

**The Phenomenology of Coping with a Diagnosis of Early
Stage Breast Cancer:
The Influence of Intrapersonal and Social Context Variables**

Rosemary June Callander, B.Social Studies., M. Social Work



**Submitted in March, 2003, as the total requirement for the degree of Doctor of
Philosophy, Department of Psychology, Faculty of Arts, Victoria University.**

~~WIR~~ THESIS

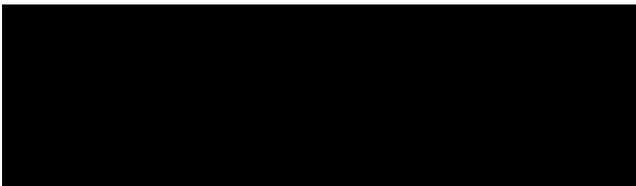
362.19699449 CAL

30001007972872

Callander, Rosemary

The phenomenology of coping
with a diagnosis of early
stage breast cancer : the

I certify that this thesis entitled “The Phenomenology of Coping with a Diagnosis of Early Stage Breast Cancer: The Influence of Intrapsychic and Social Context Variables” submitted for the degree of Doctor of Philosophy is the result of my own research, except where otherwise acknowledged, and that this thesis in whole or in part has not been submitted for an award including a higher degree to any other university or institution.



Rosemary Callander

Abstract

Despite substantial research into psychosocial factors associated with adjustment to a diagnosis of breast cancer, contradictory or limited research evidence exists in certain areas. In particular, questions arise concerning the efficacy of coping reactions such as acceptance and denial/avoidance behaviours. Using as a conceptual framework the Lazarus and Folkman (1984) cognitive-phenomenological model of psychological stress, the present study explores these questions through analysis of two cycles of in-depth interviews. Participants were 19 women with a relatively recent diagnosis of early stage breast cancer. The aim was to chart their coping reactions over a six month period. Major themes associated with healthy adjustment include high levels of acceptance, low denial, an expressed positive outlook, creation and utilisation of constructive emotional support, increased self-care, and drawing on a life philosophy. These themes reflected underlying tasks for the women, that is, making meaning of their experience with cancer and seeking to regain control over their situation. At follow-up these themes/tasks are still present although less salient for those without ongoing physical difficulties. The strengths and weaknesses of the research were evaluated and theoretical and implications for future research and clinical practice were discussed.

Acknowledgements

I am grateful to a large number of people who have provided valuable assistance to me in the course of this PhD program. Firstly, I would like to acknowledge and thank my Principal Supervisor, Professor Susan Moore, for the invaluable advice and support she has given me during the years of this project. Sue has always provided me with a blend of enthusiasm, guidance, and encouragement which helped me to persevere through the difficult times, and made the supervision process a very rewarding one. Her down to earth nature, sense of humour, and interest in my career are greatly appreciated. I would also like to acknowledge the valuable help I received from my Dr Bernadette Hood, who became my Associate Supervisor in the later stages of this PhD project. In addition, I am grateful for the help that Dr Delwyn Goodrick gave me, particularly in the area of qualitative methodology. My thanks also to my friends and fellow PhD students who formed a support group for a number of years. Our monthly meetings were characterised by laughter, tea, and (occasionally) tears, and, along with the listening and feedback, helped to make my graduate years very rewarding and enjoyable. In particular, I would like to thank Kylie Bartolo for helping me to master the intricacies of computer-related issues which was especially helpful in the later stages of thesis production.

I gratefully acknowledge the contribution of the women who took part in this study and who gave their time so generously and shared their experiences with me so willingly. Their willingness to share their stories has made this research project possible, and has enriched my life. In addition, I would like to thank those people who helped me to find appropriate participants.

I wish to thank staff in the Department of Psychology who have been supportive of this project in various ways over the years. I am also grateful for the Victoria University Scholarship which provided me with financial support for over three years. My special thanks go to Jane Trewin for her assistance and friendly advice with numerous administrative details during the course of my Candidature.

My special thanks also to the members of my extended family network who have provided me with love and support over the years. My particular thanks to my nephew, John, who helped me to negotiate various computer-related difficulties. Finally, loving thanks to my daughter Naomi who has, more than anyone, shared the highs and lows of my PhD years.

Table of Contents

Abstract	i
Acknowledgements	ii
Table of Contents	iv
List of Figures	ix
Chapter 1: Introduction and Overview	1
The Impact of Breast Cancer	1
Methodology and Design of the Thesis	3
Overview of the Thesis	4
Chapter 2: Stress and Coping: Theoretical Framework	7
Definition of Stress	7
Early Approaches to the Study of Stress	7
<i>Stimulus-based approach</i>	8
<i>Response-based approach</i>	9
<i>Transactional approach</i>	10
Cognitive appraisal	11
Primary appraisal	12
Secondary appraisal	14
Reappraisal	14
Approaches to Coping: Style versus Process	15
Definition of Coping	16
Functions of Coping	16
<i>Problem- and emotion-focused coping</i>	17
<i>Approach and avoidance dimension</i>	19
<i>Combined approach</i>	19
Revised Stress and Coping Model	21

Chapter 3	Literature Review: Coping with Cancer	25
Denial Strategies		26
<i>Review of research</i>		26
<i>Defining denial</i>		28
<i>Measurement issues</i>		29
<i>Principles for adaptive use of denial</i>		30
<i>Conclusion</i>		31
Avoidance		32
<i>Review of research</i>		32
<i>Conclusion</i>		35
Acceptance		36
<i>Review of research</i>		36
<i>Conclusion</i>		40
Social Support		41
<i>Definition</i>		42
<i>Social support and models of coping</i>		42
<i>Review of research</i>		43
<i>Conclusion</i>		50
Beliefs about Personal Control		51
<i>Review of research</i>		52
<i>Conclusion</i>		56
The Role of Meaning		56
<i>Definition</i>		57
<i>Theoretical perspectives</i>		57
<i>Research on meaning and adjustment</i>		60
<i>Meaning and coping strategies</i>		66
<i>Conclusion</i>		68
Summary of Evaluations		69
Age and Sociodemographic variables		69
Summary and Study Aims		72

Chapter 4	Method	75
	Appropriateness of Qualitative Methodology	75
	Theoretical Perspective and the Choice of In-Depth Interviews	76
	Study Participants	77
	Procedure	78
	Ethical Considerations	79
	Nature of the Interview	80
	Data Analysis	82
	Trustworthiness	88
Chapter 5	Results of Initial Interviews: Coping Strategies	90
	Initial Reactions to the Diagnosis	90
	Appraisal: “I can cope”	92
	Acceptance	93
	<i>Acceptance of diagnosis</i>	94
	<i>Acceptance of mortality</i>	96
	<i>Acceptance of treatment</i>	97
	Denial and Avoidance	98
	<i>Denial of physical manifestations</i>	98
	<i>Denial of the diagnosis</i>	101
	<i>Denial of the implications of the illness</i>	103
	<i>Denial of emotional reaction to the threat</i>	104
	Distancing	109
	Positive Focus	110
	Focus on the Present	114
	Normalise	116
	Seeking and Using Social Support	118
	<i>Support from friends</i>	119
	<i>Support from partners</i>	121
	<i>Support from other women with breast cancer</i>	124
	<i>Support groups</i>	127
	<i>Seeking help from professionals</i>	128

<i>Those who did not seek much help outside themselves</i>	129
Information-seeking	129
<i>Information relating to medical aspects of breast cancer</i>	130
<i>Information about coping with breast cancer (emotional aspects)</i>	131
Downward Social Comparison	132
Use of Humour	136
Using Causal Attribution	139
Seeking Alternative Treatment	142
Stress Management	147
Summary	150
Chapter 6 Initial interviews: Meaning and Control	151
Making Sense and Meaning	152
<i>Statements about searching for meaning</i>	152
<i>Sense making</i>	153
Searching for a cause	153
Examining beliefs	153
Confronting mortality	158
<i>Making meaning</i>	160
Considering outlook	160
Setting new priorities	162
Identifying changes in relationships	163
Summary: Meaning Issues	164
Regaining Control	165
<i>Control in the medical area</i>	166
Active partners (having a say)	166
Having confidence in doctors	171
Going along with doctors	173
Equal partner	175
Non-compliance	176
<i>Control and physical recovery</i>	177
<i>Feelings of loss of control (emotions) and regaining control</i>	180
<i>Control and relationships with friends and family</i>	186

Summary: Control Issues	187
Chapter 7 Followup -interviews: Meaning and Control	189
Making Sense and Meaning	190
<i>Sense making</i>	191
Examining beliefs	191
Confronting mortality	193
Searching for a cause	194
<i>Making meaning</i>	195
Considering outlook	196
Setting new priorities	198
Identifying benefits in terms of relationships	199
Reaching out to others	200
Summary of Meaning Issues at Follow-up	202
Gaining and Retaining Control	203
<i>Control in relation to the medical area</i>	203
Active partners	204
Having confidence in the doctors	206
Going along with the doctors	207
<i>Control in the area of physical recovery</i>	208
<i>Control of emotions and physical symptoms</i>	212
Emotional concerns of a short term nature	213
Emotional upheaval of a more ongoing nature	215
Summary of Control Issues at Follow-up	218
Acceptance and Denial/ Avoidance at the time of follow-up	219
<i>Targets of acceptance and denial/ avoidance</i>	220
<i>Changes in acceptance over time</i>	222
<i>Underlying tasks and emotions</i>	223
<i>Constellations of strategies</i>	223
<i>Acceptance in terms of three domains: emotional, cognitive, behavioural</i>	225
Summary: Acceptance and denial/ avoidance	227

Chapter 8	Discussion, Evaluation, and Implications	228
	Coping Strategies	228
	Control-related issues	230
	<i>Control in the medical area</i>	230
	<i>Control and physical recovery</i>	231
	<i>Control of emotions</i>	233
	Meaning-related issues	236
	<i>Sense making</i>	237
	Examining beliefs	237
	Confronting mortality	238
	Searching for a cause	240
	<i>Making meaning (benefit finding)</i>	241
	Meaning and Control	245
	Evaluation	247
	Implications	250
	<i>Implications for existing theories</i>	250
	<i>Research implications</i>	252
	<i>Clinical implications</i>	253
APPENDIXES		255
	Appendix A1 Invitation to Study Participants	255
	Appendix A2 Plain Language Statement	256
	Appendix A3 Interview Consent Form	257
	Appendix A4 Explanatory Statement: Follow-up contact	258
	Appendix A5 Explanatory Statement: Follow-up interview	259
	Appendix A6 University Ethics Approval	260
	Appendix A7 SocioDemographic Data Questionnaire	261
	Appendix B Interview Schedule	262
	Appendix C Matrix Analysis: Initial Interviews	263
	Appendix D1 Feedback to Study Participants: Initial interviews	264
	Appendix D2 Feedback to Study Participants: Follow-up interviews	265

List of Figures

Chapter 2 Stress and Coping: Theoretical Framework

Fig. 1 Theoretical model of appraisal and coping processes 23

Chapter 1 Introduction and Overview

The impact of breast cancer

Breast cancer is an illness of major concern to Australian women, with the lifetime risk now standing at one in eleven. Approximately 10,000 women are diagnosed with breast cancer each year in Australia, and more than 2,500 women die from the disease (AIHW, 1998). The diagnosis and ensuing treatment process can have a profound impact on the women affected and those with whom they are closely involved. It confronts them with a range of psychological, physical, and practical challenges. Apart from the shock of the diagnosis, treatment itself may be experienced as traumatic, and can include aversive side effects, such as nausea, vomiting, fatigue and physical losses. A woman's fear over her health and future may also be compounded by practical concerns such as the possible impact of her illness on employment and financial security.

Research indicates that about 25 to 30 percent of women will develop severe psychological symptoms (especially depression and anxiety) that warrant professional assistance (Gallagher, Parle, & Cairns, 2002; Kissane et al., 1998; NHMRC, 2000; Royak-Schaler, 1991). This distress can persist for at least two or three years, and has implications for women's health and well-being and also that of their families (Fallowfield, Hall, Maguire et al., 1990; Glanz & Lerman, 1992).

In recent years, improvements in medical procedures, the psychological climate surrounding the disease, and support services have helped to lessen the impact of cancer and its treatment for many women (Antoni et al., 2001). Research in the last 10 years or so has found that women with *early stage* breast cancer (i.e., Stage I or Stage II which have good prognoses), who have no prior history of psychiatric disturbance, are unlikely to develop severe psychiatric symptoms (Carver et al., 1993; Irvine, Brown, Crooks, Roberts & Browne, 1991; Penman et al., 1987; Stanton & Snider, 1993). Data from a longitudinal study by Epping-Jordan, Compas, Osowiecki, Gerhardt, and Krag (1999), for example, showed that over 80% of women in their study reported low distress during the course of treatment and recovery.

Hence, while the experience of early stage breast cancer may be a crisis in the woman's life with wide-ranging ramifications, the majority of women may successfully weather it in the first year after surgery. Moreover, there is an increasing awareness among researchers and clinicians that a substantial number of women report not only negative, but also positive, sequelae of their experience (Antoni et al., 2001; Clarke, Lavery & Ruffin, 1993). Recent stress and coping literature also highlights the role of positive coping strategies and outcomes in adversity (e.g., Folkman, 1997; Taylor & Armor, 1996).

Medical factors such as illness severity, type of treatment, and time since diagnosis are of undoubted significance in the impact of breast cancer. However, according to Glanz and Lerman (1992), at least half of the variance in psychosocial adjustment to the illness is accounted for by factors relatively independent of these medical variables, that is, psychosocial variables such as personality traits, coping strategies, and social support. Clearly it is important to understand the psychosocial factors that promote resilience or vulnerability in this situation in order to develop effective supports and intervention programs (NHMRC, 2000).

Research over the last twenty years has helped to clarify the role of some of these psychosocial factors in adjustment to breast cancer, however there are limitations in knowledge that need to be addressed. Of particular interest are issues relating to coping strategies and social support, both of which are potentially more malleable than personality traits and hence more appropriate as targets for intervention. In addition, the group of coping strategies called denial/ avoidance and the apparent converse, acceptance, require further investigation as research evidence about whether or not they are adaptive ways of coping is contradictory (Carver et al., 1993; Stanton & Snider, 1993).

Accordingly, the general aim of this thesis was to explore and describe the psychological reactions and coping responses of women with a relatively recent diagnosis of early stage breast cancer, and to document changes in the breast cancer experience and associated coping reactions over a six month period. An important element of the study was its salutogenic approach (Antonovsky, 1987), focusing on

how women were attempting to maintain their well-being during the difficult period after a diagnosis of a serious illness.

Methodology and design of the thesis

Because of difficulties in conceptualising and measuring the subtleties of coping strategies such as denial/ avoidance (Carver, Scheier & Pozo, 1992), it was considered appropriate to explore this area with qualitative methods. This methodological approach has the flexibility and sensitivity to explore complex processes and meaning of events (Marshall & Rossman, 1989). It is of particular value when researcher-generated meanings are conflicting, ambiguous, or under-developed.

In addition, the choice of qualitative methodology was also a response to a growing recognition of the need to narrow the gap between coping research and clinical practice (Sommerfield, 1997). This gap has arisen partly as a result of methodological reliance on theoretically derived coping checklists (e.g., Carver, Scheier, & Weintraub, 1989; Folkman & Lazarus, 1985). While these checklists provide an efficient and standardised way of assessing coping strategies, they have been extensively criticised because they lack comprehensibility and have limited applicability (Coyne, 1997; Coyne & Racioppo, 2000; Siegel & Scrimshaw, 2000). Furthermore, recent research suggests that there is even doubt about whether respondents understand or accurately report their coping strategies when using these coping checklists (Danoff-Burg, Ayala, & Revenson, 2000). However, before more clinically useful measures of coping can be developed, a better understanding is needed of the specific stressors and coping responses that are associated with major adverse events, such as a diagnosis of breast cancer. Indeed, Sommerfield (1997) has highlighted the need for coping studies that adopt a micro-level perspective and examine the specific coping strategies that are employed by individuals who face well-specified stressors in situations such as cancer. Moreover, Sommerfield (1997) and others have argued for, and demonstrated, the value of using qualitative methods (Folkman, 1997) and descriptive studies (Lazarus, 1990) in this task. Qualitative assessments of coping can offer an increased understanding of stressor-specific

coping strategies employed by participants, thereby potentially yielding insights relevant to research and practice.

A longitudinal design was used in the current study so that psychological reactions and coping responses could be tracked over time, allowing changes to be observed in more detail than is usually possible with a cross-sectional design. To this end, two cycles of semi-structured interviews were employed to permit an in-depth examination of coping and support issues. The data from these interviews were analysed to identify the nature of the women's experiences with breast cancer, their emotional reactions, and their coping responses, adhering as closely as possible to the conceptualisations generated by the women themselves. From such analysis a detailed appreciation of the phenomenology of coping with a diagnosis of early stage breast cancer, for this group of Australian women, could be achieved. In addition, clarifications in conceptualisation emerged which could contribute to further research.

Overview of thesis

Chapter 2 outlines the Lazarus and Folkman (1984) stress and coping model that provides the theoretical framework for this study. It opens with a brief review of the early approaches to the study of stress, namely response-based, stimulus-based, and interactional models, which preceded the formulation of Lazarus and Folkman's theory of psychological stress. According to the theory, which has been described as transactional, stress is posited to arise from a transaction between the individual and his or her environment. Stress results when a person perceives an imbalance between the demands of a stressful situation and the resources which they have at their disposal to manage such demands. Issues such as the role of cognitive appraisal in the development of stress, coping processes, and the functions of coping are canvassed. The last section of the chapter presents a revised version of the model (Folkman, 1997), which highlights the role of positive coping strategies, such as meaning-based coping processes, and adaptive outcomes.

Chapter 3 provides a review of the literature on coping with cancer, especially breast cancer. In particular, it describes empirical research in relation to key coping strategies such as denial, avoidance, acceptance, seeking social support, personal

control, and making meaning. The review outlines some of the conceptual and methodological limitations in this research, which consequently, yields contradictory findings about the adaptiveness of these strategies. This is followed by a brief review of sociodemographic variables, particularly age, some of which appear to be closely linked with the way women adjust to breast cancer. The chapter concludes with a detailed statement of the study aims.

The subsequent chapter, Chapter 4, describes the method used in the study. The choice of qualitative methodology is discussed, after which there is an outline of participant recruitment, participants' demographic and treatment characteristics, the nature of the interviews, ethical considerations, and the techniques used to analyse and validate the data.

Chapter 5 presents the results of analysis of the initial interviews. The first stage of analysis identified the coping strategies most widely used by the women, and supporting evidence from the women's accounts is presented. In addition, targets of acceptance and denial are described. Following on from that, matrix analysis (the second stage of analysis) yielded the overarching categories of making meaning and regaining control, which are outlined in Chapter 6. The various ways in which making meaning and regaining control were achieved by the women are documented.

Chapter 7 takes up the description of changes in the experiences of the women with their illness, and their associated coping responses, at the time of the follow up interviews. As in the previous chapter, this exploration centred around the overarching themes of meaning and control. The chapter concludes with a consideration of the coping strategies of acceptance and denial as reported in the second cycle of interviews, and their links with making meaning and retaining control.

The final chapter, Chapter 8, discusses the findings from both the initial and follow-up interviews, particularly those relating to control and meaning, from the perspectives of previous published research and the stress and coping model of Lazarus and Folkman. It also evaluates the design and methodology of the research, and identifies strengths and limitations of the research project. Finally, theoretical

and clinical implications are canvassed, and future directions for research are suggested.

Chapter 2 Stress and Coping: Theoretical Framework

This chapter provides an overview of the theoretical framework on which the current study is based. It includes a brief outline of the historical development of general theories of stress and their limitations, which led to the formulation of the model of stress and coping adopted in this research. The chapter also provides a description of this model, the cognitive appraisal theory of stress and coping, including a revised version of the model. This model provides a framework from which to view the breast cancer research described in Chapter 3.

Definition of stress

There has been a lot of confusion about the term “stress” because it has been used to refer to a number of different constructs over the years. Monat and Lazarus (1991) describe it as a collective term that refers to stimuli which produce stress reactions, the reactions themselves and the intervening processes.

Baume’s definition (1993) is widely accepted (Taylor, 1999). In it, stress is defined as a “negative emotional experience accompanied by predictable biochemical, physiological, and behavioral changes that are directed toward adaptation either by manipulating the situation to alter the stressor or by accommodating its effects” (Baume, 1990, p. 653). The definition emphasises the relationship between the individual and the environment, which represents a shift away from the emphasis taken in earlier stress and coping research.

Early approaches to the study of stress

The term “stress” antedates its systematic or scientific use (Lazarus, 1993). As Lazarus and Folkman (1984) point out, it was used early in the fourteenth century to mean hardship, straits, adversity or affliction. One of the earliest contributors to stress research was Walter Cannon (1932) who described the “fight-flight” response. According to Cannon, when an organism perceives a threat the body is rapidly

aroused via the sympathetic nervous system and the endocrine system. As a result, levels of catecholamines produced by the adrenal medulla increase which elevates heart rate, blood pressure, respiration, and blood sugar. In addition, blood supply to muscles increases whilst blood supply to the skin decreases.

Cannon argued that this response was adaptive as it enabled the body to respond quickly to threat by fight or flight. However, prolonged periods of arousal can be harmful because they disrupt emotional and physiological functioning which can lead to medical problems over time. This would be of particular concern in situations when an organism is unable to either fight or flee and still continues to experience stress. For example, in our modern society, fight or flight responses are mostly inappropriate for the threats we perceive and yet exposure to aversive stimuli can continue for long periods of time with resultant health problems (Taylor, 1999). Genetic predispositions appear to determine the particular health problems which develop.

Over subsequent years, other models of stress were developed by researchers, and the emphasis changed as limitations in existing models were recognised. Cox and Ferguson (1991) distinguish three main approaches to stress namely response-based; stimulus-based; and psychological (interactional and transactional).

Stimulus-based approach

In this approach, (also described as the engineering approach) stress was defined as a stimulus, and focused on aversive events in the environment such as natural disasters, illness and retrenchment (Lazarus & Folkman, 1984). Generally, stress was viewed in terms of the load or strain placed on a person. It was based on an engineering analogy which posits that if a strain or load is placed on a metal which does not exceed its “elastic limit”, it will return to its previous state once the strain has been removed. If the load exceeds this limit, permanent damage can result. Like metals, the human body can tolerate certain amounts of stress, but also has limits. Once these limits are exceeded, psychological or physical damage occurs. The model accounts for differences in stress tolerance exhibited between individuals by reference to factors such as heredity, early experience and later learning (Cox, 1978).

However, the approach does not allow for individual differences in the evaluation of events (Lazarus & Folkman, 1984). Such an intervening process does not occur in relation to metals. An additional weakness of the model is its assumption that only demanding situations give rise to stress and that undemanding situations are not stressful (Cox, 1978).

Response-based approach

This approach is also called the medico-psychological approach because response definitions of stress have been prevalent in biology and medicine (Lazarus & Folkman, 1984). It considers stress as a generalised and non-specific response to aversive or noxious environmental stimuli (Cox & Ferguson, 1991). One of the main contributors to this approach was Selye (1979). While Cannon (1932) concentrated on the effect of catecholamines on the body, Selye explored adrenocortical responses to stress. He observed the effects of a variety of prolonged stressors on rats and found that all stressors, regardless of type, produced basically the same pattern of physiological response. He believed that stress resulted in an enlarged and hyperactive adrenal cortex, shrinkage of the thymus glands and lymph nodes, with subsequent development of gastrointestinal ulcers (Taylor, 1999).

It was from this work that Selye developed his concept of the generalised adaptation syndrome (G.A.S). He posited that when an organism confronts a stressor it prepares itself for action. The physiological response itself is the same regardless of the stressor, that is, it is nonspecific. Selye believed that the body's reaction to intense and sustained stress occurred in three phases – alarm reaction, resistance phase and exhaustion phase. In the first phase, the body mobilises itself to meet the threat. In the second phase, resistance, biological adaptation to the stressor is at its peak and bodily signs of alarm disappear. If the body's reactions have been insufficient to overcome the threat and the threat is sufficiently severe and prolonged, the third phase of exhaustion results (Taylor, 1999).

Selye's model continues to be important in the field of stress for two main reasons. Firstly, it presents a theory which describes and explains the reaction of the

body to a wide variety of stressors over time. It thus provides a way of conceptualising the interplay between the environment and physiological factors. Secondly, it offers a physiological mechanism for the link between stress and illness. Selye believed that, over time, the third phase (exhaustion) produced physical illness. Indeed, research since the time Selye proposed his model has shown that prolonged stress has been implicated in a variety of illnesses including arthritis, hypertension, cardiovascular disease and immune-related deficiencies (Taylor, 1999).

Despite its impact, Selye's model has been criticised on several grounds. Firstly, the model places little emphasis on psychological factors, such as appraisal of an event, which are now believed to be important in the development of stress (Cox & Ferguson, 1991; Lazarus & Folkman, 1984). A second weakness of this response-based approach stems from the assumption that responses to stress are uniform. In fact, there is evidence that certain stressors produce distinct endocrinological responses (Taylor, 1999). Finally, Selye focused on stress as an outcome that was evident only when the general adaptation syndrome was more or less complete. However, it is now apparent that people under stress experience many adverse effects while the stressful event is occurring, and sometimes in anticipation of it. These limitations led to the development of other approaches, particularly psychological models.

As has been discussed, both the stimulus and response-based models of stress largely lacked an appreciation of the individual differences which affect a person's response to stress, and especially the perceptual, cognitive differences which underpin such differences (Cox & Ferguson, 1991; Lazarus & Folkman, 1984; Taylor, 1999). Psychological models of stress emphasise that stress cannot be explained at the stimulus or response levels alone. Rather, an adequate theory of stress must consider the way different events in the environment are appraised (or interpreted) by individuals and the way they respond.

Transactional approach

Psychological models, for the most part, can be categorised as "interactional" or "transactional" in nature. Transactional models conceive of stress in more process-

oriented terms and focus on the concept of appraisal (Cox & Ferguson, 1991). These models are described as transactional because this approach views stress as arising from a particular transaction between an individual and a stressful situation. There is the potential for stress if the individual perceives that the demands of the environment tax or exceed his or her personal resources to deal with it (Lazarus, 1993; Lazarus & Folkman, 1984). From this perspective, stress is a psychological state resulting from an internal shaping of a particular transaction between the person and the environment. In reality, this state is only one “snap shot” of a much broader and continually changing “stress process” which involves a sequence of person-environment transactions. In other words, the individual and the environment are in a dynamic relationship, one which is constantly evolving and changing. Moreover, this relationship is bidirectional in that both the individual and the environment have an effect upon each other. When the individual is “out of kilter” with their environment stress ensues which prompts coping efforts. These coping efforts are designed to improve the individual-environment fit and are themselves characterised by change (Lazarus, 1993; Lazarus & Folkman, 1984).

In contrast to earlier models, the transactional approach takes account of individual differences in response to stress and describes the dynamic process which characterises the way people respond to their environment. Moreover, it allows for feedback between various levels of the system and stages of the stress process and therefore can be described as cyclical rather than linear.

According to the Lazarus and Folkman model, two processes are critical mediators of stressful person-environment relations and their immediate and long-term outcomes: cognitive appraisals and coping (Lazarus & Folkman, 1984).

Cognitive appraisal

Cognitive appraisal refers to the process whereby the individual weighs up the significance to their well-being of any encounter with the environment. In other words, it is “the evaluative process that imbues these transactions with meaning” (Cox & Ferguson, 1991, p. 8). In addition this process is posited to take place continuously during waking life and may change as events unfold (Lazarus, 1993; Lazarus &

Folkman, 1984). These appraisals can be influenced by past experiences, individual differences (such as values, commitments, goals and beliefs about oneself and the world), mood and other social factors that are relevant to the individual at the time. They help to determine what is at stake for the individual in terms of his or her well-being (Folkman, Lazarus, Gruen & De Longis, 1986). While appraisal may be a conscious, rational and deliberate process, it may also operate at an impulsive and unconscious level (Lazarus & Folkman, 1984).

Two types of appraisals are postulated – primary and secondary – which identify the two main evaluative issues of appraisal.

Primary appraisal

Primary appraisal refers to a process during which the individual evaluates if any new event or change in the environment is relevant to his or her well-being and in what way. Events may be judged as having neutral, positive, or negative implications for the individual. If the situation is regarded as having no implications for the person's well-being, it can be regarded as falling in the category of neutral. In other words, it does not affect the individual's values, needs or commitments; nothing is to be lost or gained (Lazarus & Folkman, 1984).

A situation may be appraised as having positive implications for the individual in that it appears likely that the well-being of the person will be preserved or enhanced. The emotions associated with such appraisals include joy, happiness, love and peacefulness. However, Lazarus and Folkman (1984) suggest that it is very unusual for people to perceive situations as totally positive because such appraisals are likely to be tinged with apprehension or anxiety that things are bound to change for the worse at some stage.

When the situation is judged as negative, it is further assessed in terms of the harm or loss that has occurred, the future threat connected with the situation, and the likely challenge posed by the event – for instance the individual may perceive that growth, mastery or other gain might result from managing the stressful event. So, for the woman with breast cancer, her appraisal of “harm and loss” might include grief at

the loss of a breast, or part of it, ongoing physical discomfort, and a realisation that her relationships and self-esteem could be damaged. There is also likely to be an assessment of “threat”, that is, losses and harm that may occur in the future, which may be experienced concurrently or alternately as the situation is appraised over time (Coyne & Lazarus, 1981). For the woman with breast cancer these might include concerns about her health and what this means in terms of her life expectancy. Contrary to perceiving harm and loss, an assessment of threat allows the opportunity for anticipatory coping, and hence the woman might develop strategies to enhance her prospects of continuing in good health. Finally, appraising a situation as a “challenge” entails an assessment that the individual may be able to overcome and perhaps profit from an event. Such a perception, like the appraisal of “threat”, encourages the person to mobilise their coping efforts (Lazarus & Folkman, 1984). For example, the woman who perceives her breast cancer as a challenge is likely to feel that she can cope with the situation and may employ a variety of methods, such as seeking support and information and developing a positive attitude, to help her manage the situation and even grow as a person as a result of this experience.

Threat and challenge appraisals may occur simultaneously, and the relationship between them can change as the stressful situation evolves (Lazarus & Folkman, 1984). For example, a woman may respond to her diagnosis with strong fear, anger and anxiety (feelings associated with threat perceptions) and later the threat appraisal may diminish as she appraises the situation as more challenging than threatening. This alteration of appraisal may have resulted from active efforts on her part to view the situation in a more positive light, or because there has been a change in the environment (for example, increased expressions of loving support by spouse or family) for the better.

Whether a person focuses on harm and loss, threat or challenge appraisals seems to depend both on the situational events themselves, individual differences in terms of styles of thinking which have been shaped by past experiences, personality variables and social support (Lazarus & Launier, 1978).

Secondary appraisal

In secondary appraisal, the focus moves from stressful characteristics of the situation to a consideration of “what can I do about this?” This decision-making process involves the individual weighing up his or her available coping abilities and resources, and whether they will be sufficient to meet the harm, threat and challenge of the situation. Resources include physical, social, psychological and material assets, examples of which are a person’s health, social support, self-efficacy, and money respectively (Folkman, 1984). The degree of stress experienced is shaped by the interplay between appraisals of what is at stake (primary appraisals) and coping options (Lazarus & Folkman, 1984). For example, when the situation is appraised as involving high harm and threat, and the individual perceives that she has few resources to cope with it, substantial threat is experienced. Conversely, when perceived coping ability is high, little stress may result. However, even when a woman believes that she has considerable coping ability and resources, if she has a high stake in the outcome even a small degree of doubt can produce considerable stress.

Secondary appraisal thus helps to shape the primary appraisal process by either increasing or decreasing a perception of harm, which in turn influences the coping strategies put into effect by the individual (Coyne & Lazarus, 1981; Lazarus & Launier, 1978).

Reappraisal

The concept of reappraisal simply refers to a changed appraisal that takes account of new information from the environment or information from the person’s own coping actions. In other words, reappraisal results from changing conditions and then forms the basis for further coping, thereby creating a cyclical and ongoing process (Lazarus & Folkman, 1984).

Approaches to coping: style versus process

There have been two main approaches to the study of coping, one based on the notion of *coping styles* and the other on functional *dimensions* underlying the coping process. The former viewed coping as a function of a relatively stable disposition (or traits) of the individual to respond in predictable ways to stressful situations which was somewhat independent of the nature of the situation (Cox & Ferguson, 1991). There have been numerous measures developed to describe such styles including repression-sensitisation (Houston & Hodges, 1970) and monitoring-blunting (Miller, 1987).

These approaches have been criticised by Lazarus and his colleagues (Folkman, 1992; Lazarus & Folkman, 1984) on several grounds. In particular, they asserted that these approaches underestimate the complexity and variability of coping efforts, and evaluate coping along a single dimension or a very limited number of dimensions. They do not show how the person actually copes, or the changes in coping behaviour that occur as a stressful situation unfolds. In their view, coping comprises both change and stability with some people having preferred coping styles. However, rather than emphasising stability, they viewed coping as a process that is capable of change both during the course of a single event and between different events (Lazarus, 1993). Accordingly, an effective way of studying the coping of individuals is whilst they are undergoing stressful situations such as dealing with a serious illness such as cancer.

This approach recognises that there are unlikely to be any coping behaviours that are universally good or bad. The adaptiveness of coping strategies depends on both the particular person and the type of situation or event being confronted. Indeed it has been found that the adaptiveness of any particular coping strategy varies with the type of stressful encounter, the type of personality stressed, and the nature of the outcome variable (e.g., physical health, subjective well-being or social functioning) (Folkman & Lazarus, 1985; Folkman et al., 1986). In other words, a coping strategy that is helpful in one situation and for one person may be unhelpful in another situation or for a different person. In addition, different facets of a stressful situation may elicit different coping strategies. For example, for a woman with breast

cancer, coping with diagnosis may differ from coping with surgery, or responding to concerns of family members and friends. Hence, the particular demands of the situation as it unfolds need to be considered.

Definition of coping

Coping is defined as “the 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. 141). This definition encompasses several important characteristics which distinguish it from earlier approaches, including trait/style approaches. First, the focus is on coping which is in conscious awareness, or those thoughts and behaviours the person uses to manage the demands of the situation. Second, coping processes are not evaluated on an a priori basis, but rather on contextual criteria; no coping strategy is deemed to be more universally efficacious than another. Third, coping is clearly viewed as a changing process rather than a stable personality feature (Folkman, 1992).

Functions of coping

In contrast to trait/style models of coping, the contextual model highlights the importance of functional dimensions which underpin coping strategies (e.g., Lazarus & Folkman, 1984). This model assumes that people have a repertoire of coping options from which they choose what they believe to be the most effective strategy or strategies depending on the nature of the situation. In other words, “coping thoughts and acts are influenced by the relationship between the person and the environment in a given stressful encounter” (Folkman, 1992, p. 34). In addition, it assumes that such coping acts will change the nature of the person-situation transaction which, in turn, will lead to the development of new coping strategies. Unlike the trait/style approach, no one style of coping is investigated but there is focus on finding underlying dimensions which best describe the unlimited number of coping strategies that can be utilised in response to a stressful situation. The implicit assumption is that there are a small, or at least a manageable, number of general functional dimensions (Cox & Ferguson, 1991).

Various taxonomies of coping mechanisms or strategies have been developed mostly based on the function a particular coping strategy serves (Steed, 1998). The two that are most frequently used are “problem- and “emotion-focused” functions described by Lazarus and Folkman (1984), and the approach-avoidance dimension (Roth & Cohen, 1986). In addition, other researchers have posited taxonomies that combine these two fundamental dimensions. Each of these approaches will be described in turn.

Problem- and emotion-focused coping

The most popular description of the functions of coping (Cox & Ferguson, 1991) is that offered by Lazarus and Folkman (1984). They view coping as having two major functions: the management of the problem (problem-focused coping) and the regulation of emotion (emotion-focused coping). The former involves efforts “to change the actual circumstances of an adaptational encounter, for example, by changing the environment or oneself” (Lazarus, 1990, p. 100). In other words, problem-focused behaviours involve efforts to manage or alter the problem causing the distress, and may involve strategies to modify the stressor or minimise its impact. Emotion-focused coping strategies involve activities that alter the way the stressful person-environment relationship is viewed; no change is made to the actual problem-related issues but what is attended to in the stressful situation can be controlled by, for example, avoiding certain facts or their implications (such as denying a cancer diagnosis or minimising its importance). Hence such coping processes are attempts to palliate or eliminate emotional distress by altering what is being attended to or by changing its meaning. When such strategies are successful, the harmful or threatening situation has been reshaped into something that appears subjectively benign (Lazarus, 1990).

According to cognitive-appraisal theory, emotion-focused coping is more likely to be employed if a threatening, harmful or challenging situation is appraised as being beyond the control of the individual, and that nothing can be done to modify it in a beneficial way. Under those circumstances, the individual uses emotion-focused coping in an attempt to manage their emotional reaction to the situation and to help maintain hope and optimism. However, problem-focused coping is more likely to be

adopted when the stressful situation is appraised as being amenable to change (Lazarus & Folkman, 1984).

Whilst these two coping functions are conceptually distinguishable, both are interdependent and can work together, supplementing each other in the overall coping process (Lazarus, 2000). More specifically, the two forms of coping may facilitate or impede each other in the coping process (Lazarus & Folkman, 1984). For example, seeking information about one's cancer diagnosis (problem-focused behaviour) may also help to regulate emotional distress. On the other hand, if a person denies (emotion-focused activity) the existence of a suspicious breast lump this could lead to delay in seeking medical attention for it (Cohen & Lazarus, 1979). In addition, there may be a pattern or sequence of strategies. For instance, a common pattern after receiving a diagnosis of cancer is for a period of denial or minimization (emotion-focused coping), which is gradually replaced by problem-focused efforts relating to treatment programs, accommodating to the limitations resulting from the illness, putting effort into maintaining or developing relationships, and generally trying to get on with life (Lazarus & Folkman, 1984).

In practice it can be difficult to determine whether a particular strategy is problem-focused or emotion-focused, because any thought or behaviour can include both functions of coping (Lazarus & Folkman, 1984). For example, returning to work after a serious illness may be a form of problem-focused coping, however, if the return to work helps the person to feel "normal" again, this can be viewed as an emotion-focused form of coping. This can be clarified by understanding both the context of the behaviour and the underlying patterns of motivation and meaning systems which determine coping (Folkman & Lazarus, 1980; Lazarus & Folkman, 1984). However, Lazarus (1993, 2000) points out that there has been a mistaken tendency in coping research "to pit the problem-focused and emotion-focused coping functions against each other to compare their respective efficacy" (p. 669). In other words, it is necessary to understand the way the two functions operate as a single coping unit.

The empirical work of Lazarus and his colleagues has demonstrated that most people use both forms of coping in stressful situations, as well as most of the basic

strategies of coping (e.g., Folkman & Lazarus, 1980; Folkman et al, 1985; Folkman et al, 1986). In addition, they have shown that both problem- and emotion-focused coping usually occur together, a finding supported by Tennen, Affleck, Armeli and Carney (2000). Tennen et al.'s study entailed prospective, detailed examination of the daily patterning of problem- and emotion-focused coping with pain. They found that participants were over four times more likely to use emotion-focused coping on a day when problem-focused coping had occurred than on a day without it.

Lazarus and colleagues, in the studies cited above, also demonstrated that coping strategies change from one stage of a stressful episode to another. Taken together, these findings show the complexity of the coping process. As Folkman points out, "coping processes continuously change as a function of ongoing appraisals and reappraisals of the shifting person-environment relationships" (1992, p. 34), and that these shifts may be a result of coping efforts or changes in the environment that are independent of the person.

Approach and avoidance dimension

A second fundamental distinction made in the coping literature is that based on approach and avoidance (Steed, 1998). Cognitive and emotional *approach* strategies bring the person into more immediate contact with the stressful situation and "allow for appropriate action and/or the possibility for noticing and taking advantage of changes in a situation that might make it more controllable. Approach strategies also allow for ventilation of affect" (Roth & Cohen, 1986, p. 813). Avoidant strategies, on the other hand, enable the person to reduce stress and help prevent anxiety from becoming overwhelming. In other words, coping activities are oriented either toward or away from the threat.

Combined approach

As Steed (1998) points out, problem- and emotion-focused coping behaviours might include approach and avoidance strategies. For example, direct problem-solving (such as seeking information after a cancer diagnosis) is an *approach* strategy and withdrawal from the situation has the function of *avoidance* (Steed, 1998). In

relation to emotion-focused efforts, *avoidance* activities include denial, wishful thinking and distancing. Emotion-focused *approach* strategies include efforts to identify, understand, and express emotions that accompany the stressor (Stanton, Danoff-Burg, Cameron & Ellis, 1994; Stanton, Kirk, Cameron, & Danoff-Burg, 2000). The fact that almost all coping measures developed in the past few decades include scales that assess the problem-focused/emotion-focused dichotomy and approach-avoidance coping (although not always as independent dimensions) is an indicator of the importance of these dimensions to researchers in the coping area (Parker & Endler, 1996).

Whilst there are differences between the problem/ emotion focused and approach/ avoidance approaches, the functions of coping that they describe can be conceptualised together (Steed, 1998). In such a typology, coping behaviour is designed to approach a problem and make efforts to resolve it, or behaviour is designed to avoid the problem and focus primarily on dealing with the concomitant emotions (Holahan, Moos & Schaefer, 1996; Moos & Schaefer, 1993). However, there is considerable disagreement in terms of the best number and combination of scales to measure coping behaviours. In addition, there are problems in terms of conceptual overlap between scales that reflect the difficulties inherent in reducing the complexity of coping behaviour to a few dimensions (Steed, 1998). As Steed points out, problem-focused coping has the most conceptual clarity, but it has identifiable subsets including planning, instrumental action, and cognitive self-control among others. The problem is particularly acute in relation to emotion-focused coping where a single scale may incorporate conceptually distinct forms of it.

Consequently, Steed (1998) identifies “a need to clarify the notion of emotion-focused coping and to define its differing functions” (p. 195). However, as was indicated earlier, this is not an easy task because any thought or behaviour can include both emotion- and problem-focused functions of coping; the function being served depends on the person and the situation. In addition, any one coping strategy “may perform different functions for different individuals in the same situation, or different functions for the same individual over time” (Steed, 1998, p. 195 –196).

Cox and Ferguson (1991) discussed the need to shift the emphasis from what a person *does* to what the coping behaviours *do* (psychologically) for the person. For example, Pearlin and Schooler (1978) suggested that coping behaviour could be classified as a) responses that change the situation b) responses that alter the meaning or appraisal of the stressor, and c) responses intended to control distressing feelings.

A focus of the current study is to assess coping strategies in women with a diagnosis of early stage breast cancer by returning to the conceptualisations of the women themselves.

Revised stress and coping model

Recently Folkman (1997) presented a revised stress and coping model. She points out that contemporary theories of coping focus on the regulation of distress, often overlooking the presence of positive emotion and its role in coping with stress. Folkman based her recent theorising on the findings of a longitudinal study, (The University of California at San Francisco Coping Project) which she and colleagues conducted, of the partners of men with AIDS. The study used a combination of questionnaire data and interviews, with narratives from the latter being analysed qualitatively. It showed that, throughout the profoundly stressful process of caring for their partners and their bereavement, both positive and negative psychological states were commonly experienced. In addition she distinguished four types of coping processes that were associated with positive psychological states during caregiving and bereavement. These are positive re-appraisal, goal-directed problem-focused coping, spiritual beliefs and practices, and “the infusion of ordinary events with positive meaning” (p. 1212). She goes on to say that there is a common underlying theme for these four types of coping, namely seeking and finding positive meaning.

It was interesting to note that the research team was not initially looking for positive psychological states as they had focused their assessment almost exclusively on the stressful aspects of the caregiver’s experiences. However, several participants pointed out to them that they were missing out on an important part of their experience by only concentrating on its negative aspects. As Folkman reports: “They

said that we needed to ask about positive events as well if we were to understand how they coped with the stress of caregiving.” (p. 1215)

In Folkman’s (1997) view, the original Lazarus and Folkman (1984) model did not adequately accommodate positive psychological states in the stress and coping process. According to the Lazarus and Folkman model, coping processes lead to an event outcome such as favourable, unfavourable resolution or no resolution. Whilst a favourable event outcome usually leads to positive emotion and the cessation of coping activity, unsatisfactory outcomes (such as no resolution or an unfavourable resolution), as may often be the case with cancer, lead to distress and further coping efforts. However, Folkman (1997) modified the model at this point to better accommodate positive psychological states. At this point a third type of coping, meaning-based coping (as described above), may come into play (Folkman & Greer, 2000). She outlines three possible pathways for the operation of these meaning-based processes, as can be seen in Figure 1.

The figure shows the original and revised stress and coping model, and presents three pathways by which positive psychological states operate in response to stress. According to the first pathway, positive psychological states are engendered by meaning-making processes used by individuals to cope with the stressor itself. By contrast, the second pathway describes coping which occurs as a response to distress, as opposed to the actual stressor. Folkman posits that people are motivated - consciously or unconsciously- to gain some relief from significant and ongoing stress by creating positive psychological states, even if they are short-lived. For example, some people might bestow positive meaning on ordinary events, making them positive events. Finally, the third pathway refers to the flow from positive psychological states back to appraisal and coping. In other words, the coping methods used to engender the positive psychological states, and the positive psychological states themselves, are perceived as sustaining renewed effort to cope with the stressful situation.

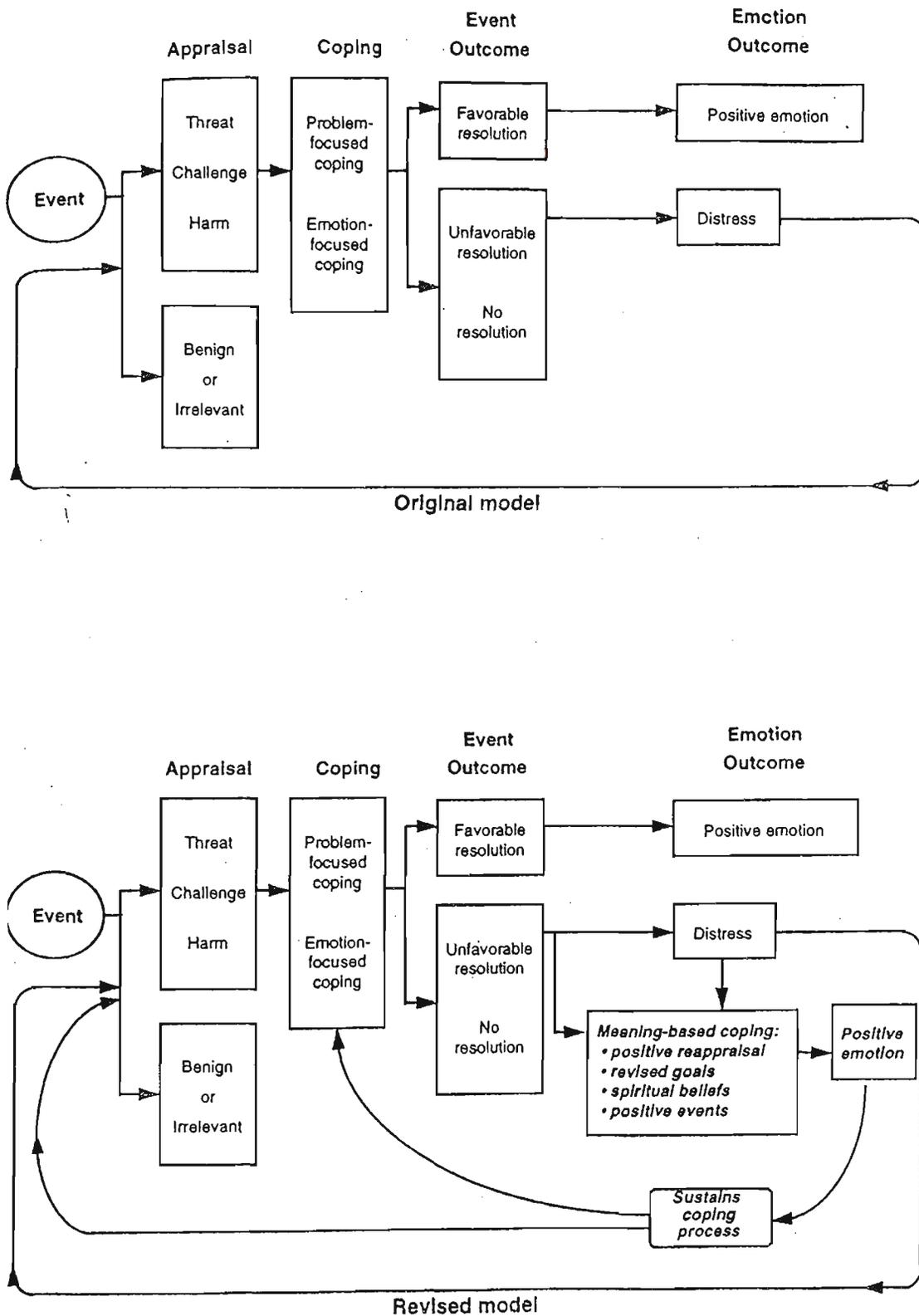


Figure 1. Theoretical model of appraisal and coping processes

In her conclusion, Folkman calls for further research, across a variety of highly stressful situations, to enlarge understanding of positive psychological states in the coping process. In particular, she spells out the need to learn what helps to sustain positive psychological states, what helps to activate the search for these states and how much of them (both in terms of intensity and duration) is needed to be beneficial. In addition, she asserts the need to learn more about characteristics of individuals that may contribute to assist them to generate and sustain positive psychological states. The current research takes up this challenge by focusing on positive coping among women with a diagnosis of early stage breast cancer.

The Lazarus and Folkman (1984) model of stress and coping has been widely adopted by researchers interested in exploring coping with cancer. The next chapter reviews a range of theory and research, much of it based on this model, that relates to coping with cancer in general, and breast cancer in particular.

Chapter 3 Literature Review: Coping with Cancer

Research on breast cancer shows that most women use multiple coping strategies and that coping processes change over time in response to the varying demands of their illness and the broader context (Carver et al., 1993; Epping-Jordan et al., 1999; Glanz & Lerman, 1992; Grassi & Molinari, 1988; Heim et al., 1987; Heim et al., 1993; Heim et al., 1997; Hilton, 1989; Stanton et al., 2000). The review by Glanz and Lerman (1992) identifies three main lines of research into cognitive-behavioral strategies used by women to cope with the stress of breast cancer which seem to have particular importance in terms of adjustment: beliefs about personal control, avoidance/denial, and active information seeking. In addition, recent research indicates the value of acceptance as a coping response (Carver et al., 1993), and also making meaning (Fife, 1995; Taylor, 1983). Finally, perceiving that social support is adequate is also widely recognised as being beneficial for women with a diagnosis of breast cancer (Taylor, Lichtman, & Wood, 1984). Research in all these areas is complex, and hampered by conceptual confusion and problems of definition. Its complexity is due at least in part to the overlap between several variables postulated to assist adjustment. The remainder of this section will summarise findings and limitations in relation to these lines of research, with the exception of active information seeking in which findings are relatively consistent about the benefits of such strategies at certain stages of the treatment (for example, treatment planning) and for the recovery process (Glanz & Lerman, 1992).

The focus is on studies published in the last ten to fifteen years in order that recent developments are canvassed. This helped to highlight areas where further research was needed, which influenced the choice of the thesis research question and aims. The literature review in each of these areas begins with a description of relevant quantitative studies, followed by qualitative studies if available. This choice was made because most research in these areas relating to coping with early stage breast cancer is quantitative, many of these studies involving quite large samples. As was described in Chapter 1, there has been a methodological reliance in coping research on theoretically derived coping checklists from about the mid-1980s. However, over the last decade qualitative assessments of coping have been recognised as offering valuable insights

into stressor-specific coping strategies. Hence both quantitative and qualitative studies are reviewed. The qualitative studies tend to complement the findings of the quantitative studies, and provide fresh ways of understanding issues that quantitative studies could not adequately explore.

Denial strategies

Research into the family of coping strategies called avoidance/denial and their relation to adjustment to breast cancer has produced conflicting results. Glanz and Lerman (1992) cite several studies conducted in the early 1980's (e.g., Timko & Janoff-Bulman, 1985) which found a positive relationship between the use of avoidance-denial and improved adjustment or reduced post-surgical distress. This led Glanz and Lerman to conclude that avoidance and denial may have a "protective effect" on women undergoing surgery and treatment for breast cancer (p. 208). However, more recent research has noted important differences between avoidance and denial, both conceptually and in terms of research findings. Hence they will be considered separately. The section begins with a review of studies of denial in relation to breast cancer with the focus on the issue of whether denial is adaptive or maladaptive. This is followed by a brief overview of the way denial is defined in the literature, including components of denial that have been identified. As the empirical research yields inconsistent findings, measurement issues are also considered along with the difficulty in accessing thoughts and feelings in relation to denial, and problems with external evaluation of denial behaviours. Finally, principles for the adaptive use of denial are presented along with recommendations for future research.

Review of research

Studies of coping with breast cancer, and cancer in general, have produced inconsistent and often contradictory findings, and this is particularly true of the adaptiveness or otherwise of denial processes (Goldbeck, 1997; Livneh & Antonak, 1997; Jarrett, Ramirez, Richards & Weinman, 1992). For example, a study of 122 breast cancer patients by Dean and Surtees (1989) found that women who used denial as a coping strategy had a better chance of remaining recurrence free during a three month follow-up period after surgery than women using coping strategies such as

fighting spirit, stoic acceptance or hopelessness/ helplessness. Similarly, in a prospective study of breast cancer patients, the researchers found that women using either denial or fighting spirit were significantly more likely to be disease-free five years post-surgery than women employing stoic acceptance or hopelessness/helplessness (Greer, Morris & Pettingale, 1979). However, the measurement of psychological responses was based on clinical judgements of verbatim statements from structured interviews, which left room for some doubt about the validity of the underlying constructs. Burgess, Morris and Pettingale (1988) attempted to replicate this finding in a study of 178 newly diagnosed cancer patients (107 with breast cancer) using a more systematic semi-structured interview, the Faith Courtauld Schedule for Coping with Cancer, but were largely unsuccessful. Subsequently, Friedman and associates (Friedman, Nelson, Baer, Lane, & Smith, 1990; Nelson, Friedman, Baer, Lane, & Smith, 1989) further investigated the coping styles among women treated for breast cancer. For example, the study by Nelson et al. (1989) attempted to objectify the constructs of denial and fighting spirit, but provided only partial support for these results. While fighting spirit was positively correlated with measures of adjustment, denial was not significantly related to any of the adjustment measures used. They also found that avoidance was negatively linked to adjustment. Similarly, Friedman et al (1990) found no relationship between denial and any adjustment measures in their study of 49 women with breast cancer. Two later studies (Greer, Morris, Pettingale, & Haybittle, 1990; Pettingale, Morris, Greer, & Haybittle, 1985) confirmed the earlier findings of Greer et al. (1979). For example, Greer et al. (1990) used clinical ratings of denial and emotional distress in a study of 69 women with early breast cancer. They found that significantly more women who used denial had higher survival rates and less recurrence at 15-years post surgery compared with women who had employed other coping responses.

On the other hand, other studies have found that denial is associated with negative or mixed effects. For example, Weisman and Worden (1976) found that denial, as well as passivity and acceptance were associated with greater vulnerability in their sample of 120 cancer patients (37 breast cancer patients). Cooper and Faragher (1993), in a study of 2,163 women undergoing diagnostic tests for breast cancer, found that women who responded with denial were more likely to have malignancies, whilst those who responded with anger were more likely to have a benign diagnosis.

Similarly, Carver et al. (1993) found that the use of denial and disengagement predicted distress in their sample of 59 breast cancer patients. A recent study by Epping-Jordan et al. (1999) of 80 women with early stage breast cancer lends further support to the relationship between denial, behavioural disengagement coping and distress.

Clearly then, empirical studies of denial in breast cancer patients have produced mixed results with regard to the adaptiveness or maladaptiveness of denial, a situation which is mirrored in studies of denial in patients with physical illness in general (Goldbeck, 1997). These inconsistent findings stem from difficulties in defining denial, the diversity and unreliability of measures used for its assessment, the use of different clinical samples, and the choice of heterogeneous outcome measures (e.g., physical versus psychological, short-term versus long-term) (Goldbeck, 1997; Jarrett et al., 1992). In addition, assessment of denial as a fixed state, rather than as an ongoing process (Lazarus & Folkman, 1991), and the limitations of quantitative measures in tapping into subtle, intrapsychic processes such as denial also play a part.

Defining denial

Denial is “an abstract and complex psychological concept”, with definitions of it being influenced by the choice of the underlying theoretical or empirical framework (Goldbeck, 1997, p. 576). According to Lazarus and Folkman (1991), denial “is usually defined as the disavowal of reality” (p. 202). However, they also point out that denial is composed of related or distinguishable components which differ in terms of what is being denied (the object of denial) – Goldbeck’s review (1997) presents components proposed by a range of writers. For example, Wool and Goldberg (1986) identified four objects of denial, namely denial of physical manifestations of illness, the reality of diagnosis, the implications of an illness, and of emotional reactions to illness. Cohen and Lazarus (1979) argued that denial should be distinguished from avoidance, which they argued was a related but different concept. They posit that while denial is the attempt to negate a problem or situation, avoidance involves acceptance of the reality of a threat, but there is a conscious effort not to think about it. Hence for a woman with breast cancer, trying not to think about the situation or seeking to distract herself from distressing thoughts about it are forms of avoidance, not denial. In addition, some other cognitive coping processes that have been classified as denial are probably better

viewed as positive thinking, or minimisation which do not disavow reality (Lazarus & Folkman, 1991).

Measurement issues

As mentioned above, a number of different methodologies - including clinical rating and various rating scales - have been employed to assess the effectiveness of coping strategies, including denial. For example, Carver et al. (1993) used a two-item measure of denial, that included aspects of avoidance coping. Similarly, Greer et al.'s (1979) original assessment of denial came from structured clinical interviews and included patients' cognitive avoidance and minimisation responses. Likewise Burgess et al. (1988) used a combined denial-avoidance measure.

A second issue is identified by Cohen and Lazarus (1979), who discuss the tendency by researchers to view denial as a fixed endpoint or static state of mind rather than as a process or constant changing transaction. As they indicate, a process like denial is subject to challenge and change, and its use may differ in discussions with different people. For example, a woman may deny the diagnosis of breast cancer to her GP but leave the office and burst into tears overwhelmed by the thought of having cancer, or share her thoughts and feelings with another professional. This may be an unconscious process, in which the woman apparently believes one thing but "knows" the true state of affairs on a deeper and possibly unverballed level. The process of denial, then, is influenced by such variables as the circumstances, the available evidence, the social pressures and personality. This in turn has implications for the assessment of the denial process; it suggests the need to observe the coping pattern at various times and different stages of the stressful encounter. However, much of the research on denial has been cross-sectional.

Another measurement issue involves the difficulties in accessing thoughts and feelings in relation to denial. As Carver, Scheier and Pozo (1992) say:

"many of these facets of denial and avoidance coping are hard to measure and thus hard to study. Some of them are subtle qualities of experience that are not

easily spelled out in assessment devices and not easy for people to recognize in their own behaviour." (p. 176)

In fact, some of the thoughts, feelings and behaviours might not be in conscious awareness.

Sorting out the adaptiveness or otherwise of denial/avoidance strategies is further complicated by the conceptual difficulties in trying to specify whether or not a particular response by a woman with breast cancer implies denial. For instance, when a woman says she feels optimistic that she will recover, or tries to make something positive from the experience of having breast cancer, is she actually engaging in denial? Similarly, if she says she is trying not to dwell on her feelings of distress so that she can "get on with life", is she using denial?

As can be seen, there are a number of difficulties in relation to identifying, measuring and evaluating (interpreting) the coping strategy of denial. However, existing research indicates that denial strategies have significance for adjustment of women coping with breast cancer although the findings are contradictory. In addition, these contradictions cannot be easily resolved because of conceptual and measurement difficulties in relation to avoidance/denial. The implications of this for the current research proposal will be elaborated later in this chapter.

Principles for adaptive use of denial

As Lazarus and Folkman (1991) point out, it is possible to provide support for both the costs and benefits of denial and denial-like processes. They outline four principles that specify the conditions under which denial and denial-like forms of coping might have adaptive or maladaptive outcomes. They are:

1. If there is nothing constructive a person can do to manage a harm or threat, denial and denial-like processes may provide some comfort and thus enhance coping. On the other hand, if denial results in a lack of action of potential importance, such as compliance with treatment, then it would be maladaptive.

2. While it may be adaptive to deny certain facets of a situation, denial of the whole situation is likely to be maladaptive. Patients with cancer may deny the implications in terms of possible life-threat from their diagnosis, which is less dangerous than denying the fact that they **have** cancer as the latter would interfere with treatment. Denial of implication is like illusion or positive thinking which may be a valuable psychological resource, and not a disavowal of reality.
3. In situations that are changeable and which vary in terms of controllability, the best coping strategy may be one that reduces arousal (that is, possibly some denial processes) without preventing a person from attending to information that is relevant to their situation.
4. There are time-related implications in the use of denial. For example, denial may be less harmful and more helpful in the early stages of a crisis, such as a diagnosis of cancer, when it may be difficult to take the whole situation on board, than in later stages.

Clearly, it is important to evaluate denial carefully being mindful of what is being denied, what the situation is (controllability, timing factors) and person factors (e.g., psychiatric history).

Conclusion

Denial is a complex concept which has been defined and measured in many ways. Hence it is not surprising that empirical research has yielded inconsistent and often contradictory findings. In addition it can be seen that problems are posed by the fact that it is difficult to tap into a person's thoughts and feelings, some of which may not be in conscious awareness. These difficulties suggest the need for research in which denial is clearly defined and conceptualized including clarification of which dimensions or facets of denial are being considered. In addition, the process nature of denial needs to be acknowledged, along with the various influences of situational and temporal factors.

Avoidance

Review of research

In comparison with denial, research in the last ten years or so has tended to produce more consistent findings about the association between avoidant coping and psychological morbidity. Cognitive avoidance has been reported to be commonly used as a coping strategy, at least by women with breast cancer (Jarrett et al., 1992; Thomas & Marks, 1995), and has been linked with increased distress in a range of studies. For example, in a correlational study of 227 women with early stage breast cancer, Hilton (1989) investigated the relationship between a set of coping strategies (the Revised Ways of Coping Scale, Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986) and a set of psychosocial variables including perception of uncertainty, commitment, threat of reoccurrence appraisal, and perception of control of the course of disease. She found that those women using escape-avoidance, who did not positively reappraise their situation, and who rejected responsibility for their situation also demonstrated low commitment, high uncertainty, and threat of disease recurrence and felt not in control of the cancer course. Further, those women who did not use escape-avoidance, who sought social support, used problem-solving, positive reappraisal and self-control showed low threat of recurrence and a high perception of control of the cancer situation.

Other cross-sectional studies also add to the body of evidence for the association between avoidant coping and poorer adjustment. For instance, a study by Dunkel-Schetter, Feinstein, Taylor and Falke (1992) explored the relationship of patterns of coping and emotional distress in 603 cancer patients, of whom 42 percent had breast cancer. Using the Ways of Coping-Cancer Version Questionnaire, they extracted five factors of coping from their data: seeking and using social support, focusing on the positive, distancing, cognitive-escape avoidance, and behavioral escape-avoidance. They found that escape-avoidance was associated with more emotional distress, which, as they point out, is consistent with the findings of Weisman and Worden (1976-77). Similarly, Rodrigue, Behen and Tumlin (1994), using a different measure of coping strategies, examined the relationship between

psychological adjustment and coping strategies in 132 cancer patients, of whom 29% had breast cancer. They found that the coping strategy of avoidance (as well as acceptance-resignation) was highly associated with negative affect. Manne et al., (1994) explored relations among coping, physical symptoms, and affect in 43 women undergoing adjuvant chemotherapy for breast cancer. All women were assessed at the same point in their treatment; coping was assessed with the revised version of the Ways of Coping Questionnaire (Folkman et al., 1986). They found that escape-avoidance was associated with emotional distress.

Further support for this position can be found in longitudinal studies by Stanton and Snider (1993) and Carver et al. (1993). The former carried out a prospective study of 117 women attending a surgical practice for breast biopsy during an 18-month period, of whom 36 received a diagnosis of cancer. They were administered a battery of tests before biopsy, after diagnosis and (for those with cancer) after surgery. The tests included, as predictors, measures of locus of control, dispositional optimism, cognitive appraisal (for example, threat and challenge), and coping. This last was assessed with the revised 66-item Ways of Coping Questionnaire (Folkman et al., 1986), whilst psychosocial adaptation was measured with the Profile of Mood States (McNair, Lorr, & Droppleman, 1971). They found that cognitive avoidance coping "was a particularly important predictor of high distress and low vigor" at all measurement points, that is, pre-biopsy, 24 hours before surgery and several weeks after surgery (p.16).

Carver et al. (1993) also explored coping with a diagnosis of breast cancer in a study that was both prospective and longitudinal in design. They followed their sample of 59 women over a twelve-month period and found avoidance coping was consistently related to higher levels of distress (and predicted distress at the six-month follow-up). They further assert that their findings "complement and extend" those of others in the area of stress and coping, which show that "avoidance coping is positively tied to concurrent distress...(and) is also a prospective predictor of distress when confronting a major stressor or chronic burden" (p. 385).

Two recent studies have examined the relationship between coping (including avoidance coping) and adjustment using more fine-grained distinctions among coping

strategies. The first of these is a study by Epping-Jordan et al. (1999) which examined the process of psychological adjustment to breast cancer at diagnosis and at 3- and 6-month follow-ups in 80 women with Stage I-Stage IV breast cancer. They assessed dispositional optimism, anxiety/depression, stress response symptoms (intrusive thoughts and avoidance of these thoughts) and coping (Coping Strategies Inventory, Tobin, Holroyd, Reynolds, & Wigal, 1989). This scale contains four secondary scales which assess problem- and emotion-focused engagement and disengagement. This reflects their view that coping responses can be distinguished along two dimensions, the first involving either engagement or disengagement strategies and the second focusing on either the problem or one's emotions about the stressor (Compas, Connor, Osowiecki, & Welch, 1997). The engagement/disengagement dimension corresponds to approach/ avoidance behaviours (see also Holohan, Moos & Schaefer, 1996) whilst the problem/emotion dimension addresses the target or focus of avoidance/non-avoidance. Problem-focused engagement involves problem-solving and cognitive restructuring; problem-focused disengagement is composed of problem avoidance and wishful thinking. Emotion-focused engagement comprises social support and expressed emotion, whilst emotion-focused disengagement is composed of social withdrawal and self-criticism. Like Carver et al. (1993), they found that coping responses accounted for distress in different ways across the three measurement points. At diagnosis, and after 6 months, both problem-focused and emotion-focused disengagement were associated with more negative psychosocial outcomes, but these were not evident at 3 months. Best outcomes were associated with problem-focused engagement. Although Epping-Jordan et al. (1999) use a separate measure of avoidance as an outcome measure, it would not be unreasonable to consider disengagement as a comprehensive conceptualisation of avoidance as a coping strategy. This study demonstrates some of the confusion in the use of this term.

The second study, by Stanton et al. (2000), is also supportive of engagement (non-avoidance) as a positive strategy, including both emotion- and problem-focused engagement. Stanton and her colleagues investigated the way emotionally expressive coping related to psychological adjustment to breast cancer in a longitudinal study of 92 women with early stage breast cancer. As they point out, studies of adjustment to cancer indicate that using cognitive and behavioural avoidance is associated with

poorer levels of adjustment. In addition, they propose that emotion-approach coping (i.e., coping through actively processing and expressing emotion: Stanton et al., 1994; Stanton et al., 2000) is “the opposing strategy” to cognitive and behavioural avoidance (p. 875) and would be beneficial. However, conclusions in the empirical literature often indicate that emotion-focused coping is maladaptive (e.g., Moos & Schaefer, 1993). Stanton and her colleagues assert that measures of emotion-focused approach coping have been inadequate for several reasons; for example, emotion-focused strategies comprise several distinct mechanisms, including strategies aimed at both avoiding and approaching (e.g., emotional expression) the stressor. This causes interpretational difficulties when these opposing strategies are included in the same scale. Hence their study of women with breast cancer used scales, developed by Stanton, Danoff-Burg, Kirk, and Cameron (2000) to overcome conceptual and methodological difficulties, to assess coping through processing and expressing emotion. The women completed measures within 20 weeks following medical treatment and three months later. They found that women who coped through expressing emotions surrounding cancer at study entry had enhanced physical health and decreased distress over the next few months compared with those low in emotional expression.

Research in other low-control situations also shows a negative association between avoidance and adjustment, for example Terry and Hynes, 1998 (IVF patients), Major, Richards, Cooper, Cozzarelli, and Zubeck, 1998 (Abortion), and Billings, Folkman, Acree and Moskowitz, 2000 (HIV/AIDS).

Conclusion

The studies described above show that there is considerable evidence for the association between the use of avoidance coping and poorer psychological adjustment. However, recent studies using more fine-grained distinctions among coping strategies have highlighted the complexities in this area and the need to consider both the targets of the coping strategy as well as the way avoidance behaviours may be operationalised. The use of a range of measures of avoidance also means that it is difficult to compare results across studies.

Acceptance

Review of research

Similar difficulties in conceptualisation and measurement have characterised research relating to the coping strategy of acceptance. The positive adaptive significance of acceptance was highlighted by the study conducted by Carver et al. (1993), which not only found that denial was related to higher levels of distress, but that its converse, acceptance, was used widely by the study participants and appeared to have beneficial effects for them. Indeed, acceptance was the coping response most often reported at each measurement point, apparently becoming more common during the 12-month study period, and predicted less distress. In this study, coping was measured by a self-report inventory called COPE (Carver et al., 1989), which assesses a wide range of coping responses, including both denial and acceptance.

Carver et al.'s (1993) findings highlight the problems in definition and conceptualisation of the notion of acceptance. According to Carver et al. (1992):

"acceptance means restructuring one's understanding of the situation one is in - assimilating a new reality. In contrast, refusal to accept the reality of the problem (denial) means attempting to cling to a worldview that is no longer valid" (p. 183).

This definition, with its positive overtones of "coming to grips" with a difficult situation, is quite different in emphasis from the way the term "acceptance" was used in earlier research. For instance, studies conducted at the Faith Courtauld Research Unit (London) used the term to mean stoic acceptance, which has negative overtones of giving up on life. Thus, Greer and Watson (1987) describe the category of stoic acceptance as:

"The patient accepts the diagnosis, does not seek further information and adopts a fatalistic attitude. Example: 'I know what it is, I know it's cancer, but I've got to carry on as normal, there's nothing I can do'" (p. 444).

Researchers at the Courtauld Research Unit, having begun work in the early 1970's on breast cancer and coping responses, went on to develop the Mental Adjustment to Cancer (MAC) scale which, as discussed previously, identified four categories of mental adjustment (psychological responses) to cancer: fighting spirit, denial, stoic acceptance and helplessness/ hopelessness. Their research, which included a five-year and ten-year follow-up, found that those women who responded with fighting spirit or denial were more likely to have recurrence-free survival than those who reacted with stoic acceptance or helplessness/ hopelessness. In addition, stoic acceptance and helplessness/ hopelessness were linked with increased psychological vulnerability. However, a later study at the unit, with a larger sample of 178 breast cancer patients, was unable to replicate these four categories of coping response (Burgess et al., 1988).

Similarly, Weisman and Worden (1976-77) defined "acceptance" with negative overtones and also found it to be associated with greater psychological vulnerability. Given this subtle, yet important difference in the usage of the term "acceptance", it is not surprising that the results from the research by Carver et al. (1993) appear to be inconsistent with earlier findings. Further research exploring the use by women of this coping strategy, as conceptualised by Carver and associates, would help to clarify its prevalence, benefits and the underlying psychological processes (of coming to terms with a new reality) which it reflects.

In the last ten years or so other researchers have further explored the role of acceptance in relation to coping with cancer. For example, the study by Rodrigue et al. (1994), referred to in the previous section, used the Medical Modes Coping Questionnaire which is composed of three scales – confrontation, avoidance, and acceptance-resignation. As the authors say, acceptance in this scale is characterised by passivity and capitulation, that is, acceptance with negative overtones of giving up. They found that coping strategies characterised by acceptance-resignation were highly associated with negative affect. Similar findings were reported by Ferrero, Barreto and Toledo (1994) who explored the relationship between adjustment to cancer and quality of life in a longitudinal study of 68 newly diagnosed non-metastatic breast cancer patients. They used a Spanish version of the Mental Adjustment to Cancer (MAC) scale (Watson et al., 1988) and found that "Fatalism" (passive acceptance) responses

were negatively correlated with well-being. Finally, Heim, Ladislav, and Schaffner (1997), in a prospective and longitudinal study of 74 women with breast cancer, report that “poor coping” includes a pattern of resignation-fatalism combined with a passive-avoiding attitude or blaming self and environment.

On the other hand, recent research by Astin et al. (1999), Shapiro et al. (2001) and Cotton, Levine, Fitzpatrick, Dold and Targ (1999) suggests that acceptance, defined with positive overtones, may play an important role in well-being. More specifically, Cotton and colleagues (1999) examined the relationships among spiritual well-being, quality of life and psychological adjustment in 142 women diagnosed with breast cancer. Among other things, they used the Mini-Mental Adjustment to Cancer scale (Watson et al., 1994) and found a positive correlation between fatalism and quality of life. As they say, given the definition of fatalism used, the correlation seemed unusual which suggested to them that the concept of fatalism may be more complex. Consequently a member of their team conducted further research into the construct with a sample of 120 women diagnosed with primary and metastatic cancer (Fitzpatrick, Levine, Zelman & Heide, 2000). Preliminary findings suggest that fatalism is positively related to quality of life, as well as spirituality, and that it “might be better construed as a type of acceptance, rather than stoic resignation” (Cotton et al., 1999, p. 434).

These findings are supported by the work of Astin et al. (1999) and Shapiro et al. (2001). This team of researchers set out to explore the construct of control because they argued (Shapiro, Schwartz & Astin, 1996) that the relationship between control and health is not a simple linear one. They also assert that acceptance, which they define as a “positive yielding mode of control”, is an integral part of control. This issue is overlooked in Western psychology because it has a bias to instrumental or a “positive assertive mode of control”. As they say, this bias:

“is reflected in most psychological control assessment inventories and many coping questionnaires, which do not distinguish between positive yielding (acceptance) and negative yielding (too little control)” (p. 1218).

They define positive yielding as acceptance in which “one is able to let go of active control efforts and accept the situation or oneself without resignation or helplessness”. Negative yielding, on the other hand, is “passivity in which one is fatalistic or feels helpless and fails to use active control efforts when they can or should be used” (Astin et al., 1999, p. 102).

Astin and colleagues (1999) explored the relationship of modes of control and desire for control to psychosocial adjustment in a longitudinal study of 58 women with stage I or stage II breast cancer. Their results showed that at 8-month follow-up, women who had a high desire for control and were high in positive yielding (acceptance) showed the best psychosocial adjustment, whereas women who had a high desire for control and were low in positive yielding showed the poorest adjustment. These findings suggest that balanced use of active and yielding (acceptance) control efforts may lead to optimal psychosocial adjustment. Further support comes from the findings presented by Shapiro and colleagues (2001) from a component of a larger ongoing psychosocial intervention study in which the authors examined the relationship between quality of life and psychosocial variables as well as the psychological control construct. The sample consisted of 63 women diagnosed with stage II breast cancer who were within two years posttreatment. Preliminary analyses showed that quality of life and emotional well-being were significantly correlated with positive assertive control and positive yielding control (acceptance). As the authors point out, their measure of positive yielding mode of control was similar to the measure used by Cotton and colleagues (1999), and hence the findings of both groups are consistent.

This review of studies of “acceptance” as a way of coping with breast cancer highlights the confusion in terms of the way acceptance is conceptualised, and also the variety of ways in which it is measured. Given this confusion, it is not surprising that contradictory findings have emerged about the value of acceptance as a coping strategy. While recent researchers have begun to clarify its conceptualisation, it appears there is a need for further refinement in conceptualisation and measurement of acceptance (Shapiro et al., 2001). For instance, Gottlieb (1997) highlights the need to explore various dimensions of acceptance including cognitive and affective components. He says:

“acceptance and resignation are not necessarily passive modes of adaptation that involve surrender and defeat. Instead, they involve both the realistic recognition that certain aspects of one’s self or one’s circumstances cannot be altered and an accompanying emotional calm.” (p. 27)

If that calm is not present, there may be anger and defiance. In addition, he posits that it is important to ascertain which aspect of a chronically stressful situation a person is being called upon to accept or resign to. For example, a woman with breast cancer might find it relatively easy to accept a diagnosis of breast cancer, but not the reality of disfigurement, or lymphoedema or a poor life expectancy. As he points out, there is also a dearth of longitudinal studies about the adaptive value of acceptance at different points in time.

Some of these issues were addressed in a recent qualitative study by Wright and Kirby (1999) of adjustment among end-stage renal failure (dialysis-dependent) patients, their partners and home dialysis nurses. They found that acceptance of illness was an important part of adjustment, and delineated three components, namely emotional acceptance, behavioural acceptance and cognitive acceptance. In addition, they noted the dynamic nature of acceptance, such that changing conditions could affect the extent and degree of acceptance. Studies of this nature would be useful in the further exploration of adaptive coping of women with breast cancer.

Conclusion

The studies described above show that acceptance appears to be a coping strategy used widely by women who are trying to come to terms with a diagnosis of early stage breast cancer. Research has produced contradictory findings about the association between the use of acceptance and psychological adjustment, which appears to stem from problems in conceptualisation. Acceptance defined with positive overtones of “coming to grips” with a situation appears to be associated with enhanced psychological well-being. On the other hand, acceptance which is conceived in terms of resignation and “giving up” is associated with increased psychological vulnerability. However, the fact that studies have used a wide range of measures also means it is difficult to compare results across studies. Recent work suggests the need for further

clarification of the concept of acceptance and refinement in measurement. Qualitative studies could usefully extend understanding in this area.

Social Support

It is widely recognised in the literature that social support is psychologically beneficial for women with breast cancer (e.g., Holland & Holahan, 2003; Northouse, 1988; Taylor & Dakof, 1988; Zemore & Shepel, 1989). Reviews have been presented by Glanz and Lerman, 1992; Helgeson and Cohen, 1996; Irvine et al. 1991; Nelles, McCaffrey, Blanchard and Ruckdeschel, 1991; and Royak-Schaler, 1992. More specifically, studies cited by Glanz and Lerman (1992) suggest that these benefits include improved adjustment, emotional well-being and reduced fear of recurrence. In an Australian study of 30 survivors of breast cancer (Clarke et al., 1993), the researchers found that "the single most important factor in assisting these women to cope with breast cancer...is social support" (p. 68). On the other hand, there is also evidence that not all social support is helpful (Helgeson & Cohen, 1996).

In addition, despite the consistent suggestion in the research literature of the relationship between social support and positive adjustment, there are conceptual and methodological problems which mean that some areas of ambiguity remain (Helgeson & Cohen, 1996; Irvine et al., 1991; Nelles et al., 1991; Taylor & Dakof, 1988). For example, there is disagreement about the best way to define and measure social support, and many samples used in studies are small and unrepresentative. In addition, there is a lack of a clear theoretical framework to explain how and why social support helps women cope with breast cancer - that is, the mechanisms underlying the beneficial effects of social support (Nelles et al, 1991). Finally, the majority of studies have been cross-sectional and hence the issue of causality cannot be addressed (Alferi, Carver, Antoni, Weiss, & Duran, 2001; Helgeson & Cohen, 1996).

This section will present a definition of social support and its place in the stress and coping model before outlining some key findings in relation to perceived adequacy of support, and helpful as well as unhelpful support. In addition it will describe recent studies in a number of important areas where findings are limited or contradictory. These areas include the relationship between helpful types of support and adjustment,

types of support that are helpful at various stages following a diagnosis of breast cancer, whether some sources of support are more beneficial than others, the reciprocal nature of the relationship between support and distress, the role of person characteristics and interpersonal variables in understanding the relationship between social support and adjustment, and the processes that occur in informal helping relationships that affect well-being.

Definition

Social support is usefully defined as interpersonal transactions involving "functions performed for an individual under stress by significant others such as family members, friends or professionals" (Nelles et al., 1991, p. 22). These functions are classified in various ways but usually include emotional concern, instrumental aid and informational aid (including information relevant to the environment and to self-appraisal). Research has differed in terms of its focus on the size of the support network, its perceived adequacy and types (that is, functions) of support (Roberts, Cox, Shannon & Wells, 1994). Perceived social support refers to perceptions of the adequacy of the support offered to the individual and its impact on emotional well-being. There is evidence that perceived adequacy of support is more predictive of positive outcomes than availability of support and hence it is important to differentiate between social support networks and perceived adequacy of support (Hann, Oxman, Ahles, Furstenberg, & Stukes, 1995). They might also exert different effects on health and psychological functioning (Roberts et al., 1994).

Social support and models of coping

According to cognitive appraisal model, social support and coping share common functions. For example, problem-focused coping and instrumental support have the same aim of changing the situation that is causing stress. On the other hand, both emotion-focused coping and emotional support try to reduce or manage the negative emotions arising from stressful situation. By reconceptualising support as coping assistance, models of coping and theories of support can be integrated (Thoits, 1986).

Review of research

Studies relating to the adequacy of social support that women experience following treatment for breast cancer have produced conflicting results. Some researchers (for example Peters-Golden, 1982) found that the majority of women felt that the support they received was inadequate. Other studies (e.g., Lichtman & Taylor, 1986; Zemore & Shepel, 1989) reveal a more positive picture about the support available to women in their studies. For example, Lichtman and Taylor (1986) found that the 78 women in their sample reported a high level of social support, with over 75% rating their husbands, other family members and friends as providing a great deal of support. These findings are supported in a study by Zemore and Shepel (1989) who used questionnaire data from 301 breast cancer patients and a comparison group of 100 women with benign breast lumps. They found that the cancer patients perceived greater emotional support from friends and family than did the comparison group. Indeed, their research suggests that the women with breast cancer felt a strengthening of their relationships with important others.

Improvements in treatment and support services since the 1980's (Antoni et al., 2001) may partly account for this more positive picture. However, as is pointed out by Achte et al (1988), defensive reporting may be contributing to findings of closer relationships with main sources of support, such as family members. It would seem advisable, then, for future research to continue to address the issue of adequacy of support.

A number of descriptive studies have explored the issues of the kinds of support women desire from their network members. Several studies found that women identified emotional support as the most helpful kind of support, regardless of which network member was the provider. In addition, informational support from health care professionals was perceived as helpful, but unhelpful when the provider was family or friends (Helgeson & Cohen, 1996). Instrumental support is perceived to be less commonly provided (Pistrang & Barker, 1995).

A related issue which has received some attention is the nature of the problems in social support experienced by women with breast cancer, that is, unhelpful

behaviours (Taylor & Dakof, 1988). In the study by Taylor and her colleagues of 78 women with breast cancer, the researchers found that relatively few of the women reported rejection by family and friends. However, about 42% reported that they were rejected or isolated by a particular person, including spouse, relatives, close friends and casual friends. Of particular interest is the finding that a third of the women reported that, although they were generally satisfied with the support they received from their spouse since diagnosis of breast cancer, there was one persistent communication difficulty with their spouse. In essence, the difficulty arose because the women felt a need to express their fears about the possibility of their cancer recurring and death, whilst their spouses expressed the view that talking about it would not be helpful for their wife's adjustment and health. In other words, there was a preference, by the spouses, for concerns to be put out of mind and ignored.

According to Taylor and Dakof (1988), this preference seems to be a typical problem for individuals who have suffered other misfortunes (traumatic incidents) apart from cancer. Supporting evidence for this view comes from Pennebaker (1992), who reports on research he conducted with colleagues on the psychosocial and health effects of a large earthquake in San Francisco (which occurred in 1989), which found a similar pattern in coping response amongst the 1,000 residents in their sample. They monitored reactions over almost a year, and found that over a period of several weeks, residents talked less about the earthquake experience although they still would have liked to talk about it. The reason for their constraint (inhibition) was that other people did not want to listen. This may have important implications as Pennebaker suggests that there are links between inhibition and an increase in health problems. It would seem, then, that adequate opportunity to express fears and anxieties in relation to breast cancer merits further attention (Stanton et al., 2000).

Other studies have identified a number of unhelpful behaviours, including minimizing the problem, forced cheerfulness, being told not to worry, medical care being given without emotional support, and insensitive comments of friends (Dakof & Taylor, 1990; Lavery, 1997). As can be seen, a number of these behaviours discourage open communication and discussion of feelings.

Another area in which research findings are limited is the relationship between types of support that are helpful to women with breast cancer and adjustment, and the types of support that are most helpful at various stages following a diagnosis of breast cancer (Clarke et al., 1993; Nelles et al., 1991; Northouse, 1989; Taylor & Dakof, 1988). In terms of the latter, a descriptive study of thirty women found that the participants indicated that they needed mainly information and emotional support at the time of diagnosis, whilst later in treatment practical support (such as help with housework and children) assumed more importance (Clarke et al., 1993). As the women began to resume their normal lives, emotional support was found to be very useful again.

The former issue is addressed in a review by Helgeson and Cohen (1996). The authors concluded that emotional support, in addition to being the most desired by patients, also helps adjustment to breast cancer while there is little evidence that instrumental support is beneficial. However, this view of instrumental support has been challenged by the authors of a recent, prospective study (Alferi et al., 2001) of 51 Hispanic women being treated for early stage breast cancer. The researchers examined the relationships between distress and different types (emotional and instrumental) and sources (spouse, family members, friends) of support, with measurement at presurgery, postsurgery and at 3-, 6-, and 12-months. They found that emotional support from friends and instrumental support from spouse at presurgery predicted lower distress postsurgery. Whilst these findings confirm that social support has emotional benefits for breast cancer patients, they contradict Helgeson and Cohen's conclusion about the value of instrumental support.

In addition, their findings show that the benefits occurred early in the cancer experience which would explain why another prospective study (Bolger, Foster, Vinokur, & Ng, 1996) found no benefit from support by significant others. In the latter study, participants were assessed for the first time 4 months after surgery. Hence their finding is consistent with the findings of Alferi et al. (2001), which showed no benefit from support by that time.

The study by Alferi et al. (2001) also highlighted two other important areas in relation to support where knowledge is limited, namely whether some sources of

support are more beneficial than others, and the reciprocal relationship between support and distress. In terms of the former, the researchers found no evidence of benefit from support from family members apart from the spouse. They acknowledge this result was somewhat surprising given that family is emphasised as a key source of support among Hispanics, and could offer no explanations. Overall, more questions were raised which required further research.

On the other hand, the issue of the reciprocal relationship between support and distress has attracted attention from several recent studies, including the one by Alferi et al. (2001). For example, the study by Bolger et al. (1996) addressed this issue with a sample of 102 breast cancer patients and their significant others who were interviewed at 4 and 10 months after diagnosis. They found that support provided by significant others eroded over time and that supporters withdrew in response to psychological distress. These findings were consistent with those of Alferi et al. (2001) who found that distress at several time points predicted erosion of subsequent support, particularly instrumental support from women in the family. However, a decrease in support did not occur in every source of support (especially the spouse) and it was more likely for instrumental than emotional support. On the other hand, illness-related disruption of recreational and social activities at 6-months elicited greater support at 12 months. Another longitudinal study (Moyer & Salovey, 1999) examined this issue with a sample of 93 women with breast cancer and a subset of partners who completed assessments of social support and psychological distress at the time of surgery and 3- and 13-months post-treatment. Their findings also showed that high levels of psychological distress led to relative decreases in social support. Like Bolger et al. (1996) and Alferi et al. (2001) they found that, unlike psychological distress, physical limitations predicted relative increases. These findings suggest that extreme life stresses, such as breast cancer, “may overwhelm significant others, eroding their ability to provide effective support” (Bolger et al., 1996, p. 283). Taken together, these findings point to the need for further research in this area. In addition, they highlight the dilemma confronting victims of life crises: If they reveal high levels of distress, they risk driving away significant others, but if they are not open about their distress, they may not receive the support they need (Bolger et al., 1996). Bolger et al. (1996) also suggest that this may be one reason that people confronting extreme life stress, such as breast cancer, turn to sources of support outside their informal social network, such as support groups.

Despite these general trends, it is also important to recognise that different kinds of social support may be valuable for different individuals. For instance, it may be particularly important for women who are high on emotional control (and who tend to inhibit expression of feelings) to have ready access to emotional support (Royak-Schaler, 1992). Studies by Ell, Mantell, Hamovitch and Nishimoto (1989) and Roberts et al. (1994) provide additional information about the variable effects of social support which hinge on personality characteristics. The former explored the relationship between sense of control, social support and coping in a sample of 369 patients with breast, colorectal or lung cancer (55 percent of whom had breast cancer). They found that there were significant independent associations between support and control and adjustment. Roberts et al. (1994), on the other hand, explored the impact of social support in a sample of 135 women with breast cancer and found that the significant association between social support and adjustment was substantially weakened or eliminated when they controlled for the response bias of social desirability. Such findings reinforce the central role played by characteristics of the person in understanding the relationship between social support and adjustment to breast cancer.

It is widely recognized that both breast cancer patients and their families are intricately involved in the coping process following diagnosis and treatment for breast cancer (Baider & Kaplan De-Nour, 1988; Royak-Schaler, 1992). Ten years ago there was relatively little research that drew data from a wider range of sources (Clarke et al., 1993; Northouse & Swain, 1987). However, during the last decade there has been increasing recognition of the need to draw data more widely than the woman herself. For example, a study by Hannum, Giese-Davis, Harding, and Hatfield (1991) explored the role of individual and marital variables in 22 breast cancer patients and their husbands. They found that the best predictors of the woman's psychological distress were the husband's coping behaviours and the couple's rating of the quality of their relationship, while the husband's distress was predicted by both his own and his wife's coping behaviour. Similarly, Lavery (1997) found that cancer patients and their partners (56 breast cancer patients, 50 breast cancer partners, 47 prostate cancer patients, and 41 prostate cancer partners) reacted to the cancer experience as interpersonal units rather than as individuals. In addition, reciprocal effects of patients' and partners' coping were found; the coping of partners and perceptions of marital

dissatisfaction were significant predictors of distress for patients. Such findings demonstrate the importance of interpersonal as well as individual variables in determining coping and adjustment.

Other researchers have argued for the need to move away from global measures of perceived support and to focus more on specific processes that occur in relationships that affect well-being (Pistrang & Barker, 1995). One example is the study by Pistrang and Barker (1995) of 113 women who had received a diagnosis of breast cancer within the previous year. The researchers used structured interviews to examine the process of informal helping (dyadic communication where one person in a relationship is attempting to alleviate the emotional distress being experienced by the other). They found that satisfaction with the partner relationship was positively associated with psychological well-being, and that good communication with the partner was characterised by high empathy and low withdrawal. As the authors point out, this last finding is consistent with other studies suggesting that partner's avoidance of open discussion about the cancer experience can be difficult for the patient. However a recent study by Manne (1999) further highlights the complexity of variables that need to be considered. In her study of 129 cancer patients (57 with breast cancer), Manne examined the impact of spouse criticism and avoidance on cognitive processing. She found that spouse criticism interfered with cognitive processing of cancer, and that spouse criticism and avoidance may have differential effects on cognitive processing. The author called for future research to examine spouse criticism more closely and advocated the use of observational methods as part of that exploration.

Another study by Pistrang and Barker (1998) used observation and self-report to examine several process and outcome variables in informal helping that occurred when 26 breast cancer patients (disclosers) talked about illness-related concerns with their partner and, in a separate conversation, with a fellow patient. From the observer's perspective, the fellow patients were more helpful, empathic, and supportive, less critical, and used more self-disclosure than the partners. However, the disclosers rated both conversations highly. In addition, the observers noted that higher discloser depression was associated with greater helpfulness, more exploration of feelings, and higher supportiveness from the fellow patient, whilst it was associated with less helpfulness and more criticism from the partners. In other words, partners and fellow

patients appeared to have different styles of helping. Whilst the authors acknowledge the limitations of their semi-naturalistic study design, they also suggest that future research is needed to examine more closely the impact of different types of informal help on the quality of life of people experiencing cancer. They point out that it is difficult to study informal helping with traditional experimental designs, and that naturalistically oriented research designs are appropriate.

In a similar vein, a study by Hilton (1994) examined the communication patterns of 41 couples where the woman had a recent diagnosis of early stage breast cancer. The results showed that there were three major types of discussion patterns about doubts, fears and emotional issues, which related to the degree to which the couples shared similar or different views about the importance of talking. One group tended to talk openly or reasonably openly, while a second group did not talk to each other – although some of these talked to other people. In the third group there were divergent views among the couples about the importance of talk, and here it was noted that there were more problems in communication. On the whole, selective open disclosure was seen to be the most satisfactory of the patterns.

As part of her research Lavery (1997) conducted semi-structured interviews with 16 breast cancer patients and their partners, and 12 prostate cancer patients and their partners to gather detailed information about their individual and interpersonal coping efforts, and social support issues. A number of her findings supported previous research; for example, partners were the most important source of instrumental and emotional support for breast cancer patients. In addition, new findings emerged from the data including the identification of interpersonal coping strategies such as “protective buffering” (one partner or the other regularly denies their anxieties and concerns to the other) and “active engagement” (both partners were mutually engaged in meeting the demands of the illness in a variety of ways).

The study of informal helping also encompasses support groups. The value of support groups is another area where research evidence is limited, although existing findings suggest that there is again variability in importance that women place on this type of support. For example, Clarke et al. (1993) found that the women in their study had very definite ideas about support groups and the role they played. In fact, nearly

half of the 30 women believed that a support group was not for them. However, some research evidence suggests that women who regularly participate in support groups may have both a better quality of life and survival rate than those who do not (Cunningham, Phillips, Lockwood, Hedley & Edmonds, 2000; Spiegel, Bloom, Kraemer & Gottheil, 1989). Helgeson and Cohen (1996) suggest that the effectiveness of peer discussion groups, which aim to provide emotional support, is not very convincing. On the other hand educational groups, aimed at providing informational support, were probably more effective. However, they also point out that both methodological weaknesses and conceptual problems characterise the literature, and hence they conclude that it is premature to discard the belief that peer discussion groups are beneficial. A detailed evaluation of the large literature on the value of intervention groups for illness populations is beyond the scope of this thesis (see, for example, Helgeson, Cohen, Schulz, & Yasko, 2001). However, given the potential importance of these outcomes for women and their families, further research is needed to extend findings in this area.

Conclusion

There is a consensus among researchers that social support is psychologically beneficial for women with breast cancer. However, not all social support is helpful. The area is complex because social support is a multi-dimensional construct. It can be seen that various questions in relation to social support need to be addressed in future research. These questions include further consideration of the perceived adequacy of social support for women with breast cancer, not only in terms of the overall amount of support being received, but also the types and sources of support that are available and how they match up with the needs and characteristics of the individual. In addition, research needs to address the interpersonal processes that occur in informal helping relationships. Qualitative research methods could be usefully employed to help develop a more detailed understanding in relation to a number of these questions. In addition, such methods could help to identify and describe new variables that may be of particular relevance to women with breast cancer, as is likely to be the case with interpersonal processing.

Beliefs about personal control

Beliefs about control are central to several social psychological approaches to the study of adjustment to life stressors (Taylor, 1983). For example, Taylor's theory of cognitive adaptation to threatening events proposes that the adjustment process revolves around three themes, of which perceived control is one. Those people who believe that they are able to regain control over the stressful event and life in general cope better with that situation. Indeed, research indicates that, across a wide variety of situations, perceived control has been related to emotional well-being, more successful coping with stress, behaviour change that may promote good health, better health and improved performance on cognitive tasks (Thompson & Spacapan, 1991).

However, the last decade or so has seen a growing recognition of the multidimensional nature of the control construct (Pallant, 2000; Shapiro et al., 1996). Hence researchers have broadened their focus to consider not only a sense of control over external events but also other targets of control, including control of internal states such as emotions, thoughts, and physical reactions (Thompson, Nanni & Levine, 1994; Thompson, Sobolew-Shubin, Galbraith, Schwankovsky, & Cruzen, 1993). This is reflected in the Taylor's (1999) definition that perceived control "is the belief that one can determine one's own behavior, influence one's environment, and / or bring about desired outcomes" (p. 210).

The role of control over emotions and cognitions is also central to the stress and coping model (Folkman, 1984; Lazarus & Folkman, 1984). In their model, beliefs about control in general and in particular situations are seen to have an impact on coping. As was described in Chapter 2, coping efforts may be focused on aspects of the problem (aimed at influencing the disturbing event itself) and/ or the emotions (aimed at dealing with the emotional impact of the event). Although problem-focused coping efforts have typically been portrayed in the literature as the more adaptive, emotion-focused coping strategies are also recognised as being important. Indeed, the ability of the individual to regulate their emotional responses will strongly affect the effectiveness of efforts to manage the problem itself. As Folkman (1984) points out, while a certain

degree of emotional arousal may facilitate coping, excess emotion such as fear, anxiety and anger may inhibit clear thinking, planning and problem solving.

These developments within the psychological literature on control are mirrored in research in relation to breast cancer. Earlier research efforts focused on examining the adaptive value of people's perceptions of control, whilst more recent research reflects an attempt to explore the multi-dimensional nature of the control construct and the ways that people manage to maintain a sense of control in what is, essentially, a low-control situation. The remainder of this section provides a review of some key studies relating to both research emphases.

Review of research

The diagnosis of breast cancer and the ensuing treatment can cause feelings of helplessness and loss of control (Anderson, Kiecolt-Glaser, & Glaser, 1994). In addition, such feelings have been found to be related to anxiety, depression, and poor prognosis among cancer patients (Burgess et al., 1988; Stanton & Snider, 1993). On the other hand, some individuals are able to maintain a sense of control, which appears to have significant benefits in terms of adaptation. For instance, Taylor, Lichtman and Wood (1984), in a study of 78 women with breast cancer, found that both belief in personal control over the cancer and a belief in their physician's control (vicarious control) of the cancer were significantly associated with good adjustment. These findings were supported and extended in a study by Taylor, Helgeson, Reed and Skokan (1991) of 55 male and female cancer patients (of whom 33 were women), which demonstrated that among patients with a good prognosis, beliefs that others had control over their health was positively associated with good adjustment. In addition, Ell and colleagues (1989) and Lowery, Jacobsen and DuCette (1993) found that a personal sense of control was related to better psychosocial adaptation. A related construct is the individual's attribution of blame for the onset of cancer, which has also received attention in the research literature. For example, Timko and Janoff-Bulman (1985) reported that feelings of invulnerability (to recurrence of breast cancer) and the belief of a cancer-free future were strongly associated with psychosocial adaptation. They found that attributions of blame (for cancer onset) to one's own personality or to others were related to poorer psychosocial adaptation, while attributions to one's behaviour

were positively related to adaptation – such behaviours are more amenable to control. Similarly, Taylor et al. (1984) reported findings which suggest that blaming others for the onset of cancer is related negatively to good psychosocial adaptation.

Other researchers have looked at the relationship between beliefs about control and coping strategies used. Hilton's (1989) study of 227 women with breast cancer found that women with a high sense of control over their cancer situation were more likely to use problem-solving, positive reappraisal, escape-avoidance and self-controlling strategies to help their adjustment. At much the same time, researchers at the Faith Courtauld Research Unit in London conducted a study (Burgess et al., 1988) with 178 cancer patients (of whom 107 had breast cancer) and found that those who scored high on internal locus of control were more likely to use positive/confronting responses to diagnosis, whilst those having low internal locus of control were more likely to use “hopeless/helpless” responses. In other words, those women who believed that events in relation to their health were contingent on their own behaviour (high internal locus of control) were more likely to exhibit positive/ confronting responses, whilst those who believed these events were not contingent upon their own actions but on luck, fate or powerful others were more likely to respond with helplessness.

As was noted earlier, more recent research in relation to control demonstrates the complexity of this area, and some researchers have tried to clarify which aspects of control beliefs are most crucial, for whom and under what circumstances. For example, Thompson et al. (1993) studied 71 cancer patients (of whom 42 percent had breast cancer) to explore the role of control in coping with a major life stressor. They made the important distinction between control over the event versus control over the consequences. In addition to finding that higher perceptions of control were associated with better levels of adjustment, they also found that it was more important for participants to believe that they could control their daily emotional reactions and physical symptoms than that they could control the course of the disease. These findings were supported in a study by Thompson et al. (1994) that explored central versus consequence-related control in a sample of HIV-positive men. Central control (i.e., beliefs about control of the illness itself) was less closely related to depression than consequence-related control. As the authors point out, in situations such as coping with a diagnosis of cancer, control over the cancer itself and its outcome is problematic.

However, people may be able to develop ways to compensate by exercising control in other areas.

A growing body of research explores the degree to which patients desire control in the medical area. As was noted earlier, seeking information is an important coping strategy which can enhance feelings of control in coping with breast cancer (Glanz & Lerman, 1992). However, there are mixed results regarding patients' desire for input in relation to decision making about medical treatment across a range of medical settings (Auerbach, 2001). It appears that, while patients want detailed information about their illness and treatment, far fewer report that they want to be involved in decision making (Auerbach, 2001; Thompson et al., 1993). In addition, the stated desire not to be involved in decision making (that is, for the physician to take the responsibility) was greater in situations where the illness was more severe, and where the patient was older and less well-educated (Auerbach, 2001). Studies in the breast cancer area reveal a similar picture (for example, Degner et al., 1997; Hack, Degner, & Dyck, 1994). In the study by Degner et al. (1997) 1,012 women with breast cancer were asked about their preferences in relation to involvement in treatment decision making. The researchers found that 22% women wanted to select their own cancer treatment, 44% wanted to collaborate with their physician in decision making, and 34% preferred to delegate this responsibility to their physician. Given the limitations in measurement of desire for control in health care, further research is needed to extend and validate findings in this area (Auerbach, 2001).

The study by Thompson et al. (1994), referred to above, also considered the distinction between primary and secondary control. As the researchers point out, Rothbaum, Weisz, and Snyder (1982) proposed a two-process model of control. They argued that if control cannot be achieved by acting directly to change the environment (primary control), a sense of control can still be maintained by less direct means such as the use of cognitive strategies to accept the situation as it is (secondary control). However, secondary control is different from helplessness because "the control process involves a belief that some aspect of the situation is being improved through acceptance" (Thompson et al., 1994, p. 540).

As has already been described in the section on “acceptance”, Shapiro and colleagues also argue the need to explore the construct of control in greater depth (Shapiro et al., 1996). They point out that the relationship between control and health may not be a simple, linear one: it is not a simple matter that control is good and the more you have the better. They developed a measure which assesses sense of control in both general and specific domains (i.e., from self or other), and desire for control. In addition, it includes measurement of four distinct modes or characteristic ways of gaining a sense of control. They describe these modes as “positive assertive” (active instrumental control where the individual attempts to alter herself or the environment), “positive yielding” (acceptance), “negative assertive” (overcontrol in which the individual uses active control efforts inappropriately or excessively), and “negative yielding” (passivity where the individual is fatalistic or feels helpless when active control efforts could or should be used) (Astin et al., 1999).

Astin and colleagues (1999) examined the relationship of modes of control and desires for control to psychosocial adjustment to breast cancer. As reported earlier, they found that women who used a balanced mode of control (i.e., both assertiveness and acceptance) showed the best psychosocial adjustment. Moreover, they agree with Carver and colleagues (1993) who suggested that “ultimately the accommodating side may prove to be fully as important, or even more important...[as the] active striving side” (p. 387).

Further support for these modes of control and their relationship to emotional adjustment for women with breast cancer comes from their recent study with women with stage II breast cancer (Shapiro et al., 2001). As was described earlier, the study found that greater use of both positive yielding (acceptance) and assertive modes of control was related to greater quality of life and emotional well-being. Moreover, a higher use of negative yielding (passivity) was associated with greater emotional distress. As the authors noted, this finding is consistent with earlier research that women who exhibit helplessness and resignation have an increased risk of psychological distress.

Conclusion

In conclusion, while research examining the relationship of beliefs about personal control to emotional adjustment and coping strategies employed by women with breast cancer has produced promising results, further clarification is needed regarding which types of control beliefs are most important and for which people.

The role of meaning

Over the last ten years or so there has been increasing interest in the concept of meaning and its relationship to psychological well-being (Fife, 1995; Folkman, 1997; Zika & Chamberlain, 1992). Essentially, this interest indicates a growing recognition of how important it is for people to make sense or meaning out of their lives and the multitude of experiences of which life is comprised. Wong and Fry (1998) suggest that this “amazing surge of interest in meaning seeking” is a result of the conjunction of a number of factors including both a social climate of “millennial angst” in Western civilization along with the philosophical underpinnings and methodological tools needed to facilitate the scientific study of meaning seeking. Indeed, Wong and Fry (1998), assert that “there is now a critical mass of empirical evidence and a convergence of expert opinions that personal meaning is important not only for survival but also for health and well-being” (xvii).

This section will begin by presenting a definition of meaning and the place of making meaning in a range of approaches to coping with severe adversity. This is followed by a description of studies which explore the relationship between meaning making, psychological well-being and physical health, particularly in the breast cancer domain. Several important issues that theory and research are currently attempting to clarify are outlined, including ongoing challenges in conceptualisation and methodological limitations. In addition, studies that highlight the range of coping strategies associated with making meaning of the cancer experience are considered.

Definition

An ability to find meaning in life has been defined as:

...the cognizance of order, coherence, and purpose in one's existence, the pursuit and attainment of worthwhile goals, and an accompanying sense of fulfillment. (Reker & Wong, 1988, p. 221)

This definition indicates that the concept of meaning is multidimensional, having cognitive, motivational and affective components. The cognitive component refers to the way individuals make sense of life in general and specific life events. For the individual, this involves tapping into his or her belief system or world view which encompasses existential issues such as the purpose of existence and whether or not there is order and purpose in the universe (and in specific events). The motivational component relates to the value system developed by the individual. The value system functions as a guide for living and determines the goals we adopt and the way we live our lives. Meaning is derived both from pursuing and attaining of the goals we have selected. Finally, the affective component refers to the feelings of satisfaction and fulfillment that accompany the realisation of personal meaning.

It is believed that the individual's sense of meaning is generally stable, although it may change gradually during life in conjunction with shifts in belief and value systems. (Reker & Wong, 1988)

Theoretical perspectives

Theoretical and empirical work suggests that having a sense of meaning plays a critical role in the way the individual reacts in the face of adversity, including life-threatening events such as cancer (Antonovsky, 1987; Frankl, 1959; Kleinmann, 1988; Mages & Mendelsohn, 1979). As Kleinmann (1988) says, "...Nothing so concentrates experience and clarifies the central conditions of living as serious illness" (xiii). Indeed, the ability to make meaning of illness appears to be linked

with better psychological well-being and the presence of particular coping strategies (Fife, 1995; Folkman, 1997; Lewis, 1989; Schnoll, Knowles, & Harlow, 2002; Taylor, 1983; Zika & Chamberlain, 1992).

Much of the theoretical foundation for the concept of meaning was put forward in the writings of Victor Frankl, which were given practical application in a form of therapy which he called Logotherapy. On the basis of his own experiences as a prisoner in a concentration camp, Frankl (1959) proposed that all men have a will to meaning, and that meaning can be found under all conditions, including those of extreme suffering. Further he posited that those who cannot find meaning in their existence are more likely to give up in the face of adversity. Those whose search for meaning is blocked experience existential frustration which can lead to a pathological condition which Frankl called “noogenic neurosis”. Similarly, Maddi’s (1967) concept of “existential neurosis” described a condition in which a person believes that life is meaningless, experiences feelings of apathy and boredom, and a lack of selectivity in actions. The writings of both Frankl and Maddi have been a key source of inspiration for further development of the life-meaning concept both through theory and research (Zika & Chamberlain, 1992).

The concept of meaning has also influenced psychological models of stress and coping. In the Lazarus and Folkman (1984) model it is expressed in the notion of patterns of commitment (based on values and beliefs) held by the individual. These are seen to be a relatively stable feature of personality which influence the way individuals appraise and respond to stressful events. Those stressors which appear to challenge important commitments are likely to be appraised as a threat, which may increase the vulnerability of the individual to stress. However, there is a concomitant increase in motivation to counter the threat. Without such commitments, the individual would find that life was meaningless.

As was described in the previous chapter, Folkman (1997) has revised the original stress and coping model to give greater recognition to meaning-based coping as an important way of managing in situations where there are unsatisfactory outcomes, as is often the case in cancer. According to Folkman, this type of coping

helps the person to relinquish untenable goals and develop new ones, make sense of what is happening, and find benefit in the event (Folkman & Greer, 2000).

While agreeing with much of the stress and coping model, Antonovsky (1987) developed the concept of meaning further and gave it expression in the personality construct of sense of coherence. The construct is composed of three inter-related factors which Antonovsky called comprehensibility, manageability and meaningfulness. Of these three dimensions, it was meaningfulness which was deemed to be most important as it motivated people to find order and ways of supporting it. Antonovsky argues that people who have a strong sense of coherence are more likely to perceive the things they experience in life as meaningful. Research exploring the impact of sense of coherence on health, while limited, lends support to the importance of this construct and its relevance to understanding what factors enable people to cope more effectively in the face of stressful life events (Korotkov, 1998; Mullen, Smith & Hill, 1993; Zika & Chamberlain, 1992). Indeed, Mullen et al. (1993), in their study of cancer patients and their spouses, argue that their findings also support Frankl's theory that "meaning undergirds psychic health" (p. 41)

A similar line of theorising and research in relation to meaning has been put forward by Wortman and her colleagues, who acknowledge the work of Antonovsky in this area. They were dissatisfied with the stress and coping model because they felt that it did not adequately explain the variability found in response to stressor situations (Wortman, Sheedy, Gluhoski & Kessler, 1992). On the basis of research they carried out during the 1980's and 90's into the way people cope with loss, primarily bereavement, (although they see it as being equally applicable to cancer) they conclude that the concept of world view appears to be particularly important as a protective resource:

We believe that individuals' appraisals of and reactions to stressful life events are importantly influenced by their philosophical perspective on life or their view of the world. Events that can be incorporated into a person's view of the world may cause little disequilibrium and resultant distress; those that shatter a person's view of the world may cause intense distress and result in subsequent health problems. (Wortman et al, 1992, p. 229)

In other words, they focus on what the adverse experience means or represents to the person affected, including whether or not there has been a search for meaning, and whether he or she has come up with a meaningful account of what had happened.

A closely related line of work is found in the “life scheme” model of Thompson and Janigian (1988) who explored differences in people’s ability to find meaning following an extreme stressor. They proposed that the search for meaning is shaped by an individual’s world views, goals and life events. Findings of their research are supportive of the way these constructs appear to work (Thompson & Pitts, 1993, p. 3).

As was mentioned in the previous section on control, making meaning is also pivotal to Taylor’s (1983) theory of cognitive adaptation to threat. According to Taylor, making meaning involves an effort both to understand the event – why it happened, what its impact is – and its significance, which involves addressing the question of “what does my life mean now?” Taylor proposes that, in the face of an adverse event, the individual tries to offset its negative implications by perceiving gains or benefits, such as finding meaning through the experience. This may involve reorganisation of priorities and beliefs in order to extract benefit and meaning. In addition, this endeavour to make meaning (or control) rests on the operation of “positive illusions”, or “looking at known facts in a particular light” (p. 1161).

As can be seen, making meaning is pivotal to a number of theories of cognitive adaptation to threat. While there is significant overlap between the ideas, there are differences in emphases that translate into varying lines of research, some of which are further explored in the next section.

Research on meaning and adjustment

Research that focuses on the way people cope with cancer has highlighted the role of making meaning and its relationship to psychological adjustment. One of the earliest and best known was the longitudinal study of cancer patients by Weisman and Worden (1976-77). They highlighted what they termed “the existential plight” faced

by those with cancer, which they found to generally occur within the first 100 days of diagnosis. During this period, the person was clearly confronting existential concerns such as the meaning of life, death and illness.

Taylor et al.'s (1984) study of women with early stage breast cancer – referred to in the previous section on control - found that finding meaning was related to adjustment. Whilst they set out to explore the relationship of attributions and beliefs about control to adjustment, it is clear that, for them, meaning and some aspects of control are closely intertwined. For instance, they operationalised cognitive control as “construing benefit from the cancer experience” which they found significantly predicted adjustment (p. 498). In addition they say that “attributions are an important way of finding meaning and a sense of control” (p. 499). Moreover they also say that efforts to find meaning in the cancer experience were reflected in changes in attitudes toward life (p. 499).

Other studies have focused more specifically on the relationship between making meaning and psychological adjustment. For example, a study by Lewis (1989) of 57 cancer patients showed that higher levels of finding meaning in their situation was related to higher self-esteem and lower anxiety. Similarly Mullen et al. (1993), in their study of 42 cancer patients and their spouses, found that those who could make sense out of life and who perceived their world to be meaningful experienced lower levels of psychological distress.

Another study which lends support to these findings was undertaken by Smith et al. (1993). This study explored the relationship between perspectives on death, spiritual awareness (of which finding meaning is a part) and psychological distress with 116 cancer patients. They found that those patients with a sense of meaning and a positive perspective on death experienced less psychosocial distress. More recently Fife (1995), who developed a meaning in illness scale, tested it on 422 cancer patients and found, among other things, that meaning predicted psychological adjustment.

Davis, Nolen-Hoeksema and Larson (1998) have recently challenged the evidence that has been put forward in support of the role that finding meaning plays in the adjustment process following loss and trauma (including illness such as cancer).

They assert that the available evidence is meager and that “definitions of meaning have been too broad to facilitate a clear understanding of the psychological processes involved” (p. 561). In relation to the former, they point out that some published studies have reported no significant association between finding meaning and adjustment to an adversity (e.g., Fromm, Andrykowski & Hunt, 1996) or small to moderate cross-sectional associations. Given the cross-sectional design of most of these studies, the significant associations reported between meaning and adjustment are open to alternative interpretations, such as prior level of emotional distress or trait differences such as dispositional optimism.

In terms of the definition of meaning, they point out that theorists have used the term to refer to substantially different concepts. For example, some theorists focus on the individual’s appraisal of the significance of the event and how he or she thinks it impacts life goals and purpose. In this instance, finding meaning refers to the ability of the individual to develop new goals and perhaps become wiser (e.g., Taylor, 1983; Thompson & Janigian, 1988). Taylor’s (1983) proposal that people perceive gain or benefit to offset the negative implications of a traumatic event is one example of this approach. Davis et al. (1998) refer to this as the *benefit-finding* construal of meaning.

Other theorists have focused on the ability of people facing adversity to develop an explanation for their situation which allows them to make sense of it within their existing life schemas or world views (e.g., Timko & Janoff-Bulman, 1985; Wortman et al., 1992). This approach encompasses responses by the individual that make sense of the situation by attributing responsibility to God, personal responsibility or lifestyle and behaviours. In other words, these behaviours help to make sense of the event in an explanatory sense, which Davis and his colleagues refer to as *sense making*. As these authors point out, there are other construals of meaning, but benefit finding and sense making are the most frequently cited in the trauma and coping literatures.

Similar attempts to sharpen conceptualisation can be seen in the recent theorising of others (e.g., Affleck & Tennen, 1996; Bower, Kemeny, Taylor & Fahey, 1998). For example, Affleck and Tennen (1996) make the distinction between beliefs

about benefits that may be seen to arise from adversity (*benefit-finding*) and the use of that belief as a strategy to cope with the situation (*benefit-reminding*). On the other hand, Bower et al. (1998) distinguish between *cognitive processing* and *finding meaning*. In their approach, cognitive processing refers to the process of “actively thinking about a stressor, the thoughts and feelings it evokes, and its implications for one’s life and future” (Bower et al., 1998, p. 979).

Research findings using these more conceptually focused definitions of meaning show that the differing construals of meaning are related to adjustment in different ways. For example, Davis et al., (1998) in their prospective, longitudinal study of loss of a family member, demonstrated that both making sense of the event and finding benefit in the experience independently play roles in the adjustment process. In addition, they found that making sense of the loss is associated with less distress, but only one year after the loss. Reports of benefit finding were most strongly related to adjustment at 13 and 18 months after the loss. On the other hand, Bower et al.’s (1998) study of HIV- seropositive men, who had recently experienced the loss of their partner, was also prospective and longitudinal and included measures of changes in immune status and health. These investigators used semi-structured interviews to assess both cognitive processing and the discovery of meaning, which was reflected by shifts in values, priorities and perspectives. They found that men who used cognitive processing were more likely to find meaning from their loss. Furthermore, men who reported discovery of meaning showed slower decline in CD4 T cell levels (a measure of immunity) and lower rates of AIDS-related mortality. In other words, cognitive processing by itself was not sufficient to produce beneficial health effects. As Taylor et al. (2000) point out, such results are consistent with the work of Janoff-Bulman and others. On the basis of their findings, they assert that the ability to construe meaning from adverse circumstances is a psychosocial resource that is health protective.

Antoni et al (2001) also draw attention to the lack of conceptual focus in the area of meaning making. Their primary interest is in the literature that relates to positive sequelae of traumatic events, that is, in an emphasis on finding meaning. As they point out, even within that literature there are different terms used, such as *benefit finding*, *positive contribution*, *meaning making* and *growth*. As they say, “it is

not clear to what extent the concepts overlap, neither is it clear whether there exists some core element that transcends the various concepts” (p. 29). They suggest that theorists such as Fife (1995), Folkman (1997), Janoff-Bulman (1992) and Taylor (1983) posit that the core element may be meaning making.

Recent research by Folkman and her colleagues (e.g., Folkman, 1997; Folkman, Moskowitz, Ozer & Park, 1997) has focused on meaning-based coping processes which they believe support positive affect during chronic stress situations, such as cancer and HIV/AIDS. They argue the importance of having a focus on positive, rather than negative outcomes in the stress process, hence their focus on positive affect (Folkman & Moskowitz, 2000). As has been noted earlier, the meaning-based processes that support positive affect are positive reappraisal, problem-focused coping (centring around identification and mastery of goals that are perceived to be engaging by the individual), and infusing ordinary events with positive meaning. These three processes are described by Folkman and Moskowitz (2000) as involving “creating, reinstating or reinforcing meaning in the midst of stress” (p. 651). This approach emphasises the importance of *situational meaning* – the evaluation of the personal significance of a stressful situation - rather than *global meaning*, which, as they say, encompasses more abstract, generalised meaning related to the beliefs and fundamental assumptions people hold about the world and their place in it.

Two studies of breast cancer patients add further evidence to the growing body of knowledge about the relationship between making meaning and adjustment. The first, is a study by Spiegel et al. (1989) which looked at the effect of psychosocial intervention (weekly support group meetings for a period of one year) on survival time in 86 women with advanced breast cancer. The study demonstrated that those women who had been involved in the intervention had survival times significantly longer than those who did not. Whilst these findings show the value of the psychosocial intervention and the importance of social support, it is also worth noting that the group meetings incorporated discussions of ways in which the women could use their experience and thus extract some meaning out of their cancer. In other words, an important component of these findings could have been the role of making meaning.

The second study, by Antoni et al. (2001), is also an intervention study. The authors tested the effect of a 10-week group cognitive-behavioural stress management intervention among women who had recently been treated for early stage breast cancer. The women were first assessed within 2 months of their surgery and the intervention took place soon after that assessment. They were reassessed soon after the intervention, again after a 3-month follow-up, and again after a 9-month follow-up. Several findings that relate to the whole of their study sample, and one relating to a subset of their sample, warrant comment in the context of this review on meaning making. Firstly, they found that, as well as reducing the prevalence of moderate depression, the intervention also increased participants' reports that having breast cancer had made positive contributions to their lives. In fact, most of the women reported that their lives had changed in positive ways because of their cancer diagnosis. The second finding concerned the relationship between benefit finding and emotional processing. The investigators also included a measure of emotional processing because they were interested to test whether it might be a mechanism for the effects of the intervention. Their findings suggested that benefit finding was related to increased emotional processing. In other words, those women who reported higher levels of emotional processing also reported more benefits. However, there was no evidence for causal primacy of emotional processing. A third noteworthy finding was that reports of benefits did not correlate with measures of distress in their sample. The authors suggest that reports of positive outcomes "do not simply represent an absence of distress; rather, they seem to have an affirmative meaning of their own" (p. 28).

There was also evidence of differential effects of the intervention, namely that the intervention had its greatest impact on those who were least optimistic about their future at the time of the first assessment. As Antoni et al. point out, their findings lend support to the work of Tedeschi and Calhoun (e.g., Calhoun & Tedeschi, 1996) who have written extensively on the issue of growth after trauma. They have suggested that clinical intervention can help promote such growth by encouraging the development of a new organisation within themselves, and their lives, such that benefits are identifiable compared to the person's pre-trauma organisation. Indeed, Antoni et al believe that theirs is the first randomised trial to show such an effect.

Taken together, their findings add to the growing body of support in relation to the positive outcomes of traumatic events. Whilst they do not resolve questions of conceptualisation of meaning they highlight the need for more consideration of such questions, by showing that at least certain changes in meaning (that is, perceiving benefit from a traumatic event) can be fostered by a group intervention.

Meaning and coping strategies

As can be seen in the review above of selected studies of meaning and adjustment, a number of the studies also demonstrate a connection between the tendency to make meaning of cancer and the use of particular coping strategies. For example, in addition to showing a relationship between making meaning and adjustment, the study by Fife (1995) also provided information about the link between coping strategies and making meaning. Her results showed that, for her sample, finding meaning in their illness was predicted by social support and such coping strategies as denial, avoidance and positive focusing. More specifically, positive focusing and the use of denial were associated with having a more positive meaning, while avoidance was strongly related to developing a negative meaning. It is worth noting that Fife's explanation of denial that it is "an indicator of the extent to which the individual tended to minimize the impact of cancer on daily life" (p. 1026).

Some studies have explored the relationship between making meaning and coping strategies which used women with breast cancer, for example Taylor et al (1984) and Hilton (1989). The findings from Taylor et al's (1984) study highlight, though indirectly, the link between the coping strategy of making attributions and constructing meaning, as well as the use of information-seeking. In relation to causal attributions, they found that about 90 percent of their sample had developed some explanation for their breast cancer. In addition, they postulate that some sorts of information-seeking can be seen as attempts to make meaning through increasing understanding and knowledge of the disease.

Hilton (1989) explored the relationship between factors such as control, commitment and coping strategies with 227 women who had been diagnosed with breast cancer. She based the concept of commitment on the theoretical work of

Lazarus and Folkman (1984) and Antonovsky (1979) among others. She found a relationship between level of commitment (and control) and the use of certain coping strategies. For instance, she found that those exhibiting low levels of commitment and control were more likely to use escape-avoidance strategies, while those with high levels of commitment were more likely to use problem-solving and positive reappraisal strategies. As Hilton says, motivated (high commitment) women are prompted by the diagnosis, "...to create meaning out of the experience and to focus on personal growth as reflected by the use of positive reappraisal strategies" (p. 51).

These findings are enhanced and supported by a number of qualitative studies of the search for meaning in cancer patients. For example, Hilton (1988) interviewed 16 women with breast cancer to describe the experience of uncertainty for the women. The coping strategies that she identified included focusing on the positive; seeking support and information; using behaviours that minimised, avoided and denied the significance of their cancer; increased levels of attention to health; and stress management strategies. She also found that there had been changes in attitudes and relationships and reappraisal of beliefs and values for many of the women. While her study was not framed specifically in terms of the search for meaning, one of her most striking findings taps directly into this area:

Particularly striking were their reappraisals and their perceptions of the preciousness of life and an increased emphasis on a quality of life and completing life goals. This is in agreement with Frankl's (1978) philosophy that the essential transitoriness of human existence adds to life's meaningfulness. When one is unable to change a situation, then one is challenged to change oneself. (p. 233)

O'Connor, Wicker and Germino (1990) used interviews with 30 cancer patients (18 with breast cancer), who had been recently diagnosed, to explore what was involved in the process of the search for meaning. Key behaviours they identified included sorting out the significance of the cancer (including searching for a cause), expressing thoughts about existential issues such as the possibility of death, reviewing their lives, making changes in outlook towards self, life and others and maintaining hope. Two factors, which were found to facilitate the process of making

meaning, were the presence of social support and faith. Apart from religious beliefs, faith also encompassed broader personal faith and a belief in spiritual support.

Whilst not directly commenting on meaning making, an Australian study by Clarke et al. (1993) also described a number of positive changes that women in their study reported they had made in their life as a result of having breast cancer. These included changes in outlook, diet, exercise, lifestyle, and priorities. Such coping strategies could be interpreted as attempts to find benefit in their situation or to derive meaning.

More recently Shapiro, Angus and Davis (1997) explored the experiences of three women with breast cancer and their partners, focusing on meaning and identity. She identified shared characteristics in relation to the construction of meaning which included the struggle to understand the reason for the cancer; increased levels of self-care; and drawing on beliefs and values. In addition she noted the importance that the context of social support and makes the point that “With connection, came meaning.” (p. 548)

Luker, Beaver, Leinster, and Owens (1996) interviewed 105 women two weeks after diagnosis and 21 months later in order to explore the meaning they gave to their illness and its impact on coping strategies. They found that most women perceived their illness as a challenge, which was connected with an expressed need to use the experience in a positive way and the use of active coping strategies. Many of these women commented on the changes they had experienced in their lives, especially in an increased appreciation of what was important to them which helped them prioritise areas of their lives.

Conclusion

It can be seen, then, that there is a growing body of evidence of a positive relationship between the ability to find meaning in cancer and psychological adjustment. Recent research, particularly in the HIV domain, suggests that there is also a link between making meaning and physical health. In addition, some relationships between finding meaning in cancer and coping strategies are emerging which appear to be fairly well-supported both by qualitative and quantitative research. On the one hand, there seems to be a strong association between positive reappraisal

strategies and positive problem-solving and making meaning, and, on the other hand, an inability to make meaning and use of avoidance strategies. However, lack of clarity in conceptualisation and methodological limitations means that many areas of uncertainty remain. In particular issues around which aspects of meaning are most important and for whom, and how this evolves over the course of time, require further clarification.

Summary of evaluations

At this point it is worth noting some general observations about the research described in this chapter: that is, research relating to denial, avoidance, acceptance, social support, beliefs about control, and making meaning. Overall, in the last two decades there have been considerable advances in understanding of the relationship between the use of these coping strategies and adjustment of women with early stage breast cancer. The vast majority of studies used quantitative methodology, although the nineties saw an increasing number of qualitative studies, reflecting a growing recognition of the usefulness of the latter. However, as has been reported, lack of clarity in conceptualisation and methodological limitations (for example, small samples in some earlier studies) has resulted in inconsistent findings, especially in the areas of denial and acceptance. Whilst there have been refinements in conceptualisations and improvements in methodology, particularly in recent years, current findings need to be supported and extended by further research in these areas. In addition, it can be seen that some areas are difficult to investigate with quantitative research methods. For example, aspects of denial and acceptance are difficult to assess with standard measures, as are interpersonal processes in informal helping, which was noted in the review of social support studies. Hence qualitative research methods may be particularly useful in extending knowledge in these areas, which could lead to improvements in conceptualisation and measurement.

Age and sociodemographic variables

As Glanz and Lerman (1992) indicate, there is little research evidence to show that sociodemographic factors influence adjustment to diagnosis and treatment for breast cancer. They were unable to find any studies showing significant effects of race,

marital status, education or income on adjustment. However, as they say, this lack of findings may not mean that these factors are unimportant. Rather it may reflect the bias in study samples, which consist predominantly of white, middle-class women. More recent studies also report a lack of significant relationship between key socio-demographic variables and adjustment. For example, Stanton et al. (2000) found no significant association between psychological adjustment and education, ethnicity, employment and marital status. Similarly, Alferi et al. (2001) found that years in the United States, income and education did not relate to distress, while Epping-Jordan et al. (1999) did not find a relationship between education and distress. While there is no clear link with adjustment, evidence indicates that lower socioeconomic status (SES) is associated with higher rates of disease or death for women in the USA, and that people with lower SES are more likely to be given diagnoses of breast cancer at an advanced stage (Merkin, Stevenson & Powe, 2002). Other research suggests that SES, among other variables, mediates the impact of ethnicity on survival for people with cancer (Meyerowitz, Richardson, Hudson, & Leedham, 1998). In Australia, figures in relation to illness and death patterns show that those with lower SES have higher age-standardised death rates for almost all known causes of death, and that they experience more acute and chronic ill-health (Turrell, 1995).

On the other hand, there is a growing body of evidence that age at time of diagnosis affects psychological adjustment. For example, Northouse and Swain (1987) found that younger women reported more distress than older women in the early stages of their treatment. Royak-Schaler (1992) cites studies which report that patients over fifty have less difficulty with anxiety and depression than do those under fifty. Likewise, Penman et al. (1987) also found that older women showed more favourable psychosocial outcomes than younger women. In addition, Hilton (1988) studied 227 women, ranging in age from 31 to 89 years, who had been diagnosed with breast cancer from one month to 28 years prior to time of the study and found that older women had less fear of recurrence. Consistent with these findings are those of Vinokur, Threatt, Vinokur-Kaplan and Satariano (1990) who followed a sample of 274 breast cancer patients over the course of the year following diagnosis, and found that the younger women viewed breast cancer as a greater threat to their lives and showed poorer mental health than older women. Vinokur et al. (1990) point out that contradictory research findings in relation to the effect of age on adjustment are not surprising, as studies

typically used small, nonrepresentative samples. In particular, elderly women were often not investigated, despite the fact that "fifty percent of all cases occur in patients 60 years of age or older" (p. 1242).

A number of North American studies published in the last decade have also shown that age was inversely related to distress (Carver et al., 1993; Epping-Jordan et al., 1999; Manne, 1999; Shapiro et al., 2001; Stanton et al., 2000) and tension (Stanton & Snyder, 1993). An Australian study, referred to in an earlier section, by Lavery (1997) also found that younger women reported significantly higher levels of anxiety and mood disturbance. Younger age has also been found to be associated with more support seeking, having more positive attitudes and more behavioural escape-avoidance (Dunkel-Schetter et al., 1992). Halstead and Fernsler (1994) also found statistically significant differences in coping strategies between elderly and middle aged women.

One of the early studies to highlight the importance of age as a factor in adjustment was conducted by Mages and Mendelsohn (1979) with over sixty patients with different types of cancer. Their study included a prospective sample of 31 patients who were investigated through intensive, semi-structured interviews early in treatment and then six to twelve months later. One finding they report is that older adults tend to face cancer with less anger than younger people, and seem able to deal more easily with their illness. As they say, older people "seem, by virtue of their age, to have faced their mortality and so the issue of dying per se has less intensity" (p. 277). Hilton (1988) also interprets her results as being consistent with the theory that older persons find the issue of cancer less threatening as they have faced their mortality.

Other researchers also make suggestions about the mechanisms underlying the psychological benefit associated with older age. Clarke et al. (1993), who report that the age and life-cycle stage of the women in their study was a very important factor, say that older women were "more likely to see breast cancer as another practical problem to be dealt with on their journey through life" (p. 7).

Recently Siegel, Gluhoski and Gorey (1999) explored some of these issues in a study with 51 younger women. These authors point out that very little is known about the adjustment of women younger than 36 years, and yet a preponderance of evidence

suggests that younger age is associated with poorer adjustment to breast cancer. They used unstructured interviews to explore the unique issues associated with being a young woman diagnosed with breast cancer. The women described a range of stressors including concerns about the impact of their illness on their husbands and children, lost opportunities for childbearing, feelings of being different, uncertainty about their future, and coping with a sense of unfairness at the untimeliness of the diagnosis. In addition, the authors reported that “evidence of altered belief systems about themselves and the world ran through their narratives concerning the adaptive challenges their illness posed for them” (p.1). The authors conclude that future research should examine these issues for young women with other samples and try to gauge more specifically how their youthfulness influenced various aspects of their illness experience. In addition, they suggest that research might include a comparison group of older women so that the impact of age could be investigated more directly.

Taken together, these findings suggest the need for a closer examination of the impact of age, with particular emphasis on different adaptational challenges associated with breast cancer for younger and older women. This study focuses on description of strategies for coping rather than comparing groups or types of women, but age still is a worthy topic for further research. As was highlighted in the section on meaning, it would appear that the issue of beliefs about self and the world may play an important role.

Summary and study aims

Research over the last fifteen years has demonstrated the importance of personality factors, coping reactions and social support for the adjustment of women to diagnosis and treatment for breast cancer. However, there are areas in which contradictory or limited research evidence exists, particularly in relation to the role of coping reactions such as denial/avoidance and acceptance, and aspects of social support. Whilst there is theoretical support and recent research evidence to suggest the importance of these areas, research is hampered by problems in conceptualisation and measurement, especially in relation to denial/avoidance and acceptance.

With these findings in mind, the current study is designed to explore the way women respond to a relatively recent diagnosis of early stage breast cancer, both in terms of their appraisal of its significance, their coping reactions, and the way these change over time. Using the Lazarus and Folkman (1984) cognitive-phenomenological model of psychological stress as a conceptual framework, the proposed research considers psychological and social support factors and how they relate to the ways in which women appraise their situation, the coping strategies they employ and the consequences for well-being. By employing qualitative methodology, it is hoped that earlier problems with measurement in relation to the coping reactions of denial/avoidance and acceptance can be overcome and greater clarity in conceptualisation achieved.

More specific aims include:

- To explore appraisal and coping strategies within the revised Lazarus and Folkman stress and coping model (Folkman, 1997), and with an emphasis on a salutogenic orientation
- To focus on conceptually ambiguous strategies such as denial, avoidance, and acceptance
- To examine issues of social support through investigation of the coping strategy of seeking support
- To identify and describe changes in the use of coping strategies over time through the use of a longitudinal study design
- To provide opportunities for women to speak for themselves about their experiences and their coping strategies so that new theoretical constructions, measurement tools, and clinical interventions can be developed which are a reflection of women's goals, needs, and tasks.

The following chapter, Chapter 4, describes the method used in the study and the appropriateness of qualitative methodology for these aims. Chapter 5 outlines the findings of the first cycle of interviews, which involves extensive use of supporting and illustrative quotes from the women in the study. A substantial portion of these findings relate to appraisal, and coping strategies such as acceptance, denial and seeking support. Chapter 6 continues an exploration of these findings, documenting

the overarching themes or categories of coping responses, namely regaining control and making meaning. Chapter 7 describes changes in the use of coping strategies over time, and looks more closely at the development of new theoretical constructions. In the final chapter the findings and emergent conceptualisations are discussed in relation to the literature, the study is evaluated in terms of its aims, and implications are canvassed.

Chapter 4 Method

This chapter describes the method used in the study. After discussing the appropriateness of qualitative data for the study aims, it considers reasons for the choice of interviews as the means of data collection, and the theoretical perspective which guided their use in the study. This is followed by a description of the study participants, study procedure, ethical considerations, and the nature of the interview. The next section outlines the qualitative analysis that was undertaken, and the final section addresses the issue of trustworthiness of the findings.

Appropriateness of qualitative methodology

Qualitative methods, such as in-depth interviews, are well suited to an exploration of the way women cope with a diagnosis of breast cancer – both in terms of the way they appraise the meaning and significance of their situation and the nature of the coping reactions employed. Strauss and Corbin (1990) point out that:

“Some areas of study naturally lend themselves more to qualitative types of research, for instance, research that attempts to uncover the nature of persons’ experiences with a phenomenon, like illness.” (p. 19)

In addition, they say that qualitative methods are well suited to exploring the intricate details of phenomena that are difficult to convey with quantitative methods. This is because qualitative methodology has the flexibility and sensitivity to explore complex processes and meanings of events and to identify potentially relevant variables (Marshall & Rossman, 1989).

An in-depth exploration of women’s coping reactions in response to a diagnosis of breast cancer involves the sorts of intricacy and complexities of meaning and process that writers in the area of research methodology have identified as being well suited to the use of qualitative methodology. Further support for this view comes from a discussion by Carver and colleagues (1992) of the coping reaction of acceptance in their study of women with breast cancer. They suggest that:

“reports of acceptance among these patients reflect the occurrence of deeper and more extensive processes, in which the women are working through their experience in some way, integrating it into their evolving worldview ...such active attempts to come to grips with the problem may well be the mechanism for the beneficial effects of acceptance” (p. 183).

In other words, for a better understanding of coping reactions such as acceptance (and its ostensible converse, denial) it is necessary to explore complex intrapsychic processes, which are still largely uncharted. While it is extremely difficult to tap such processes adequately through measurement tools, methods such as in-depth interviewing have the necessary flexibility and openness to the individual and their particular situation.

Theoretical perspective and the choice of in-depth interviews

In-depth interviews were selected as the primary method of data collection because they are well suited to gathering the perspectives of individuals on aspects of their own experiences and beliefs (McCracken, 1988; Smith, 1995). Unlike structured interviews, questionnaires or surveys, the researcher is able to follow up particularly interesting issues that emerge in the interview and encourage the participant to provide a fuller picture (Smith, 1995). Two cycles of interviews, six to eight months apart, were used so that it was possible to chart the changes over time in both the external situation and coping responses of the women.

This study adopted a theoretical position in which it is assumed that what a woman says in the interview has some ongoing significance for her and that there is some relationship between what she says and beliefs that she can be said to hold. In other words, what a participant says is viewed as having some meaning and reality beyond the interview itself, and that it reflects her psychological world. According to this perspective, a woman's responses are not simply a way of pleasing the interviewer or trying to enhance herself in the eyes of the interviewer. Such a position has been described as a *phenomenological* perspective (Smith, 1995). However, the importance of the social context in helping to shape meaning is also recognised, which is in keeping with a *symbolic interactionist* position. In other words, people

“create shared meaning through their interactions, and those meanings become their reality” (Patton, 1990, p. 75).

Whilst these theoretical perspectives influenced the nature of the interviews, this does not mean that the canons of phenomenology, for example, were strictly followed in this study. Patton (1990) highlights the value of adopting a range of perspectives rather than rigidly adhering to the canons of one particular paradigm. While paradigms are useful for illuminating fundamental assumptions about the nature of reality, at the pragmatic level of conducting research it is important to have the flexibility to adopt a wide range of methods. For example, the researcher used a methodology influenced by some of the tenets of grounded theory, as will be further described in the section on data analysis. However, an already existing theory, Lazarus and Folkman’s (1984) model of stress and coping, had been adopted prior to the commencement of the study and shaped various aspects of it (for example, the selection of interview questions).

Another example of mixing methods is the limited use of descriptive statistics (percentages and numbers) to further illuminate the findings. Although it is unusual in qualitative studies to identify the numbers of women who used particular coping strategies, the researcher did this consistently as it is one clear way to give a sense of trends in this sample.

Study participants

Nineteen women with a diagnosis of early stage breast cancer took part in the initial interview. Early stage breast cancer is defined as “tumours of not more than five centimeters diameter with either impalpable or palpable but not fixed lymph nodes and with no evidence of distant metastases” (NHMRC, 2000, p.1). The women had been informed of their diagnosis by their general practitioner or specialist. Most of the women had been diagnosed in the twelve months prior to the first interview. They ranged in age from 32 to 70 years, with over half of them being in the 30 to 50 years age bracket. All of the women, except one, were married and living with a partner. On average they were well-educated with the mean number of years of education being 15.4. In terms of employment, four were working full time, nine part

time, four nominated home duties, one was on long-term sick leave and one was retired. The majority of participants were White Australians, with one participant being Asian. Seventeen of the women had children, and six had children living at home. All of the women had been treated surgically for breast cancer, with fourteen having had breast-conserving surgery such as lumpectomy, biopsy and partial mastectomy, and five had a full mastectomy. In addition to surgery, eleven women had chemotherapy and nine had radiotherapy. Some women had undergone more than one form of surgery or post-operative therapy. Sixteen of the women participated in the follow-up interviews. The two cycles of interviews were conducted during 1996 and 1997.

Procedure

The criteria for selection of potential participants were that they had been diagnosed with early stage breast cancer within the last twelve to eighteen months. Participants were recruited from a variety of settings including the Victorian Breast Cancer Action Group (BCAG), the Breast Cancer Support Service of the Cancer Council of Victoria, and several regional cancer support groups. In addition, several participants were recruited by word-of-mouth. In each instance potential participants were provided with a written or verbal description of the study by a third party, and could then contact the researcher if they were interested to be involved. BCAG included an item in their bi-monthly newsletter to which women could respond, and a leaflet about the study was sent to the various support groups to inform their members (see Appendix A1). In this way nineteen women were recruited into the study.

This method of recruitment is described as “snowball” or “chain sampling” which, as Patton (1990) points out, is one form of purposeful sampling which enables selection of “information-rich” cases for study – in other words, participants from whom a lot can be learned in relation to the study questions. As they self-nominated, it is likely that the women felt that they were, on the whole, coping reasonably well (and were not expressing high levels of distress), which fitted well with the study’s focus on adaptive coping responses. However, the sample did include several women who were having difficulty coping, at least at certain times, which provided the opportunity to examine a wide range of responses. While it was not part of the study

criteria to recruit according to specific characteristics, such as age or socioeconomic status, it was interesting that the participants did span a reasonably broad range in terms of these characteristics. This helped to provide some noteworthy contrasts.

When potential participants contacted the researcher and indicated their willingness to be involved, an appointment was made to interview the woman at a mutually convenient time. All interviews, except one, were conducted in the homes of the participant. One participant preferred to be interviewed in the home of the researcher, at least for the initial interview. The length of the interviews ranged from one hour to two hours with a mean interview time of 1.5 hours. The initial interview with one participant was split over two appointments, by mutual agreement, as more time was needed to adequately address all the issues. Before the interview was begun each woman was asked to read The Plain Language Statement and sign the Informed Consent Form (see Appendixes A2, A3). With the approval of the women, the interviews were taped and all interviews were later transcribed.

At the end of the interview, each participant was asked if she would be prepared to be involved in a follow-up interview about six months later. All the women gave the researcher permission to ring them at a later date about a follow-up interview (see Appendix A4, A5). As indicated earlier, when the researcher contacted the women about six months later, sixteen were willing to be involved in a follow-up interview. Of the three who did not participate in the follow-up interview, one was undergoing treatment for a recurrence of breast cancer, one was hospitalised and about to have major heart surgery and the third woman withdrew because her husband was not happy for her to be involved. In this last instance, the woman's husband had read the transcript of her interview that the researcher mailed to her at the woman's request. Apparently he had not liked some of the things she had said in the interview, which had included some mixed feelings about his reaction to her illness and she did not want to run the risk of upsetting him further.

Ethical considerations

Steps were taken to safeguard the interests of the women, and to minimise potential risks connected with the interviews. Given the sensitivity of some issues that could arise in the interviews, it was possible that temporary emotional distress

could be experienced by some study participants. This would add a further undesirable stress to women with a relatively recent diagnosis of breast cancer. The safeguards included the voluntary nature of involvement, and the use of an explanatory statement that alerted potential participants to the fact that some of them could find certain interview questions to be sensitive ones for them. In addition, they were made aware that they could elect to not answer particular questions, or they could withdraw from the study at any time. Contingency arrangements were also in place to provide a participant with further support if it was needed.

Ethics approval was received from the Human Research Ethics Committee of Victoria University (see Appendix A6).

Nature of the interview

As noted earlier, data collection was from two cycles of in-depth interviews that were conducted six to eight months apart. A semi-structured interview schedule was developed to guide the interview covering the circumstances around a participant's diagnosis and treatment, her initial emotional reactions, subsequent appraisal and coping responses. In keeping with the qualitative method, the interview schedule was not rigidly adhered to. Rather questions were used as a guide, and were not necessarily asked in any fixed order; they served as a basic checklist during the interview to ensure that all the relevant topics were addressed (Patton, 1990). The topics included in the guide were based on the researcher's review of literature in the area of breast cancer, the broad theoretical framework outlined in Chapter 2, and two pilot interviews with women who had a relatively recent (within the previous two years) diagnosis of early breast cancer. Data from those interviews are not included in the study findings.

The interview began with some biographical questions which allowed the researcher to ascertain relatively straightforward socio-demographic details such as age range, marital status, information about children (where relevant), work and education, and type of treatment undergone (see Appendix A7). Seeking information at this point had a dual purpose; it cued the researcher to the realities of a woman's situation which would inform her subsequent story, and it helped to ease the woman into the interview with non-threatening questions. Once biographical details were

established, each woman was interviewed using the checklist of broad, open-ended questions which allowed her to answer the topics in a manner and depth that was relevant to her own unique experience of breast cancer. However, questions for second-cycle interviews were largely determined by the content of the initial interview with each woman, and centred round changes (if any) in her health experience, her perception of her situation and coping reactions during the six months since the first interview.

More specifically, the checklist for the initial interview covered three major domains of interest which were addressed by a number of questions (see Appendix B). The first domain related to the way the woman perceived her situation (primary appraisal). The first question asked how she found out that she had breast cancer and what her reactions had been at the time. During the course of the account that followed the researcher used “floating prompts” (McCracken, 1988), in an unobtrusive way, to encourage the woman to continue her story. For example, a simple paraphrasing of what the woman had just said, followed by the use of a checking question, such as “Have I understood you correctly?” might assist the woman to enlarge or move on to other issues of relevance to her. For some women, this opening question and the use of floating prompts enabled an account to emerge spontaneously that addressed most of the areas that the researcher wished to cover in the interview. However, the researcher also had a series of “planned prompts” in case some areas had not been covered or only partially. For example, “What was the most difficult aspect of your breast cancer for you to come to terms with? What was it about that particular aspect that made it difficult for you?”

The second domain related to the woman’s perceptions of her ability to cope with the situation (secondary appraisal). If the woman had not already addressed this area in her story, several questions (planned prompts) could be used. For example, “In the weeks following your diagnosis, do you recall what your thoughts were about your ability to deal with the cancer and its associated difficulties?”

The third domain involved the coping reactions that the woman was aware that she had employed during the previous few months to help her manage the situation. Sometimes the researcher would introduce the area by suggesting that people use a

variety of methods to deal with stressful or difficult situations and then ask what the participant had done to help her cope with the first few months after diagnosis. For example, one facet of coping reactions central to the study aims was seeking social support. Often this area was spontaneously covered during the woman's account, however the interview guide included some questions to use as planned prompts if necessary. For example: "What have been your most important sources of support? What sorts of support have they given you? What other supports would you have liked, if any?"

The interview guide also included one or two rounding-off questions. For example, asking whether the woman had any questions she wanted to ask about the research, whether there were any other matters she wanted to mention, and the next steps in study.

Data analysis

The method of analysis was based on the principles described by Strauss (1987), Smith et al (1995), and Miles and Huberman (1984). From the outset the researcher had adopted an overarching conceptual framework, parts of which she wanted to explore in relation to women responding to a diagnosis of breast cancer. Hence the primary purpose was not to develop new theory but to enlarge knowledge in a particular area of it. Despite this difference from "grounded theory", many of the associated methods provided guidelines for rigorous data analysis.

Once verbatim transcripts of the interviews were completed the process of coding the data began. Initially this involved "open coding" (Strauss, 1987), which Strauss and Corbin (1990) describe as "the process of breaking down, examining, comparing, conceptualizing, and categorizing data" (p. 61) with the research questions in mind. This involved taking a sample of five interviews, reading them through and then, during a second reading, scrutinising the data, assigning initial labels to a "unit of meaning" (Dey, 1993) which were then recorded in the right hand margin of the transcript, until all the data had been assigned a label. Sometimes the unit of analysis was a phrase or a sentence, sometimes a paragraph depending on the content. After completing this process for the five interviews, a list of these labels

was assembled on a separate sheet of paper, which constituted a preliminary list of topics describing the data from this subset of interviews. The next step involved rewriting the list and grouping related topics. During a subsequent reading of this subset of interviews key quotes were highlighted, and ideas and queries were noted in the other margin. Where this rereading produced new, potentially useful ideas these were incorporated into the list of labels.

The result of this process was a first draft of a coding scheme which was then used to code a further subset of five interviews. When material in subsequent interviews was not adequately described by the labels, a new label was recorded in the interview and list of labels. At the same time the researcher continued to highlight quotations and queries and insights were added in the margin. From this coding of the second subset of interviews several more labels or topics were added to the coding scheme which produced a revised coding scheme. This scheme was used to analyse the remaining interviews, and to recode the data that were coded using the earlier drafts of the coding scheme.

After coding of the interview data was completed a second level of analysis was begun which roughly corresponds to “axial coding” (Strauss, 1987). During this step the focus was on aspects of the data which most directly related to the research question, namely coping strategies employed and changes in coping over time. Rather than using the cutting and pasting of information about analysis units (that is, coping strategies) into individual files, a comprehensive matrix was developed for use as both an analysis tool and a way of aiding conceptualisation and display of data (Miles & Huberman, 1984). The choice of coping strategies was based on the coping strategies that were identified through the coding and categorisation process.

The matrix was drawn up on ten sheets of poster paper with the participants listed down one side and nineteen coping strategies along the top. The process involved working with one transcript at a time in order to identify occurrences of the strategies and their salience. Key examples of each strategy, if used, were recorded in the matrix and page numbers specified. In essence, the matrix helped to identify both the occurrence of strategies and patterns of occurrence (see Appendix C for a copy of two pages from the original matrix).

An example of a small section of the matrix can be seen below. It shows some of the data recorded in relation to appraisal and five coping strategies for two participants. The words in italics describe the salience of the particular strategy in the interview, and quotes are identified which illustrate the use of the strategy.

Extract from Matrix of coping strategies identified in the initial interviews

ID	Appraisal	Acceptance	Deny/ avoid	Positive focus	Present focus	Seek support
01	<i>Shock, fear.</i> "I just knew I would cope with it" (p.4), also (p.2)	<i>Clear.</i> "I thought I had to face the fact..." (p.6) also p.7	<i>Little.</i> Of life threat .."I don't think about it" (p. 13)	<i>Strong.</i> "given me incredible strength" (p. 14) also p. 16	<i>Some.</i> "I live day to day" (p. 2)	<i>Strong.</i> "I just demanded what I needed" (p. 2). Also p. 16, p. 18
02	<i>Little fear.</i> "everything was going to be all right" (p. 5, p.8)	<i>Clear.</i> "It came back positive so that was it" (p. 7) Also p. 11, p. 24	<i>Little</i> "Push some worries aside" (p. 41)	<i>Strong.</i> "Be positive" (p. 48). Also p. 18, p. 42, p. 28	<i>Strong.</i> "Deal with things as they happen" (p. 18). Also p. 24, p. 35	<i>Little.</i> Spoke to one woman who'd had breast cancer (p.16)

In parallel with the matrix, an analysis log was kept in which the researcher recorded observations made both about the process (for example, decisions about collapsing categories) and connections that were emerging in the data. Its purpose was to provide a trail of evidence for the reader. This stage of the analysis took about four to five hours for each participant and constituted an exhaustive examination of the data.

During the course of matrix construction strong linkages between different coping strategies were observed. For example, on the basis of coping strategies

identified in the interviews, “drawing on life philosophies and beliefs” and “making meaning” were listed as two separate categories, but the analysis revealed that they were tending to co-occur. This prompted a re-thinking of the relationship between them and, in conjunction with further reading, the decision was made that drawing on life philosophy and beliefs was one expression of making meaning.

Once the task of entering data into the matrix of coping strategies for all nineteen of the initial interviews was completed, the process of writing up the findings began. More specifically, the findings were written up in relation to each of the categories listed on the matrix (appraisal, acceptance, denial/avoidance, focus on the positive, focus on the present, normalise, work, seek support, seek information, social comparison, causal attribution, stress management, humour, alternative treatment, helping others with breast cancer, philosophy/life beliefs, life experience, control, meaning and miscellaneous). One category, “distancing”, was added in the writing up as it became clear that this group of behaviours was not adequately accounted for under the other categories such as “focus on the present” and “work” where it was initially included. The data recorded in the matrix formed the basis of the writeup, supplemented by checking data by rereading the interviews.

The process of making decisions about collapsing categories and the delineation of higher-order categories continued during the course of writing up findings from the initial interviews. For example, one entry in the analysis log records that, after the write-up of the category of “normalise” was finished, the researcher scanned matrix data relating to the next category of “work”. This revealed that most of the matrix data pertaining to that category had been reported in relation to the previous category, and hence the two categories were collapsed.

The last two strategies listed in the matrix were “making meaning” and “control”. It was clear from the outset that, both from the women’s accounts and the relevant literature, that cognitions about meaning and control would be important. What the researcher had not realised was the way in which the other coping strategies would link with them, that is, that they really acted as overarching themes. In other words, all the coping strategies could be seen as having the function of enhancing control or a sense of meaning. Moreover, sometimes these strategies appeared to

serve both functions. The process of close scrutiny of the data entailed in the matrix development, reading relevant literature on making meaning and control, and discussions with the researcher's supervisor all pointed to this relationship.

In order to be thorough with the data in relation to these two higher-order categories, the initial write-up of meaning and control took the form of a case study on each participant. In some ways, this is akin to "selective coding" (Strauss, 1987) in that it involved a further scanning of the interview data to examine illustrations of these higher-order categories. This resulted in a detailed description for each participant of behaviours and descriptions in relation to making meaning and enhancing control. The material in these case studies was then coded around the various indicators of meaning and control that had been identified in the literature, or which had emerged through analysis of interview data. For example, efforts to regain control may include strategies such as causal attribution, seeking information, and developing a positive attitude; meaning can be derived, among other ways, through exploring existential issues, changing outlook on life, and finding benefit in the experience. The final step was to write up the findings in relation to meaning and control around these indicators.

The analysis of the follow-up interviews involved a similar series of steps to those undertaken in relation to the initial interviews. Once again, after transcripts were completed all the interviews were coded in terms of new demands to be confronted, appraisal and coping strategies (including making meaning and exercising control), and changes made by the women. In addition, quotes were highlighted which illustrated these areas most clearly.

Having completed the coding a matrix was assembled that explored the themes of making meaning and retaining control for each of the sixteen women. Whilst it would have been interesting to assemble the matrix for all the coping strategies, time constraints, the volume of data, and the fact that the overarching themes encompass all the strategies prompted the decision to concentrate on meaning and control. The matrix included an indication of the degree to which these themes emerged in each of the interviews, quotes (referenced with page numbers from the transcripts) and related observations. The quotes and observations were described in

terms of the indicators for making meaning and retaining control that had been developed through analysis of the initial interviews. For example, in terms of making meaning it was noted whether the woman demonstrated making positive or negative meaning, or both, and how this was indicated through such means as drawing on sense of purpose and beliefs, self-care, changes in outlook and identification of positive effects. This can be seen in the sample from the matrix below.

ID	Meaning	Control
01	<p><i>Very strong, positive</i></p> <p>“Pivotal experience” (p. 1)</p> <p>“valley of death...added to life” (p. 2)</p> <p>“Make connections to others” (p. 2)</p> <p>Other benefits (p.3, p.4, p.5, p.7)</p>	<p><i>Quite strong</i></p> <p>“I’ve given up control a lot” (p. 8)</p> <p>Trust in doctor (p. 6)</p> <p>“manage my level of stress” (p. 4)</p>
02	<p><i>Some, positive</i></p> <p>“changes in psyche but not just from breast cancer” (p. 2)</p> <p>Positive: “a degree of understanding” (p. 2, p. 4)</p>	<p><i>Some</i></p> <p>“some things outside your control” (p.3)</p> <p>Writing as a form of emotional control...”getting rid of it” (p. 7)</p> <p>Some downward comparison (p.1, p.3)</p>

As with the initial interviews, the next step was to develop comprehensive computer files of examples of making meaning and retaining control for each of the women. These were structured round the indicators for each of these themes. In addition, analysis of the coping strategies of acceptance and denial/avoidance was undertaken through a further coding of the case study files. The quotes assembled in these files encompassed these strategies because acceptance usually was associated with making positive meaning and retaining control, and denial/avoidance with making negative meaning and sense of loss of control (see Chapter 7 for fuller discussion). The coding categories were based on those that emerged from analysis of acceptance and denial/avoidance in the initial interviews, with the addition of several

new categories suggested by the data. Both the matrix and the case study files were then used to assist the writing up of the findings from the follow-up interviews.

Trustworthiness

Lincoln and Guba (1985) argued for the importance of “trustworthiness” of the findings in qualitative research and described a range of ways in which this could be achieved. In this study, trustworthiness of findings was enhanced in a number of ways, some of which are already described above. These included the use of rigorous procedures used in coding and analysis; discussions with the researcher’s supervisor; and keeping a reflexive journal during the period of analysis. The journal involved writing up of findings in which decisions about method were recorded, as were observations about the data and links with relevant literature. These journal entries were dated and referenced to the data and stage of analysis. The journal of analysis log means that there is a “paper chain” of evidence which can be accessed for checking (Miles & Huberman, 1984).

Two additional activities, which were undertaken to strengthen the credibility of the findings were an independent coding of two transcripts and several member checks (Lincoln & Guba, 1985). The independent coding was carried out by another PhD student who was experienced in qualitative research methods. Agreement among the readers was very high in the application of the coding categories. The few differences in interpretation that did occur were discussed and agreement achieved.

There were three ways in which member checks were achieved. Firstly, all the participants were given the opportunity to have a copy of the transcripts of their interview for checking or for further comment. Two women took up this option after the initial interview, and neither wished to make any changes. However, as was mentioned earlier, the husband of one of the women read the transcript and was unhappy about some of the content that related to their marriage. As she did not want to put any further strain on their relationship she decided not to take part in the follow-up interview. This was a regrettable and unforeseen aspect of member checking.

Secondly, the researcher had undertaken to give written feedback to the women about the findings from the study as they became available. To this end a comprehensive, six-page summary of findings was forwarded to each of them from the initial interviews and, at a later date, a somewhat shorter summary from the follow-up interviews (see Appendix D). At both times, in the accompanying letter, the women were invited to contact the researcher if they had questions or further comments to make about the findings. One woman rang the researcher to give an update on her progress. When the researcher forwarded the summaries of the follow-up interviews three of the women could not be contacted, and sadly, one of them had died from a recurrence of her breast cancer.

The third way member checking was achieved was through a presentation of findings from the initial interviews that the researcher gave to women attending a regular, monthly meeting of the Breast Cancer Action Group (BCAG). Two of those attending the meeting were also participants in the study. When the study was completed a summary of the overall study findings was also sent to the BCAG.

Chapter 5 Results of Initial Interviews: Coping Strategies

This chapter presents a description of the women's initial reactions to diagnosis, followed by an analysis of the processes of appraisal, acceptance of the threat or denial/ avoidance of it. Four different targets of acceptance and denial are identified and described, namely acceptance of diagnosis, treatment, emotional reactions, and life-threat. A range of strategies for coping, with examples, is then discussed. These strategies include distancing, having a positive focus, focusing on the present, normalising, seeking social support, information seeking, downward social comparison, use of humour, using causal attribution, seeking alternative treatment, and employing methods of stress management. These strategies can be seen as serving the functions of regaining control and making meaning, which is explored in Chapter 6.

Please note that throughout Chapters 5, 6, and 7 quotes are presented in italics with three dots representing irrelevant material omitted from the quote, and two dots representing a pause on the part of the interviewee. The use of bold in some quotes is to indicate emphasis given to particular words by the interviewee. Several of the quotes introduced in Chapter 5 are purposely repeated in Chapter 6 to illustrate particular (new) points.

Initial reactions to the diagnosis

The initial reactions of the women to the diagnosis of breast cancer provide valuable insight into both their subjective experience and the process of appraisal. These reactions were quite varied, with four women reporting little distress. However the majority (fifteen women) indicated they were very shocked and overcome, to some degree, by feelings of fear, anger and grief. For some of the women this period of strong distress lasted only a day or two, while for others it continued, on and off, until surgery was over and the results of various tests were known which indicated whether the cancer had spread to the lymph nodes.

The strength of these initial reactions can be gauged in many of their responses. For example, when her doctor told her that she had cancer, one woman said that it “nearly knocked me flat” (10, p.4) and then went out to her car and “howled my eyes out.” Similarly, another woman said that the day she was diagnosed was:

Probably the most devastating day I've ever had...It was numbing. That's probably about the only word for it I think. I lived in shock until I had the surgery. (17, p.1)

In addition to the shock and fear, there was often a mixture of other emotions, including anger and grief. A wide range of emotions is reflected in such statements as:

It's very volatile.. you're coping with anger one minute, fear the next, depression and then “oh it's not really happening”. All of these things are happening in a matter of a couple of hours and they're very extreme. (01, p.3)

However, while some women gave immediate expression to these feelings, others kept them at bay.

As mentioned earlier, while most of the women in the study reported strong initial reactions to their diagnosis of breast cancer, four women indicated that they experienced a fairly mild reaction. Two of the women had been diagnosed with very early signs of breast cancer which had been detected through routine mammograms, and so for them the degree of threat was less severe and treatment less extensive. One of these women (13, p.1) reported that she was “taken aback” and experienced some initial distress, but said that she felt no fear about the breast cancer. The other woman commented:

I just feel that as you get older, you're going to get something ..so I wasn't shocked by the breast cancer. I don't think I was even disconcerted by it. You know, that's life. (03, p. 5)

I don't think it's as big an issue for me as it is for some people. (03, p.12)

I'm not concerned about body image, or if I am it's not with breasts because they're under jumpers and things...The breast operation really wasn't a problem. I'm much more concerned about something like having a stroke. If I were to lose either mobility or brain that would be awful, which I suppose is more mind-image than body image. What's important is being able to think and read, and talk and listen to music..all of that is miles more important to me than body parts. So, yes, all the things that are important to me are intact. (03, p.5)

The remaining two women, one of whom was in her early thirties and the other in her early seventies, both required mastectomies but did not report any feelings of shock or distress. One of the women said that she had a strong conviction that “everything was going to be all right” (02, p. 5).

The extent to which these atypical responses might be considered as evidence of denial will be discussed later in this chapter.

Appraisal: “I can cope”

As was described in Chapter 2, appraisal refers to the cognitive process in which the woman weighs up the significance of her situation and her ability to cope with it. In this process she considers whether the situation involves harm/loss, threat or challenge (primary appraisal), and assesses her own resources and coping options (secondary appraisal). Out of these two processes, she makes a decision about the manageability, or otherwise, of the situation and the coping strategies she will use. The process of appraisal is ongoing; it may be necessary for the woman to reassess the significance of the situation as events unfold as well as her choice of coping reactions.

The reactions described above showed that many of the women in the study viewed their diagnosis as entailing a threat to their life and, for some, shattered their sense of physical security. However, as the women took stock of their situation and

made decisions about treatment, many of them came to view their situation as a challenge. For example, one woman said that part of her way of coping was:

...seeing this whole thing as a challenge that I can just take up and make the best of. (11, p. 25)

Most of the women expressed the belief that, overall, this was a situation that they could manage, as can be seen in the following:

I never really doubted that I could cope with it. I just knew I would cope with it. (01, p. 4)

*I think I always believed I could handle it. It was more a matter of **how** rather than a matter of “can I or can’t I?” (06, p.31)*

In the interviews, these comments often came after discussion of the resources that the women had to draw on, whether that be within themselves or external. External resources included partners, family member and friends. This sense of being able to cope, but not in isolation, comes out clearly in the following statement where the woman had just described how she and her family have pulled together and supported each other:

And I think that even if the results - I realise it’s all very well for me to say this - but if they hadn’t been good, I still think that would have been our way of coping. Life would have been different, very different, but .. we could have coped. That’s the feeling I’ve got. (08, p.10)

Acceptance

In this study, acceptance is defined as “restructuring one’s understanding of the situation one is in – assimilating a new reality” (Carver, Scheier, & Pozo, 1992, p. 183). It has positive overtones of attempting to come to grips with what might be a difficult situation. In this study the reports of the women indicated that various targets, or facets of their situation, could be distinguished. These included acceptance

of the diagnosis (that is, the reality of having breast cancer), their emotional reactions to it, of its implications in terms of life threat, and of treatment. As emotional reactions have already been described in the section on *initial reactions*, and will be also addressed in the section on *denial*, they are not considered further at this point.

Acceptance of diagnosis

Most of the women spoke directly about having accepted the reality of the diagnosis of breast cancer and the need to deal with treatment and recovery. For some, especially those who had described having fairly mild reactions to their diagnosis, this acceptance seemed to come quite quickly as is reflected in the following comment:

With my medical background I knew that the diagnosis was a possibility, so I accepted it. And from the time of the diagnosis I was thinking what would be the treatment for that. So I think I accepted it fairly quickly. (12, p.1)

For a number of the women acceptance did not happen immediately but rather was a fairly gradual process, as is expressed in the following:

There was a bit of me that kept saying "this is a joke, this is a nightmare and somebody suddenly is going to say, ha ha fooled you...And it took actually about three weeks before it really settled into my consciousness that this is not just some academic exercise.. this is real. (06, p. 4)

I suppose I denied it up until the day I had to go into hospital for surgery the next day. ...They wouldn't let me be admitted on the morning of the operation. It brought it back to reality that it was happening. There was no point in denying it; you had to go with it. It (surgery) was my best chance at living, but I had no choice so I had to accept it. (17, p.13)

This sense of having no choice but to accept the diagnosis and, for some, the unpleasant reality of disfiguring surgery, is echoed by others:

It was a case of have to (accept it). I mean there was nothing could be done about it. It (the breast) had to go and that's all there is to it...Well, as my husband said "It's got to come off, so that's all there is to it." (15, p. 32)

While there was no real choice about the reality of the breast cancer and the need to accept it and come to terms with what it entailed, there was a choice to be made about *how* to respond to the situation. This nexus is clearly described in the following:

I used to always wonder how people would cope, you know, like how would you cope with ... if you hear such and such has got cancer, you go "Goodness, I wonder how they're coping." But for me there wasn't much choice. I mean you could either sit in a corner and do nothing, or you can get on with it and do the best you possibly can. And it wasn't until I was actually faced with the choice that I realised that there wasn't anything in between. There was either the sort of, you know, give up and throw in the towel, or really just get on with it, and it was at that stage that I think I decided that I would make the best of it that I could. And that sort of stayed with me right the way through. (11. p. 18)

For some women, the acceptance of the reality of the diagnosis was accompanied by a fighting attitude as can be seen in the following descriptions:

I think we all cried for about two days, and the third day I was going in to hospital. I had a shower, a lovely long shower - and it was the first night I'd slept - and in that shower, that's when the change happened. I said, "Bugger this! (laughs) I'm not going to let it defeat me." ...And I was just going to do anything I could possibly do to make sure that I got through it, and I was going to win. That was my decision. (19, p. 3)

*I used to think that I was never a strong person. (But) As soon as I got the diagnosis I got all the weeping over and done with. I became so **hell-bent** on defying the odds and beating it and it not coming back. It must be just an instinct that takes over. (17, p. 12)*

On the other hand, another woman describes how there was no sense of “fight” in her acceptance of her situation:

I haven't felt any aggressiveness towards it (that is, cancer). People always say “You're putting up a good fight” or “battle”. I haven't seen it in those terms: it is part of me ... and it is something to be cured or treated rather than fought... I didn't feel like throwing it in. I didn't feel like making any strident statement or taking any aggressive stance. Take what happens and go from there. That's what I do! (laughs) (04, p. 29)

Acceptance of mortality

The reports of the women indicated that the majority had clearly registered that breast cancer represented a potential threat to their lives. For example, one woman recounted that she'd made her will before her operation while others spoke of the difficulty of not thinking the worst. However, two women denied that there was any threat to their lives, a response which will be looked at more closely in the section on the coping reaction of denial. In addition, four women reported that other illnesses that they had experienced entailed more threat to their lives than breast cancer did, so for them the associated threat was not a major concern.

When the women spoke about this threat and how they dealt with it, their responses frequently indicated an increased awareness of time and acceptance of mortality:

*And I suppose that's what an illness, such as I have, **does**. It makes me really aware that the time I see ahead could be long, or it might be a year. So all of a sudden you have this piece of time that you've got to do good things with because it mightn't last very long. If it doesn't, it doesn't. As far as I'm concerned I'll enjoy and do good things with it. ...So it does give you an appreciation, I suppose, of the use of time and of mortality. Not that I'm scared of dying, but there is an awareness there that it happens anyway.* (03, p.7)

We are all in the process of dying from the moment we're born, which essentially is true and I believed it at one level. Now I believe it at that level, but also

at a different level as well. And there's no other way of explaining it...Until you cross that bridge, you can't understand it...When you have a diagnosis of something like cancer or heart disease - and it has to be a disease or whatever that you know is going to shorten your life - cancer does it in a way that no other disorder does it, I would argue...Dying to me is now a very real possibility... death is much more real. (06, p.5)

Acceptance of treatment

One woman whose treatment with chemotherapy was unexpectedly difficult, because of reactions to one of the drugs, talks about her attitude to engaging in treatment and coping with it along the way:

Basically I had made up my mind or accepted that I was going to do it and I just did. (p. 15)

I thought, after the surgery (lumpectomy), "That's a proper operation but it's not major surgery." I didn't feel all that bad. But when I started having the chemo and the radio and the clot and all that sort of thing, that really ..it really knocked me. And I could accept that being tired was a way of life, or my hair ..people couldn't tell..I mean, I still haven't got it all back but losing a lot of hair or looking always really sick or not having any energy or anything like that, I just accepted it. I didn't even have to try...I just automatically shifted. I just go with it, without even trying. (p. 21)

As can be seen, acceptance was a coping strategy widely used by women in the study. However, when the targets of acceptance were considered – that is, diagnosis, implication of life threat and treatment – there were clearer differences between the women. For example, whilst a majority of women indicated that they had considered the implication of threat to their life, two rejected that there was a threat and four reported that other illnesses entailed a higher degree of threat for them. In addition, while some women described having experienced considerable emotional distress before coming to terms with the situation (and a sense of calm), others

reported little distress. The linkage between acceptance, level of threat and the issues of control and meaning will be further explored in Chapters 6 and 7.

Denial and avoidance

As was discussed in the literature review, there is a lack of clarity of conceptualisation in the family of coping strategies described as denial/avoidance. This section begins with a brief definition of key terms and outlines a framework for considering targets (components) of denial. This framework is then used to present the study findings in relation to the coping strategies of denial and avoidance.

For the purposes of this study, denial is defined as an unconscious process which results in the disavowal of an external or internal threat (Lazarus & Folkman, 1991): in other words, a refusal to accept the reality of a problem. While avoidance and suppression can look the same as denial, they involve acceptance of the reality of a threat but there is a conscious effort not to think about it or to keep away from any circumstances that may bring stressful material to the forefront of awareness.

The term “extreme denial” is used to describe the behaviour of individuals “whose denial of symptoms or other aspects of the illness is so complete that their physical well-being, social attachments, and ultimate prognosis are jeopardized” (Wool & Goldberg, 1986, p. 5-6). Wool and Goldberg (1986) suggest that denial of symptoms for more than three months can be regarded as extreme denial.

Wool and Goldberg (1986) distinguish four types of denial: denial of the physical manifestations of the illness; denial of the diagnosis; denial of the implications of the illness; and denial, or isolation, of emotional reaction to the threat embodied in the illness. As these authors suggest, by specifying the objects of denial, it is possible to make clearer judgements about whether a particular manifestation of denial is adaptive or maladaptive.

Denial of physical manifestations

Seventeen of the women in the study acted promptly when they detected a breast lump, either seeking an immediate medical opinion or monitoring the lump for a period of weeks and then going to their doctor. Two of the women, both of whom were middle-aged, delayed seeking medical care for over three months after noticing

a lump. Their response to detecting a breast lump will be examined in detail in order to explore the extent to which denial, avoidance or suppression may have been operating.

One of these women had a history of lumpy breasts and had been having mammograms every couple of years since she was forty which may have produced a false sense of security when she did detect a lump and hence contributed to her delay in seeking medical care:

I always had fairly lumpy breasts, and being aware of that fact .. I've had regular check-ups and mammograms every couple of years since the age of about forty. So when I did discover the lump I had just had a mammogram a couple .. of months prior, and it didn't show up so therefore it obviously, I thought, was okay. And I felt a lump and I thought "Oh well this is just hormonal" cause quite often breasts will, you know, swell and subside. (This) just didn't go away and I thought "Oh well"; didn't really want to know about it. And I'd knock it or turn in bed and it would really hurt, so I was keeping a check on it and it did get bigger and it was permanently sore. So I went along to see the doctor and he said "No, there's nothing wrong; it's just milk ducts or nothing to worry about", so I didn't want to hear anymore and I thought "Okay, that's fine." (18, p.1)

Clearly, there was some sense of not wanting to know, and she was busy working full-time so it was an effort to get time to visit the doctor. Hence it was another four months before she went along to another doctor, this time a female, who was very thorough and ordered an ultrasound which showed there was a problem. For this woman there was no actual denial of the presence of a lump, but there was some denial of the fact that it may be breast cancer, which was compounded, unfortunately, by the failure of a recent mammogram to detect the lump and the first doctor to check it out thoroughly. As she said, she delayed seeking help because:

Life is busy and I kept thinking, "Well, I had the mammogram", so therefore I thought I was fine. (18, p.2)

However, with hindsight she could say that she felt that it could be breast cancer even though the mammogram and first doctor had not detected it:

My intuition told me that I really should do something about it 'cause I wasn't convinced. I knew where the lump was but he's ... if I had sat up and said "Give me your hand; here it is," I'm sure he would have found something." (18, p.2)

A little later in the interview she explained that she had a good idea what a breast lump would feel like from having done a workshop on breast examination through the local community health centre:

I knew what to feel ... and it felt like that, but I was very aware and yet I just didn't go with the gut feeling. I didn't really want to know about it I guess. (18, p.3)

For this woman, the breast lump and the threat of breast cancer were in conscious awareness but she suppressed this and did not act on it for about four months initially and another four months after that.

The second woman also suspected the possibility of breast cancer but delayed seeking medical help for about six months after detecting the lump and for the same sorts of reasons as were given by the first woman:

I think I suspected for some time that there was a problem there because I had found a lump (in the) middle of last year, but because I was so busy with the business it was easier to just ignore it, and I did this... and I just didn't feel for the lump anymore after that time because there was so much going on. (10, p.1)

Several months later she read an article in the newspaper about a woman dying of breast cancer. This prompted her to check the lump, which she found had grown larger. At that point she told her husband who told her to see her doctor. However she delayed for another few months:

Anyway I was busy babysitting grandchildren and Christmas was coming, so again I just decided to ignore it, just deny, you know put it out of my mind and I did this until Christmas. All the time I was not very well. I'd had a lot of pain; I hadn't slept on my left shoulder all year because I had a lot of pain in my left arm and my left shoulder and shoulder blade ... but I was blaming arthritis - I've got arthritis in the lower back. (10, p. 1)

She went to the doctor in the New Year because of the pain and feeling unwell, but did not tell the doctor about the lump because she was put off by her attitude. It was only after another few weeks of much pain and feeling very unwell, and her husband's urging, that she consulted a different doctor who was recommended by a friend:

When you've got so many other things on your mind, you just don't want any extra to worry about so you put it out of your mind. I suppose that's denial, but (wry laugh) ... that's what you do. I had too much on my plate to worry about to have me being unhealthy, I suppose. (10, p. 15)

Clearly, then, there was "extreme" denial which resulted in over six months of delay in seeking medical care, despite an awareness that the lump had grown and that she was suffering from a lot of pain which she suspected was more than she should feel from arthritis.

Neither of these women showed total denial of the lump in their breast, however both had delayed seeking a medical assessment of their lump for over three months, which is consistent with the criteria for denial proposed by Wood and Goldberg (1987). It is, of course, even more difficult to identify denial in cases such as these when medical opinion was sought (though not specifically for a breast lump in the case of the second woman) and seemed to indicate there was no cause for concern.

Denial of the diagnosis

It is widely accepted that short-term denial is quite a common reaction to a diagnosis of a life-threatening illness such as cancer. Kubler-Ross (1969) defined denial as the initial phase in a natural process of adaptation to a life-threatening illness which gave the person time to mobilise other ways of coping with the situation. In her view, denial was often replaced by anger, depression and acceptance which she viewed as being more adaptive responses. However, denial could re-appear when needed to reduce high levels of emotional distress.

In this study, many of the women described having denied, or having tried to deny, the reality of their diagnosis. For all of these women this was, indeed, a fairly

short-lived reaction but one they registered quite clearly. As was seen in the section on *Initial reactions*, one woman described a feeling that “this is not really happening”. By contrast, two women vigorously denied the diagnosis of breast cancer when it was presented to them by their doctor. One woman had actually found her lumps several months earlier when she was doing breast self-examination, which she did each month because she had a history of lumpy breasts. However she was not concerned about it being breast cancer because she had been to her local doctor who had suggested a mammogram, which did not show anything. As she explained:

A couple of months after that I was sure it was bigger so I went back to the usual doctor. She was sure it was not a breast cancer but decided to send me to (breast surgeon) for a check-up. So I wasn't actually concerned at that point and he was away so I wasn't able to see him for about another six weeks. So when I waltzed into his surgery that afternoon I was quite sure that it was just one of these things you get when you are perimenopausal...So when he was sure it was breast cancer .. it was a tremendous shock, and, looking back on it now, I went through the grieving, denial and all that sort of stuff in his surgery. I argued with him that it couldn't possibly be breast cancer because two doctors had told me it wasn't, and I had a negative mammogram, and I was fairly assertive about the fact that I couldn't possibly have it. And he was terrific in that he just said “You're right”, and he showed me the mammogram and explained how, if there is a benign lump it will show up on the mammogram, (but) there's ten percent of cancers that don't. (19, p. 3)

The second woman, who had delayed seeking medical care for over six months, (described in the section on denial of physical manifestations) continued to use denial when first told by her doctor, following on mammogram and ultrasound, that she had breast cancer:

I went (to the doctor) and she told me they had found something, and they suspected it was cancer. It took me a bit to hold myself together at that point. Also she said we need to make an appointment with the surgeon and then she said “Look, I've put a lot on you today. Is there anything you want to talk about?” And I said, “No, I've just got this feeling”, still denying it, I said “I've just got this feeling I'll turn up on (at specialist's) and the lump will be gone”. And (doctor) looked at me and she said “It will be there still”, she said. “(Participant's name), it's cancer.”

And you know that sort of nearly knocked me flat. It took me a lot to - because I'm not a person that goes to pieces in front of other people; I still hold myself together - and of course I held myself together, and I went out in the car and howled my eyes out. (10, p. 3-4)

After this definite statement from the doctor, the woman accepted the reality of the diagnosis.

Denial of the implications of the illness

The third component or target of denial relates to whether or not the women accepted the life-threatening implications of their breast cancer. In the study, most of the women accepted the life-threatening nature of the disease (see section on *Acceptance*), although, over time, they mostly chose to distance it from their conscious thinking in order to get on with living. Several women did not think that their breast cancer contained much life-threat given the very early stage of development of their cancer. This appraisal seemed justified from the medical facts of their situation for two of these women but appeared less justified for the third woman, whose cancer included some nodal involvement (an indication that the cancer has spread beyond the breast). She spoke directly about her resistance to accepting any life-threat when that issue had been raised with her by a woman who had, herself, had breast cancer several years earlier:

And I said "No I haven't faced that", and I didn't, and I didn't want to... And then my daughter actually said something about it, and I said "I'm not going to die from breast cancer." And I really don't think, even now looking back, that I really felt that I was going to die from it. I really didn't face that. (16, p. 8)

Similarly, the woman who had delayed seeking medical care for over six months also showed some signs of denying the implications of the disease, although she also expressed some doubts about how long she would live as a result of it. She explained how she was able to keep thoughts about cancer out of mind:

I think about things with the business and that, and so I don't think about the cancer I don't think. I try to put it out of mind. And I talk about it in the past because he's (surgeon) has taken the lump out see and I feel, well, that it's gone, and we're

having the chemo and all this other business, and you know that's just a precaution if there's any little dots (escaped cancer cells) there, and so I suppose I talk about it in the past tense that it's not there anymore...I sort of think I've had the lump taken out and I haven't got it... So I suppose if that helps me, I'll think that. (10, p. 26)

However, a little later in the interview she implied some doubts about her own stance when she volunteered that “the only negative thought” she had was when she allowed herself to register the widely-held belief that cancer “will get you in the end” (p. 30). It was as though she was consciously trying to use denial but did not find it completely satisfactory given her other experience with friends and acquaintances who had had cancer.

For her, denial was used as a way of coping when additional worries would make it difficult for her to cope. Hence, as she said:

I've sort of become a bit of an ostrich I think (small laugh) ... both with the business and the cancer. That's the way I probably cope with it. (10, p. 44)

In her situation, it would appear that the denial was counterproductive as it meant that she delayed obtaining medical treatment. In addition, it seemed to be leaving her with a residue of worry that she would not directly address and hence prevented her from seeking support in relation to it.

As was mentioned earlier, once the stage of diagnosis and hospitalisation was over, many of the women began to put the breast cancer at a distance in their thinking. The distancing behaviour is not viewed as denial because those women who used that strategy also consciously acknowledged the threat to their lives, as will be discussed in the next section.

Denial of emotional reaction to the threat

Extreme emotional distress is more likely to be experienced at certain nodal points in the treatment process, especially beginning of treatment, completion of treatment and recurrence (Wool & Goldberg, 1987). It is possible that some denial or suppression of affect is used at these key points to help maintain feelings at a manageable or fairly stable level. The women in the study had been diagnosed less

than fourteen months prior to the first interview from the time of diagnosis and none had experienced a recurrence. In addition, a number were still undergoing treatment. However, strong reactions were described in relation to the first two of these key points, especially the former, that is the early stages of diagnosis and treatment.

As was described in the section on *Initial reactions*, most of the women expressed shock, fear and anger when they received their diagnosis, which is consistent with registering a life threat. In addition, many of them verbalised this threat or expressed it behaviourally (for example, making a will). Hence for those women there was no apparent denial of their emotional reaction to the threat. However, as was discussed then, four women described having a mild reaction to their diagnosis, which may represent some form of denial either of an actual threat or of their emotional reaction to it. The former has already been discussed and largely dismissed so it is the latter scenario that needs further investigation: namely, denial of emotional reaction to the threat.

As was mentioned in the section on *Initial reactions*, two of these women, both in their sixties, had been diagnosed with very early signs of breast cancer from routine screening and their subsequent treatment was less severe than for most in the study (biopsy and radiotherapy; lumpectomy and radiotherapy). As the extent of treatment and probable severity of threat was substantially less than for most of the other women in the study it might be expected that their emotional reaction would be fairly mild. One of these women reported feeling “taken aback” and having “a bit of a sob” to her partner. His response was to play down the situation, and not give emotional support then or during active treatment. In addition, there was a self-acknowledged tendency on the part of this woman to “hold too much back”:

I think my sister said to me that I actually held too much back, (kept) too much to myself over the years. I think the marriage situation I was in caused that. My husband was an alcoholic - there wasn't much communication there - and he used to say things like "Don't tell me your troubles." So you get used to ...(changes tack) ..and I was probably a quiet person to begin with and keep things to yourself a bit; (I) love to hear other people's problems but you didn't worry them with how you felt, so it's possibly just become a way of life. (13, p. 7)

It would seem, then, that her emotional reaction may have been somewhat suppressed, both because of her long-standing tendency to “hold back”, and her partner’s unsupportive response. It is interesting to note that she did not seek out others to share her experience with, though she acknowledged that she would have liked more emotional support in the first few months after diagnosis.

It was also interesting to note that this woman expressed feelings of frustration and anger at the effect of treatment on her body - especially as she had to come off HRT which reactivated menopausal symptoms - when active treatment might not have been actually necessary:

*I do remember saying to (partner) one night - and I did get a bit teary but I remember I felt angry - that I wished I'd never had the bloody mammogram. I was probably in the middle of one of my night sweats because they were a constant problem... I **did** feel angry and frustrated, and they (doctors) could not tell me how long you could have this sort of cancer and not die of it... So there was this frustration. (13, p. 5)*

Hence it appeared that there was not marked denial of feelings, although she less readily shared feelings of vulnerability with others. On the other hand, for the second of these two women there was a self-confessed tendency to use denial in some problematic situations:

How do I cope with situations? I think I have a tendency to pretend they're not there...(chuckles) I'm aware of that; so I bury them somewhere. (03, p. 8)

The other two women who reported mild reactions to their diagnosis and treatment – and who both had lumps removed by mastectomy – showed very little or no sign of suppression of feelings. However, one of the women did report a tendency to “push aside” worries about her breast cancer. This arose when the researcher asked her whether or not she had any particular worries or difficulties in relation to her breast cancer to which her response was:

(I) probably pushed it aside, haven't I? ... There might have been little things but probably I thought to myself "That's probably not worth worrying about." (02, p. 41)

In addition, she had described feeling that she had to protect her family, and especially her husband, because he worried a lot. It would seem, then, that she may have developed a long-standing tendency to suppress emotions to protect her partner and family. This, in conjunction with holding strong beliefs of “being guided” to the “right specialist”, may have helped to minimise the strength of negative feelings such as anxiety, sadness and fear. It seems likely that, when she became aware of difficult feelings, she coped with these by using a combination of strategies including being positive, downward social comparison and seeing purpose or meaning in her experience.

Turning now to the women in the study who did describe feelings of shock and distress, it is possible to see that some of them showed denial of emotional reaction to a greater or lesser extent. One very clear example of emotional suppression, but not denial, came from a woman who herself worked in the oncology field. She described herself as having coped with her feelings in the early weeks by putting everything on an “academic level”:

So I thought, “Oh yes, it really is breast cancer, and I’m going to have to deal with this... Okay, this is the way it goes, this is what I have to do.” And I was into that real “Okay, my worst fears are confirmed; where do I go from here? Well, this is what I need to do.” And I suppose that was my way of coping; putting it all on an academic level... There was no way I could subjectively cope with it at that time, no way. I had to put all my feelings on hold because the fear and (pauses) yes, I had to squash all that down. I just couldn’t deal with it right then. (06, p. 2)

A little later she clarifies that her suppression was indeed quite conscious:

*I wasn’t in denial. No, it was not denial. I was very much aware of what I was doing.... I think I knew it (reality of diagnosis and implications) on an objective level but I wasn’t prepared **then** to deal with the feelings that were associated with that, for a variety of reasons, and I just sort of knew “I’ll deal with that later, not now. Right now I want all my energy focused on the objective and dealing with everybody else.” I was having enough trouble dealing with everybody else’s anxieties and fears and concerns and worries, and I couldn’t, didn’t,.. I actively chose not to look at my own fears. When I pulled them down, I pulled them down*

selectively, and just dealt with them bit by bit. I used meditation and a few other things to deal with how I'm feeling about various things. (06, p. 8)

Several other women also described using other strategies to manage (suppress) their feelings. For example, one single woman described her emotional reactions after surgery as having been extremely difficult for her to handle:

*The emotional responses that I got, particularly when I got out of hospital ...I was staggered at the depth and strength and **rapidity** of the diverse emotional responses in the space of twenty four hours, and that was really hard to take. One moment I'd be fine, the next I'd be crying, the next moment I'd be feeling quite happy, and the next moment I'd be feeling really anxious, then I'd be depressed, then I'd be crying, then I'd be happy again and then I'd be enjoying having a lovely dinner with friends, and it all took place so quickly. That's frightening and shocking and surprising. It is so unlike normal life. ... I felt that I had totally lost contact with the person that I had been... it was being cast adrift from yourself. (07, pp. 17-18)*

At these times, this woman tried to manage these frightening feelings in a variety of ways including avoiding looking at a photo that reminded her of her former self in happier times which brought up anguish because she felt she could no longer recognise herself as being the same person:

(I would) avoid the issue by not looking at the photo. What I would do when I felt worst was walks, frantically meditate, listen to music, try and structure my day as much as possible, tell myself not to think about these things, get help, read .. whatever I could think of doing. (07, p. 19)

Clearly, this woman was acutely aware of the strength of the emotions engendered by the breast cancer, and for her it was necessary to make the feelings manageable by damping them down, or suppressing them, in a variety of ways.

Overall, the women's descriptions indicate the value of identifying denial in terms of the facets of the experience (targets) which are being denied. Denial of pre-diagnosis symptoms and the diagnosis itself was only used by two of the women, whereas most women did not attempt to deny the associated life threat, although they chose to "put it in the background" over time. Similarly, most women did not deny

their emotional reaction to their diagnosis, although several appeared to make attempts to minimise the strength of their reaction.

Distancing

This category refers to cognitions which demonstrate that the woman is consciously aware of an unpleasant reality (e.g., threat of recurrence) but makes an effort to put it in the background of her thinking, that is, put it at a distance. It is reflected in such statements as “don’t dwell on it”, “tried to forget about it” and “tried not to worry”. It has similarities to the concept of avoidance, but the latter is generally conceptualised as seeking to escape from an adverse situation or difficult feelings, and is seen in such behaviours as using fantasy, and wishful thinking (Dunkel-Schetter et al., 1992). Distancing, on the other hand, enables the individual to “compartmentalise” their concerns in order that they can more fully engage with their lives. A number of the women in the study used this strategy, and it often seemed to be used in conjunction with strategies such as focusing on the present and normalising as can be seen in the following comments:

Though I’m looking forward to the end of the treatment, I think I’ve really got to live with it (uncertainty) for the next five years. There’s no good saying “I haven’t got it. Hooray.” So I won’t say, “I haven’t got it”, but I’ll put it at the back of my mind because I don’t want it playing on my mind for the next five years; you’ve got to try to carry on as normal. All you can do is go for your check-ups and worry about it then, otherwise you could make yourself a nervous wreck. That is what I’m trying to think to myself, “Try and do what you can.” (14, p. 6)

This particular woman used this strategy along with keeping busy and keeping things normal:

I don’t have time to be morbid because I’m always doing something; going out shopping, doing housework, or (I) go over to (daughter’s) house and do a bit of light housework for her ... and look after her children while she goes and does her shopping. So I won’t sit about and feel sorry for myself. (14, p. 7)

Similarly, another woman acknowledged the way taking care of her granddaughter – which she did on a regular basis- helped distract or distance her from her concerns about her breast cancer:

I think if I hadn't got her (grand-daughter) in the house I think I'd have dropped by now. Right now I'd be sitting there doing nothing, thinking, whingeing. It's (breast cancer) not to cry over; I mean it's done and it had to be done. (15, p. 1)

Another woman also showed that she appreciated going to work because it gave her time out from her feelings and concerns:

*Work's been **the** most important - being able to run away and forget about it. I walk into work and they say "Hello, how're you going?... Fine." Things are normal. I just work. And being able to forget about ... I don't forget about it altogether. I'm still at the stage where I think about it every day. I'm looking forward to the stage where I get through a day or a week without having to think about it. But it's wearing off; so time is healing. I look forward to the time when I mark a (specialist's) appointment on the calendar and then forget about it at that stage... As long as they (results of follow-up tests) all show clear, I suppose it's not too much to deal with. It takes one step at a time, and not too much worry down the track; that's what I'm trying to do. (09, p. 15)*

Similarly, she coped with thoughts about life-threat by not dwelling on them:

You know in the back of your mind that it (her cancer) could be very serious, and of course it's life-threatening, but you don't dwell on it. What would be the point? (09, p. 21)

Positive focus

Many of the women verbalised the importance to them of making the most of their situation and being as positive as possible. In other words, having accepted their situation, they demonstrated their willingness to come to grips with their new reality in a constructive way. The women's accounts indicated that adopting a positive focus was reflected in a number of ways including: directly verbalising their belief in the

importance of having a positive attitude and when they had used it; identifying bonuses or benefits that have arisen out of their experience with breast cancer; speaking confidently about their plans for the future; and establishing new priorities and goals in their lives, including increased levels of self-care.

The following excerpts show the importance most of the women placed on having a positive attitude and how they used it to cope with different aspects of their situation, including coming to terms with the diagnosis, the process and effects of treatment and follow-up medical appointments:

From then on I decided that I was going to put everything negative out of my life, and I would just concentrate on the positive .. and I was just going to do anything that I could possibly do to make sure that I got through it, and I was going to win. That was my decision. (19, p. 3)

The most important thing is that they're (women) told what to look for and they're made aware that they should be looking over a number of years... And the other is to be positive. (02, p. 48)

When I go back for another mammogram, I hope there'll be nothing there. I'm fully expecting there won't be, so that's a positive outlook...I try to look at life that way; to wake up in the morning and think "what is good about today?" ..and there is usually something. (03, p. 12)

For one woman, being positive involved concentrating on what was more important to her: her appearance or her sense that she was still essentially the same person:

I did hang on to the fact that I was still me, regardless of the way I looked. I mean this isn't the way I want to look right now either.. it's going take me a while to lose the weight again and get back to sort of looking the way I want to look. But I never stopped feeling like me right the way through...That's the same with having had the mastectomy too. I mean that was certainly a bit of a shock the first time I saw it after surgery and getting used to the way I looked. But I mean it doesn't horrify me

or anything..I just needed one breast gone, that's all. I sort of just, you know, focus on the positive part of the fact that it's still me. (11, p. 32)

In effect, many of the women were saying that positive thinking could exert a favourable influence on the course of their recovery, which is directly spelled out in the following:

You've got to have a level of being positive and being bright rather than dragging everyone else down with you. Someone's got to be strong so it may as well be me so it (recurrence of BC) doesn't, maybe, happen again. (17, p. 2)

Whilst these women believed that it was important for them to be positive, this did not mean that they could be positive all the time. Rather, being positive seemed to be a goal towards which they were working, as can be seen in the following:

Maybe now is a particularly difficult time because you're sort of off all your various things (treatment) and you've got to concentrate on the positive thought. But that doesn't totally get rid of the idea at the back of your mind that the a particular ache or pain could possibly be a secondary, although the next moment you say "I've always had that pain fleetingly" or "That's not a bad pain. That's a muscular pain." And you have to keep really forcing that in your mind. (19, p. 4)

Some of the women found support for their positive focus from other women who had survived breast cancer:

I've had one lady - I ran into her a couple of weeks ago - who went through kinder with me, and she told me that she went through breast cancer ten years ago...It's a very positive sign that she's ten years down the track and I was glad I ran into her. (09, p. 20)

The positive attitudes of most of the women also expressed themselves in the bonuses or benefits that many of them described which had occurred as a result of their experience with breast cancer. Some of these benefits related to their own sense of themselves and what they were capable of:

I think, if anything, it (BC) has given me incredible strength..I don't see it as a bad thing. I sort of feel that it's my biggest adventure to date, and I coped with it pretty well, and life's about adventures and this is the biggest one I've ever had so far. (01, pp.13-14)

I've come out a lot stronger even with this...more confident. If I can face this, I can face anything. (02, p. 18)

*I hope it's taught me more about myself, and I hope that the intensity and depth of personal relationships doesn't evaporate, although I know that **will** happen because those deep, intense, personal relationships are part of the human response to a crisis, and then everyone goes back to being normal again. So I guess I was lucky having those experiences rather than not having them at all. (07, p. 17)*

In addition to these intra-personal gains, other benefits were experienced in relationships with others, both with family and friends and at work. For example, one woman talked about the increased closeness that had resulted with her own mother as a result of confronting her own mortality:

*It's been interesting because my mother and I have talked a **lot** about death, her dying, which **will** happen and this year we talked a lot about it. It's very bonding for us in that way...It's been nice because I think she feels a lot more comfortable now just to talk about her own death without feeling that she is upsetting me. And I don't get upset. (01, p. 14)*

Another woman spoke warmly about the support she had received from family, friends and work colleagues. She described their reaction when she returned to work after a short holiday:

*I've got that support at work as well. And I said to H (husband), "It's surprising that I've worked with these people for many years, and if I have a couple of weeks (holiday) now they **all** give me a hug and a kiss now. It's changed. There's*

been lots of positives in that side of it. So the support I've had has been really wonderful. (09, p. 6)

In addition to identifying a range of bonuses, many of the women spoke about having increased their level of self-care, which included such things as making changes to lifestyle and diet. For example, one woman in her thirties said:

I've tried to change my lifestyle and I'm attending the Gawler Foundation as part of that because they look at things like changing your diet, meditating .. and I think with doing those things, I am doing something positive for myself. (12, p. 8)

A number of the younger women with children spoke of the need to make time for themselves and relaxation and, sometimes, the difficulty doing that:

I read a lot more. I like reading... If I've got a book, I'll sit and read for an hour before I go and collect the girls (from school), whereas before I would rush off and do something. So I've relaxed and slowed down a little bit. (09, p. 18)

The following comments are typical of the optimistic approach most of the women had to their future and which show them remaining engaged with important life-goals:

I've got a lot to live for so I keep looking forward... In a way, that's what keeps you going; having something to look forward to. (14, p. 11)

I consider that I am fortunate with all the things there that I want to do, and I think that's what the basis of life is. (13, p. 13)

Focus on the present

Another coping strategy that was used to some extent by all the women was focusing on the present rather than looking too far ahead. Statements that were indicative of this approach included “living each day and enjoying each day”, worrying about possible problems (in relation to their breast cancer) when they arose

rather than in advance, dealing with “one step at a time” and “taking things as they come”. The close link between this strategy and being positive is apparent in the words of one of the women who described how she coped with the threat of recurrence:

Yes it can happen and I'm not naive enough to think that it can't. However you have to be positive and face that when you get a bit closer to it. (09, p. 3)

The remark “If it happens it happens” was frequently used to express the reason for adopting a focus on the present. For example, one woman in her early forties felt that the “message” in her breast cancer was that she was “not invincible” and as a result had begun to “live with time differently now”. As a professional woman working in a competitive area she “saw time as the enemy”, but now she had changed that:

I'm sure it will change but I feel very much I live day to day...It feels very good. I'm much more relaxed (laughs). I've stopped worrying about anything anymore. I just say 'If it happens, it happens'. (01, p. 8)

An older woman described the same sort of approach when she said:

I think what's the use of worrying about something that might happen. ... There's no use worrying about something that might happen to you, but deal with things as they happen. (02, p. 18)

While some women tried to adopt this focus on the present, it was not always easy to achieve. For instance, a younger woman, who was about half way through chemotherapy at the time of the interview, voices some of this difficulty:

I'm still at the stage where I think about it (breast cancer) every day. I look forward to the time when I mark an appointment on my calendar and then forget about it at that stage. ... It takes one step at the time, and not too much worry down the track. That's what I'm trying to do. (And a little later) I've been a worrier really. I probably would worry about it (things going wrong) rather than wait to see if it does.

Whereas now I've learned not to do that. 'All right, it could happen but worry about it when it does.' (09, p. 15)

For one young woman who had been diagnosed only a few months before the interview, there was an underlying sense of urgency:

It's important to use it as a positive experience, not a negative experience. Life is really too short. You've just got to live every day and enjoy every day, and the things you don't enjoy, get them out of your life. (17, p. 18)

As was noted above, this strategy was used very widely by all the women in the study, and often in conjunction with other strategies such as having a positive focus and distancing. These clusters of strategies will be further explored in the next chapter.

Normalise

The majority (13) of women in the study also described using behaviours that “normalized” their lives, by which is meant making efforts to return life to its usual patterns, routines and order. This is expressed in statements such as trying to make life as normal as possible, carrying on as before (breast cancer), not letting breast cancer change their way of life and wanting to be treated as normal.

The importance of keeping things normal was articulated clearly by one of the older women in the study who had been diagnosed with very early stage breast cancer five months earlier:

I don't want to be changed by it. I just want to be rid of it; not so I don't have to think about it, but just because I want to do other things. So it's a case of pushing it away where it belongs and getting on with it (life). It's just a bit of a nuisance or a disruption. (03, p. 12)

Another woman in her forties, whose treatment involved lumpectomy followed by chemotherapy and radiotherapy, also placed importance both on working as much as possible while having adjuvant therapy and having “normalcy”:

Work for me has always been very important. Work very definitely defines who I am... Work is also, I suppose, a source of friendship and support. Probably three people at work I would say have been particularly supportive, not by being ... I don't appreciate sappy stuff... I suppose part of what I find most helpful is people treating me normally... We talk about normal stuff, but that normalcy is part of her being a normal person still and me being a person still, and that's actually supportive. (06, p. 21)

Another woman, whose husband had been able to take some weeks off work over the time of hospitalisation and early recovery period, indicated that retaining usual patterns and routines as much as possible was important for her school-age children:

I think that we were able to keep things fairly normal right the way through and that made it easier for them I think. (11, p. 7)

In addition to seeing the value of normalcy for her children, she also valued it highly for herself and found it difficult when people treated her as though she was different. As she said:

*Feeling different, not just physically, but feeling that I was a different person and that people were treating me differently, **that** I found quite hard to cope with, and still do in a certain sense. Good friends have been wonderful, and family have been wonderful, but there's another group of people that know you but don't know you that well, and in their eyes you seem to be the person with breast cancer... It was nice, once I was able to go back to work again .. and to be there and doing the normal things and feeling fairly anonymous again was really nice after having been a patient and somebody with breast cancer. It was nice to feel that I could still be the same normal person again. ...I do think of myself a bit differently, but it was hard to sort of accept people thinking of me very differently. (11, p. 15)*

This need (for normalcy) is summed up by one woman who said, in a joking manner:

To be truly supportive, treat me like a human being. Yes, I do have a life-threatening illness, but there's the rest of me, folks! I still garden, I still think, I still

work, I still have a house to run, a mortgage to pay and all those normal things. (06, p. 27)

Overall, then, these statements show the desire of many of the women to return life to its usual patterns and routines, both for themselves and their families. In particular they show a strong desire to be treated as a normal person, rather than be marked out as different because of having breast cancer. However, pursuing normalcy did not necessarily mean that they were endeavouring to forget about breast cancer: its place and meaning in their lives will be elaborated in the next chapter. Those women who did not describe much need for normalcy or show much normalising behaviour tended to be women who did not have children living at home, or women who had never had children. In addition, one woman had ongoing health problems that were a result of the treatment process, which meant that her life was still far from normal.

Their statements also highlight the way people in their social networks enable and support normalcy. This issue also links with a woman's sense of control, an issue which is further addressed in the next chapter.

Seeking and using social support

As was shown in the previous section, friends and family were helpful in re-establishing a sense of normalcy for many of the women during the period of diagnosis and treatment and, in that way, were providing positive support. This leads into a more direct consideration of seeking social support as a coping strategy and how it was experienced by the women in the study. In fact, all of the women in the study indicated that they had used social support as a way of helping them to cope at the time of, and since, their diagnosis. The support they received was often a combination of practical, informational and emotional support. It is emotional support that is the particular focus of this section as it seemed to be a type of support which was highly valued by the women. Informational support is discussed separately in the next section on information-seeking as a coping strategy.

Four main sets of behaviours reflected the need for emotional support namely, sharing feelings and experiences with partners, family and friends, seeking support

from other women who had themselves experienced breast cancer, attending a support group, and seeking professional help. The majority of the women (fourteen) were active in seeking such support and clearly rated it as being a very important part of the way they coped.

Support from friends

Most of the women in the study had actively sought and received positive support from friends. One woman in her early forties, who was in a relationship of fairly short duration at the time of diagnosis, was very clear about what she needed and described actively recruiting the help of a close friend who lived interstate:

I rang her up and said "You're it (laughs). Come over. I need you." So she was on the plane immediately and she was fabulous...I only wanted one key person, and I wanted it to be a woman and I wanted it to be someone who I knew would pick up the pieces... I mean, could cope if I fell apart, or got angry. (01, p.2)

This friend was able to shield her from contact with people when she felt unable to face them and also provide her with the space to safely express the fluctuating emotions she was experiencing in the days following diagnosis and surgery.

She was very clear that she wanted empathy and **not** sympathy (in the sense of pity):

So I sought out people who didn't give me that (sympathy). They gave me humour or context or shared experience. (p. 16)

Another woman of a similar age, who was not living with a partner, was similarly active in seeking out her friends:

I also knew how very important my friends would be to me and spent a lot of time telling people, and telling them that I was going to need them, and warning them, too, that initially I would deal with things extremely well, and then I was going to fall into pieces and so they were to make sure that they kept up contact with me because I wasn't going to be able to find that easy to do later on. (07, p. 5)

She was well aware that she would need lots of practical assistance after she came out of hospital:

I didn't have a problem telling people. It was something that was happening to me and I needed them to know, and I couldn't see any point in hiding it. And if they didn't know they wouldn't be able to help me, and there were going to be lots of things I couldn't do. When I got out of hospital I wouldn't be able to eat unless my friends cooked for me, and I would not be able to travel unless friends drove me around. (07, p. 7)

However, as a single person, it was her need for emotional support which was harder to engineer, although friends helped in that way too:

I really missed the sort of emotional support that I and my first partner were able to offer each other .. being able to cuddle up in bed, and yes I missed that a great deal ... but there was not going to be anyone for me who could offer me that sort of support. (pauses) As for other sorts of emotional support, I miss having someone close in my life who can offer that, but I have a wealth of other sorts of emotional support from friends. (07, p. 9)

This proactive approach is echoed in the words of another woman in her thirties who felt fortunate to be well-supported by her husband but who also valued the help of friends:

I took the option and told everybody. One, because I thought I would need everybody to cope because that's the kind of person I am. (And) I wanted things to be as normal as possible so that if I rang friends to ask their child to come and play, they wouldn't say no because it would be too difficult for me. (09, p. 6)

Likewise, a married woman in her early thirties comments:

I didn't want to upset them (friends), but as soon as I got the news I wanted everybody told - I'm that sort of person - rather than keeping it closed within. (17, p. 11)

Later in the interview, this woman commented on the importance of talking with other people:

You need to talk. If there's something bothering you, you need to talk about it.
(17, p. 15)

This sentiment was echoed by several other women as can be seen in the following:

I found I feel more relieved the more I talk about it to people...I've been brought up that you don't hide what you've got because it's nothing to hide. I mean you can't help what you've got and you want to live life to the fullest, and just because you've got cancer it doesn't stop you from doing it. (15, p. 3)

*It surprised me how often I used to like to talk about it, and that was my way of coping. My coping was to talk about it. So I was a bit like these people who say, "Now I had an operation last year..." You know, those **boring** people. (laughs) But I didn't mind talking about it to whoever would listen. (acting out) "I've had breast cancer and look at me now!" And then I got a thrill when they'd say, "That's fantastic! You're wonderful!" And so that was really good for me.* (08, p. 9)

As can be seen from these quotes, the potential benefits to be gained from talking with friends included relief of feelings, and validation and affirmation, as well as the normal enjoyment of contact with friends. In addition, friends were a valuable source of practical assistance, especially during the first weeks of recovery after surgery. However, a number of women did have experiences where they felt let down by one or more friends. When this happened it seemed to be partly a result of their friends not being able to cope with their own feelings of discomfort and anxiety that were aroused by the life-threatening illness of breast cancer.

Support from partners

Of the seventeen women living with partners at the time of their diagnosis, about six women were very happy with the emotional support given to them by their husbands, which was described by them in the following ways:

His first reaction was to grab me and say "We'll get through this", and that was sort of what we both hung on to the whole way through really .. just the need to get each other through it, and he was good. (11, pp. 7-8)

I guess my greatest support came from my husband who was really terrific, and still is, although I think that it's been a wearing-down process for him too, emotionally. (18, p. 14)

When I was diagnosed we were going to go away (for two months) because he had long service leave ... so he actually had three months off to take care of me, and he's just been wonderful. He's also a very down-to-earth guy who says that you do what you have to do...He goes out of his way to show me that it (mastectomy) really has made no difference. ... So I could go into hospital and not worry about the girls. I could concentrate on me and say, "I need to deal with this; he's got to deal with home." So I consider I had it really easy. (09, p. 7)

Of the other women living with a partner, six had definite reservations about the emotional support they had received from their partner:

You need to talk. If there's something bothering you, you need to talk about it. Like my best person is my mother. She's fantastic! She'll sit there and listen and she's not judgmental .. whereas I think it's a bit too close to home for my husband to handle. (17, p. 15)

Another woman who had sought emotional support from her husband found that her request was sometimes interpreted as a request for her husband to take charge in some way:

I think that (husband) felt - and I think he has a tendency to do this anyway - "Well, it's all been put back into my lap again". I read that Men are from Mars, Women are from Venus book and I think some of the things that it said were quite insightful or quite consistent with our experience. If I say something to (husband), what I'm wanting to do is just to talk about it, but he sees it as a problem for him to solve and that's not what I'm asking for ... it's not an uncommon reaction I don't think. (04, p. 15)

One woman in her sixties describes her partner's response when she was upset at the time of diagnosis and subsequently:

I just felt I was going to die .. I just kept crying, then I'd be all right for a little while and then I'd cry. And I kept saying to my husband that we'd better go make our wills, and he'd say "Oh don't be silly!" I don't think he felt it. He just put a barrier up I think. He just put a barrier up... Even now there is still a bit of a barrier. Where I'd cry and you'd maybe just want someone to put their arms round you and say "Come on now", he'd say "Stop your crying! Nothing's going to happen." Maybe he didn't want to face it, or couldn't understand it ... I don't really know. (14, p. 2)

While her husband provided her with practical assistance in a number of ways during her hospitalisation and the ensuing chemotherapy and radiotherapy, she missed not having his emotional support.

This sentiment is echoed by another woman whose partner preferred not to talk about the breast cancer or her concerns, although he helped in practical ways:

If anyone asked me if (husband) was supportive, I couldn't really say that he was supportive; supportive yes in the fact that he will drive you to appointments but (he) didn't want to discuss things - the emotional support. And I don't think he has ever been the sort of person to do that. (13, p. 11)

Several of the women indicated that they had not sought much emotional support from their partner; rather they had tended to protect or buffer them from some of their worries associated with the breast cancer. One woman, in a long-standing marriage, commented:

I had to protect my family in a way because my husband worries a lot, so I knew I had to break it (diagnosis) in stages to him... So I had to be the strong one. I always have had to be, in a way, in the marriage. (02, p. 6)

She did not express any need for additional support, gaining most of what she needed through reading and contact with a counsellor while she was in hospital. Similarly, another woman in her early sixties was also happy with the support she received (see p. 4) from family but indicated she may have used some protective behaviours:

If you spend your life not always articulating what you think because someone else around you might worry about it - you know, sometimes they might say "Oh dear,

she's going to die tomorrow" - you can sometimes cover up, can't you?.. you're protecting other people and maybe yourself. So maybe I've been doing that. (03, p. 3)

Another woman, in a long-standing marriage, felt well-supported by friends and family but acknowledged some difficulty in talking openly with her husband about the life-threat associated with her breast cancer. As she said:

He's a worrier. He's the one that's probably more emotional than me. In fact my oldest son said, before I went into hospital for the operation, "You're the strong one mum.. you'll have to be strong because my father ends up in tears all the time." (10. p. 29)

As can be seen from this sample of comments in relation to emotional support from partners, about one third of the women felt very well-supported whilst the remainder either felt unhappy with the level of support they received or limited the amount of support they looked for from their partner because of the perceived need to protect the other person. Many of those who were disappointed with the level of support from their partner, or who were not living with a partner, reported that their best source of support was from other women who had experienced breast cancer themselves or from other family members such as their mother or daughter.

Support from other women with breast cancer

The following comments reveal that many women in the study gained valuable support from other women who had themselves experienced breast cancer. As can be seen, they valued being understood, being able to share experiences and feelings, and gleaning hope from another woman's ability to survive breast cancer:

Other people who have gone through the same thing are the ones .. the only ones who have got any idea. (04, p. 15)

Sharing experiences with other people too has been great...(One woman) was one week ahead of me in treatment, just lives close by in (township) so we've been to a few seminars and things together and that's been really good just to share that. The only thing we have in common has been the fact that we've both had breast cancer, but we've actually become quite close and I think we will probably always stay friends now. (11, p. 23).

Another woman who was not living with a partner, talked about the comfort she gained from being able to ring a friend who had herself recently been treated for breast cancer:

You go through the terrors. You're facing a life-threatening illness so of course the issue of death, dying, pain, all those things come. They usually come in the middle of the night...I'd ring her (friend) up and say "I'm having the terrors" and we'd sit and talk about the terrors. And that was a comforting thing because you really can't talk to anyone else unless they've gone through the terrors themselves. (01, p. 3)

This woman was struck by the strength of the kindred feeling she experienced with other women in hospital who were also being treated for breast cancer. While she was in hospital she did a lot of walking in company with her drainage bottle and she describes her reaction in meeting other women with drainage bottles - that is, those being treated for breast cancer:

*And if you saw the bottle, I found this strange thing started to happen which is totally non-verbal; there'd be a communication which was actually **not** verbal, which was why it was so powerful ... And there was this real **knowing** about 'we were all together' - we were all waiting (for test results), some of us knew, some of us didn't know - and it was tremendously bonding. And I used to tell people coming to see me that "It is **so** bonding. I actually feel incredibly **connected** to these women". At some very non-verbal level, we're all together; we're one. (01, p. 10)*

This woman later spoke of this connection as being "spiritual" though she found it hard to describe. She also felt this connection and support as a result of a number of letters she received from women who had themselves had breast cancer who were sharing their experience and their survival.

Another woman also verbalised this sense of connection:

Other ladies that you meet who have been through it... you can immediately get a rapport. There's a lady - and I haven't spoken to her yet - who does emergency teaching at S's (son) school and we saw each other across the carpark, and we were both at the same stage of hair growth. And it was funny; just at that distance I could

*see that she suddenly saw me and I saw her, and there was this sort of .. **connection**, and you could feel that. And there's a lady at A's school who had it about three years ago, and she said one day "Are you having chemotherapy?" - because she saw all the hats. "I had it three years ago and I sympathise" or something like that... And it's interesting, you don't necessarily say anything to her about that from then on, but there's that immediate empathy. (19, p. 10)*

A number of women had been contacted by other women who had themselves had breast cancer, either in person or through letters and phone calls. They were able to provide information, hope, and a model of survivorship:

I've asked different people about what they've had done. I mean, the aunt at W (country town), I didn't even know she'd had the boob off... and as she said, she's had it ten years now but she's got to the stage where she can't have chemo anymore so I don't know what happens after that. But she's fought it for ten years so if I could fight it for ten years, why not? 'Cause you know I want to fight it for another fifty years not just ten years. (15, p. 30).

Clearly, then, the support provided by other women who had experienced breast cancer themselves was extremely valuable, providing a sense of sharing and connection, hope for survival as well as practical information that could be gleaned from the other's experiences. For one woman, an added dimension of the support she had from another woman who was, like her, currently having treatment for breast cancer was that it was reciprocal. As a person who was used to relying on herself and not asking much help from others, this was a more comfortable way of receiving support.

This woman, and a number of others, verbalised the sense that, while support was important, essentially you are "on your own" as can be seen in the following, that is the limitations of support:

The only people who really know what it's like are the ones who have gone through it and I talk to them...I feel as if I have to rely on myself because basically, no matter how close you are to other people or what you think the situation is, that's really all you've got. (04, p. 18)

There is nothing more than a life-threatening illness to make you aware you are alone - you are alone anyway of course. It doesn't matter how close your family or community is, you are alone suddenly, and you sort of need some way in which another person who is alone can somehow bridge it. (01, p. 17)

At least for some of the women, support from other women who had experienced a similar situation was a way of breaking down some of the sense of aloneness that they felt at times.

Support groups

Another indicator of the active way in which many women in the study sought and used social support was their participation in cancer, particularly breast cancer, support groups. In fact, over half (eleven) of the women were actively involved in support groups, which they found valuable for the same sorts of reasons as were outlined above. The following comments highlight the various functions of support groups:

What I found helpful for myself was having that contact with the (breast) cancer support group right from the beginning, and even before surgery itself. (12, p. 12)

I've had a lot of help too from (support group) .. and that's been a tremendous help ... just to be able to chat with them and talk to them has been great. (16, p. 9)

I go to a group in town that's at (hospital) for a support/therapy group, and there's eight women in the group there and that's really quite interesting because we're all very different (but) we have this one thing in common, but it means you actually find that there are a lot more things in common as well. To be in there sharing their experiences is really good. (11, p. 23)

One woman expressed the value of having a place where you can still talk about breast cancer at a time when friends and family have stopped wanting to listen:

I don't think I really talk (about breast cancer) outside of the therapy groups that I go to... People don't really want to hear it all the time; they don't want you to be talking about yourself, so I don't usually. (18, p. 16)

A final, and less obvious function of support groups was articulated by one woman who worked in the helping professions. While not herself a member of a breast cancer support group, she was a member of a professional support group. She commented on a program she had seen on television about the support group in America run by Prof. David Spiegel for women with metastatic breast cancer:

*I remember seeing that those groups of women getting together, talking about their feelings, increased their survival rates. It's pretty powerful stuff. I looked at the video on it and I thought it was very interesting because what you get, in the group I'm involved with, what you're actually sharing is life philosophy. And life philosophy is actually the **map** that says, "This is the next step." And I think when people lose a sense of what is the next step they are very vulnerable, whatever the situation. And I thought basically it is a **philosophy** group. People talk about it as sharing feelings and you do share feelings, but what I saw in that video was people sharing their philosophies, and how they get up in the morning, how they cope with looking at themselves having no hair, and how they take the next step. (01, p. 18)*

As this woman asserted, support groups may have a powerful role to play in terms of helping women work out their philosophy of life given their experience with breast cancer which may have dramatically changed some of their beliefs about themselves and about life. This issue will be further pursued in the next chapter in relation to making meaning.

Several of the women mentioned some of the "negatives" associated with being in a support group. These included the difficulty in learning of recurrence of breast cancer for some members, and even death. This had the potential to rekindle feelings of distress and heighten awareness of the potential threat to their own lives.

Seeking help from professionals

About six of the women in the study, most of whom were also members of a support group, had also sought professional counselling since their diagnosis. Usually this contact was relatively short-term and was reported to be beneficial.

Those who did not seek much help outside themselves

It is perhaps not surprising that in this, a self-selecting study, most of the women had actively sought out support from a variety of sources. In a sense, maybe involvement in the study had the indirect benefit, for some women, of accessing another means of support; it may have provided an opportunity to review and organise their own emotional and cognitive processes through the sharing of their experiences with the researcher. Indeed, some time after the study one woman wrote a letter to the researcher in which she indicated that this had been her experience.

However, there was a small number (five) of the women who were less active in seeking out social support and their perceptions about their experience of support are also important. Their comments indicated a range of reasons for not seeking much help from others, including the desire to be independent, having learned to be fairly self-sufficient, and not perceiving much need for it. It is perhaps worth noting that they also were all in long-term relationships where the partner did not appear to be providing good emotional support.

Overall, it was clear that most of the women in the study sought and received social support, particularly emotional support, from a variety of sources including friends, family members, partners, other women who had experienced breast cancer, support groups and helping professionals. The functions of this support included relief of feelings, validation and affirmation. However, some also reported disappointment with perceived support, especially from partners, and from support groups. In addition, a small number of women appeared to be less active in seeking support from others.

Information-seeking

Most women in the study reported that they had sought out information about breast cancer as a way of helping them to cope. This was particularly true in the first few weeks after diagnosis when it was necessary to make decisions about treatment, and later on when they wanted information about treatment and its side-effects. In addition, they wanted to find out about the ways other women had coped with both the physical and psychological tasks that confronted them. This information was

sought from a variety of sources including doctors, nurses, other women who had had breast cancer, support groups, the Cancer Council of Victoria, or books and magazines.

Information relating to medical aspects of breast cancer

In the first few weeks after diagnosis there was usually a large amount of information to absorb, which was provided by their surgeons and other health professionals with whom they had contact soon after diagnosis or during hospitalisation. Several women described this initial desire to be well-informed which decreased over a period of weeks:

You come home from the hospital bulging with information that you're trying to take in; you want to read everything and be well-informed. However, we're not doctors so we don't understand it. So there came a day when chemo started and I'd read everything ... I got to the stage where I threw all the reading in the filing cabinet where I could find it if I needed it. I stopped reading every day and more or less tried to get my life back on to something else. (09, p. 7)

Yes I still do ask (questions of doctor), but I think now I more or less don't really want to know any more and I think you can read... a few things that you hear about and you just make your own general assessment. I think, they've done their job and you sort of forget about it.... I have been reading a few books and if I go along to the support group there are often interesting speakers or there'll be information that if you feel you want to read about it you do... But I'm not going to read everything. I don't want to create any more unnecessary stress in my life. I think sometimes there comes a point where you just have to put it aside and get on with it. (18, p. 12)

However, for most of the women, having good information during the course of diagnosis and treatment was extremely important. Several women described the importance of knowing what was happening or might be likely to happen during treatment:

I prefer to know than be naive. Like I've asked my doctor up front what he's thinking and what he wants to do and what it all means, rather than going there and

have him pat me on the hand and have a check and send me off. I prefer to know what he's thinking and where he wants me to go, rather than just be led. (17, p. 6)

The importance of information at various stages in the diagnosis and treatment process is highlighted by another woman's comment, which also shows how she used information to help her make treatment decisions and cope with the emotional issues that arose as a result of losing a breast:

Information was a big thing at different stages. At some stages it was totally irrelevant but at other stages it was vitally important. For example, when I wasn't sure about whether I would need further treatment, especially radiotherapy, and because I didn't know very much about carcinoma in situ, it was hard for me to work out on what grounds would treatment be appropriate or not appropriate. The hospital, and particularly the surgeon, were not informative. Fortunately I have those research skills and background so I was able to do a Medline search to get a range of appropriate journal articles to make sense of all that.... The emotional aspects of losing my breast, one of the things that was important was meeting the Breast cancer support service woman, prior to the operation, who talked about the loss of her breast in terms of grieving...So I started, mentally, a process of grieving before the operation. (07, p. 9)

Later in the interview she also described how reading articles on coping with cancer, located through a specialist library, in order to "read through the processes that I was going through." This enabled her to assess her own coping skills and explore what else she could be doing.

Information about coping with breast cancer (emotional aspects)

Other women described how information about the ways other women had coped was helpful once they were out of hospital:

If I'm feeling sad I've got a book there that I adore reading that's a book on breast cancer, and I sit there and read about different women and how they've coped with it, and I find that good. (17, p. 14)

However, other women indicated that they preferred to gather information by talking with other people, especially women who had had breast cancer (see earlier section on support groups) or friends with experience in the health field:

I thought I probably would want to read everything on the subject, but I actually found that most of the books that I found haven't been of much use to me. It seems I find that the useful things have been listening to people and talking to people. (11, p. 24)

Clearly, for most women, having good information about the medical and psychological aspects of breast cancer was an important coping strategy that is perhaps summed up in the following comment by one woman:

(You've) got to deal with it (cancer) and the more you find out the better. Some people I've spoken to don't want to know, but I like to know what I can. (14, p. 11)

However, there was one woman who preferred not to actively seek out information who said:

I'm happy just knowing what I know at the moment. (Husband) has wanted to ask questions. He goes off crook at me because he says, "You don't ask questions"... I feel I don't need to know. I feel what they (health team) tell me is enough at this point. (10, p. 35)

Although this woman had confidence in her specialists, her lack of interest in seeking further information also could have been a reflection of her tendency to use denial as a way of coping with breast cancer. In addition, she had little contact with others who had had breast cancer - either informally or through a support group - and so was not likely to glean further information through those channels.

Downward social comparison

This coping strategy refers to those behaviours in which a woman compares her own situation with another person's, and appraises the situation of the latter to be more difficult or less favourable than her own in some way. About thirteen women used this strategy to some extent and the focus of their appraisal varied according to

their own circumstances; for instance, the amount of support they perceived themselves as having, the extent of treatment they required and their age.

Several women commented on the fact that they felt fortunate when they compared themselves to others, because they had good social support which facilitated their efforts to cope. For example, one woman said she felt “well-resourced to cope” largely because she had very good support, in which she felt fortunate when comparing herself to others:

I saw a lot of women, when I was in hospital, who didn't have a lot of supports like that; they had a lot of people but they didn't have a lot of, what I thought was, really good psychological support. (01, p. 4)

Similarly, another woman in her thirties felt fortunate:

*My husband's extremely good... So I've **had** no other problems, so I've had time to focus on this and deal with it. If I feel like sitting and crying about it, I do. For other women with problems, it must be extremely difficult... I've been fortunate that everything else seems to have gone my way. (09, p. 19)*

A number of women, whose treatment had involved lumpectomy, felt that they were more fortunate than women who had lost a breast:

It's (breast) nearly the same as the other one now. I did feel a bit funny at first, but it would have been worse if I'd lost my breast. (14, p. 20)

I must admit though, when the bandage first came off I didn't know what to expect. I really am very fortunate, I really am very lucky because I am just (slight pause) normal, sort of... So I feel a bit of a pretender when I think of some people who've had much worse. (08, pp. 6-7)

Some of the women whose treatment had involved mastectomy found other ways in which their situation appeared to be more favourable than that of others. For example, one woman in her thirties with young children expressed this view:

As a mother, my first thought was also “I’m glad this is happening to me and not one of my children.” As I said to (husband), “Give me anything, do anything, I’ll endure anything now I know my children will be all right.” I see this girlfriend with the diabetic son, and we have another friend .. whose little boy has been battling leukemia for the last few years So I can cope with this (breast cancer) because I know my kids are all right. (09, p. 9)

Another older woman who had a mastectomy also expressed some regret at losing her breast, particularly as she had always thought her breasts were one of her best features. However, she comforted herself with the following:

I thought it (cancer) could have been somewhere else; but anywhere else could have been worse. (02, p. 14)

A woman in her fifties, compared her situation with that of Raelene Boyle whose story she had followed in the media:

I watched Raelene Boyle to see how she coped with it and I thought, “I don’t think I could cope with half a boob; I’d rather the whole lot gone like it has, than half, because I’d still be looking at the half that’s left and get more upset over that than having the whole lot removed... And I only had nine (nodes removed) so I think to myself, “Well, mine doesn’t sound like it was as bad as hers even though I lost the whole breast, but I didn’t have as many glands taken out. (15, p. 27)

A number of older women felt that having breast cancer as a younger woman would have been harder:

It (confronting mortality) happens to quite young people too, and it is much more of a shock to them because they don’t see themselves as being anywhere near the end of their life. So these things must be much worse for young people. Things like breast cancer would be a terrible shock if you were thirty. (02, p. 7)

Several women who underwent adjuvant treatment observed that other people receiving similar treatments were clearly worse off than them:

The radiotherapy process was interesting, and I had nothing wrong with me compared to a lot of other people there for treatment. (13, p. 3)

When comparing their situation with that of others less fortunate, several of the women referred to scenarios involving children, even if they did not have children themselves. For example, one woman in her forties who had no children said:

*I go to a lot of conferences and have been hearing ... people tell me the most **horrific** stories about children. And I think, compared to that, this (cancer) is a lot, but what if I had lost a child? What if my twelve year old son had been killed in a car accident in front of my eyes? **That** is a tragedy. (01, p. 14)*

Another woman in her thirties felt that not having children made it easier for her:

I think it's been made a lot easier for me because we don't have any children. I don't know how I would have coped if there was a child around. It's been good where I have just been able to concentrate on myself. (12, p. 9)

As can be seen, then, the particular circumstances of the women shaped the nature of the comparisons they made between themselves and others who appeared to be less fortunate. They appeared to find comfort from these comparisons, which helped them to accept their own situation more readily.

Frequently the use of downward comparison went along with expressing a *positive focus*. This conjunction of strategies can be seen clearly in the following:

And the other (important thing) is to be positive. And when I say, "be positive", I mean to say that so many things happen to you. I mean you could have an airplane drop on your house. There are so many (worse) things that could happen to you, and even if you do have to have a breast off, look at the things people have been born with a lot worse than that. But it's not the end of the world, is it? (02, p. 48)

It is interesting to note, as in several of the above quotes, that downward social comparison and optimistic appraisals are often linked. This finding will be discussed further in relation to other studies in the discussion chapter of this thesis.

Use of humour

Another coping strategy that was employed by most of the women in the study was the use of humour. Despite the difficulties they were confronting, even in the midst of diagnosis and treatment, the use of humour is apparent. As Carver et al. (1993) point out, humour has been little studied in relation to coping with stressful situations and it is not included in most coping inventories. In fact, in their study, the use of humour emerged as a prospective predictor of lower levels of distress over a twelve-month period following treatment for early stage breast cancer.

Some women spoke directly about how important humour had been to them in helping them to cope with what was happening. For example, one woman in her early forties spoke about humour as one important thing that gave her a sense that she could cope with breast cancer and its implications, especially at the time when she was discussing the likely impact of surgery - in her case, a lumpectomy:

I found humour wonderful. I have a friend who had this wonderful sense of humour and I remember coming out from seeing the surgeon and he told me what sort of (breast) scars I was going to have and how I was going to look after surgery, so you can imagine I was very vulnerable. And she sat down and - she was like this all the time - and she said, "What did he say?" And I told her, which was actually that you're not really going to notice it looking down (on the breast) this way, but if you look this way (upwards from underneath the breast) you will see the scar. And she said, "You know what he is trying to tell you? He's trying to tell you don't get on top (during sex) anymore!" (laughs heartily) And we just cracked up laughing ...She always would bring humour ... I used to really wait for her to come. (01, p. 4)

A woman of about seventy, who valued the importance of fun in life, said:

Humour is very important...If you could laugh at yourself, don't take yourself too seriously .. that comes about to the same thing. You have to take what life gives

you... So, a sense of humour is very important. I think laughter is a very good medicine. (02, p. 55)

Another woman of about sixty also commented on the role of humour:

I always approach things like that; make a joke of them. (laughs) But sometimes making jokes of things is only a way of covering up deeper worries, isn't it? My mother used to accuse me of that, (of) turning every tragedy into a joke. It was true too. (03, p. 9)

Humour played a number of important roles including helping to put things into perspective, overcoming awkward situations, and coping with painful feelings of loss and depression about such things as loss of a breast or hair loss. The role of humour in putting things into perspective is clear in the following statement:

I didn't think I had much of a sense of humour. I think of it more as a sense of proportion. (small laugh) But I can see the funny side of things, the sort of ridiculous aspects of things that happen to me. (04, p. 27)

Humour was also helpful for one woman in her fifties when dealing with awkwardness in her sexual relationship with her husband after her lumpectomy:

Even though it (the breast) doesn't look much different, there's still not much sensation there and it feels different. So, how do I cope with that? I guess we talk about it ... so when you're talking about coping, I think communication and a sense of humour is important in this situation. (08, p. 11)

Several women who lost their hair during chemotherapy used humour and being positive as a way of coping at that time. One woman in her thirties was initially very distressed when her hair fell out, but quickly noted the advantages in not having hair to deal with when getting ready for work:

There was a morning I was on my way, late, for work - mind I get up half an hour later now because I don't have any hair or makeup to do (laughs), so there are benefits - so I was on with my scarf and off to work. I wouldn't have been able to get off to work that quickly when I had hair. So I have a giggle, and it's not good to dwell on it. (09, p. 6)

This same woman also joked about her hair regrowth with her young daughters:

So my hair's back to a number one (very short)... and I tease the girls that when I get to a number two I'll have a stud through my nose and be very trendy. (laughs) (09, p. 7)

Similarly, a woman in her late forties, found her teenage sons quite supportive in their different ways, including seeing the funny and positive side of having no hair:

The oldest boy is always talking about his "punk" mum (laughs) because I'm the trendsetter: when everybody else was shaving their head, I had a shaved head too. (laughs) (19, p. 7)

One woman, whose treatment involved a partial mastectomy, joked about the fact that she used to complain about having large breasts:

I always complained about my breasts being so large ... you get all the back ache and shoulder ache because you're so heavy... I've always hated having the large breasts, but I will never go crook about them again. (laughs) If I ever mention anything, they (friends) all remind me, "Don't ever go crook about them again", and I said I never will. (10, p. 16)

Another woman in her late fifties talked about having to adjust to a number of things going wrong with her body, of which the breast cancer was the latest, and the importance for her of using humour to lift her mood, and to help her "accept and fight" her cancer:

I said to her (sister), "I'm not much good; I've got no teeth - because I had to have them out due to my diabetes - I've got no womb, I had to have my varicose veins stripped about four or five years ago (laughs)... you have to have a laugh .. got no hair. You've got to laugh about it otherwise you'd get really depressed. (14, p. 11)

Clearly, humour played an important part in the way in which most of the women in the study coped with their breast cancer, and often from quite soon after diagnosis. However, it seemed to be more widely used once surgery was over and adjuvant treatment was underway when it seemed to be particularly helpful in coping with the changes they were experiencing to their bodies such as hair loss. The

multiple functions that humour served relates to both the themes of regaining control and making meaning, which will be discussed in Chapter 8.

Using causal attribution

It has been well documented that a diagnosis of cancer can prompt the affected person to ask “Why me?” and search for a cause (or causes) for it. Taylor et al. (1984) in their study of 78 women with breast cancer found that about 65 percent had a theory about the cause of their cancer, and that this figure became 95 percent when the women were prompted to discuss it further. As there are few cases of breast cancer where the cause is known, (as fewer than ten percent have inherited breast cancer), the answers may include self-blame, attributions to objects (for example, being on hormone replacement therapy or excessive stress), and attributions to other people (for example, being hit by someone in the breast) (Timko & Janoff-Bulman, 1985).

In this sample, twelve of the women made unprompted comments that showed they were seeking a cause, or had found what they thought was the cause, of their breast cancer. Of these twelve, most of them felt that stress had been involved in the development of their breast cancer. Two menopausal women thought that being on hormone replacement therapy might have contributed to the development of their breast cancer. None of the women used self-blame or attributed their breast cancer to other people.

The following remarks are typical of the reactions of those who felt that stress was a major factor in the development of their breast cancer. For example, one woman in her thirties, while very happily married, revealed that her earlier life had been very stressful, and believed it had caused her breast cancer.

The hardest thing at first was being angry and not having anything to blame because you can't pinpoint it as to why, though I do blame the stress. (09, p. 7)

One woman had read about the connection between stress, being physically rundown and the development of cancer. It seemed to make sense to her as she'd had a cold for a couple of months not long before she found the lump:

So you wonder if that did have anything to do with it. It was also mentioned in this book, (being) under a lot of mental stress. Well, I've had a lot of stress and it makes you wonder. You think, well why me? That's one of the first questions you ask. So that book mentioned stress and being rundown and I had both. (14, p. 12)

Another woman had been subject to a lot of stress over the previous few years because both her husband and her aged parents had experienced serious illness, which she felt had contributed to the development of her breast cancer:

I boil it down and I think it was the stress because I hadn't .. been kicked in the boob. I mean I was hit (at 8 years), but the point is I'm 50 this year, and when I was eight, starting to develop, I don't think it would have been accumulating from then. (15, p. 7)

Others were not so definite about the link between stress and the development of cancer, but indicated that it was likely that it was a contributing factor:

Stress and cancer don't go together too well, and it's not actually the stress of the environment or the stress of the job so much as how you cope with it and you deal with that stress, and I think that I'm not very good .. I mean I don't believe that I do handle stress very well, and maybe that .. over the years your immune system wears down and creates all these monsters. (18, p. 6)

The woman who was a practising general practitioner had not come to a definite conclusion about what had actually caused her breast cancer but felt that it, like other cancers, was linked to diet and lifestyle:

I think lifestyle is important; things like relaxation and diet. I think everyone is leading too fast a pace of life and that's why I'm trying to change life in that way. (12, p. 10)

A number of the women made unsolicited assertions that they did not believe there was a link between stress and the development of their breast cancer. They felt that it had implications of personal responsibility that they found difficult to accept. For example, one woman, whose breast cancer had been diagnosed as hormone-related, said:

When it (breast cancer) is related to hormones, I question a lot of the other stuff about stress. But I think that's my way of coping because I hate the thought that I was ..(responsible). It's sort of like the people who say to me, "Oh, you've got such a positive attitude! You'll be right." That makes me cross because what happens if I'm not right? Does that mean it was my fault? (08, p. 2)

This same dilemma of finding a cause that did not carry a sense of personal blame was echoed by another woman:

You wonder, "Why? Why?" But again I don't want to load myself up with too much guilt. I don't want to feel that I got breast cancer because it was something I did or didn't do. I don't think that's very constructive either, so I try not to worry too much about that. (11, p. 20)

Several women appeared to be still sorting out what they thought may have caused their breast cancer. For example, one woman had described herself as having experienced a lot of stress in the previous two years, dating from the death of her mother, but she did not specifically say that stress was the cause of her cancer. It seemed that her questioning was ongoing, but was transformed into a (serious) joke:

I just wonder how it (breast cancer) starts. That's what amazes me ..how it started there in the first place. I just say it was because I went off crook about having big breasts all the time (and) God came and got me (laughs).. that's what I say. And that's what I say to my friend, so now if I go to say something, (it's) "Oh, oh, don't go and talk about your big breasts. (10, p. 40)

Another young woman, whose diagnosis was only two months prior to the interview, showed that she was still trying to sort through the issue of cause:

In a way I'd like it to be genetic because then I'd have a reason for getting breast cancer, because if it's not genetic, why did I get it? I don't think my life is too stressful, so I don't really think that stress has caused it, but I'd just like a reason. (17, p. 5)

Overall, then, it can be seen that the search for a cause, or causes, for their breast cancer was quite widespread among the women in the study. The most widely

nominated cause was stress, either as a sole or contributing factor. However, this was actively rejected by a number of women who did not accept the implication of personal responsibility for their cancer that it seemed to carry. Others had clearly thought about the issue of cause, and instead of asking “Why me?” had turned the question on its head and, on the basis of their knowledge, had asked instead “Why not me?” For others, the search for a satisfactory explanation was still underway.

The issue of causal attribution and its relationship to perceived control and making meaning of their situation will be addressed in the next chapter. At this stage, suffice it to say that there did seem to be a clear link between being well-informed about the nature and incidence of breast cancer and the absence of causal attribution.

Seeking alternative treatment

There is an increasing acknowledgement that many people seek alternatives to medical therapy in addition to conventional medical treatment when confronted with illness. In addition, attention to diet and exercise, formerly more the domain of alternative health practitioners, has become an important part of conventional medical practice. Hence it is not surprising that the use of alternative treatment is found amongst women with breast cancer (see, for example, Lavery and Clarke, 1996) with many women using help from a range of sources including meditation and relaxation, naturopathy, Reiki, therapeutic massage and acupuncture. Indeed, Lavery and Clarke (1996) found that using alternatives to medical therapy, including seeking advice from alternative medical sources, was a significant predictor of adjustment in a positive direction. It is important, then, to recognise this coping strategy and understand the functions that it has for the women who adopt it.

Of the 19 women in the study, eight were using some form of alternative treatment to complement conventional medical treatment. One of these women was using alternative therapies as her primary form of treatment with conventional medical treatment as a back-up. In addition to these eight women, a number mentioned making changes to diet and lifestyle, which are discussed in relation to stress management.

The woman who was using alternative therapies as her main type of treatment was unique in the study, not only in her choice of treatment, but also because she was the only one who had a previous diagnosis, five years earlier, of early stage breast cancer. Given this difference, material from her interviews has not been included in most of the findings but it is of particular relevance to this section. Her earlier experience with breast cancer, when she had been treated with a lumpectomy, and her rather traumatic experience during diagnosis - a two hour biopsy process that left her with fifteen scars in her breast - meant that she decided to follow the path of alternative treatment. As she said:

I don't want to be part of being deformed. (05, p. 11)

In addition, her beliefs about the cause of her cancer, namely stress-related, meant that she believed that conventional medical treatment would not really cure her or prevent a further recurrence.

The major components of her alternative therapy program were consulting a trained medical practitioner who specialised in Chinese medicine and naturopathy, and Reiki therapy. With this therapy program, she felt she was doing the best she could to cure herself of breast cancer and remain physically undamaged as there were no known harmful effects of the treatment she was pursuing.

Several of the women who were using alternative therapy to complement their conventional medical treatment spoke about their reasons for doing that. For example, one well-educated and fairly assertive woman claimed that the medical profession showed "tunnel vision" about what could be useful facets of a holistic treatment program:

If you talk about anything else - an alternative treatment that could be used - you almost see the expressions on their faces of "What have we got here?" (small laugh) Am I being questioned? Are they not satisfied with the treatment that I am giving them?" ... as though you are actually questioning their treatment, rather than that there could be other things included with their treatment. At the end of chemotherapy I was pretty rundown, and maybe some form of vitamin supplement or

something like that, and I might have been able to take a higher dose of chemotherapy. But the research hasn't been done by the medical profession; there's a lack of balance. I suppose I would have liked them to at least be looking at the other things that are going on, because a lot of women I have spoken to are doing other things as well. And why are they doing other things? I think they would be a lot happier if they were getting a holistic approach. (19, p. 1)

A similar point was made by another very articulate woman, who described herself as having changed her diet and having “loaded up” with vitamins since her breast cancer. She put forward some strong views about the potential benefit of alternative approaches to women:

There is a lot of evidence that isn't brought into the public health arena about alternative forms of looking at breast cancer - health, diet and basically about those sorts of lifestyle issues. ... I think there's a very important message coming out of alternative areas that can get blanketed over which women should look at, such as, "Is diet a factor?" (in the development of cancer) So the (mammogram) screening has a positive and a negative impact...I haven't really thought it through all that much, but my concern, a little bit, is that breast cancer has become a political issue and ...I think it is very important to put public money in, but .. mammogram is an easier thing to sell as a political tool. I work in the area of technology and I know how technology and selling technology can be used politically...It's powerful! ...It's a high tech, high budget but high political clout and the low tech, low budget, community based self-care issues - which don't have a high political profile but could actually help women feel that they could start doing something for themselves - isn't getting the exposure. In fact, it's being sidelined. (01, p. 12)

The former of these two women also gave other reasons for using alternative approaches and the importance of timing in relation to their use. She chose to consult an acupuncturist at the end of chemotherapy to try and combat the infections that she had been getting because her immune system became rundown during chemotherapy. Clearly, her reasons for doing so related to the issue of self-care. In addition, she had anticipated that the end of active medical treatment would be a difficult time:

*One thing that I did talk to (counsellor) a lot about - and I anticipated it- that with breast cancer you have about eight months of treatment, and it's a real commitment, and then suddenly it finishes. And I sort of anticipated that it would be a difficult time, and that helped. In a way, that was a strategy; anticipating when you're going to have a difficult time and thinking about it in advance... And so what I did was I put aside things that I wanted to do, and things to look forward to. And also, after I had finished the treatment, that's when I followed up the alternative therapies. I'd done the meditation and made sure I had a good diet - I changed my diet significantly ... so I did all those things through the treatment, but then I decided I would look forward to something **afterwards** ... as a way of carrying through and slowly tapering off my connection with treatment. But, as it's turned out, I also did it to give myself as much chance as I could of not having a recurrence. So I think it's been of psychological benefit as well as maybe physical benefit. (19, p. 11)*

As she said a little later, her involvement in seeking alternative therapy was “like an insurance policy” (p. 12), one that had both psychological and, possibly, physical components to it.

Another woman who actively sought to implement other activities - including involvement in a support group which also taught relaxation and cognitive therapy, diet and exercise - towards the end of adjuvant therapy said:

It was a funny feeling once chemo had finished 'cause you think, “Well what do I do now?” That was a funny sort of thing because from when ..I'd been eight months since I was first diagnosed to the end of chemo, and a lot of time was merely preoccupied with getting through the cycle of chemo and keeping things normal and keeping myself as well as I possibly could. And all of a sudden that finished and it was like somebody had (short laugh) taken it away. “Well, okay, what do I do now? What's next?” And I'm still working through that too. I mean, I think it's important to feel that I'm actually doing something quite constructive about my health from now on... so as not to feel that there's nothing going on. (11, p. 12)

Both of these women felt the gap left at the end of active treatment and both wanted to do something positive for themselves or actively contribute to their own care.

Doing something positive for herself was also part of the reason why another woman, a general practitioner, sought alternative therapy. As was noted in an earlier section (Causal Attribution) she believed that lifestyle could contribute to the development of breast cancer:

I've tried to change my lifestyle and (am) attending the Gawler Foundation as part of that because they look at things like changing your diet, meditating and (short pause) I think with doing those things, I am doing something positive for myself. (12, p. 8)

As with the previous women, she started her involvement in a weekly cancer support program several months after active medical treatment had finished.

Two other women in the study had sought help from the general practitioner who practised Chinese medicine who was mentioned earlier in this section, although none of these three women knew each other. One of these women mentioned benefits of both a physical and spiritual nature that she gained from this doctor:

I've also read an interesting book that (doctor) lent me called "Faithless Faces" which is .. all about different cultures and native cultures and it's quite spiritual I guess, but you just take what you like and what you feel is good for you ... so perhaps that was (doctor's) way of getting me more aware of spirituality....I'm never quite sure what she's going to tell me next or what approach she will use next but, yes, it's helping me. Perhaps it's just helping me deal with the issues that I need to deal with... I do feel that she's really good for me in picking up what you need, you know vitamins or minerals, whatever is lacking .. So I get those from her as well. (18, p. 22-23)

The other woman also found her contacts with this practitioner were very helpful, but this information was not discussed until the follow-up interview.

As can be seen, the women who had used alternative therapy attested to the benefits, both psychological and physical, which they had gained from it. While they

felt the physical benefits of these therapies, it is the psychological benefit that is of more concern here. Indeed, it appeared that there were important psychological benefits for them, which included filling the void sometimes felt at the end of conventional medical treatment, and feeling actively engaged in their own self-care thereby having a degree of reassurance from maximising their chances of non-recurrence of the breast cancer.

It is interesting to look at the links between the use of alternative therapy and other coping strategies which are present in the first-cycle interviews. From the above, there is a clear link between using alternative therapy and being positive and actively engaged in doing whatever they can for themselves, which shall be discussed further in the next chapter.

Stress management

As was mentioned above, while eight of the women had sought treatment from alternative health practitioners, many more had taken steps to improve their health and psychological well-being by adopting informal stress management techniques. Such techniques included exercise, changes to diet, meditation, yoga, Tai Chi, visualisation and self-talk, reading, writing, gardening, prayer, and music. Typically, the women used a combination of these techniques and their choice seemed to be determined by personal preference and the needs of their situation. The most widely used technique was meditation, which was mentioned by eight women. It seemed to be particularly useful in helping the women to deal with their fears and anxieties, as can be seen in the following:

When those (anxious) thoughts come into your mind you look upon them as negative thoughts which aren't going to be of very much use, so you just let them fleet in and fleet out again. And I think that meditation is a great help in that respect because the strategies you learn in meditation stop your mind from working ... and one of the ways is to visualise your thoughts as little clouds floating off, and so you acknowledge that those thoughts are there and then just let them float away. And that's a similar sort of way that I tried to use it for those anxious thoughts, including

those aches and pains that you get. And the same with the insecurities that you get.
(19, p. 6)

This woman also valued meditation as time for herself, and as a way of gaining perspective:

Meditation has been terrific; I have become addicted to meditation. I make sure I put that time aside, and that's time for yourself. Even though I might be very busy I find that it helps to put things into perspective by having that twenty minutes or half an hour just quietly meditating. (19, p. 11)

Other women also commented that meditation helped them to cope with their anxieties and fears, and to help create some distance from these concerns:

I already knew about relaxation and meditation - I do meditation anyway. I already knew about all the diet stuff... and I have a reasonably healthy diet, and I like to do regular exercise, so all that stuff I thought, "All right, I'll just do a bit more of it." And certainly relaxation and meditation were, well I knew from past experience, very important for buying a slice of time free from the anxiety, the worries, the depression, the concerns. (07, p. 12)

Part of the benefit of meditation mentioned above was that it involved those women taking space or time for herself, which is a central feature of all the stress management techniques. In fact, a number of the women referred directly to the importance of taking space for themselves, irrespective of age. For example, a woman of about sixty said:

I haven't taken to religion or drink - I usually have a drink or two in the evening.. that's normal for me - or done anything like meditation. (laughs)... I'd never even considered that idea of coping strategies. I think, actually, that "time alone" is an important one for me, so I might have been making, consciously, more time by myself. (03, p. 9)

A woman in her early forties, who described herself as an extrovert, noted a marked need for more personal space:

I found an incredible need to actually be on my own which, as a fairly sociable person in a fairly sociable profession, suddenly I didn't want. And that's actually stayed with me, it's been the legacy that I have found I crave my time alone much more than I ever did, and that started as soon as I was diagnosed. I just spend a lot of time alone and I find that very healing. (01, p. 5)

One woman of about forty with several young children described the combination of strategies that she has implemented, including making time for herself:

I'm walking around the block (large area in rural setting) and trying to watch my diet, but I'm trying to make a bit more time that ..I suppose the other change that I've made is I'm trying to take a bit more time for myself. Working part-time and with the age of the children, and a new house and everything, there's not a great deal of time left over for me; but I'm actually consciously trying to make a bit more time to do the things that I want to do. A few people have said to me that I should be meditating and relaxing and things like that, but it's not really me. I have tried a couple of times but that's not something that I find easy to do, so I'm tending to make my relaxation time the half an hour that it takes me to walk around the block, which is a bit of time for me and a bit of time away from the children. (11, p. 12)

For one young woman with small children, whose diagnosis was two months prior to the interview, it was still difficult to make time for herself but it was a high priority:

I kept saying when I got this that my life had changed, that I would devote a bit more time to myself rather than everybody else. Eventually that will change. Eventually I will dedicate a day to myself ... When the weather picks up I might go back to playing golf or something. (17, p. 11)

It seemed that an important component of taking “time for self” seemed to be making time to enjoy life, which often went along with a belief in the importance of living time well. This was evident in the words of one woman in her sixties who had not adopted new strategies but had found help through doing “little things”:

I think just enjoyment in things - like taking the dog for a walk - that I can still do; just being able to do little things. I get great pleasure out of the garden, going for a walk .. the dog and I have lovely walks and it doesn't matter what the weather. (13, p. 11)

This section has shown that the women used a variety of informal stress-management techniques to help them cope with the difficulties experienced in the time since their diagnosis. The strategies which they put into effect helped them to cope with the feelings of fear, depression and anxiety, and later, with uncertainty. In addition, these methods meant that they were focusing on themselves and their own needs in a way that many of them had not done before. In this way, they were hoping to help themselves feel well and enjoy their lives. This strengthened priority also relates to making meaning and will be discussed further in the next chapter.

Summary and Conclusion

In this chapter initial reactions to diagnosis and subsequent attempts to cope have been described. These strategies have included appraisal, acceptance, denial and avoidance, distancing, focusing on the positive, focusing on the present, normalising, downward social comparison, seeking social support, information-seeking, use of humour, causal attribution, seeking alternative treatment and stress management. Most of these strategies were used by the majority of women in the study, especially acceptance, focusing on the positive and seeking social support. The least used strategy was denial, particularly denial of the early symptoms and the diagnosis. In addition, very little mention was made of escape-avoidance strategies such as wishful thinking. As has been indicated, these coping strategies tended to be used in constellations or clusters. An exploration of these clusters pointed to the overarching themes of making meaning and sense of control, which is the subject of the next chapter.

Chapter 6 Initial interviews: Meaning and Control

This chapter presents findings from the initial interviews in terms of two overarching categories (themes), namely making sense/ meaning and regaining control. During the analysis process it became clear that most of the women in the study were attempting to make sense and meaning out of their experience with breast cancer and attempting to regain or retain a feeling of control in their lives. Evidence for this could be seen in both direct statements about meaning and control, and in behaviours and cognitions that are linked with meaning and control, both in clinical and research literature (see Chapter 3 for research relevant to control and making meaning). Hence, as the analysis continued the researcher tapped into a range of writing on the two concepts and research, both quantitative and qualitative, which helped to shape the classes of behaviour that indicated sense/ meaning making and control efforts which emerged from the interviews. In addition, it became apparent that the individual coping strategies, described in the previous chapter, contributed in different ways to a sense of making meaning and control, which can therefore be described as overarching categories or themes (see Method chapter for a fuller description as to processes used to come to this conclusion). In other words, control and sense/ meaning making efforts can be conceptualised as coping strategies in their own right, and as being overarching (or higher order) categories in that they encompass the coping strategies described in the previous chapter.

As Taylor (1983) and Lazarus and Folkman (1984) suggested, coping behaviours often will serve more than one function. Moreover, as was discussed in the literature on control, some writers have suggested that making meaning is a form of control, called secondary control (Rothbaum et al., 1982). It is not the intention of the researcher to claim that the examples of making sense/ meaning and control presented in this section are categorically only serving one function or the other. Indeed, without asking each woman what the goal was of a particular behaviour, it would be impossible to be sure. Even if asked, many people would probably be unsure about their precise motivation in adopting a particular coping strategy. However, in the context in which they arose, a judgement was made that the reported behaviour appeared to be more strongly aligned with one function.

Making sense and meaning

The following section describes the ways in which the women in the study appeared to be making sense and meaning out of their experience with breast cancer. Chapter 3 reported that ‘sense making’ and ‘benefit finding’ (making meaning) are two key construals of meaning used in the trauma and coping literature, and the findings from the initial interviews were consistent with those construals. Sense making encompassed cognitions and behaviours that appeared to help the women understand their experience in an explanatory way. These included, searching for a cause, re-examining beliefs, and confronting mortality. Making meaning (benefit finding) comprised behaviours and cognitions that enabled the women to shape new goals and purpose, including perceiving gain and benefit. Key behaviours in relation to this construal of meaning were, making changes in outlook, setting new priorities, and identifying benefit from their experience, especially improvements in their relationships with others. This section begins with some examples of direct statements from the women about their search for meaning, followed by a description of the ways in which they sought to make sense and meaning of their experience.

Statements about searching for meaning

Although no questions about meaning were directly asked, several of the women verbalised the need to take time to consider what their experience with breast cancer actually meant for them. For example:

*You know, I **need** to think about it. I like to have time to think about the fact that I had cancer this year and what does that mean. (01, p. 9)*

When something like this has happened to you, you do feel like, “Is it something that I did or didn’t do?” I suppose that’s sort of what I’m trying to do now is to get the peace and quiet and “me” time back into my life again to consider those sorts of things.. now there’s time to sit back and think what it all really means. (11, p. 20)

When something like this happens I suppose you can ignore it if you want to, but it really makes you confront other things. (04, p. 23)

Sense making

Searching for a cause

Others, while not directly verbalising the need to make sense and meaning, were clearly acting on this need in other ways, such as sharing their questions in relation to “Why me?”. Given that a section in the previous chapter has already explored the responses of the women in relation to the question of “Why me?” (see *Causal attribution* in which twelve of the women were noted as looking for a cause for their illness, most commonly stress) this next section will move on to examine the other indicators of making sense.

Examining beliefs

It is widely recognised that beliefs about ourselves, the world and the way things work are of fundamental importance in guiding everyday activity and are probably especially important when life brings adversity such as a diagnosis of breast cancer. In the words of Lazarus and Folkman (1984), beliefs are “preexisting notions about reality which serve as a perceptual lens” which will influence the way we appraise our environment and shape our response to it (p. 63). Whilst normally beliefs operate at a tacit level and are not in conscious awareness, in times of adversity or major change we may become more aware of the beliefs which underpin our lives and their influence on appraisal. This is particularly true in situations where our beliefs are challenged by external events, perhaps precipitating adoption of some new beliefs. In that situation, it is likely that the way in which our beliefs affect appraisal will become apparent.

Lazarus and Folkman (1984) indicate that there are many sets of beliefs which are relevant to appraisal. Two very important categories of belief that they nominate, because of their particular relevance to stress theory, are beliefs about personal control over events and beliefs about existential concerns such as God, fate and justice. As Lazarus and Folkman (1984) point out, existential beliefs “enable people to create meaning out of life, even out of damaging experiences, and to maintain

hope” (p. 77). This section will deal with findings from the study in relation to existential beliefs, and beliefs about control will be discussed in the second part of this chapter.

The majority of women in the study had drawn on their existential beliefs and broader beliefs about life and how it should be lived - which can also be called “life philosophy”. For over half the women (nine) this issue of life beliefs was very strong, being couched in religious terms for some and broader philosophical terms for others. Several women believed that their breast cancer had come for a purpose and the task, and challenge, for them was to recognise the purpose and learn a lesson that was entailed. For example, one woman described how she had adopted a similar stance to her mother, a practising Buddhist:

And she (mother) said, “It’s come for a purpose. Look at it in that way; it’s come for a purpose... Now learn the lesson and get on with your life.” And I think that’s exactly it...I’ve changed a lot of my life; I’ve changed a lot of things because I think the message that I have is “You’ve just learned that you’re not invincible.” (laughs) (01, p. 7)

A similar view can be seen in the following:

If it’s (cancer) been given to you, it’s been given to you for a reason, and maybe it’s to make you stronger, to put your life back in perspective. Maybe this is my chance to say, “You haven’t been doing enough for yourself; do something for yourself.” I try to look at it that way, (that) everything is done for a reason. (17, p. 18)

I’ve believed for a very long time that life is a series of lessons; that at some level you have to learn before you can step on to the next stage. And I still believe that this is, at some level that I don’t fully understand, this is a giant lesson that has within it a whole lot of little lessons that I’m going to have to work out. And I suppose, philosophically, I believe that if I don’t learn the lesson this time, something else is going to come along (laughs), so I’d better learn it right this time. (06, p. 13)

While none of these women described themselves as religious they held beliefs in God and a broad belief in the importance of the spiritual dimension of life.

One woman for whom religion was very important couched her questioning about purpose in terms of why she had survived breast cancer when others younger than her had died:

I guess I wonder why God has spared me, and then I guess he's sort of given me the ability to smile and cope and help other people. (16, p. 9)

For those who did not directly express a strong belief about the purpose of their breast cancer, there was still a sense of wanting to make something purposeful or valuable out of their experience. This is clearly articulated by one woman whose period of active treatment had just finished:

Now there's time to sit back and think what it all really means. And if I can make something positive out of the whole experience then that's to my benefit I think. I don't want to look on it as a negative, horrible block of my life that I just forget about and put behind me. I think if I can turn it around and some way make it something useful, which in a lot of ways it already has been - because it has altered relationships, and it certainly makes you stop and think about the important things in your life, and the important people too. (11, p. 20)

For one woman, purpose came through acting as a positive model of coping in the face of adversity, which could be useful for others in similar situations:

In a funny sort of way, with having so many people caring for me, I can see how being the centre of attention - and I guess that was my way of coping too - I conducted parties... surrounded by flowers and friends and my hair still looked good and it was almost, "And look how positive I am!" So I guess that's my way of coping; that perhaps someone can learn something from me as well .. that you can have something and make the most of it. And I guess that's my philosophy. ... I have a friend whose daughter died of cancer and we're not dissimilar. She's a very religious person and her way of coping was - she spoke at the funeral and was just beautiful -

that the good that will come out of this .. that there will be a lot of people who perhaps can have faith in God or .. It was just the way she was; she had to see that something good would come of this tragedy and that was what she did. And I guess this was my thing too, that things go wrong but you've just got to keep going. (08, p.6)

One woman, still only in her early thirties, described using her experience to alert other younger women to the reality of breast cancer:

It's shocked everyone that I'm so young, and that was my biggest concern at first, and I thought "Why me?" But since then I've been in the system (treatment) and can see that I'm average... I went to the breast clinic a few weeks ago and I watched two girls in the waiting room, and one would have been 26, and she was very distressed. And I've since heard of a lot of people in their twenties, and so I think it's getting a lot younger. Anyway, as I say, it has had a snowball effect. Even when I was in hospital, about four friends said to me, "What do I do?" And I said, "Well, I'm no expert.. but do your breast self-examination, get a pamphlet and when you go to the doctor, ask them to show you. And the scarf (for bald head) is a dead giveaway and friends have said to me, "Do you mind us talking about it?" And I say no because I suppose I'm using that as a snowball effect too, that if you know of someone (with breast cancer) you'll be more aware. (09, p. 6)

Several other women also spoke of their desire to contribute to a general awareness of breast cancer among women:

People need to be made more aware; they are very naive. And they say, "Oh if I do self-exam I don't know what I'm looking for." Well I didn't know what I was looking for and when I found the lump I knew it wasn't right. So they need to be reached. Maybe one day I'll sit down and write a letter to the media about it; it has to start somewhere. (17, p. 17)

The message that I like to tell people too, just offhand, (is) to be in tune with their bodies and make sure that you are as responsible as possible and go off and have your mammogram. (18, p. 27)

Three women who worked in the helping professions spoke of the way they thought their experience had been valuable to them in their jobs. For example, one woman, a general practitioner, spoke of being able to use her experience of talking to a nurse from the breast cancer support staff both before and after surgery:

Having a nurse to come to talk to me and talk about things like wound care (helped), and when she rang me up before the surgery we talked about practical things like what nightgowns to bring, whereas that's not the sort of thing that doctors would think about. And that's helped because it's made me more aware of how I can prepare patients better as well. (12, p. 7)

Another woman, an oncology nurse, believed that she had a better appreciation now of the experience her patients were undergoing, especially in terms of what they were experiencing in relation to chemotherapy and radiotherapy and their side effects, as well as their anxieties about their future:

I've learnt a lot; lessons like you think you can know, but until you've really been in it you don't. And, at some level, I always knew that but it's been made very, very real to me. I always knew that I didn't understand exactly how a patient felt ... but there were some aspects that I would have believed that I had some understanding of, and I thought I knew more about it than I did. So I'm not sorry for the lessons that I've learned. (06, p. 13)

Overall, it was clear that the women in the study perceived that their experience had a purpose, or that a purpose could be made from the experience - that is they could use the experience - which would help give it meaning and value. Indeed, for some of the women, being involved in the study probably had some value in terms of making meaning. Thus, they expressed the hope that other women in a similar situation could benefit by their experience, and some had a particular message that they felt it was important other women should hear - such as breast cancer awareness. Others, outside the actual taped interview, made comments to the effect that it was helpful to talk over their experiences. Part of its value appeared to be in making sense of their experiences.

Confronting mortality

As was seen in the previous chapter, when findings in relation to the coping strategy of *acceptance* were presented, a number of the women described how their experience of breast cancer had caused them to confront the reality of their own mortality. This appeared to encourage a keener awareness of the finite nature of life, which, for some, also enhanced the value of time and the importance of using it well. This was clearly conveyed by one woman who said:

I suppose that's what an illness, such as I have had, does. It makes me really aware that the time I see ahead could be long, or it might only be a year. So all of a sudden you have this piece of time that you've got to do good things with because it mightn't last very long... So it does give you an appreciation, I suppose, of the use of time and of mortality; not that I'm scared of dying, but there is an awareness there that it happens anyway. (03, p. 7)

For one woman in her early forties, this was the first time she had acknowledged her own physical vulnerability, and the fear she felt sometimes expressed itself in nightmares. She used her experiences to refine her appreciation of life and death:

I know it's a nightmare and I know it's about death, and I know that fear now. I know what it feels like and tastes like and .. somebody said to me, "It's the valley of the shadow of death that you have gone through, and that's what the valley is like." When they say, "Go to the valley of the shadow of death," that is what anyone who is facing a life-threatening illness goes through. There is a period when you are in the shadow and .. that's the shadow of death hangs over you. But you do move through it no matter how sick you are. I watched my mother's friend go through that and come out of it just before she died, and, for me, that enriches your life. That's what life is; life is death and it's hard.. life and death come in one package. (01, p. 14)

Despite having confronted the reality of death in her work as an oncology nurse, another woman found that her diagnosis of breast cancer heightened her awareness of her **own** mortality:

Dying to me now is a very real possibility. I mean, the statistics will tell me because I've had all this treatment and stuff, the chances of me having five years of disease-free survival are very good; in fact they're up around the 95% chance now. But I could be in that five percent... You think differently, you respond differently; death is much more real. (06, p. 6)

As she described it, confronting the possibility of her own death as a reality raised a mixture of feelings and questions about life:

We don't know that we know that we know etc. that we're dying until you're confronted with this sort of reality and having to deal with the anxieties and fear: Is there a life after death? Is this all a big hoax? Is all this real? What is real? Am I just a figment of somebody's imagination, or am I real even? Then you get into those philosophical questions: Am I here because I think I'm here? (06, p. 10)

In confronting these life and death issues, she had developed her own beliefs about the meaning to be gained from a person's life, even when they have died:

Every death is different and, at some level, that you remember them means they live on; and the lessons that you learn from that death, that the family have learnt from that person, will live on. So, at some level, they live on, and I very much believe it. And I think it's a really important concept to promote .. that you live on. (06, p. 34)

It is acknowledged in the literature (e.g. O'Connor et al., 1990) that when someone, in the course of dealing with their own illness, confronts their own mortality, they often engage in a review of their life up to that point. Several women in the study had clearly taken stock in that way, as can be seen in the following example:

I think I am quite an accepting sort of person... For thirty years or more all I wanted out of life, or all I could expect out of life, was that my children live long enough to remember me and I haven't changed that. I assume that (husband) will remember me (laughs). ...If I died now, there are things that I would like to do and things that I haven't managed very well, but basically I've got all the things that have been important to me. ... So what if you don't get everything you want; it doesn't really matter. I think what I wanted was continuity rather than immortality. (04, pp. 24-25)

Another woman was clearly mindful of her mortality, and indeed had confronted its reality in the course of dealing with other serious health problems that she had experienced for some years. Her response was to fight to live as long as she could to enjoy her family:

Eventually you're going to die. You can die of one thing or another; it's just what nature wants to bring you away. It's the only answer you can give it, because it's no use sitting there and thinking, "Oh God, am I going to die tomorrow?" It's not the attitude you take. (15, p. 24)

These statements show that these particular women, in confronting their own mortality, were making decisions about what that meant about the life that they were living, and what they valued and believed was important to them. Frequently this process of re-evaluation prompted them to make changes in outlook and relationships, which are described next. In other words, they were engaged in ways of making meaning (benefit finding) from their experience.

Making meaning

Considering outlook

Over half of the sample reported changes in outlook which seemed to set other changes in train, both in terms of their relationships to self, life, and others. Changes in outlook could be seen in statements about a greater awareness and appreciation of beliefs about life and its spiritual dimension. For example:

I think it made me aware that I did have a strong philosophy about my life. When I was in hospital, I thought, "Gee, I really do have a lot of philosophy about all this", that gave me a strong sense of it's place somewhere. And probably, in some ways, I think that is what life is, and it (cancer) really hasn't changed anything. As somebody said to me, "You've just had to do something that you've never had to use before, but it was always there", and I think that's probably true. (01, p. 10)

I believe that it is important to really connect with yourself and what's around you. I believe that's really important ... to get your energy from out there...It's probably only since I've had cancer, but I'm probably more aware of it, more aware of the spiritual side of things, and more aware of myself and realising that you've got to know yourself, you've got to believe in yourself and .. you need energising, so to speak. (18, p. 20)

For several women who held established religious beliefs, there appeared to have been a strengthening of beliefs. One woman said:

I suppose, if anything, (there's) maybe a strengthening and a sort of reassurance that you know what I believe in, and where I am is where I want to be in that sense. (11, p. 26)

Other women expressed a change in outlook in an increased appreciation of life, as can be seen in the following:

My optimism hasn't changed, not at all. In fact, in a funny sort of way, I think I am happier now. I've read about this - I think in fact it does give you another chance; like every day is fantastic! Like, you walk round the golf course and hit a bad ball and you think, "Oh isn't it a beautiful day!" And I look at trees and things (enthusiastically) .. but maybe that is getting older as well. So it's very hard to define what's caused it, but it's made me think about a lot of things. (08, p. 12)

Setting new priorities

Changes in outlook were often reflected in a reconsideration of priorities. For example, one woman's experience with breast cancer strengthened her already existing belief that the life she and her husband led was too pressured:

We are always doing something else rather than sort of savouring the present, and I've been saying that for years and years and years ... and this has just confirmed it... And that's something I have to decide what to do about. (04, p. 22)

For another women this re-evaluation encompassed her whole lifestyle, including the role of work in her life:

I would like to work less than what I am actually doing now and do other things as well, but I don't know what other things I want to do yet. But yes, I think work has become less important since the diagnosis; it's not the main thing in life anymore. (12, p. 9)

Others showed that the quality of time spent with family had become more important. For example:

I guess you see things in a different light, and some things you don't tend to put off things if there's a chance of doing something ..some of the pleasurable sorts of things. So (I'm) doing more of those things and spending a lot more time with (spouse) and family, and enjoying (things) more, and I guess not getting so stressed out. (16, p. 18)

Others expressed the need to place themselves higher on their own list priorities, or more at their centre of their own universe. This was described in the previous chapter in the sections on stress-management and using alternative health care, where it was clear that many of the women had adopted increased levels of self-care. The following statements are typical of this sentiment:

Now I sometimes think more of me. I want some time for me and trying to work things out. I don't want to put a lot of stress on my shoulders. (18, p. 14)

I think I have learned to get in touch with my body more and just live with it.. and live with time differently now... (Before breast cancer) I think I saw time as the enemy; running a business, time was the enemy. (01, p. 9)

As can be seen, a number of women had re-examined beliefs about life and their outlook on life which had resulted in a reconsideration of their priorities - of how they wanted to live their lives and spend their time. It seemed as though it had become more important to live their time well - whether it be short or long. For some, there was a distinct desire to return to normal as quickly as possible, but even in that scenario there was an increased appreciation of time.

Identifying changes in relationships

In addition to giving higher priority to close relationships, a number of the women reported that there had been improvements in their close relationships, particularly with family. These changes seemed to have given their experience of breast cancer an extra level of meaning and an increased appreciation of the value of these relationships in their lives. Some examples of these positive changes have already been presented in the section on *social support* in the previous chapter, but several others also stand out. For example, one woman spoke of a number of positive personal changes that her experience with cancer had triggered, including an increased closeness with her elderly mother:

*My mother and I have talked a **lot** about death, her dying, which will happen and we used to talk about it, but this year we talked a lot about it. It's been very bonding for us in that way.... It's been nice because I think she feels a lot more comfortable now just to talk about her own death without feeling that she is upsetting me. And I don't get upset. (01, p. 14)*

Other women reported similar improvements in their relationships with family members, including spouses and female siblings, as can be seen in the following:

My sister, surprisingly, has been really supportive. I say surprisingly because she and I were never close, but we took to ringing each other - she's in Sydney. I would ring her one week and she would ring me the next, and that actually was very good. (06, p. 25)

People that I've been fairly close to I'm now even closer to; I think (it) actually brought us together more, which has been great. (11, p. 16)

Even my husbands and my relationship has changed... We've been married for 21 years this year, and you do tend to sort of take each other for granted I suppose, without thinking how strong the relationship really is and valuing it. And I mean he was there for me the whole way through and still is, and it makes you just stop and look. It hasn't changed it so much as just made you aware of how strong it really is, more appreciative. And with my sisters too; they don't live very close so we don't see very much of each other, but they were very concerned and very supportive of me when it all happened too, and that's really nice. It's just sort of reinforcing of something that you don't stop to think about. (11, pp. 22-23)

In addition to these changes in family relationships, new and valuable relationships developed for over half of the women in the study as a result of developing contacts with other women who had been diagnosed with breast cancer both in the course of their everyday lives and through becoming involved in support groups (see section on *social support* in previous chapter for examples). When taken together with those who spoke directly about the benefits to close relationships, it can be seen that the majority of the women had experienced positive changes in relationships.

Summary: Meaning issues

It can be seen that all the women in the study engaged in behaviours to make sense and meaning of their experience to a greater or lesser extent. Thoughts and behaviours which seemed to be most clearly indicative of the women's efforts to make sense of their experience, apart from statements about their desire to make

meaning, included searching for a cause, re-examining beliefs, and confronting mortality. On the other hand, cognitions and behaviours which reflected the process of making meaning included considering changes in outlook, setting new priorities, and identifying benefits from their experience, especially improvements in their relationships with others. The way many of these cognitions and behaviours clustered together with other coping strategies (for example, acceptance and being positive clustering with meaning making efforts) is considered further in Chapter 8.

Regaining control

As was discussed in Chapter 3, beliefs about control held by women are important for their adjustment to breast cancer. It appears that those women who believe that they can, in some way, control their illness are better adjusted than those who do not (Taylor et al., 1984; Thompson et al., 1994). However, such beliefs are complex. For instance, a woman might hold beliefs about being about to control the growth of the cancer, the likelihood of it recurring and whether or not their doctors and/or treatments can control it. In addition, research with cancer patients showed that perceived control over daily emotional reactions and physical symptoms was more important than beliefs about control over the course of the disease (Thompson et al., 1993).

In this study, many of the women spoke spontaneously about their beliefs and feelings about control. They described feelings of loss of control in different areas of their lives, especially in the early stages of diagnosis and treatment, and spoke of their subsequent efforts to regain it. These descriptions fit within the framework of areas of perceived control which were delineated by Thompson et al. (1993). They outlined four areas which included perceived control of emotions/physical symptoms, relationships (with spouse, family and friends), medical treatment (and information) and physical recovery (course of the disease). This section, then, looks at expressions of feelings and beliefs about control reported by the women in this study and associated coping strategies. It begins with statements reflecting perceptions of control in relation to medical treatment, after which control in the areas of physical recovery, emotions and relationships are explored.

Control in the medical area

This section presents statements from the women which demonstrate their feelings of control or lack of control in relation to treatment, as well as the ways in which many women sought to retain or regain a degree of control in this area. Their coping strategies included being actively involved in treatment decisions, asking questions (especially of their specialists), reading relevant information, putting their trust in their doctors and following doctors' orders. Whilst the majority of the women used a number of these strategies, four groups of women could be distinguished on the basis of the degree of control they sought to exert and the behaviours they reported using. These groups are described as "having a say" (active partner), putting trust in their doctors, following doctors' orders (unquestioning) and being an equal partner. The first group (of 8 women) refers to participants who were basically happy to go along with treatment but who showed their desire to be actively involved through reserving their right to make their own decisions, asking questions, reading the information they were given and seeking additional information. While women in the second group asked questions and sought some additional information, they did not assert their right to make treatment decisions; rather they accepted the decisions of their doctors because they had trust in them. The women (two) in the third group were similar to the second group but conveyed a feeling of "going along with" doctors orders without a strong sense of trust ("I have no real choice.") One of the women in this group would not ask questions or seek any additional information. And finally, the fourth group refers to one woman who was in the unusual position of making a significant input into treatment decisions because of her training as a medical practitioner.

Active partners (having a say)

A number of the women described a sense of having lost control when they were undergoing surgery and adjuvant treatment and gave voice to the feeling that their lives had been "taken over". These sentiments were expressed very clearly by one woman who said:

You had no control..control was taken from you. And I was happy enough with my surgeon and he wasn't going to mutilate me, which is what I see the mastectomy as being – although I wouldn't sign the form to give permission for the operation until I knew they wouldn't do a mastectomy because I was really afraid that I'd wake up with only one breast. (17, p. 7)

Clearly, one way that she retained some control was to use her right to make her own decision about choice of treatment. In addition, she actively sought as much information as possible from her surgeon:

I prefer to know than be naïve. Like, I've asked my doctor upfront what he's thinking and what he wants me to do and what it all means. (17, p. 6)

Another woman, who also tried to be an active partner in her own treatment, indicated that she achieved this by asking questions of her specialists:

I didn't have any trouble accepting the situation and I went in apparently quite vigorously in search of success, asking questions and that sort of thing. But I like to know the situation and I like to feel as if I can control .. and that doesn't mean that I expect to be able to impose my will, but to have a choice, to have the information to make an informed decision. (04, p. 23)

Another woman, whose breast cancer was detected at a very early stage, gave voice to her desire to be in control of the decision about undertaking treatment:

It was interesting I almost rang to cancel the radiotherapy just before it started. But then I decided that I would and then I felt much better. I felt that I had decided myself whereas previously I felt that they were deciding for me. They give you the opportunity of saying yes or no, but it really takes more than the half hour consultation you have to decide. So the sense of being in control of the decision is an important one. But I do feel as if I was given all the information, but a lot of it comes very quickly and it's technical and you don't entirely apply it to yourself somehow for a little while. (03, p. 3)

Having access to a health care professional who is able and willing to provide good information about treatment can also enhance feelings of control, as can be seen in the following:

When we first were starting chemo, she (nurse) spent a good hour and a half with myself and my husband and went through just what all the drugs were and what their likely side effects were and how I would be likely to be feeling. Once something's known, it's just that much easier, because if you don't know that that's linked to what you are doing or what you are taking, I would think everything would be a bit of a scare. If you're feeling differently, or having aches and pains that you haven't felt before, you'd be relating it to the fact that something was going wrong; whereas if you know that that's just a normal, or the expected side-effect, it's not a worry. You can work your way through it; you know that there's an end to it. (11, p. 11)

So far, this section has looked at the experiences of women who were active partners in the treatment process. All of these women felt they had been informed well by their specialists and associated carers and complied with the treatment suggested by them while asserting their rights to be active partners in treatment decisions. However several women who wished to be actively involved in decisions felt that they had not been sufficiently well-informed. Indeed, one of these women, a trained nurse, refused to comply with one component of treatment. She had been experiencing troubling menopausal symptoms and did not want to take tamoxifen:

I did say to (surgeon) that I was having terrible trouble with night sweats etc and I'd read enough about tamoxifen to know that it would exacerbate these feelings even more, and I said I wouldn't go on tamoxifen. And (surgeon) was very annoyed with me I think at that stage, but I was quite firm that I didn't want to have it at this stage .. that I didn't want to feel worse. (13, p. 3)

Apart from the doctor from the breast-screening service who discussed the results of her mammogram (and biopsy) with her, she felt frustrated by not being given enough information:

He really has been the person throughout the whole thing who has told me most. After that another of my beefs was that they don't really tell you enough. (13, p. 2)

In addition, she felt this situation was compounded by the fact that there were gaps in knowledge and changes in approaches to treatment that created confusion. For instance, the diagnosing doctor said it was okay for her to stay on HRT, while her own surgeon asked her to come off HRT:

Looking back, I shouldn't have come off it straight away – not cold turkey – so that caused some problems. (13, p. 2)

I got a booklet from ACCV and it said that some women do need to go back on HRT. However, no-one has been willing to tell me I could do that, so I still haven't gone back on HRT. (13, p. 3)

She expressed her frustration with this confusion and limitations in knowledge, which meant that perhaps all her treatment and attendant discomforts had been unnecessary given that her cancer was detected at a very early stage.

Another woman also felt that she was not sufficiently well-informed about aspects of medical treatment, for instance whether or not she would benefit from adjuvant therapy, and conducted her own research to gain the necessary knowledge:

The hospital, and particularly the surgeon, were not informative. Fortunately I have those research skills and background, so I was able to do a Medline search to get a range of appropriate journal articles making sense of all that and that helped a great deal.... (07, p. 9)

One woman was basically happy with her specialists but expressed frustration that they seemed to stay within the confines of conventional medical approaches and knowledge:

The doctors were really good and would answer all the questions that I asked, but generally I feel that they have a bit of tunnel vision as to the all round care... At the end of chemotherapy I was pretty rundown, and maybe some form of vitamin supplement, or something like that, and I might have been able to take a higher dose of chemotherapy. But the research hasn't been done by the medical profession - there's a lack of balance. (19, p. 1)

As a result of her dissatisfaction she actively sought out alternative therapy (acupuncture). She also gleaned additional information about diet for herself:

If you've been through the chemotherapy like I've been through, you get an enforced and sudden menopause. I would find that for about two weeks after each treatment I would get severe night sweats ... but the moment my digestive system was good enough I would get back on to soya milk and I would have a lot of it and my night sweats would diminish very quickly. Now that sort of information (from doctors) would be helpful. I was lucky I found it out by myself because I was involved in a women's health group through a community centre; but you see that's something I could have been told. (19, p. 2)

As was discussed in the previous chapter, a number of women sought additional help and information from alternative health care practitioners. Whilst they did not directly verbalise feelings of frustration that their specialists did not have a broad enough focus for their care, they were clearly looking for more information and ways of optimising their own physical well-being.

As can be seen, the women whose experiences have been described so far in this section all tried to be active partners in their treatment, mindful of their ability to have the final say about whether or not to proceed with treatment and make choices at different points. In addition, they asked questions of their specialists and associated carers, gathered information from others and undertook further reading. Some of these women felt that their needs for information from those treating them were not met, and made efforts to gather the information in other ways so that they were in the position to make informed decisions. It appeared that access to good information from their specialists, asking questions and, for some, being able to have a say in

decision making, fostered feelings of control in the medical area for this group of women.

Having confidence in doctors

Another group of seven women spoke of their strong feelings of trust or confidence in their specialists which, according to Taylor et al. (1991) can be viewed as “vicarious control”. In addition, this is a coping strategy which appears to confer benefits in terms of emotional adjustment. Some typical comments from the women in the study were:

My surgeon was highly recommended to me ..I had been told that “he’s one of the best” so I have confidence in him. I thought he explained it extremely well. So I was very confident with him. (01, p. 5)

I felt directly I went there (to surgeon) that I was being sent to the right one that was going to look after me and everything was going to be okay. (02, p.6)

The doctors are good ‘cause they are fully explanatory to you; they explain it the best way they can... And one of the social workers, she was very good. When (husband) couldn’t be there I only had to ring once I knew a doctor was coming and she was there with me all the time, ‘cause as she said to me, “It’s always better with two sets of ears than one, because you don’t listen and hear everything that they’re saying”. (15, p. 27)

I have found everyone at the (hospital) wonderful .. and I guess they all give off that air of confidence, so you have confidence in them. (09, p. 8)

However, while these women expressed confidence, this did not mean that they did not want to seek further information, as can be seen in the following:

When the mastectomy was on I read everything I could and spoke to everyone I could. The doctor would tell me something at the hospital and I would come home and ring the Anti-Cancer Council and see what they could tell me about the same

thing. So I did a lot of checking and extra work, but when the chemo started I decided just to let it go and float with it. They're the experts, not me, no matter how much reading I do about it, so you just deal with your part as you go along. (09, p.8)

Similarly, another woman who was happy with her surgeon and knew of his respected position in this area said:

*I read avidly at first .. some of it I didn't want to read including articles on tamoxifen and the side effects of that, and I probably wondered what I was letting myself in for. But my philosophy is .. "I'm going to this doctor; I **have** to trust him...If he says, "We'll do this" then I will do it. I guess it's blind faith. I mean, I ask questions, but whatever he says, I will do. (08, p. 11)*

One of the women in this group who expressed confidence in their specialists verbalised the difficulty in sometimes getting enough information:

I've got the booklets but I wanted to know the more medical side of things, which you can't always find out. (14, p. 5)

In addition, she was reluctant to impose on her doctors at times when she really wanted more information. An example of this was when she was experiencing discomfort from the side-effects of chemotherapy, such as nausea and constipation, which she put up with longer than she needed to:

I felt so ill, and you keep thinking, "Will I call the doctor?" and you don't know and think you've got to put up with it if you're having the treatment to get rid of the cancer. (14, p. 4)

The combination of confidence in their doctors and using some additional coping strategies was typical of this group of women. However, by contrast with the previous group of women who wished to be active partners in treatment, they did not voice any desire to make decisions about treatment unless that choice was actually offered by their specialists.

Going along with doctors

Two women went along with their doctors' decisions but seemed to lack the sort of confidence in them which characterised the previous group. In addition, both of them indicated feeling out of control. For example, one woman said:

I suppose my life was turned upside down; I did what I was told and went through the motions... (18, p. 5)

I kind of feel that you are on a production line. I mean, you're passed on from your GP to the surgeon to your oncologist to your radiologist and so forth and back again. They're all very nice but .. I guess you feel that you're just a number. (18, p. 10)

In addition, she indicated that she was reluctant to be involved in making the decision about whether she would have a lumpectomy or mastectomy:

I had to make up my mind whether to have the mastectomy or the lumpectomy and I guess I still think perhaps I should have had the whole thing off. That was a difficult choice cause I would have preferred to leave it in (surgeon's) hands. (18, p. 26)

Unfortunately this particular woman had been misdiagnosed by the first doctor she consulted about a breast lump, who told her it was "just milk ducts" and nothing to worry about. Her confidence was also somewhat shaken during treatment when the oncologist forgot to tell her to start on tamoxifen until she asked her GP about it:

I guess I was a little bit put out with the oncologist because I was supposed to be taking tamoxifen ...he'd forgotten to put me on it, and that bothered me a little cause I thought. "Oh there's this gap of a few months that I should have been taking it." (18, p. 11)

As a result, she felt that she could not really rely on her doctors and had to be vigilant herself:

You really have to be on the ball and not rely on (them) .. and follow things through, question them and query and if you're not happy, well do something about it. (18, p. 11)

Similarly, the second woman in this group clearly felt her life was out of control at the time of diagnosis and treatment and coped with this by “going along” with the doctors, albeit reluctantly. For example, at the time of driving to hospital for surgery she voiced her feelings to her husband:

I feel like it's (cancer) has taken over; I've got no control of my life anymore... Everyone was telling me (what to do) and I just didn't want to go (to hospital). I suppose I wanted to make my own decisions but I felt that this once everything had been sort of taken out of my hands and I just had to go along with it. (10, p. 4)

And later in the treatment process she expressed a similar sentiment:

Your whole life's taken over by all the blood tests and the doctors and the chemo and everything else. (10, p. 7)

However, she did go along with medical advice:

These are really people who know their business and that's all you can do really .. take their advice .. And I suppose all the people you meet along the way, they seem to know exactly what they are doing and they've all been extremely helpful and very nice and .. and that all helps to jolly you along I suppose. (10, p. 18)

In addition, this particular woman did not wish to ask questions or do any extra reading. As she said:

I didn't want any extra information really, because probably I'm happy just being .. knowing what I know at the moment. (Husband) has wanted me to ask questions. He goes off crook at me because he says, "You don't ask questions!" ... I feel I don't need to know. I feel what they tell me is enough at this point. (10, p. 35)

Both these women, then, went along with treatment decisions but lacked the clear sense of trust that was apparent in the previous group, and did not wish to contribute to treatment decisions. In addition, both verbalised a sense of losing control in this area during the time of active treatment, which was in contrast with the women who had confidence in their doctors.

Equal partner

It is interesting to note the somewhat unique position of one woman in relation to this issue of confidence and feelings of control, which is in marked contrast to the two women who went along with treatment. Because of her medical training and work as a general practitioner (GP) she felt prepared for the diagnosis, the process of making decisions about treatment alternatives and the treatment process itself. For example, when her surgeon told her that the lumpectomy had revealed the tumour was more extensive than they had originally thought she focused her energies on making a decision about whether to have a breast reconstruction:

When the breast surgeon mentioned mastectomy, right at the same time he mentioned reconstruction, so I think I was concentrating more on the reconstruction than the mastectomy itself. In fact, in the time between the lumpectomy and the mastectomy that was the main thing I was trying to decide on; whether to go ahead with the reconstruction rather than just the mastectomy. ...I'm glad that I made the decision to have the reconstruction at the same time, though I wasn't glad straight away after the surgery because that was more of the surgery to have. It was actually a longer operation and more recovery time as well. (12, p. 3)

Indeed, when I asked her if the previous six months (since diagnosis) had held any surprises she said:

I don't think so; I feel that I am in control of what's happening. (12, p. 9)

This feeling of being in control may well have been enhanced by the attitude of her surgeon:

When I saw the surgeon he spoke to me as a medical person rather than as a lay person which was good. (12, p. 12)

Hence it appeared that she felt she could rely on both her own knowledge **and** that of her surgeon and work in partnership with him, which enhanced her feelings of control in this area of her experience with breast cancer.

Non-compliance

As was mentioned in the previous chapter, one woman in the study group was in a different position from the others in the study because she had been treated for early stage breast cancer several years earlier, and had been diagnosed with another cancerous breast lump several months prior to the first interview. She had followed conventional treatment for her first breast cancer, but decided to adopt alternative medical treatment options because she regarded the former as being too “mutilating”. Basically, hers was a position of non-compliance which can be viewed as taking the maximum amount of control in the area of medical treatment. In this case however the control may not necessarily be adaptive.

Overall, it is clear that many of the women in the study experienced feelings of loss of control in relation to medical treatment. Five groups could be distinguished on the basis of the amount of control that was sought in this area. Control sought ranged from maximum individual control (non-compliance with conventional medical treatment and exclusive involvement in alternative treatment), to least individual control (going along with the doctor). The majority of the women reported coping actions that characterised either the *active partner* or *trust in doctor* group. In both of these, active involvement was sought in the form of reading and asking questions. However, women in the former group actively sought to have a say in treatment decisions, unlike those in the latter group who chose to put their trust in their doctor.

It appeared that those women who were able to achieve the degree of control that they wanted in this area reported less sense of losing control during the stage of active treatment.

Control and physical recovery

Most of the women in the study reported using coping strategies that have been linked with enhancing control in the area of physical recovery. Thompson et al. (1993) found that changing diet and lifestyle, exercise, and adopting a positive attitude were the three most commonly used coping strategies in relation to this area. The findings from the women in this study are consistent with this, as was described in the last chapter – in particular, see sections which describe the strategies of *having a positive focus*, *seeking alternative treatment* and *stress management*. There it was demonstrated that nearly all the women had adopted a positive attitude, eight used some form of alternative treatment, and most women used a variety of stress management techniques. While the researcher did not ask the women if they believed they could control the course of their breast cancer and influence their chances of recovery by using such strategies, several spoke spontaneously of their belief in this connection, and for the others it seemed to be assumed or, at least, hoped for. Given that there are no certainties about the success of breast cancer treatment, there was at least a desire and hope, and belief for some, that they could adopt strategies that would give them a “fighting chance” to make a full recovery.

The belief and hope that they were adopting behaviours that would promote recovery can be seen in the following:

Once I got the diagnosis of breast cancer I couldn't do much about that; I couldn't have reversed it. But I could influence the treatment and the future prognosis as well. So I think that's my outlook on life: I concentrate on what I can do to help myself, rather than concentrate on the diagnosis. (12, p. 6)

For this woman, helping herself included change in diet and lifestyle, with the latter including an increased emphasis on relaxation and the use of meditation.

A similar belief and range of coping was described by another woman:

And also, after I finished the treatment, that's when I followed up the alternative therapies ... as a way of carrying through and slowly tapering off my connection with treatment. But, as it's turned out, I also did it to give myself as much chance as I could of not having a recurrence. (19, p. 11)

This second woman had also deliberately begun exercising more actively which included Tai Chi and walking as much as possible, strategies which are consistent with maintaining control. In addition she had modified her diet during the course of treatment:

I'd done the meditation and made sure I had a good diet; I changed my diet significantly and went mainly on to organic fruit and vegetables, and steered clear of chicken because apparently they put oestrogen in chicken - both the (surgeon) and oncologist said they thought that oestrogen would turn up as being, one way or another, fairly significant in the cause of breast cancer. I virtually went off all caffeine. So I did all those things through the treatment. (19, p. 11)

One woman spoke of her belief in the importance of giving women information about alternative treatment and lifestyle approaches so that they are empowered to do something extra for themselves:

There is a lot of evidence that isn't brought into the public health arena about alternative forms of looking at breast cancer – health, diet and basically about those sort of lifestyle issues... I think there's a very important message coming out of alternative areas that can get blanketed over which women should look at, such as, "Is diet a factor?" (in the development of cancer)... But for me, personally, I've changed my diet – I had a very healthy diet anyway – but I've loaded up with vitamins and try to drink soy milk, and I think, from my point of view, that's probably all I can do. Other women have asked me what they can do. I've said to them basically there is very little you can do is get your head in the right place... We are all living in the same sea of uncertainty, and the medical profession is really unable to help. They're

tracking genetic factors and genetic indicators, the treatment is still fairly primitive, and will be in our lifetime. (01, p. 12)

Whilst others did not spell out a connection between lifestyle, attitude and physical recovery, some spoke of their desire to be actively involved in their own recovery. For example, one woman said:

It's important to feel that I'm actually doing something constructive about my health from now on ...so as not to feel that there's nothing going on. (11, p. 12)

For her this included having a positive attitude, and taking care of herself through improved diet, exercise and relaxation.

The attitude of doing whatever you can to help yourself was also expressed by another woman who said:

You've got to go along and do everything possible ..(take) what's offered to you. (02, p. 30)

Part of her recovery process was to engage in exercises to regain mobility in her hip (an earlier problem) and the affected arm, which could also help prevent the onset of lymphodaema:

So directly, when I could, I wanted to get back to doing my exercises you see, and also (surgeon) told me immediately to start climbing up the wall. You climb up the wall with your hands because that stops the other problems, the lymphodaema. (02, p. 27)

These women, then, had all taken an active role in influencing their recovery particularly through diet, lifestyle and exercise. For all of them, having a *positive attitude* was also important and its role in enhancing recovery was expressed directly, if somewhat tentatively by one of the women:

You've got to have a level of being positive and being bright rather than dragging everyone else down with you. Someone's got to be strong so it may as well be me so it (recurrence of BC) doesn't, maybe, happen again. (17, p. 2)

Overall, then, most of the women used coping strategies (diet, exercise, lifestyle and positive attitude) to enhance their chances of recovery. Even those who directly stated the connection between use of these strategies and recovery spoke of it in terms of influencing, rather than controlling as they were well aware that there is no known cure for breast cancer. Even the woman who spoke of the need to cure herself by changing her beliefs made no claims that her choices would control her recovery:

As I said, it's like Russian roulette; if you're going through all the motions and doing all the other things, while you're feeling well and on top of it, keep going with it. Once you start to fall in a heap, you then know that it hasn't worked (wry chuckle), but you tried. (05, p. 9)

In addition, those who were actively engaged in influencing their own recovery tended to be those who had adopted active roles in relationship to issues of treatment. This was particularly noticeable for two women who had voiced their belief and hope in being able to influence their recovery, and who also adopted positions which enhanced control in relation to treatment.

Feelings of loss of control (emotions) and regaining control

Whilst the initial reactions of women in the study were described in the previous chapter, some of them will be re-examined at this point in order to highlight the feelings of loss of control experienced by women in the study and the coping strategies they used to regain a sense of emotional equilibrium. As was noted in that chapter, most of the women had experienced strong to extreme feelings of distress which some described in terms of loss of control.

Feelings of loss of control were particularly marked for one of the younger women. She had undergone surgery (mastectomy, no adjuvant therapy) just two months prior to the interview, and had very clear memories of feeling out of control

since her diagnosis. In fact, she described her initial reaction as “totally shocked... I was scared rigid-shocked” and felt that this meant that she was going to die. In addition she said:

*I was staggered at the depth and strength and **rapidity** of the diverse emotional responses in the space of twenty four hours, and that was really hard to take. One moment I'd be fine, the next I'd be crying, the next moment I'd be feeling quite happy, and the next moment I'd be feeling really anxious, then I'd be depressed, then I'd be crying (speaking rapidly), then I'd be happy again... and it all took place so quickly. That's frightening and shocking and surprising; it is so unlike normal life. (07, p. 17)*

Given the strength of feelings of loss of control it is not surprising that she spoke of a remarkably wide array of coping strategies to help retain a sense of control. Among these was seeking help from a psychologist to deal with her feelings:

*I go and see a psychologist. I was very frightened at the intensity of things from my first partner's death, the way it came back, and I lost confidence in my ability to deal with the **big** problems. (07, p. 12)*

In addition, she tried to enhance her way of coping, especially in dealing with severe anxiety, by reading about coping strategies reported in the research literature:

There were other times where it was very difficult to deal with what appeared to be an appalling anxiety and I learnt about my ability to catastrophize in an enormous and very frightening way (laughs)... I always have had this ability to catastrophize and imagine the worst and it's probably one of the reasons that I'm generally a very well-organised person. But I also raided the Institute's library on texts on psycho-oncology so I could read through the processes that I was going through, and there's coping skills that are recommended and therapy processes that are offered, and I used to try and identify in my own mind what I did to cope. (07, pp. 14-15)

Another strategy she used was planning or anticipating difficulty which can be seen in the preparatory grieving she undertook for the loss of her breast. She had been alerted to likely feelings of loss of her breast by a counsellor from the breast cancer support service with whom she spoke prior to her operation:

I started, mentally, a process of grieving before the operation including.. I got my sister, who is a photographer, to take the “before” photos on the day before going to the hospital so that if I ever wanted to look at myself how I used to look then I would be able to do that. And on the morning of the operation I said goodbye to my breast before I was wheeled out. (07, p. 9)

She even used different sorts of music to help her cope with varying feelings:

I used different sorts of music for different needs ... There’s a piece of music which I consider my “left breast music”. It’s a very sad but controlled piece of music by Shostokovech which to me is a very deep, emotional piece of music and it’s the music that I listened to before my operation when I was crying to myself, saying goodbye to my left breast. (07, p. 14)

One older woman of about sixty, struggled with feelings of fear and distress especially in the three weeks while she waited to have her lumpectomy:

But that three weeks ..I was crying. I thought I was going to die and was talking to my husband about making my will. It just hits you so bad .. I just felt I was going to die. I just kept crying, then I’d be all right for a little while and then I’d cry. (14, p. 2)

The strong feelings of distress abated once the operation was over and she became reconciled to living with some uncertainty as she waited for the next check up with her surgeon:

It was the waiting that got me down. And I know I’m waiting now for a result, but I know I’ve got to have the nine months before they tell me anyway. So, though I’m still tensed up a bit about waiting it’s not as bad because you know you’ve got to

have the nine months and then they'll give you a test, so you sort of begin to realise that you've got to accept it. That's the only way; you've just got to accept it and fight it. (14, p. 11)

She found that reading about other people's experiences with cancer and how they coped helped at times when she was struggling to retain emotional control:

I got books from the library - my daughter got them – and I was reading how different people had coped with it ...I was interested in other people's stories – who'd had it themselves – and how they'd coped. There was a book called "Get well" and that was good. I'd sit in the corner or lay on the bed for quarter of an hour and just say, "You're going to get over it," and talk to yourself like that...Sometimes (I'd) stand in front of the mirror and I'd have a row with the cancer. I'd say, "Get out of my damn body," or something like that ...you've got to talk it out of your body. (14, p. 7)

Other women described similar initial reactions. For example, one woman said that her diagnosis came as "a tremendous shock" as she had been vigilant about doing breast self-examination and having regular checkups with the doctor because she had a history of lumpy breasts. Her reaction can be seen in the following:

And when I got home the flood gates opened, and I think I cried for about two days...I think we all cried for about two days, and the third day I was going in to hospital. I had a shower, a lovely long shower, and in that shower that's when the change happened. I said, "Bugger this! I'm not going to let it defeat me." And from then on I decided that I was going to put everything negative out of my life, and I would just concentrate on the positive, and I was going to do anything that I could possibly do to make sure that I got through it, and I was going to win. (19, p. 3)

As can be seen, her response was one of taking control again after a relatively short period of feeling out of control. For her this involved a variety of coping strategies, but particularly, as can be seen above, a focus on the positive.

Another woman minimised the threat of loss of emotional control in the initial weeks after diagnosis by consciously putting the emotions on hold to be dealt with at a later date:

I did actually make the choice not to deal with the emotions right then. I believe you don't have any control over what you feel. I do believe that what you do about it you have control over....I couldn't stop the feelings of fear, anxiety, uncertainty. What I did about it was temporarily I said, "Yes, I'm aware of all those feelings but they're going to go on the shelf until I can deal with them.... I felt that I still needed to be fairly in control of the physical things, what was happening to me right now; do this, do that, arrange transport.. all the dumb, mundane things. (p. 32)

When she felt ready, she took the feelings off the shelf, one at a time, and dealt with them through meditation. It seemed that she never felt actually overwhelmed by her feelings, although she did mention that fear was a recurring feeling which she'd had to deal with a number of times.

Another participant who also felt the loss of control very acutely said:

It (cancer) has taken over; I've got no control of my life anymore. (10, p. 4)

For her this was particularly difficult to accept given her former independence:

Well I suppose I've always has control of my life and now I feel I'm just doing as I'm told by everyone. And I've always been a very independent person, most stubborn in some ways, and never done anything I didn't want to do myself. (10, p. 18)

She spoke of her preference to keep her feelings and worries under control, at least in front of other people. This was apparent at the time of her diagnosis when her GP had told her that her lump was breast cancer:

And you know that sort of nearly knocked me flat. It took me a lot to..because I'm not a person that goes to pieces in front of other people, I still hold myself together,

and of course I held myself together, and I went out in the car and howled my eyes out.
(10, p. 4)

One of her main ways of coping with distressing feelings was praying:

When I'm awake during the night I pray, especially those nights where my mind is very busy; I try to take my mind off it by praying ... I use prayer when I'm upset to settle down. (10, p. 40)

This coping response went along with a tendency to avoid thinking about things that might upset her, such as thoughts about her prognosis. While it was clear that she felt a loss of control of her life and her feelings, her primary coping response was avoidance, which was in contrast to the responses of other women in the study. Indeed, her response to symptoms of breast cancer and her diagnosis had been marked denial. These differences in coping responses will be discussed further in Chapters 7 and 8.

Whilst many of the women reported that the time of diagnosis and treatment was when they felt most loss of control, some also reported that experiencing associated physical symptoms engendered a similar reaction as can be seen in the following:

Your independence is taken away. You're in hospital and you've got people showering you, and trying to put a bra on - I couldn't do that for a while because your arm is almost rendered useless. So, not only have you had this diagnosis, but physically you're destroyed for a while too. (17, p. 8)

In summary, most of the women described experiencing intense emotional distress, that is a sense of being out of control, a reaction which was clearly very frightening in its own right for some. They reported having used a range of coping responses to help regain a sense of emotional control. These included being positive, seeking professional help, reading about how other women with breast cancer had coped, prayer, meditation and listening to music. In addition, some of the women also spoke of turning to partners, family and friends when distressed, which will be looked at further in the following section.

Control and relationships with family and friends

As issues in relation to *seeking social support* and *normalising* were explored in the previous chapter, only a small sample of comments will be used here to highlight the link between social support and feelings of control.

A number of the women spoke of their need to talk about their experience and the relief that sharing it brought:

I found I feel more relieved the more I talk about it to people.. I've been brought up that you don't hide what you've got because it's nothing to hide. I mean, you can't help what you've got and you want to live life to the fullest, and just because you've got cancer it doesn't stop you from doing it. (15, p. 3)

It appeared that by communicating her experience with others, she ensured that her illness did not become a silent area of her life which might potentially hinder her relationships with others. In addition, it opened her up to the possibility that they would be able to affirm her worth, whatever her “illness”.

Similarly, communicating with others, who had themselves had breast cancer, had value in terms of expressing feelings and learning from others, both related to control, which can be seen in the following:

I wanted to speak to women who could remember what it was like – the emotional ups and downs, how they dealt with the crisis – to be able to talk to somebody with for whom it was very fresh, and I'm finding value from two different sources. (07, p. 13)

There was tremendous value for one woman in being able to share her “night terrors” with a good friend who herself had experienced breast cancer:

You go through the terrors. You're facing a life-threatening illness so of course the issue of death, dying, pain, all those things come. They usually come in the

middle of the night...I'd ring (friend) up and say, "I'm having the terrors" and we'd sit and talk about the terrors. And that was a comforting thing because you really can't talk to anyone else unless they've gone through the terrors themselves. (01, p. 3)

It appeared that she both gained relief and regained more emotional control from sharing it with her close friend.

Another woman showed how speaking to her husband when she was feeling concerned about some aspect of her illness was similarly beneficial:

If I find that something has been occurring too often for my liking, I might just mention it to (husband) and he says something reassuring and that helps me to release the thought. (19, p. 6)

This sample of statements indicates the way in which most of the women in the study sought support from people who were important to them. The sense of comfort and reassurance from being able to turn to others was very clear and undoubtedly enhanced a sense of control, at least in that area of their lives.

Summary: Control issues

Overall, many women in the study reported feelings of loss of control in different areas of their lives including the medical area, physical recovery, emotions and relationships. They described an array of ways they had used to cope with these feelings of loss of control, and ways that helped them to regain control. In the medical area, the women varied in terms of the amount of control desired. The majority chose to be actively involved in reading and asking questions of their specialists, although a number preferred to leave treatment decisions to their doctors. It seemed that those women who were able to achieve the degree of control that they wanted in this area reported less sense of losing control during the period of active treatment. Many women also undertook a range of activities to strengthen their chances of physical recovery. It appeared that those women who sought to be actively involved in the medical area were more likely to pursue additional means of

assisting their physical recovery. In the area of emotions, most of the women had experienced times of loss of control, especially in the early stages of diagnosis and treatment. Those who reported fewer feelings of losing control in this area were more likely to have appraised their situation as being not particularly threatening. For most of the women, it appeared that the area of relationships with close family and friends helped to enhance feelings of control.

The changes in patterns of meaning and control over time is reported in the next chapter, along with a description of changes in relation to the coping strategies of acceptance and denial.

Chapter 7 Follow-up interviews: Meaning and Control

As described in an earlier chapter (Chapter 4), all the women had agreed that the interviewer could contact them six months or so after the time of the initial interview to discuss the possibility of involvement in a follow-up interview. About seven months after the initial interview the researcher rang each of the women. Sixteen of the women agreed to a second interview, which again took place in their homes. Three of the women did not participate in the follow-up interviews. One was having treatment for a recurrence of breast cancer and did not feel well enough to participate, whilst a second woman was in hospital having a major heart operation. The third woman did not wish to be interviewed again as she and her husband were experiencing marital problems and he was not happy about her involvement in the study.

The interviews started with a question about each woman's physical progress over the time since the initial interview and the nature of any ongoing medical treatment. By that time the sixteen women had all finished active medical treatment and were involved in follow-up appointments with their specialists, mostly at periods of three to six months. Other questions related to how they were feeling, how things had been going for them in general, and how they had coped with any difficulties and concerns that had arisen. In addition, if areas of concern had been raised by a woman in the initial interview, the researcher followed up on these to monitor changes in them.

From the follow-up interviews it was clear that most of the sixteen women had continued their process of adjustment and were feeling that life had become much more normal for them, particularly once they had finished active treatment and had recovered their former levels of physical energy. Regaining former levels of physical energy seemed to take at least several months, particularly for those who had undergone chemotherapy and radiotherapy. However, for a minority of women there were continuing or new difficulties resulting from their breast cancer, or other demands which further taxed their ability to cope.

There were a number of ongoing difficulties resulting from breast cancer and new stressors reported by the sixteen women. Two women had developed lymphoedema, a painful swelling of the arm which can result from the removal of the lymph nodes under the arm at the time of surgical intervention. The lymph nodes can also be damaged by radiotherapy. One woman had marked oedema which had resulted from treatment for breast cancer and which required additional treatment, and two had a second breast lump investigated which proved to be benign. Several women also described varying degrees of discomfort associated with menopausal symptoms which appeared to have been triggered by adjuvant treatment.

In addition, a number of women reported having encountered demands (stressors) that were unrelated to the breast cancer. One of these was an unplanned pregnancy which was of particular concern because, as the woman had been advised, it could increase the chances of a recurrence. Other major stressors included the death of a parent, diminished physical health of a parent, severe work stress and family hassles.

Clearly, for many of the women with these additional, and sometimes, ongoing concerns there had been periods of marked physical and emotional distress. However, at the time of the follow-up interviews, most of them felt they had coped reasonably well and were managing any ongoing worries. On the other hand, three women indicated that these new demands, which were occurring at the time of the interview, were very difficult to manage. This chapter tracks the ways in which the women coped and were still endeavouring to cope with these demands through exploration of the themes of making sense/ meaning and keeping control. In addition, it presents findings in relation to the strategies of acceptance and avoidance/denial as they emerged in the follow-up interviews.

Making sense and meaning

The analysis of the follow-up interviews revealed that many women were continuing, in various ways and to varying degrees, to make sense/ meaning of their experience with breast cancer, although this was not as salient as in the initial interviews. Those women who reported having new or additional demands resulting

from the breast cancer, or who had experienced a further demand which could affect their breast cancer, reported using a range of coping behaviours that comprise making sense/ meaning. For them the threat of breast cancer appeared to be largely “in the background”, although it impinged more directly for those with ongoing problems. On the other hand, those women who had not experienced further concerns relating to their breast cancer regarded it as being mostly “in the past”, and were less active in making meaning.

As in the previous chapter, the two main categories of sense and meaning-making strategies are used to describe the findings from the follow-up interviews. It is worth noting that, on the whole, these issues were raised spontaneously by the women in the course of describing their experiences over the previous seven months. In other words, the researcher did not ask specific questions in relation to these areas of meaning.

Sense making

Examining beliefs

On the whole, the women did not talk as much about their beliefs and what the purpose of their breast cancer might be as in the initial interviews. However, the comments of a number of women showed that this issue was still on their minds. For example, thoughts about the purpose of their breast cancer can be seen in the following:

Maybe the breast cancer was a sign to say, “Put your life back .. prioritise things and look at things clearly”, which I have. (17, p. 10)

You just trust the Lord knows what he’s doing and I think, you know, that I’m sort of guided to the different ones (who she supports) and being able to help so many people, sometimes by just talking about things. People are saying, “Thank you for coming and just talking to me ... so I guess I feel I’m still wanted around here. (16, p. 10)

I think breast cancer has been good in a way because it's made me look at my life and my lifestyle and I suppose evaluate all the different things and see what sort of changes I can make in my life and lifestyle, so I don't think I want to push it to the back of my mind. I suppose it's more like a learning sort of thing that's happened. (12, p. 4)

For all of these women, such statements of beliefs and purpose were consistent with what they had said in the initial interviews. Likewise, those for whom consideration of beliefs and purpose were not salient in the first interviews, did not address them in the follow-up interviews. However, it is worth noting that there was one participant, for whom purpose and beliefs had come out strongly in the first interview, who had little to say on these issues in the follow-up interviews. At the time of the second interview she was very preoccupied with new difficulties in her working life which had arisen, at least partly, as a result of her breast cancer. In fact, she seemed to be struggling with negative meaning – which will be further described in the following sections - which perhaps had undermined the beliefs she had expressed initially. However, she was still able to identify some benefit or purpose in her experience as it helped her to understand better the clients she assisted in her role as a nurse working with cancer patients:

To me the best is that sometimes I can validate where people are at, without actually saying anything about my own experience. I would say something like, "I would guess that these sorts of foods are a no-no.." and they say, "Yes, oh yes." So I can let them know that other people have gone through this stuff and survived; that they are strong and we can help them get through this, and those sorts of things. (06, p. 8)

Most of the women who did not directly express thoughts and beliefs about their breast cancer in this interview, still demonstrated meaning-making efforts in other ways. It may be that many of them had moved on from consideration of their beliefs to a more hands-on engagement with living through and beyond breast cancer and making their experience meaningful.

Confronting mortality

About five women spoke about their feelings and thoughts about confronting mortality. The following sample shows these women still appeared to be actively dealing with issues relating to their own mortality. For example, this issue seemed to be particularly salient for one woman who worked as a nurse with cancer patients:

Sometimes I find it really, really hard when I have a person my age or younger who's premenopausal, who's at a similar stage, and they're now obviously in progressive disease and having treatment for that... So, because I'm confronted with it, a bit of me says "Well, they didn't have anything bad about them either. Is this going to be me in another two years?" (06, p. 9)

Similarly another woman who had delayed seeking treatment for many months, revealed that she was dealing with thoughts about mortality:

You're inclined to think, "Is something going to happen later on?" and you feel like you're always looking for something (further symptoms) ...And as I said, previous to last year I always thought I'd outlive (husband) as women normally do...I never used to think that he'd be on his own, but I do now. I think I might be the first to go. I'm only fifty one this year so it seems a strange thing to think about it at this age, but I think about it now where I never used to. And I think about, "Am I going to be around to see the first grandchild married?" ..So I ask questions of myself like that. (10, pp. 2-3)

All of the women for whom confronting mortality had arisen quite strongly in the follow-up interviews had experienced a renewed physical threat or difficulty relating to their breast cancer, apart from one woman whose delayed treatment had led to poorer prognosis. In those circumstances, the women seemed to revisit many of the emotions and reactions they'd had at the time of their diagnosis, of which confronting their mortality was a part.

Searching for a cause

About six of the women spoke again about the perceived cause of their breast cancer or the issue of “why me?”. Of these, four believed that stress was a likely cause of their breast cancer as can be seen in the following:

A lot of good came out of it. And I've decided that if there are any family issues or anything, I come first before anybody else. I sort of think you're meant to take the stress out of your life. Breast cancer and stress are meant to go together. (17, p. 2)

Stress may be affecting your immune system. I don't want that stress to get my immune system down again. I don't know whether I mentioned it to you but I was going through a very stressful period when I developed cancer. ...I wasn't surprised, when I thought about it, that I had developed breast cancer. (19, p. 8)

On the other hand, one woman spoke of the cause of her breast cancer as being related to HRT and diet:

I saw somewhere recently where Victoria's got the highest level of breast cancer than the rest of Australia. You wonder what it is. I feel in some ways mine's hormonal because I was on the hormone replacement therapy. I think that's really got something to do with it. And I also wonder what's in our food – our meat and chicken that we're eating a lot of now – whether we're obviously getting a lot of the hormones from those ...cause a lot of them (livestock, poultry) are given those. (16, p. 8)

One woman described how she had been reading further and thinking through her whole experience with breast cancer ...”what has happened and why it happened, and what it's meant to me” (11, p. 10). Whilst she had not drawn any conclusions about a particular cause of her breast cancer, she reasserted that she did not want to have to cope with feelings of guilt on top of everything else:

A couple of my friends, very well meaning friends, made me feel as if I'd somehow made it happen to me by inundating me with relaxation tapes and telling me, suggesting that it was something in my lifestyle that made it happen. It may well be but I've decided not to accept the guilt of that anyway because ..I've had breast cancer; I don't need guilt for why it happened on top of it... So that was something I had to work through, sort of feeling not only "Why me?" because the "Why me?" is still there, but is it perhaps something I did or didn't do? But I just don't think ... that serves any useful purpose now anyway. I certainly was happy to think about the fact that I needed to look at my lifestyle, which I think I've done, and perhaps make some changes, which again I've either done or am doing. But I don't particularly need to take on board any guilt attached to it. But I think I've just accepted that it was a thing that's just..that has happened to me. (11, p. 11)

Overall, these women showed that they were, in some ways, still mindful of the issue of "Why me?" and that they still thought about the possible causes of their breast cancer. They had drawn their own conclusions, made some changes on the basis of what they believed were some likely causes (stress, HRT and diet) and accepted what had happened and endeavoured to put it in the past.

Making meaning (Benefit finding)

As in the initial interviews, most of the women also spoke of changes in outlook and relationships that had followed on from their experience with breast cancer and the re-examination of beliefs that occurred for some. For many it was clear that their experience had prompted a change in outlook which flowed on into various areas of their lives such as their relationships. From analysis of the follow-up interviews they appeared to be making four main types of changes: considering outlook, setting new priorities, identifying benefits in relationships with others and outreach to others. Whilst the first three categories of change were clear in the initial interview, the fourth was not apparent at that stage. It involved a level of reaching out to others in adverse situations (many of them cancer-related) which was quite striking.

Considering outlook

A number of women spoke, in general terms, of a change in their outlook. One woman gave a particularly graphic description of her new overview and its impact on her relationship with her partner:

I think it has given me a helicopter-view of my life really. Before, time was .. I was down in it and I was running along in its path, and I think with this experience I lifted up and looked over my whole life... We're talking about our future: How will we plan our lives now? What is important? And I don't think I was like that before. I think I was more immediate, day to day. (01, p. 4)

Another woman also spoke in terms of seeing her life more clearly and the impact this had on her, including an appreciation of her own spirituality and connectedness with life:

Going to (naturopath), I think she's been very spiritual and she subtly points you in a different direction. ...I'm very aware of everything that goes on during the day now, whereas before I was working and I'd just have much more tunnel vision and I didn't see what was going on around me, and I wasn't appreciating what was going on cause I was too caught up in my own stressful day to day existence. And now I have much more time and I make time to sit down and talk with people, go for a walk and look at everything around me. (18, p. 10)

The same sort of message is clear in the following:

I think I'm going to be protective of myself forever, in a way. I'm going to try and keep all the positives of the change of attitude and the positives of looking at things differently and take that with me, and leave behind all the negative stuff that might have been around before I was diagnosed. ...Once you've had a diagnosis like that you will never be the same, but if all is well at the end, you can actually take out of that experience a heck of a lot of positive stuff and you can start looking at life in an entirely different way. What is it they say? The flowers in spring smell a lot

sweeter; sayings like that I can understand entirely. And when you go away on a holiday it is so much more special than before. (19, p. 3)

For several of the women who were struggling with ongoing difficulties, the change in outlook was either seen in negative terms (negative meaning) or as a mixture of positive and negative aspects. For example, one woman who was faced with an unplanned pregnancy, went through a period of emotional turmoil before reframing the situation and finding a renewed positive outlook:

I look at life entirely differently to what I probably did six months ago, and then I look at life differently again twelve months ago. I got to the stage when I became pregnant of thinking that life was just totally unfair; is there anything else that can be thrown at me? ...I'd had to deal with the death (of birth mother) that had happened a month before my diagnosis, I had to deal with the diagnosis, my husband had his tonsils out and that didn't go well and then I was pregnant. It was just like, what else can go wrong? It just proved to me that life is exceptionally cruel. And I thought I was being really positive (at time of first interview) and really focused and take one day at a time, but I think the pregnancy brought me back to reality. I don't think I'd coped as well as I thought I had. (17, p. 1-2)

Until you're faced with it you don't know what strength you have. I always thought I'd never cope, but actually I think as time is getting on I am getting stronger. ...You've really got to put things into perspective and I think maybe that this is what the disease has given me, a new slant on life. The baby's given me, not a second chance of life because I don't see that I need a second chance, but it's giving me something else that obviously, maybe I was missing. (17, p. 14)

On the other hand, another woman spoke of a change in her outlook on her future as being coloured by fears of recurrence and a lack of confidence in herself:

I think I've lost a bit of my confidence I used to have. I used to be able to have lots of people, and cook for lots of people, and always be an organiser, like "We'll go here and do that". Whereas now I don't want to really be with a lot of people. ...I've become more of a watcher than a participator, and I'm happy doing that. I'm not

really keen on meeting new people, whereas before I used to be always meeting new people. (10, p. 1)

Clearly, this change in feelings and outlook had also had an impact on her relationships. On the other hand, there were several women whose experience with breast cancer had not caused a noticeable change in outlook either at the time of the initial or the follow-up interview. Typically, these women had very good prognoses and they perceived the threat from breast cancer to be very small. In addition, they were often older women who felt that some changes in outlook could be attributed as much to the ageing process and other experiences of adversity as to breast cancer.

Setting new priorities

For many of the women, their experience with breast cancer and reconsideration of their beliefs also prompted them to consider where they themselves fitted in the scheme of what was important in their lives. As a result of this process, they often decided to place higher priority on themselves and their own needs. In other words, many of them spoke of increasing their own levels of self-care. For example, one woman who had three adult children, said:

I think I need to look after myself better. I think I have neglected myself all my life because I was ..nobody every nurtured me when I was young, and I had my first child when I was nineteen. So from eighteen on, when I was married, I was always doing things for other people. (04, p. 9)

As a result she had put into place a number of new ways of caring for herself better, which included exercise and social contacts and resigning from a stressful job.

For another younger woman, self-care was apparent in planning to have more relaxation with family on weekends by buying an on-site van in a good location:

I am very busy, and that probably isn't going to change, so what I'm trying to do is find a counter balance to it. I'm quite happy to run around and go full-pelt for the week days but we need to have that counter balance of being able to get away and

do some reading and relaxing and (have) some time together on the weekends. (11, p. 7)

Similarly, another woman showed an increased level of self-care by reducing the level of work-involvement:

It's probably become more of an issue, but I'm not sure whether I'd put that down to breast cancer or not, or whether I'd put that down more to my age and the fact that I have been a busy person and achieved enough .. like I feel that I don't have to prove myself anymore. (08, p.1)

For one woman, making time to attend two support groups was an important way in which she cared for herself:

It's good to mix with other people that have had a similar ..people that understand. I suppose, in a way, that is finding time for myself because that is doing something that I want to do so I am finding a couple of hours for myself twice a month. (17, p. 8)

This comment also demonstrates that increased levels of self-care may also be serving the need to maintain a sense of control, especially in terms of increasing their chances of physical recovery from breast cancer in the long term. This issue will be addressed directly in the next section of this chapter.

Identifying benefits in terms of relationships

It was apparent that a change in outlook often went hand in hand with changes in relationships, as could be seen in some of the women's statements in the section on *Considering outlook*. In addition, there were some very clear statements about changes in relationships with family members and friends in the follow-up interviews, which can be seen in the following comments:

My two sisters tell me that it's made a difference to them. The fact that I've been able to go through it with them in a way, share a lot of that with them, and I

think I've probably found that with other people too, with friends. And I've been quite happy to talk about the way that I've been feeling and share things and let them share in it. And I think that's been quite enriching for them in a way...I now feel that I'm probably much better at talking to people about things or letting them know about how I feel about things than I would have been beforehand. (11, p. 13)

I think you grow stronger and you do, I think you gain a lot of very close friends and true friends out of it as well. You gain through that. ... And I think I feel closer to my family through it as well. (16, p. 22)

A number of women also made specific reference to improvements in their relationship with their partner:

There's been a lot of women at (support group) who, through their breast cancer, have had a separation or split up in their marriages... whereas I think in our case it's gone the opposite (way). (16, p.26)

Not all the women commented on changes in their relationships in the follow-up interviews, but the statements of those who did were consistent with those made in the initial interview.

Reaching out to others

As mentioned earlier, the number of women who had given support to other people who faced a similar sort of adverse experience, sometimes relative strangers, was quite marked. For example, as already described in the section relating to beliefs, one woman spoke of "feeling guided" to talking with different people facing difficulties. Others spoke of their gratitude for the support they themselves had received and their urge to share what they had learned from it, as can be seen in the following:

Last week I was told that a friend of a friend of mine, who I'd met socially a couple of times, had just been diagnosed with lymphoma. I was really amazed at my response, because I'd only met him at a few dinner parties and things, and I said to

her that I wanted his name and number and asked her to ring him and tell him I'd be ringing him and that I'd had breast cancer. And I rang him ... and we met at a hotel and I sat down and said, "You have to find people like me, because I had to find people." And I was amazed at how clear I was... We sat for two hours in that hotel, and he said to me, "I haven't laughed before!" And I said, "No, because when you face a life-threatening illness you go through the dark night of the soul; you go through the valley of the shadow of death, and you come out the other side and you can laugh. ...I find that I seek out people who've had that experience. (01, p. 2)

When I do hear about it (someone with life threatening illness) I have to make that connection, because people made that connection to me and I valued it enormously and I understand now what they offered me. (01, p. 2)

Another woman who had received good support from others in similar positions, also spoke of the willingness to help others where she could:

I've received a lot of support from people I didn't really know that well, and that's wonderful, that sort of comradeship or people wanting to help has made a big difference. So I'm sure that I would, given a role reversal, be willing to do that too. (11, p. 14)

For others, there was an acknowledgment that reaching out to give support was of mutual benefit. For example, one woman spoke of helping a friend who had been diagnosed with ovarian cancer:

I've been as supportive of her as I can be because I could see she was going through all the shock that I went through after my diagnosis, and I think it's actually been quite good for both of us. (19, p.2)

Similarly another woman spoke of a small informal support network she had organised:

I developed a network of two other women who had had breast cancer...I provided support to them and it was sort of a mutual thing, and I think that was a good thing to do. (04, p. 5)

The type of outreach provided varied widely. For example, one woman's sharing with others came through attending a cancer support group and volunteer driving of cancer patients to treatment for radiotherapy:

I go to the (local) cancer support group That's more or less out of interest's sake and not because I feel the need. I do volunteer driving; drive patients to (hospital) for radiation which I quite enjoy doing. (13, p. 1)

I do like helping others by listening to what they say, and taking people to (hospital) and hearing their stories. Some of them are having a difficult road. (13, p. 3)

Whilst some elements of reaching out were present for one or two of the women in the initial interviews it was much more widely described at the time of follow-up. It seemed to mark a significant movement in emotional and social well-being for many of the women which shall be discussed further in the next chapter.

Summary: Meaning issues at follow-up

Taken together, these findings in relation to the various ways of making sense and meaning of their experiences show that a majority of the women in the follow-up interviews described feelings, thoughts and actions associated strongly with this theme. More specifically, they demonstrated ongoing efforts to continue to make sense of their experience through describing their beliefs and thoughts about the purpose of their breast cancer, confronting existential issues, and pursuing questions about "why me" and the possible cause of their cancer. In addition, efforts to make meaning could be seen in cognitions and behaviours such as considering their outlook on life, setting new priorities for themselves, identifying benefits in relationships with others, and reaching out to others in similar situations. Efforts to make sense and meaning were clearest amongst those women who had experienced further cancer-

related problems or problems which could have an impact on their prognosis. Despite the continuation of ongoing uncertainty about their prognosis, many of the women had maintained a strong sense of meaning which was largely positive. On the other hand, several women with marked continuing physical difficulties reflected thoughts and feelings which indicated that their sense of meaning, on balance, was more negative than positive.

Gaining and Retaining control

Issues in relation to control were still quite strong in the follow-up interviews for the majority of women. As with meaning-making efforts, control-related issues and activities were most salient for women who had experienced additional problems related to their breast cancer. In order to describe the findings in relation to the theme of control in follow-up interviews the same areas of control will again be used: namely medical, emotions/physical symptoms and physical recovery. Control in the area of relationships is not described as it did not emerge clearly in the follow-up interviews.

Control in relation to the medical area

As would be expected, issues in relation to the medical area did not emerge as strongly in the follow-up interviews. However, it must be recalled that three women did not participate in the follow-up interviews, one of whom had had a recurrence, another had major heart surgery during the follow up period, and the third had other chronic health problems. Of the sixteen women who took part in the follow-up interviews, most had finished the active treatment stage and were usually having three to six monthly checkups with their specialists (surgeon, oncologist, radiologist). For them breast cancer was mostly “in the past”, apart from their checkups. However, as was described earlier in the chapter, about seven women had encountered further physical health problems that were either cancer-related or were a result of their treatment for breast cancer, or which had implications for their breast cancer. These included another breast lump, lymphodaema, symptoms relating to fast-onset menopause (menopausal symptoms triggered by chemotherapy) and an unplanned pregnancy.

Whilst all the women were asked to comment on their physical progress and the course of treatment since the initial interview, the women for whom breast cancer was largely “in the past” usually only spoke briefly about it, but appeared happy on the whole with the course of their recovery and ongoing contact with their specialists.

Some typical comments from the women for whom breast cancer was largely “in the past” included:

I had a mammogram the other day and the radiologist said it was absolutely fine. ...The mammogram is a nuisance rather than anything else. I don't worry about it and I feel fine. (03, p. 1)

I still have that optimistic attitude that I'm doing everything that's possible, and feel very well. ...Everything is fine, and I feel very confident in my doctors' ability, both the surgeon and the gynaecologist. So I feel very at ease with all that. (08, p. 1)

On the other hand, the seven women with additional or ongoing health problems spoke about their further contact with the health professionals caring for them, and issues in relation to control were again apparent. The styles relating to control in the medical area which were identified in the initial interviews still held true for the follow-up interviews, and hence will be used to help describe the findings in this section. Those with additional problems came from the categories described as *active partners*, *having confidence in doctors* and *going along with doctors* and will be considered in that order.

Active partners

As was described in the previous chapter, the women who fitted into the category of wanting to be active partners retained a high degree of control in the medical area by reading, asking questions and actively contributing to decisions about their own treatment. As it may be recalled, some of the women in this group had been happy, on the whole, with the care they had received whereas several had cause for

complaint. Within the former group, four had further problems. For example, one woman had ongoing physical reminders of the breast cancer because she had developed lymphoedema, which she described as “not bad” (04, p. 1), and oedema which was a result of the chemotherapy and other problems:

*I had surgery on my leg to remove a vein that had been caused by the damage from the thrombosis. I mean it's all these things that keep coming, that keep cropping up. I had very good medical attention and I liked the people I had, and they liked me – you sort of work out how to like people you deal with – but everyone concentrates on their own little area and nobody wants to look outside that, so I think that's a bit frustrating. But even though I think I was well looked after, **it's just one thing after another**, and it's caused by what they've done (half-laughing). I haven't had symptoms of cancer, just side effects of what they've done to me. (04, p. 2)*

As in the initial interview she affirmed her style of retaining control which included asking questions and making her own decision on the basis of information provided:

I felt as if I've had a say. I go in with sheets of questions and ask questions, and I really have had a good response from all of the people with whom I've dealt, and I think that has been a very positive thing. And I know of a lot of people who haven't. (04, p.5)

The same active style was also shown by the woman who had faced the difficult decision of whether or not to terminate an unplanned pregnancy. She had been advised that being pregnant could increase the chances of a recurrence of breast cancer. She again asserted her right to make choices in relation to treatment. If anything, she had become more assertive in this area:

I've got like that with doctors now; I'll tell them what I want. I'm paying for this service, so we'll do it my way or we don't do it at all. When I went in for the partial mastectomy I was really timid, but I've really come of age. I think, well it's my body and I have a right to say what happens with it. (17, p. 14)

As mentioned earlier, several of the women in this *active partners* group revealed that they were not satisfied with the medical care they had received in the time since the initial interview. For example, one woman who developed lymphodaema was very unhappy with the medical care that she received, which heightened her sense of being out of control as can be seen in the following:

It got to the stage where I no longer had any confidence or trust in the doctors at the (hospital), and that in itself was not helping me... It got to the stage where the pain was quite bad and my mobility was decreasing. (07, p.2)

As in the initial interview, this woman regained control in the medical area by asking questions of her surgeon and oncologist. As she found their responses inadequate, she then sought information through reading and finally took the difficult step of transferring to another hospital.

Having confidence in the doctors

There was only one woman from the group of women characterised in the initial interview as keeping a sense of control in the medical area by having confidence in their doctors who had new health concerns. These concerns revolved around having developed early-onset menopause as a result of her treatment. As she was experiencing a number of uncomfortable symptoms and feeling some uncertainty about it all, it was not surprising that she re-visited, albeit fairly briefly, the issue of her relationship with her doctors. Again, having confidence and faith in her doctors came through quite clearly and helped her cope with her anxieties about new health concerns:

We may think we are informed as much as we want and speak to as many people as we want, but the specialists, they're dealing with it all the time, so I do take their knowledge and experience to mean quite a lot. (09, p. 2)

As (husband) said, we have put a lot of faith in the doctors that are dealing with me in the sense that at the moment I have checkups once every three months, so

maybe I store them (worries) all up and write a list and go to them and say, "Look here's what's happened over the three months". (09, p. 4)

Going along with the doctors

One of the two women who had been described in the initial interviews as *going along with the doctors* was still experiencing some uncomfortable and somewhat troubling symptoms which may have been related to treatment. As in the initial interview, one woman tended to avoid asking questions, preferring to leave the initiative up to the doctors:

I'm not an asker of questions and I go to doctors and I take a lot on trust. (10, p. 10)

When I went back in (month) – the last appointment for that year with (surgeon) – and he'd organised blood tests because I'd had a sore back and bruising, and (husband) came along with me because he says I don't ask enough questions or tell him enough. I like to just go there, get it over with, and come home. But (husband) told him I'd been having a lot of back pain and getting these bruises so (surgeon) had organised the blood tests and said he's sent copies to (oncologist) who I was seeing a few days later. After I saw (oncologist) I came home and (husband) asked how I went and the results of the blood tests. I said, "He never mentioned it and I never asked." (Husband) said, "Well why didn't you ask?" And I said, "Well if there was anything wrong he would have told me. Let's just push on again and forget about it. I'll see him again (six months time)." So I get like that every so often; it's another one of these factors with me..put it right out of my mind, and whatever it is it's just going to go away. And we just hope that's the case. (10, p. 8)

However, she clearly felt some concern herself about the symptoms:

You feel like you're always looking for something (like lumps). ...I come up with all these rashes on my arms with the heat, and I've been getting these rashes on my body ... and I still get the bruises that just pop up every so often. And I start to get a bit concerned about them and wonder why I'm still getting them when it's been a

couple of months since I finished the treatment. I thought this again might be the Tamoxifen. I don't know. (10, p. 3)

While this particular woman was feeling more in control of her life now that active treatment was finished, she indicated that symptoms such as bruising, back pain and rashes were causing her some concern. However, she did not actively seek to discuss these with her specialists, preferring to leave her surgeon and oncologist to broach any concerns with her. The consequences of her approach, in terms of underlying worry, will be considered further in the next section relating to control of emotions.

Overall, the women who had experienced further health problems, which had resulted from their breast cancer or which had the potential to affect their recovery, showed that the issues in relation to control in the medical area were still quite salient for them. Their style of trying to regain and retain control was consistent with their preferences displayed in the initial interviews. Some of them asserted the right to be active in making decisions about treatment, and most found it valuable to ask questions of their specialists and seek information from other sources. Moreover, two of them reported that they had become more confident in asserting their right to be active partners.

Control in the area of physical recovery

It was clear that most of the women had maintained quite a high level of commitment to increased levels of self-care – as was seen in the section on making meaning – and were thus active in promoting their chances of physical recovery. Analysis of the follow-up interviews showed that fifteen of the women had continued to act on changes in diet and lifestyle, exercise and holding a positive attitude which Thompson et al. (1993) identified as the most common strategies for exerting control in the area of physical recovery. Some of them indicated that they had not necessarily continued implementing these actions to the same level as was reported in the initial interviews.

In terms of *diet and lifestyle*, some typical comments were:

I'm eating a lot more vegetables in my diet and bread and trying to keep away from too much meat and chicken. (16, p. 9)

I've always thought you are what you eat, and I feel that I've never really eaten the wrong food. But I'm still conscious of the fact that if I don't go through my regime of what I should be eating.. I might not be here, or I might not be as well. (05, p. 7)

Another woman asserted that her “diet has changed for ever” (19, p. 5) to being basically vegetarian with a little fish, free-range eggs and high in soy products. A similar approach can also be seen to be similar in the following:

I'm not very good at keeping up to doing meditation on a daily basis, but I do that every now and then, and I was changing my diet as well to a more vegetarian sort of diet, and that's still going. So there have been some changes; they are not major sort of changes, but I'll keep trying. (12, p. 5)

This last woman also spoke about her reasons for doing meditation which demonstrates the benefits she believes it to have for her physical well-being:

It helps me to slow down and to take stock of what's going on. I think it's got benefits both for my physical health, mental health, emotional health, and I do try and meditate at work as well. (12, p. 5)

A number of women spoke about *forms of exercise* which they had implemented, some since the time of the initial interview. For example:

(Golf is) two days a week now so that's fairly strenuous for me at the moment, and then I walk, I try to walk other days, so then I'm doing something at least five days a week. (18, p. 2)

Several others mentioned they had started going for walks when they could. Two of the women with young children found it difficult to get as much time as they would like to exercise but were fitting in what they could manage:

I've been trying to walk to keep fit and exercise, just basically get outside as well. (09, p. 13)

In addition, two of the women mentioned that they were doing specific sorts of exercises that had been recommended by medical personnel for coping with cancer-related physical limitations. For example, one woman was attending a lymphodaema clinic where staff suggested an exercise program to help manage her lymphodaema:

I've got a basic set of exercises that allow me to keep the lymphodaema under control and allow me to work out the things that are exacerbating it apart from the bra and the keyboarding. (07, p. 2)

Similarly, another of the women had been given exercises to help counteract back problems that had resulted from oedema:

I have kept up doing the back exercises that the physio gave me. Anyway it works and I think I've made some positive changes. (04, p. 9)

Her comment also highlights the role of *having a positive attitude*, the third type of strategy associated with control in the area of physical recovery. Whilst only a few women made unsolicited comments about the importance of being positive, it was also implicit for most of them except the three with ongoing physical concerns. This could be seen in statements reported in the section on making meaning, particularly comments relating to perceived benefits in terms of outlook. For example, the woman coping with an unplanned pregnancy came to view it as a “gift” and said:

Maybe this is a turning point in my life where this is the good starting to happen or something. Maybe I'm just trying to look at it over-positively, but I think it's better to have a positive attitude than a negative. (17, p. 5)

The same emphasis on a positive approach is clear in the following:

I think I'm going to be protective of myself forever, in a way. I'm going to try and keep all the positives of the change of attitude and the positives of looking at things differently and take that with me, and leave behind all the negative stuff that might have been around before I was diagnosed. (19, p. 21)

Other comments in relation to adopting a positive attitude which have not already been reported in other sections include those from one woman, a practising psychologist, who described her optimism and philosophy about the importance of maintaining it:

I still have that very optimistic attitude that I'm doing everything that's possible, and feel very well and confident. No, confident is not the right word. Yes, optimistic. Confident sort of is implying that it's really got something to do with me, whereas I don't think that's the case. We are not all-powerful. (08, p. 1)

Having a positive approach seemed to be particularly helpful for some women as a way of coping with uncertainty about the possibility of a recurrence, as can be seen in the following:

So I wouldn't want to choose to have it (breast cancer), but it's had some very positive things for me personally. And, the thing is I could get another cancer tomorrow. Actually I met a woman who is very similar to me – very small cancer, no treatment, just lumpectomy. She was fine and then ten years later she found another cancer. She said when she got that second cancer she thought that was it. But then she thought, "Well, just go through the same thing" because again it was little, and so she then thought, "Oh well, I've got another ten." And I thought, well what is the worst scenario? The worst scenario is that I'll get another cancer, and you're not going to live forever anyway. (01, p. 5)

Clearly, then, maintaining a positive attitude was important for many of the women in the follow-up interviews. It appeared to help the women to create a sense of meaning and control, both in terms of coping with anxiety (control of emotions) and enhancing their chances of physical recovery through keeping themselves relatively stress-free. It was certainly true that many of the women, who believed that

stress might have been implicated in the development of their breast cancer, were active in adopting a positive approach and various other strategies to enhance their physical recovery and reduce the likelihood of a recurrence. This picture is strengthened if the use of an alternative health practitioner is included as a strategy to promote physical recovery which, as was seen in Chapter 5, it obviously was.

It was also notable that the three women with ongoing physical concerns and associated distress –further described in the next section - made little or no mention of efforts in relation to the area of physical recovery. The two with quite marked physical restriction were receiving treatment which included some physical exercises, but made no mention of other activities. This is probably not surprising as most of their energies would have been taken up with those regimes, and the researcher had not specifically asked them about their activities in this area. It was certainly true that both of them had specified efforts to enhance physical recovery in the initial interview. However, this was not the case for one woman (10) either in the initial or follow-up interview who did not appear to be making particular efforts in this area.

Control of emotions and physical symptoms

At the time of the follow-up interviews, most of the sixteen women reported less emotional distress relating to their breast cancer. In other words, their general sense of feeling more in control of their lives was also reflected in the area of emotions. About half of the sixteen women described having at least some periods where they were anxious or worried about their breast cancer. This was especially true at the time when they were due to have a checkup with one of their specialists, or when other problems related to the breast cancer became apparent. However, three of the women appeared to be struggling with a strong, fairly pervasive sense of loss of emotional control. The findings in relation to emotional control will be presented first by examining a sample of the experiences and coping reactions of those with emotional distress of a more short term nature - either focused round medical checkups or the emergence of further physical problems - as opposed to the three women for whom control of emotions was a more enduring challenge.

Emotional concerns of a short term nature

As was seen in the section relating to control in the medical area, a number of the women were feeling really well and did not report feeling anxious even at the time of medical checkups. However, the following comments reveal that, for others, a complex array of emotions sometimes surfaced quite strongly at the time of a scheduled checkup:

I have great confidence in my surgeon and my doctor and ... I did get upset when I saw him because, you know, he checked me out and I was fine. I asked him, "When are you never going to want to see me?" And he said, "I'm never going to not want to see you." And I knew that, but when he said it I got very upset. And I said, "It's sort of like I want to walk away from it, but you remind me I can't walk away from it." And he said, "Yes, that's right, but you're right to walk away from it. Forget about it. Ignore me until the day you come." I think in many ways it's (breast cancer) sort of a low-level hum in my life. (01, p. 6)

I'll have symptoms of ill health and I'll go into panic mode from time to time about "Oh metastases already!" But I know that that's what I'm doing and I can usually turn that off. I notice that as the next appointment approaches I become a little bit more anxious about it, and then I'm away again. (07, p. 7)

There is a clear sense that some of the women had to gear themselves up emotionally in case they had to face more unfavourable news about their breast cancer. However, those feelings tended not to linger once they knew that their specialist was satisfied with their progress.

In general it seemed that issues in relation to control of emotions and physical symptoms were, as in relation to the medical area, strongest for those women who had experienced further cancer-related problems. Perhaps the exception was the woman whose severe shock at diagnosis appeared to have continuing repercussions, although to a much lesser extent. She articulated clearly the issues in relation to control (including in the area of emotions) at diagnosis and over time:

I felt it between the days when I was diagnosed and when I went into hospital; that was the greatest amount of time when I felt that I wasn't in control. The way I gained control I think was through information. ... I made up my mind that I wasn't going to let it get out of control, and I made up my mind fairly soon because I felt that what was going on was just a waste of time, and I didn't want to waste energy crying about it, and I think after that I decided, that's it. And that's when I started taking the control back, and I think that keeping the diet, keeping the meditation, still seeing my Chinese therapist is all part of keeping control of what's going on. (19, p. 7)

It is worth noting that this woman also thought stress may have been part of the reason she developed breast cancer as she was going through a very stressful time when she developed breast cancer. Not surprisingly, she consciously adopted a number of strategies that would protect her from further emotional upheaval. For instance she limited her attendance at support groups to information-based sessions:

I will select the times I want to go because of the information I want. ...I'm a great believer in support groups, so I find it interesting for me to say that I'm not too sure how involved I want to be with a support group. So I'm very picky about what I do with it and what I get out of it, and I'm sure it's a form of protection... from stress because it's really quite uncomfortable. There's been a few times.. like there was the evening we all turned up there looking forward to our activity and we learned that a member who'd been there a month before, and who was perfectly fine, had died. And to hear about it so suddenly was quite difficult for me. (19, p. 1-2)

Likewise she actively avoided telling some people about her breast cancer and, if she did, was careful not to put herself in the position of being a victim. (p. 8)

I hate seeing the pity and the fear in people's eyes, and so by not telling them I'm keeping the control. (19, p.7)

However, it was clear that regaining control over thoughts and associated feelings took time and energy:

I feel as though the inner healing is progressing; it's getting easier as time goes on. I know there was a time way back when I wondered if I would ever get through a day without thinking about it, but most of the time I don't think about it, and that's good because when you're thinking and worrying about something that's tremendously tiring, draining. (19, p. 5)

Another younger woman described how she had sought professional help to deal with the welter of feelings which she needed to express and sort out. She had found it difficult to do this as she felt protective of her husband and young children:

So there was never a right time to let go, but I have now...And if I want to cry, I cry. I don't care. I pick my moments. I might read a book that's a bit sad or something, just to sort of get it out. I think letting it out bit by bit is better than letting it build up, which is what I did. (17, p. 4)

For all four of these women, concerns about their situation involved an emotional burden that required much cognitive processing. An important part of their way of coping with this was to seek professional help.

Emotional upheaval of a more ongoing nature

As mentioned earlier three of the women with additional medical problems appeared to be grappling with feelings of being out of control at the time of the follow-up interview. Two of them appraised their prognosis (in terms of their breast cancer) as being quite good but their additional problems appeared to be such that there were real quality of life issues, and a concern that these problems would never get better. The third woman knew that her prognosis was not as favourable and this, along with physical symptoms, appeared to be troubling her quite deeply. When these women employed their usual coping strategies to regain emotional control, they did not appear to be sufficient to manage their distress.

The issues in relation to retaining emotional control and managing physical symptoms were very strong for one of the younger women. The lymphodaema she had developed was extremely disabling and she had become very depressed. As a result she sought psychological help and had begun taking antidepressants several

weeks prior to the follow up interview. The extent of her distress is clear in the following:

The lymphodaema for me meant that I felt distorted and mutilated. There was a physical sensation that my body was distorted and mutilated. I was doing okay with my body having been mutilated and I can live with myself not having a breast, but to feel it all the time was the thing that really made me feel terribly depressed, and I didn't want to live feeling like that all the time. (07, p. 5)

She did not receive satisfactory help from the hospital where she had been treated, and in essence “felt abandoned” by them:

The breast clinic didn't seem to be too worried when I told them that suicide had become a positive option for me. (07, p. 2)

She described how her usual coping strategies, such as those of cognitive therapy which she had spoken of using at the time of the initial interview, were not sufficient to manage her feelings of depression:

*I very consciously applied all those techniques when I got lymphodaema and when I started to become very depressed. And while those techniques were useful to some extent to control the excesses of underlying depression at times, they did nothing to influence what I felt to be the underlying river of depression. And I felt that I was having to use **so much** of my thinking time just exercising these skills, that that was all I had time to do. ... That was about the time that I realised that I needed antidepressants. (07, p. 11)*

In addition, the thought of suicide had become a positive option:

The way that I dealt with it (lymphodaema) was to think of suicide very positively. So I was exerting control, (wry laugh) not in a helpful or positive way, but the way I could exert control on my life was to make a decision about whether I wished to live or not. So I guess the way I resolved how I need to feel I've got control of my life is to decide to control dying. (07, p. 11)

As well as seeking professional help, talking with friends was also very important, particularly as she did not have a partner:

I could still talk about it at the time, and I realised that one of the things I needed to do was to talk with my friends about how I was feeling, and I'm lucky that I have got a couple of friends who I could talk about those feelings with. (07, p. 6)

Clearly, this woman had used a number of strategies to deal with the depth of depression she felt as a result of the disabling effects of lymphodaema.

Another younger woman also had experienced a range of additional problems which she found very difficult to manage. She was struggling with fatigue and some nausea, even though she had finished chemotherapy about five months prior to the follow-up interview, as well as hot flushes. In addition, she was dealing with a hip problem that had developed during the course of treatment for breast cancer, and work-related concerns. She spoke of a general feeling of things being out of control, and a sense that her usual ways of coping were not working well enough:

At work generally I'm out of control. I really don't know what's happening with my health...my breast is sore, my hip is sore, my arm is sore, my shoulder's sore and there doesn't seem to be any end to that. So that is out of my control ...I've always been able to pull it (worries) off the shelf, pull it apart and put it together again and somehow get a handle on an issue and work out how to deal with it. This time I take things down off the shelf and it doesn't matter which way I look at it. It's like there is just no future and no way of getting a handle on it. (06, p. 16)

The third woman in this group with ongoing difficulties had probably the poorest prognosis of the women in the follow-up group. As was seen in the section on control in the medical area, she expressed an ongoing concern about the possibility of a recurrence. In addition, she described other troubling indicators of anxiety:

I got up this morning like that (shaky), and it eases off after an hour but I often wonder if that's like a type of fear or something about what might happen because

you don't know what your subconscious is thinking about do you? But I don't go round with it on my mind the whole time. (10, p. 4)

In fact, her main way of coping with this was to keep busy, consciously blocking out unwanted thoughts:

I'm pretty good, if I really don't want to think about something, at just putting it right out (of mind) and usually you keep your mind active and do other things. (10, p. 5)

It was clear for all three women, who were experiencing physical distress of an ongoing nature, the emotional cost was high. They had used a range of coping strategies to help retain control of their situation and the ensuing emotions, and had found that previously successful strategies were no longer sufficient. For one of the women, this included a reliance on strategies related to denial and avoidance. In addition, it seemed that they were unable, at least at the time of the interview, to make positive meaning out of their experience with breast cancer.

Summary: Control issues at follow-up

As was seen with levels of sense/ meaning making earlier in this chapter, the reports of the women in the follow-up interviews showed that issues in relation to control remained important. Whilst the majority of the women had not had further cancer-related problems, seven had experienced additional concerns. For them, issues in relation to control in the area of medical treatment were quite strong. They continued to engage in strategies that would enable them to retain the level of control which they desired. As in the initial interviews these strategies included asking questions of their specialists, reading, asserting their right to make choices, and having faith in their doctors. In addition, two reported having become more assertive in this area.

In the area of physical recovery, most still placed a high priority on increased levels of self-care and were doing what they could to improve their chances of physical recovery. Their main ways of doing this were by diet and lifestyle choices,

exercise, and maintaining a positive attitude in an effort to keep themselves relatively stress-free.

In terms of control over emotions, over half of the women described having periods over the preceding eight months where they were anxious or worried about their breast cancer. For six of the women these were relatively short-term concerns, such as the detection of another breast lump, which proved to be benign, or anxiety at the time of scheduled medical checkups. They used a wide range of coping strategies to manage these emotions including belief in God, faith in their doctor, seeking support, expressing their feelings, seeking professional help, downward comparison, being positive and acceptance. However, for three of the women emotional distress seemed to be more ongoing. Two of these women were feeling somewhat out of control because of marked, ongoing decrements in their physical abilities. Both had used a wide range of coping strategies both at the time of initial diagnosis and when their additional physical problems developed, but reported that they were no longer sufficient to manage their feelings. The third woman was shadowed by fears about her prognosis, as well as ongoing physical discomfort, as her long delay in seeking treatment meant that her breast cancer was quite advanced at diagnosis. Her main coping strategies, which included keeping busy and avoidance of thinking about her breast cancer, did not prevent her underlying fears from intruding into her conscious thoughts and general enjoyment of life.

Acceptance and avoidance/denial at the time of follow-up

It may be recalled that issues in relation to the strategies of acceptance and denial/ avoidance were central to the development of this study and that findings from the initial interviews showed that acceptance was widely used by, and appeared to be helpful for, the majority of women in the study. Given the importance of these issues, this section presents findings in relation to these strategies which emerged from analysis of the follow-up interviews.

Analysis revealed that changes over time in the situation of the women, which were outlined earlier in this chapter, were also reflected in some variation in the use of acceptance and denial/ avoidance behaviours. It became clear that the framework,

which was used to describe these coping strategies in the initial interviews, needed modification in order to describe how they unfolded in the follow-up interviews. Hence, this section presents a modified framework for consideration of these strategies, along with examples from the women's comments. The framework includes revised targets of acceptance and denial/ avoidance, recognition of changes in levels of acceptance over time, the mechanisms underlying acceptance, and other coping strategies that appear to be widely used along with acceptance. Finally, an alternative framework for examining some aspects of this data is considered.

As in the initial interviews, there was evidence that acceptance was being used much more widely than denial strategies/ avoidance, a matter which shall be discussed further in the next chapter. Indeed, examples of avoidance and suppression of feelings were described in the section on control in the emotional area. Denial is not described because there was no evidence that denial of emotions was being used by the women. Hence, in the following outline and presentation of data, direct reference is usually made to acceptance only.

Targets of acceptance and avoidance/denial

In the Chapter 5, which presented findings from the initial interviews, coping strategies identified as comprising acceptance and denial/ avoidance were described in terms of four targets, namely pre-diagnosis symptoms, the actual diagnosis, the life threat entailed in the diagnosis and the emotional reaction to it. However, in the follow-up interviews it was clear that, with the passage of time and the occurrence of new cancer-related demands for some of the women, some of these targets were no longer as relevant. In addition, other factors, relating to the observation of change over time, or process aspects, had emerged.

More specifically, three main changes relating to targets of acceptance and denial/ avoidance were observed. Firstly, the women appeared to have long passed the point of coming to terms with pre-diagnosis symptoms of breast cancer and only one woman alluded further to this. The same was largely true in relation to the second target of response to the diagnosis of breast cancer, with only a few women referring to the time of their initial diagnosis. However, because a number of women

had experienced additional cancer-related problems, they spoke of coming to terms with these new experiences of threat, harm or loss (that is, with new and pertinent facets of their situation in relation to breast cancer). For them, the coping strategies of acceptance and, to a much lesser extent, avoidance were in evidence. Thirdly, there was a similar change in focus from the breast cancer itself to further cancer-related problems when the targets of emotional reactions and implications in terms of life threat were explored. Consequently, the targets of acceptance and avoidance in the follow-up interviews include the diagnosis of a new problem (for example, another breast lump, lymphodaema, early-onset menopause), emotional reactions to it and response to the implications of the more recent problem (and the initial diagnosis).

The following examples illustrate how some of the women had to come to terms with a new problem (or target), their emotional reactions to it and its implications. For instance, one of the younger women in her thirties struggled with acceptance of early-onset menopause over a period of time, until she read a brochure at the doctor's about a checklist of symptoms associated with the menopause and she had nineteen of the twenty symptoms:

So from that day I just said that it's no good fighting it and trying to ignore it, which is probably what I was doing. ...So as I said, I've accepted it now, and I'm not happy about it, but what can you do? I mean, if you're just going to get bitter and angry and upset about it what good is that going to do anybody. It won't do anybody good in this house so you just get on with it..do it..cope with it. ...The bottom line is the same as when I was diagnosed with cancer. What can you do about it? You've got two choices: cope with it or fall in a heap, so I cope with it. (09, p. 9)

It shows that the focus of her adjustment was no longer primarily on the breast cancer itself, but the new demand of early-onset menopause. In addition it conveys some of her emotional response to it, which included a period of apparent avoidance.

In terms of response to the implications of a new demand, the following shows how pain and physical restriction associated with lymphodaema had influenced the way in which another woman in her thirties, thought now about the possibility of her own mortality:

*Once the lymphodaema came up I was hoping that I would get far worse cancer so that I could die far more quickly, so the issue of my mortality was something to be desired rather than something to be feared. One of the things that made me feel so depressed was that I wouldn't die in a hurry. (wry laugh) ...I don't mind so much. You **can** die at any time. It may not necessarily be breast cancer. I might die in the next week or so; I'm not terribly fussed about that...It was more of an issue a few months back when I was coming to the realisation that I can no longer necessarily live to the ripe old age that women in my family normally do. And having got to that point, it doesn't seem to matter. (07, p. 9-10)*

Hence for those women in the study who faced additional cancer-related demands, the process of acceptance was clear, although the focus was no longer on the breast cancer as such. On the other hand, the women in the study who had not experienced further cancer-related problems had moved further away from the breast cancer experience, and made few verbal statements of acceptance. However, they were complying with follow-up treatments and continuing to implement a range of lifestyle changes which demonstrated at least an acceptance of the reality of their breast cancer. Some actually felt it was important for them to keep it fairly close to the forefront of their awareness because it helped remind them of the importance of changes they had made in their lives.

Changes in acceptance over time

The second aspect of the framework relates to changes in the use of acceptance and avoidance over time. It is already clear that there was a change in the targets or objects of acceptance and avoidance over time. In addition, the analysis revealed that a number of the women, especially those who had experienced additional cancer-related problems, reported increased levels of acceptance. It appeared that their additional problems had prompted a further struggle with the various facets of their situation which moved them on to another level of acceptance. Such reports also showed that levels of acceptance may fluctuate over time, that acceptance is a dynamic process.

The comments above also demonstrate how acceptance sometimes emerged over time, and how there can be a movement to increased levels of acceptance in relation to different aspects of their situation. This can also be seen in the following:

It comes back to achievable goals and not achievable goals; they're a lot closer in now, and time is more condensed. I suppose I've gone back and thought, "Well if I died tomorrow, or this year, would I be happy and contented?" I'm not happy to die, you understand, but it would be all right. Whereas if you had told me (that I was going to die) even two years ago, I would probably have said, "No, hang on a minute. I still have lots and lots to do." Now I'm more into saying, "That's the way of things and that's all right." So at some level it has changed a lot. (06, p. 9)

Underlying tasks and emotion

A third aspect of the framework concerns the mechanisms which appear to be part of the acceptance process, that is, some of the underlying tasks and emotions. From the women's comments, both in the initial and follow-up interviews, it appeared that some of those who reported acceptance had negotiated a struggle with feelings such as fear, anger, and sadness from which they emerged with a sense of acceptance of their situation. In this way it is akin to the grieving process, which, given that many of them perceived and experienced harm or loss, is understandable. This notion of struggling with difficult feelings which leads, for many, to acceptance and, for some, perceived growth shall be considered further in the Discussion (Chapter 8).

Constellations of strategies

The final feature of the framework, which emerged from analysis, concerns the presence of constellations of coping strategies which are associated with, and perhaps facilitate, the process of acceptance. In other words, there appeared to be certain coping strategies, particularly having a positive attitude, identifying a sense of purpose in their experience with breast cancer and drawing on personal beliefs, that clustered together with the use of acceptance by the women. As a number of examples used in the sections on control and meaning included statements which

showed this clustering of strategies, only a few examples are given here to support the point.

One of the clearest statements which shows the linking of acceptance, being positive and having a sense of purpose is the following:

It's made me much stronger. I think I'm a much stronger person now than I was before it all started. I certainly wouldn't choose this way to go about making myself strong, but if I can do the best with what I have to go through too, I'm quite happy to accept that ... make the best of it, turn it into something positive... You sort of feel like you've been somewhere else that other people haven't been and got through it. You know you got through it sort of physically and mentally too and I think that makes you feel really quite powerful. (11, p. 12)

Similarly, the clustering of acceptance, being positive and beliefs is apparent when one young woman spoke of her struggle to come to terms with an unplanned pregnancy:

It was meant to be. Obviously it was a gift that was given to me and I accept that now. ...It's a gift I have been given. Maybe this is a turning point in my life where this is the good starting to happen or something. Maybe I'm just trying to look at it over-positively, but I think it's better to have a positive attitude than a negative. (17, p.5)

The presence of these clusters of coping strategies highlights the complexity of the coping process and also carries implications for future research and clinical intervention which will be considered further in the Discussion chapter.

This finding highlights the relevance of another way of viewing the data on acceptance in this study which derives from a schema postulated by Wright and Kirby (1999). Their schema describes acceptance in terms of three components, namely emotional, cognitive and behavioural, which are considered below.

Acceptance in terms of three domains: emotional, cognitive and behavioural

Wright and Kirby (1999) reported their qualitative study of ten patients and their process of adjustment to dialysis-dependent renal failure. The central theme they identified was described as adopting a new approach to being and living, of which acceptance of illness was a key component. They described acceptance as comprising emotional, behavioural and cognitive components. The emotional component was characterised by patients having primarily positive affect. Behavioural acceptance, in their study, was manifested in the patients' readiness to engage in their self-care regime. And, finally, cognitive acceptance could be seen in an absence of worry about their illness and treatment. In addition, sometimes these components would co-occur, whilst for others their acceptance might manifest in one of these only, typically in the behavioural.

Wright and Kirby (1999) suggested that their conceptualisation of the process of adjustment to this particular illness could well be applicable to other chronic illnesses. The findings in relation to acceptance in this study on women with breast cancer appear to fit quite well with their framework, especially as they emerged in the follow-up interviews. On reflection, it seemed that their framework helped to describe responses that related to *how* patients were adjusting to illness, whereas the framework described earlier related to targets of acceptance or, in other words, *what* patients were coming to terms with. Both are important facets of the process of acceptance which, together, describe (and perhaps have the potential to explain) a more complete range of responses.

Their delineation of the behavioural component was particularly useful for it helped to describe data relating to responses to treatment which did not appear to fit very well with the targets used in relation to the initial interviews. For example, one woman's acceptance came out very clearly in behavioural terms in the initial interviews, and re-emerged in the follow-up interviews as can be seen in the following:

I think I'm a strong, solid sort of person too (like husband). But I've become amazingly compliant and accommodating and adaptable. But I think I have been all

*the time because my reaction now has been consistent with my reaction throughout my whole life. And I think I am an accommodating person, at least intellectually. And I **did** accept the treatment and that sort of thing, and I accepted it in a way (that) it wasn't a problem for me... And I think I define myself in a very small, tight, strong way, but it's not dependent on very much else, so I don't need much else to make me feel contented, or not frightened. I think that maybe a lot of people have never done that, whereas I suppose I had to right from the time I was a child. (04, pp. 6-7)*

In this statement, it can be seen that there was also a strong cognitive component in her acceptance, which helped to keep her engaged with treatment despite the numerous additional health problems it resulted in. Whilst Wright and Kirby described the cognitive component as being characterised by an absence of worry, it may also be characterised by the presence of a belief system which is actively drawn on and which may help to reduce worry or anxiety.

Another interesting aspect of applying this framework relates to the way that it fits well with the finding from the follow-up interviews that most women were expressing their acceptance primarily in behavioural terms. In addition to complying with treatment regimes, the behavioural component readily encompasses the variety of self-care activities which most of the women engaged in voluntarily. In other words, most of the women had moved from an acceptance of their situation in emotional and cognitive terms to behavioural manifestations. This progression will be discussed further in the next chapter.

Finally, it is also notable that the clusters of coping strategies identified above for the women who had encountered additional cancer-related problems, seem to involve dimensions that can be described as cognitive and emotional. Hence, being positive (emotional acceptance) and having a sense of purpose or belief about their experience with breast cancer (cognitive acceptance), worked together to help produce a level of acceptance which, in turn, often became reflected in behavioural terms. Indeed, for many women, those behavioural manifestations included not only treatment and self-care activities, but also an ability to move outwards to helping other women in a similar situation. In this way, it reflects a similar movement

towards behavioural manifestations of acceptance as was described in the last point, which again shall be considered further in the next chapter.

Summary: Acceptance and denial/ avoidance

As in the initial interviews, acceptance was used much more widely than denial/ avoidance strategies. Indeed, there was no evidence, from the follow-up interviews, that denial was being used by any of the women. In addition, there were changes in the acceptance trajectory during the period of time between the initial and follow-up interviews. Women whose recovery continued without further problems tended to make few statements about acceptance as that task for them appeared to be mostly complete. Their acceptance was expressed primarily in behavioural ways, especially through continuing compliance with treatment and pursuing self-care activities. However, women who had experienced additional problems appeared to move through the acceptance process again, this time with the focus (target) being on the new cancer-related problem. This seemed to prompt further internal processing (grappling with feelings and thoughts) which appeared to result in a different level of acceptance. An interesting facet of this processing was the way in which many of these women used a cluster of strategies, especially being positive, beliefs and a sense of purpose, along with acceptance. Finally, an alternative schema for understanding acceptance proposed by Wright and Kirby (1999) was considered which describes acceptance in terms of emotional, cognitive and behavioural components. Their schema complements the framework described earlier, which considered targets of acceptance (**what** patients were coming to terms with), as it focuses on **how** patients were adjusting to illness. Both are important aspects of the acceptance process which, together, describe a more complete range of responses.

These findings in relation to the overarching themes of control and meaning, as well as the coping strategies of acceptance and denial/avoidance, are discussed in the next chapter.

Chapter 8 Discussion, Evaluation and Implications

Coping strategies

In Chapter 5 a broad range of coping strategies used most widely by study participants to manage their cancer situation were presented. These included appraisal of challenge, acceptance, denial/ avoidance, distancing, having a positive focus, focusing on the present, normalising, seeking social support, information seeking, downward social comparison, use of humour, using causal attribution, seeking alternative treatment, and employing methods of stress management. These strategies were conceptually grouped into two categories based on the functions they served: regaining control, and making sense and meaning. Rather than discussing the strategies separately, this chapter focuses on these themes of control and meaning which encompass the individual coping strategies. This choice is designed to allow discussion of the data in a more thematic, integrated manner. However, given that the need to clarify conceptualisation in relation to the coping strategies of acceptance and denial is central to the present study, further brief comment is warranted. In addition, some general observations relating to the coping strategies overall are worth noting.

In the previous chapter, the strategies of acceptance and denial were reviewed and discussed in relation to recent literature that offer new ways of conceptualising these strategies. It is also important to comment on the findings of the present study relating to these two strategies in terms of the broader research literature. In particular, the fact that acceptance was used widely by the women in the study, and was associated with efforts to make meaning and regain control, is consistent with the findings of other researchers (Astin et al., 1999; Carver et al., 1993). In terms of denial, the present study showed the need to consider denial in terms of different targets, which supports the findings of previous research (Wool & Goldberg, 1987) and the notion that the adaptiveness or otherwise of denial-like strategies is determined by the context in which it is used (Lazarus & Folkman, 1984; 1991).

Three observations relating to the coping strategies overall are worth noting. Firstly, the fact that a wide range of coping strategies were reported by the women is

consistent with the findings of other breast cancer studies (e.g., Carver et al., 1993; Clarke et al., 1993; Heim et al., 1993; Heim et al., 1997; Hilton, 1988). However, a number of strategies discussed by the women in this study are not well represented in the coping literature. For example, focusing on the present, normalising the situation, and re-ordering priorities are not represented in either of the two major coping assessment devices: the Ways of Coping (WOC; Folkman & Lazarus, 1980) or the COPE (Carver et al., 1989). On the other hand, there are some coping strategies included in these standardised instruments that were reported by very few women in the present study. This was particularly clear in the case of both denial (of breast cancer symptoms and the diagnosis) and escape/ avoidance. Undoubtedly these potentially, maladaptive strategies could be used more widely by other women with breast cancer, but the fact that the women self-selected into the study probably meant that most had to be willing to confront the reality of their illness and be prepared to talk about their experience with it.

In addition, most of these coping strategies could be described as emotion-focused because they were oriented to management of aspects of their cancer situation (that is, emotional responses) that could not be changed through direct means (Lazarus & Folkman, 1984; Folkman, 1984). However, as was described in Chapter 2, the distinction between emotion-focused and problem-focused strategies may not be clear-cut in practice. For example, in the current study some women who employed meaning-based coping processes, which by definition are emotion-focused (Folkman, 1997) used strategies such as redefining priorities which had the potential to have an effect on the cancer situation.

Finally, the findings from the follow-up interviews indicated that many of the women had continued to use these coping strategies, though perhaps not as actively unless there had been further cancer-related problems. Other longitudinal studies have also found that, over time, women report using these strategies less frequently, presumably because the situation has become less stressful as they recover physically or learn to manage their circumstances more effectively (e.g., Carver et al., 1993; Epping-Jordan et al. 1999).

Control-related issues

The study findings show that feelings of loss of control were reported by most of the women, particularly at the time of diagnosis and active treatment. Over time, most women reported having regained a sense of control over their lives. However, the development of additional cancer-related problems by a minority of the study participants meant that feelings of loss of control were again experienced. The women also described having used a variety of methods to help re-establish a feeling of control. Such findings are consistent with a range of research which indicates the importance of perceived control in relation to cancer (for example, Astin et al., 1999; Hilton, 1989; Taylor, 1983; Thompson et al., 1993). In addition, the women's descriptions of areas in their lives where they felt a loss of control and tried to regain control supported previous research, especially the findings of Thompson et al., (1993). These included control in the medical area, in terms of physical recovery, and of their emotions.

Control in the medical area

The accounts of the women indicated that they differed considerably in terms of the degree of control they wanted in relation to their medical care. The vast majority wanted to be well-informed by their specialists, have useful information to read about breast cancer and treatment, and ask questions. It is widely recognised that *seeking information* is an important coping strategy which allows the person to feel more in control of the situation as it provides one means of exerting influence on the stressful environment, or aspects of the self (Lazarus & Launier, 1978). Research has shown that it is a common strategy used by cancer patients to gain control in the medical area (Thompson et al., 1993). For women with early stage breast cancer, information is often used to help reduce uncertainties which they experience as a result of the diagnosis, and it guides decision making (Clarke et al., 1993; Hilton, 1988; Lavery 1997). Information-seeking has also been shown to predict adjustment for women with breast cancer (Lavery & Clarke, 1996). Once a woman is well-informed, she feels equipped to take some control and participate more effectively in treatment decisions. In this study, when information provided by the medical treatment team was inadequate, several women sought it through other respected

sources. For at least one woman, inadequate information from her doctors contributed to exacerbated levels of distress. In addition, some of the women sought information about breast cancer from sources outside the medical profession, for example books and magazines, as has also been found in other Australian research (Lavery & Clarke, 1996). Such information may be more understandable and less overwhelming than that supplied by their doctors. It can also be accessed and digested at the woman's own pace, enhancing a sense of control.

On the other hand, only about half the women in the study wanted to be actively involved in treatment decisions. It appears that while patients want detailed information about their illness and their treatment, far fewer report that they want to be involved in *decision making* (Auerbach, 2001; Degner et al., 1997; Thompson et al., 1993). Moreover, the stated desire to follow doctors' orders was greater in situations where the illness was more severe, where the patient was older and less well-educated (Auerbach, 2001). It is likely that having adequate information contributes to a sense of control (Auerbach, 2001), and that compliance with doctors' orders also endows a sense of control for many women (Taylor et al., 1984).

One final noteworthy finding was that, while most women reported that their desire for control in the medical area remained the same over the course of their treatment, several women indicated that they became more assertive with their medical specialists over time. Given the lack of longitudinal explorations of control in this area, this finding provides new information that suggests the need for further research.

Control and physical recovery

Most of the women were active in their efforts to improve their health and enhance their chances of recovery. This was shown in their reports of using coping strategies such as diet and lifestyle, exercise, maintaining a positive attitude and alternative health treatment. At the time of follow-up, they had continued with these efforts, although not necessarily to the same level as reported in the initial interviews. Such findings are consistent with the research of others in the area of breast cancer and cancer more generally (e.g., Hilton, 1988; Lavery & Clarke, 1996; Taylor et al.,

1984; Thompson et al., 1993). However, few studies have tracked the use of such strategies over time.

The proportion of women who reported making changes in diet and exercise (over 60%) was higher than is found in other studies. For example, Taylor et al. (1984) reported that 49% made changes in diet, while 26% made changes in exercise patterns. Lavery (1997) found that 31% made improvements in diet, and 25% reported changes in exercise patterns. However, in both studies, the mean time since diagnosis was considerably longer (2.5 and 3.8 years respectively) so the women's recollections may partly account for the difference. On the other hand, the women in the present study may be unusually active in these areas.

Similarly, eight women in this study (more than 40%) had used alternative therapies, compared to 25% of women interviewed by Lavery (1997). While some of the women indicated that using alternative therapies was an important way to exercise some control in the situation, research (Astin, 1998) indicates that there are also other reasons that patients adopt alternative medicine. In particular, it seems that the choice may be made because of the compatibility of these methods with patients' values, worldview, spiritual/ religious philosophy and their beliefs about health and illness.

For the women in this study, it appeared that changes in diet, exercise, and the use of alternative therapies contributed to a sense of having some control over the cancer situation and their chances of remaining free of a recurrence. Given that perceived control of cancer and its consequences is positively related to adjustment (Lowery et al., 1993; Taylor et al., 1984; Thompson et al., 1993) and psychosocial adaptation (Ell et al., 1989), it suggests that most women in the study had good levels of this valuable personal resource.

Along with diet, exercise and the use of alternative therapies, keeping a positive attitude was a coping strategy used by almost all the women in the current study, which seemed to be an important way that they retained a sense of control in the area of physical recovery. This was true both at the time of the initial interviews and at follow-up. Thompson et al. (1993) reported that 14.5% of their sample used this strategy to enhance control in relation to this area. However, it was also used to

enhance control in the areas of emotions/ physical symptoms (16.5%) and relationship with family (6.1%). In total, then, 37.1% reported using a positive attitude as a way of exercising control. Lavery (1997) also found that 44% of the women nominated it as an important coping strategy.

It appears that positive attitudes towards diagnosis and outcome may be especially important to women in the recovery phase after hospitalisation (Northouse, 1989). On the other hand, Lazarus (1993) described positive thinking as a relatively stable form of coping, linked with personality, which is helpful in a variety of situations. This view is supported by the finding that women in this study reported this as an important coping strategy at the follow-up interviews when they were well past the recovery phase, and is consistent with the findings of Lavery (1997).

Thompson et al. (1993) point out that there has been a tendency for popular culture and some medical practitioners to promote positive attitudes, diet, unconventional remedies and reduction of stress as ways of coping with cancer, and even controlling physical recovery. However, Dunkel-Schetter et al. (1992) found that certain factors such as age, education and religiosity were predictors of coping behaviour, including using positive attitudes. For example, if a woman is unable to feel positive about her situation, she may feel further burdened by guilt that she is “failing” to do the right thing. Like the use of alternative therapy, having a positive attitude has important links with making meaning and so will be further discussed in the section on meaning.

Control of emotions

Most of the women in the study described periods when they felt some loss of control in terms of their feelings (emotions). This was particularly the case at the time of diagnosis when their levels of uncertainty were high and their lives were disrupted with active treatment. Their accounts indicated that the majority accepted and openly expressed these, sometimes, extreme emotional responses, whilst a minority appeared to suppress the feelings to a certain extent. Whilst this expression of feelings was often shared with a partner, a close friend, or another important support person, sometimes it was important to ventilate some of these emotions alone and process the

thoughts and concerns that were associated with them. Apart from acceptance, expression and processing of emotions, and sharing feelings with a supportive other, a range of other coping strategies were used to help manage their emotions including listening to music, prayer and faith, meditation and adopting preventive measures to minimise the likelihood of further extreme distress. The follow-up interviews also revealed that a substantial minority had experienced further episodes of emotional upheaval related to their breast cancer, which appeared to be ongoing for several of the women. At the time of the follow-up interviews, most of the women reported that they had come to terms with their breast cancer, had regained a sense of control, and were actively engaged with their lives. In other words, they seemed to have adapted relatively well to their diagnosis of breast cancer and its consequences.

Such findings are consistent with previous theorising and research which highlights the importance of control in the area of emotions (e.g., Lowery et al., 1993; Thompson et al., 1993; Stanton et al., 2000). In particular, it supports the position advocated by Stanton and her colleagues (Stanton et al., 1994; Stanton, et al., 2000) that the expression and processing of emotions (emotion approach coping) is an adaptive way of coping with early stage breast cancer. Processing of emotions appears to have most value when it leads to expression of emotion, but may be counterproductive if used for a prolonged period. Whilst expressing emotions has been recognised in some qualitative studies as being an important way of coping for women with breast cancer (e.g., Hilton, 1989), most quantitative studies have not used adequate measures of emotion approach coping (Stanton et al., 2000). This has resulted in the conclusion in the empirical literature that emotion-focused coping is maladaptive. On the other hand, measures of seeking social support, which often include items such as expressing feelings, (e.g., Dunkel-Schetter et al., 1992) have been shown to be related to positive adjustment. Taken together, this study adds to a growing body of evidence about the adaptive value of expressing and processing emotions for women with early stage breast cancer. It also lends support to the assertion that perceived and enacted support enhance individual perceptions of control for many women (Ell et al., 1989).

The findings also shed some light on the issue of mechanisms which underlie the beneficial effects of emotionally expressive coping. Stanton et al. (2000) outlined

three possible mechanisms, the first of which suggests that expressive coping may aid in the clarification and pursuit of personal goals. For example, in the process of expressing a sense of loss of control, “one may begin to distinguish what one can and cannot control, to channel energy toward attainable goals, and to generate alternative pathways for bolstering control” (p. 880). As was reported in the two previous chapters, many of the women who were active in expressing and processing their emotions also showed efforts to make meaning of their situation, which included rethinking of priorities and outlook. Indeed, acceptance of emotions seemed to be associated with making meaning. In other words, it appeared that expressive coping may have been an important part of goal clarification and pursuit. In addition, as has already been discussed in the previous section on *physical recovery*, they had enhanced control through using various methods to promote physical recovery.

A second mechanism by which expressive coping may confer benefit is through habituation. According to this proposal, if repeated expression results in a diminution of the negative emotions and associated physiological arousal, the individual may conclude that the painful and difficult feelings do abate. This in turn makes it possible to conceive that the situation is not as catastrophic as was originally thought, and that some benefit can be extracted from it (e.g., Affleck & Tennen, 1996). Again, the apparent connection in the present study between expressing emotions and the use of meaning making lends support to this possibility. Indeed, Stanton et al. (2000) also found a positive relation of coping through positive reappraisal (meaning making) and expressive coping.

Lastly, it is possible that coping through emotional expression is effective because it may elicit positive social response. Stanton et al. (2000) found that emotionally expressive coping was a unique predictor of adjustment, over and above the contribution of variables such as perceived receptivity of the social context and coping through seeking social support. In other words, supportive relationships may be one vehicle through which emotional expression yields benefits, however, there also appear to be other helpful outlets. The present study suggests that other useful outlets, not dependent on the social context, might include expressing emotion through more solitary strategies such as listening to music, prayer and meditation.

One final point, which warrants further comment, relates also to the issue of social support. A finding that came out clearly in the follow-up interviews was that a number of women encountered further cancer and non-cancer related stressors which resulted in some loss of control of emotions and attempts to regain control. In this scenario, the normal avenues for gaining support may diminish or be eroded over time, particularly if the level of psychological distress is high (Alferi et al., 2001; Bolger et al., 1996; Moyer & Salovey, 1999). Hence, it may be necessary for the woman to find other outlets for emotional expression. It is noteworthy that a number of women in the present study who reported marked levels of distress initially, some of whom experienced further substantial distress through later cancer-related stressors, described having used a range of outlets that were not dependent on availability of support from their usual social network, as well as solitary strategies such as those already noted. Probably the three most widely used ways of processing and expressing emotion that drew on support outside their usual network were seeking professional help, developing friendships with women who had themselves experienced breast cancer, and attending a support group. All these approaches had the potential to minimise the possible erosion of supportive relationships with significant others at the same time as effecting emotional expression, along with other benefits that might evolve out of such relationships.

Meaning-related issues

The accounts of the women showed that all had tried, to a greater or lesser extent, to understand their experience with breast cancer (sense making) and most reported positive changes that had resulted from it (benefit finding). As was reported in Chapter 3, sense making and benefit finding are two key construals of meaning used in the trauma and coping literatures (Davis et al., 1998), and the study findings lend support to the importance of those distinctions. It is important to recall that the issues in relation to meaning were largely raised spontaneously by the women and these distinctions emerged during the analysis process and through further reflection in the light of relevant research. *Sense making* was indicated in three main domains namely, exploring beliefs about life and the purpose of the breast cancer experience, confronting their own mortality, and addressing the question of “why me?” On the other hand, the women’s descriptions of *benefit finding* fell into four categories which

included considering outlook, setting new priorities, identifying benefits in relationships, and reaching out to others. At the time of follow-up many of the women were still engaged, to varying degrees, both with making sense of, and finding benefit in, their experience with breast cancer. Whilst most appeared to have derived a mainly positive meaning from their experience, several women who had experienced ongoing concerns indicated that they were struggling with negative meaning.

Sense making

Examining beliefs

At the time of the initial interviews the majority of the women described efforts to make sense of their situation by drawing on beliefs about God and life. Nine of the women indicated that their beliefs figured strongly in their cognitive processing of the cancer experience, whilst they emerged less strongly for others. These beliefs were couched in religious terms for some and broader spiritual/philosophical terms for others. In addition, fourteen either nominated a purpose they perceived in their experience with breast cancer, or indicated that they were seeking one. Moreover, as was discussed in the previous chapter, statements about beliefs and purpose often were associated with the use of *acceptance* and *being positive*. By contrast, at follow-up only six women spoke about the perceived purpose of their breast cancer and/ or their religious beliefs. In addition, these women did not speak about it as much as in the initial interviews. This decreased attention was consistent with the women's statements that their breast cancer was now perceived to be "in the past" or "in the background" of their lives.

These findings attest to the important role of beliefs in God and purpose in life (including in illness such as breast cancer) for this group of women as they sought to come to terms with their illness, as well as the coping strategies of acceptance and positive attitudes. Not only is this supportive of Lazarus and Folkman's (1984) view of the importance of such beliefs, but also of other breast cancer research (Carver et al., 1993; Cotton et al., 1999; Fitzpatrick et al., 2000; Lavery, 1997; Shapiro et al., 1997). For example, Carver et al. (1993) found that drawing on religious beliefs was

an important coping strategy. Indeed, acceptance, positive reframing, and use of religion were the most common coping reactions reported by women in their study. Similarly, Northouse (1989) reported that patients in her study drew strength from their religious beliefs in order to help them cope, especially in the early stages of their illness experience. Recent studies which have investigated both religious and existential beliefs have yielded similar findings. For instance, Cotton et al. (1999) found a positive relationship between spiritual well-being, quality of life and psychological adjustment. In addition, cognitive strategies such as positive thinking, faith and finding meaning in life were positively related to spiritual well-being. As was described in Chapter 3, the research of Cotton's team also highlighted the role of a "spiritually focused acceptance" for women adjusting to breast cancer (Fitzpatrick et al., 2000).

As was noted earlier, at the follow-up interviews it appeared that the women were less involved in consideration of their beliefs. This finding would need to be validated in further research as the women were not directly asked about this. However, it does suggest that the women were more active in making sense of their situation in the earlier months after their diagnosis, which is consistent with the findings in Northouse's (1989) study. Similar patterns can be seen in the two other domains of *sense making*, which will be discussed next.

Confronting mortality

The process of making sense of their experience involved confronting the possibility of dying from breast cancer for a number of the women. In the initial interviews seven women spoke directly about confronting their mortality. This number does not include those who indicated having concerns about the possibility of a recurrence, and was raised spontaneously by the women. For some of these women it was clear that such thoughts had aroused strong fear, anxiety, and even terror which needed to be resolved as has already been described in relation to control of emotions. Typically those thoughts and feelings were strongest in the early stages of diagnosis and treatment. Others, mostly older women, seemed to have considered this prospect with a fair degree of calm. Those women who reached a point of accepting death as a normal part of life, and those with religious convictions, seemed less troubled about

thoughts of their death. In addition, the women who spoke of confronting mortality also reported taking stock of their lives and reviewing their priorities. At the time of follow-up, five of the women who had described thoughts about mortality six months earlier spoke spontaneously about the issue again. Thoughts and concerns about the possibility of death appeared to be strongest for the three women who were coping with additional physical problems. As was discussed in an earlier section, issues in relation to control of emotions were strong for those three women.

These findings indicate that existential concerns were important for a significant number of the women in the study, and their processing of such issues was part of the way they endeavoured to make sense of their situation. This picture is consistent with findings from a number of cancer studies (O'Connor et al., 1990; Weisman & Worden, 1976-77). Weisman and Worden (1976-77) found that the "existential plight" was strongest in the first one hundred days after diagnosis and treatment, which seemed to be true for the women in the present study. Weisman and Worden also indicated that this plight might pass very quickly for some and not be troublesome, which also fits with the variability in reaction for the women in the present study. The apparent association between acceptance of mortality, beliefs about life and religious beliefs also supports the findings of Smith et al. (1993) who found that "normalization" of death and spirituality was related to acceptance of death and lower levels of distress. On the other hand, this study also highlights how such concerns may be reactivated for those women who have a recurrence of cancer or other cancer-related problems. Other researchers have also noted the connection between thoughts about death and "taking stock" (O'Connor et al., 1990), and it did appear that confronting mortality might have precipitated a process of reflection on their lives for some of the women in this study. In confronting their mortality, the women thought about the nature of life, their own life as they had been living it, and what they valued and believed in. Some followed up this process by reconsidering their outlook and priorities, and making changes in their lives which will be discussed further in the section on *making meaning*.

Searching for a cause

The third way that women used to make sense of their situation was seeking a causal explanation for their breast cancer. In the first cycle of interviews, fourteen women (74 percent) described having thoughts about “why me?” Most of these fourteen women thought that stress was implicated, and two post-menopausal women thought that hormone replacement therapy (HRT) may have contributed. None of the women blamed other people for their breast cancer, nor did they blame themselves. Indeed, two said that they believed it was important not to “load themselves up” with guilt and further stress, and several pointed out that they had no reason to believe that they should be “immune” to breast cancer. A number of these women seemed to be still looking for a satisfactory explanation. At the follow-up interview seven women (44 percent of the sixteen involved in second cycle interviews) again mentioned the perceived cause of their breast cancer, thus suggesting that the issue was still on their mind although to a lesser extent than in the initial interview. Of these seven, five perceived that stress was the likely cause of their breast cancer. It was noteworthy that these five women were also very active in levels of self-care, both physical and emotional, as will be described further in the next section. HRT and diet was nominated by one woman as a likely cause. The three women who had further cancer-related problems were not among those in the follow-up interviews who described seeking a cause. In fact, in the initial interviews two of these women had espoused the view that they had no reason to believe they should be immune to breast cancer.

Studies of causal thinking in cancer patients have produced mixed findings about how widely it is used. For example, Taylor et al. (1984) reported that 65 percent of women in their study of women with varying stages of breast cancer initially said they had a hunch or theory about the cause of their cancer. However, with probing this number increased to 95 percent. On the other hand, Lowery et al. (1993) reported that 50 percent of the breast cancer patients in their study indicated that they had searched for an answer to the question “Why me?” In an Australian study of women with breast cancer whose diagnosis had been, on average, 9 years

before the research, Lavery and Clarke (1996) found that 70 percent of the women had made a causal attribution about their cancer's origins. Hence the findings of the present study sit well within the range reported in other studies. Given that this information was not elicited by a direct question, it is quite likely that the figure of 74 percent is an underestimate of the pervasiveness of seeking a causal explanation by the women in the present study. Such findings highlight the fact that this way of making sense of their breast cancer is very common. Perhaps, even more remarkably, many of the women in the studies just cited had been diagnosed some years prior to involvement in the research. Indeed, it was possible that some women could not recall having such thoughts, although those thoughts may well have occurred. Therefore it was noteworthy that 44 percent of women in the present study made unsolicited comments about their causal attributions, indicating that seeking meaning was still on their minds, although not to the same extent.

The empirical support for the value of seeking a causal explanation for cancer is mixed (Lowery et al., 1993) and investigation of this issue was beyond the scope of the present study. However, it is interesting to note that many of the women who thought their breast cancer was related to stress also reported high levels of self-care. These women were actively involved in their efforts to maximise their health and well-being, which will be discussed further in the following section relating to *making meaning*. The dual functions of causal attributions – in terms of meaning and control – will also be discussed in a later section of this chapter

Making meaning (benefit finding)

As was noted earlier, the women in the study described a number of changes or benefits as a result of their experience with breast cancer including changes in outlook on life, setting new priorities, identifying improvements in relationships (to self, friends, partners and family), and reaching out to others. At the initial interview, ten women (53 percent) commented on positive changes in their outlook, whilst four women mentioned this again in the follow-up interview. By contrast, three women appeared to have developed less positive outlooks at the time of follow-up. Similarly, in the first interview the majority reported that they had begun to give a higher priority to some of their own needs (self-care) and were also active in making changes

in diet and lifestyle. Most of these women referred to continued efforts in these areas at follow-up. In terms of changes in relationships, most spoke of improvements in close relationships, and four of these women again referred to this at follow-up. By contrast, two of the women who reported decrements in outlook also described negative changes including less support and an inclination to withdraw from social contact. Finally, in the initial interview two women spontaneously spoke of reaching out to others in similar situations whilst this number increased to eight (of sixteen women) at follow-up.

The domains of benefit finding (making meaning) that emerged in the present study are very similar to those described in other general cancer (e.g. O'Connor et al., 1990) and breast cancer studies (e.g., Antoni et al., 2001; Fredette, 1995; Hilton, 1988; Shapiro et al., 1997; Taylor, 1983; Taylor et al., 1984). In addition, in the present study benefit finding, in one or more domains, was reported by the majority of women which appears to be consistent with other studies of women with breast cancer. For example, in terms of "changes in outlook", Taylor et al. (1984) indicated that over 70 percent of their respondents reported that cancer had made them think differently about their lives, and that 60 percent of these perceived that this change was positive. Whilst the number of women who reported positive changes in outlook was somewhat less in the present study (53 percent), this figure was probably an underestimate as this information was shared spontaneously rather than in response to a direct question.

Folkman and Greer (2000) have pointed out the similarities between such meaning-related processes as benefit finding and benefit reminding (Affleck & Tennen, 1996), positive illusions (Taylor & Brown, 1988), goal revision and substitution (Folkman & Stein, 1997) and positive reappraisal (Folkman & Lazarus, 1984). A central feature of all these processes is that they "involve positive reframing whereby the person wrests positive value from the situation by reappraising the situation as having provided benefit", such as improved relationships with others, an increase in faith or wisdom, or a sense having become stronger or more competent (Folkman & Greer, 2000, p. 14). For the woman with breast cancer, these processes constitute important ways of developing and sustaining a feeling of psychological well-being. The findings of the present study add an in-depth picture of the process of

making meaning, or positive reappraisal, from the perspective of women with early stage breast cancer.

The value of such coping processes for women with breast cancer is highlighted in studies which investigate the relationship between positive reappraisal and psychological adjustment (e.g. Taylor et al., 1984). For example, Carver et al. (1993) included a measure of positive reframing in their investigation of coping processes and found that it was used widely by the women in their study and was related to lower levels of concurrent distress. It also correlated with other coping strategies linked with positive reactions such as active coping, planning, acceptance, use of social support, religion and use of humour. This pattern is consistent with that found by Dunkel-Schetter et al. (1992), whose factor of “focus on the positive” included such items as “found new faith” and “rediscovered what is important in life”(p. 83). While the present study did not include any formal measures of adjustment, the women’s reports indicated that they were, on the whole, coping remarkably well and that coping strategies such as acceptance, seeking social support, use of humour, and making meaning were an important part of the way that they managed their situation. It is worth noting that humour was used by most of the women in this study and would seem to warrant more investigation as a strategy for coping with stressful situations. The use of this strategy appeared to help women regain a sense of perspective (meaning function) and deal with situations that aroused distressing emotions (control function).

Some of the descriptions of the women also showed that they either had, or were in the process of, redefining priorities to more accurately reflect their values, and setting new goals that gave better expression to their priorities. This could be seen in statements about the need to place a higher priority on their own needs, especially those relating to their health and well-being, and a higher priority on time spent with family. Such processes are more action-oriented or instrumental than cognitive reframing and help to develop a sense of meaning and purpose, as well as a sense of personal control (Folkman, 1997; Folkman & Greer, 2000). Indeed, research with cancer patients suggests that the ability to restructure goals, as well as beliefs, is related to positive adjustment (Thompson & Pitts, 1993).

The fact that the majority of women described changes, mostly positive, in a number of relationships also highlights the importance of that domain in terms of making meaning. This is consistent with the findings of others who suggest the intertwining of “connection with others” and meaning (e.g. Hilton, 1988; Shapiro et al., 1997), a point which is also affirmed by Folkman in the context of HIV/ AIDS (1997).

One of the most striking findings in relation to making meaning to emerge from the present study, which ties in closely with the last point, was the marked increase in the number of women who reported reaching out to others during the follow-up interview. To the knowledge of this writer, few other studies have found such a pattern which the longitudinal nature of the study was able to track, although Nelson (1996) also found that one way women gained meaning from their breast cancer was from helping others. As was seen in Chapter 7, at least some of these women felt resourced by the support they themselves had received from others in the early months after diagnosis which prompted them, in turn, to reach out to others in similar situations. This would seem to be an area worthy of further investigation in other breast cancer studies to establish the extent to which this coping process is used, what factors appear to promote its development, and how it evolves over time.

There has been some debate in the empirical literature as to whether or not benefit finding constitutes a form of denial which might prove to be maladaptive in the long term because it inhibits the individual from engaging with the full severity of the problem and with the use of a range of strategies needed to deal with it effectively (Affleck & Tennen, 1996). This issue has been part of the broader debate on the relation between “positive illusions” (Taylor & Armor, 1996; Taylor & Brown, 1988) and mental health. The findings of the present study show that most of the women were well aware of the difficult and even traumatic aspects of their experience with breast cancer. Hence it appears that, for them, finding benefit in their experience did not signify denial. In fact the opposite may have been the case; the use of denial as a main way of coping seemed to be connected with a sense of negative meaning and a lack of benefit finding.

Taken together, the findings in relation to making meaning suggest that the majority of women in this study reported that their lives had changed in positive ways because of their experience with breast cancer. This finding adds to existing studies indicating that there can be beneficial as well as harmful consequences from having to confront and deal with this life-threatening illness. In addition, some of these positive changes suggest that the women demonstrate both resilience and the possibility of psychological growth. Such findings also add to a growing literature in other areas suggesting that traumatic events can lead to positive outcomes (e.g., Affleck & Tennen, 1996; Aldwin, Sutton, & Lachman, 1996; Antoni et al., 2001; Bower et al., 1998; Calhoun & Tedeschi, 1998; Davis et al., 1998; Folkman, 1997; Park, Cohen & Murch, 1996; Schaefer & Moos, 1992). Similar to these studies, it seems that sometimes benefits were perceived quite early after diagnosis and treatment, despite having also experienced marked levels of distress at times. Indeed, it seems that making meaning enabled some of these women to achieve a degree of acceptance and resolution of their experience, allowing them to re-engage actively with their lives (cf. Folkman, 1997; Taylor, 1983).

Meaning and control

Whilst the previous sections of this chapter have considered the findings of the present study in terms of meaning and control as they relate separately to existing research and theorising, there are two issues pertaining to the relationship between the functions that warrant specific comment. The first concerns the overlapping nature of this relationship. As has been shown in the previous two chapters, many of the coping strategies widely used by the women in the study appeared to serve the functions of regaining and retaining a sense of control in various areas of their lives, and making sense and meaning of their experiences with breast cancer. Whilst particular coping strategies may have been described mostly in the context of one function, for instance, regaining control, they may also have contributed to making meaning. It appeared that specific cognitions, such as using acceptance, humour, causal attribution, and having a positive attitude, served both control and meaning functions. In addition, the analysis revealed that those women who reported having regained a good degree of control were also more likely to have developed positive meaning from their experience. Conversely, those women who reported an increased

lack of control in areas of their lives, also shared thoughts and feelings which were indicative of a concerning degree of negative meaning. In other words, these themes of control and meaning seemed to be closely inter-related.

Such findings are consistent with the theorising of Taylor (1983) who suggested that cognitive adaptation revolves around three main themes: a search for meaning, an effort to regain mastery (or control), and an attempt to restore self-esteem. In this study, the theme of restoring self-esteem did not emerge strongly and, where it was apparent, it seemed to be encompassed within either the control or meaning functions. Taylor (1983) also points out that specific cognitions “may change their meanings from situation to situation, they may be functionally overlapping... and they may serve several functions simultaneously” (p. 1171). For example, developing a causal explanation can both serve to establish a sense of meaning and increase a sense of control. Indeed, as was noted in Chapter 3, Rothbaum et al. (1982) have posited that efforts to find meaning in the face of a very stressful experience represent a form of control, interpretive control, which they argue is a secondary form of control. When secondary control efforts are adopted, the individual tries to “flow with” the experience rather than trying to change it. Such a view highlights the flexibility of coping strategies, and suggests that women in this situation have a repertoire of strategies which usefully serve more than one purpose. Hence, if certain coping cognitions, such as exercising control over physical recovery do not appear to be successful there is still much scope for exercising coping efforts in other ways. This suggests the importance of recognising and researching multiple cognitive adaptive efforts simultaneously, rather than the adaptive value of specific cognitions in isolation.

The second issue revolves around the picture of changes in meaning and control over time. For many of the women, both retaining control and making sense and meaning remained important themes around which coping strategies revolved six months after the initial interviews. This exploration had not been previously been researched in-depth in relation to coping with breast cancer, and could serve as a useful basis for future studies with other groups of women in this situation.

In conclusion, from the accounts of the women in the study, a tapestry of their efforts to regain control and make meaning out of their experience with breast cancer has emerged. Through an in-depth exploration of their coping efforts as they faced up to the demands and challenges of their illness, a more detailed understanding has been gleaned of the ways women in this situation endeavour to seek and gain both control and meaning. It highlights the way in which the women drew both on resources from within themselves as well as those in their social networks, treatment team, and wider support networks. In keeping with a salutogenic orientation, it points to ways that we may learn from women who are doing relatively well, not just those who are perceived to be having problems. In this way, it presents the challenge to explore these constructs further and to use this information to inform theories of stress and coping and to develop intervention strategies to effectively support women who are confronted with this illness.

An evaluation of the study and the implications of its findings are presented in the next two sections.

Evaluation

This section evaluates the design and methodology of the study. In evaluating its design and methodology a number of strengths and limitations need to be considered in the light of the study aims. The study was designed to address areas of confusion in the literature by exploring and describing coping reactions in women with early stage breast cancer through a longitudinal study using qualitative methodology. By identifying and describing stressor-specific coping strategies generated by the women themselves it was hoped that a greater understanding of the woman's "lived experience" would also be achieved. As each woman's context and actual coping strategies may change and evolve over time, this longitudinal, qualitative study also made it possible to capture new ways of doing things. In other words, the social and temporal context is reflected in the qualitative data.

A number of potential limitations must be acknowledged. First, the relatively small, self-selected nature of the sample, most but not all of whom were attending support groups, means that no claims can be made about the generalisability of these

findings to other groups of women with breast cancer. On the other hand, given that a key emphasis of the study was its salutogenic orientation, if the sample was comprised mainly of women who believed they were coping well on the whole, this provided the potential for more “information rich” accounts. In addition, the relatively unstructured nature of the interviews means that it is not possible to provide reliable prevalence estimates for the various coping strategies identified.

There have also been a number of important changes in treatment and support for women with breast cancer since this study was conducted which might also limit the generalisability of the findings. As was pointed out in Chapter 4, data for this study were collected in 1996 and 1997. In Australia a number of significant developments have occurred since that time. For instance, 1995 saw the National Health and Medical Research Council release of *Clinical Practice Guidelines for the Management of Early Breast Cancer*, which were developed to improve clinical practice and health outcomes for women with early breast cancer (NHMRC, 2000). These were followed five years later by the publication of psychosocial clinical practice guidelines, which were designed to assist members of a woman’s treatment team to provide evidence-based supportive care to meet her psychosocial needs (NHMRC, 2000). In Victoria, the *Breast Disease Service Redevelopment Strategy* was launched in 1999, which has supportive care as a strong focus (Breast Care Implementation Advisory Committee Breast Disease Service Redevelopment Strategy Melbourne). Since then a range of initiatives have been introduced throughout Victoria to improve the quality of breast care services. In this process, the needs and views of consumers have been an important focus, and they have been envisaged as being in partnership with clinicians, health care managers and Government. Clearly, such changes have the potential to make a substantial difference to the nature of medical care and support services that a woman receives.

Secondly, while it appeared that most of the women in the study appeared to be coping well, and that many of their self-reported coping strategies were perceived by them as being helpful, no claims about the effectiveness (adaptiveness) of particular strategies can be made. A systematic examination of the link between use of a strategy and an outcome was beyond the scope of the present study. Rather, the emphasis was on exploration and description of the specific coping strategies the

women used to help them manage their situation. However, some of the coping strategies have been investigated in other research and were found to be consistently related to positive adjustment. Future research is needed to examine the adaptiveness or otherwise of a number of the specific strategies identified here, and hopefully they could be used to inform future coping assessments.

A third limitation arises in the potential for bias, both on account of the participants' and researcher's interpretations. In relation to the former, many of the findings were consistent with the existing literature, which supports the notion that the women's accounts were true reflections of their functioning. In addition, the interviews revealed that highly personal, sometimes negative disclosure occurred which suggested that the women were not trying to present a one-sided picture of themselves. Rather, their non-verbal language (including body language, tone of voice, expression of emotions) and their willingness to engage in the research all indicated their desire to provide a truthful account of their ways of coping with their illness. However, research that verified the responses of participants by comparing them with those provided by family members or significant other people, such as doctors or specialist breast nurses, would strengthen the findings. In respect of the potential bias in the researcher's interpretation, as was described in Chapter 4 a number of steps were put into place to limit its potential impact on the study findings. These included extensive use of supporting and illustrative quotations, the use of an independent coder for a sample of the interviews, and various methods of returning the women's accounts to them for their information and comment.

A final limitation results from the largely retrospective nature of the study which depended on the recall of events. Whilst there were two cycles of interviews, six months apart, there were still substantial periods of time for the women to recall and some detail about coping strategies may have been lost. Conducting three or four cycles of interviews in the same period would have helped to more accurately capture the fluctuations in coping strategies used at different stages of the coping and adjustment process. However, there are already significant burdens placed on women in the early stages of diagnosis and treatment, hence it would be difficult to recruit participants to a study involving that level of commitment. In addition, the time

constraints on the development and completion of a Ph.D thesis mean that such a study design would not be feasible.

Implications

This section considers the implications of the findings from this study for existing theories and associated research literature, for future research and for clinical practice. A description is presented of the contribution this study has made to an understanding of women's emotional reactions to their diagnosis of early stage breast cancer, their coping responses, and the way these may change over a six month period. This is followed by a discussion of the implications of these findings for future research and clinical practice.

Implications for existing theories

The cognitive-phenomenological theory of stress and coping is widely respected and used to study the ways individuals cope in a variety of contexts, including coping with cancer. Central to this model are two processes: appraisal and coping. According to this model, when a person is confronted with a stressor, such as a diagnosis of breast cancer, the person makes an appraisal, or evaluation, of the personal significance of the event and the adequacy of his or her resources for coping. This, in turn, influences emotion and subsequent coping. Coping consists of those thoughts and behaviours a person employs to regulate their distress (emotion-focused coping), manage the problem (problem-focused coping), and maintain positive well-being (meaning-based coping). Finally, coping exerts an influence on the outcome of the stressful situation and the way the person appraises it.

Stress and coping models are, by necessity, very complex. They are "intricate *systems* models that depict individual functioning as an interactive, dynamic process" (Sommerfield, 1997, p. 134). One of the basic tenets of systems thinking is *holism* which posits that the total functioning of the person must be understood within her or his broader context, and cannot be understood from the analysis of isolated parts of the system. Hence there is a need for research that is holistic and person-centred (Sommerfield, 1997).

The current study, with this theoretical framework and guided by the general tenets of systems theory, explored coping with a diagnosis of early stage breast cancer. The individual coping efforts of the women and aspects of their broader context, encountered through their experiences of seeking and receiving support from their social network and their medical team, were explored at two points in time. The findings were supportive of the importance of, in particular, emotion-focused coping and meaning-based coping for the women in the study.

Taylor's (1983) theory of cognitive adaptation with its emphasis on the role of positive illusions in helping to maintain a sense of meaning, control and self-esteem, provides a picture of a set of adaptive beliefs (positive illusions) and coping processes that are also encompassed within the stress and coping model. This theory arose out of Taylor's study of women with breast cancer, but has been applied to, and studied in relation to a range of situations where individuals face severe, adverse events. The findings of the present study are consistent with this theory, and lend further support to the significance of the themes of meaning and control for women who are trying to cope with a diagnosis of breast cancer. The present study also provides a detailed picture of changes in relation to the themes of meaning and control over time which extends the findings of previous research in this area.

One of the most compelling aspects of the findings was the extent to which the women reported benefits from their experience, which is conceptualised as an aspect of making meaning. This was no Pollyanna-like wish-list, but rather a position reached in their journey through much pain, distress, and difficulty. They had, to a large extent, confronted their fears and losses, and many had re-engaged with their lives after breast cancer with somewhat changed goals and priorities. Indeed, many of them appeared to have grown psychologically as a result of their experience. Moreover, their growth seemed to be reflected in their ability to reach out to others in similar situations. Hence the study findings are consistent with a burgeoning literature related to the positive sequelae of trauma, and the value in adopting a salutogenic orientation that facilitates the recognition of positive as well as negative outcomes of stress such as was the subject of this study. It also points up the remarkable resilience of most women in these circumstances, and their needs for

support from those within their social network, their treatment team, and the wider society.

Research implications

Through an in-depth exploration of the coping reactions of the women, a detailed description of a broad range of most widely used coping strategies was developed. Central amongst these were the coping strategies of acceptance, denial, and avoidance which have yielded conflicting results in terms of their adaptiveness in the research literature. The accounts of the women in this study provide rich information about the possible targets of acceptance, denial and avoidance, and the cognitive, emotional and behavioural ways in which these strategies are enacted. These multiple targets and domains highlight the difficulty of most existing, standardised measures of coping to adequately capture the dynamics of strategies such as acceptance and denial in one or two items. The information from this study could be used to generate measures that might overcome some of these limitations.

Similarly, the wide variety of other ways in which women sought to regain control, and to make sense and meaning of their experience, could also be used to inform future coping assessments. In addition, quantitative assessments could be used to assess the effectiveness of coping strategies identified in this study through qualitative means. In this way, quantitative and qualitative assessments of coping can complement and usefully inform each other. At the same time, future qualitative research could more closely examine the links between these qualitatively identified coping strategies and outcomes to explore their effectiveness.

Much more research is needed which seeks data more widely than the woman herself. Many questions arise in relation to the needs of those who are close to women with breast cancer, and the best ways to provide to support them as they endeavour to care for and support their significant other. In particular, it would be important to explore issues in relation to control and meaning in this wider context.

Clinical implications

Several main issues arise from this study which have implications for those who offer supportive services for women with breast cancer. Firstly it would appear to be very important that practitioners, both medical and allied health professionals, be aware of the value in fostering women's own efforts of control, whether in the emotional, medical, or physical recovery area. Likewise, efforts to make sense and meaning of their experience with breast cancer could be assisted in a variety of ways. For example, one way is to create a climate of challenge by helping a woman to clarify what is meaningful for her and identify relevant, achievable goals (Folkman & Greer, 2000). This process taps into both the needs for meaning and personal control. Other interventions could focus on encouraging behaviours to achieve the woman's goals, which may be difficult if the woman has lost confidence in her own abilities to reach any goals. A third way is to help maintain a woman's positive mood, even though depression and anxiety may be present. In this approach, encouraging a woman to identify positive aspects of her experience may be helpful.

Secondly, there is a clear need for practitioners to remain alert to other cancer-related problems, as well as additional stressors, that may place ongoing demands on women who have had treatment for early stage breast cancer. Even women who appear to have adapted positively to their diagnosis and treatments are likely to have trouble marshalling their resources to deal with new and ongoing stressors. In addition, clinical programs designed to enhance a sense of control and positive meaning could incorporate a number of findings from this study and subsequently be evaluated before and after intervention programs.

A third issue, which is relevant to both control and meaning, is the importance of making accessible to women the findings of studies about coping with breast cancer. In this context, accessibility includes descriptions of findings that are understandable to the lay person. Much of the information from the current study has been returned to the women so that they could learn from each other's experiences. Indeed, the women in the study were keen to know what the experience of others had been and frequently sought out information (in books, from support groups, and

friends) from which they could glean insight into the way other women had coped with their breast cancer.

Finally, the results of this study are in keeping with the move to ensure that there are ample opportunities for women to reach out to each other through support and advocacy groups. While this is not of interest to some women, many women do feel well-supported by, and learn from, other women with breast cancer in the context of such groups.

Appendix A1

Invitation to Study Participants

AN INVITATION TO BE INVOLVED IN A STUDY

Coping with a diagnosis of early-stage breast cancer

As part of my research project for my PhD in Psychology at Victoria University of Technology, I am conducting research into the ways women cope with a relatively recent diagnosis (within the last twelve months) of early-stage breast cancer. The purpose of the study is to explore the coping reactions of participants, the way these reactions may change over time and the major social and emotional factors (for example, reactions of others to whom they are close) which affect their coping.

It is hoped that information from this study will increase knowledge about ways of coping that appear to be most helpful and least helpful for the women involved, and how these may change over time. This knowledge, in turn, may contribute to the development of interventions that give women the opportunity to modify the impact of breast cancer on themselves and those to whom they are close.

I am keen to make contact with women in this situation who are prepared to be interviewed for about an hour and a half, either in their own homes or at a mutually convenient location. There will also be one short questionnaire to complete which asks socio-demographic questions. All information will be confidential and anonymous, and participants have the right to withdraw from the study at any time. Results of the study will be published in an appropriate journal and will be available to groups and organisations that take part in the study, as well as to participants themselves.

You don't have to feel that you are coping well in order to be involved in the study. I would like to interview women from a wide range of backgrounds and ages, women who feel they are having difficulty coping, as well as those who feel happy with the way they are coping.

If you would like further information or would like to register your willingness to participate in this study, please contact me at Victoria University of Technology, Psychology Department, St Albans campus. The phone number is (03) 9365 2326, or you can ring me at home on (03) 95767275.

Thank you for your cooperation

Rosemary Callander
Psychology Department
Victoria University of Technology
St Albans campus.

Appendix A2

Plain Language Statement

EXPLANATORY STATEMENT: FIRST INTERVIEW

Title of Project: **Coping with a diagnosis of early-stage breast cancer.**

Investigator: Rosemary Callander (B.Soc.Stud., M.S.W)
Psychology Department
St Albans campus
Victoria University of Technology.

Supervisor: Professor Susan Moore, Psychology Department,
St Albans campus
Victoria University of Technology.

As part of my research project for my PhD at Victoria University of Technology I am conducting interviews with women who have received a relatively recent diagnosis (that is, diagnosed within about the last six months) of early-stage breast cancer. We know that a diagnosis of breast cancer often comes as a major shock to the women concerned, as well as to those with whom they are closely involved, and can constitute a serious crisis in their lives. The purpose of this study is to explore the ways in which women cope with the diagnosis and ensuing process, and the major social and emotional factors which affect their coping.

I am keen to hear from women in this situation who are prepared to be interviewed for about an hour and a half, either in their own homes or at a mutually convenient location. There will also be one short questionnaire to complete which asks socio-demographic questions. All information given will be confidential and anonymous. No real names will be recorded on the interviews. While the interview will be audiotaped, participants may ask that the tape recorder be turned off at any time. Taped responses will be transcribed without identifying information and the tapes will be erased.

The questions will include issues that may be sensitive ones for some women. Those who participate may choose not to answer particular questions or finish the interview. Similarly, participants are free to withdraw from the study at any time.

From my experience as a social worker, researcher and parent, I am aware that sharing adverse experiences can be both difficult and very helpful. Those who choose to participate will be providing information that may be of value to other women who face a diagnosis of breast cancer in the future, and who may benefit from increased knowledge in this area.

Any questions regarding this study, which conforms to Victoria University of Technology ethical guidelines, can be directed to either myself – Rosemary Callander at Victoria University of Technology on 93652326 – or my supervisor, Professor Susan Moore on 93652335.

If you wish to find out more information about breast cancer and related support services you can consult:

Breast Cancer Support Service/ CanHelp
Anti-Cancer Council of Victoria
Phone 92791111

Thank you for your co-operation.

Rosemary Callander

Appendix A3

Interview Consent Form

VICTORIA UNIVERSITY OF TECHNOLOGY

Consent Form: Initial Interview

I,....., have read and understood the information above and any questions I have asked have been answered to my satisfaction. I agree to participate in the interview and to complete the questionnaire, realising that I may withdraw from the study at any time.

I agree that the research data collected for this study may be published or provided to other researchers on condition that my name is not used.

Signature

Date.....

Appendix A4

Explanatory Statement: Follow-up Contact

EXPLANATORY STATEMENT: FOLLOW-UP CONTACT

A number of women who have been interviewed for this study on coping with a diagnosis of early-stage breast cancer are being invited to participate in a follow-up interview in about six months time, or in a one-off discussion group with a small number of women to be held about four months from now. Both the second interview and discussion group will explore changes in the ways participants have coped over the time since the first interview and factors that have been influential in any changes that have occurred.

Some of the women in the study may also be asked if someone to whom they are close (for example, partner, older child, close friend) would be prepared to be interviewed at a later stage, or be involved in a one-off discussion group for “significant others”. The interviews and discussion group would explore coping reactions of significant others and how they matched with those of the women. However, there is no compulsion for women who are interviewed to agree to the involvement of someone to whom they are close.

As in the initial interviews, all information given will be confidential and anonymous, and the participants may withdraw from the study at any time.

.....

Consent Form

I,..... agree that the investigator, Rosemary Callander, may approach me about further follow-up, including:

1. a second interview
2. one-off discussion group
3. involvement of on “significant other” in an interview or one-off discussion group
4. I do not wish to participate in further follow-up

Please circle the appropriate number(s).

Signature..... Phone no:

Date.....

Appendix A5

Explanatory Statement: Follow-up Interview

EXPLANATORY STATEMENT: SECOND INTERVIEW

Title of Project: **Coping with a diagnosis of early-stage breast cancer**

Investigator: Rosemary Callander (B.Soc.Stud., M.S.W)
 Psychology Department
 St Albans Campus
 Victoria University of Technology

Supervisor: Professor Susan Moore
 Psychology Department
 St Albans Campus
 Victoria University of Technology

A number of women who are participating in this study on coping with a diagnosis of early-stage breast cancer are being interviewed to explore changes in coping reactions over the previous six months or so and factors that may have been influential in any changes that have occurred. As in the initial interviews, all information given will be confidential and anonymous, with the same code name being used as in the first interview. Once again, while the interview will be audiotaped, participants may ask that the tape recorder be turned off at any time, and the taped responses will be erased after being transcribed.

Participants are reminded that the questions may include issues that are sensitive ones for some. As in the first interview, those women who participate may choose not to answer particular questions or finish the interview. In addition, they are free to withdraw from the study at any time.

Any questions regarding this study can be directed either to myself – Rosemary Callander at Victoria University of Technology on 93652326 – or my supervisor, Professor Susan Moore on 93652335.

Thank you for your cooperation.

Rosemary Callander

Appendix A6

University Ethics Approval



MEMORANDUM

TO: Professor Susan Moore
Psychology

FROM: Ms. Palmina Fichera
Secretary, Human Research Ethics Committee

DATE: 16 January, 1996

SUBJECT: Approval of application involving human subjects

At its meeting on Thursday, 12 December, 1995, the Human Research Ethics Committee considered an application for project *The phenomenology of coping with a diagnosis of early-stage breast cancer: The influence of intrapsychic and social context variables*.

It was resolved to approve application HRETH 87/95 (HREC 95/232) from 1 November, 1995 to 1 November, 1997.

If you have any further queries, please do not hesitate to contact me on 4704.

A handwritten signature in black ink, consisting of a large, stylized loop followed by a long, sweeping horizontal line that tapers to the right.

Appendix A7

SocioDemographic Data Questionnaire

BACKGROUND INFORMATION

1. **Age:** please tick one of the following age ranges:

30-39 40-49 50-59 60-69 70 and above

2. **Marital status** (please tick whichever applies to you at the moment)

single, never wed married or living with mate divorced or separated
 widowed

3. **Do you have any children?** yes no. **If yes, how many?**

What are their ages? _____

4. **How many years of education have you completed?** (Circle the appropriate number)

1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 or more
Primary school Secondary school College or university

5. **Employment status:** (please tick one) Employed full time Employed part time

Unemployed Full time student Retired Homemaker

6. **What type of work are you currently doing:** (please tick one)

housework unskilled service clerical sales skilled
 managerial professional agricultural proprietor or self-employed
 other - please specify _____

7. **When were you diagnosed with breast cancer?** _____ (year) _____ (month)

8. **What type of treatment have you had?** (please tick any that apply to you)

Lumpectomy Mastectomy Radiotherapy Chemotherapy
 Hormone therapy Alternative therapies No treatment
 Other (please specify) _____

9. **If you had surgery, please indicate (if known):** Size of tumour _____

Number of lymph nodes involved (if any) _____

Appendix B

Interview Schedule

INTERVIEW SCHEDULE

Perception of the situation

- How did you find out that you had breast cancer?
- What was your reaction when you found out?
- How did you feel (at the time of diagnosis, treatment, and now)
- What has been the most difficult aspect for you to come to terms with in the first few months after the diagnosis? What was it about that particular aspect that makes is/ made it difficult for you?
- How do recall feeling during those first few months?
- What was the reaction of partner, family (children if appropriate) to your diagnosis and treatment?
- What impact has the experience of the last few months had on your life?

Perceptions of ability to cope

- At the time of learning about the diagnosis, and in the weeks following, what were your thoughts about your ability to deal with the cancer and its associated difficulties?
- What sorts of resources (help) were you aware that you could draw on?

Coping reactions

- What did you do to help you cope with the difficulties in those first few months?
- What else would have helped?
- People use a variety of methods to deal with stressful or difficult situations. What did you do?
- Are there some aspects of having breast cancer that you are having trouble coming to terms with?
- Who or what have been your most important sources of support?
- What sorts of support have they given you?
- What other sort of support would you have liked, if any?
- Have there been particular financial, physical or other difficulties (e.g., getting to treatment) which have required assistance?

Rounding off

- Do you have any questions that you wish to ask me about the research?
- Are there any other matters that you want to mention?
- Discuss the possibility of involvement in a further stage of the research.

Appendix C

Matrix Analysis: Initial Interviews

**See pocket inside the back cover of the thesis.
(For examination purposes only)**

**Transcripts of interviews available to the examiners from the researcher on
request.**

Appendix D1

Feedback to Study Participants: Initial Interviews

SUMMARY OF FINDINGS FROM FIRST INTERVIEWS

You may recall that the main aim of my research was to explore the way women in the study responded to a relatively recent diagnosis (within the last twelve months or so) of early-stage breast cancer and their ways of coping both initially and over time. By drawing this information together I hoped to help clarify the psychological tasks and processes which confront many women who are faced with a diagnosis of breast cancer and to highlight those strategies and supports which seem to be particularly helpful in this situation. The following summary is organised round a description of the most frequently used methods of coping that were described in the interviews.

You may be interested to know a few details about the nature of the overall study group. For instance, the age range was from 33 to 70 years (at the time of first interview), and over half of the group was in the 30 to 50 years age bracket. Most women were married or living with a partner and most had children, though only six had children still living at home.

Initial reactions

The majority of women experienced a wide range of feelings at the time of diagnosis including shock, fear and anger. Reactions described included 'scared', 'shocked', 'angry', 'depression', and 'numbing' and sometimes these feelings were all happening within the space of a few hours. However, four women recalled having a fairly mild reaction - for example, 'taken aback' - or putting their feelings 'on hold' to be dealt with at a later stage. Two of these women had been diagnosed with very early signs of breast cancer which had been detected through routine mammograms, and for which there was no palpable lump and so the degree of threat was less severe and proposed treatment less extensive than for others.

"I can cope"

After taking stock of their situation and making decisions about treatment, most women began to feel that they could and would manage the tasks and changes that accompanied the breast cancer and several spoke of seeing "this whole thing as a challenge" to be taken up. There was a strong sense of "I can cope" or "I could handle it". This did not mean that there weren't days when they wished it wasn't happening, but overall there was a sense of being able to cope.

Acceptance

Once the shock of the diagnosis was overcome, a process which sometimes took several weeks, all the women accepted the reality of the diagnosis and the need to deal with treatment and recovery. For some, especially those who had experienced fairly mild reactions to their diagnosis, this acceptance seemed to come quite quickly and without much difficulty. For example, one woman said, "I just accepted it. I don't even have to try."

A number of women spoke about having no choice but to accept the diagnosis and the need for treatment. However most perceived that they did, in fact, have a choice about how they could respond within themselves. As one woman put it:

You could either sit in the corner and do nothing, or you can get on with it and do the best you possibly can.

Several women described their acceptance as going along with adopting a fighting attitude towards the breast cancer, though others were clear that for them the breast cancer was to be “cured and treated rather than fought”.

Most of the women felt that the breast cancer constituted a threat to their lives and to their physical self as they had previously known it. In facing this new reality, many of them described having confronted and accepted their own mortality. This was found to be a strengthening process, an example of which is seen in the following quote:

*And I suppose that's what an illness, such as I have, **does**. It makes me really aware that the time I see ahead could be long, or it might be a year. So all of a sudden you have this piece of time that you've got to do good things with because it mightn't last very long... So it does give you an appreciation, I suppose, of the use of time and of mortality.*

Having a positive attitude

Along with acceptance, having a positive outlook on life and the current situation was also very important for women in the study. This positive focus was reflected in a number of ways including directly verbalising a belief in the importance of having a positive attitude. For example, after recovering from her shock and grief reaction that followed diagnosis, one woman said:

From then on I decided that I was going to put everything negative out of my life, and I would just concentrate on the positive.

It was also used by many women to help them cope with different aspects of the treatment process and their own reactions to it. One young woman, in describing her reactions to a changing body image following on from mastectomy and chemotherapy, says:

I did hang on to the fact that I was still me, regardless of the way I looked... I just focus on the positive part of the fact that it's still me.

Whilst the women believed it was important for them to be positive, for many this did not mean they could be positive all the time. Rather, being positive seemed to be a goal towards which they were working. For example, in coping with anxiety about the threat of a recurrence, one woman recalled that she had to keep concentrating “on the positive thought” when she was experiencing bodily pains that could possibly be due to a secondary.

These positive attitudes also expressed themselves in the **bonuses or benefits** that many of them described which had occurred as a result of the experience with breast cancer. Some of these benefits related to an increased awareness of their own strength and ability to cope with difficulty. One typical comment was:

I've come out a lot stronger even with this .. more confident. If I can face this I can face anything.

In addition to these personal gains, some talked about benefits they had experienced in relationships with others, especially in terms of greater closeness, both with family and friends and at work.

Others were very clear that part of being positive, for them, was expressed in increased levels of self-care, such as greater attention to diet, exercise and relaxation. As one woman put it:

I think with doing those things I am doing something positive for myself.

Finally, positive attitudes were also conveyed through the optimistic approach, expressed by most women, to their future and the way in which they were clearly remaining involved with important life-goals. This can be seen in the following:

I consider that I am fortunate with all the things there that I want to do, and I think that's what the basis of life is.

Distancing

Once they were through the early stages of coming to terms with their diagnosis and treatment, some women chose to try and forget that they had cancer, or at least put it towards the back of their minds and not spend too much time thinking about it:

I don't think about the cancer. I try to put it out of my mind. And I talk about it in the past because ... I feel that it's gone.

You know in the back of your mind that it could be very serious, and of course it's life-threatening, but you don't dwell on it. What would be the point?

For some women who were working, going to work was a welcome and temporary 'escape' or a time when they could 'switch off' from thinking about breast cancer, especially in the days and weeks following diagnosis. For others, keeping busy and being involved in everyday routines helped them to avoid dwelling on it. For example, two women mentioned that doing things with their grandchildren was a welcome, if at times tiring, distraction.

While these behaviours were, in some ways, helping the women avoid thinking about the breast cancer, it did not mean they were denying it as a reality or the chance of recurrence. In fact, some of these women spoke of their preference to face up to unpleasant situations, and of remaining vigilant about their health even though they may have "put it aside".

Seeking support

Other research has demonstrated the importance of social support for the adjustment of women facing breast cancer and the findings from this study are consistent with that. Practical support, information and emotional support were all valued highly by the women in this study. Many were quite active in seeking support, and the following is typical of this reaction:

I took the option and told everybody .. I thought I would need everybody to cope because that's the kind of person I am.

Over half of the women felt that their best source of emotional support was from other women who had had breast cancer. As one woman said:

Other people who have gone through the same things are the ones who .. the only ones who have got any idea.

About five women were happy with the emotional support given to them by their husband. However, for others there were reservations and they found that their partner, many of whom were having difficulty coping with their own reactions to the illness, was not able to provide them with the emotional support they needed. While many of these partners provided practical support, such as help with housework or transport to medical appointments, the women turned to a close friend or relative if they needed to talk about their anxieties and concerns. The response of partners was well-summed up by one woman:

I think it's a bit too close to home for my husband to handle.

Eight women were active members of support groups and found that was very helpful for them both in terms of information about a range of issues related to breast cancer and also for emotional support. As one woman said, she found the support group a "tremendous help". However, two women mentioned a couple of "down" sides to their experience with support groups. For instance, one woman felt that the group did not cater well enough to the needs of her particular age-group, and the other mentioned the difficulty she experienced on one or two occasions when group members were expressing feelings of anger and grief, or the group was confronted with the loss through death of one of its members.

Drawing on life beliefs

Many of the women spoke about the fact that the experience with breast cancer had prompted them to recognise and draw on their beliefs about life and the place of experiences such as this one. Sometimes these included religious beliefs:

Well I believe that there's a God .. I believe that there's something out there stronger than me that I can rely on for support and that's been helpful too.

For those with religious beliefs, prayer was mentioned as being helpful for them.

Some women, while not endorsing religious beliefs, had a strong sense of beliefs about life which one woman described as her philosophy of life:

*I think it (breast cancer) made me aware that I did have a strong philosophy about my life ... that gives me a strong sense of **its place** somewhere.*

For a number of these women, there was a belief that their breast cancer had a purpose, that it contained a lesson or lessons that had to be learned. For example, there were lessons to be learned in relation to recognising that “I am not invincible” or that there were unresolved tensions in a woman’s life which required resolution.

Using humour

One coping reaction, that has been little studied, which came out strongly in the interviews was using humour. Despite the difficulties being confronted, even during the stressful times of diagnosis and treatment, the use of humour was clear. The following quotes are typical of this:

So my hair’s back to a number one (very short) .. and I tease my girls that when I get to a number two, I’ll have a stud through my nose and be very trendy.

Humour is very important.

I didn’t think I had much of a sense of humour. I think of it more as a sense of proportion (laughs) But I can see the funny side of things; the sort of ridiculous aspects of things that happen to me.

You’ve got to have a laugh about it, otherwise you’d get really depressed.

One woman, in discussing the impact of surgery on her sexual relationship with her partner said:

I think communication and sense of humour is important in this situation.

Alternative health care

About half the women had used alternative approaches to health care and most of these women had consulted an alternative health practitioner. The methods used included use of vitamins, minerals and herbal medicines, acupuncture, meditation, Reiki and massage. Usually these methods were adopted towards the end of active, orthodox, medical treatment - for instance towards the end of chemotherapy and radiotherapy. One woman had chosen to use alternative methods of treatment over orthodox medical treatment, though she was still monitoring the progress of her breast cancer through regular mammograms.

On the whole, the women found these methods to be beneficial for them and not just on a physical level. As one woman explained, she wanted to do something to “slowly taper off her connection with treatment” and also ..”to give myself as much chance as I could of not having a recurrence.”

Underlying tasks

From the analysis of the interviews it is possible to distinguish two important tasks or goals to which many of the coping strategies described above were directed, namely exercising control and making meaning.

Feelings about **losing control and efforts to regain control** came out quite clearly for about half the women. Typically the women were most likely to feel out of control at the time of diagnosis and during the treatment process, especially if there was a high degree of shock and if they felt hurried into treatment, as was often the case. As one woman said, "My life was turned upside down."

Most women wanted to be actively involved in decisions about treatment, especially in relation to type of surgery, and sought out information so they could make an informed decision. Several were happy to place their trust - 'lend' their control - to the specialists, and were happy with the explanations and alternatives provided by them.

Apart from seeking information, women used a variety of strategies to increase their feelings of being in control, especially of their feelings, which included stress management (such as meditation and relaxation), seeking help from a counsellor and talking with others.

Secondly, the majority of women appeared to be engaged, to a greater or lesser extent, in the process of integrating their experience with breast cancer into their lives, of **making sense and meaning** of it. Some women voiced this task directly:

Now there's time to sit back and think what it all really means. And if I can make something positive out of the whole experience, then that's to my benefit I think.

*I **need** to think about it. I like to have time to think about the fact that I had cancer this year, and what does that mean.*

Others had struggled with the question "Why me?" in their efforts to make sense of the experience. A number mentioned explanations that linked cancer to stress-related factors, and several suggested that religious or spiritual forces might provide a reason for their experience. However, while searching for a reason, these women were not wanting to impose an additional burden of guilt to an unwanted and difficult experience.

A number of women used the experience to make changes in their lives, especially changes related to self-care, and in this way were helping to make some meaning or sense out of the experience of cancer. In addition, beliefs and values were used to make meaning and to help the women deal with the demands of the situation by contributing to a feeling of inner strength and connection beyond themselves. And finally, many women spoke of their interest in sharing their experience as a way of contributing to increased knowledge and awareness about breast cancer, and, to this end were sharing their story in this study. Hopefully this connection with the broader community of women also contributed to their own sense of meaning.

Overall

Findings from the analysis of the initial interviews show that the women in this study, on the whole, viewed their diagnosis of breast cancer and ensuing treatment as a difficult and demanding time but one with which they felt they could cope both because of their own inner strengths and external supports. They are actively engaged with life and aim to make the best of their situation, and, to this end, employ a variety of coping methods. The patterns of change that occur over the course of time between the first and second interviews remains to be charted.

Appendix D2

Feedback to Study Participants: Follow-up Interviews

Summary of findings from follow-up interviews

From the follow-up interviews it was clear that there were notable improvements in both physical and emotional well-being for most women. Of the sixteen women who participated in the follow-up interviews the majority were feeling that life had become much more normal, particularly once they had finished active treatment and recovered their usual levels of physical and emotional energy. Indeed recovering former levels of physical energy seemed to take at least several months after adjuvant therapy had ended. However, for a number of women there were continuing or new difficulties resulting from their breast cancer, or other demands in their lives, which presented further tasks with which to cope.

In terms of ongoing problems related to breast cancer, two women had developed lymphoedema, one had marked oedema which was a side-effect of chemotherapy, two experienced distressing symptoms from the rapid onset of menopause as a result of adjuvant therapy and two had a second lump investigated which, happily, proved to be benign. Of the three women who did not participate in follow-up interviews, one was receiving treatment for a recurrence.

The difficulties unrelated to breast cancer, that had occurred since the initial interview, included death of a parent, diminished physical health of a parent, unplanned pregnancy, work stress and family hassles. Some of the women found it very demanding to manage these issues which came so quickly on top of dealing with breast cancer and, indeed, several were still working out the best ways of coping with these additional situations.

Changes in coping reactions over time

As you may recall one of my main objectives in the study was to explore the coping methods or strategies used by women both in the early months after diagnosis and over time. From the follow-up interviews, all the women reported much the same range of coping strategies as at the time of initial interviews, although these were not used as much by those without ongoing or additional difficulties. Several women regarded their breast cancer as being mostly “in the past”, with check-ups and anniversaries coming as somewhat unwelcome reminders of it. The majority of women were moving forward positively but were still mindful of some threat which can perhaps be summed up by the expression of breast cancer being “in the past for now” or as “a low level hum” in their life. For those with ongoing problems that had arisen from breast cancer, it was still painfully present in some ways in their experience.

One notable change in coping strategies was a decreased need to seek out support from others, whether they be family, friends or professional helpers. In fact, for a number of women, seeking support seemed to have given way to becoming **providers** of support to others in similar situations. This was consistent with the desire, which was expressed by many, to do what they could to assist other women who face the task of coping with diagnosis and treatment of with breast cancer.

Other coping strategies that were widely reported at the time of the initial interviews, such as acceptance of the situation, having a positive attitude and increased levels of

self-care practices, were still used quite widely. In relation to levels of self-care, you may recall that most women had made changes to their diet, exercise and lifestyle following diagnosis and treatment, many of which had been maintained. Several women spoke of the task of juggling their own needs for self-care and those of others, such as family. On the whole, they were learning to achieve a balance that was acceptable to them.

Once again there was a striking array of benefits, from the overall experience with breast cancer, described by many in the followup interviews. Such benefits included having increased empathy with others facing adversity, a stronger sense of personal strength, an increased sense of peace, a clearer perspective on life and one's own priorities, a strengthening in relationship with a partner, developing new and valuable friendships with other women who had had breast cancer, feeling closer to family, and flow-on benefits to those whose work involved helping other people. In relation to the last, several women described having a better understanding of clients' needs and feeling better equipped to respond to them because of their own experience.

While those benefits or positive effects were described by many women, there were also a number of undesirable consequences, some of which were experienced as a result of the new, cancer-related problems which had arisen. Of particular concern was the struggle with depression and a decrease in self-confidence which were very real for a small number of women.

The most pervasive negative consequence was the presence of ongoing uncertainty about various physical symptoms that were experienced by a number of women from time to time, and doubts about future health. This uncertainty was also felt strongly at times of scheduled check-ups, at the time of the anniversary of diagnosis, or at times when there was news of other women having died of breast cancer.

Underlying tasks of regaining control and making meaning

Issues in relation to control and making meaning came out quite strongly in the follow-up interviews. In terms of the latter, many women showed that the process of making meaning or sense out of their experience with cancer was continuing. The task of making meaning was expressed in a variety of ways. This included seeking satisfactory answers to the question "why did this happen?" and working out "what does my life mean to me now?" As was mentioned earlier, many women had maintained changes in outlook and lifestyle and re-evaluated their attitudes and priorities which can be seen as part of their answer to these questions. Indeed, at the time of follow-up, life was perceived to be more satisfying for most because they had restructured their lives as a result of their experience with breast cancer.

This meaning-making process was summed up by one woman who said:

I think what's happened is ..I see it as an experience .. this sounds weird.. but it's been a pivotal experience in my life because it's forced me to consider things I hadn't had to consider, and it's probably enhanced my life in many ways.

In terms of feelings of control, there was an increased sense of being "in control" of what was happening in their lives which was particularly noticeable for several

Antonovsky, A. (1987). Unravelling the mystery of health: How people manage stress and stay well. San Francisco: Jossey-Bass.

Astin, J.A. (1998). Why patients use alternative medicine: results of a national study. JAMA, The Journal of the American Medical Association, 279, 1548-1554.

Astin, J.A., Anton-Culver, H., Schwartz, C.E., Shapiro Jr, D. H., McQuade, J., Breuer, A.M., Taylot, T.H., Lee, H., & Kurosaki, T. (1999). Behavioral Medicine, 25, 101- 109.

Auerbach, S.M. (2001). Do patients want control over their own health care? A review of measures, findings and research issues. Journal of Health Psychology, 6, 191-203.

Australian Institute of Health and Welfare (AIHW) (1998). Australasian Association of Cancer Registries and NHMRC National Breast Cancer Centre, Breast Cancer Survival in Australian Women, 1982-1994. Canberra: Australian Institute of Health and Welfare. Cancer Series No.9.

Baider, L. & Kaplan De-Nour, A. (1988). Breast cancer – A family affair. In C.L. Cooper (Ed.), Stress and breast cancer (pp. 155-170) New York: Wiley.

Baum, A. (1990). Stress, intrusive imagery, and chronic distress. Health Psychology, 9, 653-675.

Billings, D.W., Folkman, S., Acree, M., & Moskowitz, J.T. (2000). Coping and physical health during caregiving: the roles of positive and negative affect. Journal of Personality and Social Psychology, 79, 131-142.

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, 283-294.

Bower, J.E., Kemeny, M.E., Taylor, S.E., & Fahey, J.L. (1998). Cognitive processing, discovery of meaning, CD4decline, and AIDS-related mortality among bereaved HIV-seropositive men. Journal of Consulting and Clinical Psychology, *66*, 979-986.

Breast Care Implementation Advisory Committee Breast Disease Service Redevelopment Strategy Melbourne: Victorian Government Publishing Service, 1999.

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*, 263-272.

Calhoun, L.G. & Tedeschi, R.G. (1998). Beyond recovery from trauma: implications for clinical practice and research. Journal of Social Issues, *54*, 357-371.

Cannon, W.B. (1932). The wisdom of the body. New York: Norton.

Carver, C.S., Pozo, C., Harris, S.D., Noriega, V., Scheier, M.F., Robinson, D.S., Ketcham., A.S., Moffat, F.L., & Clark, K.C. (1993). How coping mediates the effect of optimism on distress: A study of women with early stage breast cancer. Journal of Personality and Social Psychology, *65*, 375-390.

Carver, C.S., Scheier, M.F., & Pozo, C. (1992). Conceptualizing the process of coping with health problems. In H.S Friedman (Ed.), Hostility, coping and health (pp. 167-187). Washington: American Psychological Association.

Carver, C.S., Scheier, M.F., & Weintraub, J.K. (1989). Assessing coping strategies: A theoretically based approach. Journal of Personality and Social Psychology, *56*, 267-283.

Clarke, V.A., Lavery, J.F., & Ruffin, C.L. (1993). A journey through breast cancer. Reflections of thirty survivors. Institute of Nursing Research. Research Monograph Series No. 9. Geelong: Deakin University Press.

Cohen, F. & Lazarus, R.S. (1979). Coping with the stresses of illness. In G.C. Stone, F. Cohen, N.E. Adler & Associates (Eds.), Health Psychology – a Handbook: Theories, applications and challenges of a psychological approach to the health care system (pp. 217-254). San Francisco: Jossey-Bass.

Compas, B.E., Connor, J., Osowiecki, D., & Welch, A. (1997). Effortful and involuntary responses to stress: Implications for coping with chronic stress. In B.H. Gottlieb (Ed.), Coping with chronic stress (pp. 105-130). New York: Plenum.

Cooper, C.L., & Faragher, E.B. (1993). Psychosocial stress and breast cancer: The interrelationship between stress events, coping strategies and personality. Psychological Medicine, 23, 653-662.

Cotton, S.P., Levine, E.G., Fitzpatrick, C.M., Dold, K. H., & Targ, E. (1999). Exploring the relationships among spiritual well-being, quality of life, and psychological adjustment in women with breast cancer. Psycho-Oncology, 8, 429-438.

Cox, T. (1978). The nature of stress. Stress (pp. 1-25). London: Macmillan.

Cox, T., & Ferguson, E. (1991). Individual differences, stress and coping. In C.L. Cooper & R. Payne (Eds.), Personality and stress: Individual differences in the stress process (pp. 7-30). Chichester: Wiley & Sons,

Coyne, J.C. (1997). Improving coping research: Raze the slum before any more building! Journal of Health Psychology, 2, 153-155.

Coyne, J.C. & Lazarus, R.S. (1981). Cognitive style, stress perception and coping. In I.E. Kutish & L.B. Schlesinger (Eds.), Handbook on stress and anxiety (pp. 144-158). San Francisco: Jossey-Bass.

Coyne, J.C. & Racioppo, M.W. (2000). Never the twain shall meet: Closing the gap between coping research and clinical intervention research. American Psychologist, *55*, 655-664.

Cunningham, A.J., Phillips, C; Lockwood, G.A., Hedley, D.W., Edmonds, C.V. (2000). Association of involvement in psychological self-regulation with longer survival in patients. Advances in Mind-Body Medicine, *16*, 276-288.

Dakof, G.A., & Taylor, S.E. (1990). Victims' perceptions of social support: What is helpful from whom? Journal of Personality and Social Psychology, *58*, 80-89.

Danoff-Burg, S., Ayala, J., & Revenson, T. (2000). Researcher knows best? Towards a closer match between the concept and management of coping. Journal of Health Psychology, *5*, 183-194.

Davis, C.G., Nolen-Hoeksema, S., & Larson, J. (1998). Making sense of loss and benefitting from the experience: two construals of meaning. Journal of Personality and Social Psychology, *75*, 561-574.

Dean, C., & Surtees, P.G. (1989). Do psychological factors predict survival in breast cancer? Journal of Psychosomatic Research, *33*, 561-569.

Degner, L.F., Kristjanson, L.J., Bowman, D., Sloan, J.A., Carriere, K.C., O'Neill, J., Bilodeau, B., Watson, P., & Mueller, B. (1997). Information needs and decisional preferences in women with breast cancer. Journal of the American Medical Association, *277*, 1485-1492.

Dey, I. (1993). Qualitative data analysis. London: Routledge.

- Dunkel-Schetter, C., Feinstein, L.G., Taylor, S.E., & Falke, R.L. (1992). Patterns of coping with cancer. Health Psychology, 11, 79-87.
- Ell, K.O., Mantell, J.E., Hamovitch, M., & Nishimoto, R.H. (1989). Social support, sense of control, and coping among patients with breast, lung or colorectal cancer. Journal of Psychosocial Oncology, 7, 63-89.
- Epping-Jordan, J.E., Compas, B.E., Osowiecki, G.O., Gerhardt, K.P. & Krag, D.N. (1999). Psychological adjustment in breast cancer: Processes of emotional distress. Health Psychology, 18, 315-326.
- Fallowfield, L.J., Hall, A., Maguire, G.P., et al (1990). Psychological outcomes of different treatment policies in women with early breast cancer outside a clinical trial. British Medical Journal, 301, 575-580.
- Ferrero, J., Barreto, M., & Toledo, M. (1994). Mental adjustment to cancer and quality of life in breast cancer patients: An exploratory study. Psycho-Oncology, 3, 223-232.
- Fife, B.L. (1995). The measurement of meaning in illness. Social Science and Medicine, 40, 1021- 1028.
- Fitzpatrick, C.M., Levine, E.G., Heide, F., Zelman, D., Targ, E. (2000). Re-examining the construct of Fatalism in women with breast cancer: Stoic resignation versus spiritually-focused acceptance. Poster paper, 5th World Congress of Psycho-Oncology, Melbourne.
- Folkman, S. (1984). Personal control and stress and coping processes: A theoretical analysis. Journal of Personality and Social Psychology, 46, 839-852.

Folkman, S. (1992). Making the case for coping. In B.N. Carpenter (Ed.) Personal coping: Theory, research and application (pp. 31-46). Westport, CT: Praeger.

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.

Folkman, S. & Lazarus, R.S. (1980). An analysis of coping in a middle-aged community sample. Journal of Health and Social Behaviour, 21, 219-239.

Folkman, S. & Lazarus, R.S. (1985). If it changes it must be a process: Study of emotion and coping during three stages of a college examination. Journal of Personality and Social Psychology, 48, 150-170.

Folkman, S. & Moskowitz, J.T. (2000). Positive affect and the other side of coping. American Psychologist, 55, 647-654.

Folkman, S., Lazarus, R.S., Dunkel-Schetter, C., DeLongis, A., & Gruen, R.J. (1986). Dynamics of a stressful encounter: Cognitive appraisal, coping, and encounter outcomes. Journal of Personality and Social Psychology, 50, 992-1003.

Folkman, S., Lazarus, R.S., Gruen, R.J., & DeLongis, A. (1986). Appraisal, coping, health status, and psychological symptoms. Journal of Personality and Social Psychology, 50, 571-579.

Folkman, S., Moskowitz, J.T., Ozer, E.M., & Park, C.L. (1997). Positive meaningful events and coping in the context of HIV/AIDS. In B.H Gottlieb (ed.). Coping with chronic stress. (pp. 293-314). New York: Plenum.

Frankl, V. (1959). Man's search for meaning. London: Hodder & Stoughton.

Friedman, L.C., Nelson, D.V., Baer, P.E., Lane, M., & Smith, F.E. (1990). Adjustment to breast cancer: A replication study. Journal of Psychosocial Oncology, 8, 27-40.

Friedman, L.C., Nelson, D.V., Baer, P.E., Lane, M., Smith, F.E., & Dworkin, R.J. (1992). The relationship of dispositional optimism, daily life stress, and domestic environment to coping methods used by cancer patients. Journal of Behavioral Medicine, 15, 127 – 141.

Fromm, K., Andrykowski, M.A., & Hunt, J. (1996). Positive and negative psychological sequelae of bone marrow transplantation: Implications for quality of life assessment. Journal of Behavioral Medicine, 19, 221-240.

Gallagher, J., Parle, M., & Cairns, D. (2002). Appraisal and psychological distress six months after diagnosis of breast cancer. British Journal of Health Psychology, 7, 365-376.

Glanz, K. & Lerman, C. (1992). Psychosocial impact of breast cancer: A critical review. Annals of Behavioral Medicine, 14, 204-212.

Goldbeck, R. (1997). Denial in physical illness. Journal of Psychosomatic Research, 43, 575-593.

Gottlieb, B.H. (1997). Conceptual and measurement issues in the study of coping with chronic stress. In B.H. Gottlieb (Ed.), Coping with chronic stress (pp. 3-40). New York: Plenum.

Grassi, L., & Molinari, S. (1988). Pattern of emotional control and psychological reactions to breast cancer: A preliminary study. Psychological Reports, 62, 727-732.

- Greer, S., Morris, T., & Pettingale, K.W. (1979). Psychological response to breast cancer: Effect on outcome. The Lancet, *ii*, 785-787.
- Greer, S., Morris, T., Pettingale, K.W., & Haybittle, J.I. (1990). Psychological response to breast cancer and 15 year outcome. Lancet, *i*, 49-50.
- Greer, S., & Watson, M. (1987). Mental adjustment to cancer: Its measurement and prognostic importance. Cancer Surveys, *6*, 439-453.
- Halstead, M.T., & Fernsler, J.F. (1994). Coping strategies of long-term cancer survivors. Cancer Nursing, *17*, 94-1000.
- Hack, T.F., Degner, L.F., Dyck, D.G. (1994). Relationship between preferences for decisional control and illness information among women with breast cancer: A quantitative and qualitative analysis. Social Science and Medicine, *39*, 279-289.
- Hann, D. M., Oxman, T.E., Ahles, T.A., Furstenberg, C.T., & Stukes, T.A. (1995). Social support adequacy and depression in older patients with metastatic cancer. Psycho-oncology, *4*, 213-221.
- Hannum, J.W., Giese-Davis, J., Harding, K., & Hatfield, A.K. (1991). Effects of individual and marital variables on coping with cancer. Journal of Psychosocial Oncology, *9*, 1-20.
- Heim, E., Augustiny, K.F., Blaser, A., Burki, I., Kuhn, D., Rothenbuhler, M., Schaffner, L., Valach, L. (1987). Coping with breast cancer – a longitudinal prospective study. Psychotherapy Psychosom. *48*, 44-59.
- Heim, E., Augustiny, K.F., Schaffner, L., & Ladislav, V. (1993). Coping with breast cancer over time and situation. Journal of Psychosomatic Research, *37*, 523-542.

Heim, E., Ladislav, V., 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. (1996). Social support and adjustment to cancer: Reconciling descriptive, correlational, and intervention research. Health Psychology, *15*, 135-148.

Helgeson, V.S., Cohen, S., Schulz, R., & Yasko, J. (2001). Long-term effects of educational and peer discussion group interventions on adjustment to breast cancer. Health Psychology, *20*, 387-392.

Hilton, B.A. (1988). The phenomenon of uncertainty in women with breast cancer. Issues in Mental Health Nursing, *9*, 217-238.

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 Behavioural Medicine, *12*, 39-54.

Hilton, B.A. (1994). Family communication patterns in coping with early breast cancer. Western Journal of Nursing Research, *16*, 366-388.

Holahan, C.J., Moos, R.H., & Schaefer, J.A. (1996). Coping, stress resistance and growth: Conceptualizing adaptive functioning. In M. Zeidner & N. S. Endler (Eds.) Handbook of coping (pp. 24-43). New York: Wiley.

Holland, K., & Holahan, C. (2003). The relation of social support and coping to positive adaptation to breast cancer. Psychology and Health, *18*, 15-29.

Houston, B. & Hodges, W. (1970). Situational denial and performance under stress. Journal of Personality and Social Psychology, *16*, 726-730.

- Irvine, D., Brown, B., Crooks, D., Roberts, J., & Browne, G. (1991). Psychosocial adjustment in women with breast cancer. Cancer, *67*, 1097-1117.
- Jarrett, S.R., Ramirez, A.J., Richards, M.A. & Weinman, J. (1992). Measuring coping in breast cancer. Journal of Psychosomatic Research, *36*, 593-602.
- Kissane, D.W., Clarke, D.M., 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.
- Kleinman, A. (1988). The illness narratives: Suffering, healing, and the human condition. U.S.A.: Basic Books.
- Korotkov, D. (1998). The sense of coherence: making sense out of chaos. In P.T.P. Wong and P.S. Fry (Eds.), The human quest for meaning: a handbook of psychological research and clinical applications (pp. 51-70). NJ: Erlbaum.
- Kubler-Ross, E. (1969). On death and dying. New York: Macmillan.
- Lavery, J. F. (1997). The psychological impact of breast and prostate cancer on patients and partners. Unpublished doctoral dissertation, Faculty of Health and Behavioural Sciences, Deakin University, Australia.
- Lavery, J.F., & Clarke, V.A. (1996). Causal attributions, coping strategies, and adjustment to breast cancer. Cancer Nursing, *19*, 20-28.
- Lazarus, R.S. (2000). Towards better research on stress and coping. American Psychologist, *55*, 665-673.
- Lazarus, R.S. & Folkman, S. (1984). Stress, appraisal and coping. New York: Springer.

Lazarus, R.S. & Folkman, S. (1991). The concept of coping. In A. Monat & R. S. Lazarus (Eds.), Stress and coping: An anthology (3rd ed.)(pp. 189-206). New York: Columbia University Press.

Lazarus, R.S. (1990). Stress, coping, and illness. In H. S. Friedman (Ed.), Personality and disease. New York:Wiley-Interscience.

Lazarus, R.S. (1993). From psychological stress to the emotions: A history of changing outlooks. In L.W. Porter & M.R. Rosenzweig (Eds.), Annual Review of Psychology (pp. 1 – 21).

Lazarus, R.S., & Launier, R. (1978). Stress-related transactions between person and environment. In C. Pervin & M. Lewis (Eds.) Perspectives in interactional psychology (pp. 287-327). London, U.K: Plenum Press.

Lewis, F.M. (1989). Attribution of control, experienced meaning, and psychosocial well-being in patients with advanced cancer. Journal of Psychosocial Oncology, 7, 105-119.

Lichtman, R.R. & Taylor, S.E. (1986). Close relationships and the female cancer patient. In B.L. Anderson (Ed.), Women with cancer. Psychological perspectives (pp. 233-256). New York: Springer-Verlag.

Lincoln, Y.S., & Guba, E.G. (1985). Naturalistic Inquiry. California: Sage.

Livneh, H. & Antonak, R.F. (1997). Psychosocial adaptation to chronic illness and disability. Gaithersburg, Maryland: Aspen Publishers.

Lowery, B.J., Jacobsen, B.S., & DuCette, J. (1993). Causal attribution, control, and adjustment to breast cancer. Journal of Psychosocial Oncology, 10, 37-53.

Luker, K.A., Beaver, K., Leinster, S.J., & Owens, R.G. (1996). Meaning of illness for women with breast cancer. Journal of Advanced Nursing, 23, 1194-1201.

Maddi, S.R. (1967). The existential neurosis. Journal of Abnormal Psychology, 72, 311-325.

Major, B., Richards, C., Cooper, M.L., Cozzarelli, C., & Zubek, J. (1998). Personal resilience, cognitive appraisals, and coping: An integrative model of adjustment to abortion. Journal of Personality and Social Psychology, 74, 735-752.

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

Manne, S.L., Sabbioni, M., Bovbjerg, D.H., Jacobsen, P.B., Taylor, K.L., & Rodd, W.H. (1994). Coping with chemotherapy for breast cancer. Journal of Behavioral Medicine, 17, 41-55.

Marshall, C. & Rossman, G.B. (1989). Designing qualitative research. California: Sage.

McCracken, G. (1988). The long interview. Beverly Hills: Sage.

McNair, D.M., Lorr, M., & Droppleman, L. F. (1992). EITS manual for the Profile of Mood States. San Diego, C.A: Educational and Industrial Testing Service.

Merkin, S., Stevenson, L., & Powe, N. (2002). Geographic socioeconomic status, race, and advanced-stage breast cancer in New York city. American Journal of Public Health, 92, 64-70.

Meyerowitz, B., Richardson, J., Hudson, S., & Leedham, B. (1998). Ethnicity and cancer outcomes: Behavioral and psychosocial considerations. Psychological Bulletin, 123, 470-70.

Miles, M.B., & Huberman, A.M. (1984). Qualitative data analysis: A sourcebook of new methods. California, Sage.

Miller, S.M. (1987). Monitoring and blunting: Validation of a questionnaire to assess styles of information seeking under threat. Journal of Personality and Social Psychology, 52, 345-353.

Monat, A. & Lazarus, R.S. (1991). Introduction: Stress and coping – Some current issues and controversies. In A. Monat & R.S. Lazarus (Eds.), Stress and coping: An anthology (3rd ed). New York: Columbia University Press.

Moos, R.H., & Schaefer, J.A. (1993). Coping resources and processes: Current concepts and measures. In L. Goldberger & S. Breznitz (Eds.), Handbook of stress. Theoretical and clinical aspects (pp. 234-257). New York: The Free Press.

Moyer, A. & Salovey, P. (1999). Predictors of social support and psychological distress in women with breast cancer. Journal of Health Psychology, 4, 177-191.

Mullen, P., Smith, R. Hill, E. (1993). Sense of coherence as a mediator of stress for cancer patients and spouses. Journal of Psychosocial Oncology, 11, 23-46.

National Health and Medical Research Council (NHMRC) (2000). Psychosocial clinical practice guidelines: providing information, support and counselling for women with breast cancer. Commonwealth of Australia: NHMRC.

Nelles, W.B., McCaffrey, R.J., Blanchard, C.G., & Ruckdeschel, J.C. (1991). Social supports and breast cancer: A review. Journal of Psychosocial Oncology, 9, 21-34.

Nelson, D.V., Friedman, L.C., Baer, P.E., Lane, M., & Smith, F.E. (1989). Attitudes to cancer: Psychometric properties of fighting spirit and denial. Journal of Behavioral Medicine, 12, 341-355.

Nelson, J. (1996). Struggling to gain meaning: Living with the uncertainty of breast cancer. Advances in Nursing Science, 18, 59-76.

Northouse, L.L. (1988). Social support in patients' and husbands' adjustment to breast cancer. Nursing Research, 37, 91-95.

Northouse, L.L. (1989). The impact of breast cancer on patients and husbands. Cancer Nursing, 12, 276-284.

Northouse, L.L. & Swain, M.A. (1988). Adjustment of patients and husbands to the initial impact of breast cancer. Nursing Research, 36, 221-225.

O'Connor, A.P., Wicker, C.A., & Germino, B.B. (1990). Understanding the cancer patient's search for meaning. Cancer Nursing, 13, 167-175.

Pallant, J.F. (2000). Development and validation of a scale to measure perceived control of internal states. Journal of Personality Assessment, 75, 308-337.

Park, C.L., Cohen, L.H., & Murch, R.L. (1996). Assessment and prediction of stress-related growth. Journal of Personality, 64, 71-105.

Parker, J.D.A & Endler, N.S. (1996). Coping and defense: a historical overview. In M. Zeidner and N.S. Endler (Eds.), Handbook of coping: theory, research, applications (pp. 3- 23). New York: Wiley.

Patton, M.Q. (1990). Qualitative evaluations and research methods. California: Sage.

- Pearlin, L., & Schooler, C. (1978). The structure of coping. Journal of Health and Social Behaviour, 19, 2-21.
- Penman, D.T., Bloom, J.R., Fotopoulos, S., Cook, M.R., Holland, J.C., Gates, C., Flamer, D., Murawski, B., Ross, R., Brandt, U., Muenz, L.R., & Pee, D. (1987). The impact of mastectomy on self-concept and social function: A combined cross-sectional and longitudinal study with comparison groups. Women and Health, 11, 101-130.
- Pennebaker, J.W. (1992). Inhibition as the linchpin of health. In H.S. Friedman (Ed.), Hostility, coping, and health. Washington: American Psychological Association.
- 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., Greer, S., & Haybittle, J.L. (1985). Mental attitudes to cancer: An additional prognostic factor. Lancet, i, 750.
- Pistrang, N., & Barker, C. (1995). The partner relationship in psychological response to breast cancer. Social Science & Medicine, 40, 789-797.
- Reker, G.T. & Wong, P.T.P (1988). Aging as an individual process: Toward a theory of personal meaning. In J.E. Birren & V.L. Bengston (Eds.). Aging as an individual process: Toward a theory of personal meaning. In J.E. Birren & V.L. Bengston (Eds.). Emergent theories of aging. (pp. 214-246) NY: Springer.
- Roberts, C.S., Cox, C.E., Shannon, V.J., & Wells, N.L. (1994). A closer look at social support as a moderator of stress in breast cancer. Health and Social Work, 19, 157-164.
- Rodrigue, J.R., Behen, J.M., & Tumlin, T. (1994). Multidimensional determinants of psychological adjustment to cancer. Psycho-Oncology, 3, 205-214.

Roth, S., & Cohen, L.J. (1986). Approach, avoidance, and coping with stress. American Psychologist, *41*, 813-819.

Rothbaum, F., Weisz, J., & Snyder, S. (1982). Changing the world and changing the self: A two-process model of perceived control. Journal of Personality and Social Psychology, *42*, 5-37.

Royak-Schaler, R. (1992). Psychological processes in breast cancer: A review of selected research. Journal of Psychosocial Oncology, *9*, 71-89.

Schaefer, J.A. & Moos, R.H. (1992). Life crises and personal growth. In Carpenter, B.N (Ed.), Personal coping: Theory, research and application (pp. 149-170). Westport, CT: Praeger.

Schnoll, R., Knowles, J., & Harlow, L. (2002). Correlates of adjustment among cancer survivors. Journal of Psychosocial Oncology, *20*, 37-60.

Selye, H. (1979). Correlating stress and cancer. American Journal of Proctology Gastroenterology and Rectal Surgery, *30*, 18-28.

Shapiro, D.H., Schwartz, C.E., & Astin, J.A. (1996). Controlling ourselves, controlling our world: Psychology's role in understanding the positive and negative consequences of seeking and gaining control. American Psychologist, *51*, 1213-1230.

Shapiro, S., Angus, L., & Davis, C. (1997). Identity and meaning in the experience of cancer. Journal of Health Psychology, *2*, 539-554.

Shapiro, S.L., Lopez, A.M., Schwartz, G.E., Bootzin, R., Figueredo, A.J., Braden, C.J., & Kurker, S. F. (2001). Quality of life and breast cancer: Relationship to psychosocial variables. Journal of Clinical Psychology, *57*, 501-519.

Siegel, K., & Scrimshaw, E.W. (2000). Coping with negative emotions: The cognitive strategies of HIV-infected gay/ bisexual men. Journal of Health Psychology, *54*, 517-530.

Siegel, K., Gluhoski, V., & Gorey, E. (1999). Age-related distress among young women with breast cancer. Journal of Psychosocial Oncology, *17*, 1-20.

Smith, E., Stefanek, M., Joseph, M., Verdieck, M., Zabora, J., & Fetting, J. (1993). Spiritual awareness, personal perspective on death, and psychosocial distress among cancer patients: An initial investigation. Journal of Psychosocial Oncology, *11*, 89-103.

Smith, J. A. (1995). Semi-structured interviewing and qualitative analysis. In J.A. Smith, R. Harre & L. Van Langenhove (Eds.), Rethinking methods in psychology. (pp. 9-26). London: Sage.

Somerfield, M.R & McCrae, R.R. (2000). Stress and coping research: Methodological challenges, theoretical advances and clinical applications. American Psychologist, *55*, 620-625.

Somerfield, M.R. (1997). The utility of systems models of stress and coping for applied research. Journal of Health Psychology, *2*, 133-151.

Spiegel, D., Bloom, J.R., Kraemer, H.C., & Gottheil, E. (1989). Effect of psychosocial treatment on survival of patients with metastatic breast cancer. Lancet, *2*, 888-891.

Stanton, A.L., & Snider, P.R. (1993). Coping with a breast cancer diagnosis: A prospective study. Health Psychology, *12*, 16-23.

Stanton, A.L., Danoff-Burg, S., Cameron, C.L., & Ellis, A.P. (1994). Coping through emotional approach: Problems of conceptualization and confounding. Journal of Personality and Social Psychology, *66*, 350-362.

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 adjustment to breast cancer. Journal of Consulting and Clinical Psychology, 68, 875-882.

Stanton, A.L., Danoff-Burg, S., Kirk, S.B., & Cameron, C.L. (2000). Coping through emotional approach: Scale construction and validation. Journal of Personality and Social Psychology, 78, 1150-1169.

Steed, L.G. A critique of coping scales. (1998). Australian Psychologist, 33, 193-202.

Strauss, A. (1987). Qualitative analysis for social scientists. New York: Cambridge University Press.

Strauss, A., & Corbin, J. (1990). Basics of qualitative research: Grounded theory, procedures, and techniques. California: Sage.

Taylor, S.E. (1983). Adjustment to threatening events: A theory of cognitive adaptation. American Psychologist, pp. 1161-1173.

Taylor, S.E. (1999). Health Psychology. (4th ed.). New York: McGraw-Hill.

Taylor, S.E. & Armor, D.A. (1996). Positive illusions and coping with adversity. Journal of Personality, 64, 873-898.

Taylor, S.E. & Brown, J.D. (1988). Illusion and well-being: A social psychological perspective on mental health. Psychological Bulletin, 103, 193-210.

Taylor, S.E., and Dakof, G.A. (1988). Social support and the cancer patient. In S. Spacapan & S. Oskamp (Eds.), The social psychology of health (pp.95-116). Newbury Park, California: Sage.

Taylor, S.E., Helgeson, V.S., Reed, G.M., & Skokan, L.A. (1991). Self-generated feelings of control and adjustment to physical illness. Journal of Social Issues, *47*, 91-109.

Taylor, S.E., Kemeny, M.E., Reed, G.M., Bower, J.E. , & Gruenewald, T.L. (2000). Psychological resources, positive illusions, and health. American Psychologist, *55*, 99-109.

Taylor, S.E., Lichtman, R.R., & Wood, J.V. (1984). Attributions, beliefs about control and adjustment to breast cancer. Journal of Personality and Social Psychology, *46*, 489-502.

Tennen, H., Affleck, G., Armeli, S. & Carney, M.A. (2000). A daily process approach to coping: Linking theory, research and practice. American Psychologist, *55*, 626-636.

Terry, D.J., & Hynes, G.J. (1998). Adjustment to a low-control situation: Reexamining the role of coping responses. Journal of Personality and Social Psychology, *74*, 1078-1092.

Thoits, P.A. (1986). Social support as coping assistance. Journal of Consulting and Clinical Psychology, *54*, 416-423.

Thomas, S.F., & Marks, D.F. (1995). The measurement of coping in breast cancer patients. Psycho-oncology, *4*, 231-237.

Thompson, S.C. & Janigian, A. (1988). Life schemes: A framework for understanding the search for meaning. Journal of Social and Clinical Psychology, *7*, 260-280.

Thompson, S.C & Pitts, J. (1993). Factors relating to a person's ability to find meaning after a diagnosis of cancer. Journal of Psychosocial Oncology, *11*, 1-21.

- Thompson, S.C. & Spacapan, S. (1991). Perceptions of control in vulnerable populations. Journal of Social Issues, 4, 1-21.
- Thompson, S.C., Nanni, C., & Levine, A. (1994). Primary versus secondary and central versus consequence-related control in HIV-positive men. Journal of Personality and Social Psychology, 67, 540-547.
- Thompson, S.C., Sobolew-Shubin, A., Galbraith, M.E., Schwankowsky, L., & Cruzen, D. (1993). Maintaining perceptions of control: Findings perceived control in low-control circumstances. Journal of Personality and Social Psychology, 64, 293-304.
- Timko, C., & Janoff-Bulman, R. (1985). Attributions, vulnerability, and psychological adjustment: The case of breast cancer. Health Psychology, 4, 521-544.
- Tobin, D.L., Holroyd, K.A., Reynolds, R.V., & Wigal, J.K. (1989). The hierarchical factor structure of the Coping Strategies Inventory. Cognitive Therapy and Research, 13, 343-361.
- Turrell, G. (1995). Social class and health: A summary of the overseas and Australian evidence. In G.M. Lupton & J.M. Najman (Eds.), Sociology of health and illness: Australian readings, (2nd ed.) (pp. 113-142). Australian: MacMillan Education.
- Vinokur, A.D., Threatt, B.A., Vinokur-Kaplan, D., Satariano, W.A. (1990). The process of recovery from breast cancer for younger and older patients. Cancer, 65, 1242-1254.
- Watson, M., Greer, S., Young, J., Inayat, Q., Burgess, C. & Robertson, C. (1988). Development of a questionnaire measure of adjustment to cancer: the MAC scale. Psychological Medicine, 18, 203-209.

Watson, M., Law, M., dos Santos, M., Greer, S., Baruch, J., & Bliss, J.M. (1994). The Mini-MAC: Further development of the Mental Adjustment to Cancer Scale. Psycho-Oncology, *3*, 153 (abstract).

Weisman, A.D., & Worden, J.W. (1976-77). The existential plight in cancer: significance of the first 100 days. International Journal of Psychiatry in Medicine, *7*, 1-15.

Wong, P.T.P. & Fry, P.S. (1998). Introduction. In P.T.P. Wong & P.S Fry (Eds.), The human quest for meaning: (xvii-xxvi). Mahwah, NJ: Erlbaum.

Wool, M.S., & Goldberg, R.J. (1986). Assessment of denial in cancer patients: Implications for intervention. Journal of Psychosocial Oncology, *4*, 1-14.

Wortman, C., Sheedy, C., Gluhoski, V., & Kessler, R. (1992). Stress, coping, and health: conceptual issues and directions for future research. In H.S. Friedman (Ed.), Hostility, coping and health. (pp.227-256). Washington: American Psychological Association.

Wright, S.J. & Kirby, A. (1999). Deconstructing conceptualizations of 'adjustment' to chronic illness. Journal of Health Psychology, *4*, 259-272.

Zemore, R., & Shepel, L.F. (1989). Effects of breast cancer and mastectomy on emotional support and adjustment. Social Science and Medicine, *28*, 19-27.

Zika, S. & Chamberlain, K. (1992). On the relation between meaning in life and psychological well-being. British Journal of Psychology, *83*, 133-145.