up, but felt she had been out of the work force for too long, so had no confidence that she would be employed. In Week 4, she reported: "Well I've been offered a part-time job three days a week. I'm quite chuffed (pleased) with myself". In the same week, Maureen said: "I caught up with the ironing". This, for Maureen, was a major breakthrough. As evidenced by the earlier extract, Maureen had been struggling with depression. In the past few months she "could not be bothered to do the usual tasks". Two weeks later she made a cake for our coffee together. This was the first time she had cooked since her diagnosis. Changes also occurred, for some women, in their important relationships outside of the group. Many women spoke of the change they had experienced in their relationships with friends and family. Gwen and Jenny found they had re-assessed their marriages, and in coming to understand not only their own, but also their husbands meanings, they felt better able to face the future with their

partners. In fact over the weeks, I began to feel I knew some husbands as well as I knew the participants, even though we never met. George was one husband I came to know from his wife's stories. At the three-month follow-up Gwen said:

In the past I'd forego my activities. I'd be running into the waves and he would be walking sedately with his shoes and socks on. And I would forego doing what I loved. And you can imagine the stress. I was not doing what was inside me to do. He didn't necessarily want me to do that. I could have done whatever I liked. But it was my choice to stay with him, and to forego my own personality. But, things have now improved so terrifically. Last week we were at the grandchildren's place and George was left inside and I enjoyed myself outside. What a change, I did exactly what I wanted to do and allowed him to do exactly what he wanted to do. And it worked out fine.

Finally, with regard to the degree to which the group members established supportive role relationships in the group therapy, I can report that at the three-month follow up, arranged by me, all group members had remained in touch with other group members. They reported that they had frequently spoken to each other by phone, with several group members meeting together for coffee. One group, more than one year after their therapy ended, continues to meet every three months at a restaurant for a meal. The women organise this themselves, and I am delighted that they always ask me to come too.

10.6 Discussion

Historically, most of what has been written about how clients experience their therapy has been generated out of the perceptions and impressions of practitioners, researchers, and theorists (Quinn, 1996). To date, only a few studies have asked intervention participants directly and in a systematic fashion to explore, reflect on, or comment in an open-ended fashion about their experience of psychotherapy (Macormack, et al., 2001). Fortunately, within a personal construct framework, if participants change as a result of therapy, their understanding of the processes is considered important to personal construct theorists and clinicians.

In Chapter 5, I considered why, in outcome research in the past, so little has been made of interpersonal therapeutic factors with women living with breast cancer. I argued that few models of intervention are grounded in a theory that fully conceptualises the interpersonal context in which meaning-making takes place. Clearly the interpersonal context was crucial to the therapeutic changes of the participants I have described in this chapter. Personal construct concepts have helped to understand these processes. Future therapies developed for women living as breast cancer survivors, I suggest, should actively encourage the development of a network of supportive role relationships, providing breast cancer survivors with opportunities to both confirm their current meanings and elaborate new and more helpful meanings.

The qualitative findings from the group therapy for breast cancer survivors presented in this chapter offer a window into the participants' perceptions of what was helpful to them, and provide support for my personal construct model of therapy. In the following final chapter, I draw together the findings of the three studies I have now reported.

CHAPTER 11

THE FINDINGS AND IMPLICATIONS FOR BREAST CANCER SURVIVORS OF THE RESEARCH STUDIES 1, 2 AND 3

“There is always uncertainty; I don’t care what anybody says. At the back of your mind, no matter how positive you are, there is always a little bit of uncertainty. But the way I deal with that is, I think about hope. You know I live in a hope situation, not a denial situation, but a hope situation” (Linda, aged 69 years).

In this, the final chapter, I first review the research I conducted on breast cancer survivors, and discuss the major findings. As I present these findings I also address the suitability of the methods and measures I used to capture the experiences of these women. I discuss the limitations of my research, with suggestions for future research on women's adjustment to breast cancer survival. I then discuss the usefulness of the personal construct model I developed. I explore the clinical implications of the research for breast cancer survivors and those involved in their care. Finally, I draw my conclusions about the contribution personal construct concepts make to understanding women's experiences of breast cancer, and based on this understanding, how to most effectively help women adjust to the ongoing task of living as breast cancer survivors.

11.1 A Review of the Research

In the review of the literature on the psychology of surviving breast cancer (Chapter 2), ongoing thoughts about death and dying were identified as major issues of concern for breast cancer survivors. Women living with a breast cancer diagnosis are faced with the uncertainty of their prognosis and the evidence of their own mortality. Rowe (1984) suggests that how death is construed: "is central to the construct system, because it determines how the purpose of life is construed" (Rowe, 1984, p.11). Exploration of their construing of the experience of living with a breast cancer diagnosis, therefore, was not concerned with denying their uncertain futures, but exploring meanings that facilitated choice (Lane & Viney, 2000b). Fundamental to this understanding was the view that women's construing of their breast cancer experiences essentially determines how they will live.

Although the term adjustment is widely used within the psycho-oncology literature, and is a topic of central importance to the lived experience of women with

breast cancer, the psychological processes of adjustment have rarely been described (Brennan, 2001). Also, while social support has been linked in the literature with better adjustment, the processes by which this outcome is achieved have not been adequately addressed (Meyer & Mark, 1995). I therefore set out to explore the contribution that personal construct concepts (Chapter 4) could make to the field of psycho-oncology. Specifically, my *Aim* in conducting this research was to demonstrate the contribution that personal construct psychology can make to an understanding of women's experiences of breast cancer, and based on that understanding, how we may best help women adjust to living as breast cancer survivors.

The personal construct model of adjustment to breast cancer that I developed (Chapter 5), focuses on the meaning-making processes involved in adjusting to breast cancer survival, and the social context in which meanings are created. The model proposes that the distress women experience following a breast cancer diagnosis can be understood as *validation/invalidation* of their most important meanings. An important proposition of the model is that women for whom the diagnosis of breast cancer *invalidates* their most influential constructs about themselves will experience *threat*. In the face of threat to the integrity of their most influential meanings about themselves, women living with a breast cancer diagnosis anticipate support. It is proposed that invalidation of these women's anticipations about their support needs being met in the context of their social network will result in a second threat to their construct system, threat to their superordinate core role constructs. This invalidation of constructs at the very centre of their being will result in the experience of ongoing distress, and keep women in a loop of negative emotion, *dislocated* from the world of events, with little opportunity to elaborate new meanings that allow them to envisage their future with *hope*. This is reflected in Marie's words to me: "I just passed the

second anniversary of my mastectomy and treatment. Since being diagnosed I think I have experienced every emotion a person can. There were days when thoughts of my mutilated body were more than I could bear. I would like to think I am over that now, but I am not, I still have days of deep depression when I just lock myself away”.

In Study 1, a qualitative study (Chapter 6), I explored the recurrent themes identified by the participants through transcriptions of their accounts of their experiences of being breast cancer survivors. The focus group and individual interview methods provided rich sources of information, allowing the breast cancer survivors to voice their personal understandings of the effects of their breast cancer diagnosis. The findings showed breast cancer survivors live with threat to their core understandings about themselves, their relationships, and their ways of being in the world. The women who participated in Study 1 perceived that having someone who understood their experience was crucial to their successful adjustment from the acute stage of breast cancer diagnosis to the ongoing stage of being a breast cancer survivor. These women sought interpersonal understanding.

The personal construct concept of interpersonal understanding goes beyond understanding the content of others’ construct systems, to encompass understanding others as construers of meaning. The personal construct concept of social support involves two processes, again conceptualised as validation/invalidation. Support requires ‘commonality’ (validation of the content of others’ construing) and ‘sociality’ (validation of the construing processes of others). The model proposes that it is in the context of supportive role relationships that breast cancer survivors will experience *validation of the content of their construing*, their current meanings, helping them to define these meanings, and *validation of their construing processes*, confirming them as construer of meaning, thereby allowing them to elaborate their meanings. Opportunities to elaborate their meanings allow breast cancer survivors to

re-establish coherence in their life stories, and enables them to engage in new and rewarding Cycles of Experience. This is the essence of optimal functioning, characterized by openness to interaction with the environment, and an orientation towards movement into the future (Epting & Amerikaner, 1980).

Study 2, the Retreat study (Chapter 7), was conceptualised as the “validation of current meanings” study. A fundamental aspect of the Retreat was the opportunity it provided for the confirmation of a shared reality. I conducted Study 2, therefore, to examine whether commonality was enough to facilitate successful adjustment to being a breast cancer survivor. To further examine commonality and sociality, and the part these processes play in women’s adjustment to breast cancer survival, I then developed a personal construct group therapy (Chapter 8). Kelly (1955/1991) proposes that the elaborative potential of a therapeutic relationship is governed by levels of commonality and sociality. The purpose of Study 3 (Chapter 9) was to provide empirical evidence of the benefits of therapeutic support, defined as the provision of opportunities for the therapy participants to optimise both validation and elaboration. In the following section I discuss the findings of these three studies.

11.2 Major Findings from the Research

The *Aims* of Study 1 were to examine the fit of the personal construct model of adjustment to breast cancer survival and to generate information about how to work therapeutically with breast cancer survivors. The findings of Study 1 supported my model’s conceptualisation of a breast cancer diagnosis as threat to, and dislocation from, women’s systems of meaning, resulting from massive invalidation of their core assumptions about themselves and their ways of being in the world. For many of these women, their anticipations that their need for support would be met within the context of their social network, particularly by spouses and family members, were invalidated and the participants linked this invalidation to the ongoing distress they experienced.

The women in this study made clear the nature of the support they require. While they may seek reassurance from some relationships, a context in which to articulate their deepest fears, to receive acknowledgement of their fears, untroubled by concerns about upsetting those who hear them, and in a non-judgemental and accepting environment, is clearly needed.

The finding that, for so many women in the study, invalidation of their processes of meaning-making by family and friends was experienced as highly distressing, suggested that interventions should be structured to include ample opportunities for the disclosure of breast cancer survivors' meanings, for validation of their role in construing these meanings, and for elaboration of new meanings. From these findings, therefore, it was apparent that the goal of therapy with survivors of breast cancer should be to aid the development of a network of supportive relationships.

My *Aim* in conducting Study 2 was to learn more about one process of support, validation of current meanings. This study showed that, for the breast cancer survivors who attended the Retreat, validation of current meanings alone was not enough to ensure changes to their experiences of threat, threat to existence and dislocation, nor was it enough to increase their experiences of hope. Although these women reported "feeling better" following the Retreat, they were continuing to engage in unhelpful cycles of experience in response to unresolved threat to their most important meanings about themselves and their worlds.

The *Aim* of Study 3 was to provide empirical evidence of the benefits of therapeutic support. Therapeutic support was defined as the provision of opportunities for the therapy participants to optimise both commonality and sociality. Commonality provided validation of the content of the participants' current meanings, thereby helping them define their experiences. Sociality provided validation of their processes

of construing, allowing these women to elaborate new meanings that would be more helpful to their ongoing tasks of living as breast cancer survivors. This study, the first to use personal construct psychology concepts and procedures in group therapy specifically developed for breast cancer survivors, showed that together, the processes of commonality and sociality were effective in reducing levels of threat to women's psychological and physical integrity, and threat to their own existence. The personal construct group therapy was also effective in reducing the participants' levels of dislocation from non-core meanings, and increasing their levels of hope.

The effect of the group therapy was clear three months after the participants' last therapy session. This finding was particularly exciting because it suggests that the meanings the participants had elaborated in the context of the group therapy were helpful to them in anticipating events beyond this social context. In the group therapy, personal change was facilitated by making the participants' meanings more explicit to them, and by promoting alternative stories that widened the choices available to them. From the participants' perspectives, therapeutic change in the group therapy was facilitated by experiences of *Universality*, which can be described as "commonality", since the reduction in their sense of "aloneness" resulted from validation of their current meanings. Learning more about themselves from the feedback of others (*Self Understanding*) helped the women define their core meanings. The experiences of Acceptance (sociality) from the group members provided the context in which they could begin to risk testing new meanings (*Learning from Interpersonal Action*), and envisage new and more helpful cycles of experience (*The Instillation of Hope*).

11.3 The Limitations of the Research

The most important limitation concerns the small sample sizes. As an independent research project, with only one researcher in the roles of recruiter, interviewer, focus group leader, data analyst, and therapist, this problem was

insurmountable. Larger sample sizes would also have enabled me to identify which women benefited most from support, and to compare the effect of support on older and younger women.

The problems concerning the generalisability of this series of studies have been addressed earlier. The greatest problem concerns the use of a volunteer sample. This was most problematic in Study 2 where participants also selected treatment condition. While this is clearly a matter of concern, the studies were conducted to examine the processes of construing, based on personal construct conceptualisations of the nature of construing and the processes involved in facing the everyday task of living in health and in illness (Chapter 4). At this level of abstraction we can make assumptions about people in general, including women with breast cancer.

A third limitation relates specifically to my multiple roles in this research. Clearly this was not ideal. Steps were made to control for bias, and computer analysis of much of the data would have limited the degree of bias. However, I may have unwittingly biased the validity of the qualitative analyses of the women's communications. This was especially problematic in Study 1, the qualitative study. Despite the use of a second coder, it must be acknowledged that although the findings of this study confirmed those of earlier studies reported in Chapter 2, I may, even while attempting to be vigilant against bias, have found the outcomes I 'expected' to find. As I noted in Chapter 9, a further result of my multiple roles as the sole researcher and therapist was that the therapy participants were limited in the range of opportunities provided to engage in a supportive role relationship with a therapist. Conversely, because I could not always "be there" for every participant at all times, especially at times when I was involved with one member of the group, or one dyad, other group members more naturally stepped into the role of support provider than would have been the case if two therapists were available. Group members, therefore,

saw themselves as part of a supportive team, rather than defining us in terms of therapists and clients.

A fourth limitation relates to the design of these studies. Only in the third study were the participants randomly allocated to treatment conditions. Random allocation of the participants in all three studies would have increased the generalisability of the findings. As a purposeful multiple case study strategy was adopted, the findings are necessarily exploratory. While the findings are not generalisable to populations, they can, according to Patton (1990), be generalized to theoretical propositions. Because the research set out to explore personal construct conceptualisations of the underlying mechanisms of adjustment to breast cancer, I have greater confidence in the generalisability of these research findings, although it remains for future research to confirm these findings.

Further limitations relate to the collection of the participants' data. I noted earlier that comparable data collections for Study 2 participants would have improved the design of the study. Increasing the follow-up period, especially for Study 3, would also have been useful. Differential effects for the group therapy were noted at Time 3, three months after the last data collection on levels of threat to existence, dislocation and hope. Examination of their data at six months and one year would have been useful in determining if differential decreases in levels of threat and dislocation were evident after a longer period of validation, and if the benefits gained at three months were maintained in the longer-term.

In considering the measures used in these studies, the face-validity of the Derogatis Affects Balance Scale was problematic. The findings of the studies suggest self-report measures of non personal construct anxiety and depression with obvious face-validity, may reflect only women's attempts to "stay positive" rather than their underlying distress. Measures of underlying threat and dislocation were found to be

better indicators of breast cancer survivors' distress than measures of the commonly understood concepts of anxiety and depression. Although not an original intention of this research, the study confirmed that analysis of the content of breast cancer survivors' free communications is more sensitive to breast cancer survivors' underlying psychological states.

Finally, although the content analysis scales proved to be sensitive to change in breast cancer survivors' levels of threat, threat to existence, dislocation and hope, a greater range of measures would have been advantageous. In particular, as the findings support the view that the interpersonal context is crucial to women's adjustment to breast cancer survival, future outcome studies would benefit from the addition of measures of interpersonal concepts.

11.4 Suggestions for Future Research

Clearly, as stated above, future research with breast cancer survivors should be conducted with larger samples. Particularly Study 2 should be replicated with a sample of women randomly allocated to either the validation of current meanings condition, or to a wait-list control condition. In addition, replication of both Studies 2 and 3, with larger samples, could further test hypotheses on the nature of the link between social support and psychological well-being and examine the differential effects of supportive role relationships on younger and older women. Future research with larger samples should also determine the effect of time since diagnosis on treatment effect. This was not explored in this research project. Having established that the group therapy is helpful, research is now needed to determine the optimum time since diagnosis for therapy effects.

Future research directions might also focus on breast cancer survivors' partners or primary carers. To date only a few studies have examined the effect on women's adjustment to a breast cancer diagnosis of an intervention that included the

primary care person. Given the importance of the interpersonal context in which women must adjust to their status as breast cancer survivors, more studies are needed that include these people.

The studies I conducted tested a personal construct model built upon the theoretical concepts of threat. I applied this concept of human processes to a specific situation, adjustment to breast cancer. Future research might examine the usefulness of the personal construct model of adjustment to breast cancer when applied to other populations, especially populations of both men and women facing other life threatening situations including other cancers, heart disease and severe physical injury. The applicability of my model to survivors of other traumas, including domestic violence and sexual abuse, should also be tested.

11.5 The Usefulness of the Personal Construct Model of Women's Adjustment to Breast Cancer Survival

In evaluating the personal construct model of women's adjustment to breast cancer, I take, as my guiding principles, the standards proposed by Viney (2001).

These are as follows:

1. Models should be firmly based in the theory from which they emerge;
2. The propositions of the model need to be consistent with the philosophical assumptions underlying the theory;
3. Models should be clearly and concisely described;
4. Models should be parsimonious or frugal;
5. Models should be internally consistent; and
6. Models should be both comprehensive and specific. This means that models need to be sufficiently broadly based to include all the relevant events, yet precise enough to make prediction possible.

The first standard criterion of personal construct models, according to Viney (2001), is that they be firmly based in the theory from which they emerge. The *Aim* in developing my model of adjustment to breast cancer survival was to apply personal construct theory to women living with a breast cancer diagnosis. Central to personal construct theory is the belief that human life is wholly oriented towards the anticipation of events, towards making the world more predictable (McCoy, 1981). My model was, therefore, framed in terms of the anticipations of breast cancer survivors. Further personal construct concepts that aided my understanding of the processes of adjustment were threat, dislocation, validation/invalidation, role relationships, support and the Experience Cycle.

The second criterion concerns the underlying philosophical assumptions of the theory on which the model is based. Consistent with the philosophical assumption of personal construct theory, that there are innumerable possible alternative views of reality (Kelly, 1955/1991) my model is concerned with women's processes of making alternative meanings.

One function of a model is to prevent researchers and clinicians from being overwhelmed by the complexity of both the theory and the phenomenon, that the model has been developed to describe. The third criterion, therefore, concerns the presentation of the model. Viney (2001) suggests that conciseness in a model implies both simplicity of ideas and of the words used to express them. My examination of personal construct concepts relevant to an understanding of women's adjustment to breast cancer survival, and exploration of those concepts with the participants of the three studies, took three intensive years. The result of several thousand hours of exploration has been reduced to a set of eleven propositions (Chapter 5). I believe the propositions of the model encapsulate the understandings I have gained.

The fourth criterion is that the model should be parsimonious. Viney argues that the goal of a model is to account for the maximum information with the minimum number of propositions. Using a model with a finite set of propositions has enabled me to focus only on the parts of the theory that are relevant to communicate to others my understanding of the processes of adjustment to breast cancer survival.

The fifth criterion is the internal consistency of the assumptions and concepts presented. Kelly's (1955/1991) most fundamental assumption about the nature of human beings is that they are essentially interpretive, always in the process of attributing meaning to their ongoing experience. Based on this understanding, the first proposition of the model proposes that women's constructs are the paths by which they make sense of their experiences. All the following propositions of the model are framed in terms of women's processes of meaning-making, their attempts to adjust to breast cancer survival by elaborating alternative and more helpful meanings of their experiences.

The sixth criterion is the ability of the model to cover a range of issues relevant to the phenomenon of interest, and be, at the same time, specific enough to allow for predictions based upon the propositions of the model. I will first address the ability of the model to cover a range of interests. My model of adjustment is a model of interpersonal transition, applicable both to people in crisis and in the ongoing processes of living. Women facing breast cancer diagnoses are not seen as different to other women in the ways in which they respond to stressful events. Breast cancer survivors' responses to invalidation of their most important meanings about themselves and their worlds, therefore, will be the same as the responses of people facing other threatening events in their lives. My model of adjustment to breast cancer survival was derived from an overarching theory of the person. It proposes processes of meaning-making, further adding to its capacity to be comprehensive. It accounts

for the immediate issues of women at the time of diagnosis, and their ongoing issues as they adjust to living as breast cancer survivors. At the same time, the propositions were specific enough to allow for the prediction of outcomes. These predictions were tested in Studies 2 and 3.

While it was essential that the viability of the model be confirmed by meeting the standards presented, it is important to also add that without the model I would have been unable to conceptualise the recurring themes in the women's stories. I would have remained overwhelmed by the mountain of literature on the breast cancer experience. By conceptualising these women's distress as threat and dislocation, I became able to "make sense" of their experiences.

11.6 The Clinical Implications of the Research

From my review of the literature on breast cancer survival in Chapter 2, a number of further criteria, specific to my model, were proposed. These criteria relate to its clinical implications. My personal construct model was developed to address these issues. The issues are as follows:

1. The model should account for the paradox of outcomes observed: the high degree of distress linked to the disease, together with the potential for positive experiences of psychological growth;
2. The model should point to reasons why some women experience greater negative affect than others, and explain the chronicity of negative emotions in some women; and
3. The model should further understanding of the nature of the link between support and well-being, should help to identify women at increased risk of ongoing distress, and identify ways in which women diagnosed with breast cancer may best be supported.

One of the unique aspects of human experience is that people attempt to find meaning, even in incomprehensible events such as life-threatening illness and death (Feifel, 1959). This task will be made harder if the context in which to try out new meanings is unavailable. Survivors of a life-threatening illness face the task of redefining themselves, and giving meaning to their experiences of survival. When this process is successfully achieved, women, the model proposes, will be able to commit to ongoing Cycles of Experience. Kelly (1977) states: "The cycle of human experience remains incomplete unless it terminates in fresh hopes never before envisioned (Kelly, 1977, p. 9)". Kelly adds to this by stating: "The completion of the Experience Cycle is the mark of an optimally functioning person". Such a person, according to Kelly, is able to: "transcend the obvious" (Kelly, 1977, p. 4), "arriving at fresh hopes never before envisioned" (Kelly, 1977, p. 9). It is in recognising that they have overcome their adversity that women will look to the future with hope, and experience a sense of psychological growth (Lane & Marlow, 1999). It was for this reason that measures of threat, dislocation and hope were used in these outcome studies. In explaining the chronicity of negative emotions in some women, my model proposes that, if the context in which to "try out new meanings" is unavailable, then women will continue to experience distress. In turning to their role relationships for validation of themselves as construers of meaning, these women risk invalidation of their central meanings of their place in the world. Invalidation of constructs at the very centre of their being, my model proposes, results in the experience of secondary distress, and keeps them in a loop of ongoing negative emotion, with little opportunity to elaborate new meanings.

My model also points to factors that may indicate women who are at greater risk of ongoing distress than others. These will be women who lack supportive role relationships that provide the context to define and elaborate their meanings. The

extent to which these women's relationships with others are supportive will depend on the level of validation they receive of their current meanings, allowing them to define their meanings, and the level of validation of themselves as construers of meaning. These processes provide them with opportunities to elaborate new meanings, a necessary aspect of adjustment. From this, it follows, that women diagnosed with breast cancer will best be supported by the provision of social contexts in which these processes of validation and elaboration can take place.

Finally, as Brennan observes "clinicians require an intuitively plausible model which can guide their work and which, ideally, they can easily convey to their patients" (Brennan, 2001, p.3). The figure illustrating the model, in Chapter 5, allows both clinicians and women living with breast cancer to understand the processes involved in adjustment. I have also adapted the model to represent the key processes of their adjustment. This diagram, an elaboration of the Experience Cycle, is presented in Figure 10.

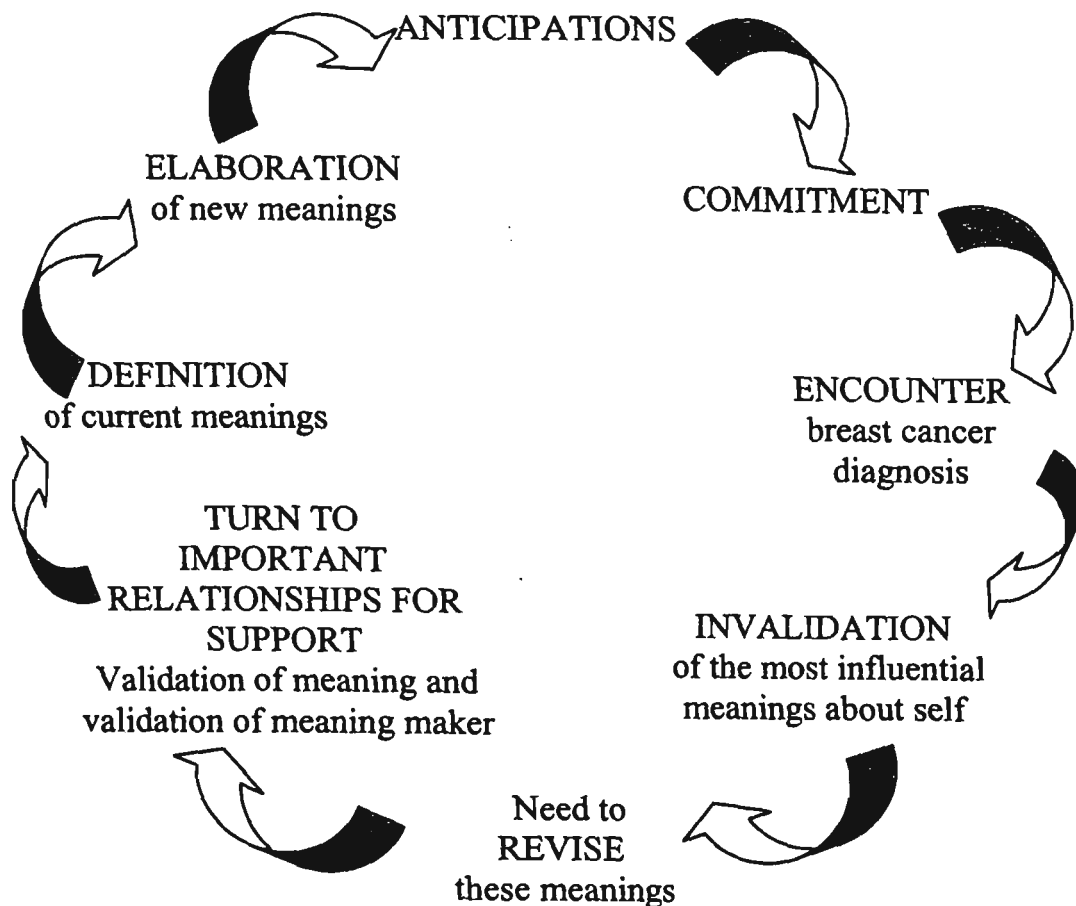


Figure 10. The figure representing women's adjustment to breast cancer survival for the purpose of communication to breast cancer survivors and those involved in their care

11.9 Conclusions

The challenge in conducting this research on breast cancer survivors, was to demonstrate the contribution that personal construct theory makes to understanding their experiences, and, based on this understanding, to show how to help women adjust most effectively to the ongoing task of being breast cancer survivors. To examine these processes of adjustment, I needed an approach that recognised and acknowledged the immense courage of these women. It also was required to enable them to voice their issues from their own perspectives, and value their attempts to make sense of their experiences. As adjustment to breast cancer survival consists of dynamic and complex processes that take place in social contexts and are mediated by

the unique meanings people place on their experiences, it was also very important to adopt a theoretical approach that allowed for an understanding of both the personal and the relational. Unlike many psychological theories, personal construct theory offers a conceptual approach for understanding the interpersonal mechanisms of adjustment to breast cancer. Personal construct concepts of the personal and the interpersonal, therefore, allowed me to “make sense” of breast cancer survivors’ stories.

To me, the biggest contribution personal construct concepts make to an understanding of women’s adjustment to breast cancer survival is that they point to ways in which not only therapists, but all those involved in the care of women diagnosed with breast cancer, can help them adjust to breast cancer survival. The personal construct concept of support requires supporters to respond, not in terms of certainties or outcomes, but by acknowledging breast cancer survivors as construers of meaning. The findings of the three studies show that in attempting to support breast cancer survivors, it is essential that we, as their therapists, carers, partners, parents, daughters, sons and friends, respond not only to the content of their communications, but also to their attempts to find meaning in their experiences. Reassurance, that “everything will be all right” for example, though well intentioned, may serve to cut women off from their means of experimentation. Breast cancer survivors offer themselves as makers of meaning in their communications about their breast cancer experiences, and to have these offers invalidated can be severely damaging (Leitner & Guthrie, 1992).

As women living with breast cancer attempt to make the unreal, real, support that offers validation of their current meanings, and of themselves as meaning-makers, will help them restore a sense of coherence to their ongoing life stories that enable them to engage in positive and ongoing Cycles of Experience. The role of

support in this restoration of meaning is captured in the following poem written by Gloria about her group therapy experience.

Strangers We Were, Friends We've Become

*Happily we have spent some time together getting to know one another.
 We have shared – laughed a little and shed a few tears.
 And in this time we have come to understand what it is that draws us
 out of isolation,
 into seeking a deeper meaning of the transformation taking place in us
 through a diagnosis of breast cancer.
 I now go forward, as I believe you do too.
 To meet the present moment with an expectation
 of a future bright and worthwhile, with thankfulness and appreciation.
 Life is not passing me by, for I am standing firm to claim its benefit.*

Gloria, December 2000

I end this report with a final thank you to the brave and caring women who contributed to this research. At every step along the way they helped me to clarify my understandings⁵, and their continued involvement in the research was invaluable. I remain forever indebted to them for their generous support and the openness with which they shared their stories of survival and dared to risk engaging in Cycles of Experience with me.

⁵ Feedback occurred informally in the community and more formally at meetings I held to specifically report my findings. Feedback was also given by the participants in response to the Research Newsletter I periodically mailed to them. See Appendix L for an example.

REFERENCES

“We’re a bit like a bundle of sticks really. By ourselves we can be a bit uncertain and fearful, but put us all together and we become very strong and confident” (Enid, 89 years).

Australian Bureau of Statistics (1999). *Australian social trends: Health status -*

Mental health. Canberra: Australian Bureau of Statistics Government Printing Services.

Australian Institute of Health and Welfare (1998). *Breast cancer survival in Australian women 1982-1994*. Canberra: Australian Institute of Health and Welfare.

Australian Institute of Health and Welfare (1999). *Breast cancer in Australian women*. Canberra: Australian Institute of Health and Welfare & Australasian Association of Cancer Registries.

Adams-Webber, J. R. (1979). *Personal construct theory: Concepts and applications*. Chichester: Wiley.

Aiken, J. L. (1996). Tamoxifen in perspective: Benefits, side-effects and toxicities. In K. H. Dow (Ed.), *Contemporary Issues in Breast Cancer*. Sudbury, MA: Jones & Bartlett.

Allbrook, M. (Ed.). (1997). *Songs of strength*. Women's Cancer Group. Sydney: Macmillan.

Alter, C. L., Axelrod, A., Harris, H., & Gobois, B. (1996). Identification of PTSD in cancer survivors. *Psychosomatics*, 37, 137-43.

American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders*. (3rd ed.). Washington: American Psychiatric Association.

Andrykowski, M. A., & Cordova, M. J. (1998). Factors associated with PTSD symptoms following treatment for breast cancer. Tests of the Andersen model. *Journal of Traumatic Stress*, 11(2), 189-203.

- Andrykowski, M. A., Cordova, M. J., McGrath, P. C., Sloan, D. A., & Kenady, D. E. (2000). Stability and change in posttraumatic stress disorder symptoms following breast cancer treatment: A 1-year follow-up. *Psycho-Oncology*, 9(1), 69-78.
- Antoni, M. H., Lehman, J. M., Klibourn, K. M., Boyers, A. E., Culver, J. L., Alferi, S. M. (2001). Cognitive-behavioral stress management intervention decreases the prevalence of depression and enhances benefit finding among women under treatment for early-stage breast cancer. *Journal of Health Psychology*, 20(1), 20-32.
- Asay, T. P., & Lambert, M. J. (1999). The empirical case for common factors: Qualitative findings. In M. A. Hubble & B. L. Duncan (Eds.), *The heart and soul of change: What works in therapy*. Washington: American Psychological Association.
- Ashing-Giwa, K., & Ganz, P. A. (1997). Understanding the breast cancer experience of African-American women. *Journal of Psychosocial Oncology*, 15(2), 19-35.
- Atkinson, J. W. (1964). *An introduction to motivation*. Princeton, NJ: Van Nostrand.
- Ayres, A., Hoon, P. W., Matheny, K. B., Cotanch, P. H., & Takayangi, S. (1994). Influence of mood and adjustment to cancer on compliance with chemotherapy with breast cancer patients. *Journal of Psychosomatic Research*, 34(5), 393-402.
- Bailey, E. J., Erwin, D. O., & Belin, P. (2000). Using cultural beliefs and patterns to improve mammography utilization among African-American women: The Witness Project. *Journal of the National Medical Association*, 92(3), 136-142.
- Bandura, A. (1986). *Social foundations of thought and action: A social cognitive theory*. Englewood Cliffs, NJ: Prentice Hall.

- Bannister, D. (1963). The genesis of schizophrenic thought disorder: A serial invalidation hypothesis. *British Journal of Psychiatry*, *109*, 680-86.
- Bannister, D. (1985). The experience of self. In F. Epting & A. W. Landfield (Eds.), *Anticipating personal construct psychology* (pp. 39-45). Lincoln: University of Nebraska Press.
- Bannister, D., Adams-Webber, J. R., Penn, W. I., & Radley, A. R. (1975). Reversing the process of thought disorder: A serial validation experiment. *British Journal of Social and Clinical Psychology*, *14*, 169-180.
- Bannister, D., & Fransella, F. (1980). *Inquiring man: The psychology of personal constructs*. (2nd ed.). London: Crook Helm.
- Baum, A., & Andersen, B. L. (2001). *Psychosocial interventions for cancer*. Washington: American Psychological Association.
- Baum, A., & Posluszny, D. M. (2001). Traumatic stress as a target for intervention with cancer patients. In A. Baum & B. L. Andersen (Eds.), *Psychosocial interventions for cancer* (pp. 143-174). Washington: American Psychological Association.
- Beck, A. T. (1976). *Cognitive therapies and emotional disorders*. New York: International Universities Press.
- Becker, E. (1973). *The denial of death*. New York: Free Press.
- Berglund, G., Bolund, C., Gustavsson, U., & Sjoden, P. (1994). A randomised study of a rehabilitation program for cancer patients: The 'starting again' group. *Psycho-Oncology*, *3*, 109-20.
- Berzon, B., Pious, C., & Farson, R. E. (1963). The therapeutic event in group psychotherapy: A study of subjective reports by group members. *Journal of Individual Psychology*, *19*, 204-12.

- Bindemann, S., Soukop, M., & Kaye, S. B. (1991). Randomised controlled study of relaxation training. *European Journal of Cancer*, 27, 170-4.
- Bland, M. (1990). *An introduction to medical statistics*. Oxford: Oxford University Press.
- Bleiker, E. M., Pouwer, F., van der Ploeg, H. M., Leer, J. W., & Ader, H. J. (2000). Psychological distress two years after diagnosis of breast cancer: frequency and prediction. *Patient Education and Counselling*, 40(3), 209-217.
- Bloch, S., & Crouch, E. (1985). *Therapeutic factors in group psychotherapy*. New York: Oxford University Press.
- Bloch, S., & Kissane, D. (2000). Psychotherapies in oncology: An exciting new challenge. *British Journal of Psychiatry*, 177, 112-116.
- Bloch, S., Reibstein, J., Crouch, E., Holroyd, P., & Hemen, J. (1979). A method for the study of therapeutic factors in group psychotherapy. *British Journal of Psychiatry*, 134, 257-263.
- Bloom. (1987). Psychological response to mastectomy. A prospective comparison study. Psychological aspects of Breast Cancer Study Group. *Cancer*, 59(1), 198-96.
- Bloom, J. (1996). Social support of the cancer patient and the role of the family. In L. Baider, C. L. Cooper, & A. K. De-Nour (Eds.), *Cancer and the family* (pp. 53-70). Chichester: Wiley.
- Bloom, J. R. (1982). Social support, accommodation to stress and adjustment to breast cancer. *Social Science and Medicine*, 16, 1329-38.
- Bloom, J. R. (1986). Social support and adjustment to breast cancer. In B. L. Andersen (Ed.), *Women with cancer: Psychological perspectives* (pp. 204-229). New York: Springer-Verlag.

- Bloom, J. R., & Kessler, L. (1994). Risk and timing of counselling and support interventions for younger women with breast cancer. *Journal of the National Cancer Institute, 16*, 199-206.
- Bloom, J. R., Stewart, S. L., Johnston, M., & Banks, P. (1998). Intrusiveness of illness and quality of life in young women with breast cancer. *Psycho-Oncology, 7*(2), 89-100.
- Boehmer, U., & Clark, J. A. (2001). Married couples' perspectives on prostate cancer diagnosis and treatment. *Psycho-Oncology, 10*(2), 147-155.
- Bolger, N., Foster, M., Vinokur, A. D., & Ng, R. (1996). Close relationships and adjustment to a life crisis: The case of breast cancer. *Journal of Personality and Social Psychology, 70*(2), 283-294.
- Botella, L., & Feixas, G. (1993). The autobiographical group: A tool for the reconstruction of past life experience with the aged. *International Journal of Aging & Human Development, 36*(4), 303-319.
- Bottella, L. (1991). Psychoeducational groups with older adults: An integrative personal construct rationale and some guidelines. *International Journal of Personal Construct Psychology, 4*, 397-408.
- Bowlby, J. (1969). *Attachment and loss*. London: Hogarth.
- Breitbart, W. (1995). Identifying patients at risk for, and treatment of major psychiatric complications of cancer. *Supportive Care in Cancer, 3*(1), 45-60.
- Brennan, J. (2001). Adjustment to cancer - coping or personal transition. *Psycho-Oncology, 10*, 1-8.
- Briggs, S. R., & Cheek, J. M. (1986). The role of factor analysis in the development and evaluation of personality scales. *Journal of Personality, 54*, 106-148.
- Broyard, A. (1992). *Intoxicated by my illness*. New York: Fawcett Columbine.

- Bultz, B. D., Speca, M., Brasher, P. M., Geggie, P. H., & Page, A. (2000). A randomized controlled trial of a brief psychoeducational support group for partners of early stage breast cancer patients. *Psycho-Oncology*, 9(4), 303-313.
- Burgess, C., Morris, T., & Pettingale, K. W. (1988). Psychological response to cancer diagnosis II. Evidence for coping styles (coping styles and cancer diagnosis). *Journal of Psychosomatic Research*, 32(3), 263-72.
- Burke, S., & Kissane, D. W. (1998a). *Psychosocial support for breast cancer patients: A review of interventions by specialist providers. A summary of the literature 1976-1996*. Sydney: NHMRC National Breast Cancer Centre.
- Burke, S., & Kissane, D. W. (1998b). *Psychosocial support for breast cancer patients provided by members of the treatment team. A summary of the literature 1976-1996*. Sydney: NHMRC National Breast Cancer Centre.
- Button, E. (1987). Construing people or weight: An eating disorder group. In R. A. Neimeyer & G. J. Neimeyer (Eds.), *Personal construct therapy casebook* (pp. 230-244). New York: Springer.
- Button, E. (1993). *Eating disorders: Personal construct therapy and change*. New York: John Wiley.
- Button, E. (1996). Validation and invalidation. In J. W. Scheer & A. Catina (Eds.), *Empirical constructivism in Europe: The personal construct approach* (pp. 142-148). Giessen: Pschosozial-Verlag.
- Cain, E. N., Kohorn, E. I., Quinlan, D. M., Latimer, K., & Schwartz, P. E. (1986). Psychosocial benefits of a cancer support group. *Cancer*, 57, 183-189.
- Calhoun, L. G., & Tedeschi, R. G. (2001). Posttraumatic growth: The positive lessons of loss. In R. A. Neimeyer (Ed.), *Meaning reconstruction and the experience of loss* (pp. 157-172). Washington: American Psychological Association.

- Campora, E., Naso, C., Vitullo, M. T., Giudici, S., Camoirano, A., Repetto, L., & Rosso, R. (1992). The impact of chemotherapy on the quality of life of breast cancer patients. *Journal of Chemotherapy*, 41(1), 59-63.
- Carter, B. J. (1993). Long-term survivors of breast cancer. A qualitative descriptive study. *Cancer Nursing*, 16(5), 354-6.
- Carter, R. E., Carter, C. A., & Prosen, H. A. (1992). Emotional and personality types of breast cancer patients and spouses. *American Journal of Family Therapy*, 20(4), 300-309.
- Carver, C. S., Pozo, C., Harris, S. D., Noriego, V., & Scheier, M. F. (1993). How coping mediates the effect of optimism on distress: A study of women with early stage breast cancer. *Journal of Personality and Psychology*, 65(2), 375-90.
- Carver, C. S., Pozo, C., Kaderman, C., Harris, S. D., Noriego, V., Scheier, D. S., Ketcham, A. S., Moffatt, F. L. J., & Clark, K. C. (1994). Optimism versus pessimism predicts the quality of women's adjustment to early stage breast cancer. *Cancer*, 73(4), 1213-20.
- Carver, C. S., & Scheier, M. F. (1998). *On the self-regulation of behavior*. New York: Cambridge University Press.
- Cassileth, B. R. (1979). *The cancer patient*. Philadelphia: Lea and Febinger.
- Cassileth, B. R., Walsh, W. P., & Lusk, E. J. (1988). Psychosocial correlates of cancer survival: A subsequent report 3 to 8 years after cancer diagnosis. *Journal of Clinical Oncology*, 6(11), 1753-1759.
- Chambless, D. (1999). Empirically validated treatments - What now? *Applied & Preventive Psychology*, 8(4), 281-4.
- Chambless, D. L., & Hollon, S. D. (1998). Defining empirically supported therapies. *Journal of Consulting & Clinical Psychology*, 66(1), 7-18.

- Chambless, D. L., & Ollendick, T. L. (2000). Empirically supported psychological interventions: Controversies and evidence. *Annual Review of Psychology, 52*, 685-716.
- Clarke, D. M., & Fairburn, C. G. (1997). *Science and practice of cognitive behaviour therapy*. Oxford: Oxford University Press.
- Cobb, S. (1976). Social support as a moderator of life stress. *Psychosomatic Medicine, 38*(5), 300-314.
- Cohen, J. (1960). A coefficient of agreement for nominal scales. *Educational & Psychological Measurement, 10*, 37-46.
- Cordova, M. J., Andrykowski, M. A., Kenady, D. E., McGrath, P. C., Sloan, D. A., & Redd, W. H. (1995). Frequency and correlates of posttraumatic-stress-disorder-like symptoms after treatment for breast cancer. *Journal of Consultant Clinical Psychology, 63*(6), 981-6.
- Cordova, M. J., Cunningham, L. L. C., Carlson, C. R., & Andrykowski, M. A. (2001). Posttraumatic growth following breast cancer: A controlled comparison study. *Health Psychology, 20*(3), 176-185.
- Coyone, J. C., & Gottlieb, B. H. (1996). The mismeasure of coping by checklist. *Journal of Personality, 64*, 959-991.
- Cunningham, A. J., & Tocco, E. K. (1989). A randomized trial of group psychoeducational therapy for cancer patients. *Patient Education and Counselling, 14*, 101-4.
- Curtona, C. E., & Russell, D. (1990). Type of social support and specific stress: Towards a theory of optimal matching. In B. R. Sarason, I. G. Sarason, & G. R. Pierce (Eds.), *Social support: An interactional view* (pp. 319-366). New York: John Wiley.

- Cutrona, C. E., & Russell, D. (1987). The provision of social relationships and adaptation to stress. In W. H. Jones & D. Perlman (Eds.), *Advances in personal relationships* (pp. 27-36). Greenwich, CT: JAI Press.
- Deadman, J. M., Dewey, M. J., Owens, R. G., & Leinster, S. J. (1989). Threat and loss in breast cancer. *Psychological Medicine*, *19*(3), 677-681.
- Dean, C. (1987). Psychiatric morbidity following mastectomy: Preoperative predictors and types of illness. *Journal of Psychosomatic Research*, *31*(3), 385-392.
- Derogatis, L. R. (1996). *Derogatis Affects Balance Scale: Administration, scoring and procedures manual*. Towson: Clinical Psychometric Research.
- Derogatis, L. R., Abeloff, M. D., & Melisaratos, N. (1979). Psychological coping mechanisms and survival time in metastatic breast cancer. *Journal of the American Medical Association*, *242*(14), 1504-8.
- Devine, E. C. (1992). Effects of psychoeducational care for adult surgical patients: A meta-analysis of 191 studies. *Education & Counseling*, *19*(2), 129-142.
- Devine, E. C., & Westlake, S. K. (1995). The effects of psychoeducational care provided to adults with cancer: Meta-analysis of 116 studies. *Oncology Nursing Forum*, *22*, 1369-81.
- Doka, K. J. (1997). The quest for meaning in illness, dying, death and bereavement. In S. Strack (Ed.), *Death and the Quest for Meaning: Essays in Honor of Herman Feifel* (pp. 241-255). Northvale, NJ: Jason Aronson.
- Dow, K. H., Ferrell, B. R., Leigh, S., Ly, J., & Gulasekaram, P. (1996). An evaluation of the quality of life among long-term survivors of breast cancer. *Breast Cancer Research & Treatment*, *39*(3), 261-73.
- Drysdale, B. (1991). Psychological treatment and reconstruction with a chronic pain patient. *International Journal of Personal Construct Psychology*, *4*, 359-370.

- Duck, S. (1973). *Personal relationships and personal constructs: A study of friendship formation*. London: Wiley.
- Duck, S. W. (1979). The personal and the interpersonal in construct theory: Social and individual aspects of relationships. In P. Stringer & D. Bannister (Eds.), *Constructs of sociality and individuality* (pp. 279-297). London: Academic Press.
- Dunkel-Schetter, C. (1984). Social support and cancer. Findings based on patient interviews and their implications. *Journal of Social Issues*, 40, 77-98.
- Dunkel-Schetter, C., Feinstein, L. G., Taylor, S. E., & Falke, R. L. (1992). Patterns of coping with cancer. *Health Psychology*, 11(2), 79-87.
- Dunkel-Schetter, C., & Wortman, C. (1982). The interpersonal dynamics of cancer: Problems in social relationships and their impact on the patient. In H.S. Friedman & M.R. Matteo (Eds.), *Interpersonal issues in healthcare*. New York: Academic Press.
- Dunn, S. M., Welch, G. W., Butow, P. N., & Coates, A. S. (1997). Refining the measurement of psychological adjustment in cancer. *Australian Journal of Psychology*, 49(3), 144-151.
- Edelman, S., Bell, D., & Kidman, A. (1999). Group CBT versus supportive therapy with patients who have primary breast cancer. *Journal of Cognitive Psychotherapy*, 13(3).
- Edelman, S., & Kidman, A. D. (1999). Description of a group cognitive behaviour therapy programme with cancer patients. *Psycho-Oncology*, 8, 306-314.
- Edgar, L., Rosberger, Z., & Nowlis, D. (1992). Coping with cancer during the first year after diagnosis: Assessment and intervention. *Cancer*, 69, 817-28.

- Ell, K., Nishimoto, R., Mediansky, L., Mantell, J., & Hamovitch, M. (1992). Social relations, social support, and survival among patients with cancer. *Journal of Psychosomatic Research*, 36(6), 531-541.
- Ell, K. O., Mantell, J. E., Hamovitch, M. B., & Nishimoto, R. H. (1989). Social support, sense of control, and coping among patients with breast, lung, or colorectal cancer. *Journal of Psychosocial Oncology*, 19(2), 3-27.
- Ellis, A. (1962). *Reason and emotion in psychotherapy*. Secaucus, NJ: Citadel.
- Ellman, R., & Thomas, B. A. (1995). Is psychological well-being impaired in long-term survivors of breast cancer? *Journal of Medical Screening*, 2(1), 5-9.
- Endicott, J. (1983). Measurement of depression in patients with cancer. *Cancer*, 53(10), 2243-9.
- Epting, F. R. (1984). *Personal construct counseling and psychotherapy*. New York: John Wiley.
- Epting, F.R. & Amerikaner, M. (1980). Optimal functioning: A personal construct approach. In A.W.Landfield & L. M. Leitner (Eds.), *Personal construct psychology: Psychotherapy and personality* (pp. 55-73). New York: Wiley.
- Epting, F. R., & Neimeyer, R. A. (1983). *Personal meanings of death*. New York: Hemisphere.
- Everson, S. A., Goldberg, D. E., Kaplan, G. A., Cohen, R. D., Pukkala, E., Tuomilehto, J., & Salonen, J. T. (1996). Hopelessness and risk of mortality and incidence of myocardial infarction and cancer. *Psychosomatic Medicine*, 58, 113-121.
- Fallowfield, L. J., Baum, M., & Maguire, G. P. (1986). Effects of breast conservation on psychological morbidity associated with diagnosis and treatment of early breast cancer. *British Medical Journal Clinical Research Education*, 293(6558), 1331-4.

- Fallowfield, L. J., Hall, A., Maguire, G. P., & Baum, M. (1990). Psychological outcomes of different treatment policies in women with early breast cancer outside a clinical trial. *British Medical Journal*, *301*, 575-580.
- Fawzy, F. I., Cousins, N., Fawzy, N. W., Kemeny, M. E., Elashoff, R., & Morton, D. (1990). A structured psychiatric intervention for cancer patients: I. Changes over time in methods of coping and affective disturbance. *Archives of General Psychiatry*, *47*, 720-5.
- Fawzy, F. I., Fawzy, N. W., Arndt, L. A., & Pasnau, R. O. (1995). A critical review of psychosocial interventions in cancer care. *Archives of General Psychiatry*, *52*, 100-13.
- Fawzy, F. I., Fawzy, N. W., & Wheeler, J. G. (1996). A post-hoc comparison of the efficiency of a psycho-educational intervention for melanoma patients delivered in group versus individual formats: An analysis of data from two studies. *Psycho-Oncology*, *5*, 81-9.
- Feather, N. T. (1982). *Expectations and actions: Expectancy - value models in psychology*. Hillside, NJ: Erlbaum.
- Feifel, H. (1959). *The meaning of death*. New York: McGraw-Hill.
- Ferlic, M., Goldman, A., & Kennedy, B. J. (1979). Group counseling with adult patients with advanced cancer. *Cancer*, *43*, 760-6.
- Ferrans, C. E. (1994). Quality of life through the eyes of survivors of breast cancer. *Oncology Nursing Forum*, *21*(10), 1645-51.
- Ferrell, B. R., & Dow, K. H. (1996). Portraits of survivorship: a glimpse through the lens of survivors' eyes. *Cancer Practice*, *4*(2), 76-80.
- Ferrell, B. R., Grant, M. M., Funk, B., Otis-Green, S., & Garcia, N. (1997). Quality of life in breast cancer survivors as identified by focus groups. *Psycho-Oncology*, *6*(1), 13-23.

- Folkman, S. (1997). Positive psychological states and coping with severe stress. *Social Science and Medicine*, 45, 1207-1221.
- Folkman, S., & Greer, S. (2000). Promoting psychological well-being in the face of serious illness: When theory, research and practice inform each other. *Psycho-Oncology*, 9, 11-19.
- Forsen, A. (1991). Psychosocial stress as a risk for breast cancer. *Psychotherapy and Psychosomatics*, 55(2-4), 176-85.
- Forster, J. R. (1991). Facilitating positive changes in self-constructions. *International Journal of Personal Construct Psychology*, 4, 281-292.
- Frank, A. W. (1995). *The wounded storyteller: Body, illness, and ethics*. Chicago: Chicago University Press.
- Frank, A. W. (1998). Just listening: Narrative and deep illness. *Families, Systems and Health*, 16(3), 197-212.
- Fransella, F., & Dalton, P. (1990). *Personal construct counselling in action*. London: Sage.
- Ganz, P. M., Hirji, K., Sim, M., Schag, C. A., Fred, C., & Polinsky, M. L. (1993). Predicting psychosocial risk in patients with breast cancer. *Medical Care*, 31(5), 419-31.
- Gilbar, O. (1991). Model for crisis intervention through group therapy for women with breast cancer. *Clinical Social Work Journal*, 19(3), 293-304.
- Gleser, G. C., Gottschalk, L. A., & Springer, K. J. (1961). An anxiety scale applicable to verbal samples. *Archives of General Psychiatry*, 5, 593-605.
- Gleser, G. C., Winget, C., Seligman, R., & Rauh, J. L. (1979). Evaluation of psychotherapy with adolescents using content analysis of verbal samples. In L. A. Gottschalk (Ed.), *The content analysis of verbal samples. Further studies* (pp. 213-233). New York: Spectrum Publications.

- Goodare, H. (1996). *Fighting spirit: The stories of women in the Bristol Breast Cancer Survey*. London: Scarlet Press.
- Goodwin, J. S., Hunt, W. C., Key, C. R., & Samet, J. M. (1987). The effect of marital status on stage, treatment, and survival of cancer patients. *Journal of the American Medical Association*, 258(21), 3125-30.
- Gotay, C. C., & Muraoka, M. Y. (1998). Quality of life in long-term survivors of adult-onset cancers. *Journal Of The National Cancer Institute*, 90, 656-667.
- Gottschalk, L. A. (1974). A hope scale applicable to verbal samples. *Archives of General Psychiatry*, 30, 779-785.
- Gottschalk, L. A. (1979). A hope scale applicable to verbal samples. In L. A. Gottschalk (Ed.), *The content analysis of verbal behavior* (pp. 1-40). New York: Spectrum.
- Gottschalk, L. A. (1987). Content-category analysis. The measurement of the magnitude of psychological dimensions in psychotherapy. In R. L. Russell (Ed.), *Language in psychotherapy* (pp. 13-70). New York: Plenum Press.
- Gottschalk, L. A. (2000). The application of computerized content analysis of natural language in psychotherapy research now and in the future. *American Journal of Psychotherapy*, 54(3), 305-311.
- Gottschalk, L. A., Bates, D. E., Waskow, I. E., Katz, M. M., & Olson, J. (1972). Effect of amphetamine or chlorpromazine on achievement strivings scores derived from the content analysis of speech. *Comprehensive Psychiatry*, 12, 430-435.
- Gottschalk, L. A., & Bechtel, R. J. (1982). The measurement of anxiety through the computer analysis of verbal samples. *Comprehensive Psychiatry*, 23, 364-369.

- Gottschalk, L. A., & Bechtel, R. J. (1995). Computerized measurement of the content analysis of natural language for use in biomedical research. *Computer Methods and Programs in Biomedicine*, 47, 123-130.
- Gottschalk, L. A., & Bechtel, R. J. (1998). *Psychiatric Content Analysis and Diagnosis (PCAD2000)*. Corona del Mar, California: GB Software.
- Gottschalk, L. A., Fox, R. A., & Bates, D. E. (1973). A study of prediction and outcome in a Mental Health Crisis Clinic. *American Journal of Psychiatry*, 130, 1107-1111.
- Gottschalk, L. A., & Gleser, G. C. (1969). *The measurement of psychological states through the content analysis of verbal behavior*. Berkeley: University of California Press.
- Gottschalk, L. A., Gleser, G. C., Wylie, H. W. J., & Kaplan, S. M. (1965). Effects of imipramine on anxiety and hostility levels. *Psychopharmacologia*, 7(303-310).
- Gottschalk, L. A., & Hoigaard-Martin, J. (1986a). The emotional impact of mastectomy. *Psychiatry Research*, 17(2), 153-167.
- Gottschalk, L. A., & Hoigaard-Martin, J. (1986b). A depression scale applicable to verbal samples. *Psychiatry Research*, 17(3), 213-227.
- Gottschalk, L. A., Mayerson, P., & Gottlieb, A. (1967). The prediction and evaluation of outcome in an emergency brief psychotherapy clinic. *Journal of Nervous and Mental Disease*, 144, 77-96.
- Gottschalk, L. A., Stein, M. K., & Shapiro, D. H. (1997). The application of computerized content analysis of speech to the diagnostic process in a psychiatric outpatient clinic. *Journal of Clinical Psychology*, 53(5), 427-441.

- Gottschalk, L. A., Winget, C. N., Gleser, G. C., & Springer, K. J. (1966). The measurement of emotional changes during a psychiatric interview: A working model toward quantifying the psychoanalytic concept of affect. In L. A. Gottschalk & A. H. Auerbach (Eds.), *Methods of research in psychotherapy* (pp. 93-126). New York: Appleton-Century-Crofts.
- Grassi, I., & Rosti, G. (1996). Psychosocial morbidity and adjustment to illness among long-term cancer survivors. A six-year follow-up study. *Psychosomatics, 37*(6), 523-532.
- Gravetter, F. J., & Wallnau, L. B. (2000). *Statistics for the behavioral sciences*. (5th ed.). Belmont, CA: Wadsworth.
- Gray, R. E., Fitch, M., Greenberg, M., Hampson, A., Doherty, M., & Labrecque, M. (1998). The information needs of well, longer-term survivors of breast cancer. *Patient Education and Counseling, 33*(3), 245-255.
- Great Britain Office for National Statistics. (2001). *Death rates from breast and prostate cancer: EU comparison, 1996*: European Network of Cancer Registries.
- Greer, S., Moorey, S., Baruch, J. D. R., Watson, M., Robertson, B. M., Manson, A., Rowson, L., Law, M. G., & Bliss, J. M. (1992). Adjuvant psychological therapy for patients with cancer: A prospective randomized trial. *British Medical Journal, 304*, 675-680.
- Hall, A., A'Hern, R., & Fallowfield, L. (1999). Are we using appropriate self report questionnaires for detecting anxiety and depression in women with early breast cancer. *European Journal of Cancer, 35*(1), 79-85.
- Harvey, J. H. (1995). *Embracing their memory: Loss and the social psychology of storytelling*. Needham Heights, MA: Allyn & Bacon.

- Heim, E., Valach, L., & Schaffner, L. (1997). Coping and psychosocial adaptation: Longitudinal effects over time and stages in breast cancer. *Psychosomatic Medicine, 59*, 408-418.
- Helgeson, V. S., Cohen, S., Schulz, R., & Yasko, J. (1999). Education and peer discussion group interventions and adjustment to breast cancer. *Archives of General Psychiatry, 56*(4), 340-347.
- Helgeson, V. S., Cohen, S., Schulz, R., & Yasko, J. (2000). Group support interventions for women with breast cancer: Who benefits from what? *Health Psychology, 19*(2), 107-114.
- Hersh, S. P. (1979). Views on the psychosocial dimensions of cancer and cancer treatment. In P. Ahmed & G. Coelho (Eds.), *Towards a new definition of health* (pp. 175-190). New York: Plenum Press.
- Heszen-Niejodek, I., Gottschalk, L. A., & Januszek, M. (1999). Anxiety and hope during the course of three different medical illnesses: A longitudinal study. *Psychotherapy & Psychosomatics, 68*(6), 304-311.
- Hilton, B. A. (1989). The relationship of uncertainty, control, commitment, and threat of recurrence to coping strategies used by women diagnosed with breast cancer. *Journal of Behavioral Medicine, 12*(1), 39-54.
- Hinkle, D. (1965). *The change of personal constructs from the viewpoint of a theory of construct implications*. Unpublished doctoral dissertation, Ohio State University.
- Hislop, T. G., Waxler, N. E., Coldman, A. J., Elwood, J. M., & Kan, L. (1987). The prognostic significance of psychosocial factors in women with breast cancer. *Journal of Chronic Disease, 40*, 729-735.

- Hobbs, M., Birtchnall, S., Harte, A., & Lacey, H. (1989). Therapeutic factors in short term group therapy for women with bulimia. *International Journal of Eating Disorders*, 8, 623-633.
- Hoehn-Saric, R., Merchant, A. F., Keyser, M. L., & Smith, V. K. (1981). Effects of clonidine on anxiety disorders. *Archives of General Psychiatry*, 38, 1278-1282.
- Holland, J. C., & Lewis, S. (2000). *The human side of cancer*. New York: Harper Collins.
- Holland, J. C., Morrow, G., Schmale, A., Derogatis, M., Stefanek, M., Berenson, S., Carpenter, P. J., Breitbart, W., & Feldstein, M. (1991). A randomised clinical trial of alprazolam versus progressive muscle relaxation in cancer patients with anxiety and depressive symptoms. *Journal of Clinical Oncology*, 9, 1004-11.
- Holland, J. C., Romano, S., Heiligenstein, J. H., Tepner, R. G., & Wilson, M. G. (1998). A controlled trial of fluoxetine and desipramine in depressed women with advanced cancer. *Psycho-Oncology*, 7(4), 291-300.
- Holland, J. C., & Zittoun, R. (1990). Psychosocial issues in oncology: A historical perspective. In J. C. Holland & R. Zittoun (Eds.), *Psychosocial aspects of oncology* (pp. 3-9). Berlin Heidelberg: Springer-Verlag.
- Holzner, B., Kemmler, G., Kopp, M., & Moschen, R. (2001). Quality of life in breast cancer patients - not enough attention for long-term survivors. *Psychosomatics*, 42, 117-123.
- Hosaka, T. (1996). A pilot study of a structured intervention for Japanese women with breast cancer. *Psycho-Oncology*, 5, 59-64.
- House, J. S., Landis, K. R., & Umberson, D. (1988). Social relationships and health. *Science*, 241, 540-544.

- Hughson, A. V., Cooper, A. F., McArdle, C. S., & Smith, D. C. (1987). Psychosocial effects of radiotherapy after mastectomy. *British Medical Journal of Clinical Research Education*, 294(6586), 1515-8.
- Jaccard, J., & Becker, M. A. (1997). Table of random numbers. In J. Jaccard & M. A. Becker (Eds.), *Statistics for the behavioral sciences*. Pacific Grove, CA.: Brooks/Cole Publishing.
- Jacobs, C., Ross, R. D., Walker, I. M., & Stockdale, F. E. (1983). Behavior of cancer patients: A randomized study of the effects of education and peer support groups. *American Journal of Clinical Oncology*, 6(347-50).
- Janoff-Bulman, R. (1989). Assumptive worlds and the stress of traumatic events. *Social Cognition*, 7, 113-116.
- Janoff-Bulman, R. (1992). *Shattered assumptions: Towards a new psychology of trauma*. New York: Free Press.
- Johnson, J. (1982). The effect of a patient education course on persons with a chronic illness. *Cancer Nursing*, 5(2), 117-23.
- Johnson, T. J., Pfenninger, D. T., & Klion, R. E. (2000). Constructing and deconstructing transitive diagnosis in constructions of disorder. In R. A. Neimeyer & J. D. Raskin (Eds.), *Constructions of disorder: Meaning making frameworks for psychotherapy* (pp. 145-174). Washington: American Psychological Association.
- Kaplan, B. H., Cassel, J. C., & Gore, S. (1977). Social support and health. *Medical Care*, 15(5 supplement), 45-57.
- Kelly, G. A. (1955/1991). *The psychology of personal constructs. Vol. 1: A theory of personality. Vol. 2: Clinical diagnosis and psychotherapy*. (2nd ed.). London: Routledge.

- Kelly, G. A. (1963). *A theory of personality: The psychology of personal constructs*. New York: Norton.
- Kelly, G.A. (1965). The strategy of psychological research. *Bulletin of the British Psychological Society*, 18, 1-15.
- Kelly, G. A. (1977). The psychology of the unknown. In D. Bannister (Ed.), *New perspectives in personal construct theory* (pp. 1-19). London: Academic Press.
- Kelly, G. A. (1980). A psychology of the optimal man. In A. W. Landfield & L. M. Leitner (Eds.), *Personal construct psychology: Psychotherapy and personality* (pp. 18-35). New York: Wiley.
- Kelly, G. A. (1986). *A brief introduction to personal construct theory*. London: Centre for Personal Construct Psychology.
- Kenny, V. (1984). An Introduction to the personal construct psychology of George A. Kelly. *Irish Journal of Psychotherapy*, 3(1), 24-32.
- Kissane, D., Clarke, D., Ikin, J., Bloch, S., Smith, G. C., Vitetta, L., & McKenzie, D. P. (1998). Psychological morbidity and quality of life in Australian women with early stage breast cancer: A cross-sectional study. *Medical Journal of Australia*, 169, 192-196.
- Kissane, D. W., Bloch, S., Miach, P., Smith, G. C., Seddon, A., & Keks, N. (1997). Cognitive-existential group therapy for patients with primary breast cancer- techniques and themes. *Psycho-Oncology*, 6(1), 25-33.
- Kitzinger, J. (1994). Focus groups: Method or madness. In M. Boulton (Ed.), *Challenge and Innovation: Methodological Advances in Social Research on HIV/AIDS. Social Aspects of AIDS* (pp. 159-175). Philadelphia: Taylor & Francis.
- Kleinman, A. (1988). *The illness narratives - Suffering, healing and the human condition*. New York: Basic Books.

- Koch, H. (1985). Group psychotherapy. In E. Button (Ed.), *Personal construct theory and health: Theory, research and practice* (pp. 302-326). London: Crook Helm.
- Kricker, A., & Jelfs, P. (1996). *Breast cancer in Australian women 1921-1994*. Canberra: Australian Government Publishing Service.
- Lambert, M. J., & Bergin, A. E. (1994). The effectiveness of psychotherapy. In A. E. Bergin (Ed.), *Handbook of psychotherapy and behavior change*. New York: Wiley.
- Landfield, A. W., & Leitner, L. M. (1980). *Personal construct psychology: Psychotherapy and personality*. New York: Wiley.
- Landfield, A. W., & Rivers, P. C. (1975). An introduction to Interpersonal Transaction and rotating dyads. *Psychotherapy, 12*, 365-373.
- Lane, L. G., & Marlow, B. (1999). Self as verb and the metaphor of dance: An explanation of the self-discovery experience within a constructivist framework. *Asian Journal of Social Psychology, 2*(3), 357-365.
- Lane, L. G., & Viney, L. L. (2000a). The meanings of a breast cancer diagnosis: A model of women's construing. In J. M. Fisher & N. Cornelius (Eds.), *Challenging the Boundaries: PCP Perspectives for the New Millennium* (pp. 121-131). Farnborough: EPCA Publications.
- Lane, L. G., & Viney, L. L. (2000b). *The meanings of a breast cancer diagnosis: The role of others in validating helpful constructions of the cancer experience*. Paper presented at the Ninth Australasian Personal Construct Psychology Conference, Bendigo, Australia [Abstract]. *Australian Journal of Psychology, 53*, S92.

- Lane, L. G., & Viney, L. L. (2000c). The role of others in validating helpful constructions of the breast cancer experience. Paper presented at the 5th World Congress of Psycho-Oncology, Melbourne, Australia [Abstract]. *Psycho-Oncology*, 9(5), S75.
- Lane, L. G., & Viney, L. L. (2001a, 15th-21st July). Role relationships and the restoration of coherence in the stories of women diagnosed with breast cancer: A group intervention. Paper presented at the 14th International Congress of Personal Construct Psychology, Wollongong, Australia [Abstract]. *Australian Journal of Psychology*, 53, S101.
- Lane, L. G., & Viney, L. L. (2001b, 15th-21st July). When the unreal becomes real: An evaluation of the personal construct group psychotherapy with survivors of breast cancer. Paper presented at the 14th International Congress of Personal Construct Psychology, Wollongong, NSW, Australia [Abstract]. *Australian Journal of Psychology*, 53, S102.
- Lane, L. G., & Viney, L. L. (in press). Towards better prevention: Constructions of trust in the sexual relationships of young women. *Journal of Applied Social Psychology*.
- Lazarus, R. S. (1990). Stress, coping and chronic illness. In H. S. Friedman (Ed.), *Personality and disease* (pp. 97- 120). New York: John Wiley.
- Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal and coping*. New York: Springer.
- Lebovits, A. H., & Holland, J. C. (1986). Use of the Gottschalk-Gleser verbal content analysis scales with medically ill patients. In L. A. Gottschalk, F. Lolas, & L. L. Viney (Eds.), *Content analysis of verbal behavior: Significance in clinical medicine and psychiatry* (pp. 133-148). Heidelberg/Berlin: Springer-Verlag.

- Leitner, L. M. (1985). The terrors of cognition: On the experiential validity of personal construct theory. In D. Bannister (Ed.), *Issues and approaches in personal construct theory* (pp. 83-103). London: Academic Press.
- Leitner, L. M., & Dill-Staniford, T. (1993). Resistance in experiential personal construct psychotherapy: Theoretical and technical struggles. In L. M. Leitner & N. G. M. Dunnett (Eds.), *Critical issues in personal construct psychotherapy* (pp. 135-155). Malabar, Florida: Krieger.
- Leitner, L. M., & Faidley, A. (1995). The awful, awful nature of role relationships. In R. A. Neimeyer & G. J. Neimeyer (Eds.), *Advances in personal construct psychology* (Vol. 3, pp. 291-314). Greenwich, CT: JAI Press.
- Leitner, L. M., & Guthrie, A. F. (1992). *The awful, awful nature of ROLE relationships. The Gavin Dunnett Memorial Lecture*. Paper presented at the First European Conference on Personal Construct Psychology, York, England.
- Leitner, L. M., & Guthrie, A. F. (1993). Validation of therapist interventions in psychotherapy: Clarity, ambiguity and subjectivity. *International Journal of Personal Construct Psychology*, 6, 281-294.
- Leszcz, M. (1992). The interpersonal approach to group psychotherapy. *International Journal of Group Psychotherapy*, 42(1), 37-62.
- Levy, S. M., Herberman, R. B., Maluish, A., Schlien, B., & Lippman, M. (1985). Prognostic risk assessment in primary breast cancer by behavioral and immunological parameters. *Health Psychology*, 4, 99-113.
- Levy, S. M., Herberman, R. B., Whiteside, T., Schlien, B., & Lippman, M. (1990). Perceived social support and tumor estrogen/progesterone receptor status as predictors of natural killer cell activity in breast cancer patients. *Psychosomatic Medicine*, 52, 73-85.

- Lewis, F. M., & Hammond, M. A. (1992). Psychosocial adjustment of the family to breast cancer: A longitudinal analysis. *Journal of the American Medical Womens Association, 47*(5), 194-200.
- Lewis, F. M., Hammond, M. A., & Woods, N. F. (1993). The family's functioning with newly diagnosed breast cancer in the mother: The development of an explanatory model. *Journal of Behavioral Medicine, 16*(4), 351-370.
- Liang, L. P., Dunn, S. M., Gorman, A., & Stuart-Harris, R. (1990). Identifying priorities of psychosocial need in cancer patients. *British Journal of Cancer, 62*, 1000-1003.
- Liberman, M. A. (1990). Understanding how groups work: A study of homogeneous peer group failures. *International Journal of Group Psychotherapy, 40*, 31-52.
- Liebert, R. M., & Liebert, L. L. (1995). *Science and Behavior*. Englewood Cliffs, NJ: Prentice Hall.
- Linn, M. W., Linn, B. S., & Harris, R. (1982). Effects of counseling for late stage cancer patients. *Cancer, 49*(5), 1048-55.
- Little, L. M., Jordens, C. F. C., Paul, K., Montgomery, K., & Philipson, B. (1998). Liminality: A major category of the experience of cancer illness. *Social Science and Medicine, 47*(10), 1485-94.
- Llewelyn, S., & Dunnett, G. (1987). The use of personal construct theory in groups. In R. A. Neimeyer & G. J. Neimeyer (Eds.), *Personal construct therapy casebook* (pp. 245-258). New York: Springer.
- Lovenfosse, M., & Viney, L. L. (1999). Understanding and helping mothers of children with 'special needs' using personal construct group work. *Community and Mental Health Journal, 35*(5), 431-442.
- Loveys, B. J., & Klaich, K. (1991). Breast cancer: Demands of illness. *Oncology Nursing Forum, 18*(1), 75-80.

- MacCormack, T., Simonian, J., Lim, J., Remond, L., Roets, D., Dunn, S., & Butow, P. (2001). 'Someone who cares': A qualitative investigation of cancer patients' experiences of psychotherapy. *Psycho-Oncology*, *10*(1), 52-65.
- Maguire, P. (1985). Improving the detection of psychiatric problems in cancer patients. *Social Science and Medicine*, *20*(8), 819-823.
- Mair, M. (1979). The personal venture. In P. Stringer & D. Bannister (Eds.), *Constructs of sociality and individuality* (pp. 35-48). London: Academic Press.
- Margolis, G. J., Goodman, R. L., Rubin, A., & Pajac, T. F. (1989). Psychological factors in the choice of treatment for breast cancer. *Psychosomatics*, *30*(2), 192-197.
- Massie, M. J., & Holland, J. C. (1984). Diagnosis and treatment of depression in the cancer patient. *Journal of Clinical Psychiatry*, *45*, 25-28.
- Mathieson, C. M., & Stam, H. J. (1991). What good is psychotherapy when I am ill? Psychosocial problems and interventions with cancer patients. In C.L.Cooper & M. Watson (Eds.), *Cancer and stress: Psychological, biological and coping studies* (pp. 171-196). Chichester: John Wiley.
- Maunsell, E., Brisson, J., & Deschenes, L. (1989). Psychological distress after initial treatment for breast cancer: A comparison of partial and total mastectomy. *Journal of Clinical Epidemiology*, *42*, 765-771.
- Maunsell, E., Brisson, J., & Deschenes, L. (1992). Psychological distress after initial treatment of breast cancer. Assessment of potential risk factors. *Cancer*, *70*(1), 120-5.
- Mayer, M. (1998). *Advanced breast cancer: A guide to living with metastatic disease*. Cambridge, CA: O'Reilly & Associates.

- McArdle, J. M., Hughson, A. V., & McArdle, C. S. (1990). Reduced psychological morbidity after breast conservation. *British Journal of Surgery*, 77(11), 1221-1223.
- McCoy, M. M. (1977). A reconstruction of emotions. In D. Bannister (Ed.), *New perspectives in personal construct theory* (pp. 93-123). London: Academic Press.
- McDaniel, J. S., Musselman, D. L., Porter, M. R., Reed, D. A., & Nemeroff, C. B. (1995). Depression in patients with cancer. *Archives of General Psychiatry*, 52, 89-99.
- Merton, R. K., Fiske, M., & Kendall, P. L. (1990). *The focused interview: A manual of problems and procedures*. (2nd ed.). New York: Free Press.
- Meyer, T. J., & Mark, M. M. (1995). Effects of psychosocial interventions with adult cancer patients: A meta-analysis of randomised experiments. *Health Psychology*, 14, 101-8.
- Miles, M. B., & Huberman, A. M. (1994). *Qualitative data analysis*. (2nd ed.). Thousand Oaks: Sage.
- Miller, S. D., Duncan, B. L., & Hubble, M. A. (1997). *Escape from Babel: Toward a unifying language for psychotherapy practice*. New York: Norton.
- Moorey, S., & Greer, S. (1989). *Psychological therapy for patients with cancer: A new approach*. Oxford: Heinemann Medical.
- Moorey, S., Greer, S., Watson, M., Baruch, J. D., Mason, A., Rowden, L., Tunmore, R., Law, M., & Bliss, J. M. (1994). Adjuvant psychological therapy for patients with cancer: Outcome at one year. *Psycho-Oncology*, 3, 39-46.
- Mor, V., Malin, M., & Allen, S. (1994). Age differences in the psychosocial problems encountered by breast cancer patients. *Journal of the National Cancer Institute Monographs*, 16, 191-7.

- Morris, T. (1979). Psychological adjustment to mastectomy. *Cancer Treatment Review*, 6, 41-61.
- Mullan, F. (1985). Seasons of survival: Reflections of a physician with cancer. *New England Journal of Medicine*, 313, 270-3.
- Nagy, S., & Viney, L. L. (1994). *Qualitative research methods in constructivist psychology*. Paper presented at the Australian Psychological Association Conference, Wollongong, NSW.
- Neale, A. V., Tilley, B. C., & Vernon, S. W. (1986). Marital status, delay in seeking treatment and survival from breast cancer. *Social Science and Medicine*, 23(3), 305-12.
- Neimeyer, G. J., & Hudson, J. E. (1985). Couple's constructs: Personal systems in marital satisfaction. In D. Bannister (Ed.), *Issues and approaches in personal construct theory* (pp. 127-141). London: Academic Press.
- Neimeyer, R. A. (1984). Toward a personal construct conceptualization of depression and suicide. In F. R. Epting & R. A. Neimeyer (Eds.), *Personal meanings of death: Applications of personal construct theory to clinical practice* (pp. 41-87). Washington: Hemisphere Publishing Corp.
- Neimeyer, R. A. (1985a). Personal constructs in depression: Research and clinical implications. In E. Button (Ed.), *Personal construct theory and mental health: Theory, research and practice* (pp. 82-102). London: Crook Helm.
- Neimeyer, R. A. (1985b). Personal constructs in clinical practice. In P. C. Kendall (Ed.), *Advances in cognitive-behavioral research and therapy* (Vol. 4, pp. 275-339). New York: Academic Press.
- Neimeyer, R. A. (1987). An orientation to personal construct therapy. In R. A. Neimeyer & G. J. Neimeyer (Eds.), *Personal construct therapy casebook* (pp. 3-19). New York: Springer.

- Neimeyer, R. A. (1988). Clinical guidelines for conducting interpersonal transaction groups. *International Journal of Personal Construct Psychology, 1*, 181-190.
- Neimeyer, R. A. (1998). *Lessons of loss: A guide to coping*. New York: McGraw - Hill.
- Neimeyer, R. A. (1999). Narrative strategies in group therapy. *International Journal of Constructivist Psychology, 12*(1), 65-85.
- Neimeyer, R. A., Epting, F. R., & Krieger, S. R. (1983). Personal constructs in thanatology: An introduction and research bibliography. *Death Education, 7*, 87-96.
- Neimeyer, R. A., & Harter, S. (1988). Facilitating individual change in personal construct therapy. In G. Dunnett (Ed.), *Working with people: Clinical uses of personal construct psychology* (pp. 174-185). London: Routledge.
- Neimeyer, R. A., & Neimeyer, G. J. (1983). Structural similarity in the acquaintance process. *Journal of Social and Clinical Psychology, 1*, 146-154.
- Neimeyer, R. A., & Neimeyer, G. J. (1985). Disturbed relationships: A personal construct view. In E. Button (Ed.), *Personal construct theory and health: Theory, research and practice* (pp. 195-223). London: Crook Helm.
- Nelson, J. P. (1996). Struggling to gain meaning: Living with the uncertainty of breast cancer. *Advances in Nursing Science, 18*(3), 59-76.
- Neuling, S. J., & Winefield, H. R. (1988). Social support and recovery after surgery for breast cancer: Frequency and correlates of supportive behaviours by family, friends and surgeon. *Social Science and Medicine, 27*(4), 385-92.
- New South Wales Cancer Council (2002). *Cancer Maps*. Available: www.nswcc.org.au/cncrinfo/research/reports/index.htm [25/2/2002].
- Northouse, L. (1981). Mastectomy patients and the fear of recurrence. *Cancer Nursing, 4*, 213-220.

- Northouse, L. (1990). A longitudinal study of the adjustment of patients and husbands to breast cancer. *Oncology Nursing Forum, Supp to Vol. 17(3)*, 39-45.
- Northouse, L. L. (1988). Social support in patients' and husbands' adjustment to breast cancer. *Nursing Research, 37(2)*, 91-95.
- Northouse, L. L., & Swain, M. A. (1987). Adjustment of patients and husbands to the initial impact of breast cancer. *Nursing Research, 36(4)*, 221-225.
- O'Mahoney, J. C., & Carroll, R. A. (1997). The impact of breast cancer and its treatment on marital functioning. *Journal of Clinical Psychology in Medical Settings, 4(4)*, 397-415.
- Omne-Ponten, M., Holmberg, L., Burns, T., Adami, H. O., & Bergstrom, R. (1992). Determinants of the psycho-social outcome after operation for breast cancer. Results of a prospective comparative interview study following mastectomy and breast conservation. *European Journal of Cancer, 28A(6-7)*, 1062-7.
- Omne-Ponten, M., Holmberg, L., & Sjoden, P. O. (1994). Psychosocial adjustment among women with breast cancer stages I and II; six-year follow up of consecutive patients. *Journal of Clinical Oncology, 12(9)*, 778-82.
- Owen, J. E., Klapow, J. C., Hicken, B., & Tucker, D. C. (2001). Psychosocial interventions for cancer: Review and analysis using a three-tiered outcomes model. *Psycho-Oncology, 10*, 218-230.
- Pallant, J. (2001). *SPSS survival guide*. Sydney: Allen & Unwin.
- Parkes, C. M. (1971). Psychosocial transitions: A field for study. *Social Science and Medicine, 5*, 101-115.
- Parkes, C. M. (1975). What becomes of redundant world models? A contribution to the study of adaptation to change. *British Journal of Medical Psychology, 48*, 131-137.

- Parkes, C. M. (1993). Bereavement as a psychosocial transition: Processes of adaptation to change. In M. S. Stroebe & W. Stroebe (Eds.), *Handbook of bereavement: Theory, research and intervention* (pp. 91-101). New York: Cambridge University Press.
- Parkin, D. M., Pisani, P., & Ferlay, J. (1993). *Estimates of the worldwide incidence of eighteen major cancers in 1985*. Lyon: International Agency for Research on Cancer.
- Parle, M., Jones, B., & Maguire, P. (1996). Maladaptive coping and affective disorders among cancer patients. *Psychological Medicine*, 26(4), 35-744.
- Parle, M., & Maguire, P. (1995). Exploring relationships between cancer, coping, and mental health. *Journal of Psychosocial Oncology*, 13(1-2), 27-50.
- Patton, M. Q. (1990). *Qualitative evaluation and research methods*. Newbury Park: Sage.
- Peters-Golden, H. (1982). Breast cancer: Varied perceptions of social support in the illness experience. *Social Science and Medicine*, 16, 483-491.
- Pettingale, K. W., Morris, T., Green, S., & Haybrittle, J. L. (1985). Mental attitudes to cancer: An additional prognostic factor. *Lancet*, 1, 750.
- Phan, T. T., & Fitzgerald, M. H. (1996). *Guide for the use of focus groups in health research*. (Vol. 1/1). Sydney: Transcultural Mental Health Centre.
- Pierce, D. L., Sewell, K. W., & Cromwell, R. L. (1992). Schizophrenia and depression: Construing and constructing empirical research. In R.A. Neimeyer & G.J. Neimeyer (Eds.), *Advances in personal construct psychology* (Vol. 2, pp. 151-184). Stamford, CT: JAI Press.

- Pierce, G. R. (1994). The Quality of Relationships Inventory: Assessing the interpersonal context of social support. In B. R. Burleson & T. L. Albrecht (Eds.), *Communication of social support: Messages, interactions, relationships, and community* (pp. 247-264). Thousand Oaks, CA: Sage Publications.
- Pisani, P., Parkin, D. M., & Ferlay, J. (1993). Estimates of the worldwide incidence of eighteen major cancers in 1985. Implications for prevention and projections of future burden. *International Journal of Cancer*, 55, 891-903.
- Pistrang, N., & Barker, C. (1992). Disclosure of concerns in breast cancer. *Psycho-Oncology*, 1(3), 183-192.
- Pistrang, N., & Barker, C. (1995). The partner relationship in psychological response to breast cancer. *Social Science and Medicine*, 40(6), 789-97.
- Polinsky, M. L. (1994). Functional status of long-term breast cancer survivors: Demonstrating chronicity. *Health & Social Work*, 19(3), 165-73.
- Postone, N. (1998). Psychotherapy with cancer patients. *American Journal of Psychotherapy*, 52, 412-424.
- Quinn, J. F., & Strelkauskas, A. J. (1993). Psychoimmunologic effects of therapeutic touch on practitioners and recently bereaved recipients: A pilot study. *Advances in Nursing Science*, 15(4), 13-26.
- Quinn, W. H. (1996). The client speaks out: Three domains of meaning. *Journal of Family Psychotherapy*, 7, 71-93.
- Rabins, P. V., Fetting, M. D., Eastham, J., & Fetting, J. (1990). The emotional impact of caring for the chronically ill. *Psychosomatics*, 31(3), 331-336.

- Rainey, L. C. (1984). Death education for oncology professionals: A personal construct perspective. In F. R. Epting & R. A. Neimeyer (Eds.), *Personal meanings of death: Applications of personal construct theory to clinical practice* (pp. 195-210). Washington: Hemisphere.
- Reis, L. A. G., Kosary, C. L., Hankey, B. F., Miller, b. A., Clegg, L., & Edwards, B. K. (1999). *SEER cancer statistics review, 1973-1996*. Bethesda, MD: National Cancer Institute.
- Rigdon, M. A., & Epting, F. R. (1985). Reduction in death threat as a basis for optimal functioning. *Death Studies, 9*, 427-448.
- Rimé, B. (1995). Mental rumination, social sharing and the recovery from emotional exposure. In J. Pennebaker (Ed.), *Emotion, disclosure and health* (pp. 271-291). Washington: American Psychological Association.
- Robson, C. (1993). *Real world research: A resource for social scientists and practitioner-researchers*. Oxford: Blackwell.
- Rosnow, R. L., & Rosenthal, R. (1998). *Beginning behavioral research: A conceptual primer*. (3rd ed.). Upper Saddle River, NJ: Prentice Hall.
- Rowe, D. (1983). *Depression: The way out of the prison*. London: Routledge Paul.
- Rowe, D. (1984). Constructing life and death. In F. R. Epting & R. A. Neimeyer (Eds.), *Personal meanings of death: Applications of personal construct theory to clinical practice* (pp. 11-28). Washington: Hemisphere Publishing Corporation.
- Rowland, J. H. (1998). Breast cancer: Psychosocial aspects. In E. A. Blechman & K. D. Brownell (Eds.), *Behavioral medicine and women: A comprehensive handbook* (pp. 577-587). New York: Guildford Press.

- Rowland, J. H., & Holland, J. C. (1989). Breast cancer. In J. C. Holland & J. H. Rowland (Eds.), *Handbook of psychooncology: Psychological care of the patient with cancer* (pp. 188-207). New York: Oxford University Press.
- Royak-Schaler, R. (1991). Psychological processes in breast cancer: A review of selected research. *Journal of Psychosocial Oncology, 9*, 71-87.
- Rudd, M., Viney, L. L., & Preston, C. (1999). The grief experienced by spousal caregivers of dementia patients: The role of place of care of patient and gender of caregiver. *International Journal of Aging and Human Development, 48*(3), 217-240.
- Saleeba, A. K., Weitzner, M. A., & Meyers, C. A. (1996). Subclinical psychological distress in long-term survivors of breast cancer: A preliminary communication. *Journal of Psychosocial Oncology, 14*(1), 83-93.
- Samarel, N., Fawcett, J., & Tulman, L. (1997). Effect of support groups with coaching on adaptation to early stage breast cancer. *Research in Nursing and Health, 20*(1), 15-26.
- Sanz, J., Avia, M. D., & Sanchez-Bernardos, M. L. (1996). The structure of the construct system in social anxiety: Qualifications due to affective confounding. *Journal of Constructivist Psychology, 9*(3), 201-212.
- Sarason, B. R., Sarason, I. G., & Pierce, G. R. (1990). *Social support: An interactional view*. New York: Wiley.
- Sarason, I. G., Levine, H. M., Bashman, R. B., & Sarason, B. R. (1983). Assessing social support: The Social Support Questionnaire. *Journal of Personality and Social Psychology, 44*, 127-139.
- Schag, C. A., Ganz, P. A., Polinsky, M. L., Fred, C., Hirji, K., & Petersen, L. (1993). Characteristics of women at risk for psychosocial distress in the year after breast cancer. *Journal of Clinical Oncology, 11*, 783-93.

- Schain, W. S., d'Angelo, T. M., Dunn, M. E., Lichter, A. S., & Pierce, L. J. (1994). Mastectomy versus conservative surgery and radiation therapy: Psychological consequences. *Cancer*, 73(4), 1221-8.
- Scheer, J. W. (1996). Introduction. In, J. W. Scheer, & A. Catina (Eds.), *Empirical constructivism in Europe - The personal construct approach* (pp. 13-17). Giessen: Psycholsozial Verlag.
- Scheier, M. F., & Carver, C. S. (1985). Optimism, coping and health: Assessment and implications of generalized outcome expectancies. *Health Psychology*, 4, 219-247.
- Scheier, M. F., & Carver, C. S. (1987). Dispositional optimism and physical well-being: The influence of generalized outcome expectancies on health. *Journal of Personality*, 55(2), 169-210.
- Scheier, M. F., & Carver, C. S. (2001). Adapting to cancer: The importance of hope and purpose. In A. Baum & B. L. Andersen (Eds.), *Psychosocial interventions for cancer* (pp. 15-36). Washington: American Psychological Association.
- Schover, L. R., Yetman, R. J., Tuason, L. J., Meisler, E., Esselstyn, C. B., Hermann, R. E., Grundfest-Broniatowski, S., & Dowden, R. V. (1995). Partial mastectomy and breast reconstruction: A comparison of their effects on psychosocial adjustment, body image, and sexuality. *Cancer*, 75(1), 54-64.
- Shah, J., & Higgins, E. T. (1992). Expectancy x value and effect: Regulatory focus as a determinant of magnitude and direction. *Journal of Personality and Social Psychology*, 73, 447-458.
- Sheard, T., & Maguire, P. (1999). The effect of psychological interventions on anxiety and depression in cancer patients: Results of two meta-analyses. *British Journal of Cancer*, 80(11), 1170-1180.

- Silver, R. C., Wortman, C. B., & Crofton, C. (1990). The role of coping in support provision: The self-presentational dilemma of victims of life crises. In B. S. Sarason, I. G. Sarason, & G. R. Pierce (Eds.), *Social support: An interactional view* (pp. 397-426). New York: Wiley.
- Silverman, D. (2000). *Doing qualitative research: A practical handbook*. London: Sage.
- Singleton, N. (2001). *Psychiatric morbidity among adults, 2000*. London: National Statistics.
- Sneed, N. V., Edlund, B., & Dias, J. K. (1992). Adjustment of gynecological and breast cancer patients to the cancer diagnosis: Comparisons with males and females having other cancer sites. *Health Care for Women International*, 13(1), 11-12.
- Snyder, C. R. (1994a). Hope and optimism. In V. S. Ramachandren (Ed.), *Encyclopedia of human behavior* (Vol. II, pp. 535-42). San Diego: Academic Press.
- Snyder, C. R. (1994b). *The psychology of hope. You can get there from here*. New York: Free Press.
- Snyder, C. R. (1998). A case for hope in pain, loss and suffering. In J. H. Harvey, J. Owarzu, & E. Miller (Eds.), *Perspectives on Loss: A Source Book* (pp. 63-79). Washington: Taylor & Francis.
- Snyder, C. R., Cheavens, J., & Michael, S. T. (1999). Hoping. In C. R. Snyder (Ed.), *Coping: The psychology of what works* (pp. 205-231). New York: Oxford University Press.

- Snyder, C. R., Scott, T. M., & Cheavens, J. (1999). Hope as a psychotherapeutic foundation of common factors, placebos and expectancies. In M. A. Hubble, B. L. Duncan, & S. D. Miller (Eds.), *The heart and soul of change. What works in therapy* (pp. 179-200). Washington: American Psychological Association.
- Sontag, S. (1979). *Illness as metaphor*. London: Allen Lane.
- Spiegel, D. (1990). Facilitating emotional coping during treatment. *Cancer*, 66(Supplement), 1422-1426.
- Spiegel, D. (1993). Psychosocial intervention in cancer. *Journal of the National Cancer Institute*, 85, 1198-1205.
- Spiegel, D. (1995). Commentary. *Journal of Psychosocial Oncology*, 13(1-2), 115-121.
- Spiegel, D., Bloom, J. R., Kraemer, H. C., & Gottheil, E. (1989). Effect of psychosocial treatment on survival of patients with metastatic breast cancer. *Lancet*, 14(Oct.), 888-91.
- Spiegel, D., Bloom, J. R., & Yalom, I. (1981). Group support for patients with metastatic breast cancer: A randomized outcome study. *Archives of General Psychiatry*, 38, 527-33.
- Spiegel, D., & Diamond, S. (2001). Psychosocial interventions in cancer: Group therapy techniques. In A. Baum & B. L. Andersen (Eds.), *Psychosocial interventions for cancer* (pp. 215-33). Washington: American Psychological Association.
- Spiegel, D., Morrow, G. R., Classen, C., Raubertas, R., Stott, P. B., Mudaliar, N., Pierce, H. I., Flynn, P. J., Heard, L., & Riggs, G. (1999). Group psychotherapy for recently diagnosed breast cancer patients: A multicenter feasibility study. *Psycho-Oncology*, 8, 482-493.

- Spiegel, D., Sephton, S. E., Terr, A. I., & Stites, D. P. (1998). Effects of psychosocial treatment in prolonging cancer survival may be mediated by neuroimmune pathways. *Annals of the New York Academy of Sciences*, 840, 674-83.
- Spiegel, D., & Yalom, I. (1978). A support group for dying patients. *International Journal of Group Psychotherapy*, 28, 233-245.
- Spira, J. L. (1997a). Existential group therapy for advanced breast cancer and other life-threatening illnesses. In J. L. Spira (Ed.), *Group therapy for medically ill patients* (pp. 165-222). New York: The Guilford Press.
- Spira, J. L. (1997b). Understanding and developing psychotherapy groups for medically ill patients. In J. L. Spira (Ed.), *Group therapy for medically ill patients* (pp. 3-51). New York: The Guildford press.
- Stanton, A. L., Danoff-Burg, S., Cameron, C. L., Bishop, M., Collins, C. A., Kirk, S. B., Sworowski, L. A., & Twillman, R. (2000). Emotionally expressive coping predicts psychological and physical adjustment to breast cancer. *Journal of Consulting & Clinical Psychology*, 68(5), 875-882.
- Stanton, A. L., & Snider, P. R. (1993). Coping with a breast cancer diagnosis: A prospective study. *Health Psychology*, 12(1), 16-23.
- Steginga, S., Occhipinti, S., Wilson, K., & Dunn, J. (1998). Domains of distress: The experience of breast cancer in Australia. *Oncology Nursing Forum*, 25(6), 1063-70.
- Stevens, J. (1996). *Applied multivariate statistics for the social sciences*. (3rd ed.). Mahway, NJ: Lawrence Erlbaum.
- Stokes, J. P. (1985). The relation of social network and individual difference variables to loneliness. *Journal of Personality and Social Psychology*, 48(981-990).
- Straker, N. (1998). Psychodynamic psychotherapy for cancer patients. *Journal of Psychotherapy Practice and Research*, 7(1), 1-9.

- Stringer, P. (1979). Individuals, roles and persons. In P. Stringer & D. Bannister (Eds.), *Constructs of sociality and individuality* (pp. 91-112). London: Academic Press.
- Supramaniam, R., Smith, D., Coates, M., Hayes, L., & Armstrong, B. (1998). *Breast cancer survival in NSW in 1973-1995*. Sydney: Cancer Council of New South Wales, Cancer Research and Registers Division.
- Tabachnick, B. G., & Fidell, L. S. (1996). *Using multivariate statistics*. (3rd ed.). New York: Harper Collins.
- Taylor, J. D. (2000). Confronting breast cancer: Hopes for health. In C. R. Snyder (Ed.), *Handbook of hope: Theory, measures and applications* (pp. 355-372). San Diego: Academic Press.
- Taylor, S. E. (1983). Adjustment to threatening events: A theory of cognitive adaptation. *American Psychologist*, *38*, 1161-1173.
- Taylor, S. E., Falke, R. L., Shoptaw, S. J., & Lichtman, R. R. (1986). Social support, support groups and the cancer patient. *Journal of Consulting and Clinical Psychology*, *54*(5), 608-615.
- Tedeschi, R. G., Park, C. L., & Calhoun, L. G. (1998). Posttraumatic growth: Conceptual issues. In R. G. Tedeschi, C. L. Park, L. Crystal (Eds.), *Posttraumatic growth: Positive changes in the aftermath of crisis* (pp. 1-22). Mahwah, NJ: Lawrence Erlbaum Associates.
- Telch, C. F., & Telch, M. J. (1986). Group coping skills instruction and supportive group therapy for cancer patients: A comparison of strategies. *Journal of Consulting and Clinical Psychology*, *54*, 802-8.
- Tjemsland, L., Soreide, J. A., & Malt, U. F. (1996a). Traumatic distress symptoms in early breast cancer I: Acute response to diagnosis. *Psycho-Oncology*, *5*(1), 1-8.

- Tjemslund, L., Soreide, J. A., & Malt, U. F. (1996b). Traumatic distress symptoms in early breast cancer. II: Outcome six weeks postsurgery. *Psycho-Oncology*, 5(4), 295-303.
- Toombs, S. K. (1992). *The meaning of illness: A phenomenological account of the different perspectives of physician and patient*. Dordrecht: Kluwer Academic Publishers.
- Tross, S., & Holland, J. C. (1989). Psychological sequelae in cancer survivors. In J. C. Holland & J. H. Rowland (Eds.), *Handbook of psychooncology: Psychological care of the patient with cancer* (pp. 101-116). New York: Oxford University Press.
- Turner, J., Wooding, S., & Neil, C. (1998). *Psychosocial impact of breast cancer: a summary of the literature 1986 - 1996*. Sydney: NHMRC National Breast Cancer Centre.
- U.S. Department of Health & Human Services. (1999). *Mental Health: A report of the Surgeon General: Executive summary*. Rockville, MD: Department of Health & Human Services, Substance Abuse & Mental Health Services Administration, Center for Mental Health Services, National Institute of Health, National Institute of Mental Health.
- Vaux, A., & Harrison, D. (1985). Support network characteristics associated with support satisfaction and perceived support. *American Journal of Community Psychology*, 13, 245-267.
- Vickberg, S. M., Bovbjerg, D. H., DuHamel, K. N., Currie, V., & Redd, W. H. (2000). Intrusive thoughts and psychological distress among breast cancer survivors: Global meaning as a possible protective factor. *Behavioral Medicine*, 25(4), 152-60.
- Viney, L. L. (1980). *Transitions*. Sydney: Cassell.

- Viney, L. L. (1981). Content analysis: A research tool for community psychologists. *American Journal of Community Psychology*, 9, 269-281.
- Viney, L. L. (1983a). Assessment of psychological states through content analysis of verbal communications. *Psychological Bulletin*, 94(542-563).
- Viney, L. L. (1983b). *Images of Illness*. Malabar, Florida: Krieger Publishing.
- Viney, L. L. (1985). Physical illness: A guidebook for the kingdom of the sick. In E. Button (Ed.), *Personal construct theory and mental health: Theory, research and practice* (pp. 262 - 273). London: Croom Helm.
- Viney, L. L. (1987). *Interpreting the interpreters: Strategies for a science of construing people*. Malabar, Florida: Krieger.
- Viney, L. L. (1988a). A PCP analysis of data collection in the social sciences. In F. Fransella & T. Laurie (Eds.), *Experimenting with personal construct psychology* (pp. 369-380). New York: Routledge & Kegan Paul.
- Viney, L. L. (1988b). Which data-collection methods are appropriate for a constructivist psychology? *International Journal of Personal Construct Psychology*, 1, 191-203.
- Viney, L. L. (1990). A constructivist model of psychological reactions to illness and injury. In G. J. Neimeyer & R. A. Neimeyer (Eds.), *Advances in personal construct psychology* (pp. 117-151). New York: JAI Press.
- Viney, L. L. (1990a). The construing widow: Dislocation and adaptation in bereavement. *Psychotherapy Patient*, 3, 207-222.
- Viney, L. L. (1990b). Psychotherapy as shared reconstruction. *International Journal of Personal Construct Psychology*, 3(4), 437-456.
- Viney, L. L. (1996). *Personal construct therapy: A handbook*. Norwood, New Jersey: Ablex Publishing.

- Viney, L. (1998). Should we use personal construct therapy? A paradigm for outcomes evaluation. *Psychotherapy*, 35(3), 366-380.
- Viney, L. L. (2001) Applying personal construct models to work with people. Keynote Address for the 14th International Personal Construct Psychology Congress, Wollongong, NSW, July, 2001 [Abstract]. *Australian Journal of Psychology*, 53, 107.
- Viney, L. L., Benjamin, Y. N., Clarke, A., & Bunn, T. (1985). Sex differences in the psychological reactions of medical and surgical patients to crisis intervention counseling: Sauce for the goose may not be sauce for the gander. *Social Science & Medicine*, 20(11), 1199-1205.
- Viney, L. L., Benjamin, Y. N., & Preston, C. A. (1988a). Promoting independence in the elderly: The role of psychological, social and physical constraints. *Clinical Gerontologist*, 8(2), 3-17.
- Viney, L. L., Benjamin, Y. N., & Preston, C.A. (1988b). Constructivist family therapy with the elderly. *Journal of Family Psychology*, 2(2), 241-258.
- Viney, L. L., Benjamin, Y. N., & Preston, C. A. (1989a). An evaluation of personal construct therapy for the elderly. *British Journal of Medical Psychology*, 62, 35-41.
- Viney, L. L., Benjamin, Y. N., & Preston, C. A. (1989b). Mourning and reminiscence: Parallel psychotherapeutic processes for elderly people. *International Journal of Aging & Human Development*, Vol 28(4), 239-249.
- Viney, L. L., Benjamin, Y. N., & Preston, C. A. (1990). Personal construct therapy for the elderly. *Journal of Cognitive Psychotherapy*, 4(2), 211-224.
- Viney, L., & Bousfield, L. (1992). AIDS and the client "in the fast lane": Narrative construction and reconstruction. *Psychotherapy Patient*, 8, 141-156.

- Viney, L. L., & Caputi, P. (2001, 15th - 21st July). *Computer-supported content analysis scales: Their use in psychotherapy research*. Paper presented at the 14th International Congress of Personal Construct Psychology, Wollongong, Australia.
- Viney, L. L., Caputi, P., & Webster, D. (2000). Computerised content analysis scales: Their use in personal construct research. In J. Ellis-Scheer (Ed.), *Proceedings of the ninth Australasian personal construct psychology conference*. Bendigo, Australia.
- Viney, L. L., Clarke, A., Bunn, T., & Benjamin, Y. N. (1985). The effect of a hospital-based counseling service on the physical recovery of surgical and medical patients. *General Hospital Psychiatry*, 7(4), 294-301.
- Viney, L. L., Clarke, A. M., Bunn, T. A., & Benjamin, Y. N. (1986). Crisis-intervention counseling: An evaluation of long-and short-term effects. *Journal of Counseling Psychology*, 32(1), 29-39.
- Viney, L. L., Henry, R., Walker, B., & Crooks, L. (1991). The psychosocial impact of multiple deaths from AIDS. *Omega*, 24(2), 151-163.
- Viney, L. L., Henry, R., Walker, B. M., & Crooks, L. (1989). The emotional reactions of HIV antibody positive men. *British Journal of Medical Psychology*, 62(2), 153-161.
- Viney, L. L., & Henry, R. M. (in press). Evaluating personal construct and psychodynamic group work with adolescent offenders and non-offenders. In G. J. Neimeyer & R. A. Neimeyer (Eds.), *Advances in personal construct psychology* (Vol. 4). New York: JAI Press.
- Viney, L. L., Henry, R. M., & Campbell, J. (2001). The impact of group work on offender adolescents. *Journal of Counseling & Development*, 79(3), 373-378.

- Viney, L. L., & Manton, M. (1973). Sampling verbal behavior in Australia: The Gottschalk-Gleser Content Analysis Scales. *Australian Journal of Psychology*, 25, 45-55.
- Viney, L. L., Truneckova, D., Weekes, P., & Oades, L. (1999). Personal construct group work with adolescent offenders: Dealing with their problematic meanings. *Journal of Child and Adolescent Group Therapy*, 9(4), 169-185.
- Viney, L. L., Walker, B. M., Lilley, B., & Tooth, B. (1993). The quality of life of palliative care staff: A personal construct approach. *Omega*, 28(3), 201-217.
- Viney, L. L., Walker, B. M., Roberts, T., Lilley, B., & Ewan, C. (1994). Dying in palliative care units and in hospital: A comparison of the quality of life of terminal cancer patients. *Journal of Consulting and Clinical Psychology*, 40, 157-165.
- Viney, L. L., & Westbrook, M. T. (1981). Measuring patients' experienced quality of life. The application of content analysis scales in health care. *Community Health Studies*, 5, 43-52.
- Viney, L. L., & Westbrook, M. T. (1982a). Patterns of anxiety in the chronically ill. *British Journal of Medical Psychology*, 55, 87-95.
- Viney, L. L., & Westbrook, M. T. (1982b). Patients' psychological reactions to chronic illness: Do they predict rehabilitation. *Journal of Applied Rehabilitation Counseling*, 13, 38-44.
- Viney, L. L., & Westbrook, M. T. (1986). Psychological states in patients with diabetes mellitus. In L. A. Gottschalk, F. Lolas, & L. L. Viney (Eds.), *Content analysis of verbal behavior. Significance in clinical medicine and psychiatry* (pp. 157-170). Heidelberg: Springer-Verlag.

- Vinokur, A. D., Threatt, B. A., Caplan, R. D., & Zimmerman, W. A. (1989). Physical and psychosocial functioning and adjustment to breast cancer. Long-term follow up of a screening population. *Cancer*, 63(2), 394-405.
- Vroom, H. (1964). *Work and motivation*. New York: Wiley.
- Walker, B. M. (1990). Construing George Kelly's construing of the person-in-relation. *International Journal of Personal Construct Psychology*, 3, 41-50.
- Walker, B. M. (1996). A psychology for adventurers: An introduction to personal construct psychology from a social perspective. In D. Kalekin-Fishman & B. M. Walker (Eds.), *The construction of group realities: Culture, society, and personal construct theory* (pp. 7-26). Malabar, Florida: Krieger.
- Ward, S. E., Viergutz, G., Tormey, D., deMuth, J., & Paulen, A. (1992). Patients' reactions to completion of adjuvant breast cancer therapy. *Nursing Research*, 41(6), 362-6.
- Watson, M., Fenlon, D., McVey, G., & Fernandez-Marcos, M. (1996). A support group for breast cancer patients: Development of a cognitive-behavioural approach. *Behavioural & Cognitive Psychotherapy*, 24(1), 73-81.
- Watson, M., Greer, S., Inayat, Q., Burgess, C., & Robertson, B. (1988). Development of a questionnaire measure of adjustment to cancer. The MAC scale. *Psychological Medicine*, 18, 203-209.
- Watson, M., Greer, S., Rowden, L., Gorman, C., Robertson, B., Bliss, J. M., & Tunmore, R. (1991). Relationships between emotional control, adjustment to cancer and depression and anxiety in breast cancer patients. *Psychological Medicine*, 21(1), 51-7.
- Waxler-Morrison, N., Hislop, T. G., Mears, B., & Kan, L. (1991). Effects of social relationships on survival for women with breast cancer: A prospective study. *Social Science and Medicine*, 33(2), 177-183.

- Weekes, P. (1998). *Giving birth to and parenting children with developmental disabilities: An application of personal construct psychology*. Unpublished doctoral dissertation, University of Wollongong.
- Weihs, K., & Reiss, D. (1996). Family reorganization in response to cancer: A developmental perspective. In L. Baider, C. L. Cooper, & A. K. De-Nour (Eds.), *Cancer and the family* (pp. 3-30). Chichester: Wiley.
- Weisman, A. D., & Worden, J. W. (1976). The existential plight in cancer: Significance of the first 100 days. *International Journal of Psychiatry in Medicine*, 7(1), 1-15.
- Weitzman, E. R., Zapka, J., Estabrook, B., & Valentine Goins, K. (2001). Risk and reluctance: Understanding impediments in colorectal cancer screening. *Preventive Medicine*, 32(6), 502-513.
- Welch-McCaffrey, D., Hoffman, B., Leigh, S. A., Loescher, L., & Meyskens, F. L. J. (1989). Surviving adult cancers II: Psychosocial implications. *Annals of Internal Medicine*, 111, 517-24.
- Westbrook, M. T., & Viney, L. L. (1982). Psychological reactions to the onset of chronic illness. *Social Science and Medicine*, 16, 899-965.
- Wilkinson, S. (1998). Focus groups in health research: Exploring the meanings of health and illness. *Journal of Health Psychology*, 3(3), 329-348.
- Wilkinson, S. (2000). Women with breast cancer talking causes: Comparing content, biographical and discursive analyses. *Feminism & Psychology*, 10(4), 431-460.
- Winter, D. A. (1992). *Personal construct psychology in clinical practice: Theory, practice and application*. London: Routledge.

- Winter, D. A. (1997). Personal construct theory perspectives on group psychotherapy. In P. Denicola & M. Pope (Eds.), *Sharing Understanding and Practice* (pp. 210-221). Farnborough: EPCA Publications.
- Wolfe, T. M., Elston, R. C., & Kissling, G. E. (1989). Relationship of hassles, uplifts and life events to psychological well-being of freshman medical students. *Behavioral Medicine, Spring*, 37-45.
- Woods, M., Tobin, M., & Mortimer, P. (1995). The psychosocial morbidity of breast cancer patients with lymphoedema. *Cancer Nursing, 18*(6), 467-71.
- Worden, J. W., & Weisman, A. D. (1984). Preventive psychosocial intervention with newly diagnosed cancer patients. *General Hospital Psychiatry, 6*, 243-9.
- World Health Organization. (2001). *Women and mental health*. Geneva: WHO.
- Wortman, C., & Dunkel-Schetter, C. (1979). Interpersonal relationships and cancer. *Journal of Social Issues, 35*, 120-129.
- Wyatt, G., Kurtz, M. E., & Liken, M. (1993). Breast cancer survivors: An exploration of quality of life issues. *Cancer Nursing, 16*(6), 440-48.
- Wyatt, G. K. H., & Friedman, L. L. (1996). Development and testing of a quality of life model for long-term female cancer survivors. *Quality of Life Research, 5*(3), 387-394.
- Yalom, I. D. (1975/1995). *The theory and practice of group psychotherapy*. (2nd/4th eds.). New York: Basic Books.
- Yalom, I. D. (1980). *Existential psychotherapy*. New York: Basic Books.
- Yalom, V. J., & Yalom, I. (1990). Brief interactive group psychotherapy. *Psychiatric Annals, 20*(7), 362-367.
- Yin, R. K. (1993). *Applications of case study research*. Thousand Oak: Sage.
- Yin, R. K. (1994). *Case study research: Design and methods*. (2nd ed.). Thousand Oak: Sage.

- Zabora, J., Brintzenhofeszoc, K., Curbow, B., Hooker, C., & Piantadosi, S. (2001). The prevalence of psychological distress by cancer site. *Psycho-Oncology, 10*, 19-28.
- Zampini, K., & Ostroff, J. S. (1993). The post-treatment resource program: portrait of a program for cancer survivors. *Psycho-Oncology, 2*(1-19).
- Zeidner, M., & Endler, N. S. (1996). *Handbook of coping: Theory, research, applications*. New York: Wiley.
- Zemore, R., & Shepel, L. F. (1989). Effects of breast cancer and mastectomy on emotional support and adjustment. *Social Science and Medicine, 28*(1), 19-27.
- Zigmond, A. S., & Snaith, R. P. (1983). The Hospital Anxiety and Depression Scale. *Acta Psychiatrica Scandinavica, 67*, 361-370.

APPENDIX A

**A SUMMARY OF THE LITERATURE REVIEWED IN CHAPTER 2
ON PSYCHOLOGICAL REACTIONS TO
A BREAST CANCER DIAGNOSIS**

Study	Participants	Time since diagnosis	Result
Bloom & Kessler (1994)	948 (70% Breast Cancer)	Within 3 months of surgery then every three months for 1 year.	Findings suggest factors that contribute to poor overall adjustment include being younger, being divorced, being widowed, having children under the age of 21 years and experiencing treatment side-effects.
Campora et al. (1992)	137 (100% Breast Cancer) 74% primary cancer 26% metastatic disease	During chemotherapy then 3 and 8 months later	Severe anxiety was reported in 19 to 28% of patients and severe depression was infrequent (3.9%). This study compared women undergoing chemotherapy for primary breast cancer and those undergoing chemotherapy for metastatic disease and found no difference in levels of anxiety between groups.
Cassileth et al. (1986)	68 (100% Breast Cancer)	Post surgery then at 3, 6 and 12 months	Anxiety levels were lower than those described for a psychiatric outpatient population but higher than those for non-patient populations.
Dean (1987)	122 (100% Breast Cancer)	Pre-surgery then 3 and 12 months post-surgery	Twenty-six percent of women had psychiatric symptoms 12 months after their operation, but most of the illnesses were mild.
Fallowfield et al. (1986)	101 (100% Breast Cancer) 47% lumpectomy 53% mastectomy	Various. Mean for Lumpectomy = 15.2 months Mean for mastectomy = 16.7 months	The incidence of anxiety states or depressive illness, or both, among women who underwent mastectomy was high (33%). Slightly more women who underwent a lumpectomy followed by radiotherapy had affective disorders, 38% having an anxiety state, depressive illness, or both.
Fallowfield et al. (1990)	269 (100% Breast Cancer)	Pre-surgery then 2 weeks, 3 months and 12 months post-surgery	The incidences of anxiety, depression, and sexual dysfunction were high. There were no significant differences in the incidences of anxiety and depression between women who underwent mastectomy and those who underwent lumpectomy.

Study	Population	Time since diagnosis	Findings
Gottschalk & Hoigaard-Martin (1986)	329 (36% breast cancer, 19% benign breast disease, 21% cholecystectomy, 24% non-surgical healthy control)	1 to 3 months post surgery and 10-12 months post surgery	The mastectomy group had significantly higher mean Gottschalk-Gleser scores for total anxiety, death and mutilation anxiety. Significant reductions were found in mean total anxiety, mutilation, and shame anxiety in the mastectomy group between the two assessments.
Hall et al. (1999)	269 (100% breast cancer)	Interview conducted during first three months following diagnosis with 266 participants	The majority of women who experienced anxiety and/or depression did so within 3 months of their initial surgery. The clinical interview identified anxiety disorder in 132 of 266 women (49.6%) and depressive illness in 99/266 (37.2%) during the first 3 months.
Hughson et al. (1987)	85 (100% breast cancer) 55% surgery plus radiotherapy 45% surgery only	One month post-surgery, then 5 and 11 months later	Approximately one third of all patients experienced depression or anxiety. One month after operation, before radiotherapy, there were no significant differences between the two groups in any of the measures of psychosocial distress. After one year approximately a quarter of all participants showed evidence of clinical depression.
Kissane et al. (1998)	303 (100% breast cancer)	3 months after diagnosis and treatment	45% of the women in this study had a psychiatric disorder; 42% of these had depression or anxiety, or both; 27.1% were experiencing minor depression; 8.6% were experiencing an anxiety disorder; 9.6% were experiencing a major depressive disorder; and 20% of the women interviewed had more than one disorder.

Study	Population	Time since diagnosis	Findings
Lewis & Hammond (1992)	111 (100% breast cancer)	Time since diagnosis various: Mean 27.4 months	Results revealed that, over time, the families experienced significantly lower levels of illness-related demands and the marriages became better adjusted. Levels of depressive mood in the women, however, remained stable. This mood negatively affected the quality of the marriage, which, in turn, caused the family to cope less frequently with its problems and to function less well.
Lewis et al. (1993)	40 (100% breast cancer)	Time since surgery various: Median 13 months	Data obtained from both the mothers with cancer and their partners revealed a similar pattern. More frequently experienced illness demands were associated with higher levels of parental depressed mood, which negatively affected the marriage. When the marriage was less well adjusted, it negatively affected the family's coping behavior.
Loveys & Klaich (1991)	79 (100% breast cancer)	Various Up to 2.5 years	Illness demands are experienced in every aspect of women's lives, including their identity, daily routines, family and social experiences, and their perceptions of the past, present, and future.
Margolis et al. (1990)	54 (100% breast cancer)	Average time since diagnosis 43 weeks.	Women who had had a mastectomy felt less attractive, less sexually desirable, and more ashamed of their breasts. They also experienced less enjoyment in their sexual relationships than they had before treatment. For these reasons, half of the mastectomy patients regretted not having chosen the breast-conserving alternative.

Study	Population	Times since diagnosis	Findings
Maunsell et al. (1989)	At Time 1 - 227 (100% breast cancer) 65% partial mastectomy 35% total mastectomy	3 months following diagnosis and approximately 15 months later	At 3 months, 38.8% of partial mastectomy participants had high distress scores compared to 25.8% of women treated by total mastectomy. Fifteen months later, percentages with high scores were identical, 35.1%, in the two treatment groups. Age appeared to modify the surgery-distress relation. The results suggest that partial mastectomy does not protect against psychological distress after breast cancer.
Maunsell et al. (1992)	205 (100% breast cancer)	Time from surgery: 3 months and 18 months	Evidence of poor psychological adjustment was present in 63.1% of women with a history of depression, compared with 14.3% of those with no such history.
McCardle et al. (1990)	119 (100% breast cancer) 56% lumpectomy, 44% mastectomy	Time since surgery 6, 9 and 12 months	There was a significant excess of severe depression in the mastectomy group. In contrast to the findings of previous research, this result suggests breast conservation reduces psychological morbidity.
Neuling & Winefield (1988)	58 (100% breast cancer)	Approx. 1 week post-surgery, then 1 month and 3 months	Satisfaction with social support was matched with measures of adjustment, and it was found that those satisfied with support from family members were significantly less anxious and depressed in hospital than were those who were not satisfied with support from this source.
Northouse & Swain (1987)	50 (100% breast cancer) and their partners	3 days after surgery, then 30 days later	Women reported more role adjustment problems than their husbands. Both the women and their partners reported levels of overall distress significantly above the level reported for the normal population. Medical and demographic factors had little relationship to participant's levels of adjustments across time.

Study	Population	Time since diagnosis	Findings
Omne-Ponten et al. (1992)	99 (100% breast cancer) 63% mastectomy, 37% lumpectomy.	4 months post-surgery then 13 months	Living with a spouse seems to protect women from developing psychosocial problems postoperatively. Women who were gainfully employed or who were given radiotherapy had a higher risk of poor adjustment after 4 months.
Pistrang & Barker (1992)	77 (100% breast cancer)	Between 10 and 50 weeks post surgery	Participants were most concerned about the uncertainty of recurrence of cancer and the effect of their illness on people close to them. Communication with partners was more problematic than communication with relatives and friends, with the largest difference in perceived empathy, indicating that women felt less understood by their partners.
Pistrang & Barker (1995)	113 (100% breast cancer)	Diagnosed within previous year	Satisfaction with the partner helping relationship was associated with psychological well-being. Though most women had a good helping relationship with another person, this did not compensate for a problematic helping relationship with their partner. Good communication with partners was characterized by high empathy and low withdrawal. Findings suggest partners play an important role in adaptation.
Schag et al. (1993)	227 (100% breast cancer)	1 month and 12 months post primary treatment	Women identified as 'at risk of' at Time 1 had significantly more problems with greater severity than the low-risk women in all areas (physical, psychosocial, medical interaction, sexual, and marital). The at-risk group had significantly more problems 1 year later. Problems at the local surgical site, psychological distress, communication with marital partners, and negative body image were more persistent in the at-risk group 1 year later.

Study	Population	Time since diagnosis	Findings
Schain et al. (1994)	142 (100% breast cancer) 44% mastectomy 56% lumpectomy	At diagnosis then 6, 12 and 24 months	At 6 months, mastectomy group reported significantly less control over events in their lives and more problems with sexual relations than did their conservatively treated counterparts. Breast conservation therapy protects women's perception of their body but does not, over time, contribute to a more positive sexual adjustment.
Steginga et al. (1998)	245 (100% breast cancer)	Less than 16 weeks post surgery	Fear of recurrence, decisional uncertainty, and issues concerning informational support, self-image and social relationships, sexuality and the physical effects of treatments were reported by women with breast cancer after surgery.
Ward et al. (1992)	38 (100% breast cancer)	At the start of chemotherapy, one week after, and at completion of radiotherapy	Approximately 30% of the women reported the termination of treatment was upsetting. For the group as a whole, depression scores decreased significantly from the first to the last measurement. Those who were most upset by termination of treatment had been more depressed since the onset of treatment.

APPENDIX B

**A SUMMARY OF THE REVIEW OF OUTCOME STUDIES
FOR PEOPLE WITH CANCER,
COMMENCING WITH WOMEN WITH BREAST CANCER**

Study and form	Approach and design	Participants	Time since diagnosis	Findings
Antoni et al., (2001) Group	1. CBT 2. Control	N = 100 100% breast cancer	Newly treated	The intervention reduced moderate depression (which remained relatively stable in the control condition) but did not affect other measures of emotional distress. The therapy also increased participants' reports that having breast cancer had made positive contributions to their lives, and it increased generalized optimism. Both remained significantly elevated at a 3-month follow-up of the therapy. The therapy had its greatest impact on these two variables among women who were lowest in optimism at baseline.
Bultz et al. (2000) Group	1. Educational for partners only 2. Control partners	N = 36 100% breast cancer partners	Diagnosed in previous 12 months	Three months after the intervention, partners had less emotional disturbance than did controls. Women whose partners received the therapy also reported less emotional disturbance and greater marital satisfaction.
Edelman & Kidman (1999) Group	1. CBT 2. Supportive	N = 60 100% breast cancer	Newly diagnosed	After therapy, participants in both groups showed significant reductions in depression, and improved quality of life relative to their baseline scores. Participants in the CBT group also showed significant improvements in quality of life and self-esteem compared with those in the supportive therapy group. These differences were no longer apparent at the 4-month follow-up.

Study and form	Approach and design	Participants	Time since diagnosis	Findings
Helgeson et al. (1999) Group	1. Education 2. Peer discussion 3. Education and peer discussion 4. Control	N = 312 100% breast cancer	Newly diagnosed	Education based groups showed benefits for women with early-stage breast cancer and these effects were maintained for 6 months. Benefits noted were increased physical functioning, enhanced self-esteem, positive body image and reduction in intrusive thoughts. There was no evidence of benefits from peer discussion group interventions.
Helgeson et al. (2000) Group	1. Education 2. Peer discussion	N = 230 100% breast cancer	Newly diagnosed	Increased physical functioning in the educational groups sample was greatest in women who lacked support from partners/physicians. Peer discussion groups were also helpful for women who lacked support from their partners/ physicians but harmful for women who had high levels of support.
Hosaka et al. (1996) Group v individual	Eclectic group or individual (CBT/ Educational/ Supportive)	N = 20 100% breast cancer Japanese sample	Unspecified	Both individual and group therapies were effective in improving levels of anxiety and depression but were less effective for changing coping styles. Participants receiving individual intervention were also interested in the group sessions because they wanted to share their knowledge of breast cancer. On the other hand, the participants assigned to the group intervention were hesitant to talk to each other in the earlier sessions.
Kissane et al. (1997) Group	1. 6 month cognitive-existential intervention 2. Control	N= 280 100% breast cancer	Post surgery and undergoing adjuvant therapies	At the end of the intervention, the intervention sample reported less anxiety and depression than the control sample.

Study and form	Approach and design	Participants	Time since diagnosis	Findings
Samarel et al. (1992; 1993) Group	1. Eclectic (CBT and supportive) 2. Supportive	N = 77 100% breast cancer and partners	Newly diagnosed	Pilot study. At two months a trend towards decreased symptom of distress in the support group with coaching was noted.
Samarel et al. (1997) Group	1. Eclectic (CBT and supportive) 2. Supportive	N = 181 100% breast cancer	Newly diagnosed	Participation in supportive group with coaching resulted in higher quality of relationship with significant other at therapy conclusion; however, this effect was not sustained 8 wks later. Participation had no effect on symptom distress, emotional distress, or functional status.
Spiegel et al. (1981) Group	1. Supportive-expressive 2. Control	N = 86 100% breast cancer	Advanced breast cancer	The women in the treatment sample had significantly lower mood disturbance scores, had fewer maladaptive coping responses, and were less phobic than the control group at the end of the intervention.
Spiegel et al. (1989) Group	As above	As above	As above	Both the treatment (n = 50) and control groups (n = 36) had routine oncological care. At 10-year follow-up, only 3 of the patients were alive, and death records were obtained for the other 83. Survival from time of randomisation and onset of therapy was a mean 36.6 (SD 37.6) months in the therapy group compared with 18.9 (10.8) months in the control group, a significant difference.
Spiegel et al. (1999) Group	1. Supportive-expressive	N = 111 100% breast cancer	Early breast cancer within 1 year of diagnosis	Results indicated a significant 40% decrease in mood disturbance scores, anxiety and depression. Similarly the impact of the cancer diagnosis was significantly reduced. Outcome was independent of stage of disease (I vs. II).

Study and form	Approach and design	Participants	Time since diagnosis	Findings
Watson et al. (1996) Group	CBT	N = 14 100% breast cancer	Mixed	Pilot Study. Described the application of a cognitive behavioural model, and tested its efficacy and applicability for breast cancer women in a group context. No significant improvement noted at completion of therapy.
Berglund et al. (1994) Group	1. Information on diagnosis and treatment 2. Control	N = 199 80% breast cancer	Unspecified	At three months, the participants in the group intervention improved significantly in fighting spirit, body image, illness-related knowledge and physical strength compared to the control sample.
Greer et al. (1992) Moorey et al. (1994) Individual	1. CBT 2. Control	N = 174 53% breast cancer	4 - 12 weeks after diagnosis	At 4 months - therapy group had significantly lower scores than controls on psychological distress measures. At 1 year - therapy group continued to report less distress.
Edgar et al., 1992 Individual	CBT	N = 205 48% breast cancer	1- newly diagnosed 2- approx. 4 months post diagnosis	Examining the effect of timing of the therapy, no significant differences between the groups except at 8 months when Group 2 were significantly less depressed, and felt more in control, maintained at 12 months. Emotional coping of participants with breast cancer improved for both groups over time.
Telch & Telch (1986) Group	1. CBT + coping skills training 2. Supportive	N = 41 36% breast cancer	Mixed	Results demonstrate a consistent superiority of the coping skills therapy over supportive group therapy and a no-treatment control. Participants receiving supportive group therapy exhibited little improvement, and untreated participants evidenced a significant deterioration in psychological adjustment.

Study and form	Approach and design	Participants	Time since diagnosis	Findings
Heinrich & Schag (1985) Group	1. CBT 2. Control	N = 51 27% breast cancer and their spouses	Approx. 2 years	Results indicate some support for beneficial effects of the treatment therapy, on adjustment, physical functioning and knowledge about the disease, but there was also support for improved psychosocial adjustment by all participants with the passage of time.
Bindemann et al. (1991) Individual	1. Relaxation training 2. Control	N = 80 20% breast cancer	Unspecified	At three months controls reported significantly higher anxiety and depression scores than the treatment group.
Worden & Weisman (1984) Individual	1. Individual counselling 2. Individual skills training 3. Control	N = 117 Approx 20% breast cancer	Newly diagnosed	No differences between groups. Both therapies significantly lowered levels of emotional distress and increased levels of problem resolution compared to controls.
Cain et al. (1986) Group v individual	1. Individual Information and CBT 2. As above in group format 3. Control	N = 80 100% women with gynecological cancer	Newly diagnosed	At six months the women who participated in thematic counselling, both group and individual, were significantly less depressed and less anxious and had more knowledge of their illness, better relationships with care givers, fewer sexual difficulties, and more participation in leisure activities than controls.

Study and form	Approach and design	Participants	Time since diagnosis	Findings
Feric et al. (1979) Group	1. Eclectic Educational/ Supportive 2. Control	N = 60 Unspecified 50% female	Newly diagnosed advanced cancer	Group counselling resulted in a significant improvement in participants' self-concept compared with the control group. Group participants also showed improvement in hospital adjustment, knowledge about cancer and perceptions of death compared to controls.
Forester et al. (1985)	1. Supportive 2. No-treatment control	N = 100 Mixed 50% female	Mixed	A significant reduction was found in both emotional and physical manifestations of distress in the patients receiving psychotherapy compared with the control group. This was true regardless of gender, or knowledge of diagnosis.
Individual Jacobs et al. (1983)	1. Education 2. Peer support 3. Control	N = 81 Hodgkin's Disease Approx. 1/3d female	Receiving or within 2 years of chemotherapy	Following education, participants experienced significant improvement in the frequency of anxiety, treatment problems, depression, and life disruption compared to the control group. Following participation in peer support groups, participants showed no improvement on any of these outcome variables.
Group Cunningham & Tocco (1989)	1. Eclectic - (coping skills training + support) 2. Support	N = 53 Cancer site unspecified	Unspecified	While both were associated with significant benefits, coping skills training had a greater effect. Participants receiving coping skills training reported greater improvements in depression and anxiety than controls. Improvements were maintained at 3-month follow-up.
Group Evans & Connis (1995)	1. CBT 2. Social Support 3. No therapy	N = 72 Mixed cancer	Unspecified Undergoing radiation treatment	Both the cognitive-behavioural and social support therapies resulted in less depression, hostility, and somatization compared with no treatment at all. At six-month follow-up the social support intervention resulted in a reduction of anxiety compared with both CBT and control samples.

Study and form	Approach and design	Participants	Time since diagnosis	Findings
Fawzy et al. (1990) Group	1. Health education and coping skills 2. Controls	N = 80 Metastatic melanoma	Newly diagnosed	At six months, lower depression, fatigue and confusion reported in intervention group than controls. Some immune cell changes observed in intervention sample. At six years, greater rate of death for controls.
Fawzy et al. (1996) Group v individual	1. Eclectic (Educational/ CBT) 2. Control	N = 104 Metastatic melanoma	Newly diagnosed	After one year, group therapy participants showed more improvement in coping skills and less confusion than both the individual therapy participants and the group controls. Clinical improvements in affective state were seen in both sets of therapy participants.
Johnson (1982) Group	1. Education 2. Control	N = 52 Unspecified	Newly diagnosed either early cancer or metastatic cancer	Participants were assessed pre and post therapy on three dependent variables, anxiety, meaningfulness in life and knowledge about cancer. Pre-post change scores for the therapy group were greater than for control group.

APPENDIX C

INFORMATION AND CONSENT FORMS FOR STUDY 1



UNIVERSITY OF WOLLONGONG

THE MEANING OF A BREAST CANCER DIAGNOSIS

INFORMATION FOR PARTICIPANTS

This research study is being conducted by Lisbeth Lane, as part of a Ph D. by research degree in Psychology, supervised by Associate Professor Linda Viney in the Department of Psychology at the University of Wollongong.

The purpose of this study is to identify specific issues that are faced by women with a diagnosis of breast cancer. You will be asked to respond, briefly, to questions on a survey form concerning details of your age; length of time since diagnosis; current treatment; time (if relevant) since last chemotherapy or radiation treatment; and whether you have been diagnosed with metastases. Following this you will be asked to join in a discussion with approximately six other women. The whole procedure will take approximately one hour. Tea and coffee will be served.

This study seeks information you may regard as personal. If, at any time, you feel uncomfortable about completing a part of the study you are under no obligation to do so. You are free to refuse to participate or withdraw from further participation at any point and so doing will in no way affect your treatment or relationship with anyone connected to the study.

The research includes participation in a group. Although confidentiality will be stressed amongst group members at all times, and the researcher expects this will be respected, the researcher can not give an absolute guarantee that other group members will abide by this. Any information you disclose will be treated confidentially by the researcher. Reporting and/or publication of the research findings will not identify any individual to others.

If you would like to discuss this research further please contact Lisbeth Lane: phone (02) 42 21 4164, Gloria Swift: phone (02) 42 22 8733 or Associate Professor Linda Viney: phone (02) 42 21 3693. If you have any further enquiries regarding the conduct of the research please contact the Secretary of the University of Wollongong Human Research Ethics Committee on (02) 42 21 4457.



UNIVERSITY OF WOLLONGONG

THE MEANING OF A BREAST CANCER DIAGNOSIS

CONSENT FORM

This research study is being conducted, as part of a research PhD. in Psychology, supervised by Associate Professor Linda Viney, in the Department of Psychology at the University of Wollongong.

I consent to participation in 'The meaning of a breast cancer diagnosis' research. I have been given an explanation of this research project and I understand I may refuse to participate or withdraw at any time and that refusal or withdrawal will not affect my treatment or relationship with anyone connected to the study.

I understand the purpose of the project requires the gathering of personal information, and any information or personal details gathered in the course of this research are confidential, and neither my name nor any other identifying information will be used or published without my written permission.

I,consent to participate in the research being conducted by Lisbeth Lane as it has been described to me in the information sheet. I understand that the data collected will be used for analysis of the meanings of a cancer diagnosis and I consent for the data to be used in that manner.

Signed

Date

.....

.....

APPENDIX D

**INFORMATION AND CONSENT FORMS
FOR STUDY 2**

(RETREAT PARTICIPANTS)



UNIVERSITY OF WOLLONGONG

THE MEANING OF A BREAST CANCER DIAGNOSIS II INFORMATION

This research study is being conducted by Lisbeth Lane, as part of a PhD by research degree in Psychology, supervised by Associate Professor Linda Viney in the Department of Psychology at the University of Wollongong.

The purpose of this study is to identify the therapeutic benefits of the Retreat. You will be asked to complete a survey and a questionnaire asking for details of your thoughts and feelings over the past seven days. The questionnaire and survey will take approximately 10 minutes to complete. You will also be asked to complete a brief written account, taking approximately 10 to 15 minutes, of what life is like for you at the time of writing, prior to, at the end of the retreat, and six months after the retreat.

This study seeks information you may regard as highly personal. If, at any time, you feel uncomfortable about completing a part of the study, you are under no obligation to do so. You are free to refuse to participate or withdraw from further participation at any point, and so doing will in no way affect your treatment or relationship with anyone connected to the study or the Retreat.

The researcher will treat any information you disclose confidentially. Reporting and/or publication of the research findings will in no way identify any individual to others unless you so desire and have given written consent.

If you would like to discuss this research further please contact Lisbeth Lane: phone (02) 42 21 4164, Gloria Swift: phone (02) 42 96 4200 or Associate Professor Linda Viney: phone (02) 42 21 3693. If you have any further enquiries regarding the conduct of the research please contact the Secretary of the University of Wollongong Human Research Ethics Committee on (02) 42 21 4457.

(NON-RETREAT PARTICIPANTS)



UNIVERSITY OF WOLLONGONG

THE MEANING OF A BREAST CANCER DIAGNOSIS II

INFORMATION

This research study is being conducted by Lisbeth Lane, as part of a PhD by research degree in Psychology, supervised by Associate Professor Linda Viney in the Department of Psychology at the University of Wollongong.

The purpose of this study is to identify the therapeutic benefits of support from others. Your results will be compared to those of other women to identify the benefits of support from other women living with breast cancer diagnoses. It is hoped that this study will add to existing knowledge about how best to help women with breast cancer.

You will be asked to complete a survey and a questionnaire that ask for details of your thoughts and feelings over the past seven days. The questionnaire and survey will take approximately ten minutes to complete. You will also be asked to complete a brief written account, taking approximately 10 to fifteen minutes, of what life is like for you at the time of writing, prior to, at the end of the retreat, and six months after the retreat.

This study seeks information that you may regard as highly personal. If, at any time, you feel uncomfortable about completing a part of the study, you are under no obligation to do so. You are free to refuse to participate or withdraw from further participation at any point and so doing will in no way affect your treatment or relationship with anyone connected to the study.

The researcher will treat any information you disclose confidentially. Reporting and/or publication of the research findings will in no way identify any individual to others unless you so desire and have given written consent.

If you would like to discuss this research further please contact Lisbeth Lane: phone (02) 42 21 4164, Gloria Swift: phone (02) 42 96 4200 or Associate Professor Linda Viney: phone (02) 42 21 3693. If you have any further enquiries regarding the conduct of the research please contact the Secretary of the University of Wollongong Human Research Ethics Committee on (02) 42 21 4457.



UNIVERSITY OF WOLLONGONG

THE MEANING OF A BREAST CANCER DIAGNOSIS II:

CONSENT FORM

This research study is being conducted as part of a research PhD in Psychology supervised by Associate Professor Linda Viney in the Department of Psychology at the University of Wollongong.

I consent to participation in 'The meaning of a breast cancer diagnosis II: The role of others in validating constructions of the cancer experience' research project. I have been given an explanation of this research project and I understand I may refuse to participate, or withdraw at any time, and that refusal or withdrawal will not affect my treatment or relationship with anyone connected to the study.

I understand the purpose of the project requires the gathering of personal information, and any information or personal details gathered in the course of this research are confidential, and that neither my name, nor any other identifying information, will be used or published without my written permission.

I,..... consent to participate in the research being conducted by Lisbeth Lane as it has been described to me in the information sheet. I understand the data collected will be used for analysis of the role of others in validating constructions of the breast cancer experience and I consent for the data to be used in that manner.

Signed

Dated

.....

.....

APPENDIX E

**THE DATA COLLECTION SET FOR
ALL PARTICIPANTS:
STUDIES 2 AND 3**



UNIVERSITY OF WOLLONGONG

THE MEANING OF A BREAST CANCER DIAGNOSIS

General Information

The questions in this survey are answered in one of the following ways:

In some questions you will be asked to answer questions which need a simple yes or no type of answer. Place a circle around the number which is true for you. For example, if asked what sex you are, you would circle the number 1.

Are you female or male?

Female..... (1)

Male..... 2

If a question asks how much you agree or disagree with a statement, circle the number to show how much you agree or disagree. For example, if you found it relatively easy to get information about breast cancer, you would circle number 2.

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Not applicable
----------------	-------	-------------------------------	----------	----------------------	-------------------

Getting access to information
when I needed it was easy

1 (2) 3 4 5 6

You will also be asked to give some written answers to questions. Write your answer in the space provided.

Participant Survey Form

The information from this survey form will only be requested the first time you fill in the questionnaire that follows.

1. Information about you

1.1 What is your age? Years

1.2 Where do you live? (please enter only your postcode or suburb)
.....

Are you? (*circle one or more*)

Taking care of home and family 1

Doing casual work outside your home..... 2

Doing part-time work outside your home..... 3

Doing full-time work outside your home..... 4

Undertaking a course of study 5

Doing paid work from home..... 6

Other (*please specify*) 7

.....

1.3 Which of the following best describes your marital status at the moment?

Married 1

Separated 2

Divorced 3

Single 4

Widowed 5

1.4 Who lives at home with you? (*circle one or more*)

Husband	1
Partner	2
Daughter/s over 20 years of age.....	3
Son/s over 20 years of age	4
Daughter/s over 12 years of age and under 20	5
Son/s over 12 years of age and under 20	6
Child/ren under 12 years of age	7
Mother	8
Father	9
Other relative or friend (<i>please specify e.g. niece, flatmate</i>)	10
.....	

1.5 Have you, since your diagnosis of breast cancer, received counselling from either a psychologist or psychiatrist?

No,	1
Yes, but not any more	2
Yes, I still am	3

1.6 Has any other family member been diagnosed with breast cancer?

No	1
Yes (<i>please specify, eg. mother, sister</i>).....	2
.....	
.....	

2 Information about your experience of breast cancer

2.1 When were you diagnosed with breast cancer? (*circle one*)

- Less than three months ago 1
- Less than 6 months ago 2
- More than 6 months, less 1 year 3
- More than 1 year, less than 2 years 4
- More than 2 years less than 5 years 5
- More than 5 years 6
- More than 10 years 7
- More than 15 years 8

2.2 Did you have one of these surgical treatments?

- Mastectomy 1
- Lumpectomy 2
- Not applicable 3

2.3 Did you have any of the following treatments?

- Radiotherapy 1
- Chemotherapy 2

2.4 If you have **ever** received either radiotherapy or chemotherapy, when was your last treatment?

- Within the last week 1
- Less than three months ago 2
- Less than 6 months ago 3
- More than 6 months, less than a year 4
- Less than 2 years ago..... 5
- More than 2 years less than 5 years ago..... 6
- More than 5 years ago 7
- More than 10 years ago 8

2.5 Have you been treated with hormones for breast cancer (eg. Tamoxifen)?

- Yes 1
- No 2

2.6 If your answer is yes, which answer best describes you?

- Still being treated with hormones 1
- Have stopped taking hormones in the last 3 months 2
- Have stopped taking hormones in the last six months 3
- Have stopped taking hormones in the last year 4
- Have not taken hormone treatment in the last year 5

2.7 Have you been diagnosed with a recurrence of your breast cancer?

- No 1
- Yes 2

2.8 Have you been diagnosed with secondaries?

- No 1
- Yes 2

2.9 Who has helped you the most with your experience of breast cancer? Please specify and briefly describe how they helped you.

.....

.....

.....

.....

.....

Thank you for your help in answering these questions.
 On the following pages are questions that ask about
 your thoughts and feelings

DABS

Below is a list of words that describe the way people sometimes feel. We would like you to tell us whether you have been having any of these feelings during the past week including today. Please indicate the degree to which you have felt each emotion by circling the number that best describes your experience. Circle only one number for each emotion and do not skip any items.

	Never	Rarely	Sometimes	Frequently	Always
1. NERVOUS	0	1	2	3	4
2. SAD	0	1	2	3	4
3. REGRETFUL	0	1	2	3	4
4. IRRITABLE	0	1	2	3	4
5. HAPPY	0	1	2	3	4
6. PLEASED	0	1	2	3	4
7. EXCITED	0	1	2	3	4
8. PASSIONATE	0	1	2	3	4
9. TIMID	0	1	2	3	4
10. HOPELESS	0	1	2	3	4
11. BLAMEWORTHY	0	1	2	3	4
12. RESENTFUL	0	1	2	3	4
13. GLAD	0	1	2	3	4
14. CALM	0	1	2	3	4
15. ENERGETIC	0	1	2	3	4
16. LOVING	0	1	2	3	4
17. TENSE	0	1	2	3	4
18. WORTHLESS	0	1	2	3	4

	Never	Rarely	Sometimes	Frequently	Always
19. ASHAMED	0	1	2	3	4
20. ANGRY	0	1	2	3	4
21. CHEERFUL	0	1	2	3	4
22. SATISFIED	0	1	2	3	4
23. ACTIVE	0	1	2	3	4
24. FRIENDLY	0	1	2	3	4
25. ANXIOUS	0	1	2	3	4
26. MISERABLE	0	1	2	3	4
27. GUILTY	0	1	2	3	4
28. ENRAGED	0	1	2	3	4
29. DELIGHTED	0	1	2	3	4
30. RELAXED	0	1	2	3	4
31. VIGOROUS	0	1	2	3	4
32. AFFECTIONATE	0	1	2	3	4
33. AFRAID	0	1	2	3	4
34. UNHAPPY	0	1	2	3	4
35. REMORSEFUL	0	1	2	3	4
36. BITTER	0	1	2	3	4
37. JOYOUS	0	1	2	3	4
38. CONTENTED	0	1	2	3	4
39. LIVELY	0	1	2	3	4
40. WARM	0	1	2	3	4

APPENDIX F

THE CONTENT ANALYSIS SCALES

THE CONTENT ANALYSIS SCALES

(from the Manual of instructions for scoring the Gottschalk-Gleser Content Analysis Scales, Gottschalk, Winget and Gleser, 1969)

In developing a means of quantifying the intensity of affect the developers of the scales attempted to include in their measures different qualities of affect, dependent on the context in which the affect is being generated. The ways in which the nature and source of distress are classified, therefore, are not intended to be mutually exclusive, distinctive or unique. The components of the general constructs measured by these scales are derived from clinical experience, and intended to be of heuristic and predictive value.

To convert categorical thematic information drawn from written or verbal statements into scales measuring the amount of a given affect, the scale developers made the following assumptions:

1. They assume that statements of a particular type reflect an equivalent amount of current emotion on the part of the data contributor, whether they pertain to feelings or events that occurring in the past, present or future. Therefore, the same weight to the statement is given, for example, to the statement "I was devastated" and "I would be devastated".
2. The more affect the person is experiencing at a given moment the greater is the possibility that they will speak of incidents that personally reflect that emotion. When the emotion is less potent, the data contributor is assumed to express it indirectly by externalisation or displacement and, hence, is more likely to express it indirectly. For this reason, progressively less weight is given to remarks about the experiences of others and about inanimate objects, than to experiences in which the data contributor is directly involved.
3. As empirical evidence suggests that spontaneous denials of emotion also indicate low levels of the emotion (Gottschalk-Gleser, 1969), denials of emotion are also counted.
4. The subtypes of distress within a scale are of equivalent importance to the relevance and magnitude of the distress of the data contributor, and are therefore additive. Thus, the weighted scores for all statements falling into the subtypes are summed to obtain a measure of the emotion. Scores are weighted as follows:

References to:

- a. self (3)
- b. animate other (2)
- c. inanimate objects (1)
- d. denial of (1)

The unit to be coded is the clause, whether independent or dependent. To account for varying lengths of texts 0.5 is added to the raw score obtained on a scale. This number is then multiplied by 100 and divided by the number of words in the text. This method avoids the discontinuity occurring when no scorable items have occurred. It also provides a uniform transformation over all samples. To reduce skewness the square root of this ratio is used as the final corrected score.

APPENDIX G

DEMOGRAPHIC CHARACTERISTICS OF THE PARTICIPANTS

Variable	Category	Frequency
Age	Less than 40 years	2
	40-54	42
	55-69	45
	70+	22
Time since diagnosis category	6 months > 1 year	12
	1 to 2 years	27
	2 to 5 years	33
	More than 5 years	26
	More than 10 years	13
Surgical treatment	Mastectomy	69
	Lumpectomy	42
Adjuvant treatment	Hormone only	17
	Chemotherapy	8
	Radiation	17
	Chemotherapy + radiation	16
	Chemotherapy + hormone	4
	Radiation + hormone	17
	Chemo + radiation+ hormone	15
None	17	
Marital status	Married	84
	Single	4
	Widowed	14
	Defacto	4
	Separated	1
	Divorced	4
Nominated support person	Husband	82
	Partner	4
	Daughter	11
	Son	4
	Other family member	9
	Friend	1

N = 111

APPENDIX H

**INFORMATION AND CONSENT FORMS
FOR STUDY 3 PARTICIPANTS**

(INTERVENTION PARTICIPANTS)



UNIVERSITY OF WOLLONGONG

THE MEANING OF A BREAST CANCER DIAGNOSIS III INFORMATION

This research study is being conducted by Lisbeth Lane as part of a PhD by research degree in Psychology supervised by Associate Professor Linda Viney in the Department of Psychology at the University of Wollongong.

The purpose of this study is to identify the therapeutic benefits of the counselling sessions you have expressed a desire to participate in. The therapeutic intervention entails attendance and participation in eight group sessions led by Lisbeth Lane, Intern Psychologist. It is important that you attend, wherever possible, all the sessions. Every effort will be made to ensure that the time and location of these groups will cause the least inconvenience. You will be asked to complete a questionnaire that asks about your thoughts and feelings. The questionnaire will take approximately ten minutes to complete. You will also be asked to complete a brief written account, taking between 10 and fifteen minutes, of what life is like for you at the time of writing, prior to, at the end of the sessions, and six months after the sessions.

This study seeks information that you may regard as highly personal. If, at any time, you feel uncomfortable about completing a part of the study you are under no obligation to do so. You are free to refuse to participate or withdraw from further participation at any point and so doing will in no way affect your treatment or relationship with anyone connected to the study.

The counselling sessions involve participation in groups. Although confidentiality will be stressed amongst group members at all times, and the researcher anticipates that this will be respected, the researcher can not give an absolute guarantee that other group members will abide by this.

Any information you disclose will be treated confidentially by the researcher. Reporting and/or publication of the research findings will in no way identify any individual to others unless you so desire, and have given written consent.

If you would like to discuss this research further please contact Lisbeth Lane: phone (02) 42 21 4164, Gloria Swift: phone (02) 42 96 4200 or Associate Professor Linda Viney: phone (02) 42 21 3693. If you have any further enquiries regarding the conduct of the research please contact the Secretary of the University of Wollongong Human Research Ethics Committee on (02) 42 21 4457.

(WAIT-LIST PARTICIPANTS)



UNIVERSITY OF WOLLONGONG

THE MEANING OF A BREAST CANCER DIAGNOSIS III

This research study is being conducted by Lisbeth Lane as part of a PhD by research degree in Psychology supervised by Associate Professor Linda Viney in the Department of Psychology at the University of Wollongong.

The purpose of this study is to identify the therapeutic benefits of counselling sessions. To evaluate the benefits of counselling it is necessary that some participants complete the questionnaires for a period of six months prior to counselling. It is expected that the questionnaires will take approximately 30 minutes of your time. If, at any time, you feel uncomfortable about completing a part of the study you are under no obligation to do so. You are free to refuse to participate or withdraw from further participation at any point and so doing will in no way affect your treatment or relationship with anyone connected to the study.

You will be asked to complete a questionnaire that asks about your thoughts and feelings. You will also be asked to complete a brief written account, taking between 10 to 15 minutes, of what life is like for you at the time of writing, at the start of the study, approximately three months later, and a further three months later. At the completion of the collection of your thoughts and feelings about breast cancer you will be invited to participate, if you wish, in a series of counselling sessions.

Any information you disclose will be treated confidentially by the researcher. Reporting and/or publication of the research findings will in no way identify any individual to others, unless you so desire and have given written consent.

If you would like to discuss this research further please contact Lisbeth Lane: phone (02) 42 72 8277, Gloria Swift: phone (02) 42 96 4200 or Associate Professor Linda Viney: phone (02) 42 21 3693. If you have any further enquiries regarding the conduct of the research please contact the Secretary of the University of Wollongong Human Research Ethics Committee on (02) 42 21 4457.



UNIVERSITY OF WOLLONGONG

THE MEANING OF A BREAST CANCER DIAGNOSIS III

CONSENT FORM

This research study is being conducted, as part of a research PhD. in Psychology, supervised by Associate Professor Linda Viney, in the Department of Psychology at the University of Wollongong.

I consent to participation in 'The meaning of a breast cancer diagnosis' research. I have been given an explanation of this research project and I understand that I may refuse to participate or withdraw at any time and that refusal or withdrawal will not affect my treatment or relationship with anyone connected to the study.

I understand the purpose of the project requires the gathering of personal information, and that any information or personal details gathered in the course of this research are confidential, and that neither my name, nor any other identifying information, will be used or published without my written permission.

I,consent to participate in the research being conducted by Lisbeth Lane as it has been described to me in the information sheet. I understand that the data collected will be used to evaluate the benefits of the group therapy and I give consent for the data to be used in that manner.

Signed

Date

.....

.....

APPENDIX I

WORKSHEETS USED IN THE PERSONAL CONSTRUCT GROUP THERAPY

Session 1: Worksheet 1

<p>At the end of a tiring day I like to </p>	
<p>I love spending time with </p>	
<p>..... makes me angry</p>	
<p>If I won ten thousand dollars I would </p>	

Session 6: Worksheet 6 (adapted from Neimeyer, 1999)

The person whose imprint is currently impacting on me and I want to trace is:

This person has had the following impact on:

- my mannerisms and gestures
- my way of communicating
- my work and pastime activities
- my values and beliefs

The imprints I would most like to affirm and maintain are

.....

.....

The imprints I would most like to relinquish or change are

.....

.....

Session 3: Example of a Completed Self Sort

NAME..... <i>Joan</i>	
1. Self as a very young child 2. Self as a teenager 3. Self in your twenties 4. Self in your thirties 5. Self just before your diagnosis	6. Self yesterday 7. Self at a time when you were very happy 8. Self as you are right now 9. Future self 10. Ideal self
<u>Sort 1</u> 1 2 4 5 6 8 <i>had a pet</i>	3 7 8 9 10 <i>didn't have a pet</i>
<u>Sort 2</u> 1 2 3 7 9 10 <i>active and fit</i>	4 5 6 8 <i>was not active and fit</i>
<u>Sort 3</u> 3 4 5 6 7 8 9 10 <i>was married to R</i>	1 2 <i>wasn't married</i>
<u>Sort 4</u> 1 6 7 8 9 10 <i>felt free</i>	2 3 4 5 <i>was very restricted</i>
<u>Sort 5</u> 1 3 4 7 10 <i>had a definite role</i>	2 5 6 8 9 <i>uncertain about role</i>
<u>Sort 6</u> 2 3 4 7 9 10 <i>in paid work</i>	1 5 6 8 <i>not in paid work</i>
<u>Sort 7</u> 1 2 3 7 10 <i>wasn't fat</i>	4 5 6 8 9 <i>was fat</i>
<u>Sort 8</u> 3 4 5 <i>had heavy responsibilities</i>	1 2 6 7 8 9 10 <i>free from heavy responsibilities</i>

APPENDIX J

**INSTRUCTIONS FOR THE CLASSIFICATION OF
THERAPEUTIC GROUP FACTORS**

Group Factors

Your task is to code each 'important event' provided by the participants into one of ten therapeutic factors, by using the definitions and examples of factors set forth below.

Guidelines for Coding

1. Although you may be familiar with the factors, please refer to the definitions and examples whilst coding.
2. When deciding on a factor to which to assign an event, you should *consider the entire report, as a unit*. This is true, even in cases in which the bulk of the report provides the background information. Do not focus on the respondent's reason for selecting a particular event or exclusively on a key word or phrase in the report.
3. In coding, the guiding question is: 'How is this event important *for this particular participant?*' (as opposed to for the group, or for the therapist).
4. Although you may encounter reported events that could be assigned to more than one therapeutic factor, *select only one factor*. It is likely that in the reported event the participant will have put emphasis on some therapeutic significance of that event. Choose one factor that represents this emphasis.
5. Some reports will include accounts of the participant's behaviour subsequent to the 'most important event' discussed. These accounts should not be considered as new 'important events', but rather, should be treated as evidence substantiating the impact of the reported 'important event'.

Catharsis

The basis of catharsis is emotional *release*, i.e. the ventilation of feelings, either positive or negative, and about either life events or other group members, which brings some measure of *relief*.

This factor operates when the participant:

- Releases feelings (leading to relief) within the group, either of past or present material; or
- Expresses feelings, such as anger, affection, sorrow, and grief, (leading to relief) which have been previously difficult or impossible to release.

Self-Disclosure

The basis of self-disclosure is the act of revealing personal information to the group. It differs from *catharsis*, which concerns the release of feelings, and from *learning from interpersonal actions*, which concerns the attempt to relate adaptively and constructively to other group members.

This factor operates when the participant:

- Reveals information, about either her past, or her feared, embarrassing, or worrisome problems, or her fantasies, which she regards as private and personal; or
- Reveals and shares personal information even though such revealing may be difficult or painful.

Learning from Interpersonal Actions

The basis of this factor is the *attempt* to relate *constructively* and *adaptively* within the group either by initiating some behaviour or responding to other group members. More important than how the group members react is the participant's effort to relate constructively and adaptively.

This factor operates when the participant:

- Tries out new, potentially positive ways of *initiating behaviour* with other group members.

These ways include:

- Expressing oneself to other group members to clarify one's relationship with them;
- Making an explicit, overt effort to develop a relationship with other group members;
- Expressing oneself to achieve closeness with other group members; or
- Tries out new ways of *responding to* other group members

Universality

This factor operates when the participant:

- Recognises that her problems are not unique to her;
- Experiences the sense that she is not alone with her feelings and problems; or
- Perceives that other group members have similar problems and feelings and this reduces her sense of aloneness.

Acceptance

This factor operates when the participant:

- Feels a sense of belonging, warmth, friendliness and comfort in the group;
- Feels valued by other group members;
- Values the support that the group offers;
- Feels cared for, supported, understood and accepted by other group members;
or
- Feels unconditionally accepted and supported even when she reveals something about herself that she has previously regarded as unacceptable.

Altruism

The basis of altruism is that the participant *can feel better* about herself, and /or *learn something positive*, about herself, through helping other group members. Altruism differs from *learning from interpersonal actions*, in that in her efforts to help other group members, the participant improves her view of herself because she experiences being of value to them. Although *learning from interpersonal actions* may involve altruistic behaviour, the therapeutic value lies in the participant's actions rather than in their effect on her self-view.

This factor operates when the participant:

- Offers support, reassurance, suggestions or comments to help other group members;
- Shares similar problems for the purpose of helping other group members;
- Feels needed and helpful;
- Can forget about herself in favour of another group member; or
- Recognises that she wants to do something for another group member.

Guidance

This factor operates when the participant:

- Receives useful information and instruction from the therapist; or
- Receives explicit advice, suggestions, guidance about a problem she is experiencing from either the therapist or other group members.

Self-Understanding

The basis of self- understanding is that the participant learns something important about herself. This can come about as the result of feedback (direct or indirect) and interpretation from other group members, both participants and therapist.

This factor operates when the participant:

- learns something important about her behaviour or assumptions or motivations or fantasies or unconscious thoughts.
- learns how she comes across to the other members of the group.
- learns why she behaves the way she does and how she got to be the way she is.
- learns more clearly the nature of her problems.

Vicarious Learning

The basis of vicarious learning is that the participant experiences something of value for herself through the observation of other group members including the therapist.

This factor operates when the participant:

- Benefits by observing the therapy experience of another participant;
- Identifies with another group member to the extent that the participant benefits herself from the other member's therapy experiences; or
- Can find models in the positive behaviour of other group members (including the therapist) towards which she can strive.

Instillation of Hope

The basis of instillation of hope is that the participant gains a sense of optimism about her progress, or potential for progress, through her treatment in the group. It differs from *vicarious learning* in which the participant sees *how* other group members improve. In *installation of hope* the participant sees *that* other group members improve.

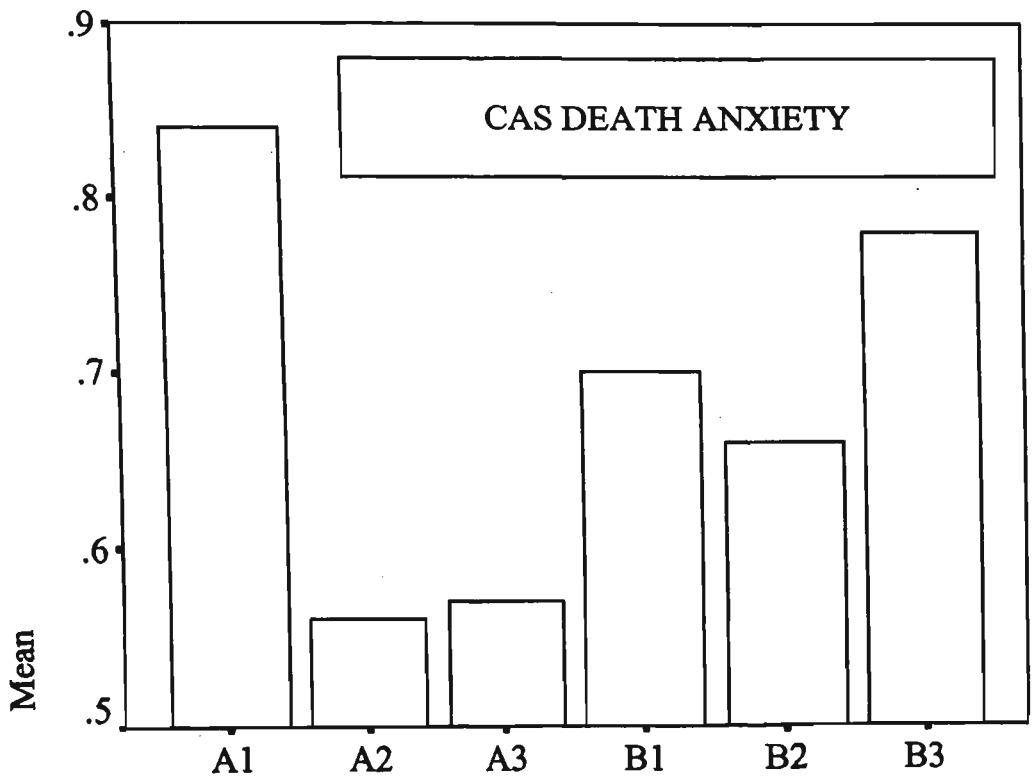
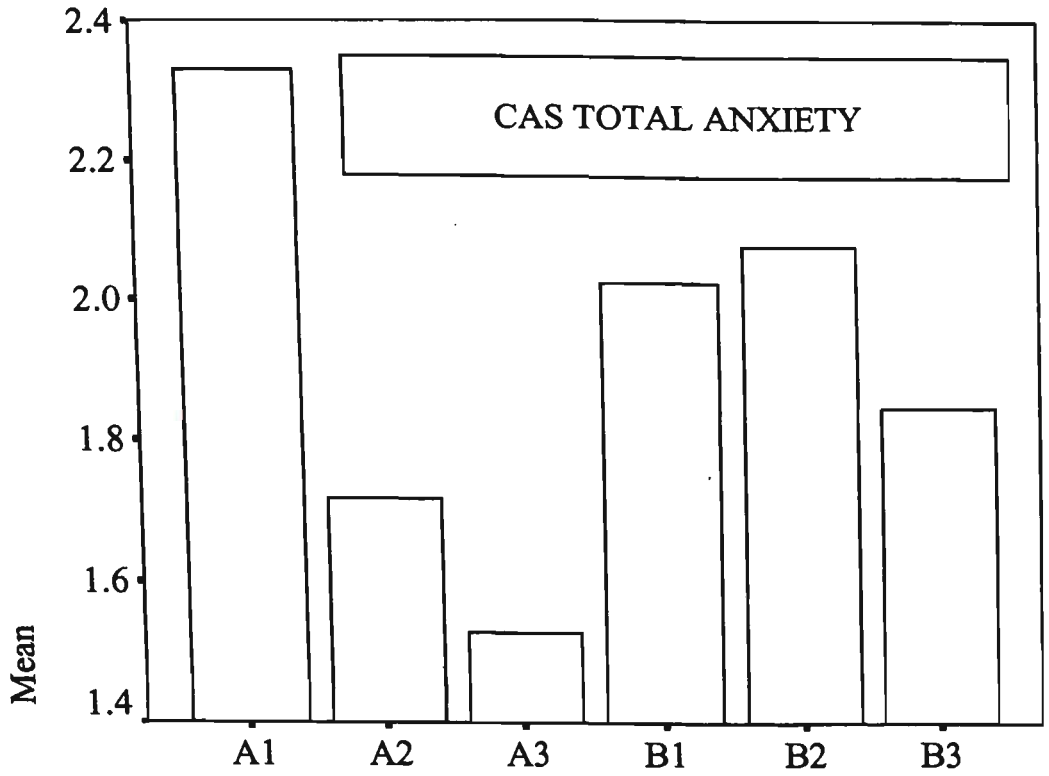
This factor operates when the participant:

- Sees that other group members have improved or are improving;
- Sees that the group can be of help to its members in working towards their goals; or
- Feels optimistic about the group's potential for help. e.g. 'I am hopeful that, or feel that, the group will help me; I can see that the group is taking me somewhere'.

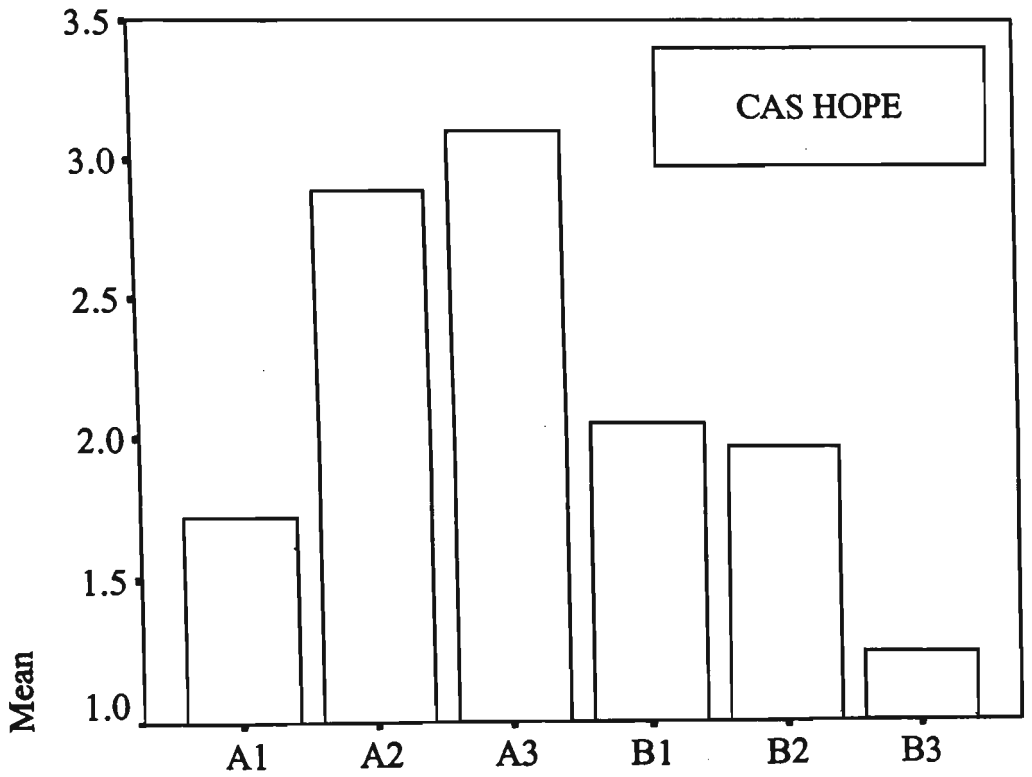
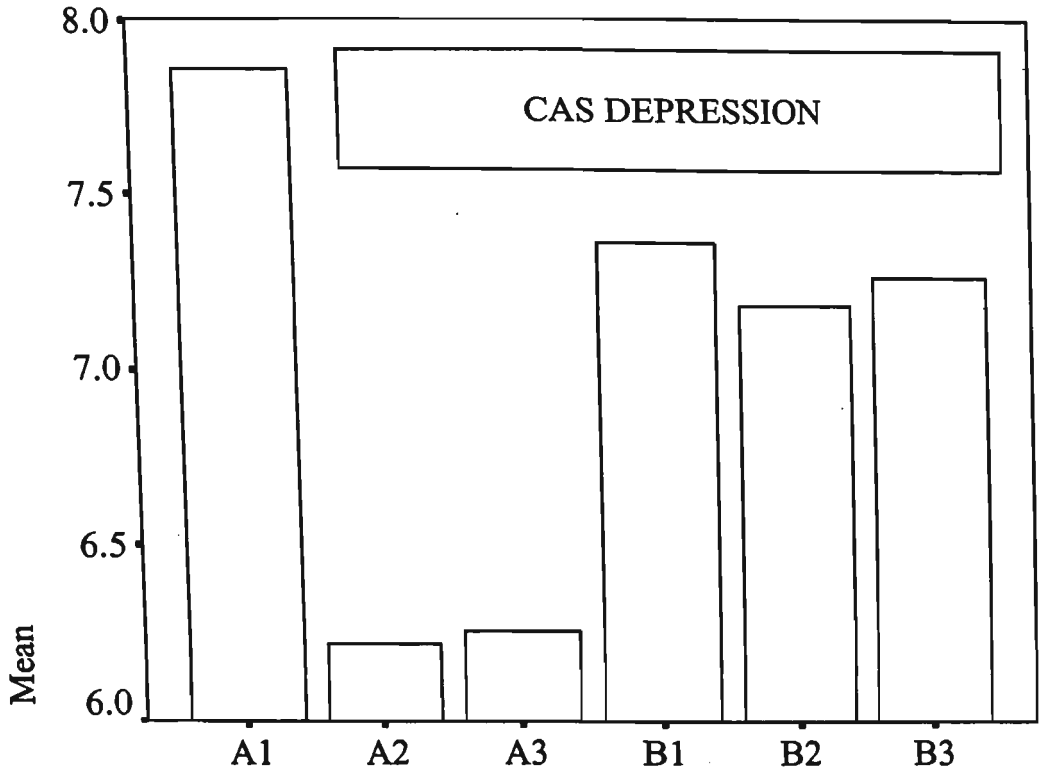
These guidelines were established by Bloch, Reibstein, Crouch, Holroyd, & Hemen, (1979)

APPENDIX K

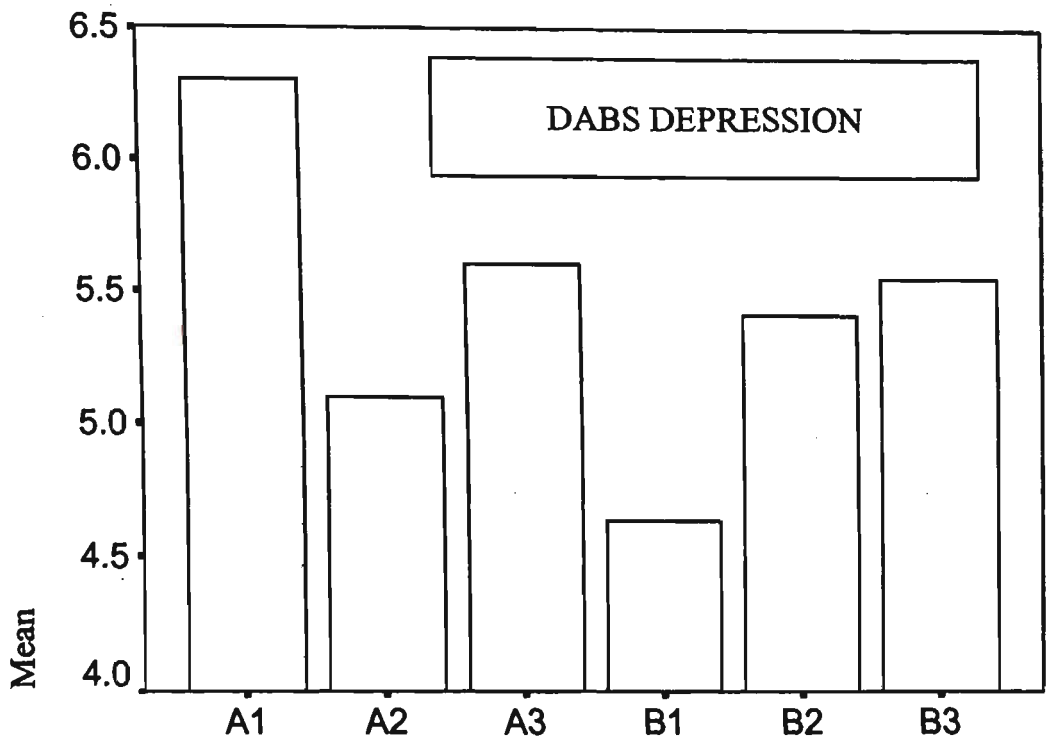
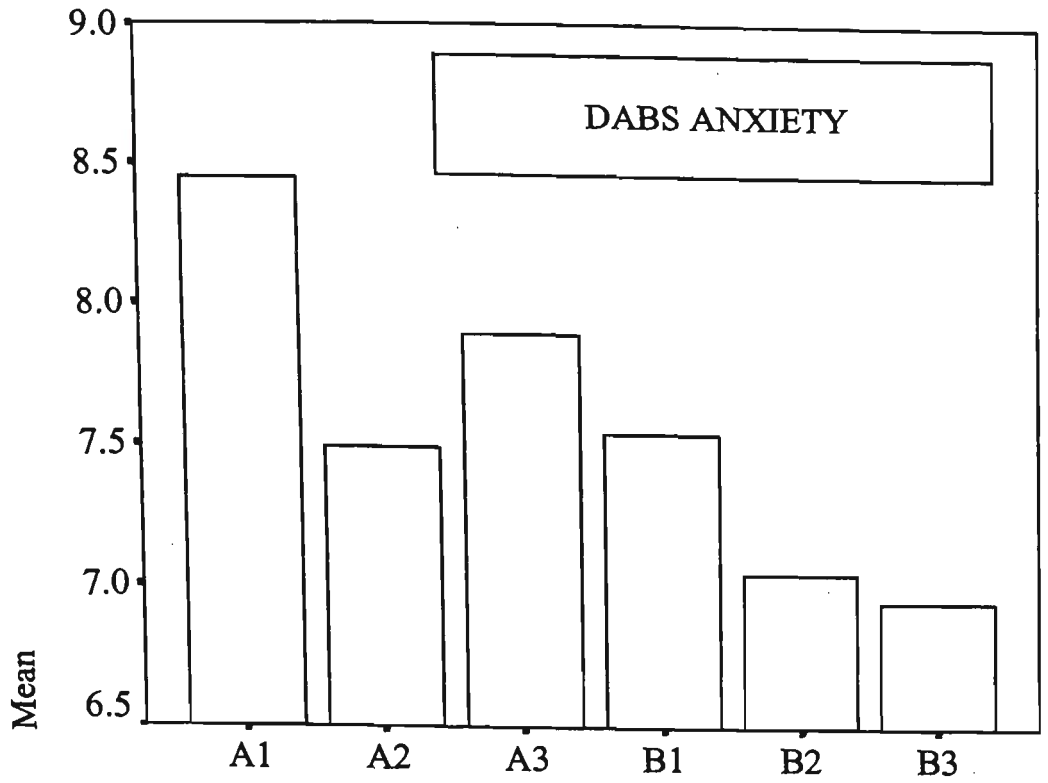
**SAMPLE MEANS FOR CONTENT ANALYSIS AND
DEROGATIS AFFECTS BALANCE SUBSCALE SCORES
AT TIMES 1, 2 AND 3: STUDY 3**



Legend			
A1	Therapy sample Time 1	B1	Therapy control Time 1
A2	Therapy sample Time 2	B2	Therapy control Time 2
A3	Therapy sample Time 3	B3	Therapy control Time 3



Legend			
A1	Therapy sample Time 1	B1	Therapy control Time 1
A2	Therapy sample Time 2	B2	Therapy control Time 2
A3	Therapy sample Time 3	B3	Therapy control Time 3



Legend

A1	Therapy sample Time 1	B1	Therapy control Time 1
A2	Therapy sample Time 2	B2	Therapy control Time 2
A3	Therapy sample Time 3	B3	Therapy control Time 3

APPENDIX L

RESEARCH NEWSLETTER

RESEARCH NEWSLETTER

AN UPDATE ON LIS' RESEARCH

I THOUGHT YOU MIGHT
LIKE EXCERPTS FROM THE
CONFERENCE PAPERS I
PRESENTED IN VICTORIA
AND EUROPE LAST YEAR

The meanings of a breast cancer diagnosis: The role of others in validating helpful constructions of the cancer experience

Lisbeth G. Lane & Linda L. Viney

The authors acknowledge the invaluable assistance of the many women of the Illawarra, Australia currently living with breast cancer, who have given not only their time, but also their trust, and have shared their experiences so generously.

The psychosocial impact of breast cancer

A review of the research literature, supported by the findings of the current study, suggests that the experience of a breast cancer diagnosis may be associated with lasting emotional concerns, specifically anxiety, depression, loss and uncertainty, long after the original diagnosis and irrespective of prognosis (Carter, 1993; Ferans, 1994; Polinsky, 1994). Fear of death, fear of recurrence, and an inability to predict the future and plan goals are consistently reported.

Parkes (1993) observes that events are 'most dangerous' when they require people to undertake a major revision of their assumptions about the world. Assumptions are fundamental to human meaning making in that they help to make events appear predictable (Kelly, 1955). A diagnosis of breast cancer is highly stressful, not least because it disconfirms assumptions previously held about self and the world. Following a cancer diagnosis, prior assumptions become inadequate, and core constructs, the constructs by which people define themselves, may now include, "self as ill", "self as vulnerable", "self as threatened". The world and events within it now seem unpredictable. The previous sense of invulnerability, of denial of one's own mortality, is gone forever. Little and his colleagues (1998) describe this phenomenon as 'mortality rendered visible'.

Loss and uncertainty

For the purpose of the study uncertainty is defined as an awareness of an inability to find meaning in what has happened in order to predict the future. The following examples of uncertainty illustrate some of the ways it may manifest itself in women with breast cancer.

"You thought you were safe, and suddenly you realise that you are at the mercy of the fates. You go along thinking that you are immortal and thinking you know everything will go according to some sort of plan, and then you realise there isn't a plan, or there might be a plan, but you don't know it".

"I never thought that I was the sort of person to get breast cancer, there wasn't any history of it or anything, and I have always been healthy and never thought of myself as a cancer candidate". "It's like living with a time bomb, you don't know if you are completely free".

"I'd been doing all the right things, swimming, exercising, eating right, why me"?

Loss challenges existing ways of living (Neimeyer, 1998) and for the purpose of this study is defined as an awareness of

having to let go of old and preferred meanings. The following examples illustrate how loss may manifest itself in women diagnosed with breast cancer.

"I was diagnosed with breast cancer and it's nearly ten years, but they took the whole breast off. I felt like this beautiful tree that had had its branch lopped off. I didn't feel feminine, I just felt awful".

"And I still feel as though, you know, I'm, how do you put it, damaged goods or something, you know, like a reject, because there's part of me missing."

As expected, the experience of loss may not only centre on the physical loss of the breast and related body image issues but also on the loss of a previous sense of invulnerability and enduring health.

"I remember thinking how dare anything invade me without my permission, which my husband still thinks that's a funny thing to say. He says, "I don't think cancer knocks on the door and says can I come in". That was my thought. How dare you invade me?"

"I wish I could be like I was before. You can't ever have that sense again. You feel like that has been taken away from you, that sense of 'I'm OK'.

The role of others in validating helpful constructions of the breast cancer experience

As social beings, it is within our relationships that we come to define ourselves (Kelly, 1955/1995; Josselson, 1996). Support from others has been shown to be an important factor in adaptation to a cancer diagnosis (Bloom, 1982; Dunkel-Schetter, 1984; Dunkel-Schetter and Wortman, 1982). Yet many women feel isolated by their cancer diagnosis. Silver and colleagues (1990) note the dilemma people in such crises face. They run the risk of driving away potential support if they exhibit high levels of distress, but frequently fail to receive much needed support if they do not display that distress. Rimé (1995) points out that many social situations are unlikely to offer people opportunities to express in depth and at length the feelings experienced, and to have these feelings validated,

leaving the individual's attempt to process their emotions incomplete. Examples of invalidation were numerous.

"I mean you can tell other people things but they can't understand. They can only think that you are going to be all right. And they always say, 'oh, you'll be all right mum, don't worry about it'. And they don't think how you feel".

"I'm not that sort of person, it's not that I dwell on it, but I find these unwanted thoughts. If I said that to my husband he'd have a fit".

The following examples illustrate the beneficial effect of validation for women with breast cancer in their relationships.

"I would not be so good in myself if I did not have a close loving supportive family and friends. I feel very special and humble to have so much love in my life".

"My husband said, you're still you. And that was wonderful when he said that, because you do feel that you're not the person that you were.

"Actually I had no problems whatsoever, I have a good husband and three good children.....and he's very supportive, I mean I'm spoilt rotten, I really am, and that's what makes it easy".

The monthly breast cancer support group (BCSG) meetings provide relationships that validate the breast cancer experience for many of the women who participated in this study.

"Going to the support group made me feel that I was not alone."

"It's one of those things a bit like bingo – all hell breaks loose to get to the cancer meeting once a month. You put everything aside – doesn't matter about the work at home as long as you get there – that's the main thing."

"Being a member of a support group there is always somebody to turn to who listens and understands. Most of all it means one is not alone – there are a number of us who have had breast cancer."

"Imagine if we had never had breast cancer and we didn't know one another. We'd just walk past each other in the street – wouldn't it be awful. We've got

such strong friendships now. I didn't want to have breast cancer but I would hate to be without all those wonderful friends".

"The Support Group is like a 'cosy woollen blanket' full of reassurance and optimism".

When anticipations concerning their relationships are validated, women can begin to construct new meanings and restore a sense of coherence to their lives.

Examples of some women's revision of their meanings follow.

"I'm a lot stronger. The changes have been incredible within myself and in my relationships with people in general".

"I think having cancer made me stop and have a look at the whole, my surroundings, the way I lived and everything like that, and what I really wanted out of my life".

"I think we've all been given prime time because you could get run over and never get to tell your family that you love them or anything. But we've had time to enjoy them and we've been given that chance where other people might not get that".

"I suppose now, looking back on it, it's changed my life. You can't say it's better than it was, because you would never want to get sick in the first place. But now I can understand the meaning of life. I think I have come to terms with having cancer".

Implications of the Research

A large body of research into the psychological benefits of psychosocial support exists. In general these studies confirm an association between health and interpersonal variables such that adaptation to a stressful, life-threatening event may be facilitated by adequately provided social support (Baider, Koch, Estacson & Kaplan De-Nour, 1998). The comprehensive review of the literature concerning psychosocial support provided by specialists conducted by Burke and Kissane (1998) concludes that such support should now be used as an integral part of comprehensive care for women with breast cancer. The review also identifies the need for future

research in this field to "tease out the effective components" (Burke & Kissane, 1998). It is to this end that Stage 3 of this study, a series of workshops currently being evaluated, will, it is anticipated, add to this body of knowledge on the beneficial effects of support.

"We're a bit like a bundle of sticks really. By ourselves we can be a bit uncertain and fearful, but put us all together and we become very strong and confident."

With thanks to Sr. Gloria Swift, Oncology Nurse Consultant for her ongoing support of this research.

For details of the references included in these excerpts or for further information regarding the studies contact:

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