AN ELECTRONIC COPING-ENHANCEMENT PROGRAMME FOR BEREAVED WOMEN ADDRESSING PSYCHOSOCIAL FACTORS IN BREAST-CANCER DEVELOPMENT

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DECLARATION

While registered as a candidate for the degree of Doctor of Philosophy the author has not been registered for any other award with any other university or institution.

No part of the material in this thesis has been submitted for any degree or other qualification at any other institution by the author or, to the best of her knowledge and belief, by any other person. The thesis describes the author's original work.

ABSTRACT

Conventional breast-cancer prevention strategies tend to focus on the reduction of physical breast-cancer risk factors while neglecting psychosocial factors potentially associated with its development. Yet, there is a wealth of evidence linking psychosocial factors such as the occurrence of and maladaptive coping with bereavement and other stressful life events, certain personality traits, and a lack of social support, to breast-cancer incidence, survival and mortality. This thesis aimed to design, implement and evaluate an electronic Coping-Enhancement Programme for the Bereaved (CEPB), addressing such psychosocial factors. Furthermore, participants' experiences of the programme were to be explored. An experimental 2x2 independent measures design with triangulation was used, employing qualitative and quantitative methodology. Participants' experiences were elicited qualitatively through blogs and message boards. The two independent variables were (1) emotional-expression-and-stress-reduction (EESR), and (2) psycho-education. Dependent variables were: (1) maladaptive coping with bereavement, (2) maladaptive coping with stressful life events, (3) social support, and (4) awareness of the connections between psychological and physical health. An additional dependent variable was conformity. A Web site containing message boards and blogs was created. Thirty-one women completed a psychological screening form and were then randomly assigned to one of four conditions (EESR-only, psycho-education-only, EESR-plus-pyscho-education, or the control group who received no intervention). They participated in online exercises designed to aid emotional expression and stress reduction ('Art and Laughter for Wellbeing') and/or received psycho-education through the reading of autobiographical accounts of breast-cancer sufferers. Participants were analysed on the dependent variables three times: before the programme to obtain a baseline measurement, after the programme, and at six-week follow-up. Thematic analysis was used to illustrate the process of the CEPB, as well as to confirm or disconfirm quantitative results. Analyses of covariance revealed that after the programme, taking part in 'Art and Laughter for Wellbeing' was associated with lower maladaptive coping with bereavement, while reading autobiographical accounts of breast-cancer sufferers was associated with lower maladaptive coping with stressful life events. Participation in both conditions was associated with higher levels of social support, and taking part in either condition was associated with lower levels of conformity. The latter effect persisted at follow-up. Mixed analyses of variance showed changes over time in three dependent variables. The CEPB was generally viewed as useful, helpful and enjoyable by participants. Implications for future research are discussed, and a biopsychosocial model of breast-cancer prevention is proposed.

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ABBREVIATIONS

ANCOVA	Analysis of Covariance
ANOVA	Analysis of Variance
BA/BSc	Bachelor Degree
BSSS	Berlin Social Support Scales
CD3T	Cluster of Differentiation 3 T-Cell Co-Receptor (an indicator of immune function)
CECS	Courtauld Emotional Control Scale
CEPB	Coping-Enhancement Programme for the Bereaved
CertHE	Higher Education Certificate
CES-D	Center for Epidemiologic Studies-Depression scale
df	Degrees of Freedom
DHP	British Psychological Society's Division of Health Psychology
DipHE	Higher Education Diploma
DSM-IV-TR	Text Revision of the Diagnostic and Statistical Manual of Mental Disorders, Version IV
DV	Dependent Variable
ε^2	Epsilon Squared (a measure of effect size)
EC	Emotional Control sub-scale of the Emotional Expression and Control scale
EEC	Emotional Expression and Control scale
EESR	Emotional Espression and Stress Reduction
EI	Expression-In sub-scale of the Emotional Expression and Control scale
EMM	Estimated Marginal Means
EPQ	Eysenck Personality Questionnaire
EU	Perceived Ease of Use
F	F statistic
FDC	Functional Dimensions of Coping scale
FSSQ	Duke Functional Social Support Questionnaire
GP	General Practitioner
HDHQ	Hostility and Direction of Hostility Questionnaire
HPA axis	Hypothalamic-Pituitary-Adrenal axis
HRT	Hormone Replacement Therapy
IM	Intrinsic Motivation

IV	Independent Variable
k	Cohen's kappa (a measure of inter-rater reliability for categorical variables)
M	Mean
MA/MSc	Masters Degree
MMPI	Minnesota Multiphasic Personality Inventory
N	Total sample size
n	Number of cases in a sub-group
p	Probability value
PASW	Predictive Analytics SoftWare
PDDP	Psychological Displacement Diary-writing Paradigm
PNI	Psychoneuroimmunology
PSA	Prostate-Specific Antigen (a tumour marker in prostate cancer)
PTSD	Post-Traumatic Stress Disorder
r	Correlation coefficient
RAE	Rationality-Anti-Emotionality scale
SD	Standard Deviation
sIgA	Secretory immunoglobulin A
t	t statistic
TAM	Technology Acceptance Model
TAQ	Technology Acceptance Questionnaire
TCPI	Type C Personality Inventory
U	U statistic
UCLA	University of California, Los Angeles
UK	United Kingdom
z	z statistic
α	Alpha
$η^2$	Eta squared (a measure of effect size)

TABLE OF CONTENTS

LIST OF FIGURES

LIST OF TABLES

CHAPTER ONE

INTRODUCTION AND OVERVIEW

CONTENTS

1.1 Overview

This thesis describes the development, implementation and evaluation of an electronic coping-enhancement programme for bereaved women (CEPB), which addresses established psychosocial factors involved in the development of breast cancer.

The current chapter provides an overview of the thesis. In order to do so, the prevalence of breast cancer in the United Kingdom [UK] is reported. Furthermore, it is argued that there is a lack of preventative interventions addressing psychosocial factors involved in the aetiology of breast cancer. The main findings of the literature review chapters are presented. Subsequently, the rationale and aims of the present study are described, and an outline of the method is provided. Finally, a brief overview of the chapters detailing the results and discussion is given.

1.2 Breast Cancer in the United Kingdom

Breast cancer is the most common cancer in the UK, with approximately 130 women being diagnosed every day (Cancer Research UK, 2011). It accounts for 18% of all cancers in females (McPherson, Steel and Dixon, 2000) and, according to Cancer Research UK, claimed the lives of 12,116 women in the UK in 2008. Despite improvements in detection and treatment, the mortality rate for breast cancer in the UK is relatively high compared to the rest of Europe (Mayor, 2003; Department of Health, 2000). The number of women in the UK who will get breast cancer in their lifetime has risen from one in nine in 1999 to one in eight in 2008; this rise has largely been attributed to an increase in life expectancy, the extension of breast-cancer screening up to the age of 70, and lifestyle factors such as obesity, excessive alcohol intake, and a sedentary lifestyle (Wise, 2011; Smith, 2011). An additional contributing factor is the advanced stage of the disease at first presentation (McCready, Littlewood and Jenkinson, 2005).

A plethora of research into physical breast-cancer risk factors has been carried out. The most established risk factors include age, drinking more than two units of alcohol a day, a sedentary lifestyle, being overweight after menopause, nulliparity (having never had any pregnancies), first pregnancy at age 35 or later, having few children, not breastfeeding, using Hormone Replacement Therapy, contraceptive pill use, and hereditary factors (Cancer Research UK, 2011). However, a large portion of breast cancers cannot be attributed to known physiological risk factors (Seidman, Stellman and Mushinski, 1982; Fox, Harper, Hyner and Lyle, 1994).

Research increasingly points to psychosocial factors as being influential in the aetiology and progression of cancer generally, and breast cancer in particular. Hence, psychosocial factors in the development of breast cancer warrant just as much attention as physiological risk factors. Despite the existing evidence, psychosocial variables have received a paucity of attention, with prevention focusing largely on altering behavioural risk factors, for example, reducing alcohol consumption and increasing physical activity (e.g. Cancer Research UK, 2011; Wise, 2011). However, concentrating exclusively on behavioural risk factors neglects the interplay between biological, psychological and social variables in health and illness, as proposed in the biopsychosocial model (Engel, 1977).

Breast-cancer prevention is largely shaped by the biomedical model, and therefore focuses mostly on breast awareness and breast screening. The Cancer Reform Strategy Breast Cancer Working Group, in its document "Breast Cancer Vision for 2012" (Department of Health, 2007), recommends improvements in the breast-screening programme, as well as encouraging an increase in breast awareness, especially in economically deprived women. In this document, psychosocial factors are mainly mentioned in conjunction with stress (as a single variable with no further explanation), or with the treatment of breast cancer, where it is emphasised that women undergoing such treatment should receive adequate psychosocial support.

Stress is a major area of research in health psychology, but largely unexplored in relation to breast-cancer aetiology. Research into the role of psychological profiles and the ways in which people deal with stressors in their lives is still in its infancy. Becoming ill, especially with severe diseases such as cancer, has been documented as a way of being confronted with one's own psychological make-up. Particularly people who have consciously chosen a healthy lifestyle, and to whom none of the physical risk factors apply, may find it hard to understand how they could have been affected by a potentially terminal illness. This is reflected in the autobiographies of breast-cancer sufferers such as Farrell Yelland (2000) and Rabinovitch (2007). There is a clear need to examine other factors, particularly psychosocial ones, more closely; especially those factors for whom links with breast-cancer development have already been demonstrated. Research into these factors is presented and discussed in the literature review chapters of this thesis.

1.3 Main Findings of Literature Review Chapters

Chapter Two of the current thesis reviews the extensive research into psychosocial factors involved in the development of breast cancer, including prospective and large-scale studies. It is shown that the psychosocial factors most consistently found to contribute to breast-cancer development consist of a 'breast-cancer prone' personality, the occurrence of bereavement and other stressful life events, maladaptive coping with bereavement and other stressful life events, and a lack of social support. Although research which has failed to demonstrate a connection between these factors and breast cancer is also discussed, potential theoretical and methodological reasons for their failure to detect any connection are explored. Moreover, it is argued that an integrated model of these risk factors and how they interact is lacking (Eysenck, 1994).

Chapter Three summarises the proposed psychosocial pathways leading to breast cancer. Firstly, psychoneuroimmunological studies are examined. These have demonstrated separate links between bereavement and other stressful life events, a lack

of social support and loneliness, emotional suppression, and compromised immune functioning. Compromised immune functioning in turn may lead to an increased vulnerability to breast cancer. Subsequently, the diathesis-stress theory of disease and its application to cancer is described and evaluated. The theory posits that stressful life events and diathesis (i.e. genetic predisposition, physical risk factors, personality traits, maladaptive coping strategies, and low social support) interact synergistically to produce cancer. According to the diathesis-stress theory, both stress and diathesis on their own have a smaller effect than when combined, their combined effect being multiplicative rather than additive.

Next, the idea of breast cancer as a manifestation of the loss of the feminine role is examined and discussed, as proposed by Liste (1999), who draws on psychodynamic and psychosomatic theory. She postulates that cancer patients are likely to have more feminine than masculine traits and therefore use more feminine defence mechanisms. Cancer, it is argued by the author, often appears after an important loss, leaving the individual with little space to unfold their feminine qualities. Liste claims that breast cancer is an attempt by women to rid themselves of the breast as a symbol of certain aspects of their femininity. She suggests that the nurturing qualities of womanhood are of no significance in our modern society, which places emphasis on the production of quantifiable, measurable goods. Finally, the need for more research which elucidates the precise mechanisms governing these pathways is highlighted.

Chapter Four examines interventions which have addressed the individual psychosocial factors involved in the aetiology of breast cancer. Specifically, research implementing art therapy, Internet therapy and Internet support groups, written emotional expression, laughter and humour therapy, the reading of health-related autobiographical accounts, and approaches targeting multiple factors is discussed. Furthermore, the potential usefulness of reading autobiographical accounts of breast-cancer sufferers to

psychologically susceptible women, in order to raise their awareness of the connection between psychosocial factors and breast cancer, is examined.

Apart from Internet therapy, the presented approaches usually take place in face-to-face settings, which limits their accessibility to individuals unable to travel to the location where the intervention takes place. It is posited that the face-to-face approach is less suitable than Internet therapy for women who find it difficult to express their emotions, as these women may feel more comfortable disclosing their feelings in an anonymous Internet setting. Furthermore, there are very few studies that have focused on more than one psychosocial factor involved in breast cancer at a time, and to date there are no published studies targeting multiple factors simultaneously. Moreover, the literature review shows that most interventions are delivered to individuals who have already developed breast cancer. Besides, there are many interventions whose objective is not breast-cancer prevention, although they do target psychosocial factors which are relevant to the development of breast cancer. Thus, there is a need to design and deliver an intervention which focuses on all important psychological breast-cancer risk factors, and has the potential to reach a substantial number of women. It is put forward that this potential is realised through a Coping-Enhancement Programme for the Bereaved (CEPB), delivered over the Internet.

1.4 Rationale and Aims

Chapter Five outlines the rationale and aims of the present study. Psychologists have been involved in bereavement counselling for decades (Worden, 2008). Client groups consist mostly of people acknowledging the severe impact of their bereaved state. However, bereavement counselling as a preventative measure for people being unaware of the impact of their loss on their psychosocial and physical functioning has thus far not been reported. This is a significant omission, particularly considering the high prevalence of breast cancer among bereaved women (Chen, David, Nunnerley, Michell, Dawson,

Berry et al., 1995; Li, Johansen, Hansen and Olsen, 2003; Lambe, Cerrato, Askling and Hsieh, 2004). Furthermore, these therapeutic techniques have been mostly performed in face-to-face encounters (Wagner, Knaevelsrud and Maercker, 2005; 2007). In recent years, innovative attempts have been made to deliver therapeutic interventions, including bereavement counseling, via the Internet (Lange, Schrieken, van de Ven, Bredeweg, Emmelkamp et al., 2000; Lange, van de Ven, Schrieken and Emmelkamp, 2001; Lange, Rietdijk, Hudcovicova, van de Ven, Schrieken et al., 2003; Wagner, Knaevelsrud and Maercker, 2005, 2007). In the 21st century digital media have become an important and powerful tool of communication in health care (Wong, 2006), yet research exploring the effects of Internet-based bereavement counselling initiatives is sparse (Wagner, Knaevelsrud and Maercker, 2005). There is a strong rationale for developing an Internet-based intervention for women who have been bereaved and who, due to certain psychosocial factors, have a higher chance of developing breast cancer than non-bereaved women. At the time of writing, there were no published studies detailing the design or outcomes of such interventions. Moreover, no British intervention studies addressing the psychosocial factors potentially associated with breast-cancer development had been published at the time this project was conducted. Due to the growing prevalence of breast cancer in the UK, this seemed an important issue to attend to.

Another way in which the present study aimed to make a contribution to knowledge was by using autobiographical accounts of breast-cancer sufferers as a therapeutic tool, and by evaluating their utility for raising awareness of psychosocial factors potentially associated with breast-cancer development. An additional important aim was to explore women's experiences of coping with bereavement and other stressful life events, as well as their experiences of participating in the CEPB, in order to elucidate which aspects of the programme were the most (and least) effective, useful and enjoyable to participants.

It was expected that women who participated in the CEPB would exhibit lower levels of maladaptive coping with bereavement and of maladaptive coping with stressful life events than those who did not participate. Furthermore, higher levels of social support and of the awareness of the connections between psychological and physical health were expected.

1.5 Outline of Method

Chapter Six details the design of the psychological screening tool used to assess participants' eligibility to participate in the study and measure the most established psychosocial factors potentially involved in breast-cancer development. This involved the undertaking of two pilot studies.

The first pilot study served the purpose of establishing the face validity of the scales used in the screening tool. All participants made largely accurate judgments about what constructs the instruments purported to measure. None of the items were deemed unsuitable by any of the participants.

The second pilot study assessed the scales' internal consistency and the screening tool's usability in terms of its perceived ease of use and participants' intrinsic motivation to complete it. Two versions of the screening tool that contained different scales were evaluated. Based on the results, the most internally consistent scales were chosen for the final version of the tool. Furthermore, participants' comments helped optimise the final version, to make it easier and more enjoyable to use.

Chapter Seven details the design of the CEPB. It outlines the guidelines and recommendations which were adhered to when designing the programme; the considerations that influenced the development of its individual elements; and the design of the intervention Web site. Chapter Seven also describes Pilot Study Three, which examined the intervention Web site's perceived ease of use and participants' enjoyment

of the site. It is explained that the CEPB was designed to incorporate two elements: an emotional-expression-and-stress-reduction element ('Art and Laughter for Wellbeing'), and a psycho-educational element (the reading of autobiographical accounts of breast-cancer sufferers). Each element addressed different psychosocial factors involved in breast-cancer development. It is also emphasised that the researcher consulted an accredited counselling psychologist and specialist in women's health while designing the programme, which was planned as a group intervention. The intervention Web site was designed by the researcher, and tested by a group of 15 participants. The results of this pilot study were used to improve the Web site's usability, and to create the final version of the site. The final site contained message boards on which the programme was carried out, as well as individual blogs for each participant.

Chapter Five explains the method of the main study. An experimental 2×2 independent measures design with triangulation was used, employing qualitative and quantitative methods. The two independent variables were psycho-education (reading autobiographical accounts of breast-cancer sufferers or not reading them) and Emotional-Expression-and-Stress-Reduction (taking part in 'Art and Laughter for Wellbeing' or not taking part in the same). Dependent variables, to be measured quantitatively, included maladaptive coping with bereavement, maladaptive coping with stressful life events, social support, and the awareness of the connections between psychological and physical health. Blogs, message boards and questionnaires were used to collect data. Furthermore, three methods of data analysis were used. Triangulation of the methods of data collection and analysis enabled the exploration of the topic at hand from different perspectives.

A self-selected (volunteer) sample of 31 women (23 intervention-group participants and eight control-group participants; mean age = 43.1, *SD* = 14.7, age range 18-74) were recruited through advertisements on Internet forums, on University intranets, on the UK

Classifieds Web site Gumtree *(www.gumtree.com)*, on the social networking Web site Facebook *(www.facebook.com)*, as well as through advertising the study in interviews with newspapers, in a radio interview, and on leaflets distributed at various locations. Potential participants initially completed the online screening tool. This tool assessed the following: demographic variables; the most established physical breast-cancer risk factors; the most established psychosocial factors potentially associated with breast-cancer development (maladaptive coping with bereavement, maladaptive coping with stressful life events, 'breast-cancer prone' personality, and social support); awareness of the connections between physical and psychological health; perceived ease of use and enjoyment of the screening tool; previous experience reading autobiographical accounts of breast-cancer sufferers; Internet use and experience using the Internet.

Once their eligibility to participate in the study had been established, women were randomly allocated to one of four conditions, provided with an anonymous username and log-in details, and given access to the intervention Web site. They then participated in the eight-week long CEPB, apart from control-group participants, who received no intervention. At the end of the programme, participants filled in a second questionnaire which measured the dependent variables as well as their experience of the programme. A follow-up questionnaire was administered six weeks after the end of the programme, in which the dependent variables were measured again.

1.6. Organisation of Chapters Detailing Findings and Discussion

The findings of the current study are reported and discussed in Chapters Eight to Ten. Chapter Eight describes the process of the CEPB. Chapter Nine reports the findings of assessing the CEPB's effectiveness. Chapter Ten presents a summary and discussion of the results yielded by the current study in relation to the literature. Finally, this thesis' contributions to knowledge are presented, and a biopsychosocial model of breast-cancer development is proposed. Furthermore, limitations of the present research are discussed,

and recommendations for future research are made, highlighting the role that health

psychologists should play in the advancement of research in this area.

CHAPTER TWO

PSYCHOSOCIAL FACTORS INVOLVED IN THE

AETIOLOGY OF BREAST CANCER

CONTENTS

2.1 Introduction

The concept of a 'cancer-prone' personality dates back to 200 AD, when Greek physician and philosopher Galen, in his book *De Tumoribus*, suggested that a connection existed between the melancholic temperament and cancer (cited in Eysenck, 1994). Other early writers took a similar stance and suggested that factors such as difficulties in coping with stress, which lead to feelings of helplessness, hopelessness and depression (Gendron,1701; Guy,1759), as well as the suppression of emotions (Stern, undated; cited in Suess, Kinzel and Scribner,1973), acted as precursors of breast cancer.

At the beginning of the 20th century, the increasing discoveries made by modern medicine and Pasteur's germ theory of disease convinced physicians to focus on physical causes of disease. Thus, the interest in psychological risk factors of cancer waned, only to be revived in the 1950s (Eysenck, 1994), when a wealth of cancer-mind literature was published. Particularly, factors such as personality (Bacon, Renneker and Cutler, 1952; Blumberg, West and Ellis, 1954), stressful life events (Miller and Jones, 1958) and bereavement (LeShan, 1959; Greene and Miller, 1958) were purported to play a role in the aetiology of cancer.

This chapter reviews the research exploring the psychosocial factors which have since been examined. It focuses in particular on the literature concerned with the aetiology of breast cancer, examining personality traits, inappropriate coping with stress, experiencing bereavement and other stressful life events, and low social support. However, as many studies have not focused on breast cancer primarily, but rather examined it as part of many types of cancer, studies dealing with other cancers will also be discussed where appropriate, if they have examined psychosocial variables which are of relevance to breast cancer.

2.2   Breast Cancer and Personality

There is a sizeable body of literature exploring the connection between cancer and personality traits. Two personality profiles in particular have been proposed to be 'cancer-prone': Type I and Type C personality. Type I personality, suggested by Grossarth-Maticek (1980), is characterised by feelings of helplessness and hopelessness leading to depression. This personality type stands in contrast to the 'coronary heart-disease-prone' Type II personality characterised by feelings of anger, hostility and aggression. Grossarth-Maticek, Eysenck and Boyle (1994) investigated the occurrence of cancer and coronary heart-disease in individuals who had been to a Nazi concentration camp. They found that those with a Type I personality were more likely to develop, and die of, cancer, while in those with a Type II personality, the incidence and mortality of coronary heart disease was higher, compared to healthy controls.

Temoshok and colleagues (Temoshok and Fox, 1984; Temoshok and Dreher, 1992), on the other hand, through observation and research with cancer patients, coined the idea of the Type C personality, whose traits include the need to be overly cooperative, appeasing, unassertive, patient and compliant with external authorities. Also, individuals with a Type C personality are unable to express negative emotions, especially anger, fear and sadness. The Type C personality seems to be strongly represented among cancer patients (Temoshok and Dreher, 1992). Baltrusch, Stangel and Waltz (1988) discussed how the Type C behavioural pattern demands a constant arousal of the neuroendocrine and immunological system, which will become heavier under more severe stress. This is in line with Temoshok's (2000) findings of the effects of Type C personality profile on the immune response. In her theory, Type C is constructed as "maladaptive learned coping patterns, which represent deviations from homeostasis in that they fail to recognize, respond appropriately to, and/or resolve stressors, thus keeping the physiological stress response chronically engaged, with subsequent long-term damage to implicated biological systems" (p.450).

Closely related to this personality profile is alexithymia, a personality trait typified by the inability to verbally express emotions and the tendency to be rational and anti-emotional (Meijer-Degen and Lansen, 2006). Alexithymia is a stable trait dimension (Luminet, Rokbani, Ogez and Jadoulle, 2007) and has been linked with the tendency to suffer from somatic complaints, and a decreased immune response (Guilbaud, Kurt, Perrin, Chaouat, Berthoz et al., 2009). Alexithymic tendencies have also been associated with the development of breast cancer (Bleiker, 1995).

From the early 1950s onwards, considerable research has been carried out into both personality traits relating to the Type I personality as well as those relating to the Type C personality. In the following, this research is reviewed.

2.2.1   Retrospective Studies

In early retrospective studies, cancer research targeted individuals who had already developed cancer, and investigated which factors may have led or contributed to the development of the disease. Bacon, Renneker and Cutler (1952) studied the psychological profiles of 40 women with breast cancer and proposed that the development of the disease was associated with a masochistic character structure; inhibited sexuality; an inability to discharge or deal appropriately with anger, aggressiveness or hostility, covered by a façade of pleasantness; an unresolved hostile conflict with the mother, handled through denial and uncharacteristic sacrifice; and delay in securing treatment. Blumberg, West and Ellis (1954) found that patients with various types of cancer whose disease progressed rapidly showed a "high defensiveness or a strong tendency to present the appearance of serenity in the presence of deep inner distress" (p. 278). However, the authors did not differentiate among different types of cancer.

Greene, Young and Swisher (1956) reported that women with leukaemia had suffered from depression prior to the onset of the disease. Similarly, Greene and Miller (1958)

studied hospitalised children with leukaemia; findings revealed that a significant proportion of their participants had depression and hopelessness due to being separated from their parents. Two decades later, LeShan (1977) conducted extensive research into personality precursors of cancer and showed that the typical features of the cancer patient were a loss of hope, an inability to express hostility on one's own behalf, the loss of a crucial relationship, feelings of despair, and emotional suppression.

These findings combine features of both Type C and Type I personality. However, although the studies presented indicate a connection between cancer and personality traits, there are some methodological issues. Most of these studies relied on post-hoc, subjective personality assessments, rather than employing a prospective design. Therefore, a causal relationship between cancer and personality traits cannot be inferred; nor is the direction of this relationship clear. Furthermore, these studies lacked objective measures of personality, relying instead on self-report. Another problem is that many retrospective studies did not differentiate between different types of cancer, and it cannot be ruled out that different types of cancer may be associated with different personality types or traits.

From the early 1960s, more controlled research into personality correlates of cancer was carried out. Kissen and Eysenck (1962) investigated the relationship between neuroticism, characterised by high levels of negative affect such as depression and anxiety, and lung cancer. They found that participants who scored low on the neuroticism scale of the Eysenck Personality Inventory (Eysenck,1964) were six times as likely to have lung cancer as a person with high neuroticism score, suggesting that the poorer the outlet for emotional discharge, the less exposure to cigarette smoke was required to induce lung cancer. This finding verifies the hypothesis that lung cancer is associated with emotional suppression. The strength of these findings is highlighted when considering a methodological weakness of the study: the researchers' failure to distinguish between

individuals who suppressed their anxiety and those who were genuinely low in anxiety suggests that the association between low *N* and the presence of lung cancer may have been even stronger if this had been taken into account.

Kissen (1963) conducted a study with 161 men suffering from lung cancer and a control group suffering from other pulmonary diseases. He found that cancer patients were less likely to express their emotions than those with no cancer, and had apparently possessed this characteristic since childhood. A subsequent study conducted by Kissen, Brown and Kissen (1969) revealed similar results.

Although more controlled than the studies from the 1950s, besides employing inadequate control groups and seldom controlling for other factors known to be influential in the development of cancer, these studies still suffer from the same methodological flaw as the studies from the previous decade: because they were retrospective in design, it is impossible to infer any causal relationships from their results. In other words, based on these studies it is impossible to determine whether personality traits led to the development of cancer, or whether these traits were a result of developing cancer.

More recently in mind-cancer research, researchers have attempted to address some of the shortcomings of the early studies (Eysenck, 1994). For example, in a retrospective study Jansen and Muenz (1984) examined various personality variables, including emotional expressiveness, in women with breast cancer, women with fibrocystic breast disease, and healthy women. In their data analysis, demographical differences between the two study groups and the control group were controlled for. Among other instruments, the questionnaire battery which was administered contained the Multiple Affect Adjective Checklist (Zuckerman and Lubin, 1965), which yields scores on an anxiety scale, a depression scale and a hostility scale. The researchers reported that women with breast cancer exhibited less feelings of aggression than either women with fibrocystic breast

disease or healthy women, and also perceived themselves to be less demonstrative, expressive and aggressive than women in the other two groups. Women with breast cancer were more likely to describe themselves as timid, non-assertive, non-competitive, calm, easy-going, and suppressing anger.

While this study, with its healthy control group and its control for differences in demographic variables, had methodological advantages over most of the earlier studies in this field, it was still a retrospective study, which precludes causal inferences. Furthermore, the researchers did not control for known physical risk factors of breast cancer. This means that the results must be interpreted with caution.

Attempts have been made to integrate psychosocial risk factors in breast cancer into a theoretical framework. To this end, Tacon, Caldera and Bell (2001) compared attachment style and emotional control in 52 breast cancer survivors and 52 women without cancer. Based on attachment theory (Bowlby, 1988), which posits that experiences early in the lifespan lead to different relationship attachment styles, the authors hypothesised that women who had had breast cancer would be more likely to have an avoidant attachment style. This is characterised by the traits typical of the Type C personality: high emotional control and the concealment of negative affect, particularly anger. Avoidant attachment has been proposed as a risk factor for physical health (Kotler, Buzwell, Romeo and Bowland, 1994). As hypothesised, Tacon et al. found that survivors of breast cancer reported significantly higher avoidance and higher degrees of emotional control. While this study is important, as it represents a rare attempt to shed light on the aetiology of the 'breast cancer-prone' personality, these findings must be interpreted with caution. Due to the retrospective nature of the study it could not be determined whether an avoidant attachment style was a precursor to breast cancer, or whether it developed after the diagnosis. Perhaps the results may have been strengthened considerably had the

researchers obtained accounts of partners and/or close relatives to verify that participants' attachment style had been developed before their diagnosis of breast cancer.

In a recent retrospective study, Iwamitsu, Shimoda, Abe, Tani, Okawa et al. (2005) highlighted the impact of emotional suppression on coping with a breast cancer diagnosis. In their study, patients who suppressed negative emotions and who had chronically high anxiety levels were more likely to experience high psychological distress both before and after the diagnosis, than those who did not suppress negative emotions.

However, even these modern studies share a shortcoming with the earlier studies: in nearly all of these, patients had already developed cancer, making the direction of the causal link uncertain, as the studies were neither prospective nor experimental in nature (Hu and Silverfarb, 1988).

2.2.2   Prospective Studies Examining Breast-Cancer Incidence

To overcome the problem of determining the causal direction of the link between breast-cancer development and personality traits, some studies have employed either a prospective or a quasi-prospective design: personality variables are measured shortly before a breast-cancer diagnosis becomes known to a particular patient or researcher, in order to prevent bias stemming from the participant's and/or the researcher's knowledge of the disease status.

Schmale and Iker (1971) conducted such quasi-prospective research, which marked the advent of more controlled studies into cancer and personality variables. Their findings, gleaned from interview data collected before the patients underwent a biopsy, indicated that women presenting with cervical cancer failed to cope with stress effectively, tended to give up, and develop feelings of hopelessness and helplessness. This matches the description of the 'cancer-prone' Type I personality as posited by Grossarth-Maticek.

Greer and Morris (1975) employed a similar quasi-prospective design. They administered structured interviews and tests, including the Eysenck Personality Inventory and the Caine, Foulds and Hope (1967) Hostility and Direction of Hostility Questionnaire (HDHQ), which assesses an individual's degree of hostility and whether this hostility is directed towards others or towards oneself, to 160 women admitted to hospital for breast-tumour biopsy. Interviews were conducted on the day before their operation was to take place. To prevent bias, the interviewers had no knowledge of the provisional diagnosis. Husbands or close relatives were also interviewed separately to verify the patients' accounts. Among other variables, it was assessed how much patients expressed or concealed their emotions. Those patients who were found to have breast cancer were compared to those diagnosed with benign breast tumours. The findings indicated that women with breast cancer were more likely to be 'extreme suppressors': they rarely or never openly showed anger, and had always or nearly always concealed other feelings. These individuals also had low Acting-Out Hostility scores on the HDHQ, indicating that they were less likely to openly display hostility than those with benign breast disease. Generally, an "abnormal release of feelings" (p.151) was noted to be more common in the cancer patients, particularly in those over 40 years of age, while extreme suppression of anger was particular to participants under 40. In a similar but less well-controlled study, Schonfield (1975) revealed that denial of aggression was related to an increased risk of breast cancer.

While these results tend to support the notion that breast cancer is associated with the suppression of emotions, there are several methodological issues which prevent from drawing any definite conclusions. Firstly, the control group in this study – women with benign breast disease – was not an ideal choice, as the authors themselves pointed out. It cannot be ruled out that women with malignant breast tumours and women with benign breast tumours have certain psychosocial characteristics in common. Furthermore, benign breast conditions can be precursors of breast cancer (Harmer, 2008), which makes the

use of patients with benign breast disease as a control group even more problematic, because this could minimise any existing significant differences. Finally, the design of the study, which involved interviewing women on the day before their operation, may have influenced results in the sense that women who had been referred for a breast biopsy based on a suspicious mammogram or suspicious symptoms may already have been sensing that something was wrong; for instance, they may have received cues from their own bodies, or from their general practitioner (Stolbach and Brandt, 1988; Greer and Morris, 1978).

Six years after Greer and Morris, Morris, Greer, Pettingale and Watson (1981) conducted a similar study with some methodological improvements, including independent ratings of the interviews by researchers who had never seen the patients. Although this time the sample was only half of the size of the one used in the 1975 study, the results again indicated that cancer patients tended to suppress feelings of anger and lost control in anger less frequently than did patients with benign breast disease.

In a study investigating concepts related to breast-cancer prone personality features, Hahn and Petitti (1988) examined the Minnesota Multiphasic Personality Inventory (MMPI) data from the Walnut Creek Contraceptive Study, a large prospective study with more than 8900 women which was begun in 1969 and finished in 1988. The authors sought to determine whether depression, repression-sensitization (the tendency to engage in avoidance or approach behaviour when confronted with distressing events and feelings - Altrocchi, Parsons and Dickhoff, 1960) and lying was associated with breast-cancer incidence. Although no association was found between depression or repression-sensitization and breast-cancer incidence, women who developed breast cancer were more likely to score high on the lie scale than women who did not develop breast cancer. The authors concluded from this that psychosocial factors do not cause breast cancer. One of the problems of this study is that it used MMPI data; Eysenck (1994) has argued

that the MMPI is not a relevant test because it is not specifically designed to test theories of association between breast cancer and psychosocial variables. Another problem is that the researchers set out to investigate whether psychosocial factors *cause* breast cancer. As detailed later in this chapter, this is a flaw which many studies in this field share. Findings from other studies (e.g. Grossarth-Maticek, Eysenck, Boyle, Heeb, Costa et al., 2000), are discussed in more detail below, indicate that the relationship between breast-cancer incidence and psychosocial factors is not as simple and clear-cut as studies such as Hahn and Petitti's assume. Therefore, if the aim is to detect a simple causal relationship, positive results are unlikely to be discovered. Finally, although Hahn and Petitti found a positive relationship between breast-cancer incidence and high scores on the Lie scale of the MMPI, these results were dismissed by the authors as "not likely to be biologically important" (p.846). It is unclear why this finding was not deemed worthy of further investigation, particularly in the light of other findings that repressors are more likely to score highly on measures of social desirability (e.g. Weinstein, Averill, Opton and Lazarus, 1968; Weinberger, Schwartz and Davidson, 1979; Lane, Sechrest, Riedel, Shapiro and Kaszniak, 2000).

Scherg, Cramer and Blohmke (1981) asked women attending a breast clinic for a biopsy to complete the Bahnson and Bahnson (1979) psychosocial questionnaire, which contains scales measuring anger suppression, external control and social desirability. They compared 100 women with a breast cancer with 100 women without a cancer diagnosis. Findings indicated that women diagnosed with breast cancer who were younger than 50, were more likely to suppress anger than the controls. These findings are in line with Greer and Morris's (1975; 1978) findings. However, the psychosocial questionnaire was found to discriminate poorly between the experimental groups and the control group. Wirsching, Stierlin, Hoffmann, Weber and Wirsching (1982) reported similar results, with breast-cancer patients in their sample exhibiting rationalisation, emotional suppression, and little or no anxiety before the biopsy.

Another quasi-prospective study was described by Grassi and Cappellari (1988). Before breast-lump biopsy, 76 women completed the Courtauld Emotional Control Scale (CECS), developed by Watson and Greer (1983). This scale is used to evaluate the extent to which individuals report controlling negative emotions, specifically anger, anxiety and depressed mood. Although age and other known predictors of breast cancer were not controlled for, the results indicated that participants who were diagnosed with breast cancer scored higher on the CECS than those with benign breast disease, indicating greater emotional control. Also, breast-cancer patients exhibited lower levels of hostility.

Anagnostopoulos, Vaslamatzis, Markidis, Katsouyanni, Vassilaros et al. (1993) employed a similar study design to compare hostile and alexithymic characteristics in 180 women with breast cancer, 112 women with benign breast disease, and 156 women with healthy breasts. A random subset of 100 participants completed the Toronto Alexithymia Scale (Taylor, Ryan and Bagby, 1985). Hostility was assessed in all women using the Personality Deviance Scale (Bedford, 1978). Although no statistically significant association was reported between alexithymia scores, or hostility scores, and breast cancer, it was found that women with low denigratory attitudes towards others were more likely to receive a diagnosis of breast cancer than those with higher denigratory attitudes. This finding is consistent with studies reporting breast-cancer patients to be more likely to present a pleasant outer façade (e.g. Watson, Pettingale and Greer, 1984), a typical feature of the Type C personality.

Fox, Harper, Hyner and Lyle (1994) conducted a quasi-prospective study with 826 women awaiting mammograms at a breast clinic. The CECS was administered to participants before they had the mammogram, and the diagnosis was not known to the researcher or the participant at the time the scale was being administered. The results showed a hierarchy of most emotional suppression to least suppression to occur from the most-

diseased to the most-healthy subjects. Those who had been newly diagnosed with cancer suppressed their emotions the most, followed by those who had had cancer previously, those who had benign breast disease, and finally the healthy group, who engaged in the least emotional suppression. These results held up after controlling for known physical risk factors. However, the response rate in this study was only 41%, which may have resulted in selection bias. Furthermore, as discussed above, the same caveat applies to other quasi-prospective studies in this field: women may subconsciously have been aware of the diagnosis, either through receiving cues from their own bodies, or through information given to them by their general practitioner (Stolbach and Brandt, 1988; Greer and Morris, 1978). Nevertheless, the negative linear relationship between emotional suppression and health lends support to the notion that there is an association between emotional suppression and breast-cancer incidence.

Bremond, Kune and Bahnson (1986) reported results from an age-matched quasi-prospective study on 50 patients with breast cancer and 105 healthy controls. Through interviews, it was gleaned that the women in the cancer group were more likely than controls to want to appear as conforming to social norms and to want to be seen as a 'nice' or 'good' person. They were also more likely to suppress their emotions, especially anger.

Bleiker (1995) conducted a prospective study in which 9705 women attending a breast-screening centre for a mammogram in Nijmegen, the Netherlands, filled in a questionnaire measuring 11 personality traits. It was found that women who were later diagnosed with breast cancer tended to score higher on the 'rationality/anti-emotionality scale', based on Grossarth-Maticek, Bastiaan and Kanazir's (1985) concept of the 'rationality-and-anti-emotionality' factor. These individuals less frequently than others trusted their feelings and less frequently let their behaviour be influenced by their emotions. These findings support

the notion that alexithymic characteristics are associated with the development of breast cancer.

A recent quasi-prospective study examining breast-cancer incidence was reported by Eskelinen and Olonen (2011), who semi-structurally interviewed 115 women with breast-cancer symptoms, as well as asking them to complete standardised questionnaires. Depression was assessed with the Beck Depression Inventory (Beck, 1972). After completing the questionnaire and the interview, women underwent clinical examination. It was found that women with a breast-cancer diagnosis tended to be more depressed and were more likely to engage in self-blame than women with benign breast disease and healthy women. Although the Beck Depression Inventory assesses depression and not Type I personality *per se*, this finding could nevertheless be seen as the indication of a link between Type I personality traits (i.e. helplessness and hopelessness leading to depression) and breast-cancer development, as demonstrated in previous studies.

Some negative findings have been reported as well. For example, O'Donnell, Fisher, Irvine, Rickard and McConaghy (2000) examined breast-cancer occurrence in 1151 women with suspicious mammograms who had been referred to hospital for a biopsy. Emotional suppression was measured with the CECS, prior to biopsy. The study detected no significant association between emotional suppression and breast-cancer outcome. However, this failure to detect any relationship may be due to the fact that the authors did not include a measure of social desirability. Eysenck (1994) has emphasised the importance of including such a measure, because 'cancer-prone' individuals typically combine high scores on social desirability scales with low scores on anxiety scales. Thus, a social desirability measure is needed to accurately detect 'cancer-prone' individuals.

2.2.3   Prospective Studies Examining Breast-Cancer Survival

Prospective studies, which involve following up a group of individuals studied at one fixed point in time (T1) and analysing for mortality at another fixed point in time (T2), provide

invaluable evidence in the field of mind-cancer research (Temoshok and Dreher, 1992). According to Eysenck (1994), in this context there are two different types of prospective study: one type studies cancer patients as described above, by measuring personality and stress variables at T1 and determining survival rates at T2. The other type of prospective study uses survival time as a dependent variable, hence T2 is not fixed.

Grossarth-Maticek and Eysenck (1995) attempted to predict survival from levels of self-regulation in five groups of patients suffering from different types of cancer (breast, colorectal, stomach, bronchial or other tumours). Self-regulation was defined as the ability to adapt to circumstances, control one's emotions, cope adequately with external stressors, not to suppress one's feelings, being physically active, being assertive but not aggressive, being flexible rather than rigid, and able to alter one's behaviour to achieve satisfaction of important life aims. Physiological risk factors such as drinking and smoking were controlled for. For each type of cancer included in the study, it was found that patients only surviving one or two years had low self-regulation scores, while those surviving 18 years or more had high self-regulation scores. Thus, self-regulation predicted survival in cancer patients, independently of health-related behaviours associated with cancer.

Greer, Morris and Pettingale (1979) conducted a prospective study into survival rates among breast-cancer patients. The results indicated that survival five years after the diagnosis of breast cancer was significantly related to psychological variables which had been assessed at the beginning of the study. Specifically, women who exhibited 'fighting spirit' and actively confronted their disease were more likely to survive than those who displayed stoic acceptance of their situation, or helplessness and hopelessness. Thus, the psychologically 'cancer-prone' women had a poorer prognosis than those who had the opposite type of personality. These findings support Grossarth-Maticek's concept of the 'cancer-prone' Type I personality.

A similar prospective study into survival among breast-cancer patients was conducted by Derogatis, Abeloff and Melisaratos (1979), who reported that women who survived for more than a year scored higher on measures of hostility and anger than those who died within the first year. Shorter survival time was associated with low levels of reported hostility and higher levels of reported positive mood. Unfortunately, a measure of social desirability was not administered in this study – this would have helped determine whether the low levels of hostility and high levels of positive mood were indicators of a 'cancer-prone' personality.

Blumberg, West and Ellis (1954) administered a battery of psychological tests, including the MMPI, the Rohrschach, the Thematic Apperception Test, and the Wechsler Bellevue Intelligence Test, to 15 patients with various cancers, including breast cancer. Patients were matched for age, intelligence, and stage of cancer. It was found that those patients who died in less than two years were consistently serious, overly cooperative, overly nice, overly anxious, painfully sensitive, passive, apologetic personalities. Reports from family and friends revealed that these individuals had had these characteristics before the onset of the disease. Compared to patients who died after more than six years, those who survived for a shorter period of time had higher depression scores and lower 'acting-out' scores. Although these results lend support to the notion of a 'cancer-prone' personality, it is important to note that the sample size in this study was small, and the psychological tests which were used are currently recognised to be of low validity and reliability (see Eysenck, 1994).

In a prospective study, Stavraky (1968) studied 204 cancer patients over 40 to 66 months, administering the MMPI, Wechsler Verbal Intelligence Test and a projective personality assessment, and found that those with the most favourable outcome had strong hostility without loss of control. Similarly, Jensen (1987) followed a group of 52 women with breast

cancer for nearly two years and discovered that those who displayed reduced negative affect had a quicker disease progression than those who were not inhibited in expressing negative emotions.

Temoshok (1985) reports that in a prospective study of cancer patients, emotional expression of sadness and anger, rated from interviews which were videotaped, related to disease progression: those who expressed their sadness and anger had slower disease progression than those who were inhibited in expressing their negative emotions.

In the same year, DiClemente and Temoshok (1985), studying patients suffering from malignant melanomas, observed that among women, stoic acceptance made for a poor prognosis. More recently, Giese-Davis, Conrad, Nouriani and Spiegel (2008) discovered an association between higher repression of anxiety in breast-cancer patients and higher diastolic blood pressure, indicating chronic stress and poorer health.

The studies reviewed above support the notion that Type I and Type C characteristics are associated with shorter survival times in breast-cancer patients. It thus appears that these personality traits have a negative effect on disease progression.

2.2.4   Prospective Studies Examining Breast-Cancer Mortality

Another type of prospective study in mind-cancer research consists of investigating healthy individuals at T1 and following them up for a number of years to a point T2, when mortality and incidence of cancer is determined. Eysenck (1994) has explained that such studies are few in number, as they require large numbers of participants, particularly when studying a particular type of cancer, and the type of cancer studied will place constraints on the selection of the sample in terms of sex (e.g. breast-cancer studies will only recruit women) and age (the younger the participants, the longer the follow-up period required to

ascertain mortality). Thus, studies of this nature are relatively restricted in their coverage, which nevertheless does not diminish their relevance.

Examples of such studies include those reported by Shekelle, Raynar, Ostfield, Garron, Bielanskas et al. (1981), and Persky, Kempthorne-Rawson and Shekelle (1987), who examined mortality in a sample of over 2000 middle-aged employed men taking part in the Western Electric Study. The follow-up period was 17 years. The authors reported that presenting with depression at baseline (measured with the MMPI) was associated with a twofold increase in the odds of dying from cancer.

Converse findings have been reported by Dattore, Shontz and Coyne (1980), who collected MMPI profiles of 75 veterans with cancer and 12 without cancer, who had been tested upon entry into a Veterans Administration hospital. The MMPI profiles had been completed before the participants were diagnosed with cancer. The results indicated that individuals with cancer were more likely to be high in repression, and low in depression, than individuals who did not develop cancer within the 10 years of the follow-up period.

Shaffer, Graves, Swanck and Pearson (1987) followed 972 physicians, of whom personality measures had been obtained at baseline, over a period of 30 years and assessed incidence of and mortality from cancer. It was discovered that those who usually gave vent to their emotions had the lowest cumulative incidence of cancer, while those who tended to be 'loners' or suppress their emotions beneath a bland exterior had a higher cumulative incidence of cancer. Although the sample in this study was mostly male and the types of cancer that participants developed were not reported, the results still suggest that there is a link between cancer and emotional suppression.

Three major prospective studies assessing cancer mortality and cancer incidence have been conducted by Grossarth-Maticek and colleagues (Grossarth-Maticek, Kanazir, Schmidt and Vetter, 1982; Grossarth-Maticek, Bastiaans and Kanazir, 1985; Grossarth-

Maticek, Eysenck and Vetter, 1988). All studies selected healthy individuals on a randomised basis. Questionnaires were administered by interviewers, medical tests were applied and information on health-related behaviours such as smoking and drinking was collected. The follow-up period in all studies was 10 years. Among other traits, rational-anti-emotional behaviour was assessed, as well as the number of traumatic life-events evoking chronic helplessness. Remarkably, the psychological variables were found to be more important in the prediction of cancer than physical predictors. These results held up even after one of the studies was continued for another four-and-a-half years, and the data were independently reanalysed.

Another major prospective study which focused on breast cancer was conducted by Grossarth-Maticek et al. (2000). As many previous prospective studies had not differentiated between different types of cancer (due to the large number of participants required when assessing the occurrence of one type of cancer alone), this study recruited more than 8000 women in order to be able to focus on breast cancer only. The women were followed over 15 years, and breast-cancer incidence and mortality were assessed. Additionally, both physical and psychosocial risk factors were measured. Physical risk factors included genetic and endocrine factors; being older than 35 at first delivery; early first menstruation; irregular and lengthy menstrual periods; nutritional factors (e.g. a high fat and low vitamin diet); obesity; regular consumption of certain amounts of alcohol; and proliferative breast disease. Psychosocial risk factors were measured by a personality-stress inventory (Grossarth-Maticek and Eysenck, 1990). They included a marked inhibition in the expression of emotions and the satisfaction of personal desires and needs; behaviour characterised by inner excitement and agitation, such as anger; and rational and anti-emotional behaviour. These psychosocial risk factors were based on Grossarth-Maticek and Eysenck's (1990) theory of personal rejection. The theory posits that a relationship between a child and its parents which is characterised by strict parental demands and the suppression of physical and emotional problems leads to a later

dependence of the individual on their partner, as well as thwarted expectations of loving devotion. This results in the suppression of feelings of frustration and aggression.

It was shown that when participants were separated into a 'stressed' and 'non-stressed' group based on their scores on the personality-stress inventory, the proportion of women who developed breast cancer during the follow-up period was significantly larger in the stressed group than in the non-stressed group. Moreover, a relationship between physical and psychosocial risk factors was discovered which was termed 'synergistic' by the authors: breast-cancer incidence and mortality was higher in the stressed than in the non-stressed group for equal levels of physical risk factors. For individuals both with low levels and high levels of physical risk, psychological stress seemed to have no effect on breast-cancer incidence, but for participants with medium levels of physical risk, the presence of stress increased the risk of developing breast cancer. Thus, the results demonstrated that psychosocial risk factors were important in their own right because they seemed to potentiate the effects of physical risk factors which, by themselves, would have been less lethal. Moreover, it was found that the presence of psychosocial risk factors even magnified the effect of hereditary physical risk factors, that is, in individuals who had a close relative who had had breast cancer. Participants in the stressed group who scored higher in hereditary risk factors were more likely to die of breast cancer than participants in the non-stressed group. Thus, the results indicated a multiplicative interaction of psychosocial risk factors with heredity. This 'synergistic' interaction had in fact been shown in earlier studies (Grossarth-Maticek, 1980; Grossarth-Maticek, Eysenck and Vetter, 1988; Eysenck, 1988, 1991; Eysenck, Grossarth-Maticek and Everitt, 1991; Grossarth-Maticek, Eysenck and Boyle, 1994).

Regarding hereditary factors, Fox, Harper, Hyner and Lyle (1994) have pointed out that a large portion of breast cancers cannot be attributed to known physical risk factors. Studies often find that patients with breast cancer and healthy controls do not differ with regards to whether a family history of breast cancer is present. The authors offered the possibility

that rather than an inherited risk, a learned behaviour pattern could be modelled by family members with breast cancer to their children. Thus, some daughters may grow up suppressing their emotions and, in that way, their risk of developing breast cancer will increase.

Grossarth-Maticek et al. (2000) have mentioned that some studies have failed to detect a significant association between breast-cancer incidence and psychosocial factors because they were bivariate in nature: this means that they sought to detect one variable alone which causes breast cancer. From the findings reported above, it seems evident that the relationship between breast cancer and psychosocial risk factors is more complex, in that these factors interact with each other.

2.2.5 Experimental Studies

Strong evidence for a connection between cancer and personality factors comes from experimental studies. Experimental research in this field usually involves presenting emotional disturbance-evoking stimuli to cancer patients and observing their emotional reaction. An example is a study conducted by Kneier and Temoshok (1984), who investigated emotional suppression in Type C cancer patients. The authors compared these to coronary heart-disease patients, who typically exhibit a 'Type A' personality, characterised by anger, hostility and aggression, as well as to a healthy control group. Participants were shown slides intended to evoke emotional disturbance in participants, and incite feelings of sadness, anger, and threats to interpersonal needs or self-esteem. Reactions to these slides were recorded through the measurement of autonomic arousal, as well as asking participants how 'bothered' they had been by the slides. Cancer patients tended to deny being bothered but scored high in measures of autonomic arousal, which was termed 'emotionally repressive' by the researchers. Conversely, coronary heart-disease patients scored low on emotional repression, while healthy subjects' scores lay in

the middle. These results were consistent with the research hypotheses, and provided strong support for a connection between cancer and emotional suppression.

Watson, Pettingale and Greer (1984) presented experimental evidence for a connection between emotional suppression and breast-cancer incidence. Their investigation sought to obtain objective ratings of emotional expression under conditions of experimentally manipulated stress. They compared 30 breast-cancer patients with 27 healthy controls, showing both groups films depicting stressful events, as well as a control videotape depicting a neutral event. Participants completed the CECS, the State-Trait Personality Inventory (Spielberger, Jacobs, Crane, Russell, Westberry et al., 1979) and the Crowne Marlowe Scale (Crowne and Marlowe, 1960). This is a measure of social desirability, or need of approval, which contains 33 items describing both acceptable but unbelievable behaviours, as well as intolerable but probable ones. A high score on the Crowne Marlowe Scale is considered to be an indication of a repressive coping style, which is discussed in more detail in Section 2.3.1.

Participants' behavioural responses to the videotapes were videotaped and rated blindly for emotional expressiveness. Participants were also asked to rate their mood throughout the experimental procedure, indicating how angry, anxious or sad they felt. Results showed that the breast-cancer patients were significantly less expressive than the controls during the videotapes depicting stressful events. Breast-cancer patients were also more likely than controls to report hiding their emotions while watching the tapes, even though they seemed more inclined to emotional lability as they reported higher levels of negative feelings during the stress tapes than the control group. It thus became apparent that breast-cancer patients presented a controlled outer façade despite experiencing emotional distress. As this study used both self-report and objective measures of emotional expression, it demonstrated that there seems to be a strong positive correlation

between self-reporting emotional suppression and actual behaviour. This finding lends validity to measuring emotional suppression using self-report measures.

A study by Beck (undated; cited in Eysenck, 1994) showed that cancer patients used more words that indicated "death" and "hopelessness" than coronary heart-disease patients, which suggested that cancer-sufferers were less optimistic about the future and more preoccupied with their own mortality. Beck's findings supported the notion of a 'cancer-prone' Type I personality as posited by Grossarth-Maticek (1980).

Even in the light of such experimental evidence, it has been argued that, when investigating personality variables and breast-cancer incidence retrospectively, a cause-effect relationship is impossible to establish, as a particular individual has already developed breast-cancer at the point of study. Therefore it cannot be said with certainty whether personality factors such as emotional suppression are contributors to the development of cancer, or the result of having developed cancer (i.e. through receiving the diagnosis of cancer and medical treatment such as radiotherapy or chemotherapy – Greer and Watson, 1985; Temoshok and Heller, 1988). However, there is evidence which indicates otherwise. Bleiker, van der Ploeg, Ader, van Daal and Hendriks (1995) conducted a study with the aim of determining whether and to what extent a diagnosis of breast cancer influenced self-reports on measures of psychological personality traits. The authors found that participants' scores on most scales measuring self-reported personality traits did not change significantly over a one-and-a-half year period, apart from scores in rationality/anti-emotionality (the specific avoidance of emotion in interpersonal situations), and emotional expression and control (the extent to which emotions are expressed or suppressed): these all decreased over the time period under study. This indicates that, while certain personality traits will remain stable irrespective of the diagnosis, rationality/anti-emotionality and emotional suppression may lend themselves more to modification through therapeutic intervention. It would be desirable to achieve this

modification before the cancer has a chance to develop, applying preventative interventions.

2.3 Breast Cancer and Maladaptive Coping with Stress

A large proportion of cancer-mind research has examined the relationship between stress and breast-cancer development. Chronic stress is known to have damaging health effects, particularly on the immune system (Kiecolt-Glaser and Glaser, 1993). Coping with stress has also been implicated in the development and progression of breast cancer. The research dedicated to the detection of a connection between breast cancer and coping with stress has pointed to three main coping mechanisms: repression, denial and avoidance. Each will now be discussed in turn.

2.3.1 Breast Cancer and Repressive Coping

Lazarus and Folkman (1984) define coping as 'constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person'. A number of studies have shown connections between breast cancer and a repressive coping style, a concept derived from psychodynamic theory (Freud, 1892; cited in Singer, 1990). Repressors score high on measures of defensiveness such as the Crowne-Marlowe scale and low on measures of trait anxiety; they exhibit indicators of physiological arousal (for example, increased heart rate and skin conductance) while presenting a calm exterior (Weinberger, Schwartz and Davidson, 1979; Myers, 1995). The results of Watson, Pettingale and Greer's (1984) study, discussed above, showed that the breast-cancer group had significantly higher scores than the control group on the Crowne Marlowe scale and exhibited higher physiological arousal, indicating repressive coping.

In a prospective study, Jensen (1987) found an association between a repressive-coping personality and the progression of breast cancer: in individuals who used repressive

coping strategies, the disease progressed quicker than in those who did not employ repressive coping strategies. Similar results have been reported by Ginzburg, Wrensch, Rice, Farren and Spiegel (2008).

Conversely, Coifman, Bonanno, Ray and Gross (2007) suggest that repressive coping may in fact be beneficial, as their study found that both bereaved and non-bereaved individuals had fewer symptoms of psychopathology, experienced fewer health problems and somatic complaints, and were rated as better adjusted by close friends than those who did not exhibit repressive coping. However, it is doubtful whether this finding can be viewed as contradicting the studies that found a link between repressive coping and breast-cancer incidence. Firstly, Coifman and colleagues did not assess breast-cancer incidence, confining their assessment of somatic complaints to high blood pressure, cardiovascular disease, and respiratory illness. Secondly, neither conformity nor other traits typical of the 'cancer-prone' personality were measured. As mentioned earlier, repressors tend to score high on measures of conformity; therefore, they may appear to be well-adjusted (in order to conform to others' expectations) when in fact they are coping poorly. Therefore, Coifman et al.'s findings cannot be interpreted as providing disconfirming evidence for a link between breast cancer and repressive coping.

2.3.2 Breast Cancer, Denial and Avoidant Coping

The use of denial and avoidant-coping strategies has also been implicated in the development and progression of breast cancer. Denial is another Freudian concept and is closely related to repression. However, while repression-coping involves the use of techniques to suppress emotions that are associated with a stressful event, denial involves the rejection of any evidence supporting the reality of a stressful event (Greer, Morris and Pettingale, 1979). Temoshok and Dreher (1992) observed that a high proportion of their cancer patients used denial as a coping strategy.

Some individuals use denial as a defence mechanism against a perceived health threat (Brown and Locker, 2009). While moderate to high levels of denial have been associated with increased wellbeing in severely or terminally ill people such as cancer patients (Vos, Putter, van Houwelingen and de Haes, 2011), patients being in denial present a communication challenge for health-care professionals (Holtgrawe, Pinkert and Remmers, 2007). Furthermore, it may interfere with getting treatment, may disrupt the process of assimilating a stressful event, may adversely affect interpersonal relations, and constitutes a cumulative stressor that has been shown to depress immunocompetence (the ability of the body to produce a normal immune response following exposure to an antigen - Kreitler, 1999). Moreover, denial impedes the effectiveness of health-promotion messages: it has been found that individuals high in denial and in vulnerability to adverse effects of health behaviours such as excessive drinking tend to avoid reading health messages and to erroneously estimate their personal risk as low (Brown and Locker, 2009).

A major and methodologically strong quasi-prospective study was conducted by Cooper and Faragher (1992, 1993), who investigated the inter-relationships between stress events, coping strategies and personality in women who attended a breast-screening clinic. One thousand five hundred and ninety-six women with complaints of breast tenderness or lumpiness were included in the study. The control group consisted of those who were subsequently diagnosed to have healthy breasts. However, this could not be considered to be a wholly satisfactory control group, because these women had been sufficiently concerned about their breast health to make, and keep, a breast-screening appointment. Therefore, the control group was augmented with a sample of 567 women attending a British United Provident Association centre in London for a general medical check-up. For these women, breast screening was just part of the routine check-ups and they had not presented with any breast complaints. The inclusion of these women sets this study apart from many other studies in the field, which often have flawed control

groups. Additionally, women who were diagnosed to have very advanced-stage breast cancer were excluded from the study, as they most likely were able to anticipate their diagnosis before it was disclosed to them. The final sample consisted of 2163 women. All participants were asked to complete a 42-item life event inventory devised for a UK female sample (Cheang and Cooper, 1985), indicating whether or not they had experienced each event listed, and how upsetting the event had been. Also, an adapted version of the Bortner (1969) Type A behaviour inventory was administered. Finally, participants completed a questionnaire containing 36 coping strategies used by individuals to deal with distressing situations (Folkman and Lazarus, 1980). At the time of completing the questionnaires, their diagnosis was unknown to the women. Once the final diagnoses were available, women were classified into four diagnostic categories: (1) a normal control group; (2) women with a suspicious benign breast condition; (3) women found to have a cyst, and (4) women with breast cancer stage I or II. Findings indicated that women who used internalised coping strategies (for example, worrying, going quiet, withdrawing from others) and women who used avoidant strategies (such as keeping busy, throwing themselves into work, trying not to think about a particular stressful event) were more likely to present with breast cancer than those who used externalised coping strategies (e.g. letting feelings out, talking to friends) or anger strategies (such as getting angry with people and things to ease the problem). The researchers found age to be a mediating factor, which appeared to influence the type of coping strategies used: older women were more likely to use internalised coping strategies than younger women. It was posited that with increasing age, women are more likely to lose people close to them (such as their spouse or other family members), and therefore the number of sources of social support diminishes with time. Thus, these women may be forced to turn inwards to cope with their problems, as they have fewer people to talk to.

Cooper and Faragher's study is exceptional in breast-cancer and stress research, because it tried to overcome the problem of participants potentially being aware of their

diagnosis before it was revealed to them. Thus, the exclusion of participants in the very advanced stages of the disease, as well as the inclusion of healthy participants without any breast concerns as part of the control group, serve to make this study one of the methodologically stronger ones in this field.

Further support for a link between cancer and avoidant-coping mechanisms was provided by Grossarth-Maticek, Eysenck and Boyle (1994), who found that individuals with a Type I personality - whose characteristics include using avoidant coping strategies - was associated with the incidence of and mortality from cancer. Avoidant coping strategies have also been shown to be associated with decreased survival time in metastatic breast-cancer patients (Derogatis, Abeloff and Meliseratos, 1979). Additionally, Becker (1986) has demonstrated poor coping strategies in breast-cancer patients. In a meta-analysis examining the evidence for a link between psychosocial factors and the development of breast cancer, McKenna, Zevon, Corn and Rounds (1999) concluded that denial and repressive-coping strategies were among the strongest predictors of breast cancer.

2.4 Breast Cancer and Stressful Life Events

The occurrence of stressful life events has been linked to the incidence of various types of cancer, predominantly breast cancer. A stressful life event is defined as an either physical and/or psychological occurrence of daily life which disrupts or threatens to disrupt normal life activities (Brown and Harris, 1978). Many studies in this field have measured the occurrence of stressful life events by employing schedules or checklists, or by means of semi-structured interviews. Holmes and Rahe (1967) were the first to develop and validate a scale measuring stressful life events, the Social Readjustment Rating Scale. This checklist assigns 'life change units' to a hierarchy of common stressful life events. Supposedly severe stressful life events (e.g. the death of a spouse, or divorce) are assigned more life change units than supposedly less severe stressful life events (e.g. a change of responsibilities at work, or trouble with in-laws). Life-change units are added up

to produce a total score for each individual. High total scores indicate a high impact of stress on the individual's health. However, Butow, Hiller, Price, Thackway, Kricker et al. (2000) noted that life events inventories usually cover a limited range of experiences, and often lack sensitivity and specificity regarding their definition of a stressful life event. In other words, an event which may be perceived as stressful and having a significant impact on one individual may not necessarily be perceived as such by another individual. Therefore, studies using semi-structured interviews or open-response questions, rather than life events inventories, are more likely to elicit which events have been perceived as stressful, as well as the significance and impact of these events on the individual. As is the case in cancer-personality research, the majority of studies in this field is retrospective (asking breast-cancer patients to reflect on stressful life events preceding the diagnosis) or quasi-prospective (interviewing women before they undergo a breast biopsy) in design. Nevertheless, there are some prospective studies which followed women who had experienced stressful life events and been diagnosed with breast cancer over a set time period and assessed their survival. The methodologically strongest studies are either prospective or quasi-prospective (Eysenck, 1994). Experimental studies investigating the connection between stress and health have usually used mild stresses, for example, examination stress or having to give a public speech, as it would not be ethical to inflict stressful life events on participants (Grossarth-Maticek et al., 1994). Thus, experimental studies using major stressful life events such as divorce or bereavement are precluded. Here, the evidence for the connection between stressful life events and breast cancer is reviewed by discussing the most important studies in this area.

Cardenal, Ortiz-Tallo, Frias and Martinez (2008) compared 58 breast-cancer patients to 60 healthy controls matched for age and socio-economic status. They found that the breast-cancer patients were more likely to report having experienced a major stressful life event, such as divorce or the death of a loved one, in the past two years.

Kruk and Aboul-Enein (2004) carried out a retrospective study with 357 breast-cancer patients and 565 cancer-free comparisons. Contrary to the vast majority of studies in this field, the researchers used open-ended questions to elicit information about stressful life events from participants. This ensured that respondents were able to report the events they had *experienced* as most stressful, rather than confining them to a choice of events from a life events inventory or checklist. After controlling for physical risk factors, it was found that life events in the severest categories (death of husband, divorce, separation, death of family member, personal illness/injury, cancer or other serious diseases in family member) were reported most often in the cancer group. Women who had experienced major stressful life events in the five years before the study took place, and who had the most daily life stresses and depression, were 3.7 times more likely to have breast cancer than those who did not experience such stress. Although the study was retrospective in nature and it could not be ruled out that the knowledge of their diagnosis influenced cancer patients' responses, the results are strengthened by large sample sizes of both groups and by the open-response format of the questions pertaining to stressful life events.

Findings in line with the above studies are reported by Ginsberg, Price, Ingram and Nottage (1996), in a retrospective study with 99 breast-cancer patients and 99 healthy controls. Life events were measured with the Life Events Inventory (Tennant and Andrews, 1976). After controlling for various physical breast-cancer risk factors, the researchers found that women with breast cancer were more likely to have experienced life changes and life distress, over both a two-year and a 10-year period, than healthy controls. Women with the most life changes over 10 years were almost five times more likely to develop breast cancer than women with the least life changes. Despite the retrospective study design, which meant that the diagnosis was known to both the researchers and the participants, these findings are pertinent because many physical risk factors (diet, hormonal factors, menstrual status, age of menarche, age at menopause,

parity, age at birth of first child, use of hormones, family history of breast cancer and others) were controlled for.

The link between stressful life events and breast-cancer incidence seems to be particularly strong for young women. Peled, Carmil, Siboni-Samocha and Shoham-Vardi (2008) conducted a retrospective case-control study with 622 women under the age of 45, 255 of which had been diagnosed with breast cancer and 367 of which were healthy. Stressful life events were assessed by means of a life-event questionnaire developed by Schwarz and Geyer (1984). It was found that women who had experienced more than one meaningful life event (severe and/or mild to moderate) were more likely to develop breast cancer than those who had not. It is, however, important to note that this study, similar to the above studies, was retrospective in nature, which did not allow for causal inferences to be made. Furthermore, the subjective severity of these life events was not assessed.

In an effort to overcome the limitations of retrospective studies, Cheang and Cooper (1985) conducted a quasi-prospective study, comparing 12 patients undergoing a breast biopsy with 42 healthy controls. All participants undergoing the biopsy were interviewed before the procedure and asked to recall stressful life events which had taken place in the two years prior to discovery of their breast lump. Controls were asked to recall stressful life events in the two years prior to the interview. Forty-six women were subsequently diagnosed with breast cancer; these women reported significantly more stressful life events than the healthy controls. In a later study, Faragher and Cooper (1990) employed a similar design: the sample included 1324 women attending a surgical outpatient clinic for breast symptoms, 272 women attending a breast clinic for breast symptoms, and 567 women with no symptoms attending a primary health-care facility. Although there was little difference between the breast-cancer group and the healthy group regarding the incidence of stressful life events, the women in the breast-cancer group tended to rate the severity of these events higher than the healthy women.

The experience of stressful life events seems to not only increase the risk of developing breast cancer, but also to decrease survival time in those who have already developed breast cancer. Funch and Marshall (1983) conducted a prospective study with 208 breast-cancer patients over 20 years, using semi-structured interviews to obtain information about stressful life events. It was found that the more stressful life experiences participants had gone through in the five years before diagnosis, the shorter breast-cancer survival tended to be.

Bremond, Kune and Bahnson (1986) carried out a quasi-prospective study with 50 breast-cancer patients and 105 healthy controls. Data regarding stressful life events was collected through interviews. The results indicated that breast-cancer patients were more likely than controls to have had a stressful life event in the previous five years, especially the younger age groups.

In a longitudinal study, Forsen (1991) investigated life events, important emotional losses, difficult life situations, and psychological characteristics in 87 breast-cancer patients and 87 healthy women matched for age, parity (number of pregnancies) and language. The breast-cancer group was followed up over eight years and the impact of stressful life events preceding the diagnosis on survival was assessed. Occurrence of stressful life events and their impact was collected by administering the Social Readjustment Rating Scale (Holmes and Rahe, 1967). Forsen found that breast-cancer patients had experienced significantly more stressful life events, important losses, and difficult life situations before diagnosis, than the healthy controls. This finding held true after adjusting for marital status, education, and social class. Women who had experienced stressful life events in the 12 months before breast-cancer diagnosis, and who came from a lower social class, had shorter survival periods. Similar results have been reported by Geyer (1993).

The connection between stressful life events and breast cancer has been further demonstrated by Cooper and Faragher (1992, 1993), who in a quasi-prospective study (described above) found that the women who had experienced relatively minor life events, and who were able to deal with these situations by confronting them aggressively, were at the least risk of developing breast cancer, while those who had experienced more severe life events (e.g. serious illness of a loved one or bereavement), and who tried to deny the existence of stress, were most at risk of developing breast cancer. These findings illustrate that it is not just the occurrence of stressful life events, but also how the individual copes with these, which plays a role in breast-cancer development.

Similarly, Chen, David, Nunnerley, Michell, Dawson et al. (1995) conducted a quasi-prospective study with 119 women who had either been recalled after screening mammography because of a suspicious lesion and who were about to undergo biopsy at a local breast-cancer screening unit, or who were awaiting the results of a biopsy and had been referred to an outpatient clinic. Stressful life events were measured with the Life Events and Difficulties Schedule (Brown and Harris, 1978), and via semi-structured interviews. Coping with these events was assessed using the Coping Strategies Inventory (Tobin, Holroyd and Reynolds, 1984). Women with breast cancer were compared to women with benign breast disease. The results indicated that women who developed breast cancer had experienced more severe stressful life events in the five years before diagnosis. Moreover, these women also used significantly more negative coping strategies in response to salient life stressors than women with benign breast disease. The use of semi-structured interviews to collect data about stressful life events is an advantage of this study. The evidence would have been strengthened if a healthy control group had been used rather than women with benign breast disease. Still, the results underline, similar to Cooper and Faragher's research, that it is not just the occurrence of critical life events, but also maladaptive coping with these events, which put women at a higher risk of breast cancer.

More evidence for a link between stressful life events and breast cancer comes from a recent prospective study which followed 35,728 African American women over 14 years (Wise, Palmer, Boggs, Adams-Campbell and Rosenberg, 2011). A weak positive association was found between physical abuse in adulthood and breast-cancer occurrence. However, as this study was confined to one ethnic group only, it is unclear if its findings are true for other ethnic groups.

Further support for the connection between the development of breast cancer and the occurrence of stressful life events comes from a large-scale longitudinal cohort study conducted by Lillberg, Verkasalo, Kaprio, Teppo, Helenius et al. (2003). They investigated the relation between stressful life events and breast-cancer risk among nearly 11,000 women from the Finnish Twin Cohort, which had been established to examine the genetic, environmental and psychosocial determinants of disease and included all Finnish same-sex twin pairs born before 1958 in which both co-twins were alive in 1975. All participants completed a life-event inventory at baseline, and were then followed for 15 years. Through record linkage with the Finnish Cancer Registry, incidences of breast cancer were identified. After controlling for physical risk factors, it was shown that the accumulation of stressful life events was associated with an increased breast-cancer risk. Moreover, specific major life events – divorce/separation, death of a husband, and death of a close relative or friend – were each associated with an increased breast-cancer risk. When including only twin pairs discordant for breast cancer (i.e. one twin had breast cancer and the other twin did not), these results were confirmed. Lillberg et al.'s study presents two advantages over other longitudinal record linkage studies in this field (Ewertz, 1986; Kvikstad, Vatten, Tretli and Kvinnsland, 1994) which detected no evidence of a link between stressful life events and breast cancer. Firstly, the occurrence of stressful life events was established through completion of a life-events inventory. In this sense, it is unique, as other record-linkage studies relied solely on register data of life events (for example, deaths or divorces), which do not give any information on life events that are not

47

recorded. Secondly, various physical risk factors (e.g. smoking, diet, and contraception), which had been established at baseline by means of a questionnaire, were controlled for; other record linkage studies could only control for risk factors which could be gleaned from register data (age, parity, age at first birth). These advantages strengthen the results considerably.

Stressful life events have not just been connected to breast-cancer development, but also to its recurrence. This was shown by Palesh, Butler, Koopman, Giese-Davis, Carlson and Spiegel (2007) in a retrospective study with 94 breast cancer patients. Traumatic event history was assessed for each participant using the Structured Clinical Interview for the DSM-IV-TR (First, Spitzer, Gibbon and Williams, 2002), and each reported event was judged by two independent raters with expertise in traumatic stress and no access to disease status. Women were categorised into having experienced either a traumatic event, a stressful event (when the event did not meet DSM-IV-TR criteria for post-traumatic stress disorder), or having experienced no traumatic or stressful event. The authors detailed that nearly 42% of participants had experienced one or more traumatic events (such as rape, sexual assault, or suicide of a close family member) in their lifetime, and 29% reported stressful events (e.g. a close family member's death of cancer, immigration to another country, or parents' divorce). Those who had experienced no traumatic or stressful life events had a significantly longer disease-free interval than those who had experienced one or more traumatic or stressful events. Although the study has the same methodological limitations as other retrospective studies in this area, its results are nevertheless consistent with prospective studies that have demonstrated a link between stressful life events and the progression of breast cancer (Fawzy, Canada and Fawzy, 2003; Fawzy, Cousins, Fawzy, Kemeny, Elashoff et al., 1990).

There are studies which have examined the connection between stressful life events and cancer in general. An example is a large-scale longitudinal study by Grossarth-Maticek,

Eysenck and Boyle (1994), which investigated the link between a very severe type of stressful event, namely living in a Hitlerian concentration camp and losing family members, and the incidence of cancer and coronary heart disease. One thousand one hundred and twenty-one camp victims and 367 controls who had not been camp victims were followed over 19 years and mortality from cancer, infarct or other causes was recorded. After controlling for physical risk factors (smoking, overweight, alcohol consumption, pills, lack of exercise, high blood pressure, diabetes and a poor diet), it was found that participants who had been incarcerated in a concentration camp and had members of their family killed were more than twice as likely to die of cancer or coronary heart-disease than were the controls. Those with a Type I personality were most likely to die of cancer, while those with a Type II personality were most likely to die of coronary heart disease. Notably, physical risk factors, such as drinking alcohol and smoking, were actually lower in former camp inmates than in the comparison group, but nevertheless their cancer and coronary heart disease mortality was higher. This demonstrated that there was a high probability that the stressful experience of living in a concentration camp increased their risk of either coronary heart disease or cancer, depending on personality type.

Recent findings are reported by Metcalfe, Davey Smith, Macleod and Hart (2007), who followed 991 women and 5743 men over 30 years in a large-scale Scottish prospective study assessing general cancer incidence. After adjusting for physical risk factors and social position, it was found that women reporting moderate and high stress were more likely to develop breast cancer in the 30-year time period than those reporting low stress.

It is important to note that some studies (e.g. Priestman, Priestman and Bradshaw, 1985; Schonfield, 1975; Edwards, Cooper, Pearl, De Paredes, Leary et al., 1990; Michael, Carlson, Chlebowski, Aickin, Weihs et al., 2009; Surtees, Wainwright, Luben, Khaw and Bingham, 2010) did not find any evidence for an association between stressful life events

and the occurrence of breast cancer. However, as mentioned above, these studies all used life-event inventories or check lists, which usually cover a limited range of experiences and lack specificity and sensitivity (Butow, Hiller, Price, Thackway, Kricker et al., 2000). Moreover, studies using check lists are less likely to produce convincing evidence for a relationship between cancer and stressful life events, as they do not consider how individuals perceive the major life events they have experienced (Dalton, Boesen, Ross, Schapiro and Johansen, 2002). The strongest studies used open-response questions, allowing participants to record those life events which are most significant to and perceived as most stressful by them.

In an effort to test the hypothesis that stressful life events are associated with breast-cancer development because women who experience such events delay seeing the doctor when experiencing breast cancer symptoms, Geyer, Noeres, Mollova, Sassmann, Prochnow et al. (2008) assessed life events by means of semi-structured interviews in 240 breast cancer patients. They compared patients who had experienced stressful life events to those who had not, looking at their illness behaviour. Contrary to expectations, it was found that women with stressful life events went to the doctor earlier than those without events. This suggests that the connection between stressful life events and breast-cancer development is not due to a delay in seeking medical advice upon discovering suspicious breast symptoms, although it cannot be ruled out that other (unmeasured) behavioural factors may play a role. More research is needed to determine what these factors may be.

2.5 Breast Cancer and Bereavement

Bereavement is a stressful life event that has been studied extensively in conjunction with health. Bereavement can be seen to be part of a broader pattern in one's life whereby one forms attachments to people and things. This involves not only the death of a loved one, but also relationship losses, the loss of some aspects of the self, or the loss of treasured

objects (Humphrey and Zimpfer, 2001). It is not a one-dimensional experience; there are no set stages or patterns that all people must go through. Rather, bereaved individuals exhibit different patterns of grief reactions across time (Bonanno, 2009). Yet, there is a body of research pointing to potential adverse health effects of bereavement. Losing a spouse, for example, has been found to have strong effects on morbidity and mortality, particularly in old age, with individuals losing on average 12% of residual life expectancy after being bereaved. This appears to be chiefly due to an increased likelihood of suffering from chronic diseases (van den Berg, Lindeboom and Portrait, 2011).

A particularly strong connection has been found to exist between bereavement and breast cancer. Generally, findings have indicated that women who have experienced the separation from or loss of someone close to them may be at higher risk of developing breast cancer. Studies have either focused on the association between breast cancer and bereavement alone, or looked at bereavement as part of a range of major stressful life events.

Notably, some studies have found a link between different types of cancer and bereavement. For example, Le Shan and Worthington (1956a, b) retrospectively studied the personality of 250 patients with various types of cancer and discovered that 62% of the cancer patients had experienced a childhood loss of an extremely important and meaningful relationship, but only 10% of healthy controls had experienced the same.

However, the strongest evidence exists for a link between the incidence of breast cancer specifically, and bereavement. Bacon, Renneker and Cutler (1952) presented selected case reports of the 40 breast-cancer patients whose life histories they examined. All of them had either recently lost someone close to them (e.g. their spouse), or had experienced the loss of a parent during childhood. In another retrospective study, Becker (1986) compared 71 breast-cancer patients with 36 patients with fractures and 36 non-

cancer patients attending a gynaecological clinic. It was found that breast-cancer patients were more likely to have experienced losses or upsetting events in childhood, and had had more difficult relationships. It is important to note, however, that due to the retrospective nature of these studies, the diagnosis was known to both the researchers as well as the participants at the time of data collection, which may have biased the results. Thus, prospective or quasi-prospective studies would produce results with greater internal validity.

Geyer (1991) conducted a quasi-prospective study with 97 women admitted to hospital for breast surgery and found that women who were diagnosed with breast cancer were more likely to report severe life events, such as events involving bereavement and loss, than women with benign breast disease. A similar quasi-prospective design was employed by Jasmin, Le, Marty and Herzberg (1990), who showed that unresolved recent grief was significantly related to the risk of breast cancer. However, the number of women with breast cancer in each of these studies was quite small (33 and 19, respectively).

Studies with larger samples offer the advantage that they are likely to include more breast-cancer patients and therefore have more statistical power. An example of a study with higher statistical power is Fox, Harper, Hyner and Lyle's (1994) study, which included 72 women with breast cancer. The authors discovered that those who had experienced the death of a spouse or another close family member within the previous two years were more likely to be diagnosed with breast cancer.

An even larger-scale longitudinal Swedish register study by Lambe, Cerrato, Askling and Hsieh (2004) involved more than 20,000 participants who had lost a child between 1980 and 1996. A slightly increased incidence of breast cancer was detected in women who had lost their only child when the child was between one and four years of age. Similarly, Li, Johansen, Hansen and Olsen (2002) conducted a longitudinal Danish register study

involving 21,000 individuals who had lost a child, following them for 18 years, and found a slightly increased overall cancer risk for bereaved mothers.

In a similar vein, Jacobs and Bovasso (2000) followed more than 1200 women over 15 years. They found that women who had lost their mother during their childhood were more likely to be diagnosed with breast cancer.

Some studies have linked shorter breast-cancer survival to the experience of bereavement. In such a study, Funch and Marshall (1983) found that the more stressful life experiences participants had gone through, the shorter survival tended to be. Regarding bereavement specifically, this effect appeared to be larger for younger women than for older women. Levav, Kohn, Iscovich, Abramson, Tsai et al. (2000) investigated general cancer incidence and survival following bereavement in a cohort of 6284 Jewish Israelis who had lost an adult son in the Yom Kippur war or in an accident. They followed the cohort over 20 years and compared cancer incidence with that among non-bereaved members of the population. Bereavement was associated with decreased survival periods in those whose cancer was diagnosed before their son's death.

A few studies, which are discussed in Section 2.3 (Cooper and Faragher, 1992, 1993; Chen et al., 1995), have not only looked at the occurrence of bereavement, but also at coping mechanisms. These studies found that the incidence of bereavement, coupled with inappropriate coping mechanisms, increased the risk of breast cancer, which highlights the importance of examining coping with bereavement when assessing breast cancer risk.

Nevertheless, some research has not found any association between bereavement and breast-cancer incidence. For example, in a British study, Jones, Goldblatt and Leon (1984) assessed the registration of cancer and mortality after the death of a spouse using census data, and found no evidence for a link between cancer and bereavement.

However, as these findings were based on census data, individuals' perception of the bereavement (i.e. its severity) was not assessed. Additionally, as the researchers only concentrated on loss of a spouse, other forms of bereavement were not looked at, and coping with bereavement was not assessed. These ommisions may account for the failure to detect an effect.

Schonfield (1975) conducted a quasi-prospective study with 112 women with suspicious breast lesions, and found no evidence that breast-cancer patients had suffered losses of significant others in the years preceding the diagnosis. However, the sample only contained 21 cancer patients, which most likely resulted in low statistical power and therefore a decreased ability to detect an effect. Furthermore, the MMPI, which has been criticised for its low validity (Eysenck, 1994), was used as an assessment tool. Moreover, Schonfield used a life-events schedule, but did not measure the severity of the bereavement experience, nor did he measure how well patients coped with their bereavement.

In a recent quasi-prospective study, Eskelinen and Olonen (2010) investigated the associations between stressful life events, losses and breast-cancer development. One hundred and fifteen women with breast-cancer symptoms were semi-structurally interviewed, as well as asked to complete standardised questionnaires, prior to clinical examination. Thus, in-depth information was gleaned. It was found that women with breast cancer had significantly higher mean scores for stress in adulthood in the previous six to ten years, in the previous two to six years, and in the previous two years, than women with benign breast disease and healthy participants. Also, women with breast cancer had experienced significantly more severe losses in adulthood than women with benign breast disease and healthy women. These results indicate that women with breast cancer tended to have more life stress and severe losses than the other two groups. The authors speculated that stressful life events and losses could impact either indirectly on

breast-cancer risk by affecting women's behaviour, or directly on the hypothalamic-pituitary-adrenal axis and autonomic nervous system functioning. However, further research is needed to elucidate the mechanisms behind bereavement and other stressful life events, and breast-cancer aetiology. Nevertheless, these results support the notion of a link between bereavement and other stressful life events, and breast-cancer development. One of the study's strengths lies in its use of semi-structured interviews to assess life events and losses, rather than checklists. Still, it would have been useful to assess coping with bereavement and with stressful life events, in order to determine whether those who coped maladaptively were at a higher risk of a breast-cancer diagnosis than those who coped adaptively.

Levav et al. (2000), whose study is discussed above, found that bereavement was associated with decreased survival in those whose cancer was diagnosed before their son's death, but not in those whose cancer was diagnosed after their bereavement. However, similar to Jones et al.'s (1984) study, Levav and colleagues' study was limited in that it only focused on one type of bereavement (losing one's son in the Yom Kippur war), and measured neither its severity, nor how well parents coped with the event. Moreover, the authors did not distinguish between different types of cancer, even though it is likely that the link between bereavement and the incidence of cancer may be more specific to breast cancer than to other cancers.

In sum, there is considerable evidence to support a connection between bereavement and breast-cancer incidence. In a meta-analysis, McKenna, Zevon, Corn and Rounds (1999) concluded that the experience of loss and separation, as well as the experience of stressful life events, are among the most consistent predictors of breast cancer.

The pathways leading from bereavement and other stressful life events to breast cancer are as yet unclear. Several theories have been proposed. These are discussed in the next chapter.

2.6 Breast Cancer and Social Support

Social support is the emotional and physical support given to individuals by family, friends and spouses (Sabini, 1995). Health psychology research has consistently demonstrated a connection between social support and physical health (Reardon and Buck, 1989). A lack of social support has been linked to immune functioning. For example, Glaser, Kiecolt-Glaser, Speicher and Holliday (1985) found that individuals who considered themselves lonely had higher Epstein-Barr virus antibody titers than did those who did not consider themselves to be lonely. The data suggest a connection between stress-related immunosuppression and the risk of outbreak of Epstein-Barr virus in individuals. Some studies have shown that social support can improve wound healing (e.g. Christian, Graham, Padgett, Glaser and Kiecolt-Glaser, 2006; Kiecolt-Glaser, Loving, Malarkey, Lemeshow, Dickinson et al., 2005). Loneliness has been associated with a depressed immune system, measured in terms of natural killer-cell activity (e.g. Kiecolt-Glaser, Garner, Speicher, Penn, Holliday et al., 1984; Glaser et al., 1985). Reduced natural killer-cell activity has in turn been linked to breast cancer (Andersen, 1998).

Some studies have examined the connection between social support and cancer in general. For example, Shaffer, Graves, Swank and Pearson (1987), whose study was described above, found that individuals who were 'loners' and kept to themselves were 16 times more likely to develop cancer than those who were more sociable.

Nevertheless, the evidence in this field is particularly strong regarding breast cancer specifically. Reynolds and Kaplan (1990) followed a sample of 6928 Californians for 17 years. After controlling for age, smoking, alcohol consumption, initial physical health and

income, it was discovered that women with fewer social contacts were five times more likely to die from cancer, particularly hormone-dependent cancers such as breast cancer. Furthermore, even a feeling of social isolation without decreased social contacts was associated with a higher cancer risk. Similarly, Fox, Harper, Hyner and Lyle (1994) found that breast-cancer incidence was associated with increased loneliness and low marital quality.

The relevance of social support has also been studied in women who have already developed breast cancer. High levels of social support appear to be associated with increased survival time in breast-cancer patients (Funch and Marshall, 1983; Marshall and Funch, 1983; Weihs, Entright and Simmens, 2008). Kricker, Price, Butow, Goumas, Armes et al. (2009) examined the connection between life event stress, social support and tumour size in a five-year prospective study involving 1459 women diagnosed with breast cancer. After adjusting for physiological factors, it was shown that low support from their partner was associated with faster tumour growth in those women not living with their partner. In a similar vein, Roberts, Cox, Shannon and Wells (1994) discovered that higher support from their spouse was related to fewer symptoms of psychological distress in breast-cancer patients.

In a systematic review of the literature on social support and cancer progression, Nausheen, Gidron, Peveler and Moss-Morris (2009) concluded that the evidence for the relationship between social support and cancer progression was sufficiently strong for breast cancer, but consistently unconvincing for other types of cancer or in studies which combined different types of cancer. It thus seems that the role of social support in cancer progression may be unique to breast cancer.

Even so, an absence of the connection between social support and cancer is reported by Flensborg-Madsen, Johansen, Grønbæk and Mortensen (2011), who analysed the data of

a Danish prospective cohort study which followed participants over 13 years. The authors reported that, unlike quality of life, social relations were not predictive of cancer risk. However, social relations were measured as not having a friend to talk to about everything or not having a partner; this does not provide information as to the perceived amount of social support that individuals received. It is thinkable that individuals who have no partner or no friend to talk to still feel adequately supported, as they may be deriving their support from other sources. A validated measure of perceived social support may have been a more useful source of information.

Iwamitsu, Shimoda, Abe, Tani, Okawa et al. (2005) have suggested that emotional suppression, the key feature of the Type C personality and one of the psychological risk factors for breast cancer, may be related to low social support. Suppressing one's negative emotions may be an effective way to maintain ostensibly agreeable human relationships, but this comes at the cost of communicating emotions and thus receiving emotional support from other people. A lack of social support is therefore closely linked to the personality traits typical of women who are psychologically more at risk of developing breast cancer. Namely, the tendency to suppress negative emotions and to be overly appeasing, co-operative and self-sacrificing reduces the likelihood of individuals receiving support from their environment, partly because they do not ask for help and partly because they appear to be totally self-sufficient. Temoshok and Dreher (1992) have suggested that Type C individuals are often afraid to ask for help, or are restricted by the roles they play with their loved ones. Therefore, a lack of social support may be a symptom of an underlying problem – a reluctance to seek support from family and friends when it is needed.

2.7 Conclusion

The research discussed here presents a strong argument for the implication of psychosocial factors in the development of breast cancer. Particularly the

methodologically stronger studies, usually prospective or at least quasi-prospective in design, have provided support for the notion that bereavement and other stressful life events, inadequate coping with bereavement and other stressful life events, 'cancer-prone' personality traits, and a lack of social support are connected to the development of breast cancer. These risk factors most likely interact with each other. However, an integrated model of breast cancer and psychosocial risk factors is needed to bring more clarity (Eysenck, 1994) and to understand how they interact. Additionally, the mechanisms by which these psychosocial risk factors contribute to the development of breast cancer are still unclear. Stimulated by psychoneuroimmunological research, several psychosocial pathways to breast cancer have been proposed. These are discussed in Chapter Three.

CHAPTER THREE

PSYCHOSOCIAL PATHWAYS TO BREAST

CANCER

CONTENTS

3.1 Overview

Although, as Chapter Two has shown, there is a considerable amount of research to support a connection between psychosocial factors and breast cancer, this research does not explain how exactly psychosocial factors contribute to the development of breast cancer. Nevertheless, there is a growing body of literature which has investigated the pathways leading from psychosocial factors to the development of breast cancer and other illnesses.

This chapter discusses three areas of research that have examined psychosocial pathways to breast cancer. Firstly, psychoneuroimmunological findings are described and discussed. Then the diathesis-stress theory of disease and its application to cancer is described and evaluated. Next, the idea of breast cancer as a manifestation of the loss of the feminine role is examined. Finally, the need for more research elucidating the exact mechanisms governing these pathways is highlighted.

3.2 Psychoneuroimmunological Findings

Extensive research has been conducted in psychoneuroimmunology (PNI). PNI is the study of the interaction between psychological processes, and the nervous and immune systems of the human body. It is an interdisciplinary science that examines the neural and neuroendocrine links between immunology and psychology (Evans, Hucklebridge and Clow, 2000). Ader (2000; cited in van Wersch, Forshaw and Cartwright, 2009) suggested that PNI poses a paradigm shift and has led to the acknowledgement that "the nervous and immune systems are components of an integrated system of adaptive processes, and that immunoregulatory processes can no longer be studied as the independent activity of an autonomous immune system" (p. 167). An important step towards establishing that the central nervous system and immune system interact was accomplished by psychologists working with animal models, who demonstrated that changes in the immune system could be induced by classical conditioned stimuli (Ader and Cohen, 1993). Human studies focus

on the association between psychological traits and states, and immunity; which biological and behavioural pathways are responsible for such relationships; and if psychologically induced changes in immunity are responsible for changes in susceptibility to immune system-mediated illnesses (Cohen and Herbert, 1996). Psychological variables may influence immunity in two ways: through direct innervation of the central nervous system and immune systems, or through hormonal pathways. Cohen and Herbert have explained that behavioural changes which are associated with personality characteristics, or which occur as adaptations or coping responses, as a response to stressful events or negative emotional states may also influence immunity. For example, people experiencing stressful life events often engage in poor health practices, such as smoking, poor dietary practices, and poor sleeping habits (Cohen and Williamson, 1988). These may have immunosuppressive effects (Kiecolt-Glaser and Glaser, 1988).

Applied to breast cancer specifically, psychosocial factors affect the immune system, which - in turn - results in a change in vulnerability to breast cancer. There are three areas examined in PNI that are relevant to the present study because they constitute psychosocial factors associated with the development of breast cancer: bereavement and other stressful life events, social support, and personality. Each will now be discussed in turn.

3.2.1 Bereavement and Other Stressful Life Events and Immune Function

Stressful life events are believed to change immunity and through this increase susceptibility to immune-system mediated disease such as breast cancer. Specifically, stress responses are thought to influence immune function through their effects on coping and neuroendocrine response (Cohen and Herbert, 1996).

Studies in this area have used either naturalistic, 'real-world' stressors or acute stressors administered in the laboratory. Among the former type of research, an influential series of

studies was conducted by Glaser, Kiecolt-Glaser and colleagues, who investigated the impact of examinations on medical students' cellular immune function. Students' psychological stress levels and immune responses were assessed during a low-stress baseline period (e.g. just following a holiday), and again during a series of important exams. It was found that students reported more stress during exams and showed a decrease in functioning of a range of indicators of cellular immune response, including decreased natural killer cell activity (Kiecolt-Glaser, Garner, Speicher, Penn, Holliday et al., 1984; Glaser, Rice, Speicher, Stout and Kiecolt-Glaser, 1986) and other markers of increased immune competence (Glaser, Kiecolt-Glaser, Stout, Tarr, Speicher et al., 1985; Glaser, Rice, Sheridan, Fertel, Stout et al., 1987; Glaser, Pearson, Jones, Hillhouse, Kennedy et al., 1991; Glaser, Pearson, Bonneau, Esterling, Atkinson et al., 1993). However, it is important to note that exams are usually a short-term stressor, unlike severe long-term stressors such as bereavement, divorce or terminal illness. Therefore, it is unclear whether these results are applicable to severe and long-term stressful life events.

Nevertheless, there are studies which have examined the relationship between daily stressors likely to affect a wide range of people, and immune function. For example, Stone, Neale, Cox, Napoli, Valdimarsdottir et al. (1994) studied the role of positive daily events (e.g. accomplishing a goal, experiencing a positive interaction with their bosses) and negative daily events (e.g. losing keys, having arguments) on humoral immunity. Ninety-six male community volunteers ingested a capsule containing an innocuous novel protein daily for 12 weeks. The protein functioned as an antigen to which the immune system responded by producing antibody; this, in turn, served as an indicator of immune function. Additionally, the participants kept daily diaries and gave daily saliva samples that were used to assess amounts of secretory immunoglobulin A (sIgA) antibody produced in response to the novel antigen. The findings showed that the reporting of more desirable events was associated with greater sIgA antibody production, indicating more competent

immune function, while the reporting of more undesirable events was related to less sIgA antibody production. Furthermore, desirable events were connected to increases in sIgA antibody production over two subsequent days. This study showed that day-to-day stressors play a role in immune regulation, and suggests a benefit of positive events in health outcomes. Yet it does not show the underlying mechanism, that is, whether the association is direct or indirect. For example, stress could lead to changed health behaviours, which in turn affect the immune system negatively. In addition, the study does not give any insight into the role of severe and long-term stressful life events, such as bereavement, in immune function. Lastly, as the sample only consisted of men, it is uncertain whether these findings are also applicable to women.

The literature indicates that stressful events which last for a longer term (months or even years) have similar potential to compromise the immune system. Losing one's spouse, which can be a particularly long-term distressing life event (Clayton, 1979), has been demonstrated to have such an effect. Bartrop, Lazarus, Luckhurst, Kiloh and Penny (1977) used a cross-sectional design to study immune function in a bereaved population by comparing lymphocyte stimulation in bereaved spouses and in matched controls. Findings indicated that the bereaved group had lower lymphocyte stimulation responses, pointing towards lower immune competence. However, the cross-sectional nature of the study did not allow for the conclusion that lymphocyte responses were suppressed as a direct result of the bereavement. The detected differences could have been the result of pre-existing alterations of lymphocyte function.

In order to be able to determine a causal connection between lymphocyte suppression and bereavement, Schleifer, Keller, Camerino, Thornton and Stein (1983) carried out a prospective study with 15 spouses of women with advanced breast cancer. Participants were observed over an average of six months, and immune measures were obtained before bereavement and during the first two months of bereavement. This was the period

expected to be of greatest distress and during which immune responses had been reported to be depressed in Bartrop et al.'s (1977) cross-sectional study. Twelve of the 15 participants were also followed up during the remainder of the year after bereavement. A significant suppression of lymphocyte stimulation responses was found during the first month after bereavement, compared with responses before bereavement. This effect persisted for at least two months. The authors suggested that this persistence may be due to the magnitude and duration of the stressor (i.e. losing one's spouse), since the psychological and behavioural effects of this kind of life event often last for extended periods of time. They proposed that alterations to the immune system may mediate the long-term effects of bereavement, which include diabetes and cancer. Although the sample size was small, and only 12 of the 15 participants were followed up successfully, these results suggest a connection between bereavement and immune function.

It is uncertain what brings about these changes in immunocompetence. A number of studies have demonstrated that the use of tranquilisers, sedatives and alcohol are not uncommon among the recently bereaved, and it is has been proposed that these substances may have immunosuppressive effects (Fife, Beasley and Fertig, 1996). Furthermore, many recently bereaved individuals experience sleep loss, which has been linked to reduced natural killer-cell activity (Irwin, 1994).

A more recent study on the effects of losing one's spouse was conducted by Ong, Fuller-Rowell, Bonanno and Almeida (2011). It was found that independent of demographic variables, extraversion, neuroticism, negative emotion and health-behaviour covariates, spousal bereavement was associated with lower levels of cortisol at wakeup and a flattening of the daily cortisol rhythm. This finding was in accordance with previous research showing the long-term impact of bereavement on HPA axis dysregulation. However, the authors also found that deficits in positive emotion following loss fully accounted for the differences in observed daily cortisol slopes. They concluded that

positive emotion had a mediating effect on cortisol levels, with positive emotion during bereavement conferring not just psychological, but also physiological benefits.

The impact of stressful life events on immune function has also been demonstrated for types of occurrences other than bereavement. Baum, Schaeffer, Lake, Fleming and Collins (1985) carried out a set of studies assessing stress effects on residents of the area surrounding the Three Mile Island nuclear power plant, which was the site of a serious accident in 1979. The results showed that distress among residents remained high; even ten years after the accident more antibodies to herpes viruses were found in Three Mile Island residents than in demographically matched control-group residents. This finding suggested that the TMI residents had a significantly lower cellular immune competence. However, it is unclear what potentially confounding factors were controlled for in the study.

In a study by Kiecolt-Glaser, Glaser, Shuttleworth, Dyer, Ogrocki et al. (1987) it was shown that caregiving for relatives with Alzheimer's disease was connected to distress and elevated levels of herpes virus antibody. It is important to note that the caregivers taking part in the study did not differ from the low-stress control group in a variety of health behaviours thought to affect cellular immunity. This implies that health behaviours were not responsible for the observed differences between the caregivers and the control group. Similar results were reported by Esterling, Kiecolt-Glaser, Bodnar and Glaser (1994), who compared Alzheimer's-disease caregivers, former Alzheimer's-disease caregivers whose relative suffering from the disease had died at least two years previously, and controls. Findings indicated that former and current caregivers did not differ from each other and both had poorer natural killer cell function than the control group. This implies that psychological and immunological consequences of chronic stressors may persist beyond the cessation of the actual stressor, and that these effects may be long-term.

The problem with such 'real-world' studies is that it is difficult to glean much information regarding the biological processes at work. Therefore, the effects of stress on the immune system have also been examined in laboratory studies, using acute psychological stressors, usually 5 to 20 minutes in duration (Cohen and Herbert, 1996). Such laboratory studies are useful for exploring biological mechanisms linking psychological stress to immune function. For example, Manuck, Cohen, Rabin, Muldoon and Bachen (1991) observed that individuals with a high activation of the sympathetic nervous system, that is, high levels of blood pressure, heart rate, and the hormones epinephrine and norepinephrine (changes associated with stress), also showed the largest immune changes when confronted with acute psychological stressors. By contrast, those who had low sympathetic activity exhibited little or no change. Other studies have replicated these findings (Bachen, Manuck, Cohen, Muldoon, Raible et al., 1995; Herbert, Cohen, Marsland, Bachen, Rabin et al., 1994; Zakowski, McAllister, Deal and Baum, 1992). However, a problem with laboratory studies of this kind lies in their lack of external validity: it is unclear to what extent the effects of acute stressors administered in the laboratory simulate the effects of chronic real-life stressful events (Cohen and Herbert, 1996). Further research is needed to determine if laboratory immune reactivity is a dispositional marker of susceptibility to stress-elicited disease (Boyce, Chesney, Alkon, Tschann, Adams et al., 1995).

The connection between stress and immunosuppression seems to be particularly relevant to women with a history of cancer in their family. Bovbjerg and Valdimarsdottir (1993) explored the possibility that healthy individuals with a family history of cancer have lower levels of natural killer-cell activity. Their sample consisted of 43 healthy women, some with and some without a family history of cancer. Independent of family history, women with higher levels of distress had lower natural killer-cell activity. When the contribution of stress-induced immunosuppression was removed, natural killer-cell activity remained lower in women who had a first-degree relative with cancer. The authors posited that

heritable defects in the preneoplastic cell and reduction in natural killer-cell activity both contributed to increased cancer risk. However, these results need to be interpreted with caution, in light of the small sample size. Replication with a bigger sample would be necessary to strengthen these findings.

The mechanisms through which stressful life events increase cancer risk are unclear, but several pathways have been proposed. McDaniel, Musselman, Porter, Reed and Nemeroff (1995) have suggested that the release of glucocorticoids during both acute and chronic stress, which has been associated with compromised immune function, may leave the organism vulnerable to tumour-producing viruses, newly transformed cancer cells and other diseases subject to immunologic control. Still, this does not explain why cancer specifically is the most prevalent disease associated with stressful life events. Thus, Holland (1990) has hypothesised that psychosocial factors may act as promoters of malignant cell division. Evidence for this comes from animal studies. For example, Sklar and Anisman (1979) reported that experimental animals allowed to escape electrical shock showed reduced growth of transplanted tumours compared to 'yoked' control animals, indicating a potential psychological effect on tumour growth.

Sklar and Anisman (1981) proposed a pathway through which stress could bring about cancer. Typically, chronic stress in which the organism is unable to adapt, leads to the depletion of norepinephrine and dopamine in some brain regions, with increased levels of acetylcholine and other hormones relevant to the HPA axis. These changes are associated with immunosuppression and enhanced tumour development in a variety of animal models. On the other hand, chronic stress paradigms in which animals show adaptation to the stress usually lead to enhanced synthesis of norepinephrine and dopamine, and a decrease in stress hormones toward baseline. This ability to 'cope' effectively generally leads to enhanced immune function and deceleration of tumour growth. However, Fife, Beasley and Fertig (1996) emphasised that studies of the effects

of chronic stress on the immune system have produced conflicting results, partly because the nature of the stressor in animal studies varies, and thus individual studies may not easily be compared to one another or to other models. Moreover, studies with human participants would be needed to confirm the applicability of these proposed pathways to humans.

3.2.2 Social Support and Immune Function

Social support is another construct which has been researched from a PNI perspective. It has been shown that there is a connection between belonging to a strong social network and longevity (House, Landis and Umberson, 1988), and that perceptions of available support protect individuals from the pathogenic effects of stressful events (Cohen and Wills, 1985). Nevertheless, it has not yet been determined to what extent these effects are mediated by support-induced changes in immune function. In an attempt to elucidate this connection, Glaser, Kiecolt-Glaser, Speicher and Holliday (1985) conducted studies with first-year medical students. They found that those higher in self-reported loneliness, measured with the UCLA Loneliness Scale (Russell, Peplau and Cutrona, 1980), had lower natural killer cell activity and higher levels of herpesvirus antibody than those who described themselves as less lonely. A similar study with psychiatric inpatients revealed that lonelier patients had poorer natural killer cell function than did patients who reported less loneliness (Kiecolt-Glaser, Garner, Speicher, Penn, Holliday et al., 1984). This difference could not be explained by greater depression or more numerous stressful life events among those with less social support. Although these results lend support to the notion that loneliness and immune function are connected, it is uncertain how stable the concept of loneliness is. As the UCLA Loneliness Scale was only administered to participants once, it is unknown whether they felt similar loneliness a day, week or month later. It may therefore have been beneficial to measure loneliness repeatedly, in order to be able to assess its stability over time.

Poor marital relations, separation and divorce have also been shown to be related to poor immune function. Kiecolt-Glaser, Fisher, Ogrocki, Stout, Speicher et al. (1987), in a sample of 16 separated and divorced women, found that these women exhibited less immunocompetence (the ability of the body to produce a normal immune response following exposure to an antigen), indicated by several measures such as levels of herpes antibody and percentage of natural killer cells, than a comparison group of 16 married women. In a similar study, Kiecolt-Glaser, Kennedy, Malkoff, Fisher, Speicher et al. (1988) in a sample of 32 separated and divorced men demonstrated that these men had poorer immune function than their 32 married counterparts, as measured by levels of herpes antibody and self-reported infectious illnesses. However, the sample sizes of both studies were quite small, and replication with larger samples would be beneficial. In addition, although levels of herpes antibody are reliable measures of immunocompetence (Cohen and Herbert, 1996), self-reported illness is a less reliable measure because, firstly, it is subject to participants' willingness to disclose this information accurately, and secondly, participants may themselves not be aware of which illnesses they have. Thus, verification through medical tests would be necessary to corroborate self-reports.

Apart from self-reported loneliness and poor marital relations, perceived social support has been found to be strongly connected to immune function. Thomas, Goodwin and Goodwin (1985) examined blood samples from 256 elderly adults. Their findings indicated that the blood samples from persons reporting that they had confiding relationships proliferated more in response to phytohemagglutinin (indicating higher immune competence) than the samples from those without confiding relationships. This association was unchanged when controlling for psychological distress and health practices. Similar results were reported by Baron, Cutrona, Hicklin, Russell and Lubaroff (1990), who examined blood samples of 23 spouses of patients with cancer and found that six different provisions of social support (including emotional and instrumental social support) were associated with higher natural killer cell activity and better proliferative

response to phytohemagglutinin. This difference persisted after controlling for depression and number of stressful life events. Glaser, Kiecolt-Glaser, Bonneau, Malarkey, Kennedy et al. (1992) reported that medical students who had more available social support produced more antibody in response to a hepatitis B vaccination (indicating higher immune competence) than those reporting less available support. However, two related studies with male HIV patients failed to establish a relationship between social support and immunity (Goodkin, Blaney, Feaster, Fletcher, Baum et al., 1992; Perry, Fishman, Jacobsberg and Frances, 1992). It is thus possible that the effects of social support on immunity cannot be detected in the face of a severe immunodeficiency-causing illness such as HIV (Cohen and Herbert, 1996).

3.2.3 Personality and Immune Function

The third area of PNI relevant to the aetiology of breast cancer is personality. Connections relevant to breast-cancer development have been found between personality traits and immune function. One of these traits is emotional suppression. There is some evidence to suggest that a personality style which consistently suppresses negative emotions is associated with variation in immune function consistent with poorer health outcomes. Emotional suppressors tend to have lower cell-mediated immune responses (Shea, Burton and Girgis, 1993), decreased numbers of blood monocytes, and elevated eosinophil counts and serum glucose levels (Jamner, Schwarz and Leigh, 1988). Suppression of negative emotion has also been linked to poorer natural killer-cell activity in breast-cancer patients (Levy, Herberman, Maluish, Schliew and Lippman, 1985). Conversely, a number of studies have demonstrated that emotional expression may lead to immune changes related to positive health outcomes (Pennebaker, 1993; Futterman, Kemeny, Shapiro and Fahey, 1994; Knapp, Levy, Giorgi, Black, Fox et al., 1992). Experimental evidence for the connection between emotional suppression and immune function has been provided by Petrie, Booth and Pennebaker (1998), who investigated the immunological effects of thought suppression on 65 medical school students. Participants

were randomly assigned to write about either traumatic or trivial control topics for three consecutive days. Some participants were instructed to actively suppress their thoughts about what they had written, while others were encouraged to think about their writings. Blood samples were taken before and after each writing session. The results demonstrated that thought suppression, regardless of whether the individual wrote about a traumatic event or a control topic, resulted in a significant decrease in CD3 T lymphocyte levels, indicating decreased immune function.

In addition, emotional writing, as opposed to writing about a trivial topic, increased the levels of circulating T helper cells and the number of total lymphocytes. The authors suggested two ways in which thought suppression could affect immune function. Firstly, simply attempting to suppress one's thoughts could be construed as a stressful activity, and acute stressors have been found to affect circulating lymphocyte numbers. Secondly, the expression of emotional and non-emotional thoughts, probably through differential effects on autonomic activity, could alter immune variables in different ways, with better outcomes for emotional thoughts.

Although these findings are promising, it is important to bear in mind that the study was only able to demonstrate short-term effects on the immune system, as participants were only asked to suppress their thoughts for five minutes at a time. Still, Petrie and colleagues remarked that if short-term thought suppression can cause alterations in immunocompetence, suppression over a longer term may cause changes in immune function that could compromise health. Therefore, future research would need to focus on examining the effects of long-term thought suppression.

The biological pathways from emotional suppression to the development of breast cancer are still largely unknown, although a recent study has shed some light on the possible mechanisms involved. Tops, van Peer and Korf (2007) investigated whether individual

differences in emotional expressivity predicted oxytocin levels in response to the administration of cortisol. There is some indication that oxytocin protects against the development of breast cancer and slows its progression. The breasts contain oxytocin target tissues which express oxytocin receptors, and it appears that tumour growth is regulated by oxytocin through the oxytocin receptor (Carrera, Ramirez-Exposito, Valenzuela, Garcia, Mayas et al., 2004; Cassoni, Sapino, Marrocco, Chini and Bussolati, 2004). Thus, higher levels of oxytocin have a greater protective effect. Oxytocin is a mediator of attachment processes, with oxytocin levels decreasing in response to separation or rejection (Panksepp, Nelson and Bekkedal, 1997). Moreover, oxytocin reduces the behavioural inhibition in social interactions that leads to emotional suppression (Carter, 1998; McCarthy, 1995; Panksepp et al., 1997). The researchers administered cortisol to 18 women in order to induce oxytocin production, and discovered that those women who scored high in emotional expression and control also had higher levels of oxytocin than those who scored low.

This finding suggests a pathway leading from emotional suppression to the development of breast cancer, through individual differences in emotional expressivity, which - in turn - determine differences in oxytocin levels. Although the sample size in this study was small, the results tentatively support the notion of a link between oxytocin levels and the development and progression of breast cancer. Specifically, women who are low in emotional expression may have lower levels of oxytocin, which - in turn - may put them more at risk of developing breast cancer. This finding, however, would need to be replicated with a larger sample.

3.3 The Diathesis-Stress Theory of Disease

Influential in the research into the pathways from stress to cancer has been the diathesis-stress theory, developed by Grossarth-Maticek and colleagues (Grossarth-Maticek, 1980; Grossarth-Maticek, Eysenck and Vetter, 1988; Eysenck, 1988, 1991; Eysenck, Grossarth-

Maticek and Everitt, 1991; Grossarth-Maticek, Eysenck and Boyle, 1994). According to this theory, it is strain, rather than stress, which plays a role in the perceived ability to cope with an event. Strain is the combined effort of stress (objectively defined) and diathesis (personality, including traits, types, attitudes, behaviour and its underlying biological and environmental causes – Eysenck and Eysenck, 1985). Thus, stressful life events (e.g. bereavement) and diathesis (in the case of breast cancer, this would be genetic predisposition, physical risk factors, personality traits, maladaptive coping strategies, and low social support) are thought to interact 'synergistically', as the authors term it, to produce breast cancer. This means that both stress and diathesis on their own have a smaller effect than when they come together, the effect being multiplicative rather than additive.

It could be argued, however, that stress, strain and diathesis are interrelated. In the Swedish Adoption/Twin Study of Aging, Plomin, Liechtenstein, Pedersen and McClearn (1990) reported that genetic analyses of measures of life events during the last half of the life span showed significant genetic influence on *controllable* events, in which the individual can play an active role, but not for *uncontrollable* events, which are independent of the individual's actions. Saudino, Pedersen, Liechtenstein, McClearn and Plomin (1997) discovered that life events were a function of personality differences in older women, with all of the genetic variance on controllable, desirable, and undesirable life events being common to personality. Thus, genetic influences on life events appeared to be entirely mediated by personality. The authors argued that the environment is not independent of the individual: individuals play an active role in creating their own environments. Therefore, if measures of life events reflect genetically-influenced characteristics of the individual, genetic influence on life-event measures can be expected to be found.

Furthermore, it is thinkable that illness (e.g. breast cancer) could very well produce the diathesis (i.e. personality). Thus any distinction made between stress, strain and diathesis is somewhat artificial (Eysenck, 1994).

The diathesis-stress theory is supported by a considerable body of research conducted by Grossarth-Maticek, Eysenck and colleagues. They were able to show that both physical and psychosocial factors on their own have a weak to moderate effect, but combined they produce a very strong effect (e.g. Grossarth-Maticek, 1980; Grossarth-Maticek and Eysenck, 1988). In fact, in one study it was demonstrated that psychosocial risk factors on their own were more predictive of cancer than physical risk factors (Grossarth-Maticek and Eysenck, 1994).

Despite the evidence, it remains to be shown how exactly diathesis and stress combine to produce cancer. The following pathway has been proposed by Eysenck (1994): stress-strain (an ineffectual personality response to stress) leads to cortisol secretion, which in turn leads to immunodepression, and this in turn promotes cancer growth. However, as mentioned above, research would be needed to produce evidence for this proposed pathway.

A recent study on prostate cancer and stressful life events (Gidron, Fabre, Grosman, Nolazco, Mesch et al., 2010) showed an interaction between life events and cortisol. Among men with low cortisol, the number of stressful life events experienced were inversely and significantly correlated with prostate-specific antigen (PSA) levels, a tumour marker, while in men with high cortisol, the number of stressful life events were positively and significantly correlated with PSA. This indicates a higher vulnerability of men with high cortisol to prostate cancer. However, it is not yet known whether such an interaction also exists for breast cancer.

3.4 Breast Cancer and the Loss of the Feminine Role

Another way in which psychosocial factors may lead to breast cancer has been hypothesised by Liste (1999), who drew on psychodynamic and psychosomatic theory. Liste posited that individuals who possess traits associated with femininity, such as self-blame and repressive defence mechanisms, typically report more symptom distress and have poorer psychological health. She proposed that cancer patients, irrespective of their gender, are likely to have more feminine than masculine traits, and therefore use more feminine defence mechanisms. Liste then described how cancer often appears after an important loss, usually of a close relationship which had provided a particular individual with a space to unfold their feminine nurturing qualities. This throws the person back into a world in which only masculine values count, with no room for nurturing. Liste explained that this may result in the development of breast cancer, as a reaction to circumstances overwhelming one's habitual ways of coping. The individual is unable to transform the meaning of an event into mental representations which can be contained, repressed or acted out in some symbolised form. She believed the roots of this somatisation to lie in early infancy, where the infant's needs were not met adequately. This leads to an inability to create an internal representation of a soothing maternal environment. According to Liste, this lack may persist into adulthood.

Psychodynamic theory postulates that there is a tendency to develop neurotic symptoms when conflicting, impossible or forbidden desires find no adequate outlet. The neurotic symptoms keep the conflicting wishes from consciousness, but sometimes, it may nevertheless happen that some internal or external event (e.g. bereavement) has such a meaning to the person that they revert to an archaic mode of defence, keeping the emotional impact of the event from consciousness, which can result in physical problems. Liste cites the work of Bahnson (1981), who proposed a model in which both psychosis and cancer are the result of early deprivation, and a severely regressed individual may succumb to either psychosis or cancer. It was contended that cancer is a form of

regression at the cellular level, and that both psychological and biological processes take place simultaneously and synchronously. Cancer cells were seen as regressing to an archaic pattern of cell behaviour, that is, to the very early pattern of cell proliferation evident in the zygote. Benedette (1969; as cited in Liste, 1999) suggested that cells which become cancerous can be said to be alienated from the rest of the organism, just as the individual who is suffering from cancer can be seen as alienated from her feelings.

Tenney (1978; as cited in Liste, 1999), a gynaecologist and psychiatrist, observed that the cancer patients she encountered had often had a childhood characterised by emotional and social isolation, but usually managed to live a normal life through investing a great deal in another person or a career. She put forward that, due to these negative childhood experiences, these people were filled with feelings of self-contempt and self-destructiveness, and when they lost an important relationship, they lost their reason for being. Furthermore, Tenney suggested that it was important to see the psychological meaning behind the particular organ in which disease, malignant or not, has developed. Thus, according to Tenney, the diseased organ is an accurate physical representation of the area in which the conflict is to be found psychologically, as though the organ involved depicts the conflict that is broadcast and translated from the psyche into physical form. In the same vein, Liste hypothesised that breast cancer is an attempt by women to rid themselves of the breast as a symbol of certain aspects of their femininity. She emphasised that the breast is a symbol of nurturance, and when women lose a relationship in which they have been allowed to nurture, disease hits the organ that no longer carries any meaning. Liste attributed the steady increase of breast cancer in the Western world in recent decades to an increasing alienation between the feminine nurturing role and society as a whole. Furthermore, she proposed that the nurturing qualities of womanhood are of no significance in our modern society, which places emphasis on the production of quantifiable, measurable goods.

Although Liste's hypothesised pathway from loss of the feminine role to breast cancer is intriguing, there are some problems with it. Firstly, there is no direct empirical evidence to support this pathway; the hypothesis has yet to be tested, preferably by means of prospective studies which would allow for causal connections to be made. Secondly, much of the suggested connections are based on post-hoc data analysis and anecdotal evidence such as patient observation. Thirdly, although Liste did acknowledge that her hypothesis does not completely explain the occurrence of breast cancer and that biological and environmental factors also play a role, it does not appear to leave much room for such variables, nor does it allow for cases in which individuals develop breast cancer despite not having experienced the loss of the feminine role through loss of a close relationship. Finally, it is unclear how precisely psychological regression is mirrored in the body by the 'regression' of cells to produce cancer, nor why this regression takes place in a part of the body which symbolises the psychological conflict that the individual is experiencing. In sum, although it cannot be ruled out that Liste's hypothesis holds true for certain individuals, substantial research is needed to explore this proposed pathway to breast cancer.

3.5 Conclusion

There is a growing body of literature exploring the pathways from psychosocial factors to illness in general and breast cancer in particular. The hypothesised pathways discussed here are based on relatively few studies, and more research is needed to shed light on the precise mechanisms by which psychological and social variables contribute to the development of breast cancer. An integrated model of breast cancer and psychosocial risk factors is needed to bring more clarity to this area and to understand how all factors interact (Eysenck, 1994). However, there are no studies which follow the pathway from stress, low social support, or personality traits, through to a decreased immune response, and ultimately the development of breast cancer. Prospective research would be required;

yet, such research is very costly, time-consuming and often suffers from high levels of attrition.

Nonetheless, the fact that the nature of the pathways from psychosocial factors to breast cancer is not yet fully understood does not in any way diminish the need to intervene on a psychosocial level, in order to reduce the likelihood of breast cancer occurring. In the next chapter, interventions targeting psychosocial breast-cancer risk factors are discussed.

CHAPTER FOUR

INTERVENTIONS TARGETING PSYCHOSOCIAL FACTORS IN BREAST-CANCER DEVELOPMENT

CONTENTS

4.1 Introduction

This chapter examines interventions which have addressed the individual psychosocial factors involved in the aetiology of breast cancer that were discussed in Chapter Two. Although nearly all of the interventions introduced in the present chapter were not primarily developed to reduce the risk of developing breast cancer, they all have nevertheless addressed at least one of these psychosocial factors.

Firstly, two interventions facilitating emotional expression and coping with loss are described and evaluated: art therapy and written emotional disclosure. Secondly, the enhancement of social support is focused on, with Internet therapy and Internet support groups as examples of interventions fulfilling this function. Thirdly, stress reduction and stress management are looked at, and laughter and humour therapy are examined more closely for their stress-reducing properties. Next, psycho-education is considered, with the main focus on the use of illness stories and health-related autobiographical accounts. Finally, interventions targeting multiple psychosocial breast-cancer factors simultaneously are reviewed.

4.2 Interventions Facilitating Emotional Expression

Chapter Two showed that emotional suppression, as one of the characteristics of the 'cancer-prone' personality, has been associated with breast-cancer development. Similar links have been shown between experiences involving the loss of a loved one or of a close relationship and breast-cancer development. A multitude of approaches have been designed to assist individuals in coping with distressing events and situations, such as being bereaved. Popular examples are Cognitive Behavioural Therapy or Rational Emotive Behaviour Therapy, both of which appear to be rather effective in the treatment of a variety of psychological problems (Butler, Chapman, Forman and Beck, 2006; Cooper, 2008). However, these approaches do not *per se* encourage emotional expression. Rather, they focus on assisting clients to think rationally about their situation and their own

behaviour. With emotional suppression being one of the factors that increase vulnerability to breast cancer, it seems important to facilitate emotional expression in individuals who may be at risk of developing this disease. Individuals who find it difficult to express negative emotions may be more comfortable with either expressing themselves nonverbally, or in a way that does not involve face-to-face communication. Two forms of intervention which offer this are art therapy and written emotional disclosure. In the following, both are described and evaluated.

4.2.1 Art Therapy

Art Therapy is a form of psychotherapy, usually carried out face-to-face, which uses art media as its primary mode of communication (British Association of Art Therapists [BAAT], 2009). Clients are normally asked to produce images using a variety of materials and techniques, such as watercolour, chalk, or clay. However, the art therapist is not primarily concerned with making an aesthetic or diagnostic assessment of the client's image. Rather, he or she aims to enable a client to effect change and growth on a personal level, through the use of art materials in a safe and facilitating environment. Art therapy offers those who find it difficult to express themselves verbally an alternative, non-verbal form of expression; for example, Collie, Backos, Malchiodi and Spiegel (2006) suggested that art therapy is a suitable form of therapy for combat-related post-traumatic stress disorder (PTSD), which is often associated with avoidant or repressive coping.

There is a considerable body of research supporting the use of face-to-face art therapy when working with clients who have been bereaved or who have experienced other distressful events, such as victims of sexual abuse, war veterans, or divorcees. However, much of the literature in this field has focused on individual grief work with children or young people who have lost their parents or caregivers (e.g. McIntyre, 1990a, 1990b; Johnston, 1993; Goodman, 2002; Lehna, 1995; Kuczaj, 1998). In a review, Finn (2003)

concluded that there is evidence to support the use of grief groups, as well as the positive effect of art therapy in the treatment of this client group.

Other studies have focused on using group art therapy in working with bereaved families. Group therapy, as opposed to individual therapy, has the advantage of inclusion, with each person becoming part of the therapy of others (Blatner, 1992). Kirk and McManus (2002) described the use of group art therapy in a hospice setting, working with four families who were losing a loved one to cancer. Two one-day workshops were followed by six weekly evening sessions. At the end of the intervention, participants were asked how they had experienced the therapy sessions. All group members felt that they had benefited from the intervention, and expressed the desire to continue to meet up. However, no further outcomes were measured, such as coping with bereavement, or adjustment to the loss. Therefore, the usefulness of the intervention could not be quantified. Furthermore, it could not be ruled out that participants claimed to find the intervention beneficial in order to comply with what they felt was expected of them.

Some studies have shown that art therapy can be beneficial for bereaved women. Significant work in this area has been carried out by Ferszt, Heinemann, Ferszt and Romano (1998), who conducted weekly group art therapy sessions for eight weeks with four women who had been bereaved within the past year. Participants were observed and interviewed after ending the intervention. It was found that the women all benefited from the sessions, and felt enabled to deal with difficult feelings, such as anger, in an acceptable way. It also facilitated the expression of deep sorrow and anger in a safe place. Furthermore, the authors reported that participants saw themselves in a new way, which allowed them to reflect on their own possibilities for growth and change. However, this study suffers from the same problems as the study by Kirk and McManus described above.

In a later study, Ferszt, Hayes, DeFedele and Horn (2004) carried out an eight-week intervention involving individual art therapy with female offenders who had experienced the death of a significant person during their incarceration. The authors pointed out that women in prison often feel the need to hide their feelings, because if they allow themselves to show their sadness, they may be seen as weak and may experience ridicule rather than support and empathy (Ferszt, 2002). It is therefore reasonable to assume that being bereaved when already experiencing the stressful effects of being imprisoned may be particularly difficult. Interviews after ending the therapy sessions showed that all participants perceived them as beneficial, because they allowed them to come to terms with the loss and increased positive affect. However, no follow-up was reported, so it is unclear how long this effect lasted. Additionally, similar to the studies described above, no psychological outcomes were measured. Instead, the study relied solely on participants' evaluations of the intervention, making it impossible to quantify how beneficial the intervention had been.

There are other life events which may be experienced in a way comparable to bereavement. For example, Turetsky and Hays (2003) proposed that the transition to midlife, occurring when an individual is between 35 and 50 years old, is analogous to the stages of bereavement as described by Zisook and DeVaul (1984; 1985). These stages include an initial period of shock and disbelief, which then merges into a period of acute mourning marked by intense dysphoria, social withdrawal, and identification with the deceased (i.e. the former, younger self). This is then gradually worked through until emotional and cognitive resolution is achieved. Turetsky and Hays posited that art therapy could be used to facilitate the transition into midlife and to prevent unresolved grief, illustrating this with two case studies of individuals who were taking part in art-psychotherapy group treatment. The authors reported that art therapy helped both clients come to terms with their transition and say good-bye to their 'young selves'. However, it is not mentioned how long treatment lasted or how frequently sessions were held.

Furthermore, no outcome measures were defined nor recorded, which would have been necessary to quantify the benefits of the authors' proposed approach.

Another life event which has been compared to bereavement is marital breakdown, which involves the loss of a significant relationship (Gierveld, 2004). The longer the marriage, the more likely it is that problems are experienced adjusting to this event (Sakraida, 2005). Reynolds, Lim and Prior (2008) explored three women's experience of art therapy in this context. Participants were interviewed and asked to reflect on their experiences. Narrative analysis was carried out on interview data independently and then jointly by all authors, for the purpose of enhancing credibility. The results indicated that art therapy helped women's transition through this difficult time, and to mourn the loss of the marital relationship. Even brief experiences of therapeutic art-making seemed to have lasting benefits decades later. However, these results were based entirely on interview data, with no psychological measures, such as measures of coping, being administered. Therefore, it is impossible to quantify these benefits. Furthermore, the sample size was extremely small, and as the data were wholly retrospective and no other variables were controlled for, it is not certain if the perceived improvements were attributable to art therapy or to other, unmeasured variables. Additionally, it was neither stated what forms of art therapy were used, nor which types of art clients produced. Still, these results are positive and warrant exploration in further research, addressing the above mentioned limitations.

Altogether, although encouraging, the studies described above must be interpreted with caution due to their small sample sizes and lack of follow-up. Moreover, they lacked psychological outcome measures and baseline assessment.

Notably, art therapy seems to be beneficial for individuals who are going through an extremely stressful life event: living with cancer. Bar-Sela, Atid, Danos, Gabay and Epelbaum (2007) conducted a non-randomised controlled trial with 60 cancer patients, assessing anxiety and depression at baseline and post-intervention with the Hospital

Anxiety and Depression Scale (Zigmond and Snaith, 1983). Patients either self-referred or were referred by their doctor, then took part in anthroposophical art therapy. Bar-Sela and colleagues explained that in this form of art therapy, which is based on the philosophy of Rudolf Steiner, artistic elements are used to teach patients to act in a more conscious way. A once-weekly session was held, which involved patients painting with water-colours while supervised individually by art therapists. Nineteen people participated in four or more sessions; these comprised the 'intervention group'. The remaining patients took part in three or less sessions, and comprised the 'participation group'. Non-parametric tests were carried out to compare the intervention group and the participation group on their depression scores (Mann–Whitney U-test and Wilcoxon signed ranks test). A statistically significant improvement in depression scores was observed for the intervention group. Although these results are encouraging, the authors conceded that the design of their study did not allow for any causal inferences to be made, as placebo effects could not be ruled out. Furthermore, an untreated control group would have been necessary against which to compare anxiety and depression scores.

Reynolds and Lim (2007) conducted semi-structured interviews with 12 women with cancer. Thematic analysis revealed that creating art work as a leisure pursuit was beneficial to these women, as it helped them focus on positive life experiences, improved well-being, helped them retain positive plans and hope for the future, and enhanced their self-worth. However, these women had been recruited through UK arts magazines and they were practising art as a leisure pursuit; therefore, it can be assumed that they had a special interest in art and art-making, and were probably confident in their own artistic abilities. Thus, it is unclear if these findings would apply to cancer patients who are less well acquainted with art-making. Furthermore, the authors did not distinguish between different forms of art-making, and it is therefore not clear whether some forms were perceived more or less beneficial than others.

Similarly, Radley and Bell (2007) discussed the role of artworks produced by women with breast cancer, drawing on the work of Jo Spence and Martha Hall, two artists who suffered from breast cancer and used art, specifically photography, as a means of coping with and communicating their experiences. Like in Reynolds and Lim's research, this focused on women who used art-making voluntarily, out of their own interest, rather than as part of a structured, administered intervention. Still, both studies draw attention to the possibility that art-making may be beneficial to other cancer patients. Although the women in these studies had already developed breast cancer, it is thinkable that artworks could be used at an earlier stage, to enhance preventative breast-cancer interventions.

Art therapy has been used successfully to treat alexithymia, which, as described in Chapter Two, is the inability to recognise and verbally express emotions. Meijer-Degen and Lansen (2006) described the case of a woman, given the pseudonym Rita, with severe alexithymia who had also had a very traumatic childhood. She received individual and group art therapy for two years, with the frequency of sessions alternating between once-weekly and once every two weeks. Her therapy sessions were designed to use art materials and art techniques as a part of psychotherapeutic process, as well as using art as therapy to aid the healing process itself. Rita was provided with art materials and asked to acquaint herself with these materials by producing drawings, paintings or sculptures. She used different materials such as paint, clay and crayons, with the therapist asking her questions about her artworks, thus using them as a starting point for Rita to talk about her experiences. Rita produced artworks reflecting significant others and significant moments in her life. After the intervention, the client showed an improvement in her ability to recognise and name her emotions, and a marked decrease in depressive symptoms. However, no baseline measures of any psychological variables were taken, nor any post-treatment or follow-up measures. Therefore, improvements were not quantifiable. Furthermore, it is mentioned that the client had previously received psychotherapy for three years. It is therefore uncertain whether the self-reported improvements were due to

art therapy or to other unmeasured factors. Still, the study highlights the possibility of art therapy being beneficial to those who find it difficult to recognise and articulate their emotions.

Another artistic method used to aid individuals in coming to terms with an event and expressing their feelings about this event is photo eliciation. Participants are asked to reflect on photographs of objects, places or people who are meaningful to them. These photographs can be existing ones, or can be produced by the participant themselves, which is termed photo production. The advantage of this technique is that it enables those who do not feel artistically confident to produce images that are significant to them. Additionally, laymen's photography, unlike painting, sculpture or other forms of artwork, does not require any other materials than a camera and can be carried out anywhere. Harper (2002) contended that the parts of the brain that process visual information are evolutionarily older than the parts that process verbal information, and thus images evoke deeper elements of human consciousness than do words. Therefore, photo elicitation has the potential to evoke a different kind of information. Radley and Taylor (2003) asked nine patients hospitalised for surgery or medical investigations to take photographs during their stay in hospital. The researchers were interested in how these photographs would be used by the patients when asked to reflect on their hospitalisation. It was found that the participants tended to use their photographs to help make sense and come to terms with their experience, aiding recovery. The authors argued that remembering through these images helped in the reconstruction of the individuals' biographies following treatment for life-threatening disease, assisting a healthy recovery through establishing the present from the past in a distance separating narrator from setting. In two related studies, Radley, Hodgetts and Cullen (2005; 2006) used the same photo production technique to enable homeless people to show their situation, as well as to tell the researchers about their experiences.

Apart from visual material such as photographs, paintings or drawings, the effects of the production of other art forms, such as music, poetry or stories, on individuals' wellbeing has not been explored yet. However, it would be helpful to examine this, as not every client may feel comfortable producing these forms of visual art, and may prefer to convey their experiences and feelings by other means. Moreover, visual art would be unsuitable for visually impaired clients. Furthermore, as many individuals may not feel artistically confident enough to produce art themselves, it would be useful to look at a technique which allows clients to contribute art created by others, and to use this to convey their feelings and experiences.

It is important to note that the art-therapy studies reviewed here were all carried out in a face-to-face setting. There is a lack of research exploring art therapy carried out electronically, for example, on the Internet. Web-based interventions offer many advantages over conventional face-to-face modes of delivery. These are discussed in Section 4.3.

4.2.2 Written Emotional Disclosure

A large number of controlled experiments have been carried out examining written emotional disclosure, often also referred to as expressive writing, as a method of improving mental and physical health. This method was first developed by Pennebaker and Beall (1986). Research in this area usually entails random assignment of individuals to an experimental or control condition, with instructions to either write about their deepest thoughts and feelings regarding a stressful experience, or about relatively trivial topics. Outcome measures tend to consist of the number of doctor appointments, measures of immune function, or self-reported well-being. In a meta-analysis of studies involving written emotional disclosure, Smyth (1998) found that it enhanced reported physical health, psychological well-being, physiological functioning, and general functioning.

Written emotional disclosure has been linked to enhanced immune function, both in healthy as well as in ill individuals. Booth, Petrie and Pennebaker (1997) asked 78 healthy adult volunteers to write about upsetting events which had happened to them, for four consecutive days. Participants in the control group were asked to write about trivial topics. The results indicated that those who had written about upsetting events exhibited enhanced immune function, measured by counting circulating lymphocytes. Similarly, Pennebaker, Kiecolt-Glaser and Glaser (1988) detected a significant association between writing about traumatic events and the blastogenic response of T-lymphocytes to two mitogens, and on subjective distress of 50 healthy undergraduate students: writing about traumatic experiences improved immune function and reduced subjective distress, compared to the control group who wrote about superficial topics.

Petrie, Fontanilla, Thomas, Booth and Pennebaker (2004) conducted a randomised controlled expressive writing trial with 37 HIV-infected patients. The experimental group wrote about emotional topics, while the control group wrote about trivial topics. The authors detected an improved immune response in the intervention group following the expressive writing, measured by lymphocyte count and HIV viral load. Remarkably, this effect was similar in magnitude to effects seen with anti-HIV drug therapy.

Written emotional disclosure has been shown to be beneficial to sufferers of asthma and rheumatoid arthritis. Smyth, Stone, Hurewitz and Kaell (1999) conducted a randomised controlled trial with a volunteer sample of 61 asthma patients and 51 rheumatoid arthritis patients. Outcome measures included the pulmonary function of patients with asthma, while evaluations of rheumatoid arthritis patients were made with a structured interview completed by the treating rheumatologist. These outcomes were evaluated at baseline, two weeks, two months, and four months after writing. Participants were asked to write about the most stressful event of their lives for 20 minutes on three consecutive days a week after completing baseline assessments. Control-group participants wrote about

innocuous topics. It was shown that asthma and rheumatoid arthritis patients exhibited improved health as assessed with the outcome measures. This persisted at four-month follow-up. Although it is uncertain whether these findings extend to other illnesses, it nevertheless shows the potential of written emotional disclosure to impact favourably on health outcomes.

Another study has demonstrated beneficial effects of written emotional disclosure for alexithymic individuals. O'Connor and Ashley (2008) examined the effects of written emotional disclosure on the cardiovascular response to stress in 87 alexithymic and non-alexithymic individuals. Participants were asked to write about their most stressful life experience for 15 minutes, over three consecutive days. The control group was asked to write about what they had done in the previous day, and their plans for the next day. It was found that alexithymic participants who disclosed more negative than positive emotion words showed a reduced cardiovascular response to stress, compared with alexithymic participants who disclosed more positive than negative emotion words. Conversely, non-alexithymic participants who disclosed more positive than negative emotion words showed a reduced cardiovascular response to stress, compared with non-alexithymic participants who disclosed more negative than positive emotion words. The authors proposed that this was because a higher proportion of negative emotion words in alexithymic individuals' diaries suggested that the individual had accessed a traumatic memory successfully and was now working through the experience. Conversely, in non-alexithymic individuals, a higher proportion of positive emotion words signified 'adaptive' or 'optimal' emotional processing. Although the sample consisted exclusively of university students, which would necessitate a replication of these results with a sample more representative of the general population, it thus seems that alexithymic and non-alexithymic individuals both benefit from written emotional expression under different conditions. Similar studies have found that alexithymic individuals, as well as individuals

high in emotional suppression, benefit most from written emotional expression in terms of psychological wellbeing (Lu and Stanton, 2010; Baikie, 2008).

Improvements in physical health are often associated with marked improvements in psychological health. This was demonstrated in a study by Stanton, Danoff-Burg and Huggins (2002), who asked 70 breast-cancer patients to write about their innermost thoughts and feelings about being diagnosed with breast cancer. A comparison group was asked to write about any positive outcomes which the illness had had for them (i.e. benefit finding), while the control group wrote about the facts of their illness. All breast-cancer patients benefited both physically and psychologically from written emotional expression and benefit-finding. However, the extent to which they benefited was moderated by coping style: those who had an avoidant coping style (i.e. tried to avoid thinking or talking about their illness) were more likely to benefit from writing about positive aspects of having breast cancer, while those low in avoidance were more likely to benefit from writing about their emotions. The authors proposed that avoidant individuals may need to be repeatedly exposed to written emotional disclosure, over longer periods of time, in order to benefit from it. Similarly, Chung and Pennebaker (2008), who asked participants to write about life transitions, found that it was more beneficial to space the writing sessions out over several days, rather than several hours. Participants who had longer time periods between writing sessions found the assignments less aversive and easier to do, and perceived the exercise as more helpful and valuable. They also showed the greatest health improvements at one-month follow-up.

A recent study by Gellaitry, Peters, Bloomfield and Horne (2010) assessed the effects of an expressive writing intervention on eighty women with early-stage breast cancer. The authors demonstrated that expressive writing was associated with a higher level of satisfaction with emotional support, compared with controls who did not receive the intervention. The authors suggested that expressive writing may be a cost effective

accessible treatment that could be incorporated into the ongoing care of breast-cancer patients. Similarly, Low, Stanton, Bower and Gyllenhammer (2010) found expressive writing to be most beneficial to breast-cancer patients with low levels of social support, who reported less intrusive thoughts than those with high levels of social support, following the intervention. Yet, unlike some other studies, this study did not detect any effect of expressive writing on participants' health.

Another life experience in which written emotional expression appears to be helpful is bereavement. In a longitudinal study with 30 men who had lost their partners to AIDS, Pennebaker, Mayne and Francis (1997) showed that those who were asked to write about their bereavement experiences exhibited improved psychological and physical health 12 months after the death. Specifically, depression levels, measured with the Center for Epidemiologic Studies-Depression (CES-D) scale (Radloff, 1977), decreased; positive states of mind, measured with the Positive States of Mind Scale (Horowitz, Adler and Kegeles, 1988), increased; and fewer physical problems were reported. Similar to O'Connor and Ashley's (2008) findings, Pennebaker and colleagues found that the degree to which participants benefited from the exercise depended on the balance between negative and positive emotion words in their writings. A higher use of positive emotion words was associated with improved health. Furthermore, the increased use of words associated with insightful and causal thinking was also linked to better health and psychological well-being.

It thus seems that it is not just the act of written emotional disclosure which may be favourable to one's health, but also the type of words that are used to express one's feelings. Seih, Lin, Huang, Peng and Huang (2008) demonstrated the psychologically beneficial effects of an expressive-writing exercise termed Psychological Displacement Diary-writing Paradigm (PDDP), originally proposed by Jin (2005). This exercise instructs participants to write a diary entry in the first person pronoun, then narrate the same event

but take a different perspective using second-person pronoun. Finally, participants write the entry again, this time in third-person pronoun. PDDP is thought to promote a shift in psychological distance from one's experience to objective evaluation of the event, which helps individuals come to terms with it. The authors instructed 108 volunteers to keep a diary for 10 days using the PDDP paradigm and found that it was perceived as beneficial. Highly anxious participants benefited the most from this technique.

In sum, it can be said that written emotional expression is a useful method for facilitating disclosure of emotions and improving psychological health and well-being. Thus, it should be incorporated into intervention programmes aimed at individuals who have experienced or are experiencing stressful life events, and even more so if they tend to suppress negative emotions and/or have been bereaved. Similar to the reviewed art therapy studies, the written emotional disclosure research discussed here was carried out in a face-to-face setting. Here too is a lack of studies investigating this form of intervention delivered electronically. Section 4.3 explores the benefits of Web-based interventions.

4.3 Internet Therapy and Internet Support Groups

In Chapter Two it was shown that a lack of social support is one of the factors potentially contributing to breast-cancer development. Hence, the enhancement of social support would need to be included in any preventative intervention that addresses the reduction of psychological susceptibility to breast cancer. Interventions enhancing social support usually focus on working in groups. Support groups provide a psychosocial network and offer opportunities for sharing one's problems with others, while problem-solving and psycho-educational groups provide opportunities for interpersonal learning and ego support (Montgomery, 2002).

Most group therapy takes place face-to-face, with group members and facilitator(s) meeting regularly at a certain time and venue. This, however, can be restrictive to

individuals who are unable to travel to the venue or are under time constraints. Furthermore, those who may not feel comfortable talking to other group members about personal issues in a face-to-face setting may shy away from group therapy. Internet therapy and Internet support groups eliminate the need for travel and therefore are potentially accessible to a wide audience. Furthermore, as communication does not take place face-to-face, those who do not feel comfortable disclosing their problems in such a manner are provided with an anonymous mode of communication. For example, Klemm and Hardie (2002) showed that depressed patients with cancer were more likely to use Internet support groups than face-to-face support groups.

Group therapy is sometimes used for bereaved individuals. Kato and Mann (1999) conducted a meta-analysis of various types of face-to-face bereavement intervention studies, including group therapy. Some small beneficial effects were found of such interventions on physical symptoms experienced by bereaved people. However, methodological problems, particularly small sample sizes and high drop-out rates, prevented studies from detecting substantial effects on psychological variables. It is possible that face-to-face settings contribute to high drop-out rates because they often involve the inconvenience of the client having to travel to the location where therapy takes place. Furthermore, face-to-face group therapy may not be suitable for individuals who feel uncomfortable disclosing their thoughts and feelings to a roomful of people.

A possible way to circumvent the problems inherent in face-to-face group therapy is offered by Web-based interventions. Internet therapy and Internet support groups are growing in popularity, and are increasingly being used by individuals for support and to improve psychological well-being. The Internet is a new but rapidly growing channel for exchanging illness experiences, be it on forums or in chat rooms (Overberg, Toussaint and Zwetsloot-Schonk, 2006). Yet, there is a dearth of systematic research in this area.

Some studies have examined the use of online communication tools such as e-mail, message boards and chat rooms in supporting individuals going through stressful life events, such as having cancer. Im and Chee (2003) conducted an e-mail discussion group with 33 cancer patients recruited online through announcements on Internet sites of cancer support groups. Discussions on various topics related to coping with cancer were initiated two to three times per week by the researchers, using a group e-mail list; duration of the group was four weeks. The data were analysed by means of content analysis. The findings supported the feasibility of e-mail group discussions among cancer patients. Female participants tended to share their emotions and being emotionally supportive of other participants with warm messages, while male participants tended to share information resources related to their diseases and treatment processes. However, the study had a low response rate (only nine out of the initially recruited 33 individuals participated actively in the discussions, yielding a response rate of 27%), and it is unclear what measures, if any, were used to evaluate the effectiveness of the intervention.

Nevertheless, more systematic efforts have been made to create effective forms of Internet therapy. Lange, Schrieken, van de Ven, Bredeweg, Emmelkamp et al. (2000) developed 'Interapy', an online treatment programme for posttraumatic stress and pathological grief. An uncontrolled trial was carried out. Twenty undergraduate psychology students participated in the programme, in return for course-credit points. All of them had experienced a traumatic event; on average, it had been six years since their experience. The treatment was delivered by graduate students in clinical psychology and supervised by experienced therapists. Treatment lasted five weeks and follow-up tests were conducted six weeks after the intervention. Ten expressive-writing sessions were carried out online and conducted according to a time schedule which had been designed by the participants themselves and agreed with the researchers. The expressive-writing protocol was designed in line with Pennebaker and Beall's (1986) protocol described above. However, unlike conventional expressive-writing exercises, therapists provided feedback

to the participants on their essays. Participants were assessed before treatment, after treatment, and after six weeks (follow-up). Assessment included screening for PTSD and other psychological disorders. The findings indicated that participants improved significantly on post-traumatic stress and pathological grief symptoms and in psychological functioning; these findings persisted at follow-up. Moreover, 19 out of the 20 participants clinically recovered after the treatment. As the study did not include a control group, these changes were compared to changes in a similar but face-to-face treatment programme carried out by the authors. It was shown that 'Interapy' was of similar effectiveness to a comparable face-to-face therapy. However, there was a higher decrease of avoidance (a maladaptive coping strategy whereby an individual avoids confronting the traumatic event, as outlined in Chapter Two) in 'Interapy', compared to the face-to-face treatment.

The researchers repeated the study (Lange, van de Ven, Schrieken and Emmelkamp, 2001), this time carrying out a randomised controlled trial, with the inclusion of a control group consisting of patients on the waiting list. The results of this study replicated the results of the previous uncontrolled trial: more than 80% of the participants in the experimental group, who had participated in two 45-minute expressive writing sessions online for five weeks, showed clinically reliable improvement in trauma symptomatology, general psychological functioning and mood, improving significantly more than the patients in the waiting-list control condition. However, the sample again consisted of undergraduate psychology students receiving course-credit points for their participation, which may have influenced the outcome favourably.

Lange, Rietdijk, Hudcovicova, van de Ven, Schrieken et al. (2003) subsequently repeated the study with a non-student sample recruited online. Out of the 184 individuals who completed the screening questionnaire, 69 completed the treatment. The control group consisted of 32 patients on the waiting list. All participants had referred themselves into

treatment by visiting the treatment Web site and completing an online consent form. The results replicated the results of the previous two studies, showing that 'Interapy' was not just beneficial for psychology undergraduate students. Furthermore, effect sizes were three times as high as the effect sizes found in face-to-face experiments, as reported in a meta-analysis by Smyth (1998).

Communicating through the Internet has proven helpful to individuals coping with a stressful life event such as contracting cancer (Im, Chee, Lim and Liu, 2008). Winefield (2006) examined support provision in an e-mail support group for breast-cancer patients, which was moderated by a health psychologist and a breast-cancer nurse. The content of e-mails was categorised according to provision of emotional support or information, with the dominant theme of each message being classified as either seeking or providing emotional or informational support. All messages were coded by two independent raters. The results indicated that the majority of support group members seemed to require few visits to the Web site in order for their needs to be satisfied, because 81% wrote five or fewer messages. Those who contributed frequently were more focused on support providing than support seeking. This showed that participants do not only join online support groups to receive information and support, but some also have altruistic motivations and therefore gain personal satisfaction from providing information and support to other members.

Insightful disclosure of one's emotions appears to be associated with beneficial outcomes in breast-cancer patients taking part in Internet support groups. Lieberman (2007) administered questionnaires measuring depression and quality of life to 77 breast-cancer patients who had just joined breast-cancer message boards. A second questionnaire was administered six months later, and a final questionnaire a further six months later. Computer-based text analysis was used to examine participants' messages for insightful disclosure. The findings indicated that insightful disclosure was associated with favourable

outcomes for depression and quality of life. This is in line with the findings of a study by Shaw, Hawkins, McTavish, Pingree and Gustafson (2006), with a similar study design. The authors showed that insightful disclosure within breast-cancer support groups, used to communicate about, understand and make sense of one's breast cancer experience, was associated with improvement in mental health outcomes. Although encouraging, these results were correlational in nature and a causal relationship could not be inferred. Furthermore, the study did not have a control group of breast-cancer patients who did not participate in any online support groups with whom to compare these results.

A methodologically more controlled study was conducted by Winzelberg, Classen, Alpers, Roberts, Koopman et al. (2003). They randomly assigned 72 women with breast cancer to a 12-week, Web-based social support group they termed 'Bosom Buddies'. A new topic related to breast cancer was introduced each week and the moderator, a health-care professional, facilitated a discussion on these topics and related concerns. Participants were provided with personal stories from survivors, shared their own experiences, and kept a Web-based personal journal that was closed to review by other group members. The control group consisted of women on the waiting list. A battery of measures was administered before and after the intervention. It was found that participation in 'Bosom Buddies' reduced participants' scores on depression (measured with the CES-D), perceived stress (measured with the Perceived Stress Scale - Cohen, Kamarck and Mermelstein, 1983), cancer-related trauma measures, and reactions to pain. However, no follow-up measures were taken; therefore, it is uncertain if these effects persisted in the long-term, or even in the medium-term.

In a similar study, Lieberman, Golant, Giese-Davis, Winzelberg, Benjamin et al. (2003) conducted a 16-week online intervention for breast-cancer patients. It was found that after the intervention, breast-carcinoma patients reported decreased depression symptoms (measured with the CES-D) and reactions to pain. They also demonstrated an increase in

several areas of posttraumatic growth, measured with the Post-Traumatic Growth Inventory (Tedeschi and Calhoun, 1996). This assesses positive changes experienced by traumatized individuals. Specifically, participants expressed somewhat more zest for life and deepened their spiritual lives. Although the study suffered from a lack of randomization and had no control group, these results are in line with Winzelberg et al.'s findings.

Klemm, Bunnell, Cullen, Soneji, Gibbons et al. (2003) conducted a review of nine articles describing ten research studies investigating the effects of online cancer-support groups. Six of these studies focused on breast cancer. These studies, among other things, surveyed the reasons cancer patients participated in computer-based support networks, analysed therapeutic factors in a computer-mediated group, and compared rates of depression in face-to-face versus Internet cancer-support groups. All studies concluded that online cancer-support groups help people to cope more effectively with their disease. However, Klemm and colleagues pointed out that none of the studies included randomisation to groups or used a control group. It is clear that research in this area needs to address these limitations, including adequate control groups and randomisation procedures.

Perhaps surprisingly, Web-based treatment for bereavement seems to be more effective than conventional face-to-face bereavement interventions. Wagner, Knaevelsrud and Maercker (2005; 2007) reviewed the existing literature and argued that the effectiveness of conventional bereavement interventions was on the whole small; however, delivering counselling for complicated grief via e-mail was found to increase personal growth. These findings lend support to the utility of an online bereavement intervention.

Internet-based treatment also offers benefits for research. For example, blogs (on-line diaries) and message boards make data readily accessible to researchers without the

need for transcription (Strickland, Moloney, Dietrich, Myerburg, Cotsonis et al., 2003). For participants, the anonymity and accessibility afforded by Internet modes of communication serve as incentives to take part in online therapy (Cook and Doyle, 2002; Wagner et al., 2005; Overberg et al., 2006). This may be especially relevant for women displaying a psychological vulnerability to developing breast cancer, namely those who have little social support or tend to suppress their emotions, because they may find it easier to interact via the Internet rather than face-to-face. It has been shown that many people prefer to disclose their innermost thoughts and feelings to a computer-screen instead of to a real person (Erdman, Klein and Greist, 1985; Miller and Gergen, 1998; cited in Lange et al., 2001). Also, as mentioned earlier, a person who joins a face-to-face meeting has to be present at a specific time and place, while the Internet can be accessed by the individual at a time and place they prefer (Overberg et al., 2006). Therefore, this form of intervention offers benefits to both the participant and the researcher. However, it is important to note that the lack of synchronicity of communication on Internet message boards or via e-mail also has potential disadvantages. For example, the delay between questions and responses is potentially problematic: when probing participants for clarification of certain points they have made, one may not get a response, unlike in real-time communication, where it is possible to probe on the spot (Strickland et al., 2003). Also, a delay in responding may be perceived as distressing to clients in urgent need of attention and support. These issues need to be paid attention to when assessing the suitability of Internet-based interventions for particular individuals.

4.4 Laughter and Humour Therapy to Facilitate Stress Reduction

As explained in Chapter Two, maladaptive coping with stress appears to be one of the factors increasing vulnerability towards breast cancer. Therefore it is suggested that preventative interventions would need to address stress coping and stress management, helping individuals to cope more adaptively with stressful life events. A wide range of techniques have been developed to assist individuals in reducing and managing stress.

Van Wersch, Forshaw and Cartwright (2009) listed stress-management techniques commonly used in health psychology, such as relaxation and visualisation programmes (e.g. progressive muscle relaxation, guided imagery), and more cognitive programmes (e.g. Rational Emotive Behaviour Therapy, Stress Inoculation Therapy), as well as the monitoring of biological processes through biofeedback. However, while these techniques address cognitive or biological aspects of stress, they do not focus on the management or release of the negative emotions that contribute to stress. Since suppressed negative emotions appear to be a particular problem of the 'breast-cancer prone' personality, it seems important to apply a stress-management technique which encourages the release of such emotions as well as the expression of positive emotions. Such a technique exists in the form of laughter and humour therapy.

Humour can be defined as a stimulus that helps people laugh and feel happy, while laughter is a psychophysiological response to humour that involves both characteristic physiological reactions and positive psychological shifts (Bennett and Lengacher, 2006a). Both are uniquely human (Curtis, 1979). Matz and Brown (1998) define therapeutic humour as any kind of positive interaction that will maintain, enhance, or improve physical and/or emotional well-being. Indeed, laughter and humour have been used successfully in psychotherapy (Franzini, 2001). Notably, Albert Ellis, the founder of Rational-Emotive Behaviour Therapy (1984), strongly advocated their use in a therapeutic setting. Among the numerous documented benefits of laughter and humour are improvements related to immune-system function, such as improvement in natural killer-cell activity (Bennett and Lengacher, 2006b; Seaward, 1992), enhancements in social life and expansion of individuals' network of friends (Ruch, 1998; Salameh and Fry, 2001), and their use as an effective mechanism for coping with stress (Buckman, 1994; Fry and Salameh, 1987; Kuiper and Martin, 1998; Seaward, 1992; Wooten, 1996). Humour and laughter have also proven useful for therapists in establishing a rapport with their clients and sharing a positive emotional experience with them. Ventis (1987) pointed out that humour can

promote therapists' self-efficacy in aiding the client in coping with previously difficult situations. Furthermore, humour and laughter in therapy directed at stress relief is typically cost-effective and can easily be implemented, unlike other stress-reducing interventions such as massage, biofeedback, or exercise.

However, not all humour is positive, and distinguishing between helpful and harmful humour is important (Salameh, 1987). Thus, Saper (1987) proposed that any humour which is deprecating, humiliating or which undermines the client's self-esteem or well-being should be avoided.

Franzini (2001) suggested that group therapy is a situation which lends itself to the use of humour due to its built-in audience, but little has been written about its use in this specific setting. Dziegielewski, Jacinto, Laudadio and Logg-Rodriguez (2004) advocated the use of humour in group therapy to 'break the ice' and release tension. Shared laughter and pleasure can lead to an increase in a group's well-being, benefiting stress management both in the short and long term (Kuhlmann, 1993).

Thus, humour is useful as an essential communication tool in therapy; it can serve as a stress reducer, and should be introduced as a therapeutic tool for developing increased coping skills. However, it is also acknowledged that some clients' ability to appreciate humour may be compromised, for example, if they have experienced a painful loss or if they are unable to relax and 'let go' due to a desire to remain in control of their emotions. On the other hand, McGhee (1998) points out that humour can help clients redefine an event and thus develop a sense of control. Perceived social control is - in turn - associated with better emotional well-being, better methods of coping with stress, and improved health and physiological outcomes (Martin and Lefcourt, 1983; Solomon, 1996). Similarly, Freud (1905; cited in Dziegielewski et al., 2004) proposed that jokes and comical expressions allow individuals to defend against anxieties, fear, anger, and other

negative emotions. He argued that humour is liberating and capable of providing comfort in relieving the pain of misfortune (such as bereavement) in a mature, intelligent and constructive way. Furthermore, Freud saw humour as a tool to facilitate social relationships in a pleasurable manner.

As the stimulation of laughter has been associated with the relief of tension, clients can revise their approach to problem solving under less pressure (Gladding, 1995). However, a therapeutic relationship must be established between therapist and client before an attempt is made to use humour (Buckman, 1994); furthermore, its timing must be appropriate (Gladding, 1995).

Humour and laughter have been documented as a form of complementary therapy in cancer. Complementary treatment methods are defined as supportive methods used to complement evidence-based treatment. They do not replace mainstream treatment and are not promoted to cure disease. Rather, they control symptoms and improve well-being and quality of life (American Cancer Society, 2005), as well as 'complementing' rather than opposing conventional medical care (van Wersch, Forshaw and Cartwright, 2009).

Bennett and Lengacher (1999) surveyed the use of complementary therapies in a rural American cancer population and found that 50% of the sample reported using humour, with an additional 13% stating that they would definitely try it. A second study (Lengacher, Bennett, Kip, Keller, LaVance et al., 2002) surveyed 105 women with breast cancer, 21% of whom reported using humour or laughter therapy as a complementary treatment method. In a qualitative study, Johnson (2002) showed that cancer patients identified humour as an important factor for coping with cancer and cancer treatment. They also believed that the use of humour played a role in their spirituality and their perception of the meaning of life. Although these studies lend support to the notion of using humour therapeutically in cancer treatment, the sample sizes in all three studies were small to

moderate. In addition, they were entirely based on self-report and did not differentiate between uptake of therapeutic humour interventions and the use of humour in everyday life.

Dixon (1980) attempted to provide an answer to the question why humour seems to be so widely used among cancer patients, positing that laughter may act as a coping mechanism to reduce stress, improve self-esteem and reduce psychological symptoms related to negative life-events. The use of humour as a coping mechanism to moderate the impact of stressful events on mood states, and to improve the ability to relax, was shown in an experiment involving 40 male and 40 female undergraduate students (Prerost, 1993). Relaxation was measured though biofeedback following exposure to humorous or non-humorous stimuli. Participants were categorised as possessing either an internal or an external locus of control, assessed with Rotter's (1966) Locus of Control Scale. It was found that participants with an internal locus of control who were exposed to humorous stimuli showed enhanced relaxation during subsequent measurement of biofeedback. However, it was not measured how humorous participants perceived the supposedly humorous stimuli to be. Therefore, no distinction was made between participants who found the material amusing and those who did not, which may have weakened the results. It is thinkable that not every participant found these stimuli amusing to the same degree.

Similarly, in a study involving 143 undergraduates, Martin and Lefcourt (1983) demonstrated that a sense of humour was related to improved mood status in people when faced with stressful life events. A negative-life-events checklist was used to predict stress scores on a measure of mood disturbance. Participants' sense of humour was measured with self-report scales and behavioural assessments of participants' ability to produce humour under non-stressful and mildly stressful conditions. It was shown that sense of humour produced a significant moderating effect on the relation between

negative life events and mood disturbance, indicating a stress-buffering role of humour. Specifically, in participants with a low sense of humour, the correlation between negative life events and mood disturbance was strong, while in participants with a high sense of humour, this association was weak. Thus, individuals with a strong sense of humour were less likely to suffer mood disturbance as a result of stressful life events.

In a cross-sectional study, Danzer, Dale and Klions (1990) examined the effects of humour on induced depression in 38 female undergraduates. Participants listened to either a humorous or a non-humorous audiotape-recording after viewing depressive slides; the control group listened to no tape-recording. Heart rate and smile/frown muscle tension were recorded during slide and tape presentations. All participants completed the Multiple Affect Adjective Check List (Zuckerman and Lubin, 1965) before and after the presentations. It was found that only the humour treatment decreased the induced depression relative to pre-experimental baseline. Furthermore, heart rates were higher and participants smiled more in the humour condition than in the non-humour or the control condition. However, similar to Martin and Lefcourt's (1993) study, the sample was rather small and consisted entirely of undergraduates, which limits generalisability. Furthermore, the ecological validity of this study is unclear, as depression was induced in a laboratory setting. It would need to be determined whether similar effects can be achieved on 'naturally' occurring depression.

Humour appears to act as a moderator of negative life events on depression (Nezu, Nezu and Blissett, 1988). In a prospective study with 59 breast-cancer patients, Carver, Pozo, Harris, Noriega, Scheier et al. (1993) showed that the tendency to use humour as a coping mechanism was a negative predictor of distress in women six months after breast-cancer surgery. It also mediated the relationship between global optimism and distress after surgery. Furthermore, laughter seems to have beneficial effects for bereaved individuals. Traditional bereavement theories emphasise the importance of working

through the emotional pain of the loss (e.g. Lazare, 1989; Raphael, 1983), and have generally viewed the expression of positive emotion as an indication of denial and as a hindrance to grief resolution (Sanders, 1993). However, the limitations of this view have been identified (Stroebe and Stroebe, 1991; Wortman and Silver, 1989), and the adaptive functions of positive emotions during bereavement (Shuchter and Zisook, 1993) are beginning to be recognised more. Keltner and Bonanno (1997) investigated correlates of laughter and smiling in 39 bereaved individuals six months after their loss. Participants were recruited through newspaper advertisements and took part in a structured grief symptom interview. They also completed two questionnaire measures relating to the authors' predictions concerning laughter and enhanced social relationships. It was shown that Duchenne laughter, which is laughter involving the muscle which orbits the eye and is typically associated with pleasant stimuli and feelings (Ekman, Friesen and O'Sullivan, 1988), was associated with reports of reduced anger and increased enjoyment, the dissociation of distress, and better social relations. These findings are in line with the hypothesis that laughter accompanies the dissociation from potentially distressing arousal brought about by a positive reinterpretation of the source of distress.

In a related experiment, Bonanno and Keltner (1997) provided causal evidence for the benefits of laughter during bereavement. Facial expressions of emotion were coded from videotapes of 40 bereaved adults as they described their prior relationship with their deceased spouse six months after the loss. These were related to measures of participants' grief severity gathered at 6, 14 and 25 months after loss. The findings indicated that Duchenne laughter predicted reduced grief severity at each outcome assessment. Correlations remained significant when the overlapping variance associated with self-reported emotion was partialed out. Of course, since the experiment took place in a laboratory, its ecological validity is not wholly guaranteed. Still, one could argue that ecological validity was high due to participants talking about a real-world event (i.e. the loss of their spouse) rather than an 'artificial' event simulated in the laboratory.

Bereaved individuals often report feeling isolated from their social environment (Lehman, Ellard and Wortman, 1986; Nuss and Zubenko, 1992). It is thinkable that the social benefits of laughter are likely to enable bereaved individuals to engage in pleasurable social interactions (Keltner and Bonanno, 1997), thereby reducing feelings of isolation.

Despite these encouraging findings, it needs to be pointed out that most of the reviewed studies were retrospective in nature. Greater insight into the stress-reducing effects of humour could be achieved with prospective studies. These would enable the detection of causal links.

Apart from the psychological benefits of laughter and humour, research has been conducted into its physiological benefits. According to Wilkins and Eisenbraun (2009), laughter serves a health-boosting function. Similar to the humour research examining psychological benefits, several studies have focused on stress, an established factor in the aetiology of breast cancer. It has been suggested that laughter and humour are instinctive coping mechanisms which aid people in dealing with stressful and difficult situations (Berg and van Brockern, 1995; Carlson and Peterson, 1995). As mentioned above, humour can be helpful when an individual adjusts to stressful life situations (Vereen, Butler, Williams, Darg and Downing, 2006).

In an early study by Averill (1969) three groups of men were exposed to a humorous film, a neutral film or a sad film. Measures of physiological responses showed that participants in both the humorous and the sad conditions exhibited significant increases in galvanic skin response, indicating an activation of the sympathetic nervous system. Yet, while in participants who had watched the humorous film blood pressure remained stable, those who had watched the sad film displayed a significant increase in blood pressure. The researcher concluded that humorous stimuli have the potential to buffer some of the

negative effects of sympathetic activation on blood pressure. However, the sample was entirely male; hence it is uncertain whether these findings also apply to women.

In an effort to elucidate a biological link between laughter and stress reduction, Berk, Tan, Napier and Evy (1989) examined the effects of viewing a humorous film on a wide variety of stress hormones, using direct testing of hormone levels in serum. In the experimental group, the stress hormones serum cortisol, growth hormone and dopac significantly decreased, while in the control group, who sat in a quiet room and did not watch a film, no decrease took place. Furthermore, the authors argued that, by decreasing cortisol (which is an immunosuppressive stress hormone), laughter may act as an immune-enhancer. Although the sample size was small ($N = 10$), these results are promising.

Regarding efforts to apply a theoretical framework to these findings, the most dominant account of humour is provided by relief theory, according to which individuals experience humour and engage in laughter because they feel that stress is reduced that way (Berlyne, 1972; Kuiper, Martin and Olinger, 1993). Relief involves either a cognitive release from anxiety, or a physical release of tension (Dossey and Keegan, 2008). The physiological stress-reducing benefits of laughter are closely connected to this concept, as stress exacerbates the symptoms of many illnesses, and laughter has been shown to alleviate them (Wilkins and Eisenbraun, 2009). Thus, humour and laughter have the potential to unite mind and body (Dossey and Keegan, 2008).

This theory is supported by the findings of two experiments conducted by Kimata (2004a). In both experiments, the effects of viewing humourous videos on bronchial responsiveness to allergy-inducing substances were investigated. Both studies showed that pulmonary function in individuals with bronchial asthma was improved by positive emotional states (activated through humour and laughter), and was aggravated through negative emotional states associated with the symptoms of bronchial asthma. Although

encouraging, these findings would need to be replicated 'in the field' in order to ensure greater ecological validity.

In another experiment examining relief theory, Kimata (2004b) observed the effects of laughter on stress reduction in individuals with atopic dermatitis and various allergies. The experimental group watched a humorous video, while the control group watched a non-humorous video. Both groups typed mobile-phone messages for two hours following the viewing. Subsequently, skin-prick tests were conducted. Individuals who had watched the humorous video exhibited lower allergic reactions than those who had watched the non-humorous video. This indicated that humour could indeed aid the reduction of physiological stress symptoms. Though sound in its design, this study shares a shortcoming with many studies in this area, namely that it was not assessed how humorous participants perceived the humorous video to be; it was merely assumed that they would find it funny. Therefore, the results may have been weakened by failing to distinguish between participants who found the material amusing and those who did not.

Cann and Etzel (2008) asked 176 university students to complete three measures of sense of humour and personality measurements related to optimism, hope and happiness. It emerged that those with a sense of humour had lower perceptions of stress and higher levels of happiness, hope and optimism. However, similar to many other studies in this area, including some of the studies described above, the fact that the sample consisted entirely of students limits the generalisability of these findings.

It has been shown that believing in the benefits of laughter alone is enough for the body to experience physiological benefits. Mahony, Burroughs and Hieatt (2001) examined expectation benefits of laughter on pain threshold levels. One hundred undergraduate students were informed that humour would either decrease or increase their discomfort. After viewing a comedy video, participants completed humour ratings, and their pain

discomfort thresholds were measured. Those who were told that they would experience decreased discomfort thresholds exhibited higher blood pressure compared to those who were told that their pain discomfort threshold would increase. Like in Cann and Etzel's study, the generalisability of these findings is limited due to the sample consisting entirely of university students. Still, the results provide some evidence that people's expectations of being able to tolerate pain influence their actual ability to tolerate it. However, it is important to note that the study also found that participants who had viewed the humorous video had raised pain tolerance thresholds regardless of the expected outcomes, which indicates interplay between the actual physiological benefits of laugher and effects based on expectations.

There is some evidence to suggest that laughter is comparable to mild aerobic exercise and can improve mood in the same way that exercise does. In an experiment conducted by Szabo (2003), 39 university students either watched a comedy video, jogged at a self-selected pace, or watched a documentary video. Watching the humorous video produced similar positive mood increases and emotional stress decreases, measured with the Subjective Exercise Experience Scale (McAuley, Courneya, Rudolf and Lox, 1994) and the Spielberger State Anxiety Inventory, in participants watching the humorous video to those who exercised.

In a related experiment, Szabo, Ainsworth and Danks (2005) investigated the effects of humour, exercise, music, and sitting quietly on anxiety and total mood disturbances in 20 healthy women. Each woman completed measures of anxiety and mood disturbances five minutes before and five minutes after the intervention, which involved either watching a humorous video, cycling, listening to music, or sitting quietly. The results showed that humour had the greatest impact on reducing anxiety state and total mood disturbances. However, it is unclear how long this effect lasted, as no follow-up measure was taken.

Yovetich, Dale and Hudak (1990) also demonstrated that humour may be beneficial in the treatment of anxiety. Fifty-three male and female college students were told that they would receive a shock after a brief waiting period. Participants in the experimental group listened to a humorous tape-recording while waiting, the placebo control group listened to a non-humorous tape-recording, and the non-intervention group did not listen to any tape-recording. Although all three groups experienced an increased heart rate during the waiting period, only subjects in the humour group reported decreased anxiety. The ecological validity of this experiment as well as of Szabo's research described above is limited, as it involved a situation individuals are unlikely to encounter in real life. Furthermore, the sample consisted entirely of college students, which limits the generalisability of these findings. Still, it does provide some indication that humour may play a role in anxiety reduction.

As well as having the potential to improve mood and reduce anxiety, laughter appears to elicit similar emotions in others and therefore serves a bonding function, as well as enhancing social support (Martin, 2007; Provine, 1993). As argued in Chapter Two, both maladaptive coping with stressful life events and a lack of social support are associated the aetiology of breast cancer. It therefore seems vital to include humour as a component in any intervention targeting psychosocial breast-cancer risk factors.

To summarise, the research on laughter and humour supports the notion of health benefits such as stress reduction and enhanced coping with stressful life events such as bereavement. Particularly the findings regarding humour's stress-reducing effects imply physiological benefits. Most of the studies share a particular methodological shortcoming - the failure to measure participants' perceptions of how humorous they found the presented content. However, the fact that researchers were still able to demonstrate an influence of laughter and humour on psychological and physiological parameters indicates that this shortcoming may have in fact led to an underestimation of the effect.

Furthermore, it highlights the importance of using material perceived as funny by participants, or perhaps it would be even more appropriate to allow participants to select this material themselves, if feasible.

4.5 Illness Stories and Health-Related Autobiographical Accounts

In Chapter Two it was explained that the 'cancer-prone' personality is characterised by a set of behaviours, which includes the tendency to be overly self-sacrificing, overly compliant, and to put others' needs before one's own. It seems reasonable that making individuals aware of these behaviours and their potentially harmful outcomes may help draw their attention to the importance of modifying their behaviour. This can be achieved with psycho-education. Apart from being used to increase awareness of the importance of modifying lifestyle factors such as smoking (Huttunen-Lenz, Song and Poland, 2010) or diet (Andrewes, O'Connor, Mulder, McLennan, Derham et al., 1996), as well as in assisting patients in coping with illnesses such as breast cancer (e.g. Budin, Hoskins, Haber, Sherman, Maislin et al., 2008; Capozzo, Martinis, Pellis and Giraldi, 2010), psycho-education has been used successfully in modifying Type A behaviour in heart-attack patients, thereby reducing the risk of reinfarction (Friedman and Kimball, 1986). Additionally, increases in self-efficacy, improved problem-solving, and reductions in work-related stress have been detected as a result of a Web-based psycho-educational programme (Shimazu, Kawakami, Irimajiri, Sakamoto and Amano, 2005). In order for such programmes to be effective, individuals need to be able to personally connect to or identify with the issue or message being presented (Grunig and Hunt, 1984; Pavlik, 1988). Illness-related stories and health-related autobiographical accounts are examples of psycho-educational material which has the potential to address psychosocial factors and to promote identification of clients with the protagonists of these accounts.

The Internet is a new but rapidly growing channel for exchanging illness experiences. Many patients with serious illnesses are interested in reading about other people's illness

experiences. It appears that the more similar the protagonist of the illness story is to the reader in certain characteristics, the more likely the reader will be to be interested in the account. Overberg, Alpay, Verhoef and Zwetslook-Schonk (2007) looked at breast-cancer patients' preferences when reading illness stories on the Internet and found that participants wanted to read in fellow patients' illness stories about issues that they themselves were suffering from, thinking about, or experiencing as negative, thus taking their own story as starting point when searching for fellow patients' stories.

Roser (1990) demonstrated that personal relevance of a heart-disease prevention message influenced attitudes and intended behaviours. Similarly, in a qualitative study involving focus groups and interviews conducted with a sample of 50 women, Aldoory (2001) discovered that one of the factors affecting how relevant women found health-promotion messages was similarity: sources who were perceived to be similar to the participant led to them perceiving the health-promotion message as more relevant to them.

The literature indicates that cancer patients and cancer survivors tend to use social comparison processes to cope with their situation. Stanton, Danoff-Burg, Cameron, Kirk and Snider (1999) explained that witnessing someone whose psychological adjustment or disease prognosis is relatively poor may provide the opportunity for downward comparison with regard to well-being, fostering self-enhancement aims. This has been found to be the case with breast-cancer patients (Wood, Taylor and Lichtman, 1985). However, a more recent study by Bellizzi, Blank and Oakes (2006), examining autobiographies of cancer survivors, found that these tended to engage in parallel comparisons, in other words, compare themselves to others in a similar situation to them.

The studies discussed above targeted individuals who have already developed cancer. However, Eysenck (1994) proposed that prophylactic therapy, aimed at changing the

behaviours which are part of those personality traits shown to act as risk factors for cancer, should be an integral part of cancer prevention. With numerous autobiographies of individuals who have experienced long-term illness available (Overberg et al., 2007), it would be useful to investigate whether reading health-related autobiographical accounts of individuals displaying similar characteristics to the target population (i.e. being bereaved and having experienced stressful life events) would enhance women's awareness of their own psychological profile, as well as helping increase their awareness of the connections between psychological and physical health. Most people are unaware of their psychological profile and the ways in which they deal with stressors in their lives. Becoming ill, especially with severe illnesses such as cancer, has been documented as a way of being confronted with one's own psychological make-up. Particularly people who have consciously chosen a healthy lifestyle may find it hard to understand how they could have been affected by a potentially terminal illness. This has been documented in the autobiographies of breast-cancer sufferers such as Farrell Yelland (2000) and Rabinovitch (2007). Consequently, one way of raising awareness of psychological profiles before illness invades people's lives could be the reading of autobiographical accounts of women who have suffered from a serious illness such as breast cancer. These accounts are expected to have an especially profound impact if the narrator has features in common with the reader. Furthermore, such accounts are expected to increase awareness of the connections between psychological and physical health, as they illustrate the way in which certain psychosocial factors may contribute to the development of breast cancer.

4.6 Interventions Targeting Multiple Psychosocial Breast-Cancer Factors

There are very few, if any, preventative interventions focusing on multiple psychosocial factors involved in breast-cancer development. The approach that comes closest to this objective is Grossarth-Maticek and Eysenck's (1991) autonomy training for cancer-prone and coronary heart disease-prone individuals. This method is aimed at providing individuals with the ability to learn alternative types of autonomous behaviour, in which a

desirable state of stimulation is achieved through the individual's own activity, leading to a need-satisfying state. Moreover, clients learn to control their responses in such a way that they are no longer subject to any particular stimulation from outside persons or objects, for example, learning to relax in the face of stimuli which earlier always produced extreme tension. Thus, an individual learns that autonomous behaviour leads to more positive results (e.g. greater satisfaction) and fewer negative results (e.g. less anxiety). Autonomy training aims to equip the individual with the ability to adapt to circumstances, control one's emotions, cope adequately with external stressors, not to suppress the expression of one's feelings, be assertive (without being aggressive), flexible rather than rigid, and to be able to change one's behaviour to achieve the satisfaction of important life aims. It takes the form of exercises directed at improving self-concept, reducing dependent behaviour and initiating autonomous behaviour, achieving stable expression of feelings, and suppressing stress-creating ideas and thoughts.

Grossarth-Maticek, Eysenck, Boyle, Heeb, Costa and Diel (2000) demonstrated that autonomy training can have a prophylactic effect through reducing the risk of developing breast cancer in women who exhibited high levels of physical and psychosocial risk factors. Seventy-two women took part in the study; they were part of a larger study involving over 8000 women who had been selected randomly from electoral register lists to study relationships between psychosocial variables and breast-cancer development. Participants were matched in pairs of equal age and randomly assigned to either a therapy group or a control group. All participants in the therapy group took part in 10 weekly sessions. The authors do not indicate what treatment, if any, the control group received. Analysis after a 14-year follow-up period revealed that participants in the therapy group were significantly less likely to develop and die of breast cancer. This finding is consistent with earlier observations that cancer patients who showed spontaneous remission demonstrated a change in personality and behaviour, when compared to a control group. They transformed from a personality type characterised by

inhibition in the expression of emotion and needs to a flexible personality type capable of self-regulation (Grossarth-Maticek and Eysenck, 1991). Besides providing evidence for the notion that psychotherapy has prophylactic value and may help prevent the development of breast cancer, Grossarth-Maticek et al.'s (2000) study also provides strong evidence for a causal link between psychosocial factors and breast-cancer incidence, as well as breast-cancer mortality. Nevertheless, a potential weakness of this approach lies in its assumption of the patient's capability to rationally think about their own behaviour, and leaves little room for focusing on emotional and social aspects relevant in breast-cancer development, such as the reduction of emotional suppression and the provision of social support.

A tertiary prevention study (i.e. the prevention of disease progression and attendant suffering) was undertaken by Fawzy, Canada and Fawzy (1990; 2003) with patients with malignant melanoma. They predicted that a six-week psychiatric intervention consisting of health education, stress management, enhancement of coping skills and psychological support (from group members and staff) would influence disease progression favourably. A weak-to-moderate effect was found at five- to six-year follow up and at ten-year follow-up, with significantly more patients in the intervention group surviving compared to the control group who received no intervention. Furthermore, intervention group participants displayed more active-behavioural and active-cognitive coping styles than the control group; this persisted at six-month follow-up. Capozzo et al. (2010) replicated the study with breast-cancer patients, and observed a significant reduction in anxious preoccupation in treated patients.

Fawzy and colleagues' study has two main strengths. Firstly, it targeted several psychological risk factors. Secondly, it followed up patients for a considerable period of time to assess survival. However, it would be useful to conduct a similar intervention with 'cancer-prone' individuals, rather than just those who have already developed the disease,

because intervening at an earlier point could lead to more beneficial effects and possibly increase survival rates. Furthermore, it would be useful to have health psychologists involved in such an intervention. Fawzy et al. (2003) termed the intervention a 'psychiatric group intervention', which suggests the dominance of a biomedical model. Getting health psychologists involved who are working from a biopsychosocial approach could help ensure more focus on other aspects of disease causation.

4.7 Conclusion

The review presented in this chapter has demonstrated that there are a number of potentially effective approaches targeting the psychosocial factors involved in breast-cancer development. However, there are very few studies focusing on more than one of these factors simultaneously, and to date there are no published studies targeting all factors. Furthermore, most interventions are either delivered to individuals who have already developed cancer, or they are not primarily concerned with cancer prevention. Moreover, the majority of interventions reviewed here were designed to be delivered in a face-to-face setting. This can only reach a limited number of clients, namely those who are willing and able to travel to the location where the intervention takes place and who are comfortable disclosing intimate thoughts and feelings face-to-face to a therapist, or even to a roomful of people they have never met before.

Hence, there is a need to design and deliver a preventative intervention which focuses on all important psychological breast-cancer risk factors. Furthermore, in light of the increasing breast-cancer incidence in the UK, there is the need for an intervention that has the potential to reach a large number of women. This potential could be realised through electronic delivery via the Internet. The next chapter details the rationale, aims, hypotheses and method of the current study.

CHAPTER FIVE

METHOD: MAIN STUDY

CONTENTS

5.1 Overview

This chapter describes the rationale and aims of the present study, as well as its hypotheses and research questions. The study design, materials, participants and recruitment methods are outlined, considerations related to ethics and study procedure are explained, and data analysis is detailed.

5.2 Rationale and Aims

The following section details the rationale and aims of the current study. These aims were based on the issues discovered through the literature review, as detailed in Chapters Two, Three and Four.

Aim 1: To develop, implement and evaluate the effectiveness of an innovative electronic intervention in terms of enhancing coping with bereavement, coping with stressful life events, social support, and awareness of the connections between psychological and physical health.

The preceding literature review has identified a number of gaps in knowledge. Firstly, although there are numerous studies which have shown a link between psychosocial factors and breast cancer, there seems to be no published intervention study targeting multiple established psychosocial factors simultaneously. Eysenck (1994) advocated the need for prophylactic intervention studies which aim to help an individual change the traits associated with an increased risk of cancer; yet, only one such study had apparently been published at the time this thesis was written. The first aim of the present study was to address this need by designing, implementing and evaluating the effectiveness of an intervention focusing on the most established psychosocial factors potentially associated with breast-cancer development: maladaptive coping with bereavement, maladaptive coping with stressful life events, and a lack of social support. It was also deemed important to investigate whether participation in the intervention programme would result

in higher levels of awareness of the connections between psychological and physical health.

No studies targeting psychosocial factors potentially associated with breast-cancer development had been published in the UK at the time of conducting this project. As mentioned in Chapter One, the UK breast-cancer mortality rate is relatively high compared to the rest of Europe, which highlights the need for such interventions to be conducted in the UK.

Because, as mentioned previously, personality is normally stable in adults and cannot be changed (McCrae and Costa, 1994), 'breast-cancer prone' personality was not a dependent variable in this study, although, as outlined in Chapter Two, it constitutes another established psychosocial factor associated with breast-cancer development. Rather, certain 'breast-cancer prone' traits formed part of the inclusion criteria (see Section 5.5).

The current project made use of online data collection and online intervention. Specifically, there is a strong rationale for an Internet-based intervention, particularly when considering the target population, which includes women who may feel more comfortable revealing negative emotions in an online therapeutic setting compared to a face-to-face setting. Furthermore, at the time of writing there were no reported studies combining online art therapy, laughter therapy and expressive writing as intervention methods in the context of bereavement. Therefore, the present study aimed to develop an innovative, electronic form of bereavement-coping enhancement.

Thus far there are no published studies reporting on the usefulness of reading autobiographical accounts of breast-cancer sufferers in psychologically susceptible women for raising their awareness of the connection between psychosocial factors and

breast cancer. However, as argued in Chapter Four, there is a strong rationale for the potential effect of reading such accounts. The present study aimed to make a contribution to knowledge by using autobiographical accounts as a therapeutic tool and evaluating their utility for raising awareness of psychosocial factors potentially associated with breast-cancer development.

Furthermore, women's experiences of coping with bereavement and with stressful life events, as well as their experience of participating in the Coping-Enhancement Programme for the Bereaved (CEPB) were to be explored. This was deemed important because it would provide additional information as to which aspects of the CEPB were experienced as most (and least) effective, useful and enjoyable by participants. It was also anticipated that this exploration would yield rich, in-depth data about women's coping experiences.

Aim 2: To develop an attempt at assessing and targeting coping with bereavement, coping with stressful life events, social support and the awareness of the connections between psychological and physical health.

A further gap in the literature consists of the lack of studies combining the most established psychosocial factors potentially associated with breast-cancer development and targeting them all at once in a single intervention programme. Even Grossarth-Maticek et al.'s (2000) psychosocial breast-cancer prevention programme, described in Chapter Four, did not screen for and combine the four most established psychosocial factors identified in the present literature review. The second aim of the current study was thus to make a unique attempt at assessing and targeting the most established factors.

Aim 3: To develop an innovative psychological screening tool to assess psychosocial factors potentially associated with breast-cancer development.

The third aim of the study lay in the development of an innovative psychological screening tool. Not only was this tool to be innovative in its screening for established psychosocial variables involved in the aetiology of breast cancer, it was also to be unprecedented its use of the 'structured alternative format'; this is described in detail in Chapter Six.

5.3 Hypotheses

The following section details the study hypotheses, which were constructed in relation to the individual elements of the CEPB: Emotional-Expression-and-Stress-Reduction (EESR) and psycho-education. EESR took place in the form of 'Art and Laughter for Wellbeing', while psycho-education involved the reading of autobiographical accounts of breast-cancer sufferers. In Chapter Seven, the design and content of these elements is described in detail.

Chapter Four, Section 4.2 showed that art therapy and written emotional disclosure may have beneficial effects on coping with bereavement. Women who participated in 'Art and Laughter for Wellbeing' were therefore expected to report lower levels of maladaptive coping with bereavement than those who did not participate in the same. It was also expected that raising awareness of the potential negative effects of maladaptive coping with bereavement on one's health would lead to women taking measures to reduce their own maladaptive coping with bereavement. Thus, the hypotheses relating to maladaptive coping with bereavement were as follows:

Hypothesis 1

Women who participate in EESR report less maladaptive coping with bereavement after the programme and at follow-up than women who do not participate in EESR.

Hypothesis 2

Women who participate in psycho-education report less maladaptive coping with bereavement after the programme and at follow-up than women who do not participate in psycho-education.

Chapter Four, Section 4.4 discussed the benefits of laughter and humour in aiding stress reduction. Therefore, it was expected that women who participated in 'Art and Laughter for Wellbeing' would exhibit lower levels of maladaptive coping with stressful life events than those who did not take part in this element of the CEPB. However, it was also expected that raising awareness of the potential impact of stressful life events on one's health would result in participants recognising and taking steps to reduce their own maladaptive coping with stressful life events. Hence, the hypotheses relating to maladaptive coping with stressful life events were as follows:

Hypothesis 3

Women who participate in EESR report lower levels of maladaptive coping with stressful life events after the programme and at follow-up than women who do not participate in EESR.

Hypothesis 4

Women who participate in psycho-education report lower levels of maladaptive coping with stressful life events after the programme and at follow-up than women who do not participate in psycho-education.

The research reviewed in Chapter Four showed that the enhancement of social support is among the benefits of group interventions. Therefore, it was expected that taking part in the CEPB would be beneficial to social support levels after the intervention and at six-week follow-up. The hypotheses relating to social support were as follows:

Hypothesis 5

Women who participate in EESR report higher levels of social support after the

programme and at follow-up than women who do not participate in EESR.

Hypothesis 6

Women who participate in psycho-education report higher levels of social support after the

programme and at follow-up than women who do not participate in psycho-education.

Chapter Four, Section 4.5 reviewed research using psycho-education to bring about

changes in health-related behaviours. In line with previous findings, it was expected that

psycho-education, specifically reading autobiographical accounts of breast-cancer

sufferers, would be associated with higher levels of awareness of the connections

between physical and psychological and physical health. The final hypothesis was thus:

Hypothesis 7

Women who participate in psycho-education report higher levels of awareness of the

connection between physical and psychosocial health after the programme and at follow-

up than women who do not participate in psycho-education.

5.4 Study Design

An experimental 2×2 independent measures design with triangulation was used,

employing qualitative and quantitative methodology. This was in line with the concept of

methodological pluralism, the idea that the use of different methods enables a researcher

to use different techniques to get access to different facets of the same social

phenomenon (Carter and New, 2003; cited in Olsen, 2004). According to Olsen,

triangulation is not aimed merely at validation but at deepening and widening one's

understanding. Hence, participants' experiences of coping with bereavement and other

stressful life events, as well as their experiences of the CEPB, were explored qualitatively

through the use of message boards and blogs. Message boards could be likened to focus groups, although there are major features on which these two forms of communication differ. In particular, communication on message boards happens asynchronously, while participants of focus groups usually interact synchronously and face-to-face. The benefits of Internet message boards as a tool for psychosocial interventions were discussed in Chapter Four, Section 4.3. In addition to the advantages mentioned previously, the written, asynchronous and often anonymous nature of message-board communication, although lacking the nuances of verbal face-to-face communication, brings with it the opportunity for participants to consider and 'polish' their contributions rather than feeling under pressure through the physical presence of their fellow group members (Walther, 1999). Additionally, it seems reasonable to assume that, similar to focus groups (Madriz, 2003) message boards offer a platform for participants to share ideas, beliefs and attitudes in the company of other people with similar backgrounds and experiences. Blogs, on the other hand, were used in the present study to elicit participants' experiences, ask them questions through commenting on their blog posts and prompt them to elaborate on certain points made. This could be likened to semi-structured in-depth interviews, because women communicated with the researcher on a one-to-one basis. One-to-one communication has the potential to explore perceptions and opinions of respondents regarding complex and sensitive issues (e.g. bereavement) and enable probing for more information and clarification of answers (Bariball and While, 1994).

Quantitative methodology, used to investigate the effects of the intervention on psychosocial factors potentially associated with breast-cancer development, consisted of a 2×2 independent measures design. Table 1 displays this design. The two independent variables were psycho-education (reading autobiographical accounts of breast-cancer sufferers or not reading these) and EESR (taking part in 'Art and Laughter for Wellbeing', or not taking part in the same). Thus, intervention-group participants took part in the CEPB, while control-group participants only completed the screening tool, the post-

intervention questionnaire eight weeks later, and the follow-up questionnaire a further six weeks later; they did not participate in the CEPB.

There were four dependent variables (DVs), which were measured quantitatively: maladaptive coping with bereavement (DV1), maladaptive coping with stressful life events (DV2), social support (DV3), and awareness of the connections between psychological and physical health (DV4).

Table 1

2×2 Study Design

	EESR ('Art and Laughter for Wellbeing')	No EESR (No 'Art and Laughter for Wellbeing')
Psycho-education (Reading Autobiographical Accounts)		
No Psycho-education (Not Reading Autobiographical Accounts)		

The present study involved a triangulation of data collection methods and data analyses. Blogs, message boards and questionnaires were used to collect data. Furthermore, three methods of data analysis were used (see Section 5.9). Triangulation enabled the exploration of the topic at hand from different perspectives.

For the present study, a significance level for statistical testing at $p < .10$ was set, rather than .05 as is the convention in human sciences. This decision was made because there was a risk of large numbers of drop-outs, as has been found in other Internet studies (see Chapter Seven). Setting the significance level at .10 allowed for a greater probability to

detect effects of the intervention despite a small sample size. The consequences of making a Type I error were not deemed grave enough to necessitate a lower significance level. In other words, a Type I error was not anticipated to be harmful in the context of the present study, given that it appeared to be the first of its kind and given the large risk of drop-out. It is important to note that the convention of the 5% significance level has been criticised for its seeming arbitrariness. For example, Carver (1978) offers a critique of significance testing, stating that too much emphasis is placed on this practice, with the accepted significance level having been set arbitrarily. Instead, he suggests that researchers return to the scientific method of examining data and replicating results.

A prospective power analysis using the software Sample Power Version 3 showed that in order to analyse this study design using a 2×2 analysis of covariance (ANCOVA) and detect a large effect size ($\eta^2 = 0.138$) and achieve a power of 0.80 for a significance level of 0.10 a sample size of $N = 44$ ($n = 44/4 = 11$) would be required. In order to detect a medium effect size ($\eta^2 = 0.059$) a sample size of $N = 104$ ($n = 104/4 = 26$) would be required. After data collection had been completed, a retrospective power analysis was carried out. This showed that to detect a large effect size, the study had achieved a power of 0.69, and to achieve a medium effect size, a power of 0.38 had been achieved.

5.5 Materials

The study materials included a Web site on which the intervention took place; Web site design and pilot testing is explained in Chapter Seven, Section 7.6. Furthermore, there was a pre-intervention screening tool (screening tool design and pilot-testing is detailed in Chapter Six), a post-intervention questionnaire and a six-week follow-up questionnaire. Table 2 displays the variables contained in the screening tool, along with the instruments used and internal consistency of scales where applicable. (See Appendix A for a copy of the screening tool for intervention participants and Appendix J for a copy of the screening

tool for control group participants, who were given an almost identical screening form which differed only in its introductory briefing and in its closing.) Details of all scales and measures used are discussed in Chapter Six, Sections 6.2 to 6.7 and Section 6.10.

Applying George and Mallery's (2003) rule of thumb for evaluating alpha coefficients, the items measuring awareness of the connections between psychological and physical health, the Marlowe-Crowne scale and the Emotionality subscale of the Rationality/Anti-Emotionality (RAE) scale had poor reliability, while the remaining measures had moderate or high reliability. It is important to note that the scales with poor reliability had had high reliability in Pilot Study 2 (see Chapter Six, Section 6.9).

Table 3 displays the variables contained in post-intervention questionnaire, instruments and measurement methods used, and internal consistency where applicable. (See Appendices A and K for copies of the questionnaires administered to intervention group and control group participants, respectively.)

Apart from measures of the dependent variables, three items were included in the post-intervention questionnaire, in which participants were asked to indicate, on a five-point scale, how useful, helpful and enjoyable they had found the programme. Additionally, open-ended questions were included, asking participants to indicate what they liked and what they did not like about the programme, and whether they had any suggestions for improvement. A final question provided women with the opportunity to make any further comments they had. The adapted FDC scale measuring maladaptive coping with stressful life events and the items measuring awareness of the connections between psychological and physical health had poor reliability, while the remaining measures had moderate or high reliability.

Table 2

Variables Contained in Pre-Intervention Screening Tool, Instruments and Measurement Methods Used, and Internal Consistency in Main Study (where applicable)

Variable	Instrument or Measurement Method Used	Cronbach's Alpha
Demographic variables		
Age	Numeric	N/A
Marital status	Multiple choice	N/A
Level of education	Multiple choice	N/A
Ethnic origin	Multiple choice	N/A
Religious orientation	Multiple choice	N/A
Employment status	Multiple choice	N/A
Duration of unemployment	Numeric	N/A
Physical risk factors of breast cancer		
Parity	Multiple choice	N/A
Age at birth of first child	Multiple choice	N/A
Number of children	Multiple choice	N/A
Contact with children	Multiple choice	N/A
Breastfeeding of each child	Multiple choice	N/A
Breastfeeding duration for each child	Multiple choice	N/A
Breast cancer history (yes/no)	Multiple choice	N/A
Family history of breast cancer	Multiple choice	N/A
Oral contraceptive pill use	Multiple choice	N/A
Time since cessation of oral contraceptive pill use	Numeric	N/A
Alcohol use	Multiple choice	N/A
Time since cessation of alcohol use	Numeric	N/A
Excessive alcohol use	Multiple choice	N/A
Physical activity/exercise	Multiple choice	N/A
Time since stopped exercising	Numeric	N/A
Desire to begin exercising	Multiple choice	N/A
Overweight	Multiple choice	N/A
Consumption of a healthy diet	Multiple choice	N/A
Time since stopped consuming healthy diet	Numeric	N/A
Desire to eat more healthily	Multiple choice	N/A
Menopause status	Multiple choice	N/A
Time since menopausal	Numeric	N/A
Use of Hormone Replacement Therapy	Multiple choice	N/A
Psychosocial factors potentially associated with breast-cancer development		
If child deceased, date of death	Numeric	N/A
Bereavement status (yes/no)	Multiple choice	N/A
Details of bereavement	Open-ended response	N/A
Bereavement coping style	Open-ended response	N/A
Maladaptive coping with bereavement	Adapted Functional Dimensions of Coping (FDC) Scale	N/A
Date of most significant loss	Numeric	N/A
Bereavement suffering	Multiple choice	N/A
Stressful life events	Open-ended response	N/A
Stressful life events coping styles	Open-ended response	N/A
Maladaptive coping with stressful life events	Adapted Functional Dimensions of Coping (FDC) scale	**0.64**
Social desirability	Marlowe Crowne Social Desirability Scale	**0.49**
Social support	Duke Functional Social Support Questionnaire (FSSQ)	**0.87**
Awareness of the connections between psychological and physical health	3 items constructed for the present study	**0.55**
'Breast-cancer prone' personality traits	Rationality Subscale of the RAE scale	**0.68**
	Emotionality Subscale of the RAE scale	**0.54**
	Understanding Subscale of the RAE scale	**0.90**
	Emotional Control Subscale of the EEC scale	**0.88**
	Emotional Expression-In Subscale of the EEC scale	**0.87**
Other variables		
Usability of screening tool	Perceived Ease of Use Subscale of the TAQ	**0.74**
	Intrinsic Motivation Subscale of the TAQ	**0.84**
Prior experience with reading autobiographies of breast cancer sufferers	Multiple choice and open-ended questions	N/A
Internet Experience and Internet Use	Multiple choice	N/A
Additional Comments	Open-ended response	N/A

Note. RAE= Rationality/Anti-Emotionality; EEC= Emotional Expression and Control; TAQ= Technology Acceptance Questionnaire

Table 3

Variables contained in Post-Intervention Questionnaire, Instruments and Measurement

Methods Used, and Internal Consistency in Main Study (where applicable)

Variable	Instrument or Measurement Method Used	Cronbach's Alpha
Demographic variables		
Age	Numeric	N/A
Marital status	Multiple choice	N/A
Employment status	Multiple choice	N/A
Duration of unemployment	Numeric	N/A
2.Psychosocial factors potentially associated with breast-cancer development		
Bereavement status (yes/no)	Multiple choice	N/A
Details of bereavement	Open-ended response	N/A
Bereavement coping style	Open-ended response	N/A
Maladaptive coping with bereavement	Adapted Functional Dimensions of Coping (FDC) scale	N/A
Date of most significant loss	Numeric	N/A
Bereavement suffering	Multiple choice	N/A
Stressful life events	Open-ended response	N/A
Stressful life events coping styles	Open-ended response	N/A
Maladaptive coping with stressful life events	Adapted Functional Dimensions of Coping Scale	**0.37**
Social desirability	Marlowe Crowne Social Desirability Scale	**0.50**
Social support	Duke Functional Social Support Questionnaire (FSSQ)	**0.78**
Awareness of the connections between psychological and physical health	3 items constructed for the present study	**0.50**
Physical risk factors of breast cancer		
Breast cancer history (yes/no)	Multiple choice	N/A
Other measures		
Other factors which may have influenced bereavement coping or stressful life events coping	Open-ended response	N/A
Prior experience with reading autobiographies of breast cancer sufferers	Multiple choice and open-ended questions	N/A
Usefulness, helpfulness and enjoyableness of programme	Multiple choice	N/A
Usability of intervention Intranet sites	Perceived Ease of Use Subscale	**0.95**
	Intrinsic Motivation Subscale	**0.94**
Meaning of laughter to participant	Open-ended response	N/A
Importance of laughter to participant	Multiple choice	N/A
Perceived positive aspects of intervention programme	Open-ended response	N/A
Perceived negative aspects of intervention programme	Open-ended response	N/A
Suggestions for improvement of intervention programme	Open-ended response	N/A
Additional comments	Open-ended response	N/A

Table 4 displays the variables contained in the six-week follow-up questionnaire,

instruments and measurement methods used, and internal consistency where applicable.

The adapted FDC scale and the items measuring awareness of the connections between

psychological and physical health still had low reliability, while the remaining measures,

including the Marlowe-Crowne scale, had high reliability.

Table 4

Measures Contained in Six-Week Follow-Up Questionnaire, Instruments and

Measurement Methods Used, and Internal Consistency in Main Study (where applicable)

Variable	Instrument or Measurement Method Used	Cronbach's Alpha
Demographic variables		
Age	Numeric	N/A
Marital status	Multiple choice	N/A
Employment status	Multiple choice	N/A
Duration of unemployment	Numeric	N/A
Psychosocial factors potentially associated with breast-cancer development		
Bereavement status (yes/no)	Multiple choice	N/A
Details of bereavement	Open-ended response	N/A
Bereavement coping style	Open-ended response	N/A
Maladaptive coping with bereavement	Adapted Functional Dimensions of Coping (FDC) scale	N/A
Date of most significant loss	Numeric	N/A
Bereavement suffering	Multiple choice	N/A
Stressful life events	Open-ended response	N/A
Stressful life events coping styles	Open-ended response	N/A
Maladaptive coping with stressful life events	Adapted Functional Dimensions of Coping (FDC) scale	**0.47**
Social desirability	Marlowe Crowne Social Desirability Scale	**0.71**
Social support	Duke Functional Social Support Questionnaire (FSSQ)	**0.78**
Awareness of the connections between psychological and physical health	3 items constructed for the present study	**0.38**
Physical risk factors of breast cancer		
Breast cancer history (yes/no)	Multiple choice	N/A
Other measures		
Other factors which may have influenced bereavement coping or stressful life events coping	Open-ended response	N/A
Prior experience with reading autobiographies of breast cancer sufferers	Multiple choice and open-ended questions	N/A
Additional comments	Open-ended response	N/A

5.6 Participants and Recruitment

Participants were recruited in several ways. Before recruitment, a stand-alone Web page

containing information about the study as well as the link to the online screening tool was

set up (see Appendix B). Then, using the Internet search engine Google, addresses of

women's health-related as well as of bereavement-related Internet forums were obtained

and visited. After checking that these forums were active in terms of regular contributions

by forum members and then registering as a member of the forum, if applicable, the

researcher sought permission from either an administrator or moderator to create a

posting, advertising the study and inviting women in the UK to participate. However, in

many cases forums were not moderated and/or no contact to any administrator was

available. In these cases, the study was advertised after checking that this action complied with the forum rules. In total, 73 forums were visited; of these, administrators or moderators of three forums declined the researcher's request to advertise the study. Thus, the study was advertised on a total of 70 Internet forums. (See Appendix C for the postings used to recruit participants on Internet forums.)

A second method of recruitment involved the creation of a group on the social networking site Facebook (*www.facebook.com*). Facebook enabled the creation of groups in which individuals sharing an interest in a specific topic or issue could connect and interact. This function was used to create a Facebook group which explained the study and provided a link to the online screening tool, inviting Facebook members to participate.

Thirdly, the study was advertised on the Teesside University School of Social Sciences of Law intranet, and on the School of Health and Social Care intranet, as well as on Gumtree (*www.gumtree.com*), a UK Classifieds Web site.

A fourth means of recruitment entailed the contacting of 43 UK newspapers, with the request to publish an article about the study. Three of these newspapers complied, with one of them conducting an interview with the researcher (see Appendix D). The articles published in these newspapers all contained a link to the study information Web page.

Lastly, recruitment was carried out via the placement of flyers (see Appendix E) advertising the study in various locations, including two nurseries, various locations within Teesside University, two conferences and by word of mouth.

The following three criteria all had to be met by women eligible to participate in the study: age 18 or older; resident of the UK; and having experienced a significant bereavement in the past ten years.

Those who had experienced a significant bereavement longer than ten years ago, but claimed to still be suffering as a result of this bereavement were also eligible to participate. This ensured that women who had experienced a traumatic loss which had happened a long time ago, but still affected their wellbeing (e.g. the loss of a child) could also benefit from the intervention. How this was operationalised is explained in more detail in Chapter Six.

In addition to meeting these three criteria, women had to meet at least one of the following criteria: maladaptive coping with bereavement; maladaptive coping with stressful life events; being high in Rationality/Anti-Emotionality and Understanding (RAE) and in Emotional Expression and Control (EEC); and being high in conformity.

To determine if a potential participant fitted the criteria, scores were calculated for maladaptive coping with stressful life events by calculating a mean score for the adapted FDC items. Furthermore, a score was calculated for 'breast-cancer prone' personality by summing up scores on the RAE scale and the EEC scale and calculating an overall mean score. Additionally, a mean score was computed for conformity as measured by the Marlowe-Crowne scale. No score calculation was necessary for maladaptive coping with bereavement, since this was measured with a single item. Participants who scored higher than the median on at least one of these variables, in addition to meeting the other three criteria, were seen to be eligible.

It is important to note that women who had suffered from breast cancer in the past were not excluded from the study as long as they fulfilled the criteria. Since the main focus of the CEPB did not lie on the prevention of breast cancer – the multiple factors contributing to breast-cancer risk have been outlined in Chapter One – but rather, on contributing towards reducing psychosocial factors known to contribute towards breast-cancer aetiology, there was no reason to exclude women who had suffered from breast cancer in

the past. The enhancement of psychological wellbeing, potentially contributing to a lowered chance of the breast cancer re-occurring, would most likely be of benefit for this group too.

Table 5 displays the group sizes for each condition, before the programme, after the programme and at six-week follow-up. The table shows that attrition rates were similar for each condition apart from the control group, where only four participants dropped out in total. Initially, 80 eligible participants (14 of whom were control-group participants and 66 intervention-group participants) filled in the screening tool, and 66 intervention-group participants were assigned a username and password. Of these, 32 participants participated actively on the intervention Web site. Thirty-six participants (of whom 13 were control-group participants and 23 intervention-group participants) completed the post-intervention questionnaire, and 28 participants (of whom 10 were control-group participants and 18 were intervention-group participants) completed the six-week follow-up questionnaire. In order to ensure even numbers for each of the four conditions for the purposes of inferential analyses, the data of only eight participants were randomly selected and retained in the control group. This resulted in even group sizes of eight participants in each group after the intervention, except for the group who only received psycho-education, where $n = 7$ due to an insufficient number of participants from this particular group filling in the post-intervention questionnaire. At six-week follow-up, $n = 6$ for two of the three intervention groups, and $n = 5$ for one of the intervention groups. Therefore, from the ten control-group participants who completed the follow-up questionnaire the data of six participants were randomly selected for follow-up analyses in order to ensure even group sizes. Thus, the total attrition rate from pre-intervention to follow-up was 73% for intervention-group participants and 29% for control-group participants.

Table 5

Group Sizes Before Programme, After Programme and at Follow-Up

		EESR ('Art and Laughter for Wellbeing')	No EESR (No 'Art and Laughter for Wellbeing')
Psycho-Education (Reading autobiographical accounts)	Initial	20 (3 sub-groups)	22 (3 sub-groups)
	After Programme	8	7
	Follow-Up	5	6
No Psycho-Education (Not reading autobiographical accounts)	Initial	24 (3 sub-groups)	14
	After Programme	8	13 (8 retained for analyses)
	Follow-Up	6	10 (6 retained for analyses)

Table 6 displays descriptive statistics for participants and dropouts at each stage of the intervention programme. The mean age of the whole final sample (N = 31) was 43.13 (SD = 14.73). Eighty-four percent were White British, more than half (55%) were married, and nearly half (45%) had a higher education degree. Fifty-eight percent were Christian, while roughly one-third (32%) were non-religious. Slightly over half (52%) were employed, and most (81%) had no breast-cancer history. All participants had experienced a significant bereavement, either in the past ten years or more than ten years ago, but were still suffering as a result of this bereavement.

The mean age of the control group was significantly lower than that of the intervention group (t = 25.19, p < .0001). Furthermore, the control group differed in terms of marital status, with none of the individuals being married, whereas the majority of the intervention-group participants were married. This was most likely due to the age difference between the groups. Thirty percent of the intervention group had a breast-cancer history, while none of the control-group participants had ever suffered from breast

cancer. Finally, the intervention group seemed to have slightly more Internet experience and had been confident using the Internet for a longer time than control-group participants. However, both groups were similar in terms of their Internet usage patterns.

Examining the descriptive statistics for the women who dropped out early ('Dropouts 1'), in other words, those who filled in the pre-intervention screening questionnaire but did not participate actively nor fill in post- and follow-up questionnaires, it would appear that the level of education was lower in this group than that of the whole final sample, with a lower percentage of these women holding a higher-education degree. A larger percentage of the early dropouts were employed than in the whole final sample. Although they were similar to the final sample in Internet experience and confidence, they seemed to use the Internet more frequently and for longer periods of time compared to the final sample.

In comparison to the whole final sample, the women who participated actively, but dropped out before filling in the post-intervention questionnaire ('Dropouts 2'), had lower levels of education, with fewer women holding a higher-education degree. Furthermore, there were higher rates of breast-cancer history, employment and non-religiosity in this dropout group. Although their patterns of Internet use were similar to those of the final sample, on average they had less Internet experience and had been confident using the Internet for a shorter period of time.

Examining the descriptive statistics for the late dropouts, i.e. those who dropped out before completing the six-week follow-up questionnaire ('Dropouts 3'), it is apparent that, although similar to the whole final sample in most demographic characteristics, they had a higher employment rate, less frequent Internet use and spent less time online. It could therefore be speculated that work commitments contributed to these women from dropping out from the study; however, this is not certain.

In order to ascertain the reasons for dropping out of the study, an online questionnaire was created and the link distributed to all women in the groups 'Dropouts 1' and 'Dropouts 2'. The questionnaire had a similar format to the post-intervention questionnaire, but also asked women to indicate their reasons for not participating. (See Appendix J for a copy of the questionnaire). Two women replied, indicating that ongoing stressful life events had prevented them from participating.

Table 6
Descriptive Statistics for Participants and Dropouts

		Whole final sample		Intervention Group Only		Control Group Only		Dropouts 1		Dropouts 2		Dropouts 3
Age	M	43.13	M	49.43	M	30.57	M	45.35	M	45.56	M	51.60
	SD	14.73	SD	10.81	SD	11.35	SD	10.58	SD	13.05	SD	11.78
	Minimum	18	Minimum	27	Minimum	18	Minimum	24	Minimum	30	Minimum	42
	Maximum	74	Maximum	74	Maximum	53	Maximum	65	Maximum	65	Maximum	72
Education	O-levels/GCSE	19.4%	O-levels/GCSE	26.1%	O-levels/GCSE	0.0%	O-levels/GCSE	14.7%	O-levels/GCSE	55.6%	O-levels/GCSE	20.0%
	A-levels	12.9%	A-levels	4.3%	A-levels	37.5%	A-levels	8.8%	A-levels	11.1%	A-levels	0.0%
	Cert HE	9.7%	Cert HE	13.0%	Cert HE	0.0%	Cert HE	29.4%	Cert HE	0.0%	Cert HE	0.0%
	DipHE	12.9%	DipHE	13.0%	DipHE	12.5%	DipHE	20.6%	DipHE	22.2%	DipHE	40.0%
	BA/BSc	32.3%	BA/BSc	39.1%	BA/BSc	12.5%	BA/BSc	5.9%	BA/BSc	11.1%	BA/BSc	40.0%
	MA/MSc	9.7%	MA/MSc	4.3%	MA/MSc	25.0%	MA/MSc	17.6%	MA/MSc	0.0%	MA/MSc	0.0%
	PhD	3.2%	PhD	0.0%	PhD	12.5%	Primary school	2.9%	PhD	0.0%	PhD	0.0%
Marital Status	Single	22.6%	Single	13.0%	Single	50.0%	Single	17.6%	Single	0.0%	Single	0.0%
	Married	54.8%	Married	73.9%	Married	0.0%	Married	41.2%	Married	55.6%	Married	80.0%
	Partner	12.9%	Partner	0.0%	Partner	50.0%	Partner	20.6%	Partner	22.2%	Partner	0.0%
	Widowed	6.5%	Widowed	8.7%	Widowed	0.0%	Widowed	5.9%	Widowed	11.1%	Widowed	20.0%
	Divorced	3.2%	Divorced	4.3%	Divorced	0.0%	Divorced	11.8%	Divorced	0.0%	Divorced	0.0%
	Other	0.0%	Other	0.0%	Other	0.0%	Other	2.9%	Other	11.1%	Other	0.0%
Ethnicity	White/British	83.9%	White/British	95.7%	White/British	50.0%	White/British	97.1%	White/British	100.0%	White/British	100.0%
	White/Other	6.5%	White/Other	0.0%	White/Other	25.0%	White/Other	0.0%	White/Other	0.0%	White/Other	0.0%
	Black/British	3.2%	Black/British	4.3%	Black/British	0.0%	Black/British	0.0%	Black/British	0.0%	Black/British	0.0%
	Black/Other	6.5%	Black/Other	0.0%	Black/Other	25.0%	Other	2.1%	Black/Other	0.0%	Black/Other	0.0%
Religious orientation	Christian	58.1%	Christian	56.5%	Christian	62.5%	Christian	52.9%	Christian	44.4%	Christian	60.0%
	None	32.3%	None	30.4%	None	37.5%	None	32.4%	None	55.6%	None	40.0%
	Other	9.7%	Other	13.0%	Other	0.0%	Other	14.7%	Other	0.0%	Other	0.0%
Employment status	Employed	51.6%	Employed	60.9%	Employed	37.5%	Employed	73.5%	Employed	88.9%	Employed	80.0%
	Not employed	48.8%	Not employed	39.1%	Not employed	62.5%	Not employed	26.5%	Not employed	11.1%	Not employed	20.0%
Breast-cancer history	Absent	80.6%	Absent	69.6%	Absent	100.0%	Absent	88.2%	Absent	55.6%	Absent	80.0%
	Present	19.4%	Present	30.4%	Present	0.0%	Present	11.8%	Present	44.4%	Present	20.0%
Number of years since began using Internet	M	10.71	M	11.13	M	9.5	M	9.26	M	9.78	M	9.60
	SD	3.11	SD	3.38	SD	1.85	SD	4.09	SD	3.35	SD	3.72
	Minimum	4	Minimum	4	Minimum	6	Minimum	1	Minimum	4	Minimum	5
	Maximum	15	Maximum	15	Maximum	12	Maximum	15	Maximum	15	Maximum	15
Number of years since confident using Internet	M	9.71	M	10.26	M	8.13	M	8.12	M	7.89	M	7.80
	SD	3.52	SD	3.81	SD	1.96	SD	4.50	SD	4.83	SD	4.76
	Minimum	3	Minimum	3	Minimum	5	Minimum	0	Minimum	0	Minimum	3
	Maximum	15	Maximum	15	Maximum	11	Maximum	15	Maximum	15	Maximum	15
Weekly hours spent online	M	17.32	M	17.26	M	17.50	M	21.82	M	17.67	M	8.20
	SD	17.75	SD	19.49	SD	12.54	SD	22.67	SD	18.45	SD	7.23
	Minimum	0	Minimum	0	Minimum	2	Minimum	1	Minimum	2	Minimum	2
	Maximum	100	Maximum	100	Maximum	40	Maximum	100	Maximum	60	Maximum	20
Weekly times spent online	M	22.03	M	25.52	M	17.75	M	26.18	M	31.56	M	10.00
	SD	28.05	SD	31.56	SD	15.91	SD	30.81	SD	39.61	SD	8.60
	Minimum	0	Minimum	1	Minimum	5	Minimum	2	Minimum	3	Minimum	3
	Maximum	100	Maximum	100	Maximum	50	Maximum	100	Maximum	100	Maximum	25
TOTAL n		31		23		8		34		9		8

Note. Whole final sample: sample used for inferential analyses, comprised of participants who completed pre-, post- and follow-up questionnaires. Dropouts 1: completed screening questionnaire, but did not participate in intervention. Dropouts 2: participated in intervention, but completed neither the post-intervention questionnaire nor the six-week follow-up questionnaire. Dropouts 3: participated in intervention, but did not complete 6-week follow-up questionnaire.
CertHE = Higher Education Certificate; DipHE = Higher Education Diploma; BA/BSC = Bachelor Degree; MA/MSc = Masters Degree

5.7 Ethics Considerations

Ethics clearance was obtained for this project from the Teesside University School of Social Sciences and Law Research Degree Committee, as well as the Teesside University Research Degree Committee (see Appendix F for a scanned copy of the ethics approval documentation). Informed consent was obtained for all participants by having them read and agree to a consent form before filling in the screening tool. Participants had to provide a valid e-mail address and confirm that they were at least 18 years of age, female, and a resident of the UK. This form also contained details of the study, with its aims broadly explained, informed participants of their right to withdraw and how to do so, and provided the contact details of the researcher as well as of the Teesside Psychological Therapies Clinic's counselling department, which offered free telephone counselling and was able to refer individuals to services in their local area, if they became distressed. Participants were also advised to see their GP if they had any concerns about their health. This information was additionally placed on the intervention intranet site.

Since the researcher was working with individuals who had been bereaved, it was ensured that all participants could discuss any concerns they may have had with the researcher. This was implemented by placing an introductory posting on each message board encouraging women to share any possible concerns via e-mail or their blog, which was only accessible by them and the researcher.

On the intervention intranet site, anonymity was ensured by assigning usernames to participants in the form of flower names. Each intervention group was first given a flower name (e.g. the Rose group) and each individual group member was then allocated a colour, making up their individual username (e.g. Red Rose, White Rose, Pink Rose, and so on). Participants were asked not to reveal their real name or any kind of information which could make them or their friends, family members or acquaintances identifiable.

Participants were made aware that their anonymity would be preserved at all times, including in the reporting of results.

In line with the Teesside University Research Degree Committee's recommendations, the term 'breast cancer' was not mentioned in any study advertisements, in the screening tool or on the intervention intranet site itself, in order not to distress potential participants unnecessarily. However, since the autobiographical accounts that formed part of the psycho-educational element of the intervention were about breast-cancer sufferers, breast cancer became one of the topics discussed in all intervention groups where these autobiographical accounts were provided to participants. Furthermore, a small number of participants had suffered from breast cancer themselves and wrote about this on the message boards. Thus, it was unavoidable that breast cancer was talked about in some of the intervention groups, and for this reason the researcher made sure at all times that participants were aware of the Psychological Therapies Clinic's phone number if they needed support. Additionally, the researcher was careful to emphasise that there was no simple causal connection between psychological health and breast cancer, pointing out the role of physical risk factors, and that psychological factors constituted only part of the aetiology of this disease. Finally, all participants were offered to receive a summary of the study results if they so wished.

5.8 Procedure

After participants had filled in the screening tool and their eligibility for the study had been ascertained, they were contacted via the e-mail address they had provided when giving their consent to participate in the study, and assigned randomly to one of the four conditions.

In the intervention groups, group sizes were set at eight participants per sub-group. Women were provided with a username and password, as well as the intervention intranet

site address. Since control-group participants did not take part in the programme, they were simply thanked for filling in the screening tool and informed that they would be contacted in eight weeks' time, and following that, another six weeks later to fill in a second and third questionnaire. The structure and content of the intervention intranet site are detailed in Chapter Seven, Section 7.4.

On the main page of each intervention sub-site (see Chapter Seven, Figure 1 for a site map), each participant was encouraged to introduce herself, write a little bit about herself and her motivations to participate in the study, and what she expected from the intervention programme. Details of the contents of the programme had been placed on the front page of each site, as well as links to all site pages. An introductory e-mail was sent to all participants, informing them that they would be asked to complete a questionnaire at the end of the programme as well as a further questionnaire six weeks after that, and providing an outline of the coming eight weeks. Each woman was assigned a personal blog, in which she was asked to write about anything she wished. The blog served to record participants' experience of the CEPB as well as their life experiences, particularly those related to bereavement and other stressful life events.

During the eight weeks, an e-mail was sent to each participant each week, introducing the weekly topic of the programme (see Table 7). These weekly e-mails also served as a reminder to participate as well as to complete the personal blogs, and asked those who had not contributed yet to join in. A new topic was introduced each week, and group members had the opportunity to contribute to this topic throughout the week, in their own time. The researcher checked the intervention Intranet site several times a day and replied to each participant's message board posting and blog entry.

Following the final week, all participants were sent an e-mail thanking them for their participation, and were asked to complete the post-intervention questionnaire, the link to

which was included in the e-mail. Those who did not fill in the questionnaire were sent up to three reminder e-mails in the space of three weeks (one reminder per week). A further six weeks later, participants were sent an e-mail containing the link to the six-week follow-up questionnaire. Again, those who did not fill in the follow-up questionnaire were reminded up to three times by e-mail. Following data analysis, a summary of the findings was produced and e-mailed to all participants who had requested this when filling in the post-intervention questionnaire.

Table 7

Weekly Topics of CEPB

Intervention Week	Emotional-Expression-and-Stress-Reduction ('Art and Laughter for Wellbeing')	Psycho-education: Reading of Autobiographical Accounts of Breast Cancer Sufferers ('Emotional Health Stories)
Week 1	Welcome and introduction	Welcome and introduction
Week 2	A sad moment in your life An angry moment in your life	Catherine Walker's story Patty Coldwell's story
Week 3	A worried moment in your life	Olivia Newton-John's story
Week 4	A guilty moment in your life	Stress and Illness 1 (breast-cancer patient account)
Week 5	Coping with negative emotions The benefits of laughter and humour	Beverley Flowers' Story
Week 6	A picture which has made you laugh A film which has made you laugh	Stress as an illness trigger (breast-cancer patient account)
Week 7	A joke which has made you laugh	Stress and Illness 2 (breast-cancer patient account)
Week 8	A funny memory Review and Reflection	Review and Reflection

5.9 Data Analysis

5.9.1 Analysis of Message Board and Blog Data

Message-board and blog postings were collated into transcripts for each participant (see Appendix J). Thematic analysis was used to analyse these transcripts. Thematic analysis is a widely used flexible and useful research tool for identifying, analysing, interpreting and

reporting patterns within data which can potentially provide a rich and detailed, yet complex account of data (Braun and Clarke, 2006).

During data collection, analysis and write-up, bracketing according to Ahern (1999) was carried out in order to identify potential researcher bias. This entailed identifying underlying assumptions, preconceptions and biases by reflecting upon and writing down taken-for-granted assumptions, clarifying personal value systems, paying close attention to feelings that could indicate a lack of neutrality, and carefully reflecting on the write-up of the account to ensure that each participant's quotes received equal attention. Bracketing was carried out by means of keeping a reflexive diary (see Appendix J). By doing this, preconceptions may not have been eradicated, but their impact on the data collection process was reduced.

Thematic analysis was carried out in line with Braun and Clarke's recommendations, which involved six steps. Step 1 consisted of familiarisation with the data, by reading and re-reading postings and noting down initial ideas. In Step 2, features of the data were coded systematically and data collated to relevant codes. Step 3 involved gathering these codes into potential themes, along with all relevant data. In Step 4, specifics of each theme were then refined, with clear definitions and names, to develop the overall story which the analysis told. In Step 5, examples were extracted for reporting of the themes. Step 6 entailed relating the overall analysis back to the research question and literature. The results of the thematic analysis were used to illustrate the process of the CEPB, as well as to confirm or disconfirm quantitative results. (See Appendix G for a full description and discussion of the themes.)

Establishing Trustworthiness of Qualitative Results

Lincoln and Guba (1985) postulated that central to a qualitative account is its trustworthiness: this entails researchers ensuring that their account has *truth value*,

applicability in other contexts or with other subjects, is *consistent* in the sense that its

findings could be replicated if the inquiry were repeated with the same or similar

participants, and is *neutral* in that the findings are determined by the respondents rather

than the biases, motivations, interests or perspectives of the inquirer. In the present study,

trustworthiness of the results was ensured by applying Lincoln and Guba's evaluative

trustworthiness criteria: credibility, transferability, dependability and confirmability.

Although a number of evaluative criteria for qualitative research have been posited by

different researchers, Lincoln and Guba's criteria were focused on since they are

commonly used in qualitative research (Creswell, 1998) and offer detailed, comprehensive

techniques which can be used to conduct qualitative research that meets these criteria. In

the present study, a number of these techniques were employed; they are discussed

below.

Credibility

Credibility describes confidence in the 'truth' of the findings. Four techniques were

employed to ensure credibility: member checking, triangulation, referential adequacy and

prolonged engagement.

Member Checking

For the purposes of member checking, an online questionnaire was constructed

containing a summary of each theme (see Appendix H). Participants were asked to

indicate whether they could identify with each theme description; in other words, whether

they had had experiences corresponding to a particular theme description. A link to the

questionnaire was sent to all 32 participants who had posted on their blogs and on the

message boards. Eighteen participants responded in total (response rate = 56.3%).

Table 8 displays the results of the member checking procedure. There were two themes

that the majority of respondents could not relate to or were unsure of (*Traumatic*

Childhood Events and *Perceived Advantages and Disadvantages of Being a Woman*).

Subsequently, these two themes were reviewed and it was decided to exclude them from

the main results. (See Appendix J for a description of these two themes.)

Triangulation

Three data sources were used to collect qualitative data: blogs, message boards and

open-ended questions as part of the screening questionnaire, the post-treatment

questionnaire and the follow-up questionnaire. Thus, this study involved a triangulation of

data sources, which helped ensure a rich, robust and well-developed account (Patton,

1999).

Referential Adequacy

A portion of data (specifically, the transcripts of three participants) was identified and

archived, but not analysed. The data analysis was then conducted on the remaining data

and preliminary findings were developed. Subsequently, the researcher returned to the

archived data and analysed it as a way to test the validity of the preliminary findings. The

archived data produced findings in line with the preliminary data, thus adding to their

credibility.

Table 8

Member Checking Results

Theme	Ability to Identify with Theme (% of participants)	
Coping with Bereavement	Yes	78%
	Maybe	22%
Coping with Stress	Yes	94%
	Maybe	6%
'Breast-Cancer Prone' Characteristics	Yes	67%
	Maybe	22%
	No	11%
Traumatic Childhood Events	Yes	28%
	Maybe	11%
	No	62%
The Role of Psychological Factors in Health and Illness	Yes	72%
	Maybe	22%
	No	6%
Perceived Advantages and Disadvantages of Being a Woman	Yes	44%
	Maybe	11%
	No	44%
Experiences with Health-Care Professionals	Yes	56%
	Maybe	33%
	No	11%
Experiences of the CEPB	Yes	83%
	Maybe	11%
	No	6%

Note. Percentages may not add up to 100 due to rounding.

Prolonged Engagement

According to Lincoln and Guba, prolonged engagement is the investment of sufficient time to understand the social setting or phenomenon of interest. This requires that the researcher be involved with a site sufficiently long to detect and take account of distortions that might otherwise creep into the interpretation of the data. Furthermore, prolonged engagement helps build trust between participant and researcher. Thirdly, it allows the researcher to reach data saturation as well as theoretical saturation (Onwuegbuzie and Leech, 2007). In the current study, prolonged engagement was achieved through the eight-week duration of each intervention group and the eight months in total of data collection, in which the researcher was able to engage extensively with each participant and communicate with them both on a one-to-one basis (via blogs) as well as in a group context (via message boards).

Transferability

Lincoln and Guba (1985) contended that due to the nature of naturalistic qualitative research, it is impossible to establish external validity in the same way as it is customary in positivist, quantitative research; the researcher can only provide necessary detail that would enable others to draw conclusions regarding the results' transferability to other contexts, situations, times or people. This can best be ensured by providing a 'thick description' of the findings, including as much detail as possible. In line with this recommendation, special attention was paid to describing each theme yielded by thematic analysis of the blog, message board and questionnaire data, with all its facets and nuances. Furthermore, not only were data reported which corresponded to the theme or sub-theme, but care was also taken to include quotes which were not in line with the dominant theme and thus offered another point of view, enriching the description.

Dependability and Confirmability

Dependability entails demonstrating that the findings are consistent and could be repeated, while confirmability refers to a degree of neutrality or the extent to which the findings of a study are shaped by the respondents and not the researcher's bias, motivation, or interest (Lincoln and Guba, 1985). Both dependability and confirmability can be determined by an external audit of both the process and product of the study by one or more individuals not involved in the research; additionally, triangulation, reflexivity and an audit trail further help ensure confirmability.

In the present study, three techniques were used to establish dependability and confirmability: triangulation, external audit and reflexivity. The form of triangulation used is described above.

Reflexivity involves the investigator becoming aware of and acknowledging his or her biases and preconceptions, as they will affect what he or she chooses to investigate, the

methods used and the findings considered most appropriate (Malterud, 2001). This was achieved through the development of a reflexive diary (see Appendix J), in which regular entries were made during the research process (Lincoln and Guba, 1985). In these entries, the researcher recorded methodological decisions and the reasons underlying these, how problems were solved when they arose and how these impacted on the research process, as well as reflections on her own role in the generation of findings.

An external audit of the research process and product was carried out by a competent peer (Lincoln and Guba, 1985; Patton, 1990), a professor of psychology with years of experience in conducting qualitative research. The audit involved examination of the researcher's audit trail consisting of the original transcripts, data analysis notes, reflexive journal, comments yielded through member checking, and the write-up itself. The auditor assessed both dependability and confirmability of the results, as well as the completeness and availability of auditable documents. Furthermore, the degree and significance of researcher influence was evaluated. All were deemed satisfactory.

5.9.2   *Analysis of Post-Intervention Outcomes*

All quantitative data were analysed using the Predictive Analytics SoftWare (PASW), Version 18. As detailed in Section 5.6, 31 participants in total (including control group) were included for post-intervention analysis. To make sure the assumptions of analyses of covariance (ANCOVA) were met, the data were screened in line with Tabachnik and Fidell's (2007) recommendations. Results of evaluation of the assumptions of normality of sampling distributions, homogeneity of variance, linearity, reliability of covariates, and homogeneity of regression were satisfactory. No outliers were present.

In order to assess the effect of both intervention elements on the four dependent variables (DVs) when controlling for the pre-intervention score, 2×2 factorial ANCOVAs were performed for all four dependent variables, as well as for conformity. This is in line with

Dimitrov and Rumrill's (2003) recommendations for comparing groups with pretest-posttest data. Senn (2006) discussed the benefits of using ANCOVA over analysis of differences between outcome and baseline (so-called 'change scores'). It has been postulated that ANCOVA gives a biased estimate of the treatment effect, because the difference in baseline values between treatment groups is usually not zero, and that the analysis of change scores is therefore a better method. However, Senn demonstrated that it is not a necessary condition for the unbiasedness of ANCOVA for the expected values at baseline between the two groups to be equal. Furthermore, he presented circumstances where ANCOVA is unconditionally unbiased but the analysis of change scores is not. Furthermore, Vickers and Altman (2001) pointed out that the analysis of change scores does not control for baseline imbalance because of regression to the mean, and that ANCOVA is therefore a better approach, since it in fact is unaffected by baseline differences between groups; ANCOVA adjusts each participants' post-treatment score for their baseline score. Another advantage of ANCOVA, according to the authors, lies in the fact that it generally has greater statistical power to detect a treatment effect than the other methods. Frison and Pocock (1992) also pointed out ANCOVA's superiority over the analysis of post-treatment means or the analysis of mean changes, in terms of avoidance of bias. Thus, for the present study, ANCOVA was used to determine the effects of the CEPB on the dependent variables.

Although conformity was not a dependent variable (rather, it was included as an additional measure of 'breast-cancer prone' personality), it was measured both after the intervention and at follow-up in order to determine if the CEPB had had any significant effects on participants' tendencies to be overly compliant. The independent variables were Emotional-Expression-and-Stress-Reduction (EESR - taking part in 'Art and Laughter for Wellbeing' vs. not taking part), and psycho-education (reading autobiographical accounts vs. not reading them). The dependent variables were post-intervention maladaptive coping with bereavement, post-intervention maladaptive coping with stressful life events,

post-intervention social support and post-intervention awareness of the connections between psychological and physical health. The covariate was the pre-intervention score on the DVs.

Mixed analyses of variance (ANOVA) were performed to assess changes in the DVs over time, as recommended by Dimitrov and Rumrill (2003). There was one within-subjects factor, time, with two levels, namely the pre-intervention score and the post-intervention score on the DVs. There were two between-subjects factors, EESR and psycho-education.

5.9.3   Analysis of Six-Week Follow-Up Outcomes

As detailed in Section 5.6, 23 participants were included for follow-up analyses. Data were screened in line with Tabachnik and Fidell's suggestions, as described above. In order to assess the effect of both intervention elements on the four dependent variables (DVs) when controlling for the pre-intervention score and the post-intervention score, factorial ANCOVAs were performed for all four dependent variables, as well as for conformity. The independent variables were EESR (taking part in 'Art and Laughter for Wellbeing' vs. not taking part), and psycho-education (reading autobiographical accounts vs. not reading them). The dependent variables were maladaptive coping with bereavement at follow-up, maladaptive coping with stressful life events at follow-up, social support at follow-up and awareness of the connections between psychological and physical health at follow-up. The covariates were the pre-intervention and the post-intervention scores on the DVs.

Mixed ANOVAs were performed to assess changes in the DVs over time. There was one within-subjects factor, time, with two levels, namely the post-intervention score and the follow-up score on the DVs. There were two between-subjects factors, EESR and psycho-education.

5.9.4   Analysis of Coping Styles

Conceptual content analysis (Krippendorff, 2004) was employed to classify coping activities reported by participants into mutually exclusive categories of coping styles. The coding frame used to classify data was based on Ferguson and Cox's (1997) descriptions of 21 coping styles; additional coping styles were added to this coding frame as they emerged from the data (see Table 9). A sub-sample (20%) of responses was used to calculate inter-rater reliabilities between the researcher and an independent rater trained in the use of the coding frame. According to Banerjee, Capozzoli, McSweeney and Sinha (1999), $k > 0.75$ is considered excellent agreement beyond chance.

5.9.5   Analysis of Participants' Evaluation of the CEPB

Similar to coping style analysis, conceptual content analysis was employed to classify participants' responses to the open-ended questions on the post-intervention questionnaire into mutually exclusive categories of perceived benefits, perceived drawbacks, suggestions for improvement and additional comments made. Coding frames were developed that used emergent categories, in other words, categories were developed following preliminary examination of the data. Additionally, three items were included in which participants were asked to indicate, on a five-point scale, how useful, helpful and enjoyable they had found the programme. A sub-sample (20%) of responses was used to calculate inter-rater reliabilities between the researcher and an independent rater trained in the use of the coding frame.

5.9.6   Analysis of Screening Tool and Intervention Site Usability

Mean scores were computed for each participant on the technology acceptance items measuring perceived ease of use and intrinsic motivation, for both the screening tool and the intervention Intranet site. In order to gauge whether perceived ease of use and enjoyment of the intervention Intranet site were related to how exerienced women were in using Web sites, correlations were performed. Mean perceived ease of use and mean

intrinsic motivation were correlated with four variables: participants' self-reported Internet experience, confidence using the Internet, the average number of times the Internet was used weekly, and average number of hours per week spent on the Internet.

Table 9

Coding Framework Based on the 21 Coping Styles Identified by Ferguson and Cox (1997)

Coping Style
1.   Emotional social support Turning to others (friend, family etc.) to discuss the nature of the problem. Using others as a shoulder to cry on and from whom to seek emotional support and comfort.
2.   Situational redefinition Looking for the best things in the situation. Not directly doing anything to alter the situation, stepping back from and looking at the situation in a different manner to make it seem better.
3.   Direct action Realising that something could be done to alter the situation and then doing it.
4.   Escapism Either smoking, drinking, listening to loud music, watching TV, eating or just 'hanging around', but not directly facing the problem.
5.   Relaxation Using relaxation and meditation techniques to calm oneself.
6.   Keeping busy Keeping busy so as not to think about the problem at hand.
7.   Irrelevant means Indulging in other activities that the person is good at (e.g. sports, painting, cooking etc.) in an attempt to make themselves feel better before trying to tackle the problem.
8.   Planning Taking time out to make a plan to solve the problem at hand
9.   Self-motivation Giving themselves a pep talk/kick up the backside to motivate themselves to deal with the situation
10. Denial Refusing to believe that the event had happened, it was not real.
11. Emotional release Venting anger and emotions (e.g. screaming and shouting and smashing up things).
12. Instrumental social support Turning to others who are more expert for detailed advice on how to deal with the problem.
13. Optimism Taking an optimistic outlook on things
14. Tuning out Ignoring distractions and concentrating solely on the problem at hand.
15. Social comparison Comparing themselves with others, either real or imaginary, in a similar situation to themselves, to help evaluate their situation.
16. Religion Turning to religion and religious practices to help understand and deal with the situation.
17. Isolation Completely cutting themselves off from other company. Deliberately isolating themselves.
18. Acceptance Accepting the situation for what it was and doing nothing to alter or change it.
19. Constraint Not doing anything about the problem straightaway, but waiting for a more appropriate time to do so.
20. Secondary control Just going with the flow.
21. Checking procedures Going back over previous actions and procedures to see if a mistake had been made.
22. Struggling to cope (no specific style)[a] Feeling unable to cope, or coping badly, without a specific coping style being described
23. Coping by supporting others [a] Attending to the needs of others affected by the stressful event
24. Medication Using medication (e.g. anti-depressants, sleeping pills) to cope with the event
25. Avoidance [a] Avoiding to think about and/or deal with the situation
26. Ongoing attempts to cope [a] Currently ongoing coping with the situation, without reporting a specific coping style, and without indication of adaptiveness of coping style
27. Emotional suppression [a] Suppressing negative emotions associated with a stressful event

[a]additional coping styles that emerged from the data

5.10 Conclusion

The present study used a 2×2 independent measures design with triangulation, employing a mixture of quantitative and qualitative methods. This was deemed most suitable for investigating the hypotheses and research questions, and for meeting the study aims, because the mixed methods allowed for the research topic to be examined from different angles, thus yielding rich, in-depth data. The next chapter details the design of the psychological screening tool used for the present study.

CHAPTER SIX

DESIGN OF THE PSYCHOLOGICAL SCREENING

TOOL

CONTENTS

6.1 Introduction

This chapter details the design of the psychological screening tool which was used to assess participants' eligibility to participate in the study, and to measure the most-established psychosocial factors involved in breast-cancer development. Furthermore, two pilot studies are reported. The first pilot study involved the validation of the scales used in the screening tool, and the second pilot study assessed their internal consistency and the screening tool's usability in terms of its perceived ease of use and participants' intrinsic motivation to complete it.

A psychological screening tool was developed to assess the following dependent variables before and after the intervention, as well as at six-week follow-up: coping with bereavement; coping with stressful life events; level of social support; and awareness of the connections between psychological and physical health. Furthermore, because a 'breast-cancer prone' personality is one of the important factors in breast-cancer aetiology, scales measuring the presence of 'breast-cancer prone' traits were included, in order to be able to screen potential participants for these traits. Since personality traits become stable in adults between the ages of 20 and 30 (McCrae and Costa, 1994), a change in personality was not expected to take place as a result of the intervention. Rather, a 'breast-cancer prone' personality formed one of the inclusion criteria of the present study. This was explained in more detail in Chapter Five, sub-section 5.5.1.

Apart from psychosocial factors, the most-established physical breast-cancer risk factors were also measured, in order to be able to ascertain levels of physical risk factors among participants and thus be able to provide women with this information if they wished to receive it.

Two pilot versions of the screening tool were created (Version A and Version B; see Appendix J). They included various established scales to assess the same psychosocial

factors. Both versions of the screening tool were pilot-tested to determine which scales possessed the best psychometric properties and would thus be used to create the final version of the tool.

6.2 Scales Measuring 'Breast-Cancer Prone' Traits

'Breast-cancer prone' traits were assessed with Bleiker, van der Ploeg, Hendriks, Leer, and Kleijn's (1993) Rationality-Anti-Emotionality (RAE) scale, of which all three subscales were used: 'Rationality', 'Emotionality' (which in fact measures degree of anti-emotionality) and 'Understanding in spite of Negative Feelings' (henceforth abbreviated to 'Understanding'). Furthermore, the 'Emotional Control' (EC) and 'Expression-In' (EI) subscales of the Emotional Expression and Control (EEC) scale were used. The RAE and EEC scales were constructed by Bleiker and colleagues, based on Grossarth-Maticek, Bastiaan and Kanazir's (1985) concept of the Rationality and Anti-Emotionality factor, which is connected to the suppression of aggression and was found to predict cancer mortality very accurately. Furthermore, it is based on Temoshok's (1987) descriptions of Type C behaviour. Exploring their psychometric characteristics on a sample of over 8000 women, Bleiker and colleagues found a Cronbach's alpha of .79 for the Rationality subscale of the RAE, .69 for the Emotionality subscale, and .67 for the Understanding subscale, suggesting adequate internal scale consistency. The EC subscale measuring emotional control yielded a Cronbach's alpha of .86, while the EI subscale, which measures inward direction of negative emotions, had a Cronbach's alpha of .79.

These scales were all adapted by the author of the present thesis to the 'structured alternative format' designed by Silon and Harter (1985). This format has the advantage that participants choose to which group of women they think they 'really' or 'sort of' belong to, and therefore they can conform to either of these without feeling 'non-conforming'. For example, '*I try to act rational, so I do not need to respond emotionally*', adapted to the structured alternative format, becomes *'Some women try to act rational, so they do not*

need to respond emotionally, but other women respond emotionally'. The four-point scale asks participants to indicate which group of women they belong to, and to which degree ('sort of true for me' or 'really true for me'). Using such an answer format is particularly relevant due to the propensity of women with a 'breast-cancer prone' personality to suppress negative emotions and to score high on conformity measures. The format reduces the tendency to give socially desirable responses (Silon and Harter, 1985).

In order to be able to compare the psychometric properties of an alternative measure of 'breast-cancer prone' personality to the RAE and EEC, the Type C Personality Inventory (TCPI; Hosaka, Fukunishi, Aoki, Rahe and Solomon, 1999), adapted to Silon and Harter's structured alternative format, was used in Version B of the pilot screening tool. The TCPI was derived from Rahe and Solomon's (1997) Immunosuppressive Questionnaire, developed to measure characteristic behaviours and emotions of patients with immunosuppressive diseases, such as cancer. It has five subscales: Social (conflict avoidance), Emotions (suppression of emotions), Service (over-giving and self-sacrifice), Assertion (lack of assertiveness), and Power (hopelessness and helplessness). Hosaka and colleagues found these subscales to be of moderate to high internal consistency, yielding a Cronbach's alpha of 0.64 for Social, 0.78 for Emotions, 0.66 for Service, 0.84 for Assertion, and 0.67 for Power. Concurrent validity of all subscales, as assessed by concurrent correlations with standardised, validated psychological tests, was reportedly acceptable.

As a measure of conformity, the short version of the Marlowe-Crowne Social Desirability Scale (Crowne and Marlowe, 1960) was included in Version A of the pilot screening tool. The Marlowe-Crowne scale is an established psychological tool, asking respondents to self-report whether they engage in certain behaviours that are culturally sanctioned and approved, but are unlikely to occur (e.g. '*I never hesitate to go out of my way to help someone in trouble'*). The short version, comprising of 10 items, was chosen because of

the shorter duration of its completion, and given that it has been validated by Fraboni and Cooper (1989). Responses are measured on a four-point Likert scale, with high scores indicating high conformity.

The Eysenck Personality Questionnaire [EPQ] Lie Scale (Eysenck and Eysenck, 1975) was included in Version B of the pilot screening tool as an alternative measure of conformity. This is one of the most widely used instruments used to assess socially desirable responding (Lajunen and Scherler, 1999), and has a dichotomous (Yes/No) response format, asking respondents to indicate whether they engage in 21 socially desirable or undesirable behaviours (e.g. *'Have you ever blamed someone for doing something you knew was really your fault?'*). High scores on the EPQ Lie Scale reflect high conformity.

6.3 Scales Measuring Coping with Bereavement and Coping with Stressful Life Events

Studies in the area of bereavement and breast-cancer occurrence have usually found significant associations between the two. This is the case for bereavement occurring in a time period ranging from two years to twenty years prior to developing cancer. The majority of these studies have found a significant effect for a time period of between five and ten years. However, as Chapter Two showed, significant losses, such as the loss of a child, or the loss of a parent in childhood, have the potential to affect individuals for much longer. Thus, for the purposes of the present study, eligible participants needed to have experienced bereavement in the past ten years, or to have experienced bereavement longer than ten years ago but for this bereavement to have been particularly traumatic. In order to establish whether participants fulfilled this criterion, they were asked to indicate whether they had ever lost someone dear to them, and if so, who this was and when this had happened.

Maladaptive coping with bereavement and with stressful life events were both assessed with an adaptation of the Functional Dimensions of Coping (FDC) scale (Ferguson and Cox, 1997; re-validated by Flynn, van Schaik and van Wersch, 2004) in Version A of the pilot screening tool. The FDC scale allows for the assessment of coping behaviours as well as of coping functions, namely the functions that individuals *believe* their coping behaviours are designed to achieve. Ferguson and Cox distinguished between four functional dimensions of coping: approach, avoidance, reappraisal and emotional regulation. The main strength of the FDC scale lies in its partly open-response format, enabling participants to describe their coping behaviours in their own words. These responses are then coded and categorised. As the measurement of all four coping dimensions is a lengthy and time-consuming exercise, the scale was adapted to specifically measure avoidance, which, as outlined in Chapter Two, has been associated with breast-cancer development. The FDC scale is reported to have excellent internal reliability, with a Cronbach's alpha of .83 having been found for the Avoidance subscale using a Likert-scale response format (Flynn et al., 2004).

As an alternative measure of maladaptive coping with bereavement and with stressful life-events, two subscales (Denial and Venting) of the Brief COPE scale (Carver, 1997) were used in Version B of the pilot screening tool. The Brief COPE scale is a well-established tool for the measurement of stress-coping derived from the COPE inventory (Carver, Scheier and Weintraub, 1989), an instrument often used in health-related studies (Carver, 1997). It has 28 items. The two subscales Denial and Venting, used in Version B of the screening tool, contain four items. They were chosen because denial is one of the maladaptive coping strategies involved in breast-cancer development, and venting reflects the degree to which the individual expresses negative emotions in order to deal with a stressful situation. Low venting scores reflect higher emotional suppression. These two subscales have been shown to have very good internal consistency (alpha = .71 for Denial, alpha = .77 for Venting).

6.4 Scales Measuring Social Support

Chapter Two showed how a lack of social support has been linked to breast-cancer incidence. Thus, as argued in Chapter Four, intervention programmes targeting psychosocial factors involved in breast-cancer development need to focus on social support. The latter was measured in Version A of the pilot screening tool using the Instrumental Support subscale of the Duke Functional Social Support Questionnaire (FSSQ), developed and validated by Broadhead, Gehlbach, and de Gruy (1988). It contains eight items and was chosen for its answer format: a five-point Likert scale, asking individuals to indicate how much support they are currently receiving, ranging from 5 meaning 'as much as I would like' to 1 meaning 'much less than I would like'. This gives choices to individuals who are high in conformity, in that they can still indicate that they would have liked more support without appearing ungrateful. In addition, it is short and easy to complete on one's own. Internal consistency of the scale is high with a Cronbach's alpha of .81 (Broadhead et al., 1988).

An alternative measure of social support was used in Version B of the pilot screening tool, consisting of the Perceived Social Support subscale of the Berlin Social Support Scales (BSSS; Schulz and Schwarzer, 2003). The BSSS was originally developed for use in coping with cancer-surgery settings. It has five subscales. The Perceived Social Support subscale contains eight items measuring the social support individuals feel is available to them. Previous research has established high internal consistency of this subscale, with a Cronbach's alpha of .83 (Schulz and Schwarzer, 2003). Similar to the FSSQ, it is short and easy to complete without help.

6.5 Scales Measuring Usability

The usability of the psychological screening tool (and of the study Web site, as is explained in more detail in Chapter Seven) was operationalised through the measurement of two constructs: perceived ease of use and intrinsic motivation. Perceived ease of use

(Davis, 1989) describes the degree to which a person believes that using a particular technology would be free of effort. Intrinsic motivation (Davis, Bagozzi and Warshaw, 1992) is defined as the perception that users will want to perform an activity for no apparent reinforcement other than the process of performing the activity per se; in other words, it measures how enjoyable the technology is perceived to be. Both constructs are derived from the Technology Acceptance Model (TAM; Davis, 1989; Davis, Bagozzi and Warshaw, 1989), the most widely applied model of user acceptance and usage (Venkatesh, 2000). TAM was derived from the Theory of Planned Behaviour (Ajzen and Fishbein, 1980; Fishbein and Ajzen, 1975) and suggests that two specific beliefs, namely perceived ease of use and perceived usefulness, determine one's behavioural intention to use a technology. These beliefs have been linked to subsequent behaviour (Taylor and Todd, 1995). Intrinsic motivation, in turn, is one of the determinants of perceived ease of use (Venkatesh, 2000): the higher an individual's intrinsic motivation to use a technology (i.e. the more enjoyable the individual's experience with this technology is), the higher its perceived ease of use. These two constructs were chosen because they seemed most relevant to the psychological screening tool and to the electronic intervention that was developed as part of this study. It was important that individuals found the questionnaire easy to fill in and the Web site easy to use, in order to encourage sustained participation; furthermore, these activities should also be as enjoyable as possible to the participants, in order to minimise drop-out rates, which are typically high in online studies of this nature (Im and Chee, 2004). Both constructs were measured with the Perceived Ease of Use (Venkatesh, Morris, Davis and Davis, 2003), and Intrinsic Motivation (Venkatesh and Speier, 1999) scales used in TAM research. The perceived ease of use scale contains four items, while the intrinsic motivation scale contains three items. Their adaptation for this study consisted of modifying the item wordings to suit the technologies studied (i.e. the psychological screening tool and the intervention Web site).

6.6 Measurement of Physical Risk Factors of Breast Cancer

As outlined in Chapter One, the main established physical risk factors of breast cancer are age, a sedentary lifestyle, being overweight after menopause, nulliparity (never having had any pregnancies), first pregnancy at age 35 or later, having few children, not breastfeeding, using Hormone Replacement Therapy (HRT), contraceptive pill use, and hereditary factors (Cancer Research UK, 2011; Mezzetti, La Vecchia, Decarli, Boyle, Talamini et al., 1998; Hsieh, Trichopoulos, Katsouyanni and Yuasa, 2005; Ewertz, Duffy, Adami, Kvåle, Lund et al., 1990; Collaborative Group on Hormonal Factors in Breast Cancer, 2002; McPherson, Steel and Dixon, 2000). These were all assessed with the screening tool, in order to be able to determine levels of physical risk factors among participants.

Respondents were asked to indicate if they had ever suffered from breast cancer, if any women in their family ever suffered from breast cancer, and if so, how they were related to them. Contraceptive pill use was assessed, and if respondents had stopped taking oral contraceptives, they were asked to indicate when they had stopped. Participants were asked if they drank alcohol, and if so, whether they thought they were drinking too much. If they had stopped drinking alcohol, they were asked to indicate when they had had their last alcoholic drink. Similar questions were asked about exercise habits and intake of a healthy diet. Respondents were shown a body mass index (BMI) chart and asked whether their BMI was in the orange (overweight) or red (obese) range of the chart. This was deemed a subtler approach than asking about height and weight directly, as many women may not wish to disclose this information (Gorber, Tremblay, Moher and Gorber, 2007).

Furthermore, participants were asked if they had ever had any pregnancies. Their age when they had their first child, number of children, whether their children were breastfed or not, and duration of breastfeeding were also assessed. A further question, namely if any of their children were deceased, was included because the literature indicates that

bereavement due to the loss of a child is a particularly stressful form of bereavement (Lambe, Cerrato, Askling and Hsieh, 2004; Li, Johansen, Hansen and Olsen, 2002a, 2002b; Wijngaards-de Meij, Stroebe, Schut, Stroebe, van den Bout et al., 2005). Respondents were asked to indicate when this loss had happened.

6.7 Demographic Variables

The demographic variables age, marital status, level of education, religious orientation, ethnic origin and employment status were all assessed, in order to determine sample characteristics and representativeness. Moreover, participants' previous reading of autobiographical accounts of breast-cancer sufferers was established, as well as their experience in using the Internet and patterns of Internet use. Respondents were asked to indicate if they had ever read any autobiographies of breast-cancer sufferers, and if so, how many. They were also asked if these autobiographies had moved them emotionally, and why. Furthermore, women were asked to indicate when they had first started using the Internet, when they first started feeling confident using the Internet, how many hours and how many times they used the Internet per week. Determining experience using the Internet, pattern of Internet use, as well as previous reading of autobiographical breast-cancer accounts would help establish if a relationship existed between these variables and the degree to which participants benefited from the intervention.

6.8 Pilot Study 1: Scale Validation

The first pilot study was carried out to establish the face validity of all scales used in both versions of the psychological screening tool, in other words, if all scales measured what they purported to measure (Anastasi, 1988). Although the scales had already been validated in other studies, face validation was still carried out for two reasons: firstly, some of the scales had been adapted slightly as described above, and secondly, they were all being included in a single screening tool for the first time. Therefore, it was felt that it would be important to re-establish their face validity. Three participants were involved in

the validation: an expert (a senior lecturer in psychology), an expert in a related field (a sociologist), and a layperson (a female accountant). A structured interview was carried out with the layperson, which was then transcribed (see Appendix J for the transcript). Due to their busy time schedules, rather than face-to-face interviews, the two experts were administered an open-response format questionnaire (see Appendix J), which contained identical questions to those used in the structured interview with the layperson, and which they could complete in their own time. For every scale, participants were asked to indicate what they believed this scale measured, whether all items seemed to belong in the scale (and why), and whether there were any items they thought did not belong in the scale (and why). All participants largely made accurate judgments about what constructs the scales purported to measure. Only two items were deemed somewhat unsuitable by one of the expert participants, and these items were on scales which were not used in the main study.

6.9 Pilot Study 2: Internal Consistency and Usability

The second pilot study was carried out to establish the psychometric properties and the usability of each version of the screening tool. For this purpose, women were recruited in two different ways. Firstly, female students at Teesside University were recruited through an announcement placed on the student Intranet of the School of Health and Social Care, as well as approaching individuals face-to-face at the School of Social Sciences and Law. The author explained the study to seminar groups and lecture theatres and asked students to sign up. Secondly, postings advertising the project were placed on Internet message boards and on classifieds Web sites such as Gumtree *(www.gumtree.com)*. These postings contained details of the study and a hyperlink to the screening tool.

Version A and Version B of the screening tool were both created using the Internet survey tool Surveygizmo *(www.surveygizmo.com)*. It was ensured that both versions were identical in terms of their appearance (e.g. layout, colour scheme, font size and font type),

so that any differences in usability would not be attributable to any of these factors. One big advantage of using Surveygizmo to create the questionnaires was that a 'forced-response' format could be applied to items, which ensured that respondents could not leave the question unanswered. This reduced the risk of missing data through participants skipping questions, but it did not prevent questionnaires from only partially being filled in before being abandoned. Forced-response was applied to most items, but not to several items that had an open-response format, because these items did not necessarily apply to every respondent: for example, an open-response item asking the respondent to provide additional information about their deceased child would not apply to respondents who had never lost a child.

Before participants could fill in the questionnaire, they were asked to confirm that they were female, at least 18 years old and lived in the UK. They also needed to indicate that they consented to taking part in the study and that they understood that they could withdraw from the study at any time. Quantitative data were analysed using the Statistical Package for the Social Sciences (SPSS), Version 16.

Table 10 displays demographic characteristics, physical risk factors of breast cancer and bereavement prevalence of the sample in Pilot Study 2. Ninety-three women took part in total, but the data of four respondents had to be discarded because they abandoned the questionnaire after answering less than half of the questions. Forty-eight participants completed Version A of the form, 41 participants completed Version B. The mean age was 34.5 years. Eighty-nine per cent of participants were White British, 36% had a higher education degree, and 58% reported Christian religious orientation. Most were employed (64%), and more than half (52%) had one or more children. These demographic characteristics are similar to those reported in other studies in this area.

Table 10

Demographic Characteristics, Physical Risk Factors of Breast Cancer and Bereavement

Prevalence of Pilot Study 2 Sample (*N* = 89)

Age (years)	*M*	Minimum	Maximum	*SD*
	34.49	20	58	10.61
Marital status	Single			39%
	Married			35%
	Partner			19%
	Divorced			3%
	Not given			2%
	Separated			1%
Ethnic origin	White/ British			89%
	White/ Other			7%
	Not given			2%
	Pakistani			1%
	Other			1%
Level of education	Higher education degree			37%
	A-levels			22%
	O-levels/GCSE			14%
	Higher education diploma			9%
	Higher education certificate			8%
	MSc			7%
	PhD			3%
	Not given			2%
Religious orientation	Christian			59%
	None			29%
	Other			9%
	Muslim			1%
	Not given			2%
Employment status	Employed			64%
	Not employed			33%
	Not given			3%
Children			52% Yes	48% No
Breastfeeding history			51% Yes	49% No
Menopausal			20% Yes	81% No
HRT use			47% Yes	53% No
History of breast cancer			0% Yes	100% No
Family history of breast cancer			22% Yes	78% No
Recent and/or traumatic experience of bereavement			83% Yes	17% No
Alcohol consumption	83% Yes		16% No	1% Not Anymore
Regular exercise	53% Yes		31% No	16% Not Anymore
Consumption of a healthy diet	77% Yes		17% No	6% Not Anymore
Contraceptive pill use	25% Yes		48% No	27% Not Anymore

Note. Percentages may not add up to 100 due to rounding.

Of those women who had children, approximately half had breastfed. Duration of breastfeeding ranged from one day to 36 months, with the majority breastfeeding between three and four months. Twenty-five percent used the contraceptive pill, 83% drank alcohol but most did not believe that they drank excessively, and 53% reported taking regular exercise. Seventy-seven per cent reported eating a healthy diet. Nineteen per cent were menopausal and of these women, just over half (53%) did not use HRT. None of the women had ever had breast cancer, but 22% reported that close relatives had suffered from the disease, indicating a potential genetic risk. Thus, on the whole, the sample was fairly low in levels of physical risk factors of breast cancer.

Experience of using the Internet and frequency of use was assessed. Most had begun using the Internet in the late 1990s and at the beginning of the new millennium, and most reported feeling confident using the Internet a few years after starting to use it. Weekly Internet use ranged from one hour to over 100 hours. Most of the sample reported using the Internet on a daily basis.

Table 11 displays Cronbach's alpha coefficients of the scales measuring the dependent variables as well as 'breast-cancer prone' personality. The Emotionality Subscale (alpha = .70), EC (alpha = .86) and EI (alpha = .76) all had high internal consistency, but only one of the subscales of the TCPI (assertion) had high internal consistency (alpha = .76). Both the Marlowe-Crowne scale (alpha = .70) and the EPQ Lie Scale (alpha = .72) had high internal consistency. Based on these findings, it was decided to include the chosen subscales of the RAE and EEC in the final version of the psychological screening tool. Furthermore, the Marlowe-Crowne Scale was chosen over the EPQ lie scale despite its slightly lower Cronbach's alpha coefficient for two reasons. Firstly, its Likert-scale response format, which allows participants to indicate their level of agreement, was deemed preferable to the EPQ's dichotomous response format. Secondly, the items of the

Marlowe-Crowne scale were more in line with the 'breast-cancer prone' trait of conformity than those of the EPQ Lie Scale.

Table 11

Internal Consistency of Scales Measuring Dependent Variables and 'Breast-Cancer Prone' Personality

Variable	Scales Measuring Dependent Variable (by Version of Psychological Screening Tool)	Alpha
'Breast-Cancer-Prone' Personality	Rationality (Version A)	.64
	Emotionality (Version A)	.70
	Understanding (Version A)	.63
	Emotional Control (Version A)	.86
	Emotional Expression-In (Version A)	.76
	Marlowe-Crowne Scale (Version A)	.70
	TCPI – Assertion (Version B)	.76
	TCPI – Social (Version B)	.47
	TCPI – Power (Version B)	.63
	TCPI – Service (Version B)	.38
	TCPI – Emotion (Version B)	.40
	EPQ – Lie Scale (Version B)	.72
Maladaptive Coping with Bereavement and with Stressful Life Events	Adapted FDC scale (Version A)	.70
	Brief COPE scale – Denial (Version B)	.74
	Brief COPE scale – Venting (Version B)	.79
Social Support	FSSQ (Version A)	.85
	BSSS (Version B)	.85
Usability of Screening Tool	Perceived Ease of Use (Version A)	.51
	Perceived Ease of Use (Version B)	.81
	Intrinsic Motivation (Version A)	.91
	Intrinsic Motivation (Version B)	.74

Both tools measuring stress coping (the FDC scale and the Brief COPE) had moderate to high internal consistency. Nevertheless, the adapted FDC scale was included in the final version of the screening tool due to the advantages exhibited by its partly open response format. Moreover, the dichotomous response format of the brief COPE did not allow for the detection of moderate levels of denial or venting, which posed a further disadvantage compared to the FDC scale.

Regarding the measurement of social support, both the FSSQ and the BSSS had equally high internal consistency. Since the internal consistency of the FSSQ has been reported on more in the literature, the decision was made to use this scale as a measure of social support in the final version of the screening tool.

The perceived ease of use (Venkatesh, Morris, Davis and Davis, 2003) and intrinsic motivation (Venkatesh and Speier, 1999) subscales of the Technology Acceptance Questionnaire had moderate-to-high internal consistency for both pilot versions of the screening tool.

Finally, both versions of the screening tool were assessed with these two subscales of the TAQ. Table 12 displays mean perceived ease of use and intrinsic motivation for each item as well as the overall mean, for both versions of the screening tool. It was found that both versions were perceived to be easy to use and the process of completing the form was overall experienced as moderately enjoyable by participants.

Table 12

Usability by Version of Screening Tool

Technology Acceptance Item	*M*	*SD*	Minimum	Maximum
Learning to fill in this survey was easy.	3.67 (Version A) 4.06 (Version B)	.86 .79	1 2	5 5
I found completing this survey enjoyable.	3.30 (Version A) 3.48 (Version B)	.68 .76	2 2	4 5
Becoming skilful at completing this survey was easy.	3.36 (Version A) 3.79 (Version B)	.82 .86	1 2	5 5
The actual process of completing this survey was pleasant.	3.39 (Version A) 3.67 (Version B)	.70 .69	2 2	5 5
The survey pages were easy to navigate.	4.09 (Version A) 4.24 (Version B)	.52 .71	3 2	5 5
I had fun completing this survey.	3.15 (Version A) 3.39 (Version B)	.67 .71	2 2	4 5
Mean Perceived Ease of Use	3.71 (Version A) 4.03 (Version B)	0.53 0.67	2.33 2.00	4.67 5.00
Mean Intrinsic Motivation	3.28 (Version A) 3.52 (Version B)	0.64 0.58	2.00 2.67	4.33 4.67

Note. Responses measured on 5-point Likert scale (1=strongly disagree; 5=strongly agree)

Respondents were given the opportunity to comment on the questionnaire by typing their comments into a text box at the end of the questionnaire. Few comments were left and very little criticism was received, apart from a few comments relating to the response format of some items, which were subsequently rectified by the researcher.

6.10 Final Version of the Screening Tool

The results of Pilot Study 1 and Pilot Study 2 were used to develop the final version of the psychological screening tool, to be used in the main study (see Appendix J). Furthermore, a post-intervention questionnaire and a six-week follow-up questionnaire were

constructed. These two questionnaires are described in more detail in Chapter Five, Section 5.5.

Table 13 displays the contents of the final screening tool. Apart from demographic variables and physical risk factors of breast cancer, the instruments shown in Pilot Study 2 to be internally most consistent were used to measure psychosocial factors associated with breast-cancer development.

Two additions to the screening tool were made, following Pilot Study 2. The first consisted of an item measuring bereavement suffering. This was deemed important in order to assess whether individuals who had experienced significant bereavement more than ten years ago were still suffering as a result of their loss. The second addition consisted of three items measuring the awareness of the connections between psychological and physical health. These were intended to measure whether there was a change in awareness that psychological and physical health were connected as a result of the intervention programme. Chapter Four, Sub-section 4.5.1 explains how psycho-educational measures can be designed to make individuals aware of potentially harmful behaviours, and thus raise awareness of the importance of modifying their behaviour. In the present study, this was to be achieved by presenting participants with autobiographical accounts of breast-cancer sufferers who had 'breast-cancer prone' psychological profiles. It was expected that the reading of these accounts would result in an increased awareness of the connections between psychological and physical health. This is discussed in more detail in Chapter Seven, Section 7.4.

Table 13

Contents of the Final Screening Tool Used for the Main Study

Variable	Instrument or Measurement Method Used
1.Demographic variables	
Age	Numeric
Marital status	Multiple choice
Level of education	Multiple choice
Ethnic origin	Multiple choice
Religious orientation	Multiple choice
Employment status	Multiple choice
Duration of unemployment	Numeric
2. Physical risk factors of breast cancer	
Parity	Multiple choice
Age at birth of first child	Multiple choice
Number of children	Multiple choice
Contact with children	Multiple choice
Breastfeeding of each child	Multiple choice
Breastfeeding duration for each child	Multiple choice
Breast cancer history (yes/no)	Multiple choice
Family history of breast cancer	Multiple choice
Oral contraceptive pill use	Multiple choice
Time since cessation of oral contraceptive pill use	Numeric
Alcohol use	Multiple choice
Time since cessation of alcohol use	Numeric
Excessive alcohol use	Multiple choice
Physical activity/exercise	Multiple choice
Time since stopping exercising	Numeric
Desire to begin exercising	Multiple choice
Overweight (Body Mass Index)	Multiple choice
Consumption of a healthy diet	Multiple choice
Time since stopping consuming healthy diet	Numeric
Desire to eat more healthily	Multiple choice
Menopause status	Multiple choice
Time since menopausal	Numeric
Use of Hormone Replacement Therapy	Multiple choice
3.Psychosocial factors associated with breast-cancer development	
If child deceased, date of death	Numeric
Bereavement status (yes/no)	Multiple choice
Details of bereavement	Open-ended response
Bereavement coping style	Open-ended response
Maladaptive bereavement coping	Adapted Functional Dimensions of Coping (FDC) Scale
Date of most significant loss	Multiple choice
Bereavement suffering	Multiple choice
Stressful life events	Open-ended response
Stressful life events coping styles	Open-ended response
Maladaptive stressful life events coping	Adapted Functional Dimensions of Coping (FDC) Scale
Conformity and defensiveness	Marlowe-Crowne Social Desirability Scale
Social support	Duke Functional Social Support Questionnaire
Awareness of the connections between psychological and physical health	3 items constructed for the present study
'Breast cancer-prone' personality traits	Rationality Subscale of the RAE Emotionality Subscale of the RAE Understanding Subscale of the RAE Emotional Control Subscale of the EEC Emotional Expression-In Subscale of the EEC
4.Other variables	
Usability of screening tool	Perceived Ease of Use scale and Intrinsic Motivation scale used in technology acceptance research
Prior experience with reading autobiographies of breast cancer sufferers	Multiple choice and open-ended questions
Internet Experience and Internet Use	Multiple choice
Additional Comments	Open-ended response

6.11 Conclusion

A psychological screening tool was developed which used valid and internally consistent scales to measure the most established physical risk factors of breast cancer, as well as psychosocial factors associated with breast-cancer development. This screening tool was used to determine potential participants' suitability for the programme, and to measure the dependent variables before the intervention, after the intervention, and at six-week follow-up. The design of the Coping-Enhancement Programme for the Bereaved (CEPB) and of the intervention Web site is described in the next chapter.

CHAPTER SEVEN

DESIGN OF THE COPING-ENHANCEMENT

PROGRAMME FOR THE BEREAVED

CONTENTS

7.1 Introduction

This chapter describes in detail how the electronic Coping-Enhancement Programme for the Bereaved (CEPB) was designed. Specifically, it is presented what guidelines and recommendations were adhered to when developing the programme, as well as the considerations that influenced the planning of its individual elements. Furthermore, the design of the intervention Web site is detailed. Finally, the third pilot study, which examined the Web site's perceived ease of use and participants' intrinsic motivation to use it, is reported.

The CEPB was designed to incorporate two elements: an emotional-expression-and stress-reduction element, and a psycho-educational element. Each element addressed different psychosocial factors potentially involved in breast-cancer development. The programme was planned as a group intervention, with the author of this thesis acting as the group facilitator. Group therapy, as opposed to individual therapy, has the advantage of inclusion, with each person becoming part of the therapy of others (Blatner, 1992). Moreover, as detailed in Chapter Four, group therapy has the potential to increase social support, a vital component of the intervention, with low social support being one of the most-established psychosocial factors involved in the aetiology of breast cancer. Furthermore, a meta-analysis of 23 outcome studies found no difference in outcome between group therapy and individual therapy formats, suggesting that group therapy is an efficacious alternative to individual therapy in many circumstances (McRoberts, Burlingame and Hoag, 1998). Thus, the group format would enable many women to potentially benefit from the intervention simultaneously.

7.2 Initial Considerations

The CEPB was planned in line with Liebmann's (2004) considerations for art-group interventions, as well as with Rogers' (1957) core concepts of person-centred therapy. These are explained in the following.

7.2.1 Planning Group Facilitation

The purpose of therapy in groups is to provide a warm, trusting environment in which people can feel at ease in revealing personal matters (Liebmann, 2004). This includes caring and respect for other members, and their feelings and points of view are a priority. The recommendations detailed below are designed to help achieve a caring, client-centred group which people enjoy being in.

A therapist or facilitator always needs to have supervision arrangements, to offer support and an alternative perspective (Carroll, 1996; Liebmann, 2004). The author of this thesis was supervised by an accredited counselling psychologist and specialist in women's health for the duration of the intervention. Supervision entailed meeting with the counselling psychologist to discuss any difficulties the researcher was facing, as well as the supervisor periodically visiting the Web site and reading the communication between researcher and participants.

Person-centred therapy (Rogers, 1957) is a psychotherapeutic approach focusing on the client and attitudes of therapists towards their clients, rather than on particular techniques (Dryden, 2007). Although the present intervention was designed as a group intervention, it seemed important to place emphasis on each participant's individual needs and concerns, especially with such sensitive topics as bereavement and breast cancer. Therefore, the core concepts of person-centred therapy seemed useful to guide the author of this thesis in her interactions with the participants. In line with these core concepts, the author took special care to emphasise her genuineness, her unconditional positive regard for the client, and to offer empathic understanding. Genuineness entailed the author drawing on her own bereavement experiences whenever this seemed appropriate. Unconditional positive regard - accepting each participant without disapproval - was aided by the keeping of a reflexive diary (see Appendix J), in which the author aimed to write down any conflicting feelings she experienced, and to then reflect on these feelings and their

possible origins. Conveying empathic understanding to each participant throughout the intervention was intended to emphasise unconditional positive regard.

When planning the intervention, the decision had to be made whether to make the intervention groups open or closed. According to Liebmann (2004), a closed group runs for a fixed number of sessions with the same members. This allows for them to get to know each other and build up trust, to share experiences and emotions at a deep level. By contrast, an open group allows people to leave and join as they wish, and consequently remains at a fairly superficial level. Semi-open groups hold a commitment to attend, but membership changes slowly as people leave and newcomers arrive. In this way, group culture is maintained, while allowing for a natural or organised turnover. The present intervention groups were designed to be closed for two reasons. Firstly, members needed to be assessed initially and at the end of the programme, and for methodological reasons each group member needed to commence the programme at the same time. Secondly, it was assumed that, in line with Liebmann's suggestions, the groups would be better able to establish a rapport if membership stayed the same throughout the programme, and that this in turn would encourage the building of trust and disclosing of deeper feelings.

Outcome measures are pertinent to any intervention aimed at improving psychosocial functioning (Sexton, 1999). Therefore, it is essential to determine whether the intervention has any effects, as well as their direction. Similarly, Liebmann (2004) recommends a 'before the group' measurement for an evaluation, in addition to asking members what they are expecting to gain from the group, and, at the end, if their expectations have been met. As mentioned above, participation of all group members needed to commence and to finish at the same time, if these measurements were to be compared between groups. It was planned to assess all dependent variables three times: once at baseline (pre-intervention), once after the programme had ended (i.e. eight weeks after the baseline assessment), and then a final time six weeks after the post-intervention assessment.

The planned duration of the intervention was eight weeks. This was in line with Im and Chee's (2003) findings regarding online interventions and attrition. Specifically, the authors suggest that 11 weeks (the duration of the intervention in their study) are too long for an online intervention, because long interventions are at particular risk of attrition due to the lack of face-to-face interaction, and the resulting added difficulty in establishing a therapeutic alliance. It was therefore considered adequate to determine the duration to be eight weeks, which would hopefully allow enough time to build a group rapport while reducing the risk of drop-outs.

Concerning group size, Liebmann (2004) recommends that most art-therapy groups have between four and 12 members. Size is important to achieve group cohesion and to make sure that there are enough people to encourage interaction, a free flow of ideas, and to undertake group projects. On the one hand, smaller groups of six to eight are generally found to be more intimate and supportive, because they are more likely to achieve cohesion. Larger groups, on the other hand, are more likely to accomplish interaction and 'somewhere to hide' if someone does not want to participate.

Many groups suffer from high drop-out rates. Therapists need to recruit two or three more participants than their ideal number (American Group Psychotherapy Association, 2011). Groups that drop to very low numbers can be very difficult to maintain (Benson, 2001; Brown, 1992; Stock Whitaker, 2001). Reviewing these recommendations, the decision was made to set the initial group size at eight members per group. Thus, if two or three women dropped out, there would still be enough members to keep interactions going.

Interactions between group members were asynchronous, with individuals posting messages in their own time, as opposed to real-time interaction where the group meets and communicates online at a set time. Therefore, there was no need to agree on a day and time to meet that was convenient for everyone. Each member was e-mailed on a

designated day each week, informed of that week's topic, and encouraged to visit the intervention Web site at any time in that week.

Before starting a therapy group, the structure and framework of the group should be crystal-clear for the client (American Group Psychotherapy Association, 2011). The need for written materials is emphasised, containing information about the location of the group, the time and day that it meets, the duration of sessions, the duration of the intervention (if time-limited), and the size of the group. Liebmann (2004) suggests a preparatory session, which is a chance for the therapist to check that the clients are suitable and prepared for the programme, and for clients to check that the group is suitable for them. This is also useful for building trust between clients and facilitator, so that the first session is not quite so daunting.

Before beginning the intervention proper, the author therefore made sure to e-mail all participants the full details of the intervention. Furthermore, this information was placed on the intervention Web site. Additionally, it was planned that all group members introduce themselves, tell the group a little about themselves and what they hoped to gain from their participation in the CEPB.

Within groups, the worldviews of both the facilitator and the members often vary. Therefore, groups are a natural place to acknowledge and promote pluralism (Corey, 2008). Liebmann (2004) argues that equal opportunities are an essential element of group therapy. Thus, there should be no discrimination on the grounds of race, ethnic background, culture, religion, gender, sexual orientation, class, disability or age. It is essential to examine oneself as a contextual/cultural being, which involves expanding one's awareness of cultural and sociodemographic differences between individuals (Ivey, Pedersen and Ivey, 2001).

Due to the online format of the present study's intervention, and the anonymity this afforded the participants, individuals' race, age and other sociodemographic details were confidential and only became known to the other group members if participants chose to reveal such details in their postings. In the introductory postings created by the researcher, all women were advised not to disclose their identity (i.e. real name) to the rest of the group. Additionally, all group members were randomly assigned pseudonyms or 'screen names' in the form of flower names, such as 'red rose', 'white rose', and so on. The type of flower was the same for each group member and only the colour of flower varied across members. That way, each participant had a unique username. Women were asked to use their pseudonym in their postings. These measures all served to minimise perceived differences between individuals, and therefore minimise potential sources of prejudice.

Another consideration entailed group rules. Burlingame, Fuhriman and Johnson (2002) contended that the definition of group rules at the beginning of group therapy is essential if group cohesion is to develop. Similarly, Liebmann (2004) recommended that every group needs a few ground rules to know where it stands, and for members to know what is expected and not expected of them. These need to be established when the group starts, and usually include normal social rules such as respect for others. A further vital component is the inclusion of a 'no sexist or racist language' rule as part of the group's ground rules. This involves an awareness of written and spoken language: the facilitator needs to be ready to challenge sexist, racist or otherwise offensive language by reminding members of the ground rules, or by asking whether a stereotype is actually true in order to challenge members to think about their statements.

In line with these suggestions, the facilitator included a set of ground rules in the introductory posting on each message board, at the very top, in form of a 'sticky' topic[1]. In these rules, women were made aware that inappropriate behaviour, such as using offensive or abusive language, would not be tolerated, and that members were expected to treat each other with respect.

As part of providing equal opportunities for all group members, Liebmann (2004) proposed that the intervention venue should be easily accessible by all. This is particularly relevant to individuals with mobility problems, or to those who live in remote areas. Delivering interventions via the Internet makes these accessible to people whose access to face-to-face settings is limited (Kersting, Schlicht and Kroker, 2009). Due to its convenience, confidentiality, and reduction of stigma most clients find psychological therapies delivered via the Internet acceptable (Marks and Cavanagh, 2009).

The CEPB was delivered over the Internet. However, accessibility was still an issue in terms of potential participants needing to have access to the Internet. Because recruitment for the project largely took place online (see Chapter Five, Section 5.6), it was presumed that the women who volunteered for the study already had Internet access. Nevertheless, this method of recruitment may have resulted in selection bias. Bolger, Davis and Rafaeli (2003) warned about the risk of perpetuating a 'digital divide', namely the issue of differential access of individuals of various groups to participation in research, which could subtly steer research towards more convenient or accessible populations and away from economically disadvantaged participants. Also, computer literacy may affect individuals' willingness to enrol in electronic interventions such as the CEPB. Nevertheless, the severity of this selection bias is partially put into perspective when considering that in counselling, there are other modes of delivery catering to those who do not have Internet access, for example, telephone counselling or bibliotherapy (Febbraro,

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[1] A topic which always remains at the top of the first page, even when new topics are created.

2005). It is thinkable that these modes of delivery could also be used to facilitate health psychological interventions. Furthermore, Internet access in the UK is increasing rapidly, with nearly 80% (19 million) of all households having Internet access in 2011 (Office for National Statistics, 2011). It can therefore be assumed that the majority of potential participants had Internet access.

In order to make sure that activities were chosen which participants could cope with (Liebmann, 2004), detailed illustrated tutorials were to be placed on the Web site. These would demonstrate technical aspects of participation, such as how to create new postings, upload pictures, and link to external sites.

According to Liebmann (2004), informing group members of an intervention's aims and goals is important. Thus, the facilitator needs to make sure it is understood why the group is meeting for sessions. However, Corey (2008) argues that preferably, members will decide the specific goals of the group experience for themselves. To ensure that participants were aware of the aims of the intervention, an information page was created, explaining these. In line with the Teesside University School of Social Sciences and Law's Research Degree Committee's recommendations, no specific mention was made of breast cancer, so as not to alarm women, and to prevent the reading of the information page from inadvertently causing worry or distress. Instead, references were made to overall physical health. Cancer was merely mentioned as an example of ill-health. Additionally, in line with Corey's recommendation, each woman was asked, when introducing herself to the rest of the group, to explain what she personally hoped to gain from the intervention.

A therapy group needs to feel safe (Davis, 1980; Liebmann, 2004). This entails spelling out the precise meaning of confidentiality to participants. The intervention groups in the CEPB were 'closed-access' in that the Web site was only accessible by entering a

username and password (see Section 7.6), members were assigned an anonymous screen name, and never met face-to-face. This greatly reduced concerns surrounding confidentiality and anonymity. Nevertheless, as part of the ground rules it was explained to group members that everything they contributed needed to remain anonymous in that real names should never be used. Furthermore, participants were informed that their data would be used for analysis and reported in the present thesis, but that anonymity would be preserved throughout.

When considering the issue of attendance, it was thought to be important that group members were made aware if they were expected to contribute to every discussion, and what would happen if they missed any topics (Liebmann, 2004). Encouraging group members to attend, in terms of visiting the Intervention Web site regularly, was considered to be of great importance (Grey, 2007). The researcher sent e-mails to group members every week, letting them know what that week's topic was going to be, and encouraging them to visit the Web site and to participate. That way, the women would always be kept informed, and if they could not contribute one week, it would be easy to rejoin in the following week because the topics were 'stand-alone': in order to contribute to one topic it was not necessary to have participated in earlier discussions. Furthermore, as the interaction did not take place in 'real time' there were no 'sessions' *per se.* Therefore, if they did not contribute in any given week, members could read previous topics and contribute to them at a later point during the programme if they wished, because the previous weeks' topics were still accessible. The facilitator read these late comments too, and responded to them.

It was planned to encourage all group members to contribute, but in such a way that nobody would feel forced or pressured to participate. Moreover, the women were to be encouraged to communicate with each other, rather than just with the facilitator, to increase the potential for mutual social support.

Concerning the role of the group facilitator, the decision had to be made if the author of this thesis, also being the group facilitator, would join in and contribute to topics or not. Liebmann (2004) stated that this decision depends on a group's ethos and the framework in which it takes place. In art therapy, many facilitators choose to join in the actual artwork because they feel that if they expect others to participate and to be open, then they ought to set an example. In doing so, they are demonstrating that they are also members of the group, rather than aloof observers. Greenwood and Layton (1987, 1991) term this 'side-by-side' therapy. However, the advantages of not joining in include an increased capacity to concentrate on the organisation of materials for group members, being available to group members on an individual basis, or concentrating on observation. As mentioned above, in person-centred therapy, genuineness is one of the core concepts; Rogers (1957) advocates self-disclosure of the therapist, to help convey to the client that the therapist is genuinely involved and cares about his or her well-being. It was therefore deemed beneficial by the facilitator to contribute, at least initially, in order to help participants feel more at ease and facilitate the establishment of a therapeutic alliance (Watkins, 1990).

Furthermore, the decision of the facilitator to join in the discussions was influenced by the nomadic research philosophy of Fox (1999), who elaborated on the postmodern philosophical ideas of Levinas, Deleuze and Guattari. In these, the researcher has a caring and engaging role, and the concepts of 'celebration of difference' and 'a commitment to engagement' are the pillars. Corresponding to this, the CEPB was conceived as taking the form of a continuous process, in which actions and interactions between the participant and the researcher would be constantly geared to the objective of changing maladaptive to adaptive coping profiles. Fox (1999) put forward that in order to answer a research question, it is necessary to spend some time in exploration. This should be conducted with the involvement of all those concerned with the research, and designs which sustain differences between the 'researcher' and the 'researched' would

make the concept of 'observer bias' deeply problematic. However, Fox argued that, rather than confounding the research process, within the nomadic paradigm this 'bias' is seen as a virtue, guaranteeing that the research is relevant and adequate to answer the research question, and that the findings are relevant to the study population. Therefore, in the present study the facilitator joined in, sometimes being the first to contribute to topics, until the impression was gained that group members felt at ease and comfortable to disclose their emotions and experiences without the facilitator necessarily doing the same.

Transference often plays a role in any form of therapy (Stock Whitaker, 2001). This is the tendency of group members to 'transfer' feelings for significant figures in their lives onto the therapist. An example of this could be a client projecting their continued need for a parent onto the therapist, which can lead to overdependence or conflict. In contrast, countertransference refers to therapists' personal feelings and responses in a group, which are rooted in her or his personal needs. This could mean responding to a group member's transference as though he or she were that significant figure from the past, for example, that individual's parent. A related issue is identification, a process in which a person sees another as a similar or more ideal version of themselves and changes by modelling himself or herself on these aspects (Case and Dalley, 1992). A group member may hence identify with the facilitator, or with another member. An advantage of this lies in the fact that group members identifying with each other can provide useful motivation and discussion, sometimes leading to change (Liebmann, 2004). However, if the identification is too strong it can become restricting, as people need to work towards being more fully themselves rather than a 'clone' of another person. An additional related concern is that of projection, a process in which group members have feelings and make assumptions about other members not based on experience in the group. This can lead to them projecting their own attributes or feelings (while unaware of them) onto other participants, which in turn can lead to scapegoating of one member by all the others (Waller, 1993). The recipient of the projection or scapegoating could be a group member

or the therapist. Although the CEPB did not strictly speaking constitute a form of psychotherapy, it was thought that the facilitator should be aware of all of these group processes, in order to notice when they were happening, even if only to acknowledge them, or indeed to take appropriate action (Liebmann, 2004).

Liebmann pointed out that when group therapy ends, occasionally there will be people with 'unfinished business'. She recommended that the facilitator deal with this by providing information on other opportunities to continue working on the same lines, but trying to keep group members' experiences on a level that is easy for them to cope with. Similarly, Joyce, Piper, Ogrodniczuk and Klein (2007) mentioned that the individual should be helped to face future life demands with the tools provided in the therapy. In counselling, difficulties with ending the therapeutic relationship are part of the process (Murdin, 2000).

These recommendations were implemented in the present study in several ways. Firstly, on the last day of the week in which a given topic was active, or at least once a sizeable number of members had contributed postings to the topic, the facilitator, having checked that there was nothing else anyone wanted to add, 'closed' the topic by summarising what had been talked about and thanking all members for their contributions.

Secondly, the blogs (see Section 7.5) provided an opportunity for women to communicate more privately with the researcher and air any concerns they had. Thirdly, participants were clearly informed of the duration of the CEPB, and were provided with a detailed schedule, in order to make them aware of the time-limited nature of the programme, and to help prepare them better for the end of the intervention. Furthermore, the Teesside University Psychological Therapies Clinic's telephone number was made available, which women could ring if they required further support.

Moreover, the duration of the programme was stated on the study information page and also on various pages of the Web site. Each of the eight intervention weeks was numbered, and women were informed at the beginning of the programme what the content of each week would be. A closing week was planned for week eight, in which the women were given the opportunity to reflect on their participation – this helped the facilitator recognise whether there was any 'unfinished business' that participants wished to address.

An important component of group interventions which was acknowledged throughout the programme was the group process over time. Probably the most influential model of group development was proposed by Tuckman (1965), who argued that groups go through four stages, termed Forming, Storming, Norming, and Performing. Tuckman put forward that these stages were all necessary in order for a group to grow and become cohesive. In accordance with Tuckman's model, Liebmann (2004) postulated a progression of stages in group therapy. At the initial stage, in which the group meets and starts its activity, the leader (i.e. therapist or facilitator) will initiate things; this corresponds to the Forming Stage of Tuckman's model. Next, the group will typically progress to a stage where it finds its feet: it gets used to the way of working and misunderstandings are cleared up. Some may leave, discovering that it is not suitable for them, or not what they expected. Others become more committed. This corresponds to the Storming stage of Tuckman's model. Once the group has found its feet, mutual goals are agreed, similar to Tuckman's description of the Norming stage. At the disclosure stage, which parallels Tuckman's Performing stage, group members become more willing to disclose themselves in their artwork and the discussion. Here, they often divulge deep feelings and thoughts as they openly grapple with their most pressing problems. Finally, the session ends, which is often accompanied by a variety of feelings such as depression, confusion, anger, or relief. If it is the end of the programme, some members may ask themselves what will come next.

Being aware of these group processes helped the facilitator to anticipate potential problems and to deal with them if they arose.

Liebmann (2004) discussed the problem of outcome measurements after the group has ended. She recommended that they might be taken a week or two later, when people are clear about what they have gained from the group. The facilitator thus planned to e-mail participants a week after the programme had ended, with the request to fill in the questionnaire containing the outcome measures. Another questionnaire was to be completed six weeks after the end of the CEPB, in order to be able to assess if the effects still persisted.

The final matter which needed to be considered was the recording of the interaction in the group. In face-to-face settings, it can be a challenging task to record interactions between group members as they occur, although several methods for this have been devised (e.g. Cox, 1973). Liebmann (2004) stressed the importance of having an efficient recording system in place. Fortunately, since the intervention took place on a Web site, a record of all interaction was kept automatically. In order to prevent a loss of data, the facilitator periodically saved copies of all postings and blog entries in Microsoft Word documents.

7.2.2 Methodological Considerations

Several methodological considerations played a role in the design of the programme. The decision to make the CEPB an electronic programme was aided by the fact that electronic data collection has some important advantages. Firstly, there is the issue of feasibility: the data do not need to be inputted from paper questionnaires or paper diaries but are entered directly by the participant, and there are no audio-recordings to be transcribed. This saves costs, time and storage space (Curl and Robinson, 1994), as well as potentially decreasing human errors (Stanton, 1998). Secondly, electronic data have the

potential to be very rich (Fawcett and Buhle, 1995). Online data collection offers the possibility of informative and prompt responses of research participants (Lakeman, 1997). Internet message boards have specific advantages of their own. For one, they allow asynchronous interactions through which participants can join in the discussions at their convenience, unlike other online methods which require synchronous interactions (e.g. chat rooms). Furthermore, they are observable, relatively easy to use, accessible (at least to those who have an Internet connection and are not visually impaired), and safe (Anderson and Kanuka, 1997; Hsiung, 2000). Message boards provide a more comfortable forum for some to discuss sensitive personal health issues, and have been suggested as a feasible alternative to traditional face-to-face groups (Kramish Campbell, Meier, Carr, Enger, James et al., 2001). Moreover, they can provide effective emotional and informational support (Hsiung, 2000).

When users register and create or are given a password, this increases confidentiality. Therefore, online message boards are safer than other forms of Internet data collection that are accessible to the public without a password. Online message boards are usually administered over a longer time frame, which gives researchers the flexibility to modify the forum's technical aspects, and thus reduces the burden of participation and time pressure (Kollock and Smith, 1999; Saba and McCormick, 2001).

Electronic diaries (e.g. blogs) also have specific advantages of their own. As described by Bolger, Davis and Rafaeli (2003), because entries are date- and time-stamped, this provides a direct measure of participant compliance; in other words, researchers can check if entries were completed on time. Electronic diaries also offer major advantages in terms of data entry, management and accuracy. For instance, the process of transcribing and double-checking the data, which can be costly and error-prone, are bypassed. Web-based programmes allow researchers to save entries immediately and usually also permit participants to review and change their answers. Increased data integrity translates into

greater reliability. Finally, an electronic diary allows for interactive contact with participants: researchers can send questions and receive responses. It also offers an additional method for increasing compliance by maintaining contact with participants (Jamison, Raymond, Levine, Slawsby, Nedeljkovic et al., 2001).

However, there are also some disadvantages. Namely, there is potential inconvenience, because participants need Internet access. Nevertheless, as mentioned earlier, this access is increasing rapidly, with over nearly 80% of UK households being connected to the Internet (Office for National Statistics, 2011). Therefore, a lack of Internet access is most likely not an issue for the majority of UK residents.

Another potential disadvantage lies in the fact that Web sites which rely solely on written material are not accessible to visually impaired individuals. Furthermore, not all people possess the same level of computer literacy, and therefore some may require training where others are able to navigate sites without needing assistance. This can be particularly problematic in situations where participants never meet face-to-face with the researchers (Bolger, Zuckerman and Kessler, 2000). In the present study, this problem was addressed by providing detailed, step-by-step instructions to all participants on how to access and navigate the site, as well as on how to create postings. Still, it cannot be ruled out that some women may have had difficulties in accessing the site and/or posting messages, and that these difficulties served as a deterrent to continue their participation. The researcher repeatedly encouraged all women to report such difficulties, and provided technical support when they did occur.

7.3 Emotional-Expression-and-Stress-Reduction: Art and Laughter for Wellbeing

The emotional-expression-and-stress-reduction element of the CEPB was designed to address three of the four dependent variables: coping with bereavement, coping with stressful life events, and social support. It entailed what was termed 'Art and Laughter for Wellbeing'. It involved the use of art ('Art for Wellbeing'), specifically pictures, music and poetry, in addition to the use of humour ('Laughter for Wellbeing'), to facilitate emotional expression and stress reduction. A further aim was to enhance social support through communication with the researcher and with other group members.

The photo-elicitation technique, described in Chapter Four, provided the framework for the art element. This technique involves asking individuals to talk about photographs of places, objects or people who are meaningful to them, describing the pictures and reflecting on their reasons for photographing these specific objects or people. Harper (2002) proposed that, although most elicitation studies use photographs, there is no reason studies cannot be done with other visual images such as paintings, cartoons, graffiti or advertising billboards, or virtually any visual image. Hence, the images do not need to be photographs, and do not necessarily need to have been produced by participants themselves.

For the CEPB, a combination of photo elicitation and photo production was used. Participants were provided with images by the researcher, from which they could select suitable ones. In addition, they were given the opportunity to contribute pictures of their own (i.e. pictures that were not among the ones provided by the researcher) if they wished to do so. These images reflected scenes associated with negative emotions. Combining photo elicitation with photo production had the advantage of giving participants more choice.

Four emotions were focused on: sadness, anger, guilt and worry. These are relevant to the 'breast-cancer prone' personality because sadness, anger and guilt are negative emotions that tend to be suppressed (Temoshok and Dreher, 1992); worry and anxiety are emotions usually associated with stressful life events, particularly severe loss (Finlay-Jones and Brown, 1981).

The photo elicitation/photo production technique was further modified to include other forms of art, specifically music and poetry, in order to provide participants with a wider range of media they could choose from to reflect their emotions. Some research has suggested that music therapy is beneficial to alexithymia sufferers (Allen and Heaton, 2010). Alexithymia, as described in Chapter Two, involves a difficulty to recognise and express emotions. It is therefore thinkable that music may be helpful to aid emotional expression in individuals with 'breast-cancer prone' personality traits.

Poetry was included because many poems express negative emotions, auch as anger, guilt, sadness or worry. Using poetry written by others to express one's own negative emotions may also be particularly suited to women who have difficulty expressing their own emotions. In this sense, other people's poetry could serve as an indirect way of expressing one's own emotions, similar to using music or pictures, with the main difference that poetry constitutes a form of verbal expression.

Liebmann (2004) emphasised that here is no 'right' way of choosing a theme for the group to work on – it is a matter for each therapist to work out in the most appropriate way, according to their own preferred style, the needs of the group and the facilities at their disposal. The four 'Art for Wellbeing' topics (sadness, anger, guilt and worry) were thus tailored to the needs of the group, in line with the relevant issues surrounding bereavement and coping with stressful life events, as well as with the personality traits typical of 'breast-cancer prone' individuals.

Participants reflected on a different emotion each week. In Week One, they were asked to remember a time in their life when they had felt very sad; in Week Two, a time when they had felt very angry; in Week Three, a time when they had felt very guilty; and in Week Four, a time when they had been very worried. Apart from choosing a picture, a piece of music or a poem to reflect a particular emotion, participants were asked to accompany their choice with a short text, describing why they had chosen that particular picture, poem or song, what it reminded them of, how they had dealt with the emotion at the time, and if they felt they could have dealt with it in a better way.

The 'Laughter for Wellbeing' element focused on stress reduction. The most important consideration when designing this part of the intervention was the necessity of using humorous material which participants themselves find funny (as discussed in Chapter Four, Sub-Section 4.1.1). Therefore, the intervention was conceived in such a way that women had the opportunity to choose from a range of humorous material provided by the researcher through links to humour Web sites, or to contribute humorous material of their own if they wished to do so. Similar to the 'Art for Wellbeing' element, this part of the CEPB spanned four weeks. In Week Five, participants were asked to share a humorous picture with the other women in the group; in Week Six they were asked to contribute a humorous film clip; in Week Seven a joke; and in Week Eight a funny memory. These forms of humour were chosen deliberately: because pictures involve nonverbal communication (similar to the largely nonverbal media utilised in the 'Art for Wellbeing' component), it was deemed to be a way for women to communicate humour that was not too daunting.

In the second week, women were asked to share a humorous film clip. Again, a film clip, although it may involve other people talking, does not necessitate the individual to contribute any words of their own. The third week entailed sharing a joke, which is verbal but still rather impersonal, and in the final week, participants were asked to share a funny

memory, which is a more personal feat. In this way, the activities built up gradually from the nonverbal, impersonal to the more personal, in order to prevent group members from feeling uncomfortable or embarrassed.

Furthermore, women were informed of the psychological and physical benefits of humour and laughter in a posting which summarised the most important findings regarding humour and physical and mental health. This information was given to participants because, as mentioned in Chapter Four, simply being aware of humour's beneficial effects on health already seems to be associated with positive physiological changes (Mahony, Burroughs and Hieatt, 2001).

7.4 Psycho-Education: Autobiographical Accounts of Breast-Cancer Sufferers

Besides an emotional-expression and stress-reduction element, the CEPB was designed to incorporate a psycho-educational element. As mentioned in Chapter Four, health-promotion research indicates that if someone personally connects to an issue or message, that person will be more likely to attend to and comprehend it (Grunig and Hunt, 1984; Pavlik, 1988). It seemed important to educate women about the connection between psychological health and breast cancer, but it seemed equally important to do this in a way which enabled them to see how this issue was relevant to them, without unnecessarily worrying or frightening them.

The psycho-educational element involved the reading and discussing of short (between 150 and 200 words) autobiographical accounts by breast-cancer sufferers. These accounts were expected to increase women's awareness of the connections between psychological and physical health, because they illustrated the way in which certain psychosocial factors could contribute to the development of breast cancer. In this fashion, they were anticipated to draw women's attention to the roles of psychosocial factors, such

as maladaptive coping styles and self-sacrificing behaviour, as potential contributors to breast-cancer development.

Over the eight-week intervention, women were presented with seven autobiographical accounts. One account was presented each week. In the final week participants were asked to reflect on the accounts they had read, and to share their thoughts on these accounts. Each account involved one or more of the psychosocial breast-cancer risk factors examined in this study. The protagonists of these accounts shared one or more characteristics with the study population (e.g. emotional suppression, low social support, or being bereaved). The accounts were placed on a separate message board with the title 'Emotional Health Stories'. Women were asked to read them and offer their opinions. The researcher subsequently engaged in a discussion of each account with the participants on the message board.

The accounts came from two sources: Health Talk Online (*www.healthtalkonline.org*), a Web site containing audiovisual and written accounts of people's experiences of health and illness (only written accounts were used for the present study), and the book *All Woman: Life After Breast Cancer* by Tanya Farrell Yelland (2000), in which women recount their experiences of battling breast cancer. Permission was obtained from the Webmaster to use the accounts from Health Talk Online, but it proved impossible to obtain the same permission from Farrell Yelland, because she had died in 2007. However, as the project study Web site was closed-access and the accounts were neither being published nor being used for commercial purposes, it was deemed sufficient to reference Yelland's book as the source of the stories. Furthermore, care was taken to reference the accounts and acknowledge their source to participants. Only such accounts were chosen in which it was apparent that the individual acknowledged a potential connection between the development of their illness and psychosocial factors. It was expected that these

accounts would raise participants' awareness of 'breast-cancer prone' psychological profiles.

7.5 Blogging

As outlined in Chapter Four, written emotional disclosure appears to be a useful method for facilitating disclosure of emotions, thereby improving psychological health and well-being. Its incorporation into intervention programmes aimed at individuals who have experienced or are experiencing stressful life events such as bereavement, and even more so if they tend to suppress their negative emotions, seems important. Therefore, the CEPB was designed to include written emotional disclosure, in the form of blogging. A weblog, or blog, is a diary written online, which is accessible to Internet users. The use of blogs is rising in popularity among Internet users (Cohen and Krishnamurthy, 2005). However, the potential value of using blogs as part of a programme similar to the CEPB had, at the time of writing this thesis, apparently not yet been reported in published research.

The blogs included instructions to each participant to write about anything that was on their mind which may be troubling them, or even events or feelings they were happy about. Thus, they were encouraged to disclose both positive and negative experiences and emotions. This was in line with Pennebaker and Beall's (1986) written emotional expression protocol, which asks participants to disclose their deepest thoughts and feelings. However, one important modification was made: while Pennebaker and Beall did not provide any feedback to their participants regarding what had been written, in the present study such feedback was given, for several reasons. Firstly, interacting with participants by giving them feedback on their entries in the form of empathic responses, and asking them to elaborate further on certain points if needed, helped foster a therapeutic alliance between the individual and the researcher, with the aim of increasing social support and facilitating further disclosure so that the participant would gain more

benefit from their blogging activity. Secondly, the interaction through the provision of feedback on blog entries had the potential to increase the amount, depth and richness of the data collected. Thirdly, probing participants on their entries enabled the researcher to use prompts to elicit in-depth information regarding their coping styles, emotional suppression, and social support, to supplement the responses they had given on the screening form. Bolger, Davis and Rafaeli (2003) mentioned this potential for interactive contact between participant and researcher as one of the major advantages of electronic/on-line diaries, because it allows for a dynamic tailoring of questions for specific participants.

However, the blogs were not just intended to aid emotional expression. They also provided an additional medium for women to write about their experiences, and to provide their impressions and experience of the CEPB, what they found helpful and useful (or not), and any technical difficulties they might have experienced in accessing or navigating the Web site. Thus, the blogs constituted a valuable source of information and for this reason were provided to every intervention participant.

The women were encouraged to write a blog entry at least once a week, in line with Chung and Pennebaker's (2008) finding that spacing expressive writing sessions over time appears to be the most effective method for this exercise. Feedback was given in the form of comments underneath their blog entries, which the blog owner could reply to. Similar to Winzelberg et al.'s (2003) study discussed in Chapter Four, all blogs were designed to be only accessible to the participant and the researcher, and could therefore not be read by other group members. It was thought that this degree of privacy would serve to enhance disclosure.

7.6 Design and Testing of the Intervention Web Site

The intervention Web site was developed by the researcher using Microsoft SharePoint Server 2007, a portal-based system that works like a large Web site with sub-sections and links to different areas (Teesside University Centre for Learning and Quality Enhancement, 2009). At the time when the intervention was conducted, Teesside University used SharePoint Server 2007 across the whole organisation. It was necessary to develop the intervention Web site with SharePoint because it was built as a Teesside University intranet site, in order to ensure the security of, and secure access to, the site.

7.6.1 Site Design

The researcher was trained in the use of SharePoint by a qualified professional, an IT technician manager at Teesside University, before and during the development of the Web site. Building the Web site with SharePoint had advantages and disadvantages. On the one hand, it enabled the site to be part of the University intranet, so it could only be accessed by individuals who had been granted access, and reduced the risk of the site being hacked. Furthermore, no training in HTML or another markup language was required to use SharePoint. On the other hand, certain constraints, which were part of the SharePoint application, were imposed. These are explained in more detail below. Moreover, although the author attended several SharePoint training sessions, it still proved difficult to use this application at times, particularly when more complex functions, such as the creation of sticky threads, were required. Still, these difficulties were overcome with time and technical support.

The Web site consisted of a collection of nine sub-sites. Each intervention group had access to a separate sub-site. Thus, participants from any one intervention group were unable to access the site of any other group but their own. Control-group participants were not given access to the site; as described in Chapter Five, they received no intervention.

The content of each sub-site depended on the condition of the group: not all participants received all elements of the intervention. (The study design was described in detail in Chapter Five.) The main home page was only accessible to the researcher and contained links to all nine sub-sites (see Figure 1 for the site map). Copies of the main pages of all sub-sites in HTML format can be found in Appendix J.

A sub-site always contained the following:

1. *A home page*: on this, a short introductory text was displayed, explaining the aims of the programme and describing how to access the individual elements of the site. It also had a side-bar menu, on which there were links to the message boards and to every blog. See Figure 2 for a screen shot of a home page.

2. *Blogs*: all intervention-group participants were provided with a link to their own blog, which could only be accessed by themselves and the researcher. Each blog had an introductory posting containing instructions to the participant on how to create a posting, and what to write about. See Figure 3 for a screen shot of a blog.

Depending on intervention condition, a sub-site could contain any of the following:

1. *An 'Art and Laughter for Wellbeing' message board*: this included two sticky topics. The first was a 'Welcome and Introduction' topic, in which the group members were welcomed and the programme content for each of the eight intervention weeks was explained. Furthermore, the researcher included a short personal introduction and encouraged each group member to do the same. Additionally, some ground rules were outlined, stressing confidentiality and anonymity, and emphasising that all members were to treat each other respectfully and that abusive, discriminating language would not be tolerated. The second sticky topic was titled 'How to create a posting' and contained a step-by-step illustrated tutorial explaining how to reply to postings and how to include pictures and hyperlinks in

messages. The remaining topics consisted of the weekly intervention themes (including one topic about the benefits of laughter), as described in Section 7.3. See Figure 4 for a screen shot of such a message board.

2. *An 'Emotional Health Stories' message board*: this contained a sticky introductory topic outlining the content of the eight intervention weeks, as well as of the eight intervention themes (as described in Section 7.4). See Figure 5 for a screen shot of such a message board.

Figure 1

Map of the Intervention Web Site for the Main Study
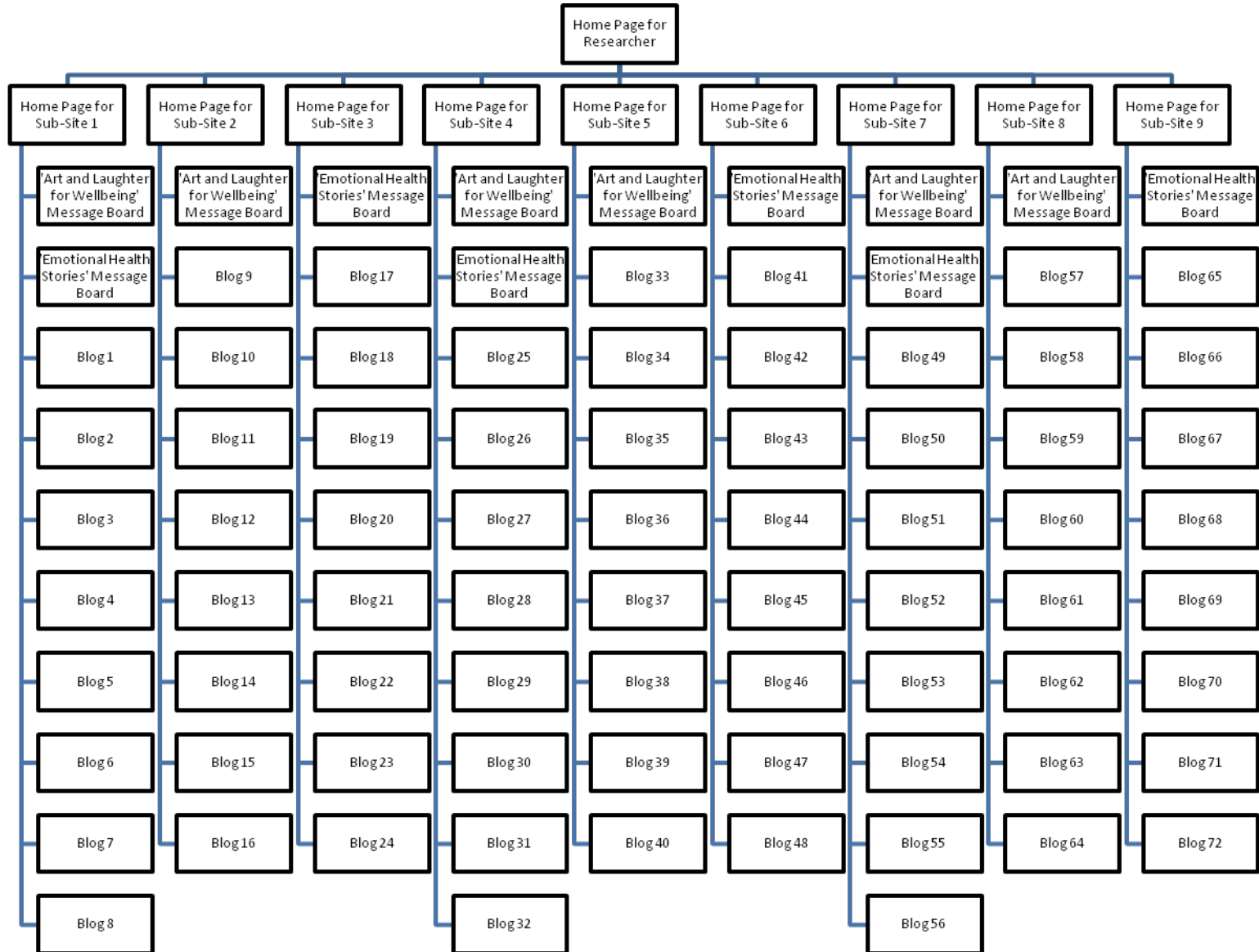
3. *Picture and link libraries*: On the sub-sites containing an 'Art and Laughter for Wellbeing' message board, picture libraries were placed, with pictures suitable to each topic. From these, participants could choose images to use in their postings. These images had been downloaded from the Internet by the author, using the Google search engine (*www.google.co.uk*). Furthermore, two link libraries were created with links that participants might find useful when searching for material to include in their postings. For example, a link to a poetry search engine was provided, enabling individuals to search for poetry which reflected emotions that were focus of the 'Art for Wellbeing' element of the intervention (sadness, anger, guilt and worry). Links to Web sites containing humorous material were also provided; these could be used by participants for the 'Laughter for Wellbeing' element of the intervention. All of these links had been collated by the researcher using the Google search engine. See Figures 6 and 7 for screen shots of link libraries, and Appendix J for a list of the links used.

Figure 2

Example of an Intervention Group Home Page
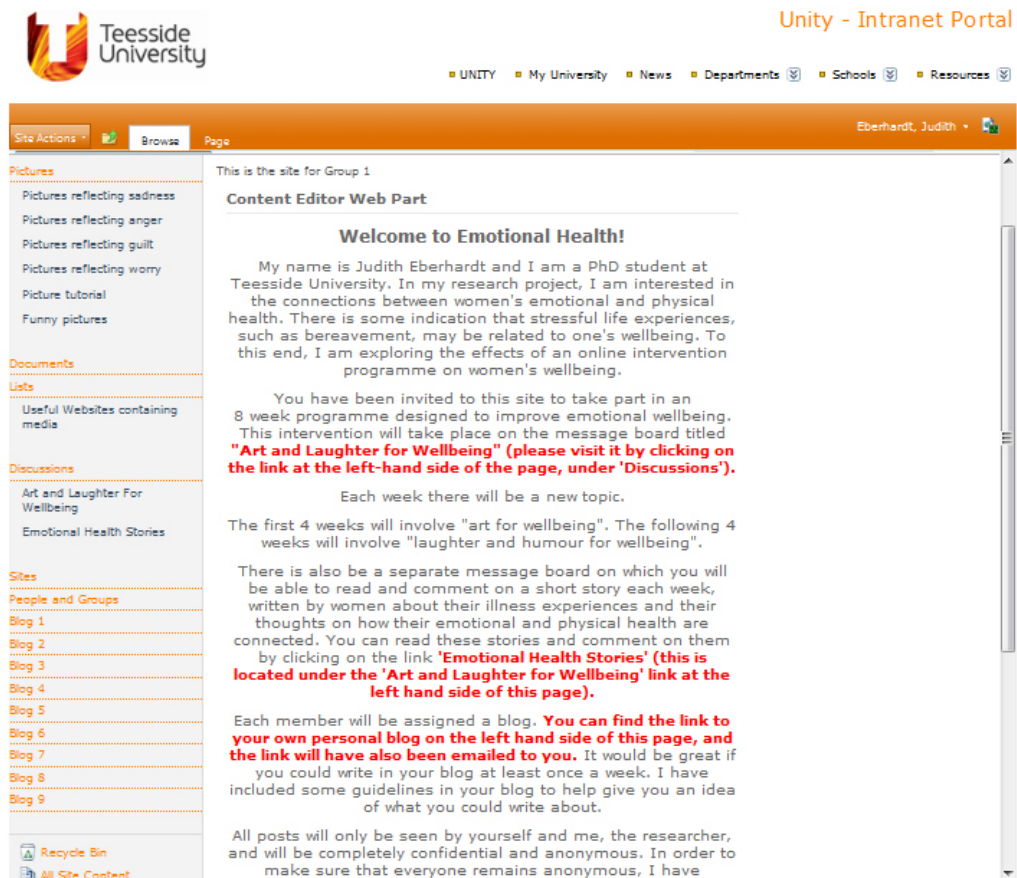
Figure 3

Example of a Blog
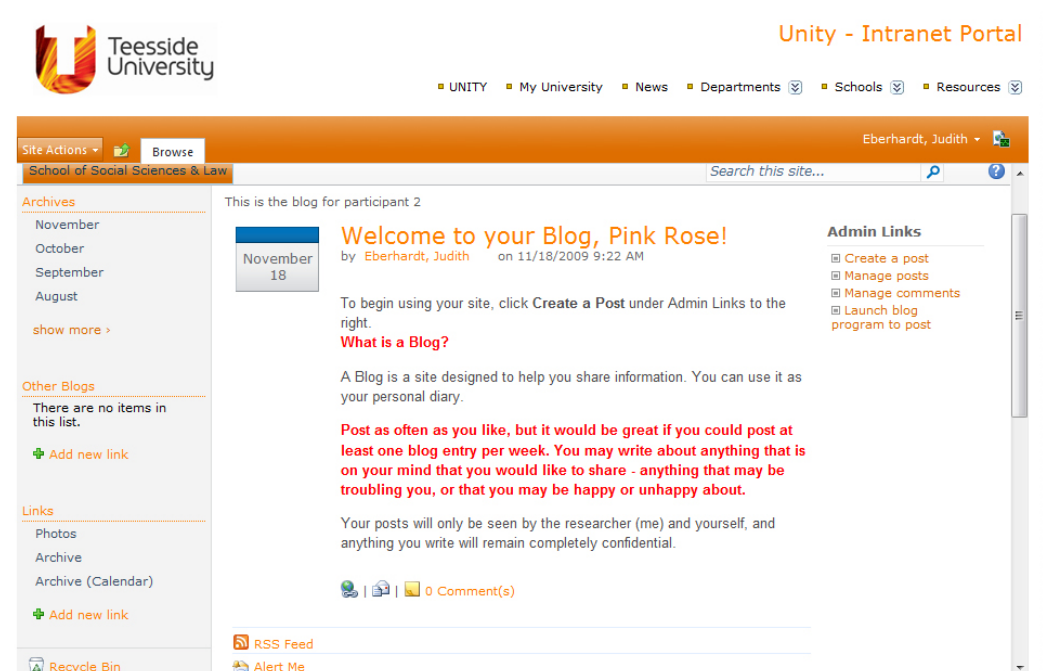
Figure 4

Example of an 'Art and Laughter for Wellbeing' Message Board

Figure 5

Example of an 'Emotional Health Stories' Message Board

Figure 6

Example of a Picture Library
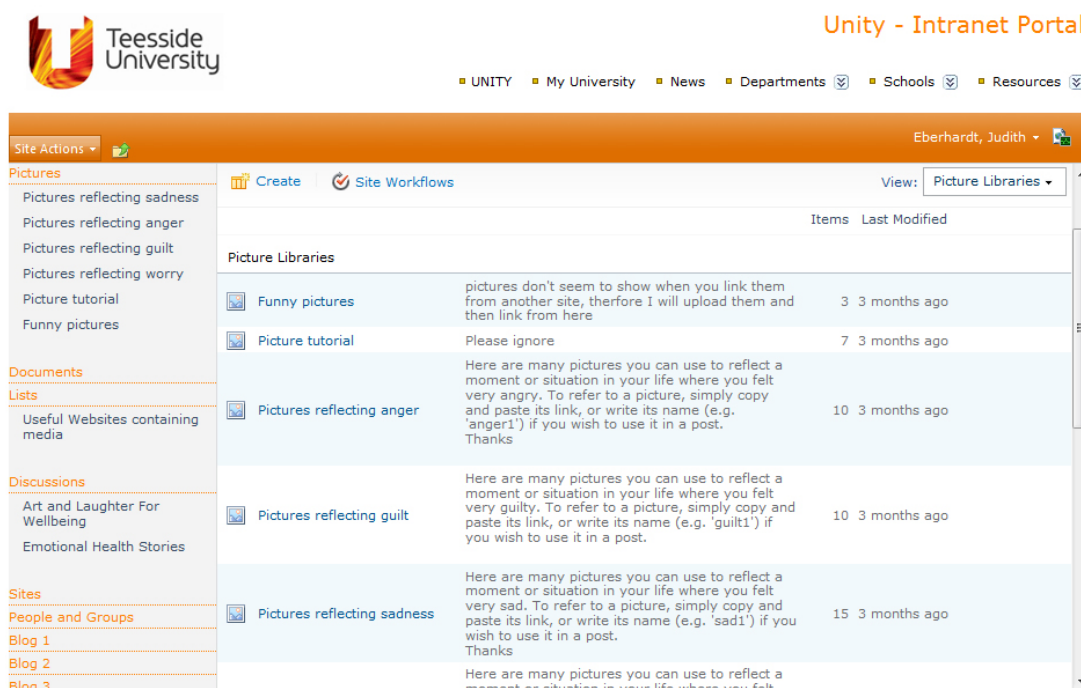
Figure 7

Example of a Link Library
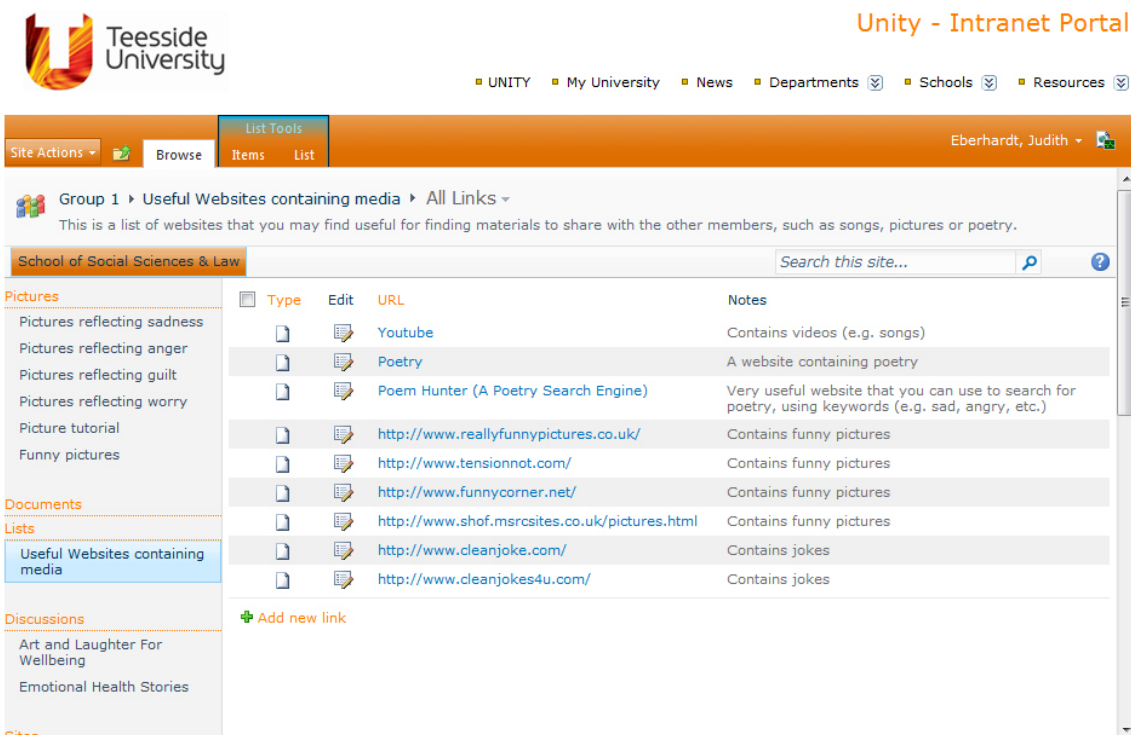
Because the Web site was located on the University intranet, it was only accessible to those who had been granted access by the researcher. Visitors needed to have a University IT account to gain access to the Web site, and furthermore needed to be added as site members by the researcher. For this purpose, University associate IT accounts were created. These were accounts for individuals who are external to the University, but are affiliated with the University in some way (e.g. consultants, visiting lecturers or, in this case, study participants). Each participant was assigned an associate account and provided with a user-account number and password, which they had to enter into a screen before they could gain access to the sub-site they had been assigned to.

Participants first completed the psychological screening form, which assessed their eligibility for the study and measured the dependent variables and other variables of interest (see Chapter Five). Upon completing the screening form, each woman was e-mailed her individual user number and password, along with instructions on how to access the site.

7.6.1 Pilot Study 3: Web Site Evaluation

In order to assess the Web site's perceived ease of use (EU) and participants' enjoyment of it (IM), four pilot sites were created as sub-sites of the main Web site. Each contained an individual element of the CEPB: Pilot Site One had a message board entitled 'Art for Wellbeing'; Pilot Site Two had one entitled 'Laughter for Wellbeing'; Pilot Site Three contained one entitled 'Emotional Health Stories'; and Pilot Site Four contained empty blogs. It is important to note that this design did not mirror the design of the main study web site, where two or more elements were cobined on each sub-site. The inclusion of just one element of the CEPB on each pilot site served the purpose of testing each element separately, before they were combined on the main site. The home page of each pilot sub-site included a text explaining the purpose of the study, as well as links to the message boards or blogs.

Twenty-three undergraduate and postgraduate students at the School of Social Sciences and Law and the School of Health and Social Care were recruited to participate in the pilot study, and assigned randomly to one of the four sites. It was necessary to recruit from a population that already had a Teesside University IT account, because at the time when the pilot study was conducted, only individuals with such an account could access the study Web site. It was only for the main study that access to the Web site for individuals outside of the University was made possible through the creation of associate accounts (see Section 6.6).

On Pilot Sites One, Two and Three, each participant was emailed the site link and asked to write at least two postings. Each message board contained four topics. The first was a 'Welcome and Introduction' topic, asking each participant to introduce themselves to the group. The second was a topic containing a picture tutorial showing how to create a posting. The third and fourth were two topics which were in line with the planned intervention: on the 'Art for Wellbeing' message board, participants were asked to post a picture, poem or music reflecting the saddest moment in their lives, and one reflecting the angriest moment in their lives, while on the 'Laughter for Wellbeing' message board, on which also two test topics were placed, participants were asked to post a humorous picture and a joke. Participants on Pilot Site One were provided with a picture library as described above. They were asked to post either a link to the picture that they wished to use, or embed the picture in their posting. They were also given the option to share files of their own which were neither in the picture library nor on the Internet. Participants were asked to indicate why they had chosen this particular picture, poem or piece of music, what situation it reminded them of, how they had dealt with the situation at the time, and if they felt that they could have dealt with it in a better way.

On Pilot Site Three the researcher placed two of the autobiographical accounts. Participants were instructed to read them and give their opinions on these accounts, as

well as indicating if they recognised themselves in these stories at all. Pilot Site Four differed from the other three pilot sites in that it only contained a blog for each participant, and no message board. Each blog included instructions on how to create a blog entry, and asked participants to create at least two blog postings. After they had created these, they were emailed a link to an online evaluation questionnaire which had been set up by the researcher using the online survey tool Surveygizmo (*www.surveygizmo.com*); see Appendix J for the questionnaire. It measured demographic variables, participants' Internet use and experience, as well as perceived ease of use and intrinsic motivation to use the pilot site.

Out of the 23 participants recruited for the study, 15 participated (nine females and five males). The mean age was 28.14 years (*SD* = 8.25). Participants were randomly allocated to one of the four sub-sites. Although the main study was only going to include women, men were included in this pilot study to determine whether there were any gender differences in terms of Web site usability. There is evidence to suggest that when evaluating a Web site, men tend to engage in cognitive appraisals, referring to evaluations based on beliefs and knowledge structures, while women tend to engage in affective appraisals based on emotions (Lee and Kozar, 2009). It was of interest how this would affect participants' acceptance of the site, although it needs to be acknowledged that the sample was small and therefore results needed to be interpreted with caution.

Fifteen participants created a total of 30 postings (two postings per participant). No information was available on the reasons for non-participation of the other eight individuals who had signed up for the study.

On Pilot Site One, participants wrote about bereavement experiences, and stressful life experiences that were associated with feeling angry. All participants provided Web links to music which for them reflected these angry and sad experiences. One participant also

shared a poem which she felt reflected her grief. On Pilot Site Two, all participants supplied funny pictures and jokes which had been found on the Internet. On Pilot Site Three, all participants offered their opinions on the autobiographical accounts. Finally, on Pilot Site Four, all participants created two blog postings. All 15 participants completed the evaluation questionnaire.

Descriptive statistics were obtained for the data using SPSS for Windows Version 16, and correlations between intrinsic motivation (IM), perceived ease of use (EU), Internet experience and Internet use were computed. Content analysis was performed on the comments left by participants to the open-response questions included in the questionnaire.

Table14 displays demographic characteristics of the sample. Seventy-nine percent of participants were White and had a partner as well as a higher education degree. Fifty-seven percent were Christian and 79% were employed.

Table15 displays descriptive statistics for EU and IM of each pilot sub-site. Pilot site Three emerged as the sub-site with the highest mean EU (M = 4.38, SD = .43) and the sub-site which participants enjoyed using the most (M = 4.33, SD = .47). Pilot site Two had the lowest mean EU (M = 3.42, SD = .63) and lowest IM (M = 2.89, SD = .69). The overall mean EU (M = 4.00, SD = .80) and overall mean IM (M = 3.76, SD = .97) gave reason to believe that the sub-sites were generally easy to use and participants found them moderately enjoyable to use.

A Mann-Whitney U test was conducted to evaluate whether there were any differences between men and women in EU and IM of the pilot sites (see Table 16). The results of the test were significant, z = -2.90, p < .01 for both variables. Women had an average rank of 89.00 for EU and 89.50 for IM, while men had an average rank of 16.00 for EU and 15.50

for IM. This shows that women on average found the site easier to use than men, as well as finding it more enjoyable. It is important to bear in mind that the main study was going to involve an entirely female sample. The detected differences between male and female participants suggest that the intervention Web site would indeed be suitable for the intended population in terms of its usability.

Table 14

Demographic Characteristics of Pilot Study 3 Sample (*N* = 15)

Demographic Variable		*M*	*SD*	Minimum	Maximum
Age (years)		28.14	8.25	20	53
					Percentage of Sample
Marital status	Single				29%
	Married				14%
	Partner				43%
	Divorced				7%
	Other				7%
Ethnic origin	White British				43%
	White Other				36%
	Black British				7%
	Black Other				7%
	Other				7%
Level of education	Higher education degree				43%
	A-levels				7%
	Higher education diploma				14%
	MSc				29%
	PhD				7%
Religious orientation	Christian				57%
	None				36%
	Other				7%
Employment status	Employed				79%
	Not employed				21%
Site type	Art for Wellbeing				27%
	Laughter for Wellbeing				20%
	Autobiographical Accounts				27%
	Blogs				27%

Note. Percentages may not add up to 100 due to rounding.

Table 15

Perceived Ease of Use (EU) and Enjoyment (IM) of Pilot Sub-Sites

Technology Acceptance Item	*M*	*SD*	Minimum	Maximum
Learning to use the website was easy.	3.33 (AW)	1.16 (AW)	2 (AW)	4 (AW)
	3.67 (LW)	.58 (LW)	3 (LW)	4 (LW)
	4.50 (AA)	.58 (AA)	4 (AA)	5 (AA)
	4.50 (BL)	1.00 (BL)	3 (BL)	5 (BL)
I found using this website enjoyable.	4.00 (AW)	1.00 (AW)	3 (AW)	5 (AW)
	3.00 (LW)	1.00 (LW)	2 (LW)	4 (LW)
	4.50 (AA)	.58 (AA)	4 (AA)	5 (AA)
	3.75 (BL)	1.26 (BL)	2 (BL)	5 (BL)
Becoming skilful at using this website was easy.	3.67 (AW)	.58 (AW)	3 (AW)	4 (AW)
	3.33 (LW)	1.16 (LW)	3 (LW)	4 (LW)
	4.50 (AA)	.58 (AA)	4 (AA)	5 (AA)
	4.50 (BL)	.58 (BL)	4 (BL)	5 (BL)
The actual process of using this website was pleasant.	4.00 (AW)	1.00 (AW)	3 (AW)	5 (AW)
	3.33 (LW)	.58 (LW)	3 (LW)	4 (LW)
	4.50 (AA)	.58 (AA)	4 (AA)	5 (AA)
	3.75 (BL)	1.26 (BL)	2 (BL)	5 (BL)
The website pages were easy to navigate.	4.00 (AW)	1.73 (AW)	2 (AW)	5 (AW)
	3.33 (LW)	.58 (LW)	3 (LW)	4 (LW)
	4.50 (AA)	.58 (AA)	4 (AA)	5 (AA)
	4.00 (BL)	1.41 (BL)	2 (BL)	5 (BL)
It was easy to get the site to do what I want it to do.	4.00 (AW)	.00 (AW)	4 (AW)	4 (AW)
	3.33 (LW)	.58 (LW)	3 (LW)	4 (LW)
	4.00 (AA)	.82 (AA)	3 (AA)	5 (AA)
	4.00 (BL)	1.41 (BL)	2 (BL)	5 (BL)
I had fun using this website.	4.00 (AW)	1.00 (AW)	3 (AW)	5 (AW)
	2.33 (LW)	.58 (LW)	2 (LW)	3 (AL)
	4.00 (AA)	.82 (AA)	3 (AA)	5 (AA)
	3.5 (BL)	1.29 (BL)	2 (BL)	5 (BL)
Mean EU	3.75 (AW)	.87 (AW)	2.75 (AW)	4.25 (AW)
	3.42 (LW)	.63 (LW)	2.75 (LW)	4.00 (LW)
	4.38 (AA)	.43 (AA)	3.75 (AA)	4.75 (AA)
	4.25 (BL)	1.06 (BL)	2.75 (BL)	5.00 (BL)
Mean IM	4.00 (AW)	1.00 (AW)	3.00 (AW)	5.00 (AW)
	2.89 (LW)	.69 (LW)	2.33 (LW)	3.67 (LW)
	4.33 (AA)	.47 (AA)	4.00 (AA)	5.00 (AA)
	3.67 (BL)	1.25 (BL)	2.00 (BL)	5.00 (BL)
Overall Mean EU	4.00	.80	2.75	5.00
Overall Mean IM	3.76	.97	2.00	5.00

Note. Responses measured on 5 point Likert scale (1=strongly disagree; 5=strongly agree). AW = Art for Wellbeing (Pilot Site One); LW = Laughter for Wellbeing (Pilot Site Two); AA = Autobiographical Accounts (Pilot Site Three); BL = Blogs (Pilot Site Four).

Table 16

Mean Perceived Ease of Use (EU) and Mean Enjoyment (IM) of Pilot Web Site for Men

and Women

| | Sex | | *U* | *z* |
	Male	Female		
Mean EU	3.15	4.47	1.00	-2.90**
	(0.58)	(0.40)		
Mean IM	2.73	4.33	0.50	-2.90**
	(0.64)	(0.53)		

**$p < .01$

Note. Standard deviations appear in parentheses below means.

Table 17 displays correlations between Internet use, Internet experience, confidence

using the Internet, EU and IM. Significant positive correlations emerged between

perceived EU and IM ($r = .81$, $p < .01$), Internet experience and confidence using the

Internet ($r = .91$, $p < .05$), and the average weekly number of hours participants spent

using the Internet and the average weekly number of times they used the Internet ($r = .55$,

$p < .05$). Thus, the easier it was for participants to use the Web site, the more they felt

intrinsically motivated to use it. Participants were likely to feel confident using the Internet

soon after they began using it, and the more hours they spent online in a week, the more

frequently they accessed the Internet in a week.

Significant negative correlations emerged between confidence using the Internet and the

average weekly number of times they used the Internet ($r = -.73$, $p < .01$), confidence

using the Internet and the average weekly number of times they used the Internet ($r = -$

$.67$, $p < .01$), and Internet experience and the average weekly number of hours they used

the Internet ($r = -.55$, $p < .05$). Thus, the more recently participants had first felt confident

using the Internet, the less time they spent online; the more recently participants had first

felt confident using the Internet, the less they used the Internet in a week; and the more recently they had started using the Internet, the less time they spent online.

In total, seven comments were left by participants, addressing issues related to EU and IM. One participant remarked that she found navigation of the site difficult. Another pointed out that it was unclear to her how to insert a hyperlink or image. A third comment concerned the posting of messages, with the participant remarking that it could have been more obvious where one was supposed to write their replies. A fourth participant stated that she found the Web site easy to use, even for beginners. Regarding enjoyment of the sites, there was one negative comment, with a male participant stating that he found it grey, dull, not pleasurable, and that he did not feel motivated to explore it. However, because the mean IM for his particular sub-site (Pilot Site Four) suggested that participants overall experienced the site as moderately enjoyable, this participant's experience was most likely an exception.

A practical suggestion was made by a participant who had been assigned to Pilot Site Two ('Laughter for Wellbeing'): he proposed that links to joke pages be provided, in order to facilitate the sharing of humorous material. It was this comment which prompted the first improvement to the intervention Web site for the proper study: the inclusion of link libraries. Secondly, an attempt was made to improve ease of use by making sub-sites visible in the side-bar menu. Thirdly, the home page text was modified to include detailed explanations of how to find the various message boards and blogs. Fourthly, the picture tutorial on each message board instructing participants how to create postings was modified to include more detailed guidance. (See Appendix J for the final version of this tutorial.)

Table 17

Correlations between Internet use (IU), Internet experience (IE), Confidence using the Internet (CI),

Perceived Ease of Use (EU), Intrinsic Motivation (IM), and Pattern of Internet use

	EU	IM	IE	CI	Average weekly number of times Internet is used
EU (average)					
IM (average)	.81**				
IE	-.10	.32			
CI	.06	.44	.91****		
Average weekly number of times Internet is used	.34	-.05	-.67**	-.73**	
Average weekly hours spent using Internet	.15	.04	-.55*	-.51	.55*

p <. 05. ** *p* < .01. *****p* < .0001.

7.7 Conclusion

An electronic coping-enhancement programme for bereaved women was designed which addressed the main established psychosocial factors involved in breast-cancer development. Following this, a Web site was developed on which the CEPB would take place. Perceived ease of use and participants' enjoyment of the site were established in a pilot study. The results of this pilot study were used to improve the Web site and to create its final version. The next chapter details the process of the CEPB.

CHAPTER EIGHT

RESULTS I: THE PROCESS OF THE CEPB

CONTENTS

8.1 Overview

This chapter describes the process of the Coping-Enhancement Programme for the Bereaved (CEPB). First, details of participants are given, including their reported bereavement experiences and most recent stressful life events. Participants' expectations of the CEPB are elucidated, and the extent to which women offered support to each other is explained. Subsequently, an overview is given of each week of the Emotional-Expression-and-Stress-Reduction (EESR) element of the programme, with examples of the media contributed by participants. Then, an overview of the psycho-educational element of the CEPB is given, focusing on participants' ability to identify with the protagonists of the autobiographical accounts, and on their reflections on the connections between physical and psychological health. Finally, an outline of women's usage of their personal blogs is presented.

Chapter Five detailed how a thematic analysis was carried out on participants' message board postings and blog entries. This yielded six themes and 17 sub-themes in total. In the current chapter, qualitative results are used in this chapter only to illustrate the process of the programme. A full description and discussion of the themes can be found in Appendix G.

8.2 Participants

Of the 66 women who had signed up for the programme, 32 women contributed message-board postings and used their personal blogs. Table 18 presents details on the active participants, including intervention condition (EESR, psycho-education, or both), type of bereavement, and most-stressful life event in the past year for all active participants, as reported in the pre-intervention screening tool. The majority of losses involved parents or spouses. Some reported the death of their grandparents. Three women had lost their children, and one had lost her grandchild, while one woman had lost her dog and one had lost her cat. Regarding most stressful life events in the past year, some stated that their

bereavement had been the most stressful event they had experienced in the past year. Others reported a variety of events, such as their own or close relatives' cancer diagnoses, health problems, or problems related to work. Notably, health-related issues dominated.

Table 18 also shows which of the participants who were active on the programme Web site dropped out during the programme. Nine women dropped out during the course of the programme; they completed neither the post-intervention questionnaire nor the six-week follow-up questionnaire. Looking at which intervention conditions the drop-outs were in, it is evident that most dropped out of either the EESR-only condition or the EESR-and-psycho-education condition (four drop-outs each). Only one woman dropped out of the psycho-education-only condition. It is important to note that a further eight women dropped out at follow-up (see Chapter Five, Section 5.6), but they are not included in Table 18, because they had at least completed the whole programme.

At the beginning of the programme, participants were asked to introduce themselves to the other group members. Having done so, participants were encouraged to contribute to the first topic(s) of the programme straightaway. For those who participated in EESR, this consisted of the first emotion to be focused on – sadness. For women taking part in psycho-education, it entailed reading the first autobiographical account. Participants taking part in both conditions were asked to do both. Additionally, all women were asked to use their personal blogs for the first time. In the following, quotes are used from participants' transcripts containing their message-board postings and blog entries (see Appendix J).

Table 18

Characteristics of Participants Active on Intervention Web Site

Username	Age	Intervention Condition	Type of Bereavement	Most Stressful Life Event in the Past Year	Dropout?
Green Daisy	51	EESR	Death of father	Death of father	Yes
Red Daisy	63	EESR	Death of father	Becoming a carer for her mother	No
Orange Daisy	40	EESR	Death of grandparents	Two of her adult children moving back home	Yes
Yellow Daisy	50	EESR	Death of father	Deterioration of son's Duchenne Muscular Dystrophy	No
Blue Daisy	64	EESR	Death of mother	Hysterectomy	Yes
White Daisy	30	EESR	Death of grandfather	Coping with mother's cancer diagnosis	Yes
Purple Daisy	72	EESR	Death of husband	Meeting a potential new partner	No
Pink Fern	49	EESR	Death of mother-in-law and of father-in-law	Death of father	No
White Fern	47	EESR	Death of husband and of father	Being diagnosed with secondary breast cancer	No
Green Fern	55	EESR	Death of mother	Being diagnosed with breast cancer	Yes
Yellow Fern	74	EESR	Death of son and of husband	Death of husband	No
Purple Fern	53	EESR	Death of father	Being diagnosed with leukaemia	No
White Rose	35	EESR + Psycho-Education	Death of father	Cancer diagnosis	No
Orange Rose	51	EESR + Psycho-Education	Death of husband	Abnormal mammogram	No
Green Rose	45	EESR + Psycho-Education	Death of mother	Husband being made redundant	No
Red Rose	49	EESR + Psycho-Education	Death of mother	Constant fatigue	No

Username	Age	Intervention Condition	Type of Bereavement	Most Stressful Life Event in the Past Year	Dropout?
Orange Iris	44	EESR + Psycho-Education	Death of father	Coping with teenage daughter and associated family tension	No
Pink Blossom	41	EESR + Psycho-Education	Death of grandmother	Problems at work	No
Red Lily	53	EESR + Psycho-Education	Death of mother and of sister-in-law	Becoming menopausal	No
Yellow Blossom	50	EESR + Psycho-Education	Death of father	Death of father	No
Red Blossom	27	EESR + Psycho-Education	Death of dog	Death of dog by euthanisation	No
Pink Jasmine	51	Psycho-Education	Death of father	Having reconstructive breast surgery cancelled twice	No
Yellow Jasmine	46	Psycho-Education	Death of grandmother	Father's diagnosis of lung cancer	No
White Jasmine	43	Psycho-Education	Death of second child, aged 17 weeks	Being diagnosed with breast cancer	Yes
Purple Jasmine	59	Psycho-Education	Death of mother	Death of father	No
Blue Jasmine	42	Psycho-Education	Death of grandparents	Death of niece's son	No
Orange Holly	35	Psycho-Education	Death of mother	Being diagnosed with breast cancer	No
Purple Holly	55	Psycho-Education	Death of mother	Death of sister	No
Green Holly	65	Psycho-Education	Death of grandson, aged 12	Coping with Type II diabetes	Yes
Blue Holly	30	Psycho-Education	Death of uncle	Brother being diagnosed with bone cancer	Yes
Red Ivy	42	Psycho-Education	Loss of baby due to involuntary termination	Struggling with job	Yes
Purple Ivy	47	Psycho-Education	Death of grandparents and of cat	Undergoing radiotherapy	No

8.2.1 Expectations of the CEPB

In their introductory posting, many participants wrote about their expectations of the CEPB. Primarily, these entailed hopes of receiving support as well as helping others in a similar situation. Where individuals expected to gain something from the programme, they hoped to receive support with stress-coping or bereavement-coping. Participant Red Daisy had recently become a full-time carer for her elderly mother and wrote:

> *Perhaps I can pick up some tips on coping with my changed life from reading of the experiences of others visiting this forum.*

(Page 1, lines 22-23)

Another participant hoped to get the opportunity to talk about losing her father:

> *There was much I needed to say to my father in the last few months of his life, that because of his terrible condition, heart failure and kidney problems I could not bring myself to add to his hurt. Taking part in this project may help me in that respect. I can at least get a few things off my chest.*

(Purple Jasmine, page 2, lines 40-43)

Pink Blossom wished to come to terms with her grandmother's death:

> *I was very close to* [my grandmother] *and I know I have never fully come to terms with her death. Maybe contributing to this research will help.*

(Page 1, lines 9-11)

Although many women had signed up for the programme with the hope of obtaining support with their grieving process or with stress coping, two women voiced their desire to help others in a similar situation to theirs through their participation. Yellow Jasmine explained:

> *I'm looking forward to taking part in this research and maybe helping others in the future.*

(Page 1, lines 16-17)

Yellow Blossom similarly stated:

I hope taking part in this might help as other people will understand more about the

effects of bereavement.

(Page 1, lines 14-15)

These women hoped that their contributions would help lead to new knowledge, which would be of benefit for others in the long run.

Yellow Fern needed support with grieving for her late husband, but she hoped to extend the same support to others:

My reason for joining this project is to help me through the grieving process and

hopefully I may be able to support others in the same or different circumstances.

(Page 2, lines 31-33)

Thus, the expected benefits of the CEPB included both giving and receiving support. It has been observed in research on Internet support forums that some users tend to give advice and support rather than receiving it, thereby facilitating communication among group members (Winefield, 2006). There appears to be a desire for some individuals to support others, which is clearly a valuable asset for a programme designed to increase social support.

8.2.2 Mutual Support

In line with expectations voiced at the beginning of the programme, some participants also provided and received social support from each other while interacting on the project Web site. Several women made efforts to reach out to other participants and offer them emotional support through their message board postings. Pink Fern commented on another participant's posting:

230

Hello White Fern, I'm Pink Fern. I wanted to say to you how very sorry I am for your loss. I can't imagine how you coped with it all. It does sound like you had a wonderful support system around you. I am so glad you have found someone else he sounds to be a lovely man and good friend.

(Page 2, lines 39-42)

White Fern reached out to her fellow group members in a similar way:

Hi Yellow Fern and Green Fern. So so sorry for your losses. They are both extremely sad.

(Page 6, lines 120-121)

Yellow Fern thanked another woman for the support she had given her, and tried to reciprocate:

Thank you for your message, you certainly must have had a tough time.

(Yellow Fern, page 6, lines 137-138)

Warm, supportive messages and offering mutual support seem to be characteristics often found in Internet support groups (Sullivan, 2003; Winefield, 2006). Furthermore, some users tend to assume the role of 'volunteer emotion workers', giving advice and support rather than receiving, and thus facilitating communication (Winefield, 2006). Notably, however, in the present study such behaviour was found in only two of the nine intervention groups. In the remaining groups, supportive interaction between group members was not observed. Thus, the majority of participants were not able to benefit from support rendered by other members; however, they did receive support and empathic understanding from the facilitator, which may have at least partly compensated for the lack of mutual support among group members.

8.3 Emotional Expression: Art for Wellbeing

As detailed in Chapter Seven, the EESR element of the CEPB entailed 'Art and Laughter for Wellbeing', which focused on 'Art for Wellbeing' for the first four weeks, and 'Laughter for Wellbeing' for the final four weeks. Four emotions were focused on as part of 'Art for Wellbeing': sadness, anger, guilt and worry. Participants were asked to contribute media in the form of pictures, poems or music, which conveyed a time in their lives when they had experienced these emotions very strongly. Furthermore, they were asked why they had chosen that particular picture, poem or song; what situation it reminded them of; how they had dealt with that situation; and whether they felt they could have dealt with it in a better way.

Participants could choose pictures provided on the Web site, or contribute pictures of their own. They could refer to a link library on the site for links to poem search engines, or contribute their own poems. A link to the Web site Youtube (*www.youtube.com*) was included in the link library, which participants could use to search for music.
Once women had chosen a picture, they either embedded it in their postings or included a hyperlink to the picture. When poems were selected, participants copied and pasted them into their postings. Since videos could not be embedded into postings due to restrictions imposed by Microsoft SharePoint, participants had to use hyperlinks in case they wished to share music they had found on Youtube or similar Web sites. In the following, examples are given of the media which participants shared.

8.3.1 Week One: Sadness

It quickly became evident for all groups receiving EESR that they were willing to write about their experiences and to use pictures, poems or music to represent the emotions they had felt, or were feeling, as a result of these experiences. The Topic for Week One was sadness. All three types of media were used by participants to represent this

emotion. For example, Orange Rose used a picture of a sunset, taken from the picture library. She wrote:

> *I've chosen the sunset picture [...], as it reminds me of my late husband. He used*
>
> *to love going to remote country pubs regardless of how far we would have to drive.*
>
> *I enjoyed our time together, as it was rare, because he worked so hard."*

(Page 1, Line 15-18)

Red Rose contributed a picture she had found on the Internet independently, without using the picture library. She wrote:

> *A sad moment in my life was 26 years ago when I had a miscarriage, it was the*
>
> *sort that the baby dies but isn't expelled straight away. My doctor advised me to*
>
> *stay in bed to try and 'save' the baby. This wouldn't happen today and you would*
>
> *be sent for scans. This photo reminds me of the baby I didn't have.*

(Page 2, lines 35-39)

When asked how she had coped with this event, she replied:

> *I was quite young at the time and I dealt with it by trying to replace the baby I had*
>
> *lost as to me it was essential to be pregnant at the time the baby I lost would have*
>
> *been born. I was pregnant again very soon after and pregnant at the time when it*
>
> *would have been born, but in hindsight I'm not sure it was the right thing to do.*

(Page 3, lines 44-48)

Green Rose chose to contribute a poem, rather than a picture:

> *Hi I have chosen to share this poem by Grace Ellery Channing. It reminds me of*
>
> *how I feel about my son who is in the army and due to go to Afghanistan in a few*
>
> *months. I am not coping very well and it makes me sad because he is so young*
>
> *and I keep crying when I see all those coffins carrying (mostly) young men. I think*
>
> *the poem is really evocative and could apply to mums, girlfriends, wives or*

> *daughters of serving members of the forces, even though it would have been*
>
> *written a long time ago.*

<div align="right">(Page 1, lines 19-37)</div>

Red Blossom chose a song to represent a sad time in her life. She wrote:

> *I chose:*
>
> *Creed 'Wash Away Those Years'*
>
> *http://www.youtube.com/watch?v=ItaOrt7aT4Y*
>
> *I have chosen this because the lyrics remind me of the abuse in my past and this*
>
> *makes me think of the moment when I finally broke down because of keeping it all*
>
> *in. I just cried and cried, for a few days, and then tried to kill myself because I*
>
> *didn't know how else to cope with the feelings I had.*
>
> *I could've definitely dealt with the situation much better but at the time I just didn't*
>
> *know how and didn't feel I had the support to do anything different.*

<div align="right">(Page 2, lines 29-39)</div>

The above examples illustrate how participants used a variety of media to represent sad times in their lives. These provided a starting point for them to write about their experiences; the researcher then probed their responses for further elaboration or clarification, thus providing women with the opportunity to express the emotions they experienced as a result of this event.

8.3.2 Week Two: Anger

In Week Two, participants were asked to contribute a picture, poem or song representing a time in their lives when they had been very angry. Red Lily contributed a picture from the picture library to represent an angry time in her life. She wrote:

I had a bad time at school at the ages of 7, 8 & 9. My father died when I was 7 and my mum moved us all into my grandparents house. I was put to the local school. I was put in dyed clothing and borrowed jumpers from a cousin. [...] Whole school surrounded me in playground and taunted me with various jibes. It got to the point where I would scream not to go to school. My mum thrashed me as did my grandmother, but I would not tell them why I didn't want to go. Even at that tender age I reckoned it was better to put up with it than tell mum, which would possibly have made situation worse.

It stayed with me for many years, only as an adult did I eventually tell my mum why. When I moved to a new school at 9 everything was fine.

(Page 7, lines 141-153)

Pink Blossom chose to contribute a poem, rather than a picture:

The poem This be the verse by Philip Larkin - although I hadn't heard it when a teenager - certainly sums up the root of my anger. My teenage years were a constant battle with my parents as I didn't share their views and they certainly weren't the kind to encourage healthy debate. My anger would manifest in breaking things, slanging matches and tears. I also kept a diary.

(Page 2, lines 24-29)

Red Blossom contributed a song to represent the anger she felt at being abused by her step-father:

Disturbed 'Meaning of Life'

http://www.youtube.com/watch?v=i99Smspy3T8

(Warning: Explicit lyrics)

This was the first song by Disturbed I ever heard and I found it at a time in my life when I was angry at everything. I had just left school for college and hadn't made many new friends. I'd been severely bullied at secondary school so I had a lot of

pent up anger and I was also at a point in my life where I realised my step-dad was

an abuser. [...] I tried to get back at the world by being destructive (graffiti,

damaging property, stealing etc.) but I also took my anger inward and started to

self-harm, drink etc. I wish I'd dealt with this anger better but feelings weren't

something that was discussed in our family and even though my mum saw some

of what I was going through she was too caught up in her own problems to help

me.

<div align="right">

(Page 2, lines 44-61)

</div>

However, generally fewer media were contributed to this topic than in Week One. Many women appeared to find it difficult to engage with this topic, and/or did not wish contribute any media. For example, Red Daisy wrote:

Had to think about this one as these days I don't get angry very often - had to learn

at an early age to keep my temper under control, otherwise it controlled me and

got me into trouble!

<div align="right">

(Page 3, lines 50-52)

</div>

Another woman did experience anger but was unable to express it:

I remember at times when I have been full of anger I could not express wondering

where it would go

<div align="right">

(White Jasmine, page 2, lines 43-44)

</div>

She explained how she had learned to keep her anger under control at a very young age and was made to believe that anger was a 'sinful' emotion:

I was raised in a very Christian home anger was sinful I've been told are family

don't do anger so I find it difficult to deal with especially after my marriage broke up

and I was left alone to bring up my children while my ex got on with his life I have

learned in recent years that anger is ok and have managed to find coping

mechanisms but I know that I still suppress a lot of feelings of anger and I cant

bring myself to be honest with people who have hurt me.

<div align="right">(White Jasmine, page 2, lines 39-40)</div>

These participants' accounts illustrate how for them suppression of anger was a learned behaviour, motivated by the 'reward' of escaping punishment through their parents or other authority figures; in operant conditioning terms, this constitutes passive avoidance learning (Skinner, 1953). As this behaviour pattern had been learned early on, it would have most likely been difficult to change.

Yellow Daisy also preferred to express her anger in words, without the use of media:

Not really sure about posting a picture that expresses the degree of anger. I feel

angry every day that my only child should be cursed with this dreadful disease. I

still feel anger towards the unfeeling consultant who diagnosed him.

<div align="right">(Page 2, lines 45-49)</div>

It thus appeared as though anger was an emotion which many participants felt less willing to use media to represent, than sadness.

8.3.3 Week Three: Guilt

In Week Three, the topic was guilt. This appeared to be an emotion which was pervasive in many participants' lives.

Pink Fern elected to contribute two pictures from the picture library. She wrote:

I have chosen two pictures guilt 4, the lady with her head bent down and hand on

face, looks like she feels really bad and thats how I frequently feel. I also chose

guilt 2 although the picture made me smile it highlights my main guilt. Traveling

with Guilt-trip airlines. I feel guilty that I cant support hubby like I should and get

angry at him. I feel guilty that I dont get on better with my Mum and that she

<div align="right">237</div>

doesnt like my hubby. I feel guilty that my Mum continually makes me feel bad and belittles me. I feel guilty that I didnt spend more time with my Dad when he was ill. I feel very guilty that when I felt ill the day before I lost my Baby girl I didnt follow my instinct and get the midwife out to see me. So all in all a lot of guilt but that doesnt effect me as much as some of the other emotions have and do.

(Page 9, lines 185-197)

Notably, although guilt was such a pervasive emotion for Pink Fern, she appeared to cope with it better than with sadness or with anger. In a similar vein, when asked by the researcher whether she had any ideas on how one could deal with guilt in a positive, constructive way, Red Daisy replied:

In a word - no!

I've been trying for ages and just when I think I've got it licked something kicks off and it's back again!

I've tried giving myself permission to feel guilty; I've tried to bury it by doing something physical, but it still lurks there in the background waiting to take me unawares ! I've come to the conclusion that it's part and parcel of being a woman - men don't seem to suffer with it in the same way - perhaps it's the way our brains are wired lol;lol !!

(Page 4, lines 88-97)

Red Daisy seemed to have come to accept guilt as an integral part of being a woman.

Red Blossom contributed a poem:

I've thought of a fairly recent situation: my dog was unwell but she had a vets appointment booked so I thought I'd just wait until then but the night before she became very ill [...] so I took her in as an emergency. She had to be euthanised that night. I felt guilty that I hadn't taken her sooner because maybe they would've been able to do something and I felt guilty for not noticing how ill she'd got [...].

238

Part of this poem by Caro Schubert-James ['Room in Your Heart'] *best represents my experience at that time...*

(Page 4, lines 78-104)

However, similar to the topic of anger, guilt seemed to be no easy topic for participants to engage with. For example, Yellow Fern wrote:

> [...] *has everyone found it as difficult as I have?*
> [...] *I resorted to the Oxford Dictionary and found these two definitions -*
> *'the fact of having committed an offence or crime' thankfully I do not fit into that category.*
> *'feeling of having done something wrong or failed in an obligation' again I have found it difficult to identify fully with this emotion. I am sure there must be many instances in my life where I have failed miserably.*

(Page 5, lines 106-114)

Yellow Fern thus preferred to use a dictionary definition of guilt, rather than a picture, poem or piece of music. It could be argued that she used an objective definition of guilt to distance herself from this emotion.

Purple Daisy too found it difficult to contribute to this topic:

> *I have very little comment to make, as I decided that guilt was too destructive an emotional in which to indulge! Unless it is the result of a deliberate planned action, and it seldom is in my life, I refuse to waste me and my time getting screwed up over it. If desirable/necessary/advisable just forget it and move on! Probably not very helpful, I guess??????????*

(Page 1, lines 5-9)

239

Similar to Week Two, some participants in Week Three wrote about their experiences without using media to represent their emotions. No poems or music were used by any participants to represent guilt.

8.3.4 Week 4: Worry

The topic in Week Four was worry. Similar to Week Three, some participants did not contribute any pictures, poems or music to represent times in their lives when they had been worried – they preferred to simply write about their experiences. For example, Yellow Daisy wrote:

> *I worry every day, although I try to keep it buried. I worry when my son gets a runny nose in case it develops into a chest infection, which could kill him. I worry about my husband and how long he and I can continue to 24/7 care before it causes our own health to break down further. I worry very much about the government demonisation of those of us who survive (I won't say live) on benefits. I worry about my son all the time.*

> (Page 3, lines 61-66)

Yellow Fern related her experiences as follows:

> *My most recent serious worry was when my husband died, there are so many things to deal with but my major concern was that I may not be able to stay in my current home.* [...] *Luckily over a period of weeks the financial problems were resolved.*

> (Page 6, lines 125-129)

Others, however, made use of the picture library to represent times in their lives when they had felt intensely worried. White Fern wrote about her chosen picture:

> *I have attached a picture which I feel sums up how I feel when I am worried - things zip round and round in your head and no matter how much you try you cannot stop thinking about the worry - eventually it feels like your head is fried!* [...] *My most recent big worry, when I was diagnosed for a second time, was about*

money. [...] I went on worrying for about 2 months and didnt tell anyone, not even

my husband. In the end I plucked up the courage to ask my Mum to loan me the

money to pay everything off - and I had worked out a monthly repayment scheme.

[...] Of course my main everyday worry is how my family will cope when I am not

here and I dont have an answer to that.

White Rose used a different picture to reflect on her experiences:

I chose this picture because it represents me, as someone who worries a lot. Last

year I was worrying a lot because my health was not good due to stress at work,

and husband was unemployed. I was worried about how to pay the mortgage and

bills, I was worried about my husband because the longer he was out of work the

more i worried he wouldn't get a job. I ended up very ill by the end of the year and I

wonder if this was caused by the worrying I did.

(Page 3, lines 58-64)

No poems or music were used by any participants to represent worry.

Towards the end of Week Four, the researcher created a posting entitled 'Coping with

Negative Emotions'. In this posting, the concept of adaptive ways of coping was

explained, and three adaptive ways of coping were described, as identified by Cox and

Ferguson (1997): approach coping, emotion coping and reappraisal coping. This posting

was created in order to raise awareness in participants of adaptive coping strategies. At

the same time, it was emphasised that each individual coped with negative emotions and

with stressful life events in his or her own way, and that any form of *adaptive* coping was

considered to be beneficial.

8.3.5 Summary

At the beginning of 'Art for Wellbeing', participants made use of pictures, poems and

songs to relate their emotions and experiences. As the weeks progressed, the usage of

media decreased, as some preferred to use just words to express their emotions. Most

241

found it easy to recall events where they had experienced sadness, guilt or worry; however, some members struggled to recall events where they had felt angry. Difficulties in experiencing or expressing anger are in line with 'breast-cancer prone' traits from both the Type C and the Type I personality constructs.

8.4 Stress Reduction: Laughter for Wellbeing

Weeks Five to Eight of the EESR element consisted of 'Laughter for Wellbeing', serving the purpose of stress reduction through the use of laughter and humour. At the beginning of this section of the programme, the facilitator created a posting about the physical and psychological benefits of laughter and humour, as identified through the literature review. This was done with the intention of raising participants' awareness of these benefits, and to encourage them to use laughter and humour in their daily lives.

Women were asked to contribute humorous material to the weekly topics: pictures, film clips, jokes and anecdotes. They were provided with a link library containing hyperlinks to Web sites containing humorous material. Examples of what participants contributed each week are given in sub-sections 8.4.1 to 8.4.4.

For some women, it became evident during this portion of the programme that they began to approach the source of their stress, and to contemplate alternative ways of coping. They had written about ongoing stressors at the beginning of the CEPB; during the course of the programme, they reported being able to identify the source of their stress and attempted to actively find a solution to the problem. For example, White Rose wrote about recognising the root of her stress:

> *Recent events have made me realise it is work that causes most of my stress.* […]
> *We are moving to another area so we can have same size house but half the*
> *mortgage. This means that I can stop working and plan to spend a year finishing*
> *my studies, getting my confidence back and becoming stress free, or at least less*

stress. I feel my main priority now is getting my health sorted and I've found this

[intervention programme] *fascinating. It's made me realise how bad stress can be,*

and sometimes there is nothing you can do about it, but where you can, it's worth

doing it.

(Page 7, lines 147-164)

It seemed as though participating in the intervention programme contributed to White

Rose recognising the usefulness of approach coping and attempting to use it in situations

where this was possible.

Approaching the end of the intervention programme, Green Rose, who had been writing

about ongoing financial problems, deliberated a potential solution:

I am […] *beginning to wonder if it's worth us selling this house and buying a*

smaller one, so we can have a bit more money. A bit difficult, as it's not going to

sell easily, but at least we have that option.

(Page 4, line 91-94)

Similar to White Rose, she displayed a shift towards approach coping.

On one occasion a participant approached the researcher for concrete advice on how to

reduce tension. She was provided with instructions how to perform relaxation exercises,

which she perceived as helpful:

Thanks for the [relaxation exercises]. *When I find the time to do them they seem to*

help, especially the breathing one.

(Pink Fern, page 24, lines 512-513)

This participant was thus able to make use of the advice offered by the researcher, which in turn helped alleviate her stress.

Another participant, during the course of the CEPB, wrote about her decision to integrate laughter into her daily life, in the form of laughing exercises:

> *I think I will start laughing exercises each morning, we've been given the ability for a reason, and I may as well use it more often, don't want my face to get fixed with a frown and a downward mouth as you see in some elderly people. It'll release those endorphins (I think) and strengthen my immune system (I hope!).*
>
> (Purple Holly, page 9, lines 193-197)

On the whole, most participants regarded the enjoyment of laughter and humour as an important part of life and as a useful way of relieving stress, even those who found it difficult to enjoy laughter. For some, participation in the 'Laughter for Wellbeing' element of the CEPB served as a reminder of the potential for laughter and humour to enhance their quality of life. In the following, examples are given of the humorous material which participants shared.

8.4.1 Week Five: A Funny Picture

In Week Five, participants were asked to contribute a picture which had made them laugh, using either the link library provided, or a picture of their own. Initially, technical difficulties were experienced by two women, with their chosen pictures not appearing in their postings. However, these problems were resolved by the researcher.

Orange Rose contributed a picture she had found through one of the hyperlinks in the link library:

> *I will try to add this one which I found in one of your suggested sites.*
>
> (Page 2, line 32)

Participant Red Blossom seemed to enjoy looking at humorous pictures in her daily life, and contributed two pictures of her own:

> *My computer is full of pictures I find amusing! I save them to show to friends or to look at where I need cheering up (I even printed a few to put on my walls!).*
>
> *Here are two of my faves:*

Pink Fern contributed a picture which reminded her of her late father's humour:

> *The picture* [...]*..its about safety around bears in the woods. Lots of the pictures made me laugh but I chose this one as I have my Dads warped sense of humour and he would have loved it.* [...] *it still makes me laugh...also my sons.*

However, in one group, which received EESR only, none of the members contributed any pictures. It thus seemed that some participants did not wish to contribute to this topic.

8.4.2 Week Six: A Funny Film

In Week Six, participants were asked to contribute a film clip which had made them laugh. For this purpose, they were provided with links to Web sites containing film clips. Here, once again the researcher made a start by contributing a link to a humorous clip. Remarkably, fewer participants contributed material than in Week Five.

White Rose was the only member of her group to participate in this topic, contributing a link to an advert that was amusing to her:

> *I find this clip funny, which is actually an advert but it makes me laugh everytime I see it. My husband thinks I'm mad for laughing at this!*
>
> *http://www.youtube.com/watch?v=jR7RYKPJBdo*

Yellow Daisy simply described a scene from a film which she found funny:

> *I laugh at the scene with the Chinese lady at the takeaway in "Dude, where's my car?" because it reminds me so much of my son - he asks for one thing "and then" the next etc.*

Subsequently, the researcher located a hyperlink to this particular scene, and posted it so that all group members could view it.

One participant admitted that she found it difficult to contribute to the topic because she preferred reading books to watching films or television. Yet, she listed some television and radio shows that she found amusing:

> *This one has been really hard for me and I still dont have a clip.* [...] *I cant say what one clip made me laugh but here are a few shows I do laugh at. Top Gear...when they do stupid things like make their own mobile homes!!! QI on the TV, Stephen Fry is so inteligent and fast with his replys.. The Goons on radio 7...every time they are on I chuckle no matter how many times I have heard them. I think I am more likely to laugh while reading a book or listening to an audio tape than when I watch tv.*

Altogether, although there were a number of contributions to this topic, women were less active on the 'Art and Laughter for Wellbeing' message board in Week Six than they had been in Week Five. However, participants continued to use their personal blogs (see Section 8.6), which may indicate that most chose to 'lurk' and read other members' postings, rather than posting anything themselves.

8.4.3 Week Seven: A Joke

In Week Seven, where participants were asked to contribute a joke, participation remained low, with just one or two participants per group contributing a joke; similar to Week Six, it is likely that most participants chose to 'lurk' on the message boards. Participants were provided with a list of links to Web sites where jokes could be found. Orange Iris contributed the following joke:

> *This guy sees a sign in front of a house "Talking Dog for Sale." He rings the bell and the owner tells him the dog is in the back yard. The guy goes into the back yard and sees a mutt sitting there.*
>
> *"You talk?" he asks. "Yep," the mutt replies. "So, what's your story?"*
>
> *The mutt looks up and says "Well, I discovered this gift pretty young and I wanted to help the government, so I told the CIA about my gift, and in no time they had me jetting from country to country, sitting in rooms with spies and world leader, cause no one figured a dog would be eavesdropping. I was one of their most valuable spies eight years running. The jetting around really tired me out, and I knew I wasn't getting any younger and I wanted to settle down. So I signed up for a job at the airport to do some undercover security work, mostly wandering near suspicious characters and listening in. I uncovered some incredible dealings there and was awarded a batch of medals. Had a wife, a mess of puppies, and now I'm just retired.*
>
> *"The guy is amazed. He goes back in and asks the owner what hewants for the dog. The owner says "Ten dollars." The guy says he'll buy him but asks the owner, "This dog is amazing. Why on earth are you selling him?" The owner replies, "He's such a liar."*

(Page 4, lines 71-83)

Pink Blossom found it easier to contribute to this topic than the previous one, sharing a joke she had been told by her son:

With having a 6 year old who likes jokes, this thread will be easier than the last one!

What is brown and sticky?

A stick!

Never fails to get some reaction which always makes me laugh!

<div align="right">(Page 4, lines 71-76)</div>

Overall, women continued to be less active on the 'Art and Laughter for Wellbeing' message board in Week Seven than they had been in the first six weeks. Yet, they continued to use their personal blogs.

8.4.4 Week Eight: A Funny Memory

In the final week of 'Laughter for Wellbeing', participants were asked to contribute a funny memory or personal anecdote. Here, the level of participation remained the same as it had over the past three weeks, with one or two members per group contributing – usually the same members who had contributed over the past few weeks.

Red Lily wrote:

At the age of about 3 I went "missing". My parents were beside themselves, which I'm sure wasn't funny at the time. However, my father ran around outside & my mum inside searching cupboards etc, both shouting my name. I didn't answer. I was too busy hiding on the bottom tray of a tea trolley watching them whiz back & forth. It wasn't until my mum heard a little giggle that I was found. It's really funny looking back at it and my mum said they laughed for ages afterwards at my sheer cheek.

<div align="right">(Page 10, lines 189-195)</div>

White Rose remembered a funny event in her life, which she associated with a time when she was not feeling stressed:

A funny memory that sticks in my mind was the day after I got married abroad, friends that had come out with us went for a meal with us. It came to paying the bill, and I only had a $50 note and was asking if anyone had change, we were trying for about 10 minutes to split the bill so everyone could contribute the correct amount. Suddenly a friend said I can do it, I've got enough to make sure everyone gets change, and then asked if anyone had change for $50! At the time we all started laughing so much, a combination of late night the previous night, and the alcohol we had drank. Although the incident wasn't that funny, we all couldn't stop laughing for ages. The more we tried to stop the more we laughed.

I think this sticks in my memory because it was around a good time in my life when I wasn't stressed, and everything was good. It was also shared with close friends.

<div align="right">(Page 5, lines 94-106)</div>

However, one participant admitted that she found it difficult to contribute a humorous anecdote, as participants had been asked to do. She found that this worsened her mood, writing in her blog:

Just thinking about trying to find something funny to report has had the opposite effect and pulled me even further down this week as it's made me realise just how long it is since I found anything even mildly amusing.

<div align="right">(Red Daisy, Page 17, lines 392-394)</div>

It is possible that other participants may have felt similarly, which would explain their failure to participate in the 'Laughter for Wellbeing' topics.

8.4.5 Summary

The 'Laughter for Wellbeing' portion of the EESR element generally attracted fewer contributions, and was associated with less participation than the 'Art for Wellbeing' portion. Some participants reported difficulties engaging with the topics. However, those who contributed did so regularly until the final week.

8.5 Psycho-Education: Autobiographical Accounts

Chapter Seven elucidated that women who took part in psycho-education were provided with autobiographical accounts of breast-cancer sufferers who exhibited one or more of the psychosocial factors involved in the aetiology of breast cancer. Seven accounts were presented over seven weeks, with the final week of the programme being reserved for a review of and reflection on these accounts. For each account, women were asked whether they thought it plausible that the protagonist's breast-cancer development was connected to psychosocial factors, and whether they could recognise themselves in the accounts. It was found that most participants agreed with the notion of a connection between psychosocial factors and breast-cancer aetiology, as posited in the accounts. Moreover, some women suggested that more effort should be concentrated on applying this knowledge to health interventions. Yellow Jasmine, for example, stated:

> *Maybe if there was more help for people with real stress then possibly there may be less cases of cancer. Of course there are lots of contributing factors to someone getting cancer and not just stress but it would be good to help to alleviate that problem from someone's life.*

(Page 5, lines 102-105)

While Yellow Jasmine's focus was on the primary prevention of cancer, which fits with Grossarth-Maticek's (2008) recommendations to target psychosocial factors (e.g. stress) in preventative cancer interventions, Purple Holly thought it useful to take a holistic approach to secondary prevention:

> *I really do think it about healing the whole of oneself, not just the isolated part in question. Louise Hay does say that disease, or as she calls it, dis-ease in the body, is caused by our attitude to life and language.*

Many participants could identify with the protagonists (see Sub-Section 8.5.2). A number of women, however, voiced scepticism over this connection (see Sub-Section 8.5.2). In the first three weeks, many participants commented on the autobiographical accounts, but in virtually all groups, participation started to decrease in Week Four. However, participants kept accessing the Web site to use their blogs (see Section 8.6), which leads to the assumption that they may have still visited the message board, but chosen not to contribute to the discussions.

8.5.1 Identification with the Protagonists

As many had experienced the significance of the connectedness of psychological and physical health themselves, it was not surprising that a lot of participants could identify with the protagonists of the autobiographical accounts presented to them. These women felt that the accounts accurately reflected what they themselves believed about the relationship between physical and psychological health. Green Rose affirmed this:

> *I think that Patty's cancer could be linked to suppressed emotions. I think that when you are really deep down scared of something you do clam up and keep it inside and that isn't good for you.*

This view was shared by Purple Holly:

> *Who's to say whether it is possible or not? The mind works in mysterious ways and is extremely powerful. It seems to me that if Patty feels she has in some way suppressed her feelings and as a result developed cancer, then she has. I guess what each of these emotional stories is showing, that given the right*

> *circumstances, anyone can get cancer, and not necessarily from a bereavement*
>
> *[…].*

Pink Jasmine's experience resembled that of the protagonist Patty Coldwell very closely:

> *Oh yes, I recognised myself* [in Patty Coldwell's story]*! I too was diagnosed with breast cancer at the age of 47, and have often wondered since if it was either a punishment for my sins or a reaction to the stressful events leading up to it.*

Yellow Jasmine speculated that Patty had been living a dual life, with an 'inner' and an 'outer' self:

> *I think that it is really sad when a person can't be themselves all of the time. […] As with lots of people Patty has experienced living a dual life - the outwards Patty and the inner Patty. This kind of lifestyle isn't healthy as it puts too much pressure on the person being the "two people". [...] I do believe that her lifestyle could have contributed to her illness. Her mind and body have been under tremendous strain for a long time and she hasn't been able to find inner peace with herself and her own feelings.*

Her distinction between inner and outer self can be found in Goffman's (1959) distinction between public and private self as part of self-presentation theory, or in Levinas' (1968; cited in van Wersch, Forshaw and Cartwright, 2009) concept of the 'en-soi' (inner self) and 'pour-soi' (social self). It is thinkable that the discrepancy between inner and outer self would be particularly strong for the 'breast-cancer prone' individual, who is concerned about hiding her true emotions from others, to appease and conform to others' expectations. It is likely that this discrepancy could lead to considerable psychological discomfort in the long run.

8.5.2 Reflecting on the Connections between Physical and Psychological Health

Despite many participants being convinced of the existence of a connection between physical and psychological health, and having experienced the same first-hand, a number of participants voiced their scepticism or uncertainty of the notion of a causal link between psychosocial variables and illness. For example, commenting on an autobiographical account, Purple Ivy did not believe psychosocial factors to have played a major role in the aetiology of her breast cancer:

> *I do not think the emotional trauma is the sole or even the main reason for my*
>
> *having breast cancer*.

(Page 1, lines 24-26)

Another participant questioned the direction of the relationship, rather than the existence of the relationship itself:

> *I think it unlikely that cancer growth is linked to or exacerbated by physical stress,*
>
> *as a "scientist" somehow that doesn't sit right with me* […]*. On the other side of*
>
> *the fence though I do think that a positive attitude can be a strong support in*
>
> *getting better.*

(Red Ivy, page 2, lines 25-29)

Still, it was clear that although she had her doubts regarding the influence of stress on the aetiology of cancer, she allowed for the influence of a positive attitude on recovery. This is in line with the concept of the 'fighting spirit' (see Chapter Two), which has been found to be associated with an increased chance of survival in breast cancer (Greer et al., 1979).

White Rose too was sceptical of a possible connection between breast cancer and stress:

> *This is interesting that all the cancer patients* [in these autobiographical accounts]
>
> *found they suffered stress before their diagnosis, but this could be a coincidence.*
>
> *The majority of people have stress in their lives and could relate that to their*
>
> *cancer, although it does say specifically within the last 18-24 month time frame.*

253

Similarly, commenting on a health-related autobiographical account, Orange Holly wrote:

> *Although it may be technically possible that the level of mental stress arising for an abrupt death of a very close loved one may be a contributory factor to physical health; I think there are so many different factors at play in relation to cancer (e.g. physical health to start, family history, etc.) that we aren't provided with in this story to make a valid judgement as to whether this was the biggest factor or not. I believe that if there was continued mental stress over the years prior to the breast cancer diagnosis then I would concede that there could be a contributory factor (although not necessarily all arising from the death of her husband).*

There were thus a number of women who were doubtful of the influence of psychosocial factors on the development of breast-cancer. It appeared that these women subscribed to either a biomedical or at the very least a simplistic view of health and illness. This did not allow for the recognition of the complex interplay between biological, psychological and social factors in the production of health and illness (Engel, 1977).

8.5.3 Summary

Overall, participants engaged actively with the autobiographical accounts, although participation began to wean from Week Four onwards. Most agreed with the notion of psychosocial influences on breast-cancer development, and some advocated a holistic approach to the treatment of disease. However, a few women voiced their doubts. Still, many participants were able to identify with the protagonists of the accounts, recognising parallels between the protagonists' and their own behaviour.

8.6 Blogs

As explained in Chapter Seven, all participants were provided with a personal blog, which was only accessible by themselves and the researcher. They were encouraged to use their blogs at least once a week, and the reminder emails encouraging women to visit the CEPB Web site and to contribute to the topics also contained reminders to use the blogs. All participants who contributed to the message boards also used their blogs. In many cases, blogs were used more often than the message boards. The facilitator interacted with all participants through their blogs, probing for clarification, offering support and empathic understanding.

There were issues that women did not feel comfortable discussing on the message boards, using their blogs to write about them instead. These were often issues that participants felt profoundly guilty about. For example, at the beginning of the programme Orange Daisy wrote about how she had left her husband and children, a decision she was still guilt-ridden about, but did not mention on the message boards when guilt was being discussed:

> *6 years ago I left my family home and moved 250 miles away to live apart from my loved ones, I left behind a husband and three children.* […] *My guilt stems from the fact that I could never make it better for* [my children] *even when I should have and could have improved their lives by actually being there I wouldn't make that change, always claiming self preservation as the reason for staying so removed. I still have overwhelming moments of crushing guilt, that I just cannot cope with, I have somehow learned to live with them, I just seem to push them to one side and get on with things knowing that if I didn't I would become totally frozen.*

(Page 1, lines 18-51)

Even if women did write about very personal issues on the message boards, they often used their blogs to reflect further on that experience. One participant, for example,

reported an emotional response after writing about her stillborn child on the 'Art and Laughter for Wellbeing' message board:

> *Have just finished introducing myself and posting a picture to reflect my sad memory. I chose my baby girl because she is frequently in my thoughts and I have many regrets about it. Its brought a lump to my throat, my heart is pounding and my eyes feel gritty with unshed tears... out of all my bereavements this one still hurts and causes me pain. I still miss both my in-laws and my darling Dad but my baby still hurts the most.*
>
> (Pink Fern, page 19, lines 388-393)

Sometimes, reasons for women's non-participation on the message boards became evident in their blog entries. For instance, in Week Two, Orange Daisy wrote about how she had avoided contributing a personal memory relating to anger, because she was concerned that this would exacerbate her ongoing feelings of anger:

> *I deliberately didn't post last week because the subject was Anger and I've been so cross just lately its unreal. And every time I come on here and start writing the words seem to spew from my fingertips rather like now! So here I stop for today.*
>
> (Page 3, lines 55-58)

In a similar vein, two women explained how they avoided using the message boards or blogs when they were already experiencing negative emotions, because they felt that this would exacerbate their negative feelings:

> *I had put off posting this week as I was really wanting to be more positive* […]*.*
>
> (Green Rose, page 6, line 120)

Pink Fern remarked in one of her blog entries:

Sorry not to have been blogging like I should…stuck my head in the sand and waited for things here to improve.

(Page 29, lines 691-692)

It thus seemed that there were some temporary negative effects associated with emotional expression through blogging and message-board postings. This is most likely due to the temporary deterioration observed in individuals who write about traumatic and distressful events, as discussed in Chapter Four. Still, it did not deter these participants from returning to the Web site to continue their participation, indicating that overall the perceived benefits most likely outweighed the discomfort experienced following their contributions.

Apart from writing about painful past experiences, women chronicled their daily lives, recounting problems as well as positive experiences. One participant, Orange Holly, had just been diagnosed with breast cancer and used her blog to document her journey. For most, their blogs served as diaries, but due to the researcher commenting on every posting, they were aware of and, in some cases, actively sought the facilitator's input and advice. Hence, the blogs became an important part of women's experience of the CEPB, providing an additional means of expression and a useful tool for communicating with the facilitator.

8.7 Conclusion

By and large all versions of the CEPB progressed as planned. Women contributed a variety of materials as part of the EESR element of the programme, and reflected on the autobiographical accounts as part of the psycho-educational element. The main issue which surfaced was the decline in active participation during the course of the CEPB. As there was a high drop-out rate before the start of the programme (see Chapter Five,

Section 5.6), this was a cause for concern. Indeed, nine more women dropped out during the programme. Yet, those who contributed regularly did so throughout the programme. The personal blogs proved to be very popular among participants, with many using their blogs more often than they did the message boards. Apart from elaborating on issues they had mentioned on the message boards, some women used their blogs to write about more personal issues, or to reflect on the topics of the CEPB. Some blog entries elucidated the reasons behind the decline in participation as the weeks went on. Thus, the blogs emerged as an important component of all versions of the programme. The next chapter focuses on the outcomes of the CEPB, as well as participants' evaluation of the programme.

CHAPTER NINE

RESULTS II: OUTCOMES OF THE CEPB

CONTENTS

9.1 Overview

This chapter details the outcomes of the Coping-Enhancement Programme for the Bereaved (CEPB). First, levels of physical-risk factors of breast cancer in the sample are presented, as well as relationships between the assessed risk factors. Secondly, post-intervention and six-week follow-up outcomes are described. Thirdly, analysis of participants' coping styles with bereavement and with stressful life events are presented. Lastly, an analysis of participants' perceived benefits and drawbacks of the CEPB is presented, as well as an analysis of the perceived ease of use and intrinsic motivation to use the screening tool and the intervention Web site.

Chapter Five described how thematic analysis was carried out on participants' message-board postings and blog entries. For the purposes of describing the outcomes of the CEPB and ensuring that the focus remains on the aims of the study, qualitative results are used in this chapter only to support or disconfirm quantitative results, where appropriate. A full description and discussion of all themes and sub-themes can be found in Appendix G.

9.2 Levels of Physical Risk Factors of Breast Cancer

Descriptive statistics were obtained for self-reported physical risk factors of breast cancer as assessed through the pre-intervention screening tool. Table 19 displays self-reported levels of physical risk factors for the whole sample. Nineteen percent of participants had a history of breast cancer, while 16% had a family history of breast cancer. Regarding risk factors relating to reproductive history, just over half (55%) of participants had not had any pregnancies (i.e. were nulliparous). The average number of children was two. Of those with children, 81% had breastfed at least one child, whereas only 19% had not breastfed. The average amount of time women had breastfed was four months. The mean age at menopause was 48. Thirty-six percent of participants were menopausal. Examining the

use of endogenous hormones, 18% of menopausal women were using hormone replacement therapy, while only 16% were using the oral contraceptive pill. Concerning non-reproductive lifestyle factors, 84% of participants reported consuming alcohol, but only 8% felt that their alcohol consumption was excessive. More than half (55%) reported exercising regularly, and nearly three-quarters (74%) reported eating a healthy diet. However, almost 39% reported having a body mass index above 26, making them overweight or obese. Thus, for this sample, the main physical risk factors were age, nulliparity, breast-cancer history and weight.

Table 20 displays significant correlation coefficients between physical risk factors of breast cancer. The older women were, the less likely they were to be nulliparous ($r = -.52$, $p < .01$), and the more likely they were to be menopausal ($r = .42$, $p < .05$) and to be older at the onset of menopause ($r = .98$, $p < .01$). Furthermore, the older women were, the less likely they were to report eating an unhealthy diet ($r = -.53$, $p < .05$).

Those with a family history of breast cancer were less likely to have breastfed at least one of their children than those without a family history of breast cancer ($r = .54$, $p < .05$). If they did breastfeed, then they were likely to have done so for a shorter period of time ($r = -.36$, $p < .05$).

Nulliparous women were less likely to report consuming alcohol excessively ($r = -.46$, $p < .01$). However, they were more likely to report eating an unhealthy diet ($r = .65$, $p < .01$). The more children they had, the more likely participants were to report excessive alcohol consumption ($r = .40$, $p < .05$); on the other hand, they were less likely to report eating an unhealthy diet ($r = -.57$, $p < .01$).

Women who had never breastfed were more likely to report eating a healthy diet than those who had breastfed at least one child ($r = -.58$, $p < .01$). However, those who had

breastfed were more likely to report exercising regularly (r = -.46, p < .05). Menopausal women were more likely to be overweight or obese than non-menopausal women (r = .38, p < .05). The higher the age at onset of menopause, the less likely participants were to report eating an unhealthy diet (r = -.70, p < .01). Finally, women who did not exercise regularly were also more likely to report eating an unhealthy diet (r = .38, p < .05).

To summarise, several of the physical risk factors of breast cancer were associated with each other. Although nearly half of participants were nulliparous, this was connected to age; thus, younger women were more likely to be nulliparous than older women and it is possible that many of them would bear children at a later point in their lives. Nulliparity in turn was linked to alcohol consumption and an unhealthy diet, which indicates that a significant number of women were likely to present with more than one risk factor of breast cancer.

Table 19

Levels of Physical Risk Factors of Breast Cancer for Whole Sample

Physical Risk Factor of Breast Cancer	Descriptive Statistics	
Age	*M*	43.13
	SD	14.73
	Minimum	18
	Maximum	74
History of breast cancer	Yes	19%
	No	81%
Family history of breast cancer	Yes	16%
	No	84%
Nulliparity	Yes	45%
	No	55%
Age at First Birth	*M*	26.00
	SD	3.63
	Minimum	20
	Maximum	34
Number of children	*M*	2.00
	SD	0.63
	Minimum	1
	Maximum	3
Breastfeeding history	Breastfed	81%
	Did Not Breastfeed	19%
Number of months breastfed	*M*	4.31
	SD	2.69
	Minimum	1
	Maximum	9.5
Menopausal	Yes	36%
	No	66%
Age at menopause	*M*	48.40
	SD	5.32
	Minimum	35
	Maximum	54
If menopausal, HRT use	Yes	18%
	No	82%
Contraceptive pill use	Yes	16%
	No	36%
	Not Anymore	48%
Alcohol consumption	Yes	84%
	No	10%
	Not Anymore	7%
Excessive alcohol consumption	Yes	8%
	No	92%
Regular exercise	Yes	55%
	No	30%
	Not Anymore	16%
Consumption of a healthy diet	Yes	74%
	No	23%
	Not Anymore	3%
Body Mass Index above 26	Yes	39%
	No	61%

Note. HRT: Hormone Replacement Therapy. *N* = 31.
Percentages may not add up to 100 due to rounding.

Table 20

Significant Correlations between Potential Physical Risk Factors of Breast Cancer

Risk Factor of Breast Cancer	Age	Breast cancer history	Family history of breast cancer	Nulliparity	Number of children	Never breastfed	Breastfeeding duration	Menopausal	Age at menopause	Contraceptive Pill Use	Excessive Alcohol consumption	Overweight or obesity	Lack of regular exercise	Unhealthy diet
Age														
Breast cancer history	.33													
Family history of breast cancer	.21	.18												
Nulliparity	-.52**	-.18	.13											
Number of children	.43*	.13	-.33	-.88**										
Never breastfed	.17	-.28	.54*	-.90**	-.52*									
Breastfeeding duration	.23	-.37	-.36*	-.74**	.27	-.60**								
Menopausal	.42*	.08	-.14	-.27	.24	.16	.00							
Age at menopause	.98**	-.18	.18	-.50	.28	.74	.52	.91**						
Contraceptive Pill Use	.33	.05	-.02	-.24	.24	-.06	.74**	.26	.28					
Excessive Alcohol consumption	.12	-.13	.01	-.46**	.40*	.12	.43	.23	.41	-.11				
Overweight or obesity	.15	.36*	.01	.08	-.02	-.37	-.08	.38*	-.61	.34	-.24			
Lack of regular exercise	-.28	-.11	.21	.20	-.17	.00	-.46*	-.25	-.50	-.17	-.10	.23		
Unhealthy diet	-.53*	-.22	-.05	.65**	-.57**	-.58**	-.48**	-.16	-.70**	-.16	-.02	.12	.38*	

Note. * $p < .05$, ** $p < .01$.

9.3 Post-Intervention and Follow-Up Outcomes: Differences Between Groups

The following section describes results of analyses of the effect of the CEPB components

on the dependent variables, as well as on conformity. Es explained in Chapter Five, the

independent variables were Emotional-Expression-and-Stress-Reduction (EESR – 'Art

and Laughter for Wellbeing') and psycho-education (the reading of autobiographical

accounts of breast-cancer sufferers). The dependent variables were maladaptive coping

with bereavement, maladaptive coping with stressful life events, social support, and

awareness of the connections between psychological and physical health. As mentioned

in Chapter Five, although conformity was not a dependent variable, it was measured both

after the intervention and at follow-up, because it was of interest if the CEPB had had any

significant effects on participants' tendencies to be overly compliant. Thus, effects on

conformity were also tested.

9.3.1 Maladaptive Coping with Bereavement

After Intervention

Table 21 presents means and standard deviations for maladaptive coping with

bereavement. Participants who had taken part in EESR-only had the lowest levels of

maladaptive coping with bereavement after the intervention (M = 1.43, SD = .79), while

participants who had taken part in both elements of the intervention had the highest levels

(M = 2.25, SD = 1.04). Participants in the control group had the second-lowest levels of

maladaptive coping with bereavement after the intervention (M = 1.88, SD = 1.36), while

psycho-education-only participants had the second-highest levels (M = 2.14, SD = 1.04).

Table 21

Means of Maladaptive Coping with Bereavement After the Programme

Group	M	SD
EESR Only	1.43	0.79
Control Group	1.88	1.36
Psycho-Education Only	2.14	1.46
EESR + Psycho-Education	2.25	1.04

Table 22 presents results of ANCOVA for maladaptive coping with bereavement after the programme. The covariate, pre-intervention maladaptive coping with bereavement, was significantly related to maladaptive coping with bereavement after the programme, $F(2, 26) = 22.21$, $p < .0001$, $\varepsilon^2 = 0.42$. There was also a significant main effect of EESR on maladaptive coping with bereavement after the programme, $F(3, 26) = 3.09$, $p < .10$, $\varepsilon^2 = 0.04$. Participating in 'Art and Laughter for Wellbeing' was associated with lower levels of maladaptive coping with bereavement after the programme, than not participating in 'Art and Laughter for Wellbeing'.

Table 22

ANCOVA for Maladaptive Coping with Bereavement After the Programme

Source	Sum of Squares	df	Mean Square	F	ε^2
Pre-Intervention Maladaptive Coping with Bereavement	17.38	1	17.38	22.21****	0.42
EESR	2.42	1	2.42	3.09†	0.04
Psycho-Education	2.06	1	2.06	2.64	0.03
Interaction	0.11	1	0.11	0.14	0.00
Error	19.57	25	0.78		

†$p < 0.10$, ****$p < 0.0001$

Six-Week Follow-Up

Table 23 presents means and standard deviations for maladaptive coping with bereavement at follow-up. The EESR-only group and the EESR plus psycho-education group had the lowest levels of maladaptive coping with bereavement at six-week follow-up (M = 1.67, SD = 1.21 for both groups), while the control group had the highest levels (M = 1.83, SD = 1.33). Participants who took part in psycho-education-only had the second-lowest levels (M = 1.80, SD = 1.30).

Table 23

Means of Maladaptive Coping with Bereavement at Follow-Up

Group	M	SD
EESR + Psycho-Education	1.67	1.21
EESR Only	1.67	1.21
Psycho-Education Only	1.80	1.30
Control Group	1.83	1.33

Table 24 presents results of ANCOVA for maladaptive coping with bereavement at follow-up. One of the covariates, post-intervention maladaptive coping with bereavement, was significantly related to maladaptive coping with bereavement at follow-up, $F(1, 17) = 5.29$, $p < .05$, $\varepsilon^2 = 0.14$. There were no significant main effects of either of the intervention elements, on maladaptive coping with bereavement at follow-up. There was also no significant effect of the covariates, nor a significant interaction effect.

Table 24

ANCOVA for Maladaptive Coping with Bereavement at Follow-Up

Source	Sum of Squares	df	Mean Square	F	ε^2
Pre-Intervention Maladaptive Coping with Bereavement	0.28	1	0.28	0.29	0.00
Post-Intervention Maladaptive Coping with Bereavement	5.20	1	5.20	5.29*	0.14
EESR	0.04	1	0.04	0.04	0.00
Psycho-Education	0.54	1	0.54	0.55	0.00
EESR × Psycho-Education	0.03	1	0.03	0.03	0.00
Error	16.72	17	0.98		

*$p < 0.05$

9.3.2 Maladaptive Coping with Stressful Life Events

After Intervention

Table 25 presents means and standard deviations for maladaptive coping with stressful life events after the programme. Participants who took part in psycho-education-only had the lowest levels of maladaptive coping with stressful life events after the programme ($M = 1.64$, $SD = 0.67$), while participants in the EESR-only condition had the highest levels ($M = 1.97$, $SD = 0.66$). Control-group participants had the second-lowest levels ($M = 1.71$, $SD = 0.58$), while EESR-and-psycho-education participants had the second-highest levels ($M = 1.88$, $SD = 0.71$).

Table 25

Means of Maladaptive Coping with Stressful Life Events After the Programme

Group	M	SD
Psycho-Education Only	1.64	0.67
Control Group	1.71	0.58
EESR + Psycho-Education	1.88	0.71
EESR Only	1.97	0.66

Table 26 presents results of ANCOVA for post-intervention maladaptive coping with stressful life events. The covariate, pre-intervention maladaptive coping with stressful life events, was significantly related to maladaptive coping with stressful life events after the programme, $F(1, 24) = 38.28$, $p < .0001$, $\varepsilon^2 = 0.57$. There was a significant main effect of psycho-education on maladaptive coping with stressful life events after the programme, $F(1, 24) = 6.45$, $p < .05$, $\varepsilon^2 = 0.08$. Reading autobiographical accounts was associated with lower post-intervention maladaptive coping with stressful life events than not reading autobiographical accounts.

Table 26

ANCOVA for Maladaptive Coping with Stressful Life Events After the Programme

Source	Sum of Squares	df	Mean Square	F	ε^2
Pre-Intervention Maladaptive Coping with Stressful Life Events	6.74	1	6.74	38.28****	0.57
EESR	0.12	1	0.12	0.68	0.00
Psycho-Education	1.14	1	1.14	6.45*	0.08
EESR × Psycho-Education	0.20	1	0.20	1.12	0.00
Error	4.23	24	0.18		

*$p < 0.05$, ****$p < 0.0001$

Six-Week Follow-Up

Table 27 presents means and standard deviations for maladaptive coping with stressful life events at follow-up. Control-group participants had the lowest levels of maladaptive coping with stressful life events at six-week follow-up ($M = 1.70$, $SD = 0.97$), while the group who had taken part in both EESR and psycho-education had the highest levels ($M = 2.21$, $SD = 0.58$). The psycho-education-only group had the second-lowest levels ($M = 1.80$, $SD = 0.96$), while the EESR-only group had the second-highest levels ($M = 1.82$, $SD = 0.70$).

Table 27

Means of Maladaptive Coping with Stressful Life Events at Follow-Up

Group	M	SD
Control Group	1.70	0.97
Psycho-Education Only	1.80	0.96
EESR Only	1.82	0.70
EESR + Psycho-Education	2.21	0.58

Table 28 presents results of ANCOVA for maladaptive coping with stressful life events at follow-up. There were no significant main effects of either of the intervention elements, on maladaptive coping with stressful life events at follow-up. There was also no significant effect of the covariates, nor a significant interaction effect.

Table 28

ANCOVA for Maladaptive Coping with Stressful Life Events at Follow-Up

Source	Sum of Squares	df	Mean Square	F	ε^2
Pre-Intervention Maladaptive Coping with Stressful Life Events	0.86	1	0.86	1.74	0.03
Post-Intervention Maladaptive Coping with Stressful Life Events	0.13	1	0.13	0.27	0.00
EESR	0.03	1	0.03	0.06	0.00
Psycho-Education	0.00	1	0.00	0.00	0.00
EESR × Psycho-Education	0.00	1	0.00	0.00	0.00
Error	8.40	17	0.49		

9.3.3 Social Support

After Intervention

Table 29 displays means and standard deviations of social support after the programme. Participants who took part in psycho-education-only had the highest levels of social support after the programme (M = 4.14, SD = 0.59), while the control group had the lowest levels of social support after the programme (M = 2.87, SD = 0.35). EESR-only participants had the second-highest levels of social support (M = 3.91, SD = 0.76), while

participants who took part in both elements had the second-lowest levels (M = 3.59, SD = 1.08).

Table 29

Means of Social Support After the Programme

Group	M	SD
Psycho-Education Only	4.14	0.59
EESR Only	3.91	0.76
EESR + Psycho-Education	3.59	1.08
Control Group	2.87	0.35

Table 30 presents results of ANCOVA for social support after the programme. The covariate, pre-intervention social support, was significantly related to post-intervention social support, $F(1, 26)$ = 38.44, p < .0001. There was also a significant main effect of EESR on post-intervention social support, $F(1, 26)$ = 7.27, p < .01, ε^2 = 0.07. Furthermore, there was a significant main effect of psycho-education on post-intervention social support, $F(1, 26)$ = 4.57, p < .05, ε^2 = 0.04. Finally, there was a significant interaction effect of EESR and psycho-education, on post-intervention social support, $F(1, 26)$ = 30.59, p < .0001, ε^2 = 0.32. Visual inspection of estimated marginal means showed that participation in neither condition (*EMM* = 2.70, *SE* = 0.18) or in both conditions (*EMM* = 3.57, *SE* = 0.17) appeared to be associated with lower post-intervention social support than participation in EESR alone (*EMM* = 4.18, *SE* = 0.18) or in psycho-education alone (*EMM* = 4.07, *SE* = 0.19).

Table 30

ANCOVA for Post-Intervention Social Support

Source	Sum of Squares	*df*	Mean Square	*F*	ε^2
Pre-Intervention Social Support	9.15	1	9.15	38.44	0.40
EESR	1.73	1	1.73	7.27**	0.07
Psycho-education	1.09	1	1.09	4.57*	0.04
EESR × Psycho-Education	7.28	1	7.28	30.59****	0.32
Error	6.19	26	0.24		

p < 0.05, **p* < 0.01, ****p* < 0.0001

Simple-effect analyses were carried out by means of ANCOVAs, with pre-intervention social support held constant. The independent variables were EESR and psycho-education. The dependent variable was social support after the programme. Pairwise comparisons were performed in each ANCOVA (see Tables 31 and 32 for estimated marginal means).

Examining the effect of psycho-education on post-intervention social-support levels of participants who did and who did not take part in EESR, it emerged that participants who only took part in EESR had significantly higher levels of social support after the programme than those who took part in both EESR and psycho-education, $F(1, 13) = 11.90$, *MD* = .69, *p* < .0001. Participants who did not take part in EESR but did take part in psycho-education had significantly higher levels of social support after the programme than those who took part in neither EESR nor psycho-education, $F(1, 12) = 27.80$, *MD* = 1.30, *p* < .0001.

Examining the effect of EESR on post-intervention social support levels of participants who did and who did not take part in psycho-education, participants who took part in

psycho-education but not in EESR had higher levels of social support after the

programme than those who took part in both EESR and psycho-education, $F(1, 12) =$

3.54, *MD* = .50, *p* < .10. Participants who did not take part in psycho-education but did

take part in EESR had higher levels of social support after the programme than those who

took part in neither psycho-education nor EESR, $F(1, 13) = 27.51$, *MD* = 1.41, *p* < .0001.

It thus appeared that taking part in either EESR or psycho-education alone was more

beneficial to social support after the programme, than taking part in both elements.

Table 31

Estimated Marginal Means for EESR/No EESR

Condition		Post-Intervention Social Support	
		EMM	*SE*
+EESR	+Psycho-Education	3.41	0.14
	-Psycho-Education	4.09	0.14
-EESR	+Psycho-Education	4.16	0.18
	-Psycho-Education	2.86	0.17

Note. EMM: Estimated Marginal Means.

Table 32

Estimated Marginal Means for Psycho-Education/No Psycho-Education

Condition		Post-Intervention Social Support	
		EMM	*SE*
+ Psycho-Education	+EESR	3.62	0.18
	- EESR	4.12	0.19
- Psycho-Education	+ EESR	4.09	0.18
	- EESR	2.69	0.18

Note. EMM: Estimated Marginal Means.

Six-Week Follow-Up

Table 33 displays means and standard deviations of social support at follow-up. Control-

group participants had the highest levels of social support at six-week follow-up (*M* = 3.96,

SD = 0.58), while participants who only took part in EESR had the lowest levels (*M* = 3.48,

SD = 0.97). Participants who took part in both EESR and psycho-education had the

second-highest levels (*M* = 3.73, *SD* = 0.62), while psycho-education-only participants

had the second-lowest levels (*M* = 3.68, *SD* = 0.41).

Table 33

Means of Social Support at Follow-Up

Group	*M*	*SD*
Control Group	3.96	0.58
EESR + Psycho-Education	3.73	0.62
Psycho-Education Only	3.73	0.41
EESR Only	3.48	0.97

Table 34 presents results of ANCOVA for social support at follow-up. Social support after

the programme was significantly related to social support at follow-up, $F(1, 18) = 4.57$, $p <$

.05, $\varepsilon^2 = 0.07$. There were no significant main effects of either of the intervention elements

on social support at follow-up, nor was there a significant interaction effect.

Table 34

ANCOVA for Social Support at Follow-Up

Source	Sum of Squares	df	Mean Square	F	ε^2
Pre-Intervention Social Support	0.30	1	0.30	1.35	0.00
Post-Intervention Social Support	1.01	1	1.01	4.57*	0.07
EESR	0.57	1	0.57	2.56	0.03
Psycho-Education	0.22	1	0.22	0.99	0.00
EESR × Psycho-Education	0.62	1	0.62	2.81	0.04
Error	3.97	18	0.22		

*$p < 0.05$

9.3.4 Awareness of the Connections between Psychological and Physical Health

After Intervention

Table 35 presents means and standard deviations of awareness of the connections between psychological and physical health after the programme, henceforth abbreviated to 'awareness'. The group who had only taken part in psycho-education had the highest levels of awareness after the intervention (M = 4.52, SD = 0.47), while participants who had only taken part in EESR had the lowest levels (M = 3.83, SD = 0.47). The control group had the second-highest levels of awareness after the programme (M = 4.46, SD = 0.43), while participants who took part in both EESR and psycho-education had the second-lowest levels (M = 4.42, SD = 0.57).

Table 35

Means of Awareness of the Connections between Psychological and Physical Health After the Programme

Group	*M*	*SD*
Psycho-Education Only	4.52	0.47
Control Group	4.46	0.43
EESR + Psycho-Education	4.42	0.57
EESR Only	3.83	0.47

Table 36 presents results of ANCOVA for awareness after the programme. The covariate, pre-intervention awareness, was significantly related to awareness after the programme, $F(1, 22) = 5.08$, $p < .05$, $\varepsilon^2 = 0.10$. There was also a significant main effect of EESR on awareness after the programme, $F(1, 22) = 3.95$, $p < .10$, $\varepsilon^2 = 0.07$. Participating in 'Art and Laughter for Wellbeing' was associated with lower awareness after the programme than not participating in 'Art and Laughter for Wellbeing'.

Table 36

ANCOVA for Awareness of the Connections between Psychological and Physical Health After the Programme

Source	Sum of Squares	df	Mean Square	*F*	ε^2
Pre-Intervention Awareness	0.97	1	0.97	5.08*	0.10
EESR	0.75	1	0.75	3.95†	0.07
Psycho-education	0.29	1	0.29	1.50	0.01
EESR × Psycho-Education	0.42	1	0.42	2.21	0.03
Error	4.18	22	0.19		

$^\dagger p < 0.10$, $^* p < 0.05$

Six-Week Follow-Up

Table 37 presents means and standard deviations of awareness at six-week follow-up. Participants who only took part in psycho-education had the highest levels of awareness at follow-up (M = 4.27, SD = 0.76), while the group who took part in both EESR and psycho-education had the lowest levels (M = 3.89, SD = 0.69). The control group had the second-highest levels (M = 4.22, SD = 0.40), while the EESR-only group had the second-lowest levels (M = 4.05, SD = 0.52).

Table 37

Means of Awareness of the Connections between Psychological and Physical Health at Follow-Up

Group	M	SD
Psycho-Education Only	4.27	0.76
Control Group	4.22	0.40
EESR Only	4.05	0.52
EESR + Psycho-Education	3.89	0.69

Table 38 presents results of ANCOVA for awareness of the connections between psychological and physical health at follow-up. There were no significant main effects of either of the intervention elements, nor of the covariates, on awareness; nor was there a significant interaction effect.

Table 38

ANCOVA for Awareness of the Connections between Psychological and Physical Health

at Follow-Up

Source	Sum of Squares	df	Mean Square	F	ε^2
Pre-Intervention Awareness	0.58	1	0.58	2.21	0.05
Post-Intervention Awareness	0.56	1	0.56	2.15	0.05
EESR	0.02	1	0.02	0.06	0.00
Psycho-Education	0.10	1	0.10	0.38	0.00
EESR × Psycho-Education	0.09	1	0.09	0.36	0.00
Error	3.91	15	0.26		

9.3.5 Conformity

After Intervention

Table 39 presents means and standard deviations for conformity after the programme.

Participants who took part in both EESR and psycho-education had the lowest levels of

conformity after the programme (*M* = 2.04, *SD* = 0.32), while participants in the EESR –

only condition had the highest levels (*M* = 2.38, *SD* = 0.25). The control group had the

second-lowest levels (*M* = 2.08, *SD* = 0.21), while the psycho-education-only group had

the second-highest levels (*M* = 2.33, *SD* = 0.23).

Table 39

Means of Conformity After the Programme

Group	*M*	*SD*
EESR + Psycho-Education	2.04	0.32
Control Group	2.08	0.21
Psycho-Education Only	2.33	0.23
EESR Only	2.38	0.25

Table 40 presents results of ANCOVA for conformity after the programme. The covariate, pre-intervention conformity, was not significantly related to conformity after the programme, $F(1, 26) = 2.11$, $p > .10$, $\varepsilon^2 = 0.03$. Although there were no significant main effects, there was a significant interaction effect between EESR and psycho-education, on conformity after the programme, $F(1, 26) = 4.49$, $p < .05$, $\varepsilon^2 = 0.09$. Visual inspection of estimated marginal means showed that participating in neither condition (*EMM* = 2.11, *SE* = 0.09) or in both conditions (*EMM* = 2.07, *SE* = 0.09) appeared to be associated with lower post-intervention conformity than participating in either EESR alone (*EMM* = 2.35, *SE* = 0.09) or in psycho-education alone (*EMM* = 2.28, *SE* = 0.10).

Table 40

ANCOVA for Post-Intervention Conformity

Source	Sum of Squares	df	Mean Square	*F*	ε^2
Pre-Intervention Conformity	0.14	1	0.14	2.11	0.03
EESR	0.00	1	0.00	0.03	0.00
Psycho-Education	0.03	1	0.03	0.42	0.00
EESR × Psycho-Education	0.29	1	0.29	4.49*	0.09
Error	1.69	26	0.07		

*$p < 0.05$

Simple-effect tests were carried out as described in Sub-Section 9.3.3 (see Tables 41 and 42 for estimated marginal means).

Examining the effect of psycho-education on post-intervention conformity level of participants who did and who did not take part in EESR, only one significant mean difference emerged: participants who took part in neither EESR nor psycho-education had significantly lower levels of conformity after the programme than participants who did not take part in EESR but did take part in psycho-education, $F(1, 12) = 4.41$, $MD = -.30$, $p < .10$.

Examining the effect of EESR on post-intervention conformity levels of participants who did and those who did not take part in psycho-education, only one significant mean difference emerged here too: participants who did not take part in psycho-education but did take part in EESR had higher levels of conformity after the programme than those who took part in neither psycho-education nor in EESR, $F(1, 13) = 5.34$, $MD = -.30$, $p < .05$. This showed that participating in either EESR or in psycho-education was associated with higher levels of post-intervention conformity than participating in neither.

Table 41

Estimated Marginal Means for EESR/No EESR

Condition		Post-Intervention Conformity	
		EMM	*SE*
+EESR	+Psycho-Education	2.11	0.09
	-Psycho-Education	2.31	0.09
-EESR	+Psycho-Education	2.35	0.10
	-Psycho-Education	2.06	0.09

Note. EMM: Estimated Marginal Means.

Table 42

Estimated Marginal Means for Psycho-Education/No Psycho-Education

Condition		Post-Intervention Conformity	
		EMM	*SE*
+ Psycho-Education	+EESR	2.18	0.09
	- EESR	2.16	0.09
- Psycho-Education	+ EESR	2.38	0.09
	- EESR	2.07	0.09

Note. EMM: Estimated Marginal Means.

Six-Week Follow-Up

Table 43 presents means and standard deviations for conformity at follow-up. Participants who took part in both EESR and psycho-education and control-group participants had the highest levels (*M* = 2.12 for both groups, *SD* = 0.33 and 0.47 respectively). The EESR-only group had the second-lowest levels (*M* = 2.14, *SD* = 0.44), while the psycho-education-only group had the highest levels (*M* = 2.38, *SD* = 0.23).

Table 43

Means of Conformity at Follow-Up

Group	*M*	*SD*
Control Group	2.12	0.47
EESR + Psycho-Education	2.12	0.33
EESR Only	2.14	0.44
Psycho-Education Only	2.38	0.23

Table 44 presents results of ANCOVA for conformity at follow-up. Pre-intervention conformity was significantly related to conformity at follow-up, $F(2, 21) = 18.10$, $p < .001$, $\varepsilon^2 = 0.26$. Furthermore, post-intervention conformity was significantly related to conformity

at follow-up, $F(2, 21) = 7.59$, $p < .01$, $\varepsilon^2 = 0.14$. Although there were no significant main

effects, was a significant interaction effect between EESR and psycho-education, on

conformity at follow-up, $F(3, 26) = 7.65$, $p < .01$, $\varepsilon^2 = 0.08$.

Table 44

ANCOVA for Conformity at Follow-Up

Source	Sum of Squares	df	Mean Square	F	ε^2
Pre-Intervention Conformity	0.94	1	0.94	18.10****	0.26
Post-Intervention Conformity	0.39	1	0.39	7.59**	0.14
EESR	0.02	1	0.02	0.37	0.00
Psycho-Education	0.01	1	0.01	0.27	0.00
EESR × Psycho-Education	0.40	1	0.40	7.65**	0.08
Error	0.94	18	0.05		

**$p < 0.01$, ****$p < 0.0001$

Simple-effect analyses were carried out as described in Sub-Section 9.3.3 (see Tables 45

and 46 for estimated marginal means).

Examining the effect of psycho-education on follow-up conformity levels of participants

who did and who did not take part in EESR, participants who took part in EESR but not in

psycho-education had lower levels of conformity at follow-up than participants who took

part in both EESR and psycho-education, $F(1, 9) = 5.32$, $MD = -.38$, $p < .05$. Participants

who did not take part in EESR but did take part in psycho-education had lower levels of

conformity at follow-up than participants who took part in neither EESR nor psycho-

education, $F(1, 7) = 28.35$, $MD = -.34$, $p < .001$.

Examining the effect of EESR on follow-up conformity levels of participants who did and who did not take part in psycho-education, only one significant mean difference emerged. Participants who did not take part in psycho-education but did take part in EESR had lower levels of conformity at follow-up than those who participated neither in psycho-education nor in EESR, $F(1, 9) = 6.66$, $MD = -.45$, $p < .05$. This showed that participating in either EESR or psycho-education was associated with lower levels of conformity at follow-up than participating in neither or in both.

Table 45

Estimated Marginal Means for EESR/No EESR

Condition		Conformity at Follow-Up	
		EMM	*SE*
+EESR	+Psycho-Education	2.34	0.11
	-Psycho-Education	1.95	0.10
-EESR	+Psycho-Education	2.10	0.04
	-Psycho-Education	2.45	0.04

Note. EMM: Estimated Marginal Means.

Table 46

Estimated Marginal Means for Psycho-Education/No Psycho-Education

Condition		Conformity at Follow-Up	
		EMM	*SE*
+ Psycho-Education	+EESR	2.31	0.11
	- EESR	2.15	0.12
- Psycho-Education	+ EESR	1.97	0.11
	- EESR	2.42	0.12

Note. EMM: Estimated Marginal Means.

This reduction in conformity for two conditions also became evident examining the results of the thematic analysis. For example, participant Red Ivy's participation in the psycho-education-only condition seemed to have facilitated the decision to leave her marriage:

I have explored my options for leaving our home, and plan to make a new start next month. […] I feel strong & galvanised in my decisions, and just hope I don't hit too many hurdles along the way dealing with the paperwork and finances. Wish me luck...

(Page 1, lines 22-23 and page 4, lines 82-84)

The same was the case for Blue Daisy, who took part in the EESR-only condition:

I have made plans to move out and divorce [my husband]... this operation has given me a life changing experience where I realise I only have 1 life and I need to live it...

(Blue Daisy, page 3, lines 50-52)

Both women had blogged about their ongoing marital problems. During the course of the programme, they made life-changing decisions. Although it is not clear whether they actually carried out their plans, it is possible that making these decisions was a sign of a reduction in conformity in these women, brought on by their participation in the programme.

9.4 Post-Intervention and Follow-Up Outcomes: Assessing Change over Time

The following section presents results of the mixed ANOVAs, which were performed to assess change over time in the dependent variables.

9.4.1 Maladaptive Coping with Bereavement
After Intervention

Table 47 shows means for maladaptive coping with bereavement before and after the programme, for all conditions. Visual inspection of means showed that the psycho-

education-only group and the control group exhibited increases in maladaptive coping with

bereavement after the programme, while the EESR-only group exhibited a decrease, and

the group who received both EESR and psycho-education exhibited no change.

Table 47

Means for Maladaptive Coping with Bereavement Before and After the CEPB

Group	Pre-Intervention Maladaptive Coping with Bereavement		Post-Intervention Maladaptive Coping with Bereavement	
	M	*SD*	*M*	*SD*
Psycho-Education Only	1.43	0.79	2.14	1.46
Control Group	1.63	1.19	1.88	1.36
EESR Only	2.00	1.41	1.43	0.79
EESR + Psycho-Education	2.25	1.17	2.25	1.04

Table 48 presents results of the mixed ANOVA for maladaptive coping with bereavement

before and after the programme. There was a significant interaction effect between time

and EESR, $F(1, 26) = 5.06$, $p < .05$, $\varepsilon^2 = 0.02$. Estimated marginal means from ANOVA

(see Table 49) showed that participants who took part in EESR had lower levels of

maladaptive coping with bereavement after the programme (*EMM* = 1.84, *SE* = 0.31) than

before the programme (*EMM* = 2.13, *SE* = 0.30), while participants who did not take part

in EESR had higher levels of maladaptive coping with bereavement after the programme

(*EMM* = 2.01, *SE* = 0.31) than before the programme (*EMM* = 1.53, *SE* = 0.30).

Table 48

Mixed ANOVA for Maladaptive Coping with Bereavement Before and After the

Programme

Source	Sum of Squares	*df*	Mean Square	*F*	ε^2
EESR	0.69	1	0.69	0.29	-0.02
Psycho-Education	1.22	1	1.22	0.52	-0.01
EESR × Psycho-Education	0.93	1	0.93	0.40	-0.02
Time	0.14	1	0.14	0.33	0.00
Time × EESR	2.20	1	2.20	5.06*	0.02
Time × Psycho-Education	1.00	1	1.00	2.30	0.01
Time × EESR × Psycho-Education	0.01	1	0.01	0.03	0.00

*p < .05

Table 49

Estimated Marginal Means of Maladaptive Coping with Bereavement for EESR

	Pre-Intervention Maladaptive Coping with Bereavement		Post-Intervention Maladaptive Coping with Bereavement	
	EMM	*SE*	*EMM*	*SE*
EESR	2.13	0.30	1.84	0.31
No EESR	1.53	0.30	2.01	0.31

Note. EMM: Estimated Marginal Means.

Follow-Up

Table 50 displays means and standard deviations for maladaptive coping with

bereavement after the programme and at six-week follow-up, for all conditions. Visual

inspection of means showed that all groups had decreases in maladaptive coping with

bereavement at follow-up, compared to after the programme, with the psycho-education-

only group showing the largest decrease (*M* = 2.60, *SD* = 1.52 after the programme and *M*

= 1.80, *SD* = 1.30 at follow-up). The EESR-only group showed the smallest decrease (*M* =

1.86, *SD* = 1.22 after the programme and *M* = 1.71, *SD* = 1.11 at follow-up).

Table 50

Means for Maladaptive Coping with Bereavement After the Programme and at Follow-Up

	Post-Intervention Maladaptive Coping with Bereavement		Maladaptive Coping with Bereavement at Follow-Up	
Group	*M*	*SD*	*M*	*SD*
EESR Only	1.86	1.22	1.71	1.11
Control Group	2.17	1.47	1.83	1.33
EESR + Psycho-Education	2.17	1.17	1.67	1.21
Psycho-Education Only	2.60	1.52	1.80	1.30

Table 51 presents results of mixed ANOVA for maladaptive coping with bereavement after the programme and at follow-up. There was a significant main effect of time, $F(1, 20) = 3.81$, $p < .10$, $\varepsilon^2 = 0.02$. Estimated marginal means (see Table 52) showed that levels of maladaptive coping with bereavement were lower at six-week follow-up (*EMM* = 1.75, *SE* = 0.25) than after the programme (*EMM* = 2.20, *SE* = 0.28). There were no significant interaction effects.

Table 51

Mixed ANOVA for Maladaptive Coping with Bereavement After the Programme and at Follow-Up

Source	Sum of Squares	*df*	Mean Square	*F*	ε^2
EESR	0.73	1	0.73	0.27	-0.03
Psycho-Education	0.32	1	0.32	0.12	-0.03
EESR × Psycho-Education	0.01	1	0.01	0.01	-0.04
Time	2.33	1	2.33	3.81[†]	0.02
Time * EESR	0.18	1	0.18	0.29	0.00
Time * Psycho-Education	0.50	1	0.50	0.82	0.00
Time * EESR * Psycho-Education	0.01	1	0.01	0.01	0.00

[†]$p < .10$

Table 52

Estimated Marginal Means of Maladaptive Coping with Bereavement over Time

	EMM	SE
Post-Intervention Maladaptive Coping with Bereavement	2.20	0.28
Maladaptive Coping with Bereavement at Follow-Up	1.75	0.25

Note. EMM: Estimated Marginal Means.

9.4.2 Maladaptive Coping with Stressful Life Events

After Intervention

Table 53 shows means for maladaptive coping with stressful life events before and after the programme, for all conditions. Visual inspection of means showed that only the EESR-and-psycho-education group exhibited a decrease in maladaptive coping with stressful life events after the programme (*M* = 1.88, *SD* = 0.71) compared to before the programme (*M* = 2.25, *SD* = 0.64). The other groups all exhibited increases after the programme, with the control group and the EESR-only group exhibiting the highest increase.

Table 53

Means for Maladaptive Coping with Stressful Life Events Before and After the Programme

	Pre-Intervention Maladaptive Coping with Stressful Life Events		Post-Intervention Maladaptive Coping with Stressful Life Events	
Group	*M*	*SD*	*M*	*SD*
Control Group	1.38	0.52	1.72	0.51
Psycho-Education Only	1.57	0.59	1.64	0.67
EESR Only	1.63	0.76	1.97	0.66
EESR + Psycho-Education	2.25	0.64	1.88	0.71

Table 54 presents results of the mixed ANOVA for maladaptive coping with stressful life events before and after the programme. There was a significant interaction effect between time and psycho-education, $F(1, 27) = 9.85$, $p < .01$, $\varepsilon^2 = 0.03$. Estimated marginal means (see Table 55) showed that participants who received psycho-education exhibited a decrease in maladaptive coping with stressful life-events after the programme ($EMM = 1.76$, $SE = 0.17$) compared to before the programme ($EMM = 1.91$, $SE = 0.16$). Conversely, participants who received no psycho-education exhibited an increase in maladaptive coping with stressful life events after the programme ($EMM = 1.84$, $SE = 0.16$) compared to before the programme ($EMM = 1.50$, $SE = 0.16$).

Table 54

Mixed ANOVA for Maladaptive Coping with Stressful Life Events Before and After the Programme

Source	Sum of Squares	df	Mean Square	F	ε^2
EESR	1.92	1	1.92	2.68	0.05
Psycho-Education	0.41	1	0.41	0.57	-0.01
EESR × Psycho-Education	0.16	1	0.16	0.23	-0.02
Time	0.14	1	0.14	1.48	0.00
Time × EESR	0.19	1	0.19	2.00	0.00
Time × Psycho-Education	0.95	1	0.95	9.85**	0.03
Time × EESR × Psycho-Education	0.19	1	0.19	2.00	0.00

**$p < 0.01$

Table 55

Estimated Marginal Means of Maladaptive Coping with Stressful Life Events for Psycho-

Education

	Pre-Intervention Maladaptive Coping with Stressful Life Events		Post-Intervention Maladaptive Coping with Stressful Life Events	
	M	*SE*	*M*	*SE*
Psycho-Education	1.91	0.16	1.76	0.17
No Psycho-Education	1.50	0.16	1.84	0.16

Follow-Up

Table 56 shows means for maladaptive coping with stressful life events after the

programme and at six-week follow-up, for all conditions. Visual inspection of means

showed that participants who took part in both EESR and psycho-education exhibited an

increase in maladaptive coping with stressful life events at follow-up (*M* = 2.21, *SD* =

0.58), compared to after the programme (*M* = 2.04, *SD* = 0.75). However, the control

group and the EESR-only group both exhibited decreases compared to post-intervention

levels, while the psycho-education-only group exhibited no change.

Table 56

Means for Maladaptive Coping with Stressful Life Events After the Programme and at Six-

Week Follow-Up

	Post-Intervention Maladaptive Coping with Stressful Life Events		Maladaptive Coping with Stressful Life Events at Follow-Up	
Group	*M*	*SD*	*M*	*SD*
Psycho-Education Only	1.80	0.74	1.80	0.96
Control Group	1.79	0.58	1.63	0.89
EESR Only	2.07	0.64	1.82	0.70
EESR + Psycho-Education	2.04	0.75	2.21	0.58

Table 57 presents results of mixed ANOVA for maladaptive coping with stressful life events after the programme and at follow-up. There were no significant main effects of EESR, $F(1, 20) = 1.20$, $p > .10$, or of psycho-education, $F(1, 20) = 0.28$, $p > .10$ on maladaptive coping with stressful life-events at follow-up; neither was there an interaction effect, $F(1, 20) = 0.03$, $p > .10$.

Table 57

Mixed ANOVA for Maladaptive Coping with Stressful Life Events After the Programme and at Follow-Up

Source	Sum of Squares	df	Mean Square	F	ε^2
EESR	0.94	1	0.94	1.20	0.01
Psycho-Education	0.22	1	0.22	0.28	-0.02
EESR × Psycho-Education	0.02	1	0.02	0.03	-0.03
Time	0.05	1	0.05	0.16	0.00
Time × EESR	0.01	1	0.01	0.02	0.00
Time × Psycho-Education	0.25	1	0.25	0.88	0.00
Time × EESR * Psycho-Education	0.05	1	0.05	0.16	0.00

9.4.3 Social Support

After Intervention

Table 58 shows means for social support before and after the programme, for all conditions. Visual inspection of means showed that the psycho-education-only group and the EESR-only group both exhibited increases in social support after the programme ($M = 4.14$, $SD = 0.59$ and $M = 3.91$, $SD = 0.78$, respectively), compared to pre-intervention levels ($M = 3.88$, $SD = 0.68$ and $M = 3.42$, $SD = 0.70$, respectively). Conversely, the control group and the EESR-and-psycho-education group exhibited decreases in social support after the programme ($M = 2.88$, $SD = 0.35$ and $M = 3.59$, $SD = 1.08$, respectively), compared to pre-intervention levels ($M = 4.00$, $SD = 0.49$ and $M = 3.81$, $SD = 1.07$, respectively).

Table 58

Means for Social Support Before and After the Programme

	Pre-Intervention Social Support		Post-Intervention Social Support	
Group	*M*	*SD*	*M*	*SD*
Control Group	4.00	0.49	2.88	0.35
Psycho-Education Only	3.88	0.68	4.14	0.59
EESR + Psycho-Education	3.81	1.07	3.59	1.08
EESR Only	3.42	0.70	3.91	0.78

Table 59 presents results of the mixed ANOVA for pre-intervention and post-intervention social support. There was a significant interaction effect between time and EESR, $F(1, 27) = 9.29$, $p < .01$, $\varepsilon^2 = 0.03$. Estimated marginal means (see Table 60) showed that participants who had taken part in EESR exhibited increased levels of social support after the programme (*EMM* = 3.75, *SE* = 0.19), compared to before the programme (*EMM* = 3.62, *SE* = 0.19), while participants who had not taken part in EESR exhibited decreased levels after the programme (*EMM* = 3.51, *SE* = 0.20), compared to before the programme (*EMM* = 3.94, *SE* = 0.20).

There was also a significant interaction effect between time and psycho-education, $F(1, 27) = 3.51$, $p < .10$, $\varepsilon^2 = 0.01$. Estimated marginal means (see Table 60) revealed that participants who had taken part in psycho-education showed slightly increased levels of social support after the programme (*EMM* = 3.86, *SE* = 0.20) compared to before the programme (*EMM* = 3.84, *SE* = 0.20), while participants who had not taken part in psycho-education showed decreased levels of social support after the programme (*EMM* = 3.39, *SE* = 0.19) compared to before the programme (*EMM* = 3.71, *SE* = 0.19).

Table 59

Mixed ANOVA for Social Support Before and After the Programme

Source	Sum of Squares	df	Mean Square	F	ε^2
EESR	0.02	1	0.02	0.02	-0.02
Psycho-Education	1.44	1	1.44	1.41	0.01
EESR × Psycho-Education	1.09	1	1.09	1.07	0.00
Time	0.34	1	0.34	2.58	0.01
Time × EESR	1.22	1	1.22	9.29**	0.03
Time × Psycho-Education	0.46	1	0.46	3.51†	0.01
Time × EESR × Psycho-Education	4.24	1	4.24	32.34****	0.10

$^\dagger p < 0.10$, $**p < 0.01$, $****p < 0.0001$

Table 60

Estimated Marginal Means of Social Support for EESR and Psycho-Education

	Pre-Intervention Social Support		Post-Intervention Social Support	
	EMM	*SE*	*EMM*	*SE*
EESR	3.62	0.19	3.75	0.19
No EESR	3.94	0.20	3.51	0.20
Psycho-Education	3.84	0.20	3.86	0.20
No Psycho-Education	3.71	0.19	3.39	0.19

Note. EMM: Estimated Marginal Means.

Finally, the time × EESR × psycho-education interaction was significant, $F(1, 27) = 32.34$, $p < .0001$, $\varepsilon^2 = 0.10$. Simple-effect tests by means of mixed ANOVAs were performed. Firstly, participants who had taken part in EESR were compared on the effect of psycho-education on social support; secondly, participants who had not taken part in EESR were compared on the same. Thirdly, participants who had taken part in psycho-education were compared on the effect of EESR on social support; and finally, participants who had not taken part in psycho-education were compared on the same.

Comparing participants who had taken part in EESR regarding the effect of psycho-education on social support, a significant interaction effect was found between time and

psycho-education, $F(1, 14) = 14.02$, $p < .01$, $\varepsilon^2 = 0.04$. Visual inspection of estimated

marginal means (see Table 61) showed that participants who took part in both EESR and

psycho-education had lower levels of social support after the programme (*EMM* = 3.59,

SE = 0.33) compared to before the programme (*EMM* = 3.81, *SE* = 0.32), whereas

participants who took part in EESR and no psycho-education had higher levels of social

support after the programme (*EMM* = 3.91, *SE* = 0.33), compared to before the

programme (*EMM* = 3.42, *SE* = 0.32). Thus, taking part in EESR appeared to be more

beneficial to social support after the programme, compared to taking part in both EESR

and psycho-education.

Comparing participants who had not taken part in EESR regarding the effect of psycho-

education on social support, a significant interaction effect was found between time and

psycho-education, $F(1, 13) = 18.44$, $p < .001$, $\varepsilon^2 = 0.23$. Visual inspection of estimated

marginal means showed that participants who did not take part in EESR but did take part

in psycho-education had higher levels of social support after the programme (*EMM* = 4.14,

SE = 0.18), compared to before the programme (*EMM* = 3.88, *SE* = 0.22), while

participants who took part in neither EESR nor in psycho-education had lower levels of

social support after the programme (*EMM* = 2.88, *SE* = 0.17) compared to before the

programme (*EMM* = 4.00, *SE* = 0.21). It thus appeared that taking part in psycho-

education was more beneficial to social support levels after the programme, compared to

taking part in neither EESR nor psycho-education.

Furthermore, a main effect was found for time, $F(1, 13) = 6.99$, $p < .05$, $\varepsilon^2 = 0.08$.

Table 61

Estimated Marginal Means for EESR/No EESR

	Condition	Pre-Intervention Social Support		Post-Intervention Social Support	
		EMM	*SE*	*EMM*	*SE*
+EESR	+Psycho-Education	3.81	0.32	3.59	0.33
	-Psycho-Education	3.42	0.32	3.91	0.33
-EESR	+Psycho-Education	3.88	0.22	4.14	0.18
	-Psycho-Education	4.00	0.21	2.88	0.17

Note. EMM: Estimated Marginal Means.

Comparing participants who had taken part in psycho-education regarding the effect of EESR on social support, a significant interaction effect was found between time and EESR, $F(1, 13) = 3.28$, $p < .10$, $\varepsilon^2 = 0.01$. Visual inspection of estimated marginal means (see Table 62) showed that participants who took part in psycho-education but not in EESR had higher levels of social support after the programme (*EMM* = 4.14, *SE* = 0.34) than before the programme (*EMM* = 3.87, *SE* = 0.34), while participants who took part in both psycho-education and EESR had lower levels of social support after the programme (*EMM* = 3.59, *SE* = 0.31) than before the programme (*EMM* = 3.81, *SE* = 0.32). It thus appeared that taking part in psycho-education alone was more beneficial to social support levels after the programme, compared to taking part in both psycho-education and EESR.

Comparing participants who had not taken part in psycho-education regarding the effect of EESR on social support, a significant interaction effect was found between time and EESR, $F(1, 14) = 40.53$, $p < .0001$, $\varepsilon^2 = 0.31$. Visual inspection of estimated marginal means showed that participants who took part in neither psycho-education nor EESR had lower social support after the programme (*EMM* = 2.88, *SE* = 0.21) compared to before the programme (*EMM* = 4.00, *SE* = 0.21), while participants who did not take part in psycho-education but did take part in EESR exhibited higher levels of social support after the programme (*EMM* = 3.91, *SE* = 0.21), compared to before the programme (*EMM* =

3.42, *SE* = 0.21). It thus seemed that taking part in EESR was associated with beneficial

effects on post-intervention social support, compared to taking part in no intervention.

Furthermore, a main effect was found for time, $F(1, 14) = 6.43$, $p < .05$, $\varepsilon^2 = 0.04$.

Table 62

Estimated Marginal Means for Psycho-Education/No Psycho-Education

Condition		Pre-Intervention Social Support		Post-Intervention Social Support	
		EMM	*SE*	*EMM*	*SE*
+Psycho-Education	+EESR	3.81	0.32	3.59	0.31
	-EESR	3.87	0.34	4.14	0.34
-Psycho-Education	+EESR	3.42	0.21	3.91	0.21
	-EESR	4.00	0.21	2.88	0.21

Note. *EMM*: Estimated Marginal Means.

Follow-Up

Table 63 shows means and standard deviations for social support after the programme

and at six-week follow-up, for all conditions. Visual inspection of means showed that

participants in the psycho-education-only and in the EESR-only group exhibited

decreased levels of social support at follow-up (*M* = 3.73, *SD* = 0.41 and *M* = 3.48, *SD* =

0.97, respectively), compared to after the programme (*M* = 4.03, *SD* = 0.61 and *M* = 3.95,

SD = 0.83, respectively). Conversely, control-group participants and those who had taken

part in both EESR and psycho-education exhibited increased levels of social support at

follow-up (*M* = 4.04, *SD* = 0.68 and *M* = 3.73, *SD* = 0.62, respectively), compared to after

the programme (*M* = 2.94, *SD* = 0.28 and *M* = 3.65, *SD* = 1.27, respectively).

Table 63

Means for Social Support Post-Intervention and at Six-Week Follow-Up

	Post-Intervention Social Support		Social Support at Follow-Up	
Group	*M*	*SD*	*M*	*SD*
Psycho-Education Only	4.03	0.61	3.73	0.41
EESR Only	3.95	0.83	3.48	0.97
EESR + Psycho-Education	3.65	1.27	3.73	0.62
Control Group	2.94	0.28	4.04	0.68

Table 64 presents results of mixed ANOVA for social support post-intervention and at follow-up. There was a significant interaction effect between time and EESR, $F(1, 20) = 6.57$, $p < .05$, $\varepsilon^2 = 0.03$. Estimated marginal means (see Table 65) showed that participants who had taken part in EESR exhibited reduced levels of social support at follow-up (*EMM* = 3.61, *SE* = 0.20) compared to after the programme (*EMM* = 3.80, *SE* = 0.23), while participants who had not taken part in EESR had increased levels of social support at follow-up (*EMM* = 3.88, *SE* =0.22) compared to after the programme (*EMM* = 3.48, *SE* = 0.25).

There was also a significant interaction effect between time and psycho-education, $F(1, 20) = 3.44$, $p < .10$, $\varepsilon^2 = 0.01$. Estimated marginal means showed that participants who had taken part in psycho-education exhibited reduced levels of social support at follow-up (*EMM* = 3.73, *SE* = 0.22) compared to after the programme (*EMM* = 3.84, *SE* = 0.25), while participants who had not taken part in psycho-education had increased levels of social support at follow-up (*EMM* = 3.76, *SE* = 0.20) compared to after the programme (*EMM* = 3.44, *SE* = 0.23).

Table 64

Mixed ANOVA for Social Support Post-Intervention and at Follow-Up

Source	Sum of Squares	df	Mean Square	F	ε^2
EESR	0.00	1	0.00	0.00	-0.04
Psycho-Education	0.38	1	0.38	0.35	-0.02
EESR × Psycho-Education	0.50	1	0.50	0.47	-0.02
Time	0.13	1	0.13	0.84	0.00
Time × EESR	1.04	1	1.04	6.57*	0.03
Time × Psycho-Education	0.54	1	0.54	3.44†	0.01
Time × EESR × Psycho-Education	2.82	1	2.82	17.82****	0.09

$^{\dagger}p < .10$, $^*p < .05$, $^{****}p < .0001$

Table 65

Estimated Marginal Means of Social Support for EESR and Psycho-Education

	Post-Intervention Social Support		Social Support at Follow-Up	
	M	*SE*	*M*	*SE*
EESR	3.80	0.23	3.61	0.20
No EESR	3.48	0.25	3.88	0.22
Psycho-Education	3.84	0.25	3.73	0.22
No Psycho-Education	3.44	0.23	3.76	0.20

Finally, the time × EESR × psycho-education interaction was significant, $F(1, 20) = 17.82$, $p < .0001$, $\varepsilon^2 = 0.09$. Simple-effect tests were carried out as described in Sub-Section 9.3.3. Comparing participants who had taken part in EESR regarding the effect of psycho-education on social support at follow-up, no significant main effects or interaction effects were found. The same was the case for comparing participants who had taken part in psycho-education regarding the effect of EESR. However, comparing participants who had not taken part in EESR regarding the effect of psycho-education, a significant interaction effect was found between time and psycho-education, $F(1, 9) = 22.42$, $p < .001$, $\varepsilon^2 = 0.28$. Visual inspection of estimated marginal means (see Table 66) showed

that participants who took part neither in EESR nor in psycho-education had higher levels of social support at follow-up (*EMM* = 4.04, *SE* = 0.24) compared to after the programme (*EMM* = 2.94, *SE* = 0.19), while participants who took part in psycho-education but not in EESR had lower levels of social support at follow-up (*EMM* = 3.73, *SE* = 0.26) compared to after the programme (*EMM* = 4.03, *SE* = 0.24). This means that taking part in neither element of the CEPB was associated with an increase in social support levels at follow-up, compared to taking part in psycho-education but not in EESR.

There was also a significant main effect of time, $F(1, 9) = 7.36$, $p < .05$, $\varepsilon^2 = 0.08$.

Table 66

Estimated Marginal Means for No EESR

	Condition	Post-Intervention Social Support		Social Support at Follow-Up	
		EMM	*SE*	*EMM*	*SE*
-EESR	+Psycho-Education	4.03	0.24	3.73	0.26
	-Psycho-Education	2.94	0.19	4.04	0.24

Comparing participants who had not taken part in psycho-education regarding the effect of EESR, a significant interaction effect was found between time and EESR, $F(1, 11) = 35.79$, $p < .0001$, $\varepsilon^2 = 0.22$. Visual inspection of estimated marginal means (see Table 67) showed that participants who took part in neither psycho-education nor in EESR had higher levels of social support at follow-up (*EMM* = 4.04, *SE* = 0.32) compared to after the programme (*EMM* = 2.93, *SE* = 0.24), while participants who took part in no psycho-education but did take part in EESR had lower levels of social support at follow-up (*EMM* = 3.48, *SE* = 0.35) compared to after the programme (*EMM* = 3.95, *SE* = 0.26). This showed that taking part in neither of the elements of the CEPB was associated with increased levels of social support at follow-up, compared to taking part in EESR only.

There was also a significant main effect of time, $F(1, 11) = 5.97$, $p < .05$, $\varepsilon^2 = 0.03$.

Table 67

Estimated Marginal Means for No Psycho-Education

Condition		Post-Intervention Social Support		Social Support at Follow-Up	
		EMM	*SE*	*EMM*	*SE*
-Psycho-Education	+EESR	3.95	0.26	3.48	0.35
	-EESR	2.93	0.24	4.04	0.32

Note. EMM: Estimated Marginal Means.

9.4.4 Awareness of the Connections between Psychological and Physical Health

After Intervention

Table 68 shows means for awareness of the connections between psychological and physical health before and after the programme, for all conditions. Visual inspection of means showed that the EESR-only group was the only group which exhibited a decrease in awareness after the programme (*M* = 3.83, *SD* = 0.47) compared to before the programme (*M* = 4.08, *SD* = 0.24). The other groups all exhibited increases, with the control group showing the largest increase (*M* = 4.13, *SD* = 0.47 before the programme and *M* = 4.46, *SD* = 0.43 after the programme).

Table 68

Means for Awareness of the Connections between Psychological and Physical Health before and after the CEPB

	Pre-Intervention Awareness		Post-Intervention Awareness	
Group	*M*	*SD*	*M*	*SD*
Psycho-Education Only	4.38	0.68	4.52	0.47
EESR + Psycho-Education	4.33	0.61	4.42	0.57
Control Group	4.13	0.47	4.46	0.43
EESR Only	4.08	0.24	3.83	0.47

Table 69 presents results of the mixed ANOVA for awareness before and after the programme. There was a significant effect of psycho-education on post-intervention awareness, $F(1, 23) = 3.04$, $p < .10$. Visual inspection of estimated marginal means showed that participants who did not take part in psycho-education had lower awareness (*EMM* = 4.13, *SE* = .10) than those who did take part (*EMM* = 4.41, *SE* = .13). However, there was no significant effect of EESR, $F(1, 23) = 1.54$, $p > .10$; nor was there any interaction effect, $F(1, 23) = 0.60$, $p > .10$.

Table 69

Mixed ANOVA for Awareness of the Connections between Psychological and Physical Health Before and After the Programme

Source	Sum of Squares	df	Mean Square	F	ε^2
EESR	0.53	1	0.53	1.54	0.01
Psycho-Education	1.04	1	1.04	3.04[†]	0.05
EESR × Psycho-Education	0.20	1	0.20	0.60	-0.01
Time	0.08	1	0.08	0.55	0.00
Time × EESR	0.32	1	0.32	2.38	0.01
Time × Psycho-Education	0.02	1	0.02	0.12	0.00
Time × EESR × Psycho-Education	0.21	1	0.21	1.58	0.01

[†]$p < .10$

Follow-Up

Table 70 shows means for awareness after the programme and at six-week follow-up, for all conditions. Visual inspection of means showed that both the psycho-education-only group and the control group exhibited decreases in awareness at follow-up (*M* = 4.27, *SD* = 0.76 and *M* = 4.11, *SD* = 0.17 respectively), compared to after the programme (*M* = 4.47, *SD* = 0.51 and *M* = 4.44, *SD* = 0.40 respectively). Conversely, the EESR-only group showed an increase in awareness at follow-up (*M* = 4.08, *SD* = 0.52), compared to after the programme (*M* = 3.95, *SD* = 0.36). The group who had taken part in both EESR and

psycho-education showed no change (*M* = 4.11 both after the programme and at follow-up, *SD* = 0.40 and 0.54 respectively).

Table 70

Means for Awareness of the Connections between Psychological and Physical Health After Intervention and at Six-Week Follow-Up

Group	Post-Intervention Awareness		Awareness at Follow-Up	
	M	*SD*	*M*	*SD*
Psycho-Education Only	4.47	0.51	4.27	0.76
Control Group	4.44	0.40	4.11	0.17
EESR + Psycho-Education	4.11	0.40	4.11	0.54
EESR Only	3.95	0.36	4.08	0.52

Table 71 presents results of mixed ANOVA for awareness after the programme and at follow-up. There was no significant effect of EESR, $F(1, 20) = 2.71$, $p > .10$, or of psycho-education, $F(1, 20) = 0.38$, $p > .10$, on awareness at follow-up; nor was there any interaction effect, $F(1, 20) = 0.01$, $p > .10$.

Table 71

Mixed ANOVA for Awareness of the Connections between Psychological and Physical Health After the Programme and at Follow-Up

Source	Sum of Squares	*df*	Mean Square	*F*	ε^2
EESR	0.84	1	0.84	2.71	0.05
Psycho-Education	0.12	1	0.12	0.38	-0.02
EESR × Psycho-Education	0.00	1	0.00	0.01	-0.03
Time	0.14	1	0.14	1.01	0.00
Time × EESR	0.29	1	0.29	2.08	0.01
Time × Psycho-Education	0.00	1	0.00	0.01	0.00
Time × EESR × Psycho-Education	0.04	1	0.04	0.28	0.00

Examining the results of the thematic analysis, the finding that awareness did not change over time may not be that surprising. Many women seemed to believe that psychological

and physical health were connected, and that psychological problems could impact on one's physical health negatively. White Jasmine stated this at the very beginning of the programme:

> *I believe that emotions play a big role in our physical well being especially if at some level they are unresolved.*

(Page 1, lines 15-16)

Another participant explained her beliefs with regards to stress and breast cancer specifically:

> *It may be possible that stress and breast cancer are connected. Any stress that's experienced must have some affect* [sic] *on our body, unless we are lucky enough to find an outlet.*

(Purple Holly, page 5, lines 100-102)

Orange Rose felt that emotional suppression was linked to physical problems:

> *I definitely think suppressing your feelings can have a physical effect. All that stress and tension has to come out somehow, and if you're working hard and trying to be all things to all people it can be hard to admit you're unhappy even to yourself.*

(Page 8, lines 40-43)

Purple Jasmine had experienced such a connection firsthand:

> *I remember enjoying good health up till the time of Mum's death, then I suffered sore throats and colds a lot. I do believe there is a connection between loss and physical and mental wellbeing.*

(Page 1, lines 24-27)

Purple Ivy presented rather detailed and elaborate ideas about the mechanisms underlying this connection:

> *I do believe stress is* […] *highly toxic to the body as it is known in long term*
>
> *situations to effect every system of the body and can have a marked effect on the*
>
> *immune system making it less able to fight any thing including cells that are turning*
>
> *cancerous. I think sudden shocks can also have the same stressing effect on the*
>
> *body's systems too. So in essence I think stress could well be a contributing factor*
>
> *to cancer getting a hold but not the one and only.*

(Page 3, lines 70-76)

Thus, she had elaborate ideas on the potential pathways to cancer development through

psychological factors having suppressing effects on the immune system, while

simultaneously allowing for other contributing factors. This view is in line with current

findings in psychoneuroimmunological research, as outlined in Chapter Three. However,

in the early weeks of the programme, one participant expressed surprise at the idea of a

connection between emotional suppression and physical health:

> *I never realised that suppressing your negative emotions could actually make you*
>
> *susceptible to illness.*

(Green Rose, page 9, lines 197-198)

Her incredulity regarding this notion is not surprising, given the dominance of the

biomedical model in Western society (Engel, 1977), with its emphasis on biological

processes (van Wersch, Forshaw and Cartwright, 2009). Still, regardless of the nature of

the relationship, a connection between physical health and psychosocial factors seemed

plausible to most participants, and some had experienced the extent of this relationship

first-hand. Purple Holly summed up her experience of the CEPB as follows:

> *I don't think* [the CEPB] *has made me think differently about health and illness, but*
>
> *more aware of taking care of myself, talking more openly about things, and more*

> *importantly, letting go of issues that necessarily don't need to take up thought time.*
>
> *Overall it's made me more aware, for which I'm very grateful.*
>
> *I'm sorry the programme has come to an end as I've got a lot out of it* [...]*!*

(Page 6, lines 128-131)

It thus seems that for her, rather than becoming more aware of the connection between physical and psychological health, an increase of the awareness of the importance of her own emotional health had taken place. It is likely that this was the case for other participants. This, however, was not measured by the items assessing awareness of the connections between psychological and physical health.

9.4.5 Conformity

After Intervention

Table 72 shows means for conformity before and after the programme, for all conditions. Visual inspection of means showed that the EESR-only group was the only group which exhibited an increase in conformity levels after the programme ($M = 2.38$, $SD = 0.25$) compared to before the programme ($M = 2.33$, $SD = 0.28$). The other groups all showed decreases in conformity levels, with the largest decrease being observed in the psycho-education-only group ($M = 2.43$, $SD = 0.15$ before the programme and $M = 2.33$, $SD = 0.23$ after the programme).

Table 72

Means for Conformity Before and After the Programme

Group	Pre-Intervention Conformity		Post-Intervention Conformity	
	M	*SD*	*M*	*SD*
Control Group	2.10	0.33	2.08	0.21
EESR + Psycho-Education	2.13	0.23	2.04	0.32
EESR Only	2.33	0.28	2.38	0.25
Psycho-Education Only	2.43	0.15	2.33	0.23

Table 73 presents results of the mixed ANOVA for conformity before and after the programme. There were no significant effects of EESR, $F(1, 27) = 0.06$, $p > .10$, or of psycho-education, $F(1, 27) = 0.02$, $p > .10$, on post-intervention conformity. There was, however, a significant interaction effect, $F(1, 27) = 14.30$, $p < .001$. Visual inspection of estimated marginal means showed that participating in either EESR (*EMM* = 2.35, *SE* =0.07), or in psycho-education (*EMM* = 2.38, *SE* = 0.08) was associated with higher conformity than participating in neither (*EMM* = 2.09, *SE* = 0.07), or in both (*EMM* = 2.08, *SE* = 0.07).

Table 73

Mixed ANOVA for Conformity Before and After the Programme

Source	Sum of Squares	*df*	Mean Square	*F*	ε^2
EESR	0.01	1	0.01	0.06	-0.02
Psycho-Education	0.00	1	0.00	0.02	-0.02
EESR × Psycho-Education	1.21	1	1.21	14.30****	0.23
Time	0.03	1	0.03	0.53	0.00
Time × EESR	0.01	1	0.01	0.15	0.00
Time × Psycho-Education	0.04	1	0.04	0.90	0.00
Time × EESR * Psycho-Education	0.00	1	0.00	0.08	0.00

****$p < .001$

Follow-Up

Table 74 shows means for conformity after the programme and at six-week follow-up, for all conditions. Visual inspection of means showed that both the EESR-plus-psycho-education group and the control group exhibited increases in conformity levels at follow-up (M = 2.12, SD = 0.33 and M = 2.22, SD = 0.40 respectively), compared to after the programme (M = 2.00, SD = 0.30 and M = 2.07, SD = 0.24 respectively). Conversely, the EESR-only group displayed a decrease (M = 2.36, SD = 0.27 after the intervention and M = 2.14, SD = 0.44 at follow-up). The psycho-education-only group exhibited no change.

Table 74

Means for Conformity Post-Intervention and at Six-Week Follow-Up

	Post-Intervention Conformity		Conformity at Follow-Up	
Group	*M*	*SD*	*M*	*SD*
EESR + Psycho-Education	2.00	0.30	2.12	0.33
Control Group	2.07	0.24	2.22	0.40
EESR Only	2.36	0.27	2.14	0.44
Psycho-Education Only	2.38	0.22	2.38	0.23

There was a significant interaction effect of EESR × psycho-education, F (1, 20) = 3.55, p < .10. Visual inspection of estimated marginal means showed that participating in neither conditions (EMM = 2.14, SE = 0.11) or in both conditions (EMM = 2.06, SE = 0.11) was associated with lower levels of conformity at follow-up than participating in either EESR alone (EMM = 2.25, SE = 0.11) or in psycho-education alone (EMM = 2.38, SE =0.12). Furthermore, the time × EESR × psycho-education interaction was significant (see Table 75), F(1, 20) = 3.51, p < .10, ε^2 = 0.02. Simple-effect tests were performed, as described in Sub-Section 9.3.3.

Table 75

Mixed ANOVA for Conformity Post-Intervention and at Follow-Up

Source	Sum of Squares	df	Mean Square	F	ε^2
EESR	0.14	1	0.14	0.87	0.00
Psycho-Education	0.01	1	0.01	0.04	-0.03
EESR × Psycho-Education	0.55	1	0.55	3.55†	0.08
Time	0.00	1	0.00	0.04	0.00
Time × EESR	0.05	1	0.05	0.93	0.00
Time × Psycho-Education	0.02	1	0.02	0.50	0.00
Time × EESR × Psycho-Education	0.17	1	0.17	3.51†	0.02

$^\dagger p < .10$

Comparing women who had not taken part in EESR regarding the effects of psycho-education on conformity at follow-up, no significant main or interaction effects were found. The same was the case comparing women who had taken part in psycho-education, and women who had not taken part in psycho-education, regarding the effects of EESR on conformity at follow-up. However, comparing women who had taken part in EESR, a significant interaction effect was found between time and psycho-education, $F(1, 11) = 6.99$, $p < .05$, $\varepsilon^2 = 0.05$. Visual inspection of estimated marginal means (see Table 76) showed that participants who took part in EESR but not in psycho-education had lower levels of conformity at follow-up than after the programme, while participants who took part in both EESR and psycho-education had higher levels of conformity at follow-up compared to after the programme. This suggests that taking part in EESR-only was beneficial to conformity at follow-up, compared to taking part in both elements of the CEPB.

Table 76

Estimated Marginal Means for EESR

	Condition	Post-Intervention Conformity		Conformity at Follow-Up	
		EMM	*SE*	*EMM*	*SE*
+EESR	+Psycho-Education	2.00	0.12	2.12	0.16
	-Psycho-Education	2.36	0.11	2.14	0.15

Note. EMM: Estimated Marginal Means

9.5 Analysis of Coping Styles

Conceptual content analysis revealed 27 mutually exclusive categories of perceived

stressors. The inter-rater reliability was satisfactory (k = 0.77, 80% agreement).

9.5.1 Bereavement Coping Styles

Table 77 presents the frequencies and percentage frequencies of coping styles for

bereavement coping before the programme, after the programme and at six-week follow-

up for experimental groups and control group. (See Chapter Five, Table 9 for definitions of

coping styles.) The most-frequently reported bereavement coping styles before the

programme for the experimental groups were emotional social support, situational

redefinition, instrumental social support, isolation and secondary control, with all these

coping styles being reported equally frequently (13%). The most-frequently reported pre-

intervention bereavement coping style for the control group was emotional social support

(38%), followed by struggling to cope (25%) and escapism (13%). There was a wider

variety of coping styles reported in the experimental groups than in the control group.

After the intervention, the most-frequently reported bereavement coping style in the

experimental groups was struggling to cope (30%), followed by secondary control (22%).

It thus appeared that for these groups there was an increase in potentially problematic

coping styles after the programme. For the control group, on the other hand, emotional

social support was the most frequent bereavement coping style post-intervention (75%), followed by situational redefinition and acceptance, which were both reported equally frequently (13%). Thus, for the control group there was an increase in potentially constructive coping styles.

At six-week follow-up, the most-frequent bereavement coping style reported by the experimental groups was secondary control (22%). Situational redefinition, emotional release, emotional suppression and struggling to cope ranked second and were all reported equally frequently (11%). The initial increase in potentially problematic coping styles after the programme therefore no longer held true at follow-up, where the increase in secondary control pointed towards a more passive way of coping. For the control group, emotional social support was still the most-frequently reported bereavement coping style at follow-up (33%); this bereavement coping style thus was consistently the most-common one for the control group.

Table 77

Bereavement Coping Styles Before Programme, After Programme and at Six-Week

Follow-Up

Coping Style	Before Intervention				After intervention				Six-Week Follow-Up			
	Experimental groups		Control group		Experimental groups		Control group		Experimental groups		Control group	
	f	*%f*	*f*	*%f*	*f*	*%f*	*f*	*%f*	*f*	*%f*	*f*	*%f*
Emotional social support	3	13.0	3	37.5	2	8.7	6	75.0	1	5.6	2	33.3
Situational redefinition	3	13.0	0	0.0	1	4.3	1	12.5	2	11.1	1	16.7
Escapism	0	0.0	1	12.5	0	0.0	0	0.0	0	0.0	0	0.0
Keeping busy	1	4.3	0	0.0	1	4.3	0	0.0	0	0.0	0	0.0
Emotional release	1	4.3	0	0.0	1	4.3	0	0.0	2	11.1	1	16.7
Instrumental social support	3	13.0	0	0.0	2	8.7	0	0.0	1	5.6	0	0.0
Isolation	3	13.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
Acceptance	2	8.7	0	0.0	2	8.7	1	12.5	1	5.6	0	0.0
Secondary control	3	13.0	0	0.0	5	21.7	0	0.0	4	22.2	0	0.0
Emotional suppression	1	4.3	0	0.0	1	4.3	0	0.0	2	11.1	0	0.0
Avoidance	1	4.3	0	0.0	1	4.3	0	0.0	1	5.6	0	0.0
Struggling to cope (no specific style)	1	4.3	2	25.0	7	30.4	0	0.0	2	11.1	1	16.7
Coping by supporting others	1	4.3	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
Medication	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	1	16.7
MISSING	0	0.0	1	12.5	0	0.0	0	0.0	2	11.1	0	0.0
TOTAL	23	100	7	100	23	100	8	100	18	100	6	100

Note. Percentages may not add up to 100 due to rounding.

9.5.2 Coping Styles Employed in Response to Most Stressful Life Events

Table 78 presents the frequencies and percentage frequencies of coping styles in

response to most stressful life events before the programme, after the programme and at

six-week follow-up for experimental groups and control group. The most-frequently

reported coping style before the programme for the experimental groups was secondary

control (26%), followed by emotional social support and direct action, which were both

reported equally frequently (13%). Therefore, a passive approach to coping was most

common in these groups. In the control group, the most-frequently reported pre-

intervention coping style was emotional social support (38%), followed by direct action

(25%); these both constituted more active ways of coping.

After the programme, the most frequent coping style reported by the experimental groups was secondary control (22%), followed by instrumental social support (17%) and direct action (13%). For the control group, situational redefinition and secondary control were most common (25% each). It thus seemed that after the programme, active coping styles were more common in the experimental groups than in the control group.

At follow-up, there was no single most-common coping style for the experimental groups. Emotional release, instrumental social support, acceptance, secondary control, struggling to cope and avoidance were all reported equally frequently (11%). For the control group, secondary control was the most common strategy (22%). It therefore appeared that at follow-up, a larger proportion of experimental-group participants were using constructive ways of coping than control-group participants.

9.5.3 Coping Styles Employed in Response to Second-Most Stressful Life Events

Table 79 presents the frequencies and percentage frequencies of coping styles in response to second-most stressful life events before the programme, after the programme and at six-week follow-up for experimental groups and control group. The most-frequently reported pre-intervention coping style for the experimental groups was secondary control (26%), followed by instrumental social support (22%) and struggling to cope (13%). The control group most-frequently reported situational redefinition (25%).

After the programme, the most frequent coping style reported by the experimental groups was emotional social support (22%), followed by struggling to cope (17%) and secondary control (13%). Thus although there was an increase in constructive coping in the form of emotional social support, problems with coping had also increased. In contrast, in the control group no specific coping style emerged most frequently.

At follow-up, secondary control was the coping style employed by the majority of experimental group participants (39%), while avoidance was the second-most frequent (17%). This shows that an improvement had taken place in the form of less problematic coping styles. Again, no specific coping style emerged as the most frequent style for the control group.

Table 78

Coping Styles in Response to Most Stressful Life Events Before Programme, After Programme and at Six-Week Follow-Up

Coping Style	Before Intervention				After Intervention				Six-Week Follow-Up			
	Experimental groups		Control group		Experimental groups		Control group		Experimental groups		Control group	
	f	%f	f	%f	f	%f	f	%f	f	%f	f	%f
Emotional social support	3	13.0	3	37.5	2	8.7	1	12.5	0	0.0	1	16.7
Situational redefinition	0	0.0	0	0.0	0	0.0	2	25.0	1	5.6	1	16.7
Direct Action	3	13.0	2	25.0	3	13.0	1	12.5	1	5.6	0	0.0
Escapism	0	0.0	1	12.5	1	4.3	0	0.0	0	0.0	0	0.0
Relaxation	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
Keeping busy	2	8.7	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
Self-motivation	0	0.0	0	0.0	0	0.0	0	0.0	1	5.6	0	0.0
Emotional release	0	0.0	0	0.0	1	4.3	0	0.0	2	11.1	0	0.0
Instrumental social support	2	8.7	1	12.5	4	17.4	0	0.0	2	11.1	0	0.0
Religion	1	4.3	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
Isolation	0	0.0	1	12.5	0	0.0	0	0.0	1	5.6	0	0.0
Acceptance	0	0.0	0	0.0	0	0.0	1	12.5	2	11.1	0	0.0
Constraint	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
Secondary control	6	26.1	0	0.0	5	21.7	2	25.0	2	11.1	2	33.3
Emotional suppression	1	4.3	0	0.0	0	0.0	0	0.0	1	5.6	0	0.0
Coping by supporting others	1	4.3	1	12.5	0	0.0	0	0.0	0	0.0	0	0.0
Struggling to cope (no specific style)	1	4.3	1	12.5	4	17.4	0	0.0	2	11.1	0	0.0
Avoidance	1	4.3	0	0.0	1	4.3	0	0.0	1	11.1	1	16.7
Medication (e.g. anti-depressants)	0	0.0	0	0.0	0	0.0	1	12.5	0	0.0	1	16.7
Ongoing attempts to cope (no specific style)	0	0.0	0	0.0	2	8.7	0	0.0	0	0.0	0	0.0
MISSING	0	0.0	0	0.0	0	0.0	0	0.0	2	11.1	0	0.0
TOTAL	23	100	8	100	23	100	8	100	16	100	6	100

Note. Percentages may not add up to 100 due to rounding.

Table 79

Coping Styles in Response to Second-Most Stressful Life Events Before Programme,

After Programme and at Follow-Up

Coping Style	Before Intervention				After Intervention				Six-Week Follow-Up			
	Experimental groups		Control group		Experimental groups		Control group		Experimental groups		Control group	
	f	%f	f	%f	f	%f	f	%f	f	%f	f	%f
Emotional social support	2	8.7	0	0.0	5	21.7	1	12.5	1	5.6	1	16.7
Situational redefinition	1	4.3	2	25.0	2	8.7	1	12.5	1	5.6	1	16.7
Direct Action	1	4.3	0	0.0	2	8.7	1	12.5	0	0.0	0	0.0
Escapism	0	0.0	1	12.5	0	0.0	0	0.0	0	0.0	1	16.7
Relaxation	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
Keeping busy	2	8.7	0	0.0	0	0.0	1	0.0	0	0.0	0	0.0
Denial	1	4.3	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
Emotional release	0	0.0	0	0.0	1	4.3	0	0.0	0	0.0	0	0.0
Instrumental social support	5	21.7	1	12.5	1	4.3	1	12.5	1	5.6	0	0.0
Optimism	0	0.0	0	0.0	1	4.3	0	0.0	0	0.0	0	0.0
Isolation	0	0.0	1	12.5	0	0.0	0	0.0	0	0.0	0	0.0
Acceptance	2	8.7	0	0.0	2	8.7	0	0.0	0	0.0	0	0.0
Secondary control	6	26.1	1	12.5	3	13.0	1	12.5	7	38.9	0	0.0
Checking procedures	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
Struggling to cope (no specific style)	3	13.0	0	0.0	4	17.4	1	12.5	0	0.0	1	16.7
Avoidance	0	0.0	0	0.0	2	8.7	1	12.5	3	16.7	1	16.7
Coping by supporting others	0	0.0	0	0.0	0	0.0	0	0.0	1	5.6	0	0.0
Ongoing attempts to cope (no specific style)	0	0.0	0	0.0	0	0.0	0	0.0	2	11.1	0	0.0
Medication (e.g. anti-depressants)	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	1	16.7
MISSING	0	0.0	2	25.0	0	0.0	0	0.0	2	11.1	0	0.0
TOTAL	23	100	6	100	23	100	8	100	16	100	6	100

Note. Percentages may not add up to 100 due to rounding.

9.5.4 Coping Styles Employed in Response to Most Stressful Life Events in the Past Year

Table 80 presents the frequencies and percentage frequencies of coping styles in

response to most stressful life events in the past year before the programme, after the

programme and at six-week follow-up for experimental groups and control group. The

most-frequently reported coping style before the programme for the intervention group

was struggling to cope (30%), followed by equal frequencies (13% each) for emotional

social support, direct action and acceptance. Direct action was the most-frequent coping style for the control group (38%).

After the programme, 22% of experimental group participants reported struggling to cope, 13% reported acceptance, and direct action, planning and instrumental social support were reported with equal frequency (9%). Hence, difficulties with coping had reduced, and constructive ways of coping had increased for the experimental groups. By contrast, no single coping style emerged as most frequent for the control group. At follow-up, both emotional social support and coping by supporting others emerged as the most-frequent coping styles (22% each), while secondary control and struggling to cope emerged as second-most frequent (11%). Thus, there was a further reduction in problems with coping. By contrast, in the control group, a less constructive coping style in the form of irrelevant means was the most frequent coping style employed (33%).

9.5.5 Coping Styles Employed in Response to Second-Most Stressful Life Events in the Past Year

Table 81 presents the frequencies and percentage frequencies of coping styles in response to second-most stressful life events in the past year before the programme, after the programme and at six-week follow-up for experimental groups and control group. The most-frequently reported coping style for the intervention group before the programme was secondary control (22%), followed by both emotional social support and situational redefinition (17% each). Emotional social support and direct action were the most-frequently reported coping styles for the control group (25% each). After the programme, four coping styles emerged as equally frequent with 13% each: emotional social support, instrumental social support, acceptance and struggling to cope. Thus, it appeared that although intervention-group participants were more likely to seek social support as a way of coping, problems with coping had also increased slightly. For the control group, however, no single coping style emerged as the most common style. At follow-up, direct

action and acceptance were the most common coping styles for the experimental groups (22% each), showing a tendency to either cope more actively or accept events that could not be influenced. Similarly, for the control group direct action was most common (33%).

Table 80

Coping Styles in Response to Most Stressful Life Events in the Past Year before Programme, after Programme and at Six-Week Follow-Up

Coping Style	Before Intervention				After Intervention				Six-Week Follow-Up			
	Experimental groups		Control group		Experimental groups		Control group		Experimental groups		Control group	
	f	%f	f	%f	f	%f	f	%f	f	%f	f	%f
Emotional social support	3	13.0	0	0.0	1	4.3	1	12.5	4	22.2	0	0.0
Situational redefinition	1	4.3	1	12.5	1	4.3	1	12.5	1	5.6	1	16.7
Direct Action	3	13.0	3	37.5	2	8.7	0	0.0	1	5.6	1	16.7
Escapism	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
Relaxation	1	4.3	1	12.5	1	4.3	1	12.5	0	0.0	0	0.0
Keeping busy	1	4.3	0	0.0	1	4.3	0	0.0	0	0.0	0	0.0
Irrelevant means	0	0.0	0	0.0	0	0.0	1	12.5	0	0.0	2	33.3
Planning	0	0.0	0	0.0	2	8.7	0	0.0	0	0.0	0	0.0
Emotional release	0	0.0	0	0.0	1	4.3	0	0.0	1	5.6	0	0.0
Instrumental social support	0	0.0	0	0.0	2	8.7	0	0.0	1	5.6	0	0.0
Isolation	0	0.0	1	12.5	0	0.0	0	0.0	1	5.6	0	0.0
Acceptance	3	13.0	0	0.0	3	13.0	0	0.0	0	0.0	0	0.0
Constraint	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
Secondary control	2	8.7	1	12.5	2	8.7	1	12.5	2	11.1	0	0.0
Struggling to cope (no specific style)	7	30.4	1	12.5	5	21.7	1	12.5	2	11.1	0	0.0
Coping by supporting others	2	8.7	0	0.0	0	0.0	0	0.0	4	22.2	1	16.7
Emotional suppression	0	0.0	0	0.0	1	4.3	0	0.0	0	0.0	0	0.0
Ongoing attempts to cope (no specific style)	0	0.0	0	0.0	1	4.3	0	0.0	1	5.6	0	0.0
MISSING	0	0.0	0	0.0	0	0.0	2	25.0	0	0.0	1	16.7
TOTAL	23	100	8	100	23	100	6	100	18	100	5	100

Note. Percentages may not add up to 100 due to rounding.

9.6 Participants' Evaluation of the CEPB

Table 82 presents participants' evaluation of the CEPB through the post-intervention questionnaire. Women who took part in the psycho-education-only condition rated the programme as most helpful (M = 4.00, SD = 0.82), while women who participated in the EESR-plus-psycho-ecducation-condition rated it as most enjoyable (M = 3.88, SD = 0.64)

and most useful (M = 3.88, SD = 0.84). Overall, the programme was perceived as helpful (M = 3.74, SD = 0.86), enjoyable (M = 3.48, SD = 0.85) and useful (M = 3.70, SD = 0.77).

Table 81

Coping Styles in Response to Second-Most Stressful Life Events in the Past Year before Programme, after Programme and at Six-Week Follow-Up

Coping Style	Before Intervention				After Intervention				Six-Week Follow-Up			
	Experimental groups		Control group		Experimental groups		Experimental groups		Control group		Experimental groups	
	f	*%f*	*f*	*%f*	*f*	*%f*	*f*	*%f*	*f*	*%f*	*f*	*%f*
Emotional social support	4	17.4	2	25.0	3	13.0	1	12.5	2	11.1	0	0.0
Situational redefinition	4	17.4	1	12.5	1	4.3	1	12.5	2	11.1	1	16.7
Direct Action	3	13.0	2	25.0	2	8.7	1	12.5	3	22.2	2	33.3
Escapism	1	4.3	0	0.0	0	0.0	1	12.5	0	0.0	0	0.0
Relaxation	0	0.0	1	12.5	2	8.7	0	0.0	0	0.0	0	0.0
Keeping busy	0	0.0	0	0.0	0	0.0	1	12.5	0	0.0	0	0.0
Irrelevant means	0	0.0	0	0.0	0	0.0	1	12.5	0	0.0	0	0.0
Emotional release	0	0.0	0	0.0	0	0.0	0	0.0	1	5.6	0	0.0
Instrumental social support	1	4.3	0	0.0	3	13.0	0	0.0	0	0.0	0	0.0
Acceptance	0	0.0	0	0.0	3	13.0	0	0.0	2	22.2	0	0.0
Constraint	0	0.0	0	0.0	0	4.3	0	0.0	0	0.0	0	0.0
Secondary control	5	21.7	0	0.0	2	8.7	1	12.5	2	11.1	1	16.7
Coping by supporting others	2	8.7	1	12.5	0	0.0	0	0.0	1	5.6	0	0.0
Struggling to cope (no specific style)	2	8.7	0	0.0	3	13.0	1	12.5	1	5.6	0	0.0
Avoidance	1	4.3	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
Emotional suppression	0	0.0	0	0.0	1	4.3	0	0.0	0	0.0	0	0.0
Ongoing attempts to cope (no specific style)	0	0.0	0	0.0	0	0.0	0	0.0	2	11.1	0	0.0
Medication (e.g. anti-depressants)	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	1	16.7
MISSING	0	0.0	1	12.5	1	4.3	0	0.0	2	11.1	1	16.7
TOTAL	23	100	7	100	23	100	8	100	16	100	5	100

Note. Percentages may not add up to 100 due to rounding.

Table 82

Programme Evaluation by Participants according to Helpfulness, Enjoyableness and

Usefulness

Programme Aspect	EESR		Psycho-Education		EESR + Psycho-Education		Overall	
	M	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*
Helpfulness	3.38	1.06	4.00	0.82	3.88	0.64	3.74	0.86
Enjoyableness	3.25	0.89	3.29	0.95	3.88	0.64	3.48	0.85
Usefulness	3.38	0.74	3.86	0.69	3.88	0.84	3.70	0.77
	n = 8		*n* = 7		*n* = 8		*N* = 23	

Note. Responses measured on 5 point Likert scale (1 = very unhelpful/ very unenjoyable / very unuseful; 5 = very helpful/ very enjoyable / very useful).

9.6.1 Perceived Benefits, Drawbacks and Suggestions for Improvement

Conceptual content analysis revealed nine mutually exclusive categories of perceived

intervention programme benefits, eight mutually exclusive categories of perceived

intervention programme drawbacks, ten mutually exclusive categories of suggestions for

improvement and seven mutually exclusive categories of additional comments made. The

inter-rater reliability was satisfactory (k = 0.80, 84% agreement).

Perceived Intervention Programme Benefits ("Is there anything you particularly liked about the programme?")

Table 83 presents the frequencies and percentage frequencies of perceived benefits of

the intervention. The most-frequent perceived benefit was the input, support and advice

given to participants by the researcher (32%). The second-most-frequent benefit

consisted of an ability to understand oneself better as a result of reflecting on one's

experiences and behaviours, as a result of the CEPB (19%). Finally, sharing was the

third-most-frequent perceived benefit, with participants valuing the opportunity to read

about other women's experiences and opinions, as well as sharing one's own experiences

and opinions (13%).

Table 83

Perceived Benefits of the CEPB as Indicated by Participants in the Post-Intervention

Questionnaire

Perceived Benefit	*f*	*%f*
Support Perceived value of input, support and advice received from researcher	10	32.3
Reflection Ability to understand oneself better as a result of reflecting on one's experiences and behaviours, as a result of the intervention programme	6	19.4
Sharing Opportunity to read about other women's experiences and opinions, as well as sharing one's own experiences and opinions	4	12.9
Important Contribution to Knowledge Perceived importance of research examining the connection between physical and emotional health	3	9.7
Blogging Opportunity to write about issues or experiences one wouldn't normally talk about, and receiving advice and support from the researcher in response to one's blog entries	3	9.7
Shift in Perspective Ability to put things into perspective and realise that there are others who are worse off, as a result of the intervention programme	2	6.5
Anonymity Anonymity of participation	1	3.2
Emotional Release Ability to get things off one's chest	1	3.2
Exploring Ideas Opportunity to explore ideas	1	3.2
Total	31	100

Note. Percentages may not add up to 100 due to rounding.

Several of these benefits were also mentioned by participants in message board postings

or blog entries. For example, the interaction with the researcher (i.e. the author of the

present thesis), through her contribution of replies and comments to all blog and message

board postings, was perceived as helpful by some participants. One woman commented

on the researcher's contributions to her blog:

> *I have quite enjoyed writing this diary and I have found the* [researcher's]
>
> *comments quite useful and thought provoking!*

<div align="right">(Orange Iris, page 13, lines 278-279)</div>

Similarly, Red Blossom found the researcher's comments on her blog postings useful:

> *Thank you for all your responses to my blog, it's been really helpful to know that*
>
> *someone was willing to listen to me and offer helpful advice.*

<div align="right">(Page 26, lines 415-416)</div>

In response to advice offered by the researcher to access the social support available in her environment, Green Rose wrote:

> *Thank you for your note* [researcher]*. I will see if I can go out with a friend*.

<div align="right">(Page 4, line 75)</div>

Another participant wrote about her father dying on the penultimate day of the programme. After the researcher had offered to keep her blog available for a longer period of time, she responded:

> *Thank you for keeping the blog open for me for a bit longer. My dad's funeral is on*
>
> *Thursday*.

<div align="right">(Yellow Daisy, page 13, lines 291-292)</div>

Thus, the advice and support offered by the researcher during the course of the programme seemed to be useful to participants. As outlined in Chapter Six, the researcher's interaction with participants was based on Roger's (1951) core conditions of person-centred therapy. Among these are the principles of therapist-congruence, whereby the therapist is deeply involved in and draws on her own experiences to facilitate the relationship; unconditional positive regard, which entails that the therapist accepts the client unconditionally, facilitating self-regard in the client; and therapist empathic

understanding, which means that the therapist has an empathic understanding of the client's internal frame of reference. Lambert and Barley (2001) claimed that core conditions such as empathy, warmth, and the therapeutic relationship have been shown to correlate more highly with clients' outcome than specialised treatment interventions. This underlines the importance of a good therapeutic relationship when considering a particular client's experience of an intervention. It is possible that the interaction between researcher and participants was perceived as helpful due to the researcher's adherence to person-centred principles.

Mirroring two of the benefits found through content analysis, some participants stated that certain elements had helped them reflect on their own lives and put things into perspective. As White Rose, who had participated in EESR and psycho-education, put it:

> *Most of the* [health-related autobiographical accounts] *I've been able to relate to because of recently recovering from cancer. It's made me look at my life over the last 18-24 months and realise it's been one of the most stressful in my life and I wonder if that has contributed if not caused my cancer. It has also made me reflect on my life and I am currently in the process of making life changes to have a less stressful life because health is far more important.*

> (Page 11, lines 232-238)

White Rose's resolve to take stress-reducing measures in order to improve her health and quality of life as a result of the programme is a desirable outcome and in line with the aims of the CEPB.

Pink Fern, who too had participated in both EESR and psycho-education, also felt that her participation in the programme had helped her put things into perspective, which she was grateful for:

> *Now the 8 weeks have gone by quickly I wanted to officially say thank you to* [the researcher] *for helping me put things in order in my head. I have enjoyed the past 8 weeks and have definitely gained something from it. Sometimes it made me really sad and upset but other times it made me accept things I hadn't done. Having an outsider tell me things I think I knew has put things in perspective.*

<div align="right">(Page 3, lines 51-56)</div>

A shift in perspective had also occurred for Yellow Jasmine, who had taken part in psycho-education only:

> *The whole experience of this emotional health exercise has definitely been very emotional for me. It has had me in tears sometimes when I have been answering - a good thing maybe when you feel it's better to let it out than hold it in! It has made me realise how privileged I am to have such good friends and family.* […] *I have total respect and admiration for the people in the group or in the health stories who have battled through and are able to talk about their experiences in the hope of helping others. I feel quite humbled when I read what they have gone through.*

<div align="right">(Page 6, lines 131-140)</div>

White Fern, who had taken part in both EESR and psycho-education, stated that taking part in the programme had resulted in a shift of focus on living, rather than dying, as well as thinking more about her own needs:

> *I have enjoyed doing the project, it has helped me focus on living and not dying, and help me reflect on what I need and not what I want. Thank you.*

<div align="right">(Page 21, lines 449-451)</div>

This shift in focus from dying towards living in White Fern could be viewed as a shift from hopelessness towards hopefulness. As mentioned above, hopelessness, one of the

features of the 'breast-cancer prone' personality, has been found to be associated with shorter survival times in breast cancer than the presence of a 'fighting spirit' (Greer, Morris and Pettingale, 1979), while a positive outlook on a difficult situation tends to have psychological benefits because it acts as a stress buffer (Eschleman, Bowling and Alarcon, 2010). Therefore, White Fern's change in focus is most likely to be associated with positive health outcomes, in addition to psychological benefits.

Towards the end of the programme, Pink Fern reflected on the experience:

> *All of the emotions have made me think a lot... sometimes upsetting me and other times putting things into perspective… It also made me realise that no matter how bad things seem to have been or are for me there are others out there for whom things are way way worse, it's been a kinda kick in the pants…* […] *Have enjoyed the questions and can't believe that it's nearly all over...*

<div align="right">(Page 30, lines 636-646)</div>

Similar to the finding that anonymity was regarded as a positive aspect of the CEPB, one woman mentioned privacy as a further positive aspect, explaining that she had kept a public blog in the past, but preferred the fact that the blog she was keeping on the CEPB Web site was private:

> *I think I do prefer that this blog is private. I find it very hard to express myself in person (especially about personal issues) but I feel I can explain my thinking better in writing. However if I knew that my friends and family might read it then I definitely wouldn't be honest in what I was writing; I always find I'm trying to hide my true self from them.*

<div align="right">(Red Blossom, page 11, lines 222-226)</div>

She thus felt that the privacy of her blog, with only the facilitator and herself being able to read the entries, allowed her to express herself more freely and honestly. Her distinction between true self and social self can be found in Goffman's (1959) distinction between public and private self as part of self-presentation theory, or in Levinas' (1968; cited in van Wersch, Forshaw and Cartwright, 2009) concept of the 'en-soi' (inner self) and 'pour-soi' (social self). It is thinkable that the discrepancy between inner and social self would be particularly strong for the 'breast-cancer prone' individual, who is concerned about hiding her true emotions from others, to appease and conform to others' expectations. It is likely that this discrepancy could lead to considerable psychological discomfort in the long run. Red Blossom's blog afforded her with an opportunity to reveal more of her private self to the facilitator, which in turn enabled the facilitator to foster a therapeutic relationship with her.

The final perceived benefit that also emerged through qualitative analysis was that of the CEPB offering an important contribution to knowledge. Purple Ivy, who had been part of the autobiographical accounts-only condition, explained how she believed that interventions focusing on the connection between emotional and physical health should become part of the services offered by the NHS:

> […] *it seems to me that there is money in research for new drugs, new treatments, the kind of thing that is all bells and whistles, that will make the drug company a fortune as and when it works but there is not so much money out there for research into already known drugs like aspirin (a big long term randomised, placebo controlled trial is needed but no-one will fund it because no-one will make anything out of it in the long run except those whose lives are saved of course), or foods, or the role of emotions because there is no money in the outcomes. Actually in the whole area of emotions it could even end up costing more because our dear old NHS* […] *would then have to look to helping people with emotional need,*

> *psychological need much earlier. I so do think the role of emotional health is under*
>
> *recognised and I suppose getting the recognition is a start, with a view to putting*
>
> *programmes in place for the long term.*

(Page 14, lines 273-286)

To summarise, several of the perceived benefits of the CEPB which emerged through content analysis were also found as part of the thematic analysis of participants' message board and blog postings.

Perceived Intervention Programme Drawbacks ("Is there anything you particularly disliked about the programme?")

Table 84 presents the frequencies and percentage frequencies of perceived drawbacks of the intervention. It was most frequently reported that the programme had no perceived drawbacks (26%), followed by problems with using the Web site, specifically relating to its navigation as well as some participants' log-in session timing out during the drafting of a blog entry or message-board posting, which led to these individuals losing what they had written (16%). Finally, a lack of participation from other group members on the message boards, which resulted in a lack of interaction between participants as well as in a dearth of contributions to the message boards, was noted as a drawback (13%).

Table 84

Perceived Drawbacks of the CEPB as Indicated by Participants in the Post-Intervention

Questionnaire

Perceived Drawback	*f*	*%f*
None No perceived drawbacks	8	25.8
Web Site Usability Problems Problems related to Web site usability: site navigation, log-in timeout resulting in the loss of one's blog entry or message board posting	5	16.1
Participation Lack of participation from other group members, resulting in a lack of interaction between participants as well as a dearth of contributions to the message boards	4	12.9
Repetitiveness Repetitiveness of autobiographical accounts, with respect on their exclusive focus on breast cancer	3	11.5
Reluctance to Disclose Reluctance to talk about oneself and one's problems because this is contrary to one's nature	2	7.7
Relevance Intervention programme seemed irrelevant to one's own life	2	7.7
Pacing Programme being too fast-paced, with not enough time being devoted to one topic	1	3.8
Time Lack of time to participate properly due to one's busy life	1	3.8
Total	26	100

Note. Percentages may not add up to 100 due to rounding.

In line with the finding that a lack of participation of other group members was perceived

as a drawback of the CEPB, one woman wrote about barriers to participation in her blog.

These involved the perception that other members were not active enough, and being too

tired to create any postings:

> *When I first joined up for this I came onto the site and found that nobody else had*
>
> *posted, so this put me off a bit. By the time I come home from work, I am so tired*
>
> *that I haven't got the energy to think about some of the topics on here.*

<div align="right">(Red Rose, page 1, lines 8-9)</div>

However, none of the other perceived drawbacks emerging through content analysis were
mentioned in message-board or blog postings.

Suggestions for Improvement ("Do you have any suggestions how the programme could be improved?")

Table 85 presents the frequencies and percentage frequencies of suggestions for
improvement of the CEPB. The most-frequently made comments related to no
improvements being necessary, or none coming to mind (35%). Seventeen percent of
comments suggested the improvement of aspects of the CEPB pertaining to the usability
of the Web site, particularly navigation of the site and problems with participants' log-in
sessions timing out while writing message-board postings or blog entries. Third-most
frequently it was recommended by participants to focus the autobiographical accounts on
a broader range of illnesses, rather than just on breast cancer.

Table 85

Suggestions for Improvement of the CEPB as Indicated by Participants in the Post-

Intervention Questionnaire

Suggestion	*f*	*%f*
None	8	34.8
No improvements necessary, or none come to mind		
Web Site Usability	4	17.4
Improvement of aspects of the intervention programme related to Web site usability: site navigation, log-in timeout related problems)		
Range of Topics	3	13.0
Broaden the range of illnesses focused on in the autobiographical accounts, rather than just breast cancer		
Links	2	8.7
Providing participants with links to assertiveness classes, or to other relevant research		
Prompts	1	4.3
More prompts from researcher to encourage participants to explore certain thoughts in more detail		
Pace	1	4.3
Devote more time to individual topics		
Additional Message Board	1	4.3
Provision of an additional message board on which members can discuss more general topics		
Counselling	1	4.3
A more counselling/psychotherapeutic approach which engages more in-depth with each individual. However, reservations were also voiced regarding the suitability of the online setting for an approach incorporating psychotherapy, as opposed to a face-to-face setting		
Participation	1	4.3
More active participation and more interaction among participants		
Screening	1	4.3
More detailed questions in screening tool pertaining to stressful life events one may not wish to share with others, in order to yield more comprehensive information from which to make links between cancer and emotional health		
Total	23	100

Note. Percentages may not add up to 100 due to rounding.

Additional Comments

Table 86 presents the frequencies and percentage frequencies of additional comments made by participants. Fifty percent of comments contained expressions of gratitude for the opportunity to take part in the CEPB and for the support rendered by the researcher. However, 14% voiced doubts over whether their own participation in the programme constituted a useful contribution to research.

Table 86

Additional Comments Made by Participants in the Post-Intervention Questionnaire

Comment	*f*	*%f*
Gratitude Expressing gratitude for the opportunity to take part in the intervention programme and for the support rendered by the researcher	7	50.0
Usefulness of own participation Concerns over whether own participation in intervention programme constituted a useful contribution to research	2	14.3
Research Perceived need for the government to invest in research targeting psychosocial illness risk factors, as well as research comparing such interventions to conventional forms of treatment	1	7.1
Emotional Effects CEPB experienced as emotionally draining, but nevertheless helpful	1	7.1
Experiences Reading about other members' experiences was experienced as enjoyable	1	7.1
Outcome Interest in finding out the results of the study	1	7.1
Problems relating Inability to relate to most of the autobiographical accounts	1	7.1
Total	14	100

Note: Percentages may not add up to 100 due to rounding.

Other Factors influencing Outcomes

Both after the CEPB and at six-week follow-up, participants were asked to report other factors, apart from their participation in the programme, which may have affected the way they coped with bereavement and/or stressful life events. Table 87 presents these perceived factors. Conceptual content analysis revealed 12 mutually exclusive categories of factors. The inter-rater reliability was satisfactory (k = 0.77, 80% agreement).

Apart from a significant number of participants reporting that no other factors had influenced their coping after the programme or at six-week follow-up (25% and 24% respectively), both after the programme and at follow-up many participants indicated that the presence or absence of social support from family, friends or other online forums affected the way they coped (25% and 24% respectively). At follow-up, several participants also reported that recent positive or negative life events which occurred during the CEPB had negatively affected their ability to cope (12%).

Importance of Laughter

Importance and meaning of laughter to participants was assessed because in the initial phases of the programme it was observed that participation tended to decline during the 'Laughter for Wellbeing' element. The assessment of importance and meaning of laughter was intended to help shed light on this decline. Conceptual content analysis revealed nine mutually exclusive categories of the meanings of laughter for participants (see Table 88). The inter-rater reliability was satisfactory (k = 0.80, 84% agreement). Thirty percent of participants saw laughter as a means of improving psychological and physical wellbeing, while 19% saw the presence of laughter as a sign of psychological wellbeing. An equal number of participants (11% each) perceived laughter to be a form of stress management; a way of facilitating social interactions; and an essential component of one's daily life.

Table 87

Participants' Perceived Factors which May Have Affected Coping with Bereavement or

Coping with Stressful Life Events, Independent of their participation in the CEPB

Perceived Factor	Post-Intervention		Follow-Up	
	f	*%f*	*f*	*%f*
An increase in actively seeking social support	0	0.0	2	8.0
Perceived lack of control over stressful life events	0	0.0	1	4.0
An increase in the release of negative emotions	1	3.6	0	0.0
Anti-depressants	1	3.6	1	4.0
An optimistic disposition	2	7.1	0	0.0
Counselling	2	7.1	2	8.0
Multiple ongoing unresolved problems	2	7.1	2	8.0
Ongoing health problems which act as stressors	2	7.1	0	0.0
Recent positive or negative life events which occurred during programme	2	7.1	3	12.0
Stress management techniques (e.g. physical exercise, poetry writing, relaxation exercises)	2	7.1	2	8.0
None	7	25.0	6	24.0
Presence or absence of social support through family, friends or other online forums	7	25.0	6	24.0
Total	28	100	25	100

Note. Percentages may not add up to 100 due to rounding. Responses given to the question: *"Apart from taking part in the Emotional Health programme, are there any other recent events in your life (positive or negative) which may have affected the way you are dealing with stressful events and/or your loss?"*

Table 88

Participants' Reported Meanings of Laughter

Meaning	*f*	*%f*
A means of improving psychological and physical wellbeing	8	29.6
A sign of psychological wellbeing	5	18.5
A form of stress management	3	11.1
A way of facilitating social interactions	3	11.1
An essential component of one's daily life	3	11.1
A form of emotional release	2	7.4
Fun	1	3.7
Happiness	1	3.7
A defence mechanism	1	3.7
Total	27	100

Note. Percentages may not add up to 100 due to rounding. Responses given to the question: *"What does laughter mean to you, both generally and for your life in particular?"*

Table 89 displays participants' reported importance of laughter. Almost half of all participants rated laughter as very important to them in their daily lives, while 30% rated it as important. Thus, laughter had significant meaning and importance to most participants.

Table 89

Participants' Reported Importance of Laughter

Importance of Laughter	*f*	*%f*
Very important	11	47.8
Important	7	30.4
Neither important nor unimportant	4	17.4
Not important	1	4.3
Total	23	100

Note. Percentages may not add up to 100 due to rounding.
Responses given to the question: *"How important is laughter to you in your everyday life?"*
Responses measured on a 5-point Likert scale (1 = not important at all; 2 = not important; 3 = neither important nor unimportant; 4 = important; 5 = very important).

9.6.2 Evaluation of Screening Tool and Intervention Web Site

Table 90 presents perceived ease of use and enjoyment (intrinsic motivation to use) of the pre-intervention screening tool. The mean perceived ease of use was high (*M* = 3.90, *SD* = 0.62), while mean enjoyment was moderate (*M* = 3.28, *SD* = 0.72).

Table 91 presents perceived ease of use and enjoyment of the intervention Web site by type of intervention group. The overall mean perceived ease of use was moderate to high ($M = 3.58$, $SD = 0.99$), while overall mean enjoyment was moderate ($M = 3.22$, $SD = 0.89$). Participants in the EESR-only condition rated the Web site highest in perceived ease of use ($M = 3.75$, $SD = 1.22$), while participants in the psycho-education-only condition rated it lowest in perceived ease of use ($M = 3.48$, $SD = 0.63$). Participants in the EESR-plus-psycho-education-condition enjoyed using the Web site the most ($M = 3.50$, $SD = 0.76$), while participants in the psycho-education-only condition enjoyed using it the least ($M = 3.19$, $SD = 0.66$).

Table 90

Pre-Intervention Usability of Screening Tool and Intrinsic Motivation to Use the Tool

Technology Acceptance Item	*M*	*SD*	Minimum	Maximum
Learning to fill in this questionnaire was easy.	3.96	0.77	2.00	5.00
I found completing this questionnaire enjoyable.	3.35	0.83	2.00	5.00
Becoming skilful at completing this questionnaire was easy.	3.61	0.84	2.00	5.00
The actual process of completing this questionnaire was pleasant.	3.52	0.73	2.00	5.00
The questionnaire pages were easy to navigate.	4.13	0.69	3.00	5.00
I had fun completing this questionnaire.	2.96	0.82	2.00	5.00
Mean Perceived Ease of Use	3.90	0.62	2.67	5.00
Mean Intrinsic Motivation	3.28	0.72	2.00	5.00

Note. Responses measured on 5 point Likert scale (1 = strongly disagree; 5 = strongly agree).

Table 91

Usability of Intervention Web Site and Intrinsic Motivation to Use the Web Site by Type of

Intervention Group

Technology Acceptance Item	EESR		Psycho-Education		EESR + Psycho-Education	
	M	*SD*	*M*	*SD*	*M*	*SD*
Learning to use the website was easy.	3.75	1.28	3.43	0.79	3.50	1.07
I found using this website enjoyable.	3.38	1.30	3.29	0.76	3.63	0.74
Becoming skilful at using this website was easy.	3.63	1.19	3.57	0.54	3.38	1.06
The actual process of using this website was pleasant.	3.50	1.20	3.43	0.54	3.50	0.93
The website pages were easy to navigate.	3.75	1.17	3.57	0.54	3.50	1.20
I had fun using this website.	3.00	1.20	3.00	0.58	3.25	0.89
Mean Perceived Ease of Use	3.75	1.22	3.48	0.63	3.50	1.08
Mean Intrinsic Motivation	3.25	1.22	3.19	0.66	3.50	0.76
Overall Mean Perceived Ease of Use	3.58	0.99				
Overall Mean Intrinsic Motivation	3.22	0.89				

Note. Responses measured on 5 point Likert scale (1=strongly disagree; 5=strongly agree).

Table 92 presents correlations between Internet use, Internet experience, confidence using the Internet, perceived ease of use and intrinsic motivation to use the intervention Web site. Significant positive correlations emerged between perceived ease of use and enjoyment ($r = .74$, $p < .001$); perceived ease of use and average weekly hours spent using the Internet ($r = .57$, $p < .001$); Internet experience and confidence using the Internet ($r = .94$, $p < .001$); and confidence using the Internet and average weekly hours spent using the Internet ($r = .46$, $p < .05$). Thus, the more participants found the Web site easy to use, the more likely they were to enjoy using it and also the more weekly hours they spent using the Internet. The more experience individuals had using the Internet, the more confident they were likely to be when using the Internet; and the more confident they were, the more weekly hours they were likely to spend online.

Table 92

Correlations between Perceived Ease of Use, Intrinsic Motivation to Use Intervention Web Site, Internet Experience, Confidence Using the Internet, and Internet Use

	Mean perceived ease of use	Mean intrinsic motivation	Internet experience	Confidence using the Internet	Average weekly number of times used Internet
Mean perceived ease of use					
Mean intrinsic motivation	.74****				
Internet experience	.13	.12			
Confidence using the Internet	.27	.16	.94****		
Average weekly number of times used Internet	.36	.20	.27	.25	
Average weekly hours spent using Internet	.57****	.26	.31	.46*	.42

* $p < .05$, **** $p < .0001$.

9.7 Summary of Findings

The following section summarises the main findings in relation to the study hypotheses.

Hypothesis 1

Women who participate in EESR report less maladaptive coping with bereavement after the programme and at follow-up than women who do not participate in EESR.

Hypothesis 2

Women who participate in psycho-education report less maladaptive coping with bereavement after the programme and at follow-up than women who do not participate in psycho-education.

In line with Hypothesis 1, participating in EESR was associated with lower levels of maladaptive coping with bereavement after the programme, than not participating. Examining changes over time, taking part in EESR was associated with a reduction in maladaptive coping with bereavement after the programme, compared to before the programme. Neither of these effects persisted at follow-up. Thus, Hypothesis 1 was retained for post-intervention outcomes. Hypothesis 2 was not retained. At follow-up, a general decrease in maladaptive coping with bereavement, compared with post-intervention levels, was observed for all groups, including the control group.

Hypothesis 3

Women who participate in EESR report lower levels of maladaptive coping with stressful life events after the programme and at follow-up than women who do not participate in EESR.

Hypothesis 4

Women who participate in psycho-education report lower levels of maladaptive coping with stressful life events after the programme and at follow-up than women who do not participate in psycho-education.

In line with Hypothesis 4, participating in psycho-education was associated with lower levels of maladaptive coping with stressful life events after the programme, than not participating. Examining changes over time, taking part in psycho-education was associated with a reduction in maladaptive coping with stressful life events after the programme, compared to before the programme. Neither of these effects persisted at follow-up. Thus, Hypothesis 4 was retained for post-intervention outcomes. Hypothesis 3 was not retained.

Hypothesis 5

Women who participate in EESR report higher levels of social support after the programme and at follow-up than women who do not participate in EESR.

Hypothesis 6

Women who participate in psycho-education report higher levels of social support after the programme and at follow-up than women who do not participate in psycho-education.

An interaction effect was found between EESR and psycho-education. Taking part in both elements was associated with lower levels of social support after the programme, than taking part in either element alone. Thus, Hypotheses 5 and 6 were retained for post-intervention outcomes.This effect did not persist at follow-up. Examining changes over time, it emerged that taking part in EESR was associated with lower social support after the programme, compared to taking part in both EESR and psycho-education. At follow-up, taking part in neither of the elements of the CEPB was associated with increased

levels of social support at follow-up, compared to taking part in EESR only and to taking part in psycho-education only. Thus, Hypotheses 5 and 6 were not retained for follow-up outcomes.

Hypothesis 7

Women who participate in psycho-education report higher levels of awareness of the connection between physical and psychosocial health after the programme and at follow-up than women who do not participate in psycho-education.

There was no significant effect of psycho-education on awareness of the connection between physical and psychosocial health, neither after the intervention nor at follow-up. Therefore, Hypothesis 7 was not retained. However, taking part in EESR was associated with lower levels of post-intervention awareness than not taking part in EESR.

Additionally, although personality traits are usually stable in adulthood, it was found that participating in either EESR or in psycho-education was associated with lower levels of conformity after the programme than participating in neither or in both. This effect persisted at follow-up. Looking at changes over time, taking part in EESR-only was beneficial to conformity at follow-up, compared to taking part in both elements of the CEPB. These results indicate a potential of the CEPB to influence personality traits, which is examined further in the next chapter.

To summarise, participation in the CEPB had an effect on all four dependent variables. Taking part in 'Art and Laughter for Wellbeing' was associated with lower maladaptive coping with bereavement after the programme, and the reading of autobiographical accounts of breast-cancer sufferers was associated with lower maladaptive coping with stressful life events, even if both effects did not persist at follow-up. Furthermore, taking part in both 'Art and Laughter for Wellbeing' and reading autobiographical accounts was

associated with higher social support after the programme, but not at follow-up. As with the lack of significant follow-up effects on the other dependent variables, this was most likely due to attrition and the resulting reduction in statistical power. Moreover, assessing changes over time, it emerged that at follow-up, taking part in either EESR or in psycho-education was associated with decreased levels of social support. It is thinkable that this was a result of ending the programme and thus withdrawing support, causing the perceived higher social support levels to drop within the six weeks after the programme had ended. Furthermore, participants reported at follow-up that the presence or absence of social support given to them by family members, friends, or through their interactions with other people on Internet support forums played a role in how they coped with their bereavement and other stressful life events. Thus, these sources of social support may have been more influential on social support levels at follow-up, than participation in the CEPB.

Conversely to what was hypothesised, psycho-education had no effect on awareness of the connections between psychological and physical health. Instead, it was found that taking part EESR was associated with significantly *lower* awareness after the programme than not taking part in EESR. Even though this effect did not persist at follow-up, it is likely that it constituted part of a defence mechanism, whereby participants denied the existence of a connection between physical and psychological health. This possibility, as well as its implications, is further discussed in the next chapter.

Non-constructive bereavement-coping styles increased after the programme, but decreased again at follow-up, indicating an initial exacerbation for some participants, which was ameliorated at follow-up, where more participants were likely to deal with their bereavement passively using secondary control. The picture was less obvious for coping with stressful life events after the intervention, although there was a clear tendency to use

more constructive coping styles at follow-up, especially in response to recent stressful life events.

Participants generally evaluated the CEPB positively, perceiving it as helpful, useful and enjoyable. They stated that the support received from the researcher was a significant benefit of the programme. In Chapter Eight, it was explained that women expected to give and receive support as part of the CEPB. It thus appeared that at least participants' expectation of receiving support had been met.

Other frequently-mentioned perceived benefits included an ability to understand oneself better as a result of the programme, and the sharing of experiences and opinions. However, problems with the usability of the Web site, a lack of active participation on the message boards, and a perceived repetitiveness of the autobiographical accounts of breast-cancer sufferers were cited most frequently as drawbacks. Suggestions for improvement most-frequently related to Web-site usability and to broadening the range of health problems focused on in the autobiographical accounts.

Examining other factors which may have affected participants' bereavement and/or coping with stressful life events, women mostly reported there either being no other factors, or a presence or lack of social support received from family members, friends and on other Internet support forums. Some reported that stressful life events occurred during the course of the intervention, and these negatively impacted on their coping ability. This negative influence shows that both post-intervention and follow-up results were affected by women's personal circumstances. Furthermore, most participants felt that laughter was important in their everyday lives, and some believed that it was a useful tool for improving one's health, while others saw it as a sign of psychological wellbeing. While participants' positive perceptions of laughter underline the appropriateness of using it as part of the CEPB, they also imply the possibility that many women already used laughter as a coping

mechanism in their daily lives. Both results are explored in more detail in the coming chapter.

In spite of the reported usability problems, the average perceived ease of use was moderate-to-high, not just for the intervention Web site, but also for the pre-intervention screening tool. Enjoyment was moderate for both the screening tool and the Web site. Generally, the easier to use the Web site was perceived to be, the more participants were intrinsically motivated to use it. These positive results imply that the Web site was appropriate and suitable for carrying out the intervention.

In the subsequent chapter, the findings presented in this chapter are discussed. Furthermore, the implications of these findings in terms of the aims of the project as well as for future research are considered, and an integrated model of psychosocial factors implicated in breast-cancer development is proposed.

CHAPTER TEN

DISCUSSION OF MAIN FINDINGS

CONTENTS

10.1 Overview

This chapter presents a discussion of the results yielded by the current study. It begins with a brief review of the previous chapters. Results of the quantitative analyses are compared to the results of the qualitative analyses. Findings are discussed in relation to the literature, and conclusions are drawn. As well as outlining limitations of the present research, the current study's contributions to knowledge in the area of psychosocial prevention of breast cancer are emphasised. Recommendations for future research are made, highlighting the role that health psychologists should play in the advancement of research in this area, and a biopsychosocial model of breast-cancer development is proposed.

10.2 Introduction

The research reported in this thesis has developed, implemented and evaluated an electronic Coping-Enhancement-Programme for the Bereaved (CEPB[2]), targeting psychosocial factors involved in the aetiology of breast cancer. Chapter One introduced the research that was undertaken and reported in this thesis, and Chapters Two to Four reviewed the literature in the subject area. Specifically, Chapter Two examined the research on psychosocial factors involved in breast cancer; Chapter Three looked at proposed psychosocial pathways to breast cancer; and Chapter Four reviewed studies that had implemented interventions targeting psychosocial factors in breast cancer. Chapter Five detailed the main study's method, stating its rationale, aims and hypotheses. It also explained which materials were used, how participants were recruited and screened, in which way the intervention was conducted, and how the qualitative and quantitative data yielded by the questionnaires and the intervention Web site were analysed. Chapter Six detailed the design and pilot-testing of the psychological screening tool, which was used to screen potential participants for their eligibility to participate in the study, as well as for measuring dependent variables and recording participants' views of

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[2] When reference is made to 'the CEPB', all three versions of the programme are implied.

the intervention programme. Chapter Seven described how the CEPB and the Web site on which the intervention was to take place were designed. It also presented the results of the pilot study evaluating the Web site's usability. Chapter Eight presented the process of the CEPB, while Chapter Nine presented its outcomes.

10.3 Discussion of Main Findings

A number of findings emerged from the present study. These are now presented and discussed in turn.

10.3.1 Coping with Bereavement and Other Stressful Life Events

Women described a wide range of strategies that they used to cope with bereavement. These were either adaptive or maladaptive. Adaptive strategies included spirituality, evoking positive memories of the deceased, and talking about one's bereavement. The usefulness of such strategies to aid adaptive coping with bereavement has been reported in the literature (Labbe and Forbes, 2010; Kim and Seidlitz, 2002; Ironson and Kremer, 2009; Ando et al., 2010). Yet, many women seemed to cope maladaptively with their losses. Although some of these losses had occurred many years ago, they still found it difficult to deal with them. The findings of two large prospective studies conducted in the UK (Cooper and Faragher, 1992, 1993; Chen et al., 1995), which detected a connection between maladaptive coping with bereavement and breast-cancer occurrence (see Chapter Two, Sub-Section 2.3.2 for a detailed discussion), underline how important it is to help decrease women's maladaptive bereavement-coping strategies while encouraging adaptive ones.

Avoidance was a common way of coping with bereavement (see Appendix G, sub-section 1.2.1): many women described how they had been avoiding confronting their loss up to the point of participating in the CEPB. All those who reported avoidant coping saw it as a negative way of dealing with their bereavement experience, but adaptive ways of coping,

such as acceptance and adjustment, proved difficult for them. Some felt that they had been prevented from achieving closure in dealing with their bereavement, because they had been unable to say good-bye to those who had passed away. Others complained of a lack of time to grieve properly. Thus, many women felt that they needed support in dealing with their bereavement.

The drawbacks of using avoidant coping are highlighted when considering Cooper and Faragher's (1992; 1993) quasi-prospective UK study mentioned above. Its findings indicated that women who used internalised or avoidant coping strategies were more likely to present with breast cancer than those who used externalised coping or anger strategies. Furthermore, Grossarth-Maticek et al. (1994) found a connection between the Type I personality, whose traits include the tendency to use avoidant coping, and an increased incidence of and mortality from cancer. Thus, the prevalence of maladaptive bereavement-coping strategies among participants clearly warranted their participation in the CEPB.

Avoidant coping was common amongst participants when dealing with bereavement and other stressful life events. But for many, not even avoidance was possible. Rather, they simply felt helpless and unable to cope. Having a social support network to buffer the effects of stress and the enjoyment of laughter and humour were seen by many women to play an important role in coping with stress, but they were not always able to access these coping resources. Those who reported maladaptive strategies, or a perceived inability to cope, seemed most in need of learning adaptive stress-reduction techniques, particularly when viewed in light of Cooper and Faragher's, as well as Grossarth-Maticek and colleagues', findings on the connections between breast-cancer development and maladaptive coping.

Looking at how women's coping styles changed over the course of the CEPB, there were improvements in terms of a reduction in maladaptive coping styles six weeks after the intervention programme. On the whole, taking part in the CEPB was associated with an increase in adaptive coping styles and a decrease in maladaptive coping styles. Thus, one of the aims of the programme was achieved.

The diversity in coping styles which emerged from the findings, and the fact that initially many of these were maladaptive, underlines the need for those women who struggle to cope adaptively to be assisted in recognising their coping resources and mobilising these. As explained in Chapter Seven, this was part of the CEPB: efforts were made to educate women about maladaptive and adaptive ways of coping, and the facilitator tried to help participants work out more constructive ways of dealing with stressful life events and bereavement. Stress-coping resources, for example, environmental resources such as social support, and personal resources such as self-efficacy and self-esteem, act as stress buffers (Wheaton, 1985; Taylor and Stanton, 2007). There is evidence to suggest that coping resources can change with psychosocial intervention. A study by Antoni, Lehman, Kilbourn, Boyers, Culver et al. (2001) found an increase in optimism in breast-cancer patients as an outcome of cognitive-behavioural stress management, compared to control group participants. Optimism and benefit-finding has been shown to predict better adjustment to breast-cancer diagnosis five to eight years after diagnosis (Carver and Antoni, 2004). It therefore seems that coping resources play a significant role in coping with stress, which makes it important to focus a stress-management intervention on the mobilisation or enhancement of existing coping resources, as well as the acquisition of new coping resources.

10.3.2 Effects on Psychosocial Factors in Breast-Cancer Development

Examining how taking part in the CEPB affected women's psychological profiles, several findings emerged. Firstly, taking part in Emotional-Expression-and-Stress-Reduction

(EESR) through 'Art and Laughter for Wellbeing' was associated with lower maladaptive coping with bereavement after the programme. Furthermore, taking part in EESR was associated with a reduction in maladaptive coping with bereavement after the programme, compared to before the programme.This means that participants were able to deal better with their bereavement, which is an encouraging finding. That this effect did not persist at six-week follow-up might mean that a longer period of intervention is necessary for a positive change in the long term. Future research would need to look into this.

The beneficial effects on maladaptive coping with bereavement after the programme are in line with previous studies utilising art therapy, which detected beneficial effects on bereavement and loss coping (e.g. Kirk and McManus, 2002; Ferszt et al., 1998; Ferszt et al., 2004). These studies were of similar duration to the present one, but reported no follow-up results; therefore, it is uncertain how they compare to the current study regarding the longevity of their effects.

In addition to the programme's positive effect on maladaptive coping with bereavement after the intervention, the present study discovered that participants rated the CEPB as useful, helpful and enjoyable. According to Donabedian (2005), in health care the ultimate validator of the quality of care is its effectiveness in achieving or producing health as well as satisfaction. Furthermore, this plays a major role in the evaluation of a service (Care Quality Commission, 2011). Thus, client-satisfaction is equally important and tends to correlate positively with clinical outcomes (Kane, Maciejewski and Finch, 1997; Ankuta and Abeles, 1993). This was also the case for the CEPB.

Another positive effect of the programme emerged: participating in psycho-education, through the reading of autobiographical accounts of breast-cancer sufferers, was associated with lower levels of maladaptive coping with stressful life events after the programme, than not participating. Furthermore, taking part in psycho-education was

associated with a reduction in maladaptive coping with stressful life events after the programme, compared to before the programme. Again, this effect did not persist at follow-up, possibly indicating the need for a longer intervention. At the same time, constructive coping styles increased after the programme and at six-week follow-up, especially for coping with recent stressful life events. It is an intriguing finding that it was not the 'Art and Laughter for Wellbeing' element of the CEPB which had an effect on maladaptive coping with stressful life events, but rather the reading of autobiographical accounts, since 'Art and Laughter for Wellbeing' constituted the element of the programme designed to aid emotional expression and stress reduction, while the autobiographical accounts posed a form of psycho-education. Accordingly, it had been expected that 'Art and Laughter for Wellbeing', rather than the reading of autobiographical accounts, would affect coping with stressful life events positively.

Nevertheless, this positive effect could be due to an increase in women's awareness of the importance of taking care of oneself, which was reported towards the end of the programme by several participants who had been assigned to the autobiographical accounts-only condition (see Chapter Nine, Sub-Section 9.4.4). Furthermore, many women stated that they were able to identify with the protagonists of these accounts (see Chapter Eight, Sub-Section 8.5.1). As mentioned in Chapter Four, delivering health-promotion messages through sources similar to the participants has been demonstrated to increase the relevance of these messages to the recipient (Aldoory, 2001), because the individual is more likely to personally connect to the message (Grunig and Hunt, 1984; Pavlik, 1988).

Although, at the time of writing, to the author's knowledge there was no other published research implementing autobiographical accounts in a form similar to the present study, previous intervention studies aiming to improve participants' coping skills, as presented in Chapter Four, yielded positive results (Grossarth-Maticek et al., 2000; Fawzy et al., 1990;

2003). Therefore, this outcome is in line with previous findings and suggests that the reading of autobiographical accounts was a useful and effective component of the CEPB.

A further positive finding that emerged concerned participants' levels of social support. After the programme, it was found that taking part in both EESR and psycho-education were associated with higher levels of social support after the programme. Furthermore, evaluations showed that the support women had received from the facilitator throughout the intervention had been useful to them. Moreover, the significance of social support as a beneficial element of the programme was reflected in the thematic analysis (see Chapter Nine, Sub-Section 9.6.1), where women also emphasised its usefulness. Hence, this result was corroborated by the findings of the analyses of three different sources of data, and is in line with other Internet intervention studies finding social support-enhancing effects, as discussed in Chapter Four (e.g. Lange et al., 2000; 2003; Winefield, 2006). It must be pointed out that none of the reviewed intervention studies used social support as an outcome measure, and in this sense the present study was unique. However, other measures related to social support were assessed in the reviewed studies, such as anxiety and depression, which tend to correlate negatively with social support (Sarason, Levine, Basham and Sarason, 1983). Therefore, an increase in social support levels was expected after the CEPB.

At six-week follow-up, no significant effects of any of the components of the CEPB on social support were found. Looking at changes over time, at six-week follow-up there were reductions in social support levels for participants who had taken part in EESR or in psycho-education, compared to post-intervention levels. This result may be explained by the fact that with the programme ending, the support given by the researcher, and thus any therapeutic alliance that had been formed with participants, ended as well, causing the perceived higher social-support levels to drop within the six weeks after the programme had ended. This speculation is reinforced by some participants reporting at follow-up that the presence or absence of social support given to them by family

members, friends or through their interactions with other members on Internet support forums played a role in how they coped with their bereavement and other stressful life events. Where such support was lacking, this was most likely going to reflect negatively on women's perceived levels of social support at follow-up.

Difficulties with ending a therapeutic relationship are part of the therapeutic process (Murdin, 2000). The author of this thesis was clear with participants about the duration of the programme, providing a detailed schedule, in order to make them aware of its time-limited nature and to prepare them better for the end of the intervention. Moreover, the phone number of the Teesside University Psychological Therapies Clinic was made available, which women could contact if they required further support. Nevertheless, ending the therapeutic relationship may have still contributed to the dip in perceived social support. Although previous research has found that members of online support forums often offer support to each other (Winefield, 2006), this was less the case for the current study, in which interaction between group members was limited. Therefore, it is more likely that participants derived social support from their interactions with the researcher. This notion is confirmed by participants' comments to this effect. Taking this into account, it may be beneficial for future interventions to put strategies in place for continuing online support beyond their end point. Furthermore, it may be useful to follow participants longer than six weeks after an intervention, to explore whether social-support levels may have changed through other means, after recognition of its benefits have been experienced. Furthermore, the use of group exercises or group tasks to encourage mutual support could be explored. Gitterman (1989), for example, studied professional tasks and skills associated with building mutual support, emphasising the role of humour in fostering this process. It has been found that mutual support promotes group cohesiveness and increases individual self-efficacy (Christensen, Schmidt, Budtz-Jogensen and Avlund, 2006).

An unexpected outcome concerned awareness of the connections between psychological and physical health. Taking part in EESR was associated with lower levels of awareness after the programme than not taking part in EESR. As mentioned previously, apparently the present study was at the time of writing unique in its assessment of this variable. It had been expected that the autobiographical accounts would lead to an increase in awareness of the mind-cancer connection, since women would most likely find it easy to identify with the protagonists of these accounts, and that therefore the message of these accounts would be relevant to them. The fact that this was not the case, and that instead participation in EESR was associated with lower levels of awareness after the programme, can only be tentatively speculated on. Perhaps the intervention programme led to a 'defence response' sparked by fear: as participants were able to recognise themselves in the autobiographical accounts (a notion which is confirmed by women's comments on these accounts), but felt unable to change their 'breast-cancer prone' behaviours, they changed their opinion of the connection between physical and psychological health to deny, or at least doubt, its existence. This possibility is supported by the findings of a study by Rippetoe and Rogers (1987), who used protection motivation theory to investigate how individuals coped with the threat of breast cancer when not planning to adopt an adaptive protective response (breast self-examination). The authors reported that when women were provided with coping information in the form of self-efficacy and response-efficacy, their tendency to engage in problem-focused coping increased. Furthermore, enhancing women's belief in their own ability to perform breast self-examination increased their intentions to use the practice and the tendency to engage in a problem-solving approach. Denial, defensive avoidance and helplessness, on the other hand, were more likely to increase when fear increased, in line with the results of a study by Janis and Feshbach (1953; cited in Rippetoe and Rogers, 1987). A subsequent study on coping with breast-cancer information similarly found that threatening health information energizes one to act in both adaptive and maladaptive ways, and that providing participants with coping information decreases the tendency to respond

maladaptively to the health threat (Prentice-Dunn, Floyd and Flournoy, 2001). While these studies focused on breast self-examination, it is thinkable that these findings also apply to preventative health behaviour in the form of stress management. It was, after all, one of the aims of EESR to reduce maladaptive coping styles and to encourage adaptive ones, thereby managing stressful life events in a constructive way.

It needs to be emphasised that in the current study participants were repeatedly made aware that the aetiology of breast cancer is multifaceted and complex, encompassing physical, social and psychological factors. This message was also conveyed in order to not alarm women unnecessarily. Still, it is possible that the autobiographical accounts led to a temporary defence reaction.

Although the effect of EESR on awareness of the connections between psychological and physical health after the programme did not persist at follow-up, it may be necessary for future studies to not only present autobiographical accounts of breast-cancer sufferers, but also provide women with self-efficacy increasing measures. This may help participants with recognising that they may be at risk, while preventing them from feeling unsure what to do about it. Previous research has found that individuals with high self-efficacy who take part in interventions aimed at changing harmful health behaviours and adopting healthy behaviours, are more likely to change their behaviour than individuals with low self-efficacy (e.g. Shahab, West and McNeill, 2011; Zing and Soyka, 2009; Schwarzer and Renner, 2000). Self-efficacy can be enhanced; therefore it is beneficial to include self-efficacy-enhancing measures in health-behaviour change programmes (Schwarzer and Fuchs, 1995; Strecher, DeVellis, Becker and Rosenstock, 1986; Schwarzer, Lippke and Luszczynska, 2011). Based on their review, Strecher and colleagues recommended that in order to promote an increase in self-efficacy, the person's relative progress towards the target behaviour be demonstrated, and that previous accomplishments be attributed to the person's own abilities. They suggested techniques such as relaxation training to reduce

anxiety in the face of behaviour change, verbal reinforcement, and the rehearsal of desired behaviour in situations where self-efficacy is prone to being low. It would be useful to explore if such measures result in more beneficial outcomes.

10.3.3 Conformity

Despite personality traits usually being stable by adulthood, an unexpected effect of the programme was found: participating in either EESR or psycho-education was associated with lower levels of conformity at follow-up than participating in neither or in both. This effect persisted at follow-up. Looking at changes over time, taking part in EESR-only was beneficial to conformity at follow-up, compared to taking part in both elements of the CEPB. This indicates a potential of the programme to reduce this trait in the medium- or even long-term. Examining the qualitative results (see Chapter Nine, Sub-Section 9.6.1), it became clear that participants valued the privacy afforded by their personal blogs, which enabled them to be frank about issues they may not normally discuss in their daily lives. For a few women, the blog appeared to serve as a 'confessional' of sorts (see Chapter Eight, Section 8.6), in which they disclosed events that they had supposedly not disclosed to anyone else before. The only other reader of their blog entries was the researcher – someone they had never met face-to-face. Therefore, they were able to let go of their inhibitions. By disclosing difficult decisions they had made (e.g. having an abortion or leaving their family), decisions which they often felt profoundly guilty about, they were able to talk about times in their lives where they had acted in a non-conforming way, without being judged or berated for these actions. Indeed, many people readily disclose information online that they would not share in equivalent face-to-face interactions (Bonebrake, 2002; Cooper and Sportolari, 1997; cited in Attrill and Jalil, 2011), and this led to the discovery that anonymity in online interactions can enhance self-disclosure compared to similar offline interactions (Baker, 2005). It has been found that the higher women's need to self-disclose, the more likely they were to see blogging as way of expressing their own voice (Chen, 2012). Thus, it is possible that for the women in the

present study who engaged in a high amount of self-disclosure, this served as a way of expressing themselves more sincerely than they would in their day-to-day lives.

As mentioned in Chapter One, repressors typically score high on measures of conformity, while scoring low on measures of trait anxiety (Eysenck, 1994). While anxiety was not assessed in the current study, the fact that conformity reduced nevertheless gives an indication that traits which form part of the 'breast-cancer prone' personality may be open to change. Eysenck has suggested that psychosocial breast-cancer prevention needs to effect a lasting change in personality, a notion which is at odds with the notion of personality as a stable construct. However, Mischel (1969) proposed that stable emotional personality traits do not exist *per se*, and that behaviours are controlled by the situations people are in, with behaviours changing as situations change. A conciliatory approach has been offered in the form of the sociogenomic model of personality traits (Roberts and Jackson, 2008). This model acknowledges the existence of traits, but also suggests that environments can effect personality trait change in a slow, incremental fashion through reinforcing behaviour which is inconsistent with these traits. Building on this, it is thinkable that participants may have learnt to modify conforming and defensive behaviour through being rewarded for self-disclosure, the reward being in the form of support and positive feedback from the facilitator. In spite of the encouraging findings regarding conformity, the reduction of this trait would need to be replicated and potentially reassessed after a longer follow-up period to determine whether it is in fact permanent.

Historically, women were socialised to be docile and obedient. Huston (1988; cited in Worell and Remer, 2003) argued that girls tend to be supervised more closely than boys and are kept in close proximity to adults, especially their mothers; this leads girls to become compliant, obedient, unassertive, quiet and attendant to the needs of others. Jack (1991; cited in Stoppard, 2010) suggests that attention be paid to discursive influences through women's beliefs about what it means to be a 'good woman' – someone who puts

the needs of others ahead of her own. For Jack, psychological problems arise when

women strive to be 'good women' and in this process lose their sense of self by silencing

themselves. This socialisation has been critiqued by feminism, which has challenged

traditional gender roles and encourages women to stand up for themselves and become

more assertive (without harming others), and expressive of their emotions and beliefs.

Empowerment feminist therapy advocates women standing up for their own rights, not to

be powerless victims; it uses assertiveness training to help clients achieve this (Worell

and Remer, 2003). It could be argued that reducing conformity is in line with this aim,

since a reduction in conformity and compliance with others' expectations is an important

component of being more assertive and empowered.

10.3.4 Experience of the CEPB

A very positive impression emerged of women's experience of all three versions of the

CEPB. The findings from the thematic analysis of message-board and blog postings, as

well as from the content analysis and other quantitative analyses of the post-intervention

questionnaire items, all showed that participants found the programme helpful, useful and

enjoyable. They derived benefits from their participation. Altogether, participants'

experiences of all versions of the CEPB lend support to their usefulness.

Examining the perceived benefits in more detail, the three most-frequently mentioned

benefits were the support received from the facilitator, an ability to understand oneself

better as a result of the programme, and the opportunity to share one's experiences and

opinions with other women. As detailed in Chapter Seven, steps were taken by the

researcher to help foster a therapeutic alliance with participants. This included the

assumption of a caring and engaging role, in line with the nomadic research philosophy of

Fox (1999), and with Rogers' (1957) core concepts of person-centred therapy:

genuineness, unconditional positive regard for the client, and empathic understanding.

Corresponding to this, all versions of the CEPB were conceived as taking the form of a

continuous process, in which actions and interactions between participant and researcher were constantly aimed at changing maladaptive to adaptive coping profiles. Furthermore, the facilitator initially contributed to the discussions with her own experiences until participants felt more comfortable, in line with Watkins' (1990) and Rogers' recommendations. It is likely that these measures helped foster participants' positive impressions of the researcher's supportive role.

It is encouraging that participants reported being able to understand themselves better as a result of their participation of the programme. Insight into one's own behaviours and motivations is a desirable goal in counselling and greater insight is associated with more favourable outcomes, but is not always easy to achieve, particularly within a time-limited approach (Hill, O'Farrell and Carter, 1983; Kivlighan, Multon and Patton, 2000). Although it is a positive outcome that a sizeable number of women felt that they had learned more about themselves, it is uncertain whether this insight translated into positive behavioural changes. This could only be determined by following participants over a longer time period and asking them to self-report any behavioural changes. Still, an increase in insight may, in terms of the transtheoretical model of behaviour change (Prochaska and DiClemente, 1983), function as a cue to action and thus equip participants with a better chance of progressing towards maintaining this change.

The opportunity to share experiences and opinions was a further beneficial element of the programme. At first glance, this appears to conflict with the finding that most participants did not interact with each other very much on the intervention Web site. Still, contributing to discussions through message-board postings was a way for every participant to share her opinions, thoughts and experiences with other group members. Because communication on the intervention Web site was asynchronous, all message-board postings were available to read for all participants at their convenience. This is one of the advantages of data collection over the Internet (Lakeman, 1997; Anderson and Kanuka,

1997; Hsiung, 2000; Townsend, Amarsi, Backman, Cox and Li, 2011). Thus, women most likely perceived the very act of posting on the message boards as a way of disclosing their experiences to other group members, regardless of whether others commented on their contributions or not. Furthermore, the facilitator interacted with all participants and commented on every posting, thereby encouraging them to contribute further.

Few criticisms were made by participants. Reported limitations included problems with using the intervention Web site, a lack of active participation on the message boards, and a perceived repetitiveness of the autobiographical accounts of breast-cancer sufferers. Regarding problems using the Web site, namely problems navigating the site and log-in sessions timing out while users created postings, both had been addressed by the researcher during the programme. One participant reported problems with her log-in session timing out while writing a posting. Subsequently, all participants were e-mailed and advised to first type and save their postings using a word processing programme (e.g. Microsoft Word), especially when creating long postings. The navigation problems were more difficult to address, since there were constraints on how much the Web site could be modified. Since it was a Teesside University intranet site, its layout could not be changed significantly. Although these difficulties had not surfaced in Pilot Study Three, when the Web site had been tested, potential problems navigating the site had been anticipated by the researcher, and therefore instructions had been placed on the front page. Although only a few women reported Web-site usability issues, it is unknown how many women intended to participate but dropped out due to such problems. High attrition rates are typical in online interventions, with attrition rates of over 90% not being uncommon and the majority of drop-outs occurring in the first two weeks of the intervention (e.g. Linke, Murray, Butler and Wallace, 2007; Farvolden, Denisoff, Selby, Bagby and Rudy, 2005; Christensen, Griffiths, Korten, Brittliffe and Groves, 2004; Wu, Delgado, Costigan, Maciver and Ros, 2005). Eysenbach (2005) suggests that the usability of an online intervention programme has a significant impact on attrition rates, but that

there are other factors that play an equally significant role, such as the perceived benefit, expectations before the intervention, or 'push factors' such as reminders by the study team.

A lack of active participation of other users on the message boards was lamented by a few participants. This problem has been documented in previous Internet research (e.g. Im and Chee, 2003; McKay, Danaher, Seeley, Lichtenstein and Gau, 2008; Christensen, Griffiths and Farrer, 2009). Because online research is particularly prone to high attrition rates, a dearth of participants may often result in a lack of contributions, which in turn may serve to discourage individuals from contributing to discussions. Although the researcher tried to counteract this by often self-disclosing initially, in some groups very few participants contributed to the discussions. The reasons for this lack of contributions in some groups are unknown. It may be the case that, as stated earlier, usability problems prevented some from participating. However, there are many other potential reasons. Efforts to establish reasons for women dropping out of the study early only yielded two responses (as reported in Chapter Five), with these two drop-outs citing personal problems.

It is thinkable that some participants chose to 'lurk' on the forums, observing interactions without posting messages themselves. 'Lurking' may still be beneficial to participants because they are able to use the information and advice contained in others' postings (Hwang, Ottenbacher, Green, Cannon-Diel, Richardson et al., 2010). Therefore, it is possible that some of the women who did not actively participate still visited the intervention Web site and benefited from the exchanges between the other women. Regrettably, no data were available on 'lurkers' in the present study. Future research may benefit from monitoring activity on the message boards and assessing study outcomes for 'lurking' participants, as well as comparing them to active participants.

The final perceived limitation to be discussed concerned a supposed repetitiveness of the autobiographical accounts of breast-cancer sufferers, with three women remarking that they would have preferred a wider range of illnesses to be covered. As the psychosocial factors focused on in the present study were specific to breast cancer, all autobiographical accounts centred on this disease. The perceived repetitiveness of the accounts shows that participants may have needed to be informed better in advance about the reasons they were provided with accounts focusing exclusively on breast cancer. As explained in Chapter Five, ethical reasons prevented the researcher from mentioning the term 'breast cancer' in the study invitation or on the study information Web site. Guttman and Salmon (2004) commented on the ethical problems associated with presenting health-promotion messages that have the potential to arouse fear, noting that these, apart from being potentially distressing, often do not lead to a change in health behaviour. Thus, participants were told that the aim would be to examine the connections between emotional and physical health. This resulted in potential participants being unaware of the fact that the focus lay specifically on breast cancer. While the ethical concerns around unnecessarily worrying or frightening women are valid, there remained the need to reconcile for participants the perceived discrepancy between the study's supposed wide focus on health, and the breast-cancer specific content of the autobiographical accounts. One solution may lie in additional accounts being provided which do not centre on breast cancer. This may help alleviate the perceived repetitiveness of the accounts. However, because it would then be difficult to determine whether the breast-cancer accounts or the accounts looking at other health problems achieved the desired effect on the dependent variable, it would be necessary to introduce a control group which only received accounts centring on non-breast cancer diseases. This would make the study design much more complex.

To summarise**,** participants' experiences of the programme served to show that the intervention was warranted. They also highlighted several beneficial aspects, as well as some aspects needing improvement.

10.4 Limitations of the Study and Future Research

Several limitations of the present study need to be discussed. These involve issues regarding the sample, as well as access to the CEPB.

10.4.1 Sample

One of the limitations of the present study lies in its small sample size. This was mostly due to the high drop-out rate. Similar observations have been made in previous Internet research, as mentioned above. Of those who dropped out, most did so after filling in the pre-intervention questionnaire. The reasons for this are uncertain – it may be the case that they changed their mind, or perhaps never received the e-mail with their log-in details and the intervention Web-site address.

Since the present study's power was barely sufficient to detect a large effect size, this means that any medium or small effects which were present went undetected. However, the CEPB was a new and unprecedented type of intervention, and it was therefore uncertain what effect size was to be expected. Thus it is encouraging that effects in the expected direction were still found. Still, it is likely that a larger sample size could have yielded more statistically significant results. This was especially true for six-week follow-up, where the effects of the programme had diminished, but may have still been present to a lesser degree (just not strong enough to detect, given the small sample size). As stated previously, a longer intervention period may be necessary to effect and detect long-term changes at follow-up. Due to time constraints, this was not possible in the present study.

Unfortunately, time constraints also did not allow for the recruitment of additional participants. Im and Chee (2003) suggest the use of motivational strategies, such as remuneration or gift certificates for participation. However, in the present study, it had been assumed that women would regard the prospect of participating in a programme designed to help improve emotional well-being as a sufficient reason to keep them interested. Moreover, the use of money or other material rewards was avoided in order to minimise biasing of results (Vohs, Mead and Goode, 2008). Furthermore, sending participants money or material rewards would have necessitated them revealing their identity (i.e. name and address), which would not have complied with the aim of preserving their anonymity. Given the high attrition rate, however, it will be necessary for future research to take additional steps to prevent such high drop-out rates.

Another limitation concerning the sample is authenticity. As all interaction between participants and researcher took place online, the researcher never met participants face-to-face and was therefore unable to verify that they were who they claimed to be. Im and Chee (2003) have pointed out that this is an issue for most Internet research, suggesting that additional steps be taken to check authenticity, such as checking participants' Internet protocol (IP) addresses. While IP addresses were made available by Surveygizmo, the survey tool used for this study, for all those who filled in a study questionnaire, this only provided information on the participant's approximate location in the UK, and thus only showed that they were in the UK at the time of filling in the questionnaire.

It has been argued that even in offline settings, researchers are reliant upon participants to tell the truth and to reflect carefully on their responses (Snee, 2008). Silverman (2001; cited in Snee, 2008) discussed the concept of the 'interview society' in which the only path to authenticity is through a face-to-face interview, and there is an inclination for other forms of research to be less trusted. Yet, it could be argued that there are authenticity issues with offline research also, and that therefore online interviews are not necessarily

less authentic than face-to-face interviews. Furthermore, the promise to preserve anonymity, which is only possible with data collection that is not face-to-face, may - in fact - encourage individuals to participate in a study. These aspects put concerns over authenticity into perspective.

Given the high attrition rate in the present study, future studies will need to take steps to address this issue even more thoroughly than it was addressed in the present study. It may be necessary to offer women some form of material reward for their participation in future research, despite the methodological implications of doing so. Furthermore, to prevent further drop-outs through, for example, participants not receiving their log-in details or other e-mail from the researcher, for example, if e-mail from the group facilitator is received in their junk-mail folder, it would be beneficial to advise participants how to prevent this from happening.

In order to improve statistical power, future studies need to ensure that enough women are recruited to account for the high drop-out rate. This could be achieved by assigning multiple researchers the task of recruitment, and recruiting over longer periods of time (e.g. Linke, Murray, Butler and Wallace, 2007).

10.4.2 Access to the CEPB

In one of the strengths of the CEPB also lies a potential limitation. Since the intervention took place online, only women who had access to the Internet and were fairly proficient at using Web sites and computers in general could participate. Thus, women who did not have Internet access, who were not skilled at using Web sites and computers in general, or who had a visual impairment, were precluded from participating. Overberg et al. (2006) have pointed out that people who are active information seekers tend to use Internet applications most often. Therefore, it is possible that the women who signed up for the present study were particularly interested in physical and emotional health matters. Smith

and Kollock (1999) have suggested that Internet populations tend to be a selected group of people. In line with this, Im, Chee, Tsai, Bender and Kim (2007) have emphasised that potential selection bias is a critical issue to consider throughout the recruitment process in Internet studies. Yet, it is important to bear in mind that nearly 80% of households in the UK have access to the Internet, and that this number is increasing rapidly (Office for National Statistics, 2011).

It could be argued that even among those who participated in the study, the experience of the intervention will have been different for each woman: the more actively she participated, the more the facilitator was able to interact with her, and therefore the intervention may have been more beneficial to those who were active than those who contributed less frequently. However, in this respect the CEPB may be no different to traditional face-to-face intervention programmes. It has been reported that the more actively clients participate in psychotherapy, the more likely they are to be satisfied with the treatment (Nelson and Borkovec, 1989). Interestingly, a study by Day and Schneider (2002) found that clients who participated in psychotherapy using distance technology (i.e. treatment delivered via video or audio) were more likely to participate actively, communicating more actively, displaying more initiative, trust, spontaneity, and disinhibition, than clients who received psychotherapy in a face-to-face setting. The authors speculated that this was due to distance-therapy clients taking more responsibility for the interaction than face-to-face clients did. This indicates that interventions delivered over a distance may in fact encourage clients' participation. Indeed, as regards the participants in the CEPB, the majority of those who contributed to the message boards and blogs made an effort to do so regularly throughout the duration of the programme, with less than a third of active participants dropping out during the intervention.

The importance of the Internet with regards to health-related topics is increasing rapidly (Teufel, Schäffeler, de Zwaan, Graap, Zipfel et al., 2011). Recent technological advances

in the use of the Internet and video technologies have greatly influenced the provision of psychotherapy and other clinical services, with tele-health interventions and tele-psychological interventions being used increasingly to treat psychological problems (Barnett, 2011). Furthermore they have been used to enhance coping with stressful life events such as bereavement (van der Houwen, van den Bout, Stroebe and Stroebe, 2010) or pregnancy loss (Kersting, Kroker, Schlicht and Wagner, 2011). It is expected that technology will be used increasingly for psychological interventions in the future, with developments in virtual reality, mood-influencing packages and services that can be based upon the needs and designs of the users themselves (Goss and Anthony, 2009).

As mentioned in Chapter Four, Internet-based approaches also have some very pragmatic benefits: they provide anonymity and the opportunity to undergo the intervention in the privacy of home; reduce contact hours between professionals and clients, which could help tackle the problem of waiting lists and shortages of therapists (van der Zanden, Kramer and Cuijpers, 2011); and eliminate travel, thus saving time and money. In short, it is anticipated that the future of many psychological and health-based intervention lies in the Internet.

Still, despite these developments and even if those without an Internet connection are in the minority in the UK, it would still be valuable to make the CEPB more accessible to those who do not have Internet access. A possible solution would be to still run the programme online, but include women who do not normally use the Internet. However, this would raise practical issues concerning training these women how to use the Internet, and making a computer with an Internet connection available to them. Alternatively, conducting three face-to-face versions of the CEPB, corresponding to the three electronic versions, would enable one to determine how effective such a programme would be, both in reaching those women who do not have Internet access, and in achieving positive

outcomes. If they are shown to be effective, they could then be implemented to supplement the electronic versions, thereby reaching more women.

10.4.3 Effecting Lasting Change

The present study showed that, although the CEPB was evaluated positively by participants and seemed to effect positive changes, these did not persist at follow-up, with the exception of the CEPB's effect on conformity. While this could be due to methodological issues, such as the lack of power to detect medium or small effects, it may have still been useful to include a cognitive element in the intervention. To effect lasting change in dealing with stressful situations, women could be taught, using cognitive-behavioural techniques, to question their maladaptive coping strategies and replace them with more adaptive ones. For example, although it has not yet been applied to an intervention similar to the CEBP, Internet-based cognitive-behavioural therapy has been shown to be successful in treating social phobia in several randomised controlled trials (Hedman, Andersson, Ljotson, Andersson, Ruck et al., 2011; Carlbring, Gunnarsdottir, Hedensjo, Andersson, Ekselius et al., 2007; Andersson, Carlbring, Holmstrom, Sparthan, Furmark et al., 2006; Furmark, Carlbring, Hedman, Sonnenstein, Clevberger et al., 2009; Berger, Hohl and Caspar; 2009).

In the current study, the researcher made an effort to encourage women to reflect on their behaviour and think of alternative, more adaptive behaviours. Still, future studies may need to explore if incorporating cognitive-behavioural elements would augment positive effects. This would require a health psychologist trained in cognitive-behavioural stress-management techniques to be involved in delivering the intervention.

Originally, it was beyond the scope of the current study to effect lasting changes in personality, due to the widely accepted finding that personality is a stable construct. However, as discussed in Section 10.3.4, it has been proposed that personality can be modified through intervention (Eysenck, 1994), which Grossarth-Maticek et al. (2000)

attempted to demonstrate in their psychosocial breast-cancer prevention study. This idea is also in line with the sociogenomic model of personality traits, as argued above. The notion that personality traits can change is strengthened by the fact that conformity was reduced after taking part in EESR or in psycho-education, and that this reduction persisted at follow-up. Unfortunately, unlike conformity, other 'breast-cancer prone' traits were not measured after the intervention and at follow-up, because changes were not expected to occur. Thus, it would be useful for future studies to investigate whether such personality modification is possible with the other 'breast-cancer prone' traits. In order to be able to determine this, it would be necessary to measure all 'breast-cancer prone' traits not just before the intervention, but also after the intervention and at follow-up.

The emotional-expression-and-stress-reduction element of the CEPB ('Art and Laughter for Wellbeing') focused largely on providing an emotional outlet for women. Some psycho-educational elements were included in the form of providing information on adaptive and maladaptive coping styles, as well as on the benefits of laughter as a stress-management technique. Still, the main emphasis was on emotional-expression-and-stress-reduction. As mentioned in Chapter Four, programmes aimed at changing individuals' cognitions usually do not incorporate much room for emotional and social support. With the present study focusing on coping with bereavement, it seemed important to allow individuals to express themselves, offering empathic understanding and support. Teufel, Giel and Zipfel (2009) have shown that in online psychotherapy, conveying empathy through distant cyberspace is possible.

The modification of individuals' cognitions was not the primary goal of the CEPB, although the author made an effort in her communication with participants to get them to reflect on their behaviour and to think of alternative, more adaptive ways of behaving. Future research may wish to explore the incorporation of cognitive-behavioural techniques, in

order to assess whether these could augment and prolong the positive effects of the programme.

Nicassio, Meyerowitz and Kerns (2004) have argued that greater attention must be paid to including elements in interventions that are designed to maintain treatment gains over time (e.g. spousal or family support, relapse-prevention training, and self-efficacy enhancement). This will make it necessary to conduct studies with longer follow-up periods. Thus, future applications of the CEPB need to aim for incorporating such elements. This could be accomplished by sending regular text messages to participants' mobile phones, for example. In these text messages, women could be asked how they are coping, and to get in touch with the group facilitator via e-mail or phone, if they had any problems or concerns they would like to talk about. In that way, participants would be supported and followed up over a longer period of time, in order to increase the likelihood that intervention gains are maintained in the long-term.

10.5 Contributions to Knowledge

To elucidate the contributions to knowledge which the present study has made, it is important to compare it with similar Internet studies, which have been discussed in Chapter Four. Lange et al.'s (2000; 2001; 2002) online treatment programme for posttraumatic stress and pathological grief termed 'Interapy', for example, contains parallels to the CEPB in that it focused on coping with bereavement and facilitated emotional expression through expressive writing. However, in 'Interapy' expressive writing was the only therapeutic tool, whereas the present study included additional elements designed to aid emotional expression and stress reduction ('Art and Laughter for Wellbeing'). Furthermore, unlike 'Interapy', the CEPB was a group intervention, allowing for participants to mutually support each other. Moreover, 'Interapy' did not include any psycho-educational elements, as did two versions of the CEPB (in the form of autobiographical accounts of breast-cancer sufferers).

Another major Internet study in this area, which bears some similarities to the CEPB, was conducted by Winzelberg et al. (2003). The study consisted of an online social support group for breast-cancer patients termed 'Bosom Buddies'. Similar to the CEPB, the intervention included a discussion board moderated by a mental-health professional. However, the facilitator explicitly refrained from providing psychological advice, or from developing a personal therapeutic relationship with participants. This stands in stark contrast to the CEPB, as part of which the development of a therapeutic relationship and the provision of psychosocial support was considered to be essential. Participants in the 'Bosom Buddies' programme were provided with personal stories from survivors for encouragement, and shared their own experiences. Similarly, the CEPB employed autobiographical accounts of breast-cancer sufferers, but with the aim of increasing awareness of psychosocial factors in breast-cancer development, and more generally in health and illness. Winzelberg et al.'s participants kept a Web-based personal journal, similar to the CEPB, which included personal blogs. Yet, participants were not provided with feedback on their journal entries. Conversely, participants in the CEPB received responses from the facilitator to each blog entry, prompting them to explore certain issues further, and getting one-to-one support in that way.

It is important to note that all participants in the 'Bosom Buddies' programme had already developed breast cancer, while in the present study the vast majority had never had breast cancer. Thus, the focus of the CEPB was on primary prevention, unlike Winzelberg et al.'s programme, which focused on secondary prevention. As argued in Chapter Four, interventions with psychologically 'breast-cancer prone' individuals are needed, rather than focusing on just those who have already developed the disease, because intervening at an earlier point could lead to more beneficial effects and possibly increase survival rates. The present study addresses this need.

Grossarth-Maticek et al.'s (2000) autonomy training for 72 'breast-cancer prone' women (see Chapter Four, Sub-Section 4.6 for a detailed description), designed to provide individuals with the ability to learn alternative types of autonomous behaviour and thereby reduce the risk of developing breast cancer, is also similar to the CEPB in that it aimed to contribute to breast-cancer prevention by intervening psychologically. Additionally, women were taught to cope adequately with external stressors, and not to suppress their feelings. These features are comparable to the present intervention, which facilitated emotional expression and stress reduction. However, there are some major differences between the two studies. Unlike the present study, Grossarth-Maticek and colleagues did not include established psychosocial factors in breast-cancer aetiology as outcome measures. Rather, they measured breast-cancer morbidity and mortality, finding that at 14-year follow-up participants in the therapy group were significantly less likely to develop and die of breast cancer than participants in the control group. Still, it is planned that the participants of the present study will be followed up over a longer time period as well, and it will be assessed in two-year intervals whether they develop breast cancer. Funding will be sought to keep following these women and to offer the CEPB, or a similar preventative intervention, yearly.

Unlike the CEPB, Grossarth-Maticek and colleagues' autonomy training did not include autobiographical accounts of breast-cancer sufferers as a psycho-educational tool. Besides, non-verbal expression, as was possible in 'Art and Laughter for Wellbeing', was not part of autonomy training. Lastly, autonomy training was carried out face-to-face, unlike the CEPB, which took place online to account for the fact that women with a 'breast-cancer prone' personality may not feel comfortable talking about their feelings in a face-to-face setting. The CEPB thus is a more comprehensive approach to the modification of psychosocial factors potentially involved in the development of breast cancer. Unlike any preceding interventions, it pays attention to the needs of 'breast-cancer

prone' women, offering means of non-verbal (though the use of pictures and music) and non-face-to-face (i.e. online) emotional expression and communication.

Comparing the CEPB to other major studies in the area, it is thus clear that the present study makes several contributions to knowledge of psychosocial prevention of breast cancer. These include the implementation and evaluation of the effectiveness of an innovative electronic intervention programme designed to enhance coping with bereavement, coping with stressful life events, social support, and the awareness of the connections between psychological and physical health. At the time of writing, the CEPB was unique in attempting to modify established psychosocial factors in breast-cancer development. It was also distinctive in using autobiographical accounts as a tool for psycho-education.

A further contribution to knowledge comes from the present study's unexpected finding that interventions such as EESR and psycho-education can have an impact on conformity. This finding is particularly salient in light of the fact that conformity is a key feature of the 'breast-cancer prone' personality.

Another notable contribution to knowledge entails the development of an innovative psychological screening tool to assess psychosocial factors potentially associated with breast-cancer development. At the time of writing, no comparable tool had been published. If breast-cancer prevention is to focus more on psychosocial factors involved in the aetiology of this disease, then such a tool is fundamental for assessing women who may be 'psychosocially at risk' of developing breast cancer.

10.5.1 A Proposed Biopsychosocial Model of Breast-Cancer Development

The literature review in Chapters Two and Three showed that there are a number of psychosocial factors that, in addition to physical risk factors, potentially contribute to the

development of breast cancer. However, what is missing is a model which integrates these factors. Such a model is important because it is necessary to look at breast-cancer aetiology as a whole, taking into account biological, psychological and social factors, if preventative measures are to be designed effectively. Figure 8 displays a proposed biopsychosocial model of breast-cancer development, based on the reviewed literature and findings of the present study. Several pathways leading to breast cancer are proposed in this model; the legend displays the evidence these pathways are based on, while the asterisks indicate potential points of intervention.

Physical risk factors have been shown to have a direct impact on breast-cancer risk (e.g. Wise, 2011; Smith, 2011). These include dispositional variables (e.g. hereditary factors), biological variables (e.g. menopause, number of children, age at first child) as well as behavioural variables (e.g. breastfeeding, alcohol intake, or consumption of a healthy diet). Regarding psychological and social factors, the experience of recent and/or traumatic bereavement and/or stressful life events is suggested as a starting point, as the literature on stressful life-events and breast-cancer incidence indicates (see Chapter Two, Sections 2.4 and 2.5). Social support moderates the relationship between bereavement/stressful life events and perceived strain: high levels of social support are likely to result in low perceived strain, while low levels of social support are likely to lead to high perceived strain. Level of perceived social support, in turn, is mediated by the extent of 'breast-cancer prone' personality, with its tendency to be overly sacrificing and compliant, and to therefore be less likely to ask for support; this has been suggested by Iwamitsu et al. (2005) and also emerged from the present study's thematic analysis (see Appendix G).

Individuals respond to perceived strain leads with either adaptive or maladaptive coping strategies (e.g. Ferguson and Cox, 1997). Maladaptive coping may result in chronic stress, which has been shown to be associated with immunological and hormonal

changes (Sklar and Anisman, 1981); these changes, in turn, may promote breast-cancer development. A 'breast-cancer prone' personality, with its tendency to engage in emotional suppression, may further exacerbate the risk of such immunological and hormonal changes taking place (Tops, van Peer and Korf, 2007).

This model allows for the fact that women without a 'breast-cancer prone' personality, or who have not experienced bereavement and/or stressful life events, may still develop breast cancer if they exhibit physical risk factors. Furthermore, low levels of social support are not necessarily always the result of a 'breast-cancer prone personality'; one may simply not have many people to turn to. This can especially be the case for older women, who with increasing age, are more likely to lose people close to them (Cooper and Faragher, 1992; 1993). Therefore, the occurrence of bereavement and/or stressful life events, coupled with a lack of social support, may already result in high perceived strain, regardless of personality. Similarly, extremely traumatic and painful bereavement or extremely severe stressful life events may by themselves lead to high perceived strain, regardless of the social support available. This was shown in the current study's thematic analysis (see Appendix G).
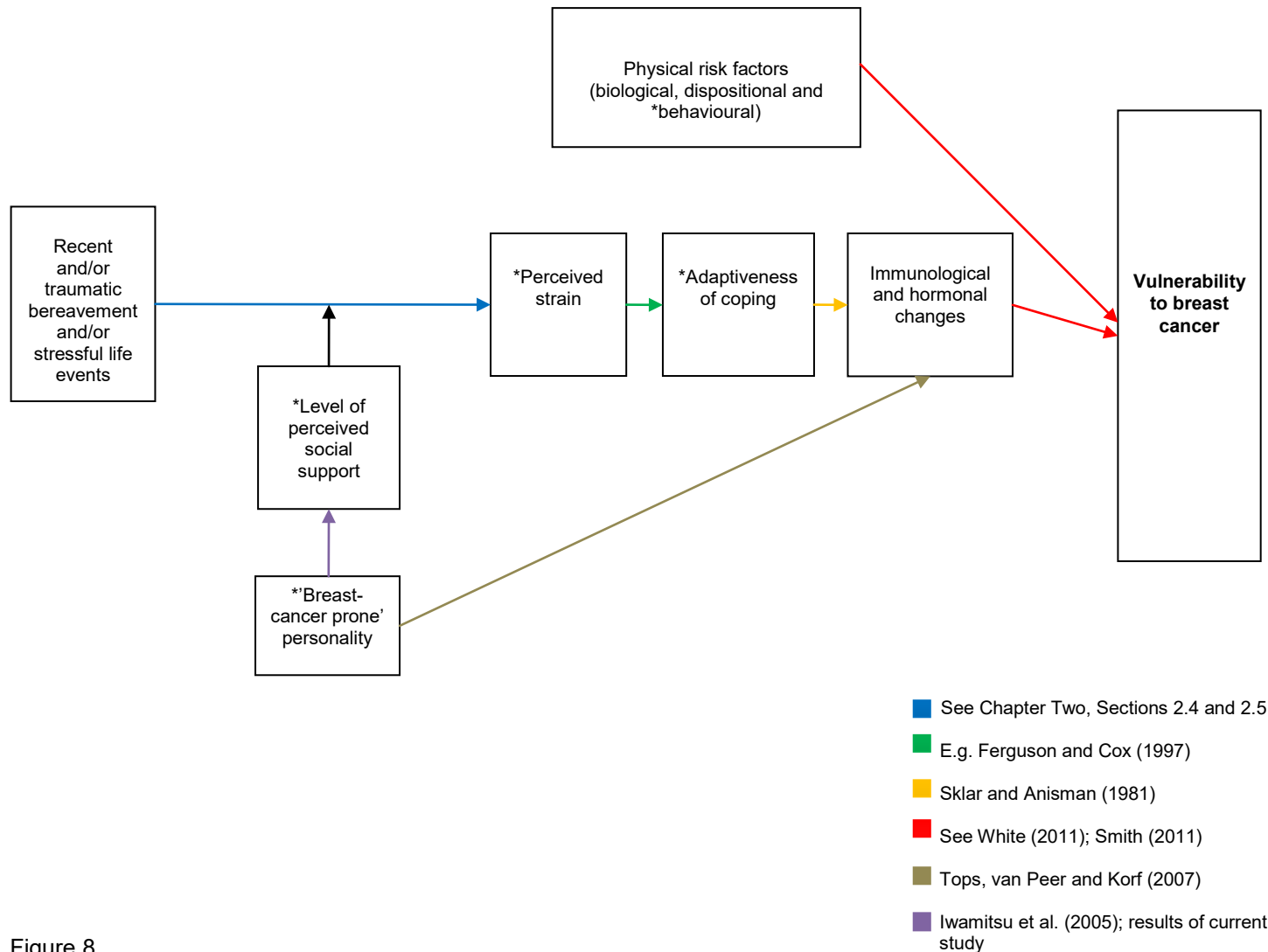
Figure 8

A Proposed Biopsychosocial Model of Breast-Cancer Development

Note. Legend displays evidence for pathways; asterisks indicate potential points of intervention.

Proposed Points of Intervention

There are five points at which intervention seems possible. Behavioural risk factors could be decreased by health-promotion programmes educating women on these risks and supporting them to make changes to their behaviour. This could involve, for example, programmes promoting breastfeeding, exercise programmes, or promoting healthy eating. With regard to the psychosocial factors, interventions increasing social support, helping women reappraise perceived strain and harness their coping resources, reducing maladaptive coping and increasing adaptive coping, and encouraging the expression of negative emotions, seem necessary in order to reduce the impact of these psychosocial variables on vulnerability to breast cancer. An intervention addressing these psychosocial factors has been offered in the present study, in the form of the CEPB. In light of the finding indicating lower conformity after the CEPB, it may even be possible to intervene on the personality level, effecting long-term changes in emotional expressivity.

The biopsychosocial model of breast-cancer development proposed above should be viewed as a suggested model which does not claim to be complete. The precise mechanisms leading from psychosocial factors to breast-cancer development are still unclear, particularly concerning the biological changes taking place as part of this process. However, what is established is that there is a complex interplay between biological, psychological and social variables that contribute to breast-cancer aetiology. This proposed model, which integrates the established physical and psychosocial risk factors, may serve to stimulate research into the pathways leading to breast cancer, as well as into breast-cancer prevention through psychosocial intervention.

Implications for Research and Practice

The United Kingdom's Medical Research Council (MRC), in its 2008 document 'Developing and evaluating complex interventions: new guidance', provides guidance on developing, evaluating and implementing complex interventions aimed at improving

health. Complex interventions, according to the MRC, are interventions which depend, among other criteria, on the following: the number of interactions between elements within conditions; the number and difficulty of behaviours required by those delivering or receiving the intervention; the number and variability of outcomes; and the degree of flexibility or tailoring of the intervention permitted. Under these criteria, the CEPB constitutes a complex intervention. The MRC further suggests that interventions have a coherent theoretical basis, and that this is used systematically to develop the intervention; a good theoretical understanding is needed of how an intervention causes change, in order to enable the identification and strengthening of weak links in the causal chain. The CEPB was developed on the basis of evidence from mind-cancer research, psychoneuroimmunological findings as well as evidence on the effectiveness of various forms of interventions. Yet, the MRC's stipulation of a sound theoretical background emphasises the need for a model which integrates existing evidence into a single coherent framework, forming the foundation for further research into the psychosocial aetiology and prevention of breast cancer. The present model attempts to provide such a framework.

Research on the proposed biopsychosocial model of breast-cancer development is likely to lead to its refinement and to more knowledge of the exact nature of the connections between its elements. There may well be parallel connections and feedback mechanisms which have yet to be detected. For example, for a woman being confronted with the information that she presents with physical risk factors of breast cancer, this may lead to perceived strain, which in turn will increase her psychological vulnerability to develop the disease. Research is likely to elucidate such mechanisms, thereby allowing for a refinement of the model and a greater understanding of the processes that lead to breast-cancer vulnerability.

10.6 Conclusion

Health-psychology interventions are becoming increasingly important in the delivery of health-care services across a range of patient groups (Nicassio and Smith, 1995). Health psychologists are playing a key role in designing, delivering and evaluating interventions aimed at reducing stress, enhancing quality of life, and providing support. Many such interventions have enhanced patients' personal mastery and coping skills (Lorig and Holman, 1993). It is important to note that according to Nicassio and Smith, health psychologists have also successfully applied psychological treatments to the health domain. These interventions include measures designed to enhance education, social support, behaviour change, stress reduction and emotional disclosure (Nicassio et al., 2004). The present study constitutes an effort to combine these components into a single electronic intervention programme, addressing the enhancement of coping with bereavement and other stressful life events, social support, and the awareness of the connections between psychological and physical health.

A long-term goal of this type of intervention programme is to contribute towards the prevention of breast cancer, addressing the neglected psychosocial aspects of the aetiology of this disease. Keefe and Blumenthal (2004) have argued that the emergence of the biopsychosocial model provided a conceptual basis for the notion that psychosocial interventions might be important in the management and treatment of patients with physical disease, which had a significant impact on the discipline of health psychology.

The British Psychological Society's Division of Health Psychology (DHP) lists one of the aims of health psychology as the identification of psychological factors contributing to physical illness (DHP, 2011). Chapters Two and Three have shown that the existing literature has identified such factors where breast cancer is concerned. A further goal listed by the DHP is the prevention and management of illness. There needs to be a shift in focus towards prevention of disease by addressing not just physical factors, but also

psychosocial factors which potentially contribute to disease development. This should by no means replace physical-prevention measures. Rather, psychosocial disease-prevention programmes should integrate, supplement and enhance existing interventions that focus exclusively on physical risk factors. The present study has attempted to develop, implement and evaluate such an intervention, delivering it in the form of an electronic CEPB. The electronic aspect of the programme is in line with current developments in health care, with tele-psychotherapy, tele-health and Internet-based health care becoming increasingly important.

The CEPB constitutes an important step towards the long-term goal of including psychosocial breast-cancer prevention programmes in routine health care. Health psychologists need to be at the forefront of research into, the implementation and evaluation of such programmes, as well as disseminating research findings to health-care professionals. Furthermore, large-scale intervention studies need to be conducted which follow women for many years after the intervention has ended, assessing breast-cancer morbidity and mortality, in order to be able to quantify the merits of the programme in terms of breast-cancer prevention. The results of such studies, providing they are conducted with methodological rigour and yield positive results, should help convince biomedical model-oriented health-care professionals of the usefulness of integrating such interventions into the existing provision.

It is paramount that health psychologists help advance this area, working in partnership with other health-care professionals, such as general practitioners and oncologists. Nevertheless, the women whom these interventions are going to be designed for also need to be included in the process. The Department of Health's (2011) White Paper "Equity and Excellence: Liberating the NHS" emphasises that shared decision-making needs to be at the forefront of delivering health care. This means not exclusively focusing on clinical outcomes, but also considering the patients' experiences and their needs. This

principle should be applied to psychosocial prevention programmes. An effort was made in the current study to provide individual support to each participant, in addition to asking women to offer their opinions on how the programme could be improved to better meet their needs. Similarly, future applications of the CEPB need to ensure that each client's individual needs are recognised and addressed.

To conclude, this study has demonstrated the value and effectiveness of three versions of an electronic intervention programme targeting psychosocial factors known to contribute to breast-cancer development. We are just at the start of a journey towards integrating psychosocial breast-cancer prevention programmes into routine health care. The ultimate objective of improving women's psychological and physical health should make this a worthwhile endeavour.

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APPENDICES

CONTENTS

Appendix A: Final Versions of Questionnaires
        A.1: Paper Copy of Final Version of Pre-Intervention Online Screening Tool for Intervention Participants

Dear Madam,

Teesside University has started a project examining the relationship between emotional factors and health and illness. There is some indication in the literature that stressful life experiences, for example bereavement, may be related to one's well-being.

How closely stressful life experiences and well-being are connected depends on a number of factors, physical as well as emotional. In our study we would like to explore this connection further, as well as the effects of an 8 week intervention programme. In order to do so, we would like you to complete an online questionnaire. In total, this will take about 15-20 minutes. Of course, you can always let us know whether you would like to discuss your answers with us, by e-mailing Judith Eberhardt (PhD student) at j.eberhardt@tees.ac.uk.

More information about the emotional health programme can be found on www.emotional-health.net

The answers you give will only be seen by the researchers of this study and will remain completely confidential. Your name will be removed and replaced by an identification number for further data analyses, which will be anonymous.

If you decide at a later stage that you would prefer to withdraw your answers, you can email j.eberhardt@tees.ac.uk.

Thank you for your time and effort.

All the best,

Judith Eberhardt, MSc, PhD Student
School of Social Sciences and Law, University of Teesside, Borough Road, Middlesbrough TS1 3BA

Consent
( ) I hereby confirm that I am a woman aged 18 years or older and that I live in the UK. I consent to taking part in this study. I am aware that I can withdraw from the study at any time.

Could you please provide your email address here:

_____

Please type your email address again:

_____

1. How old are you?

_____

2. What is your marital status?
( ) Single
( ) Married
( ) Partner
( ) Divorced
( ) Separated
( ) Widow
( ) Other

3. What is your highest level of education?
( ) Primary school
( ) O-level(s)/GCSE
( ) A-levels
( ) Higher education certificate
( ) Higher education diploma
( ) Bachelor Degree (BSc/BA)
( ) Masters Degree (MSc/MA)
( ) PhD

4. What is your ethnic origin?
( ) White/British
( ) White/Other
( ) Black/British
( ) Black/Other
( ) Bangladeshi
( ) Indian
( ) Pakistani
( ) Chinese
( ) Other

5. What is your religious orientation?
    ( ) Christian
    ( ) Muslim
    ( ) Hindu
    ( ) Jewish
    ( ) None
    ( ) Other

6. Are you employed?
    ( ) Yes - please move on to Question 8
    ( ) No

7. If No, how many years ago were you last employed?

    _____

8. Have you had any pregnancies?
    ( ) Yes
    ( ) No - please move on to Question 15

9. How old were you when you had your first child?

    _____

10. How many children do you have?

    _____

11. Are you still in contact with your children?
              Yes   No
Child 1 _____ _____
Child 2 _____ _____
Child 3 _____ _____
Child 4 _____ _____
Child 5 _____ _____
Child 6 _____ _____

12. Did you breastfeed your child(ren)?
              Yes   No
Child 1 _____ _____
Child 2 _____ _____
Child 3 _____ _____
Child 4 _____ _____
Child 5 _____ _____
Child 6 _____ _____

13. How many months did you breastfeed each child? (If this question does not apply to you, please move on to Question 14)
Child 1 _____
Child 2 _____
Child 3 _____
Child 4 _____
Child 5 _____
Child 6 _____

14. We are sorry if any of your children are deceased; could you please let us know the date when this happened, for example, 02/10/02? (If this question does not apply to you, please move on to Question 15)

_____
_____
_____
_____
_____

15. Did you ever experience any loss of somebody or something very dear to you?
( ) Yes
( ) No - please move on to Question 21

16. If yes, what was this and when did it happen?

_____
_____
_____
_____
_____

17. How have you dealt with your loss?

_____
_____
_____
_____
_____

18. Do you feel you have dealt with your loss well?
( ) Yes
( ) No
( ) Not at all
( ) I try not to think about it

19. Thinking about the loss that affected you most, what year did this happen in?

    _____

20. Are you still suffering as a result of this loss?
    ( ) Yes
    ( ) Sometimes
    ( ) No

21. Have you ever suffered from breast cancer?
    ( ) Yes
    ( ) No

22. Are there, or have there been, any women in your family from your mother's side who suffer(ed) from breast cancer?

    ( ) Yes
    ( ) No - Please move on to the next page

23. If Yes, how are you related to them? (tick all that apply)
    ( ) Mother
    ( ) Sister
    ( ) Daughter
    ( ) Aunt
    ( ) Grandmother
    ( ) Other

24. Are you using a contraceptive pill?
    ( ) Yes- Please move on to Question 26
    ( ) No - Please move on to Question 26
    ( ) Not Any More

25. If Not Any More, when did you stop taking the pill?

    _____

26. Do you drink alcohol?
    ( ) Yes - Please move on to Question 28
    ( ) No - Please move on to Question 29
    ( ) Not Any More

27. If Not Any More, when did you have your last drink?

    _____

28. If you do drink alcohol, do you think you are drinking too much?
    ( ) Yes
    ( ) No

29. Do you perform regular exercise/sport?
      ( ) Yes - Please move on to Question 32
      ( ) No - Please move on to Question 31
      ( ) Not Any More

30. If Not Any More, when was the last time you exercised/played sports?

      _____

31. If you don't exercise or play sports, would you like to start?
      ( ) Yes
      ( ) No
      ( ) Maybe

32.

Please have a look at this Body Mass Index Chart. At the top, please find your weight (in pounds) and at the left hand side, your height (in feet). Is your Body Mass Index higher than 26 (i.e. is it in the yellow or red area)?
      ( ) Yes
      ( ) No
      ( ) Don't know

33. Do you think you are eating a healthy diet?
      ( ) Yes - Please move on to Question 36
      ( ) No - Please move on to Question 35
      ( ) Not Any More

34. If Not Anymore, when was the last time you ate a healthy diet?

      _____

35. If No, would you like to start eating a healthy diet?
      ( ) Yes
      ( ) No
      ( ) Maybe

36. Are you menopausal?
      ( ) Yes
      ( ) No - Please move on to the next page

37. If Yes, since when?

      _____

38. If you are menopausal, do you use Hormone Replacement Therapy (HRT)?
      ( ) Yes
      ( ) No

39. I never hesitate to go out of my way to help someone in trouble
    ( ) False
    ( ) Sort of true
    ( ) True

40. I have never intensely disliked anyone
    ( ) False
    ( ) Sort of True
    ( ) True

41. There have been times when I was quite jealous of the good fortune of others
    ( ) False
    ( ) Sort of true
    ( ) True

42. I would never think of letting someone else be punished for my wrong doings
    ( ) False
    ( ) Sort of true
    ( ) True

43. I sometimes feel resentful when I don't get my own way
    ( ) False
    ( ) Sort of True
    ( ) True

44. There have been many times when I felt like rebelling against people in authority even though I knew they were right

    ( ) False
    ( ) Sort of true
    ( ) True

45. I am always polite, even to people who are disagreeable
    ( ) False
    ( ) Sort of True
    ( ) True

46. When I don't know something I don't mind admitting it at all
    ( ) False
    ( ) Sort of True
    ( ) True

47. I can remember 'playing sick' to get out of something
    ( ) False
    ( ) Sort of true
    ( ) True

48. I am sometimes irritated by people who ask favours of me
    ( ) False
    ( ) Sort of true
    ( ) True

49. Most stressful event during your lifetime was:

    _____
    _____
    _____
    _____
    _____

50. How have you dealt with this?

    _____
    _____
    _____
    _____
    _____

51. Do you feel you have dealt with this well?
    ( ) Yes
    ( ) No
    ( ) Not at all
    ( ) I try not to think about it

52. Second most stressful event during your lifetime was:

    _____
    _____
    _____
    _____
    _____

53. How have you dealt with this?

    _____
    _____
    _____
    _____
    _____

54. Do you feel you have dealt with this well?
    ( ) Yes
    ( ) No
    ( ) Not at all
    ( ) I try not to think about it

55. Most stressful event during the last year was:

_____
_____
_____
_____
_____

56. How have you dealt with this?

_____
_____
_____
_____
_____

57. Do you feel you have dealt with this well?
    ( ) Yes
    ( ) No
    ( ) Not at all
    ( ) I try not to think about it

58. Second most stressful event during the year last was:

_____
_____
_____
_____
_____

59. How have you dealt with this?

_____
_____
_____
_____
_____

60. Do you feel you have dealt with this well?
    ( ) Yes
    ( ) No
    ( ) Not at all
    ( ) I try not to think about it

61. I have nobody who cares what happens to me
    ( ) I strongly agree
    ( ) I agree
    ( ) I neither agree nor disagree
    ( ) I disagree
    ( ) I strongly disagree

62. I get love and affection
   ( ) I strongly agree
   ( ) I agree
   ( ) I neither agree nor disagree
   ( ) I disagree
   ( ) I strongly disagree

63. I get no chances to talk to someone about problems at work or with my housework
   ( ) I strongly agree
   ( ) I agree
   ( ) I neither agree nor disagree
   ( ) I disagree
   ( ) I strongly disagree

64. I get chances to talk to someone I trust about my personal family problems
   ( ) I strongly agree
   ( ) I agree
   ( ) I neither agree nor disagree
   ( ) I disagree
   ( ) I strongly disagree

65. I get no chances to talk about money matters
   ( ) I strongly agree
   ( ) I agree
   ( ) I neither agree nor disagree
   ( ) I disagree
   ( ) I strongly disagree

66. I get invitations to go out and do things with other people
   ( ) I strongly agree
   ( ) I agree
   ( ) I neither agree nor disagree
   ( ) I disagree
   ( ) I strongly disagree

67. I get useful advice about important things in my life
   ( ) I strongly agree
   ( ) I agree
   ( ) I neither agree nor disagree
   ( ) I disagree
   ( ) I strongly disagree

68. I get no help when I am sick in bed
   ( ) I strongly agree
   ( ) I agree
   ( ) I neither agree nor disagree
   ( ) I disagree
   ( ) I strongly disagree

69. Have you ever read any autobiographies or life stories of women who have breast cancer?

     ( ) Yes
     ( ) No - please move on to the next page

70. If YES, how many have you read (approximately)?

     ( ) 1
     ( ) 2
     ( ) 3
     ( ) more than 3

71. Did any of these autobiographies or life stories move you in any way? If so, could you describe how and why?

_____
_____
_____
_____
_____

Please indicate how strongly you agree with the following statements.

72. Experiencing stressful events, such as the death of a loved one or a divorce, can be bad for your physical health.

     ( ) I strongly disagree
     ( ) I disagree
     ( ) I neither agree nor disagree
     ( ) I agree
     ( ) I strongly agree

73. Getting support from other people, for example, getting chances to talk about personal problems, can help prevent you from contracting serious illness.

     ( ) I strongly disagree
     ( ) I disagree
     ( ) I neither agree nor disagree
     ( ) I agree
     ( ) I strongly agree

74. Bottling up your feelings when you are sad or angry, and trying to pretend everything is fine, can be bad for your physical health.

     ( ) I strongly disagree
     ( ) I disagree
     ( ) I neither agree nor disagree
     ( ) I agree
     ( ) I strongly agree

75. Please choose only one answer out of these four options

	Sort of true for me	Really true for me
Some women try to act rational so that they do not have to respond emotionally.		
Other women do act emotionally.		

76. Please choose only one answer out of these four options

	Sort of true for me	Really true for me
Some women try to understand people and their behaviour, so that they seldom respond emotionally.		
Other women act more emotionally.		

77. Please choose only one answer out of these four options

	Sort of true for me	Really true for me
Some women try to understand all interpersonal conflicts by intelligence and reasoning, trying hard not to show any emotional response.		
Other women do both.		

78. Please choose only one answer out of these four options

	Sort of true for me	Really true for me
Some women live their lives to the full, to enjoy what comes on their path.		
Other women always try to do what is reasonable and logical.		

79. Please choose only one answer out of these four options

	Sort of true for me	Really true for me
Some women do not avoid conflict when they feel something is wrong.		
Other women succeed in avoiding conflicts by relying on their reason and logic (often contrary to their feelings).		

80. Please choose only one answer out of these four options

	Sort of true for me	Really true for me
Some women try to act rationally in all situations involving other people.		
Other women do not act rationally in all situations involving other people.		

81. Please choose only one answer out of these four options

	Sort of true for me	Really true for me
Some women feel like attacking others if there are sufficient reasons to do so, but their reasoning stops them from doing so.		
Other women will follow their anger and will not be stopped by their reasoning.		

82. Please choose only one answer out of these four options

	Sort of true for me	Really true for me
Some women whose feelings get hurt will speak up and let people know that they are hurt.		
Other women will suppress their feelings and let nobody know that they got hurt.		

83. Please choose only one answer out of these four options

	Sort of true for me	Really true for me
Some women try to hide their emotions when they are in conflict with others.		
Other women will express their feelings when in conflict.		

84. Please choose only one answer out of these four options

	Sort of true for me	Really true for me
Some women do not trust their feelings.		
Other women do trust their feelings.		

85. Please choose only one answer out of these four options

	Sort of true for me	Really true for me
Some women respond emotionally to people.		
Other women respond in a more reserved manner.		

86. Please choose only one answer out of these four options

	Sort of true for me	Really true for me
Some women's behaviour towards other people is influenced by their emotions.		
Other women do not let their emotions interfere.		

87. Please choose only one answer out of these four options

	Sort of true for me	Really true for me
Some women rely on their feelings in important situations.		
Other women do not trust their feelings.		

88. Please choose only one answer out of these four options

	Sort of true for me	Really true for me
Some women try to understand the behaviour of the people who are deeply hurting them.		
Other women do not want to understand them.		

89. Please choose only one answer out of these four options

	Sort of true for me	Really true for me
Some women do not have the will to understand the people who act against their wills and desires.		
Other women nevertheless do try to understand the people who act against their wills and desires.		

90. Please choose only one answer out of these four options

	Sort of true for me	Really true for me
Some women try to understand others even if they do not like them.		
Other women will not even begin to understand the people they do not like.		

91. Please choose only one answer out of these four options

	Sort of true for me	Really true for me
Some women keep quiet when they feel unhappy or miserable.		
Other women let others know when they feel unhappy or miserable.		

92. Please choose only one answer out of these four options

	Sort of true for me	Really true for me
Some women control their behaviour if they feel angry or very annoyed.		
Other women let others see how they feel when they feel angry or very annoyed.		

93. Please choose only one answer out of these four options

	Sort of true for me	Really true for me
Some women keep quiet when they are afraid or worried.		
Other women say what they feel when afraid or worried.		

94. Please choose only one answer out of these four options

	Sort of true for me	Really true for me
Some women control their behaviour when they feel unhappy or miserable.		
Other women let others know when they feel unhappy or miserable.		

95. Please choose only one answer out of these four options

	Sort of true for me	Really true for me
Some women say what they feel when angry or very annoyed.		
Other women keep quiet when angry or very annoyed.		

96. Please choose only one answer out of these four options

	Sort of true for me	Really true for me
Some women let others see when they are afraid or worried.		
Other women control their behaviour when afraid or worried.		

97. Please choose only one answer out of these four options

	Sort of true for me	Really true for me
Some women hide their worries when they feel afraid or worried.		
Other women let others see how they feel when afraid or worried.		

98. Please choose only one answer out of these four options

	Sort of true for me	Really true for me
Some women hide their annoyance when they feel angry or very annoyed.		
Other women do not hide their emotions when they feel angry or very annoyed.		

99. Please choose only one answer out of these four options

	Sort of true for me	Really true for me
Some women do not hide their unhappiness when they feel unhappy or miserable.		
Other women hide their unhappy feelings.		

100. Please choose only one answer out of these four options

	Sort of true for me	Really true for me
Some women are often disappointed with themselves.		
Other women are often pleased with themselves.		

101. Please choose only one answer out of these four options

	Sort of true for me	Really true for me
Some women do not like the way they are leading their life.		
Other women do like the way they are leading their life.		

102. Please choose only one answer out of these four options

	Sort of true for me	Really true for me
Some women are happy with themselves most of the time.		
Other women are often not happy with themselves.		

103. Please choose only one answer out of these four options

	Sort of true for me	Really true for me
Some women like the kind of person they are.		
Other women often wish that they were someone else.		

104. Please choose only one answer out of these four options

	Sort of true for me	Really true for me
Some women are very happy being the way they are.		
Other women wish they were different.		

105. Please choose only one answer out of these four options

	Sort of true for me	Really true for me
Some women feel lonely even among their family and friends.		
Other women never feel lonely among their family and friends.		

106. Please choose only one answer out of these four options

	Sort of true for me	Really true for me
Some women feel that nobody really listens to them.		
Other women feel mostly listened to.		

107. Please choose only one answer out of these four options

	Sort of true for me	Really true for me
Some women are happy and cheerful because that is how they really feel.		
Other women act happy and cheerful while their hearts cry from loneliness.		

108. Please choose only one answer out of these four options

	Sort of true for me	Really true for me
Some women feel ungrateful that they cannot enjoy life more.		
Other women do enjoy life.		

109. Please choose only one answer out of these four options

	Sort of true for me	Really true for me
Some women wish there was a place for them where they could relax.		
Other women do have a place where they can relax.		

110. Please choose only one answer out of these four options

	Sort of true for me	Really true for me
Some women never cry.		
Other women do cry.		

111. Please choose only one answer out of these four options

	Sort of true for me	Really true for me
Some women wish that other women could see through their pretend happiness.		
Other women do not pretend their happiness.		

112. Please choose only one answer out of these four options

	Sort of true for me	Really true for me
Some women wish they could talk to a counsellor or psychologist.		
Other women have no desire to talk to a counsellor or psychologist.		

Finally, we would like to ask you some questions about your experience of completing this questionnaire.

113. Learning to fill in this questionnaire was easy.
     ( ) I Strongly Agree
     ( ) I Agree
     ( ) I Neither Agree Nor Disagree
     ( ) I Disagree
     ( ) I Strongly Disagree

114. I found completing this questionnaire enjoyable.
     ( ) I Strongly Agree
     ( ) I Agree
     ( ) I Neither Agree Nor Disagree
     ( ) I Disagree
     ( ) I Strongly Disagree

115. Becoming skilful at completing this survey was easy.
     ( ) I Strongly Agree
     ( ) I Agree
     ( ) I Neither Agree Nor Disagree
     ( ) I Disagree
     ( ) I Strongly Disagree

116. The actual process of completing this questionnaire was pleasant.
    ( ) I Strongly Agree
    ( ) I Agree
    ( ) I Neither Agree Nor Disagree
    ( ) I Disagree
    ( ) I Strongly Disagree

117. The questionnaire pages were easy to navigate.
    ( ) I Strongly Agree
    ( ) I Agree
    ( ) I Neither Agree Nor Disagree
    ( ) I Disagree
    ( ) I Strongly Disagree

118. I had fun completing this questionnaire.
    ( ) I Strongly Agree
    ( ) I Agree
    ( ) I Neither Agree Nor Disagree
    ( ) I Disagree
    ( ) I Strongly Disagree

119. Which year did you start using Web sites?

    _____

120. Which year did you first feel confident using Web sites?

    _____

121. On average, how many hours do you use the World Wide Web per week?

    _____

122. On average, how many times do you use the World Wide Web per week?

    _____

123. Do you have any comments or suggestions regarding this questionnaire?

    _____
    _____
    _____
    _____
    _____

Thank you very much for your effort and time to complete the questionnaire. I will contact you within the next few days and you will be provided with log-in details and the web address where the emotional health programme is taking place. If, for any reason you feel you would like to discuss certain issues from this questionnaire with us, then please do not hesitate to email j.eberhardt@tees.ac.uk.

A.2: Paper Copy of Post-Intervention Online Questionnaire for Intervention Participants

Dear Madam,

You recently took part in the 8-week Emotional Health programme, developed by me, Judith Eberhardt, PhD student at Teesside University.

I would now like to find out how you feel about this programme, and about any possible impact it may have had on you. The answers you give will only be seen by me, the researcher of this study, and will remain completely confidential. Your name will be removed and replaced by an identification number for further data analyses, which will be anonymous.

If you decide at a later stage that you would prefer to withdraw your answers, you can email me at: j.eberhardt@tees.ac.uk.

Please do take the time to complete this short questionnaire, as it is important to evaluate the programme and its effects, in order to assist the development of future interventions.

Thank you very much for your time and effort.

All the best,

Judith Eberhardt, MSc, PhD Student
School of Social Sciences and Law, University of Teesside, Borough Road, Middlesbrough TS1 3BA

Consent
( ) I hereby confirm that I am a woman aged 18 years or older and that I live in the UK. I consent to taking part in this study. I am aware that I can withdraw from the study at any time.

Could you please provide your email address here (please ensure that it is the same email address that you used to sign up for the project):

_____

Please type your email address again:

_____

1. How old are you?

   _____

2. What is your marital status?
   ( ) Single
   ( ) Married
   ( ) Partner
   ( ) Divorced
   ( ) Separated
   ( ) Widow
   ( ) Other

3. Are you employed?
   ( ) Yes - please move on to Question 5
   ( ) No

4. If No, how many years ago were you last employed?

   _____

5. Did you ever experience any loss of somebody or something very dear to you?
   ( ) Yes
   ( ) No - please move on to Question 11

6. If yes, what was this and when did it happen?

   _____
   _____
   _____
   _____
   _____

7. How have you dealt with your loss?

   _____
   _____
   _____
   _____
   _____

8. Do you feel you have dealt with your loss well?
   ( ) Yes
   ( ) No
   ( ) Not at all
   ( ) I try not to think about it

9. Thinking about the loss that affected you most, what year did this happen in?

   _____

10. Are you still suffering as a result of this loss?
        ( ) Yes
        ( ) Sometimes
        ( ) No

11. Have you ever suffered from breast cancer?
        ( ) Yes
        ( ) No

12. I never hesitate to go out of my way to help someone in trouble
        ( ) False
        ( ) Sort of true
        ( ) True

13. I have never intensely disliked anyone
        ( ) False
        ( ) Sort of True
        ( ) True

14. There have been times when I was quite jealous of the good fortune of others
        ( ) False
        ( ) Sort of true
        ( ) True

15. I would never think of letting someone else be punished for my wrong doings
        ( ) False
        ( ) Sort of true
        ( ) True

16. I sometimes feel resentful when I don't get my own way
        ( ) False
        ( ) Sort of True
        ( ) True

17. There have been many times when I felt like rebelling against people in authority even though I knew they were right

        ( ) False
        ( ) Sort of true
        ( ) True

18. I am always polite, even to people who are disagreeable
        ( ) False
        ( ) Sort of True
        ( ) True

19. When I don't know something I don't mind admitting it at all
    ( ) False
    ( ) Sort of True
    ( ) True

20. I can remember 'playing sick' to get out of something
    ( ) False
    ( ) Sort of true
    ( ) True

21. I am sometimes irritated by people who ask favours of me
    ( ) False
    ( ) Sort of true
    ( ) True

22. Most stressful event during your lifetime was:

    _____
    _____
    _____
    _____
    _____

23. How have you dealt with this?

    _____
    _____
    _____
    _____
    _____

24. Do you feel you have dealt with this well?
    ( ) Yes
    ( ) No
    ( ) Not at all
    ( ) I try not to think about it

25. Second most stressful event during your lifetime was:

    _____
    _____
    _____
    _____
    _____

26. How have you dealt with this?

    _____
    _____
    _____
    _____

27. Do you feel you have dealt with this well?
        ( ) Yes
        ( ) No
        ( ) Not at all
        ( ) I try not to think about it

28. Most stressful event during the last year was:

_____
_____
_____
_____
_____

29. How have you dealt with this?

_____
_____
_____
_____
_____

30. Do you feel you have dealt with this well?
        ( ) Yes
        ( ) No
        ( ) Not at all
        ( ) I try not to think about it

31. Second most stressful event during the year last was:

_____
_____
_____
_____
_____

32. How have you dealt with this?

_____
_____
_____
_____
_____

33. Do you feel you have dealt with this well?
        ( ) Yes
        ( ) No
        ( ) Not at all
        ( ) I try not to think about it

34. Apart from taking part in the Emotional Health programme, are there any other recent events in your life (positive or negative) which may have affected the way you are dealing with stressful events and/or your loss?

---

35. I have nobody who cares what happens to me
      ( ) I strongly agree
      ( ) I agree
      ( ) I neither agree nor disagree
      ( ) I disagree
      ( ) I strongly disagree

36. I get love and affection
      ( ) I strongly agree
      ( ) I agree
      ( ) I neither agree nor disagree
      ( ) I disagree
      ( ) I strongly disagree

37. I get no chances to talk to someone about problems at work or with my housework
      ( ) I strongly agree
      ( ) I agree
      ( ) I neither agree nor disagree
      ( ) I disagree
      ( ) I strongly disagree

38. I get chances to talk to someone I trust about my personal family problems
      ( ) I strongly agree
      ( ) I agree
      ( ) I neither agree nor disagree
      ( ) I disagree
      ( ) I strongly disagree

39. I get no chances to talk about money matters
      ( ) I strongly agree
      ( ) I agree
      ( ) I neither agree nor disagree
      ( ) I disagree
      ( ) I strongly disagree

40. I get invitations to go out and do things with other people
      ( ) I strongly agree
      ( ) I agree
      ( ) I neither agree nor disagree
      ( ) I disagree
      ( ) I strongly disagree

41. I get useful advice about important things in my life
      ( ) I strongly agree
      ( ) I agree
      ( ) I neither agree nor disagree
      ( ) I disagree
      ( ) I strongly disagree

42. I get no help when I am sick in bed
      ( ) I strongly agree
      ( ) I agree
      ( ) I neither agree nor disagree
      ( ) I disagree
      ( ) I strongly disagree

43. Have you ever read any autobiographies or life stories of women who have breast cancer?
      ( ) Yes
      ( ) No - please move on to the next page

44. If YES, how many have you read (approximately)?
      ( ) 1
      ( ) 2
      ( ) 3
      ( ) more than 3

Please indicate how strongly you agree with the following statements.

45. Experiencing stressful events, such as the death of a loved one or a divorce, can be bad for your physical health.
      ( ) I strongly disagree
      ( ) I disagree
      ( ) I neither agree nor disagree
      ( ) I agree
      ( ) I strongly agree

46. Getting support from other people, for example, getting chances to talk about personal problems, can help prevent you from contracting serious illness.

       ( ) I strongly disagree
       ( ) I disagree
       ( ) I neither agree nor disagree
       ( ) I agree
       ( ) I strongly agree

47. Bottling up your feelings when you are sad or angry, and trying to pretend everything is fine, can be bad for your physical health.
       ( ) I strongly disagree
       ( ) I disagree
       ( ) I neither agree nor disagree
       ( ) I agree
       ( ) I strongly agree

Finally, I would like to ask you some questions about your experience of the Emotional Health programme.

48. On a scale of 1 to 5, where 1 means 'very unhelpful' and 5 means 'very helpful', how helpful did you find the programme?
       ( ) 1 Very unhelpful
       ( ) 2 Unhelpful
       ( ) 3 Neither helpful nor unhelpful
       ( ) 4 Helpful
       ( ) 5 Very helpful

49. On a scale of 1 to 5, where 1 means 'very unenjoyable' and 5 means 'very enjoyable', how enjoyable did you find the programme?
       ( ) Very unenjoyable
       ( ) Unenjoyable
       ( ) Neither enjoyable nor unenjoyable
       ( ) Enjoyable
       ( ) Very enjoyable

50. On a scale of 1 to 5, where 1 means 'very unuseful' and 5 means 'very useful', how useful did you find the programme?
       ( ) 1 Very unuseful
       ( ) 2 Unuseful
       ( ) 3 Neither useful nor unuseful
       ( ) 4 Useful
       ( ) 5 Very Useful

51. Learning to use the Emotional Health web site was easy.
    ( ) I strongly disagree
    ( ) I disagree
    ( ) I neither agree nor disagree
    ( ) I Agree
    ( ) I Strongly Agree

52. I found using the Emotional Health web site enjoyable.
    ( ) I strongly disagree
    ( ) I disagree
    ( ) I neither agree nor disagree
    ( ) I Agree
    ( ) I strongly agree

53. Becoming skilful at using the Emotional Health web site was easy.
    ( ) I strongly disagree
    ( ) I disagree
    ( ) I neither agree nor disagree
    ( ) I Agree
    ( ) I strongly agree

54. The actual process of using the Emotional Health web site was pleasant.
    ( ) I strongly disagree
    ( ) I disagree
    ( ) I neither agree nor disagree
    ( ) I Agree
    ( ) I strongly agree

55. The Emotional Health web pages were easy to navigate.
    ( ) I strongly disagree
    ( ) I disagree
    ( ) I neither agree nor disagree
    ( ) I Agree
    ( ) I strongly agree

56. I had fun using the Emotional Health web site.
    ( ) I strongly disagree
    ( ) I disagree
    ( ) I neither agree nor disagree
    ( ) I Agree
    ( ) I strongly agree

57. What does laughter mean to you, both generally and for your life in particular?

    _____
    _____
    _____
    _____
    _____

58. How important is laughter to you in your everyday life?
     ( ) Not important at all
     ( ) Not important
     ( ) Neither important nor unimportant
     ( ) Important
     ( ) Very important

59. Is there anything you particularly liked about the programme?

     _____
     _____
     _____
     _____
     _____

60. Is there anything you particularly disliked about the programme?

     _____
     _____
     _____
     _____
     _____

61. Do you have any suggestions how the programme could be improved?

     _____
     _____
     _____
     _____
     _____

62. Is there anything else you would like to add?

     _____
     _____
     _____
     _____
     _____

63. Would you be interested to learn about the results of the study? (If so, I will email them to you once available)
     ( ) Yes
     ( ) No

Thank you very much for your effort and time to participate in my study and complete the questionnaire. If, for any reason you feel you would like to discuss certain issues from this questionnaire or the programme with me, then please do not hesitate to email j.eberhardt@tees.ac.uk.

A.3: Paper Copy of Follow-Up Online Questionnaire for Intervention Participants

Dear Madam,

You recently took part in the 8-week Emotional Health programme, developed by Judith Eberhardt, PhD student at Teesside University.

It has been 6 weeks since you completed the programme, and I would like to find out how you have been since the programme finished, and I would also like to find out about any possible impact it may have had on you. The answers you give will only be seen by me, the researcher of this study, and will remain completely confidential. Your name will be removed and replaced by an identification number for further data analyses, which will be anonymous.

If you decide at a later stage that you would prefer to withdraw your answers, you can email me at: j.eberhardt@tees.ac.uk.

Please do take the time to complete this final short questionnaire, as it is important to evaluate the programme and its effects, in order to assist the development of future interventions.

Thank you very much for your time and effort.

All the best,

Judith Eberhardt, MSc, PhD Student
School of Social Sciences and Law, University of Teesside, Borough Road, Middlesbrough TS1 3BA

Consent
     ( ) I hereby confirm that I am a woman aged 18 years or older and that I live in the UK. I consent to taking part in this study. I am aware that I can withdraw from the study at any time.

Could you please provide your email address here (please ensure that it is the same email address that you used to sign up for the project):

_____

Please type your email address again:

_____

If you remember, please type the personal flower name that you were assigned for the programme (e.g. "Red Rose", "Blue Holly", etc.)

_____

1. How old are you?

_____

2. What is your marital status?
  ( ) Single
  ( ) Married
  ( ) Partner
  ( ) Divorced
  ( ) Separated
  ( ) Widow
  ( ) Other

3. Are you employed?
  ( ) Yes - please move on to Question 5
  ( ) No

4. If No, how many years ago were you last employed?

_____

5. Did you ever experience any loss of somebody or something very dear to you?
  ( ) Yes
  ( ) No - please move on to Question 11

6. If yes, what was this and when did it happen?

_____
_____
_____
_____
_____

7. How have you dealt with your loss?

_____
_____
_____
_____
_____

8. Do you feel you have dealt with your loss well?
  ( ) Yes
  ( ) No
  ( ) Not at all
  ( ) I try not to think about it

9. Thinking about the loss that affected you most, what year did this happen in?

_____

10. Are you still suffering as a result of this loss?
    ( ) Yes
    ( ) Sometimes
    ( ) No

11. Have you ever suffered from breast cancer?
    ( ) Yes
    ( ) No

12. I never hesitate to go out of my way to help someone in trouble
    ( ) False
    ( ) Sort of true
    ( ) True

13. I have never intensely disliked anyone
    ( ) False
    ( ) Sort of True
    ( ) True

14. There have been times when I was quite jealous of the good fortune of others
    ( ) False
    ( ) Sort of true
    ( ) True

15. I would never think of letting someone else be punished for my wrong doings
    ( ) False
    ( ) Sort of true
    ( ) True

16. I sometimes feel resentful when I don't get my own way
    ( ) False
    ( ) Sort of True
    ( ) True

17. There have been many times when I felt like rebelling against people in authority even though I knew they were right

    ( ) False
    ( ) Sort of true
    ( ) True

18. I am always polite, even to people who are disagreeable
    ( ) False
    ( ) Sort of True
    ( ) True

19. When I don't know something I don't mind admitting it at all
    ( ) False
    ( ) Sort of True
    ( ) True

20. I can remember 'playing sick' to get out of something
    ( ) False
    ( ) Sort of true
    ( ) True

21. I am sometimes irritated by people who ask favours of me
    ( ) False
    ( ) Sort of true
    ( ) True

22. Most stressful event during your lifetime was:

    _____
    _____
    _____
    _____
    _____

23. How have you dealt with this?

    _____
    _____
    _____
    _____
    _____

24. Do you feel you have dealt with this well?
    ( ) Yes
    ( ) No
    ( ) Not at all
    ( ) I try not to think about it

25. Second most stressful event during your lifetime was:

    _____
    _____
    _____
    _____
    _____

36. How have you dealt with this?

_____
_____
_____
_____
_____

27. Do you feel you have dealt with this well?
    ( ) Yes
    ( ) No
    ( ) Not at all
    ( ) I try not to think about it

28. Most stressful event during the last year was:

_____
_____
_____
_____
_____

29. How have you dealt with this?

_____
_____
_____
_____
_____

30. Do you feel you have dealt with this well?
    ( ) Yes
    ( ) No
    ( ) Not at all
    ( ) I try not to think about it

31. Second most stressful event during the year last was:

_____
_____
_____
_____
_____

32. How have you dealt with this?

_____
_____
_____
_____
_____

33. Do you feel you have dealt with this well?
    ( ) Yes
    ( ) No
    ( ) Not at all
    ( ) I try not to think about it

34. Apart from taking part in the Emotional Health programme, are there any other recent events in your life (positive or negative) which may have affected the way you are dealing with stressful events and/or your loss?

    _____
    _____
    _____
    _____
    _____

35. I have nobody who cares what happens to me
    ( ) I strongly agree
    ( ) I agree
    ( ) I neither agree nor disagree
    ( ) I disagree
    ( ) I strongly disagree

36. I get love and affection
    ( ) I strongly agree
    ( ) I agree
    ( ) I neither agree nor disagree
    ( ) I disagree
    ( ) I strongly disagree

37. I get no chances to talk to someone about problems at work or with my housework
    ( ) I strongly agree
    ( ) I agree
    ( ) I neither agree nor disagree
    ( ) I disagree
    ( ) I strongly disagree

38. I get chances to talk to someone I trust about my personal family problems
    ( ) I strongly agree
    ( ) I agree
    ( ) I neither agree nor disagree
    ( ) I disagree
    ( ) I strongly disagree

39. I get no chances to talk about money matters
    ( ) I strongly agree
    ( ) I agree
    ( ) I neither agree nor disagree
    ( ) I disagree
    ( ) I strongly disagree

40. I get invitations to go out and do things with other people
        ( ) I strongly agree
        ( ) I agree
        ( ) I neither agree nor disagree
        ( ) I disagree
        ( ) I strongly disagree

41. I get useful advice about important things in my life
        ( ) I strongly agree
        ( ) I agree
        ( ) I neither agree nor disagree
        ( ) I disagree
        ( ) I strongly disagree

42. I get no help when I am sick in bed
        ( ) I strongly agree
        ( ) I agree
        ( ) I neither agree nor disagree
        ( ) I disagree
        ( ) I strongly disagree

43. Have you ever read any autobiographies or life stories of women who have breast cancer?
        ( ) Yes
        ( ) No - please move on to the next page

44. If YES, how many have you read (approximately)?
        ( ) 1
        ( ) 2
        ( ) 3
        ( ) more than 3

Finally, please indicate how strongly you agree with the following statements.

45. Experiencing stressful events, such as the death of a loved one or a divorce, can be bad for your physical health.
        ( ) I strongly disagree
        ( ) I disagree
        ( ) I neither agree nor disagree
        ( ) I agree
        ( ) I strongly agree

46. Getting support from other people, for example, getting chances to talk about personal problems, can help prevent you from contracting serious illness.

        ( ) I strongly disagree
        ( ) I disagree
        ( ) I neither agree nor disagree
        ( ) I agree

( ) I strongly agree

47. Bottling up your feelings when you are sad or angry, and trying to pretend everything is fine, can be bad for your physical health.
   ( ) I strongly disagree
   ( ) I disagree
   ( ) I neither agree nor disagree
   ( ) I agree
   ( ) I strongly agree

Thank you very much for your effort and time to participate in my study and complete the questionnaire. If, for any reason you feel you would like to discuss certain issues from this questionnaire or the programme with me, then please do not hesitate to email j.eberhardt@tees.ac.uk.

Appendix B: Paper Copy of Study Information Web Page

Emotional Health Study

INFORMATION ABOUT THE STUDY

Background

My name is Judith Eberhardt and I am a PhD student at Teesside University. In my project, I am looking at links between emotional and physical health. There is scientific evidence to suggest that emotional health and physical health are connected. For example, bereavement (i.e. having lost a loved one) and other factors, such as not talking about your feelings when you are sad or angry, and being stressed, have been linked to breast cancer.

What is the purpose of the study?

In my PhD project, I am developing an online programme for women in the UK aged 18 or older, who have experienced the death or loss of a loved one in the past (e.g. a family member, a spouse or partner, a friend or a pet) and would like to share their experiences with other women and me, the researcher.

This will take place on a web site specially created for this project. It will involve things such as art for wellbeing, laughter for wellbeing, keeping a blog, and other elements designed to improve women's emotional wellbeing.

What will happen to me if I take part?

- You will first need to fill in an online questionnaire – this can be found here: **http://www.surveygizmo.com/s/188774/emotional-health**. You will be asked to provide your email address.

- I will then contact you via email and provide you with a participant number, username and password to gain access to a personal blog (online diary) and a message board on the project website.

- In your personal blog you will be asked to write about anything that is on your mind. In some cases, you will be asked to record your weekly activities. This blog will be kept strictly confidential and will be only accessible to you and me.

- A message board will also be made available on which you will have the opportunity to share experiences with other participants.

- In order to ensure confidentiality, data from the message boards and private blogs will use your participant number rather than your name.

- The programme will last 6-8 weeks.

After 8 weeks you will be asked to complete another questionnaire in which you can reveal your thoughts, feelings and experience of the study generally.

You can take part from your own home and there will be no need to travel - all you will need is access to the Internet.

Are there any disadvantages in or possible risks of taking part in this study?

If you feel that you might need more support in dealing with your

bereavement or loss at any point during the study, you may ring the Teesside University Psychological Therapies Clinic on 01642 342314, or email me, the researcher, at: **j.eberhardt@tees.ac.uk**.

Confidentiality - who will know I am taking part in the study?
- All information which is collected about you during the course of the research will be kept strictly confidential.
- Your identity will remain anonymous at all times and only the research team will know the names of those women participating in the study.
- The information provided by you will be labelled with your unique participant number and will ensure that your identity remains anonymous.
- Confidentiality will be respected by the storage of confidential study data in locked filing cabinets and password protected personal computers situated in secure offices at the Teesside University.
- The Web site itself will be protected with security protection software.
- When publishing the results of the study no personal information about you will be revealed that may potentially identify you.

Who has approved the study?
The Teesside University Ethics Committee has approved the study.

What will happen to the results of the study?
- The results of the study will be written up and submitted as a thesis to the University of Teesside as fulfilment for a PhD qualification.
- It may also be used to inform and aid others working in health care through discussions at conferences and journal article publications.

Do I have to take part and what if I do and then change my mind?
- Participation in this study is completely voluntary.
- If you do decide to take part in the study you will be asked for your consent and to agree to a disclaimer.
- You can however still withdraw from the study any time up until 1st October 2010.
- If you do choose to withdraw from the study you can email me, the researcher Judith Eberhardt, at j.eberhardt@tees.ac.uk.
- Alternatively you can leave a letter addressed to me at the reception of the School of Social Sciences and Law or send to the following address:
  Judith Eberhardt
  School of Social Sciences & Law
  Psychology Section
  Teesside University
  Borough Road
  Middlesbrough
  TS1 3BA
- To ensure the withdrawal process is kept strictly confidential you

should include your username instead of your name.

If you have any questions or require any further information:

- Contact the researcher Judith Eberhardt (PhD student at Teesside University) via email: j.eberhardt@tees.ac.uk
- If you would like any further information about coping with bereavement or loss, these following websites may be useful:
- http://www.crusebereavementcare.org.uk/
- http://www.childbereavement.org.uk/
- http://www.bereavement.org.uk/
- Furthermore should you feel particularly distressed, we advise you to contact your GP as soon as possible.
- Thank you for taking time to read this information and if you are interested in taking part click the button below. This link will take you to the questionnaire.

INTERESTED?
(Please click the blue link.)

Appendix C: Postings Used to Recruit Participants on Internet Forums

Are you interested in women's health issues, or concerned about your own health? Would you like to take part in developing a therapy programme which will help improve women's emotional and physical health and wellbeing?
I am a health psychologist and PhD student at Teesside University. In my project, I am exploring how emotions are linked to our health. There is some indication in the literature that stressful life experiences, for example bereavement, may be related to one's well-being. I am looking for women in the UK to take part in an online emotional health programme I have developed. It consists of an 8 week programme designed to improve women's emotional health, and takes place on a web site specifically created for the project, so there is no need to travel anywhere. Participation is completely confidential, and you will be able to participate in your own time, at your convenience.

Teesside University has issued a press release about my project, which can be read here:

http://www.tees.ac.uk/sections/alumni/news_story.cfm?story_id=3376&this_issue_title=May%202010&this_issue=204

http://www.gazettelive.co.uk/news/teesside-news/2010/05/01/teesside-uni-students-seek-breast-cancer-diagnosis-helpers-84229-26352454/

If you are interested in taking part, you can find more information about the study and sign up here on the project website:
http://www.emotional-health.net

Many thanks!

Message sent to admin/moderators of forums:

Hello,
My name is Judith Eberhardt and I am a health psychologist and PhD student at Teesside University. In my project, I am exploring how emotions are linked to our health. There is some indication in the literature that stressful life experiences, for example bereavement, may be related to one's well-being. I am looking for women in the UK to take part in an online emotional health programme I have developed. It consists of an 8 week programme designed to improve women's emotional health, and takes place on a web site specifically created for the project. Participation is completely confidential.
More information about the study can be found here on the project website:
www.emotional-health.net
I was wondering if you would allow me to post a topic inviting women to take part in my study?
I look forward to your response. Many thanks for your time.

Posting on Internet forums to recruit control group participants:

Hi,
I am a PhD student at Teesside University. As part of my PhD project, I am examining changes in stress, coping and emotional health over time. This involves looking at these factors at one point and then again 8 weeks later, then comparing the two points to see if there are any changes over time.

In order to do so, I would like to invite any women in the UK aged 18 or older to

474

complete an online questionnaire now and then another one in 8 weeks time. In total, this will take about 15 minutes.
The questionnaire can be found here:
http://www.surveygizmo.com/s/304302/examining-changes-in-stress-and-coping-over-time
Many thanks!

Appendix D: Article about Current Project in Middlesbrough Evening Gazette

Teesside Uni students seek breast cancer diagnosis helpers

May 1 2010
(http://www.gazettelive.co.uk/news/teesside
-news/2010/05/01/)

by Sarah Judd, Evening Gazette

STUDENTS at Teesside University are looking for volunteers who could help them make major breakthroughs in breast cancer diagnosis.

Breast cancer is the most common form of cancer in the UK, with approximately 125 women diagnosed daily.

It accounts for 18% of all cancers in females and claimed the lives of 12,082 women in 2007.

However, despite these stark statistics, regular breast self-examination by UK women is not widespread, and Nicola Smith, a PhD student at Teesside University is undertaking a research project which explores this issue.

Nicola is seeking women over the age of 18 from across the UK to take part in her study.

Add a comment
(#sitelife-
commentsWidget-
bottom)

In addition, fellow PhD student Judith Eberhardt is looking at whether psychological factors such as bereavement could contribute towards breast cancer.

Judith is also looking for women to volunteer and take part in her separate research project.

Nicola said: "We've always been aware of the importance of breast examination in our family as my nan Joyce Hughes died of breast cancer.

"Regularly checking your own breasts can ensure it is detected early and give women the best chance to fight the disease. Women should examine their breasts monthly but anecdotally there is a very low rate of the UK's women engaging in this.

"My study aims to find out why, as there's no concrete data, and to look at determining the best way of promoting and teaching breast self-examination."

Teesside Uni students seek breast cancer diagnosis helpers

by Sarah Judd, Evening Gazette

Nicola's study will take place on the internet, on a specifically-designed website.

Add a comment
(#sitelife-
commentsWidget-
bottom)

Women can take part from their own home and all information provided will be confidential and completely anonymous.

More information about the study can be found at www.breast-aware.co.uk, or by e-mailing Nicola at g7079216@live.tees.ac.uk

Judith's project is examining links between emotional and physical health. She said: "When looking at breast cancer, health promotions usually focus on factors such as diet and exercise to help towards the possible prevention of the disease.

"They don't look at psychological factors, such as emotional isolation, loneliness, bereavement, being the loss of loved ones or pets, repressed feelings or lack of support.

"But all of these have a role to play in contributing towards the disease." As with Nicola's research, Judith has developed an online programme for women over 18 to share their experiences.

All responses take place on the internet and involve activities such as art, poem and story reading, laughter for wellbeing, and other elements.

Again, women can take part from home and participation is free, completely anonymous and confidential.

To take part visit www.emotional-health.net or e-mail Judith at j.eberhardt@tees.ac.uk

Appendix E: Flyer Used to Recruit Participants

Appendix F: Scanned Copy of Ethics Approval Documentation
   F.1: Completed Ethics Application Form

U UNIVERSITY OF TEESSIDE **CONFIDENTIAL** **REQUEST FOR ETHICAL APPROVAL**	Please return form with Section A completed to: The Secretary, Research Ethics Committee School of *Social Sciences and Law*

Section A: To be completed by the appropriate Project Supervisor or Director of Studies. *Please read Section 4 of the University's "Policy, Procedures and Guidance Notes for Research Ethics".*

1. School: Social Sciences and Law

2. Project Title:
The effects of an electronic bereavement-coping-enhancement programme on the psychological profile of women suffering from bereavement (title of PhD thesis)

3a): Name, position and address of Project Supervisor/Director of Studies:
Professor Anna van Wersch, School of Social Sciences and Law, Psychology Section

3b): Name(s) and position of other Supervisor(s):
Professor Paul van Schaik, School of Social Sciences and Law, Psychology Section
3c): Names of other collaborators on project:
Professor Philip Barker, School of Computing and Mathematics

4. Name(s) of Researcher(s)/Students working on this project:
Judith Eberhardt

Please tick type of Researcher:							
Taught Postgraduate		PG Research Student	√	Staff - higher degree		Staff - other research		Final Year Under-grad. Student

5. Expected duration of project from: June 2010   to: 30th September 2011

6. Aim(s) of Project:
This project constitutes part of an amendment to a PhD project, for which ethics approval has already been obtained. The aim is to investigate the effectiveness of taking part in a bereavement-coping-enhancement programme for improving the psychological wellbeing of bereaved women. The intervention for which ethics approval is being sought here will take place in a face-to-face setting, and results will be compared to the results of the electronic programme for which ethics approval has already been granted.

7. Briefly describe the design of the project:
A 2×2 independent measures design will be implemented. The independent variables are reading health-related autobiographical accounts (or not reading them) and psychological group intervention (taking part in the intervention or not). Participants will be randomly allocated to the conditions. All women will be asked to keep diaries. The 4 dependent variables, to be measured with a screening questionnaire containing well established scales, include coping with bereavement, coping with stressful life events, awareness of the connection between physical and psychological health, and social support. A further outcome measure, to be assessed using qualitative analysis of the diaries, is daily life experience.

8. Will the participants be: (please tick as appropriate)	University of Teesside Students?		University of Teesside Staff?	

Other: (Please specify):
Women in the Middlesbrough area recruited through newspapers, posters and leaflets

9. How many participants will be involved? 24 women

10. State how participants will be selected:
Female residents in Middlesbrough, who have volunteered to participate in the research, will be asked for their consent. Eligible women are those over the age of 18 who have experienced bereavement (as a result of death, separation or divorce) of a loved one (e.g. partner, child, parent, family member or pet) during the last five years, and who have no history of breast cancer.

11. Has statistical/methodological advice been sought on the size and design of the project?

12. What procedure(s) will be carried out on the participants? *(Explain in terms appropriate to a layperson)*

After completing a psychological screening form which assesses their suitability for this study, women will be participating in psychological group intervention sessions at the University. In groups of four, women will share art (pictures, poems, songs etc.) reflecting emotional moments in their lives. They will be asked to bring this with them into the session, show it to the group, then talk about it (i.e. why they chose it, what situation in their life it reminds them of, how they dealt with this situation at the time, and if they feel that they could have dealt with it differently). Women will also be asked to share humorous media every week – pictures, jokes, or funny stories.
The intervention will last 8 weeks. At the end of the intervention, an assessment questionnaire will be completed.

13a): What potential risks to the interests of participants to you foresee?

There are no foreseeable risks to the participants as far as the researcher is aware. The researcher will adhere to the British Psychological Society's code of ethics and conduct at all times. Informed consent will be obtained from all participants and it will be made sure that they understand the nature, purpose and anticipated consequences of the research project before they agree to participate. (Please see the attached letter and consent form.) Participants will be advised to contact the Teesside Psychological Therapies Clinic's counselling department for telephone counselling if they become distressed (this service is free). The researcher will also provide names and addresses of bereavement-counselling services in the participant's geographical area.
Participants will be advised to consult their GP if they have any concerns about their health.
As the researcher will be working with individuals who have been bereaved, all participants will be assured that they can discuss any concerns they may have with the researcher. Confidentiality will be ensured at all times – only group results will be reported, which will not be traceable to individuals.

13b): What potential risks to the Researchers do you foresee?

There are no foreseeable risks to the researcher. The intervention will be conducted at the University – the researcher will not visit participants at home.

14 a): Will informed consent be obtained from all participants? Yes
(If written, attach a copy of the consent form and information sheet) Please see attached consent form.

15: If there is doubt as to a subject's ability to give consent, what steps will be taken to ensure that the subject is willing to participate *(e.g. assistance of independent colleague/ next of kin or other means.)*

Participants will be women aged over 18 who are proficient in English, with a reading age above level 7.

16: What information will be given to subject(s)?: *(Attach copies of letters or information sheets to be given to participants.)* – Information will be given via consent form (attached).

17: Where will consent be recorded? Consent will be recorded on the consent form.

18a): Will participants be informed of their right to withdraw? Yes

19: Does the project involve any other disciplines and/or Ethics Committees? No		

20: Will payments to participants be made? No

21a): Will the project receive financial support from outside the University Teesside?
No. Researcher is receiving a doctoral scholarship from Teesside University.

22: Will any restrictions be placed on the publication of results? No

23: Are there any other points you wish to make in justification of the proposed study?
No

24: I have read the University's guidelines on ethics related to research, and to the best of my knowledge and ability confirm that the ethical considerations overleaf have been assessed. I am aware of and understand University procedures on Research Ethics and Health & Safety. I understand that the ethical propriety of this project may be monitored by the School's Research Ethics Sub-Committee.

(Please complete the following as appropriate)	*Please Tick*
▪ I have appropriate experience of the general research area.	√
▪ I confirm that I have Research Ethics Training required by my School.	√
▪ I confirm that as Supervisor that I will monitor progress of the project.	√
• I confirm that the project complies with the Code of Practice of the following Professional Body: British Psychological Society	√

25:

Signature of Staff Researcher: _____   Date: _____

OR: Signature of
Project Supervisor/Director of Studies _____   Date: 27. 04. 10

**SECTIONS B/C: SCHOOL APPROVAL or REFERRAL and UNIVERSITY RESEARCH
ETHICS COMMITTEE APPROVAL/REJECTION**

Ethical Consideration   The following points have been assessed:

1. *The merit and feasibility of the proposal*
2. *Possible discomfort, distress or inconvenience to participants and/or Researchers*
3. *Procedures for respecting confidentiality and operating with data protection legislation.*
4. *The implications of monetary or other inducements to University of Teesside, its staff, student or researchers, to participants or anyone else involved.*
5. *Potential conflicts of interest arising between the researcher's employment and the research project, or other collaborative research.*
6. *All safety risks have been assessed in accordance with the University's Risk Assessment Procedure and measures taken where appropriate to make them as low as reasonably practicable.*
7. *If the research involves human subjects, the following points have also been assessed: Procedures for:*
    - *providing explanation to participants including the preparation of an appropriate information sheet.*
    - *obtaining informed consent from participants or where necessary from their parents or guardians, including the preparation of a written consent form.*
8. *If the work may involve participants from vulnerable groups, the nature of recruitment and participation of these people.*

SECTION B: SCHOOL APPROVAL or REFERRAL
To be completed by Chair of the School Research Ethics Committee

EITHER:

a) *Following consideration by the School Research Ethics Committee, I now authorise the above project.*

Signature of Chair of School Research Ethics Committee: _____ Date: _23 June '10_

OR:

b) *The School Research Ethics Committee is unable to reach a conclusion, and the case is referred to the University Research Ethics Committee.*

Signature of Chair of School Research Ethics Committee: _____ Date: _____

The Chair of the School Research Ethics Committee must send a copy of an APPROVED Request for Ethical Approval Form to: The Secretary, University Research Ethics Committee, Research & Development Office, University of Teesside. The original of the form should be kept in the School. The ORIGINAL of a REFERRED Request must be sent to the above address for action and the Director of the School notified.

SECTION C: APPROVAL / REJECTION by University Research Ethics Committee

EITHER:

a) On behalf of the University Research Ethics Committee, I now authorise the above project:

Signature of Chair of University Research Ethics Committee: _____ Date: _____

OR:

b) The University Research Ethics Committee is UNABLE TO APPROVE the project for the following reasons:

Signature of Chair of University Research Ethics Committee: _____ Date: _____

PROTOCOL
Title: The effects of an electronic bereavement-coping-enhancement programme on the psychological profile of women suffering from bereavement (title of PhD thesis)

Introduction/Rationale

Despite the evidence supporting the role of psychosocial factors in the development of cancer, prevention tends to focus exclusively on physical risk factors. The occurrence of stressful life events (in general and bereavement in particular), maladaptive coping with stressful life events such as bereavement, Type C personality features, and low social support have been consistently linked to breast cancer (Chen et al., 1995; Grossarth-Maticek, Eysenck and Boyle, 1994; Temoshok and Dreher,1992). There is a lack of studies targeting these factors simultaneously as a strategy for breast cancer prevention. Recently, digital media have become an important tool of communication in health care (Wong, 2006), providing a strong rationale for online interventions. Another previously unexplored way of raising awareness of psychosocial risk factors is the reading of autobiographical accounts of people who have suffered from breast cancer. Thus, an electronic bereavement coping enhancement programme has been designed and is currently being evaluated for its effects on the psychological profile of women who have been bereaved. The aim of the present study is to compare the results of this intervention to the effects of a similar intervention carried out in a face-to-face setting, as opposed to the Internet setting of the electronic version. This comparison will help determine which setting is more appropriate.

Aims/Objectives/Research Question(s)

- Carry out a bereavement-coping-enhancement programme in a face-to-face setting
- Compare the effects of this programme to a similar electronic programme which has already been designed and is currently being tested as part of a PhD project

Design (inc. allocation to participant groups)

A 2×2 independent measures randomised controlled trial will be carried out. The independent variables are reading health-related autobiographical accounts (or not reading them) and psychological group intervention (taking part in the intervention or not). All women will be asked to keep diaries.
Dependent variables, to be measured with quantitative methods, include coping with bereavement, coping with stressful life events, awareness of the connection between physical and psychological health, and social support. A further outcome measure, to be assessed using qualitative analysis of the diaries, is daily life experience.

	Reading autobiographical accounts	Not reading autobiographical accounts
Art-and-laughter for wellbeing		
No intervention		-

Participants and setting

Eligible women are those who are 18 or older, have experienced a bereavement (through death, separation or the divorce) of a loved one (partner, child, parent, family member, pet) during the last five years, and who have no history of breast cancer.
The study will recruit 16 participants, each of whom will be randomly allocated to one of the four groups. Each group will thus contain 4 participants. Women in the Middlesbrough area will be recruited through advertisements in newspapers, leaflets and posters. All women will be asked to complete a psychological screening form, assessing demographic variables, measuring core bereavement phenomena, personality features, stress coping style, and social support. All variables will be measured with a screening questionnaire containing well established scales.

Materials/Interventions

The psychological group intervention will take the form of art-and-laughter for wellbeing. In groups of four, women will share art (pictures, poems or music) reflecting an emotional moment in their life. They will be asked to bring this with them into the session, show it to the group, then talk about it (i.e. why they chose it, what situation in their life it reminds them of, how they dealt with this

483

situation at the time, and if they feel that they could have dealt with it differently). Women will also be asked to share humorous media every week – pictures, jokes, or funny stories.

All participants will be asked to keep a diary. They will be provided with a blank diary for this purpose.

Procedure

Before the start of the intervention, the psychological screening form measuring the dependent variables will be administered to all participants. After the intervention, women will be asked to complete another screening form, and changes will be measured.

The duration of the intervention is 8 weeks. Eight weekly sessions lasting one hour will be conducted, in which the women will meet with the researcher at the University.

Analysis

Data will be analysed quantitatively as well as qualitatively. Quantitative analyses will be carried out to measure the effects of the intervention, as well as compare these effects to the effects of the electronic intervention. Thematic analysis (Braun and Clarke, 2006) will be carried out on participants' diaries to elucidate their experiences.

Ethics and safety

The researcher will adhere to the British Psychological Society's code of ethics and conduct at all times. Informed consent will be obtained from all participants and it will be made sure that they understand the nature, purpose and anticipated consequences of the research project before they agree to participate. (Please see the attached letter and consent form.) Participants will be advised to contact the Teesside Psychological Therapies Clinic's counselling department for telephone counselling if they become distressed (this service is free). The researcher will also provide names and addresses of bereavement-counselling services in the participant's geographical area. Participants will be advised to consult their GP if they have any concerns about their health.

As the researcher will be working with individuals who have been bereaved, all participants will be assured that they can discuss any concerns they may have with the researcher. Confidentiality will be ensured at all times – only group results will be reported, which will not be traceable to individuals. The importance of confidentiality will also be emphasised to participants (Liebmann, 2008).

There are no foreseeable risks to the researcher. The intervention will be conducted at the University – the researcher will not visit participants at home.

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F.2: Letter Granting Ethics Approval

Dr Mark Simpson
Dean

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Teesside University

2nd July 2010

Anna van Wersch

Dear Anna

School Research Ethics Committee

Project title: The effects of an electronic bereavement-coping enhancement
                           programme on the psychological profile of women suffering
                           from bereavement
Student name: Judith Eberhardt

The above proposal has received clearance, subject to the following:

- clarification in section 12 of what would happen to those who were deemed
  unsuitable to take part and the clarification in section 13 of the resultant potential
  risks to them.

If the research should change or extend beyond the indicated dates, the student must
report the nature of the proposed changes and the revised end date to the Chair/Secretary
of the Research Ethics Committee.

Yours sincerely

Barbara Cox

for Stewart Martin
Co-Chair
Research Ethics Committee
School of Social Sciences and Law

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Appendix G: Description and Discussion of Themes Found through Thematic Analysis

1.1 Overview

This chapter presents the results and discussion of the qualitative analysis of the data gleaned from message boards and participants' blogs. Each theme that emerged from the data is described and then discussed in relation to the literature. Finally, the implications these findings have are considered.

Thematic analysis of all message board and blog postings created by participants yielded six themes and 17 sub-themes in total (see Table 1). These are now described and discussed in detail.

Table 1

List of Themes and Sub-Themes

Theme	Sub-Themes
1. Coping with Bereavement	*1a. Avoidance*
	1b. Getting On with Things
	1c. Acceptance and Adjustment
	1d. Not Getting the Chance to Say Good-Bye
	1e. Lack of Opportunities to Grieve
2. Coping with Stress	*2a. Remaining Positive*
	2b. Social Support
	2c. Laughter and Humour for Stress Reduction
3. 'Breast- Cancer Prone' Characteristics	*3a. Difficulties in Experiencing or Expressing Anger*
	3b. Self-Sacrifice
	3c. Helplessness
4. The Role of Psychological Factors in Health and Illness	*4a. Scepticism*
	4b. Perceived Physical Symptoms of Stress
5. Experiences with Health-care professionals	*5a. Provision of Support*
	5b. Experiences of Psychotherapy or Counselling
6. Experiences of the CEPB	*6a. Expectations*
	6b. Benefits and Drawbacks

1.2 Theme 1: Coping with Bereavement

From participants' accounts of their bereavement experiences, different ways of coping with bereavement emerged. These were largely grouped into adaptive and maladaptive coping strategies. Maladaptive strategies were either perceived to be associated with

negative outcomes for participants, or failed to serve their purpose of managing the specific demands of the stressful situation, according to Lazarus and Folkman's (1984) definition of coping. Participants also described other aspects of the bereavement experience. Out of participants' bereavement-coping experiences the following five sub-themes emerged: *Avoidance, Getting on with Things, Acceptance and Adjustment, Not Getting the Chance to Say Good-Bye,* and *Lack of Opportunities to Grieve.*

In the following, participants are referred to by the Web site usernames they had been assigned by the researcher.

Women described a wide range of bereavement-coping strategies that were categorised as adaptive or maladaptive. Adaptive coping strategies included spiritual beliefs, with some participants explaining how these beliefs provided them with comfort:

> *Formal religion was no help at all, but I found much solace in a burgeoning interest in Spiritualism, which has provided a lot of comfort this last decade.*

(Purple Daisy, page 3, lines 55-58)

Purple Jasmine too had spiritual beliefs:

> *I believe that we all come back as something, maybe not human but a different form of life. That is a comfort to me.*

(Page 11, lines 259-261)

Participants' positive coping experiences with spirituality are in line with research suggesting that spiritual beliefs are beneficial to coping with stressful events. For example, Labbe and Forbes (2010) found lower arousal of the sympathetic nervous system and better emotional coping when exposed to a laboratory stressor in young adults high in spirituality, compared to those who rated themselves lower in spirituality. Similarly, Kim and Seidlitz (2002) showed that spirituality buffered the adverse effect of stress on emotional and physical adjustment in a sample of 113 University students. Furthermore,

Ironson and Kremer (2009) were able to demonstrate positive health outcomes of spiritual transformation for HIV positive individuals.

Another form of adaptive coping with bereavement entailed evoking positive memories of the deceased. For example, Orange Iris explained how this helped her deal with her father's death:

> *I think I coped well, obviously you are always going to miss your loved ones occasionally but generally I remember my Dad with happy memories.*
>
> (Page 1, lines 17-18)

Thus, Orange Iris did not experience memories of her father as painful. Rather, these memories were associated with positive affect and experienced as enjoyable, indicating that this strategy was adaptive.

Remembering the deceased for some also meant sharing their memories with other people, as participant White Fern related:

> *I have always kept* [my husband's] *memory alive with pictures and memories which I share with various people.*
>
> (Page 3, lines 51-53)

Here again, memories of the deceased were experienced as something to be shared with others. However, it appeared that evoking fond memories of the deceased was not a coping strategy that was used at an early stage of grieving. As Pink Fern described, for her this was only possible once she had reached a stage in her grieving process where she felt comfortable to remember her late father in a positive way:

> *Memories are soo special…especially when they are no longer with us. My mum*
>
> *isn't at the stage of grieving yet when she can remember things my dad did and*
>
> *said…but that's what keeps me going.*

(Page 18, lines 379-381)

Although Pink Fern was able to remember her father in a positive way, her mother was

unable to do so, as she was not ready yet. It has been reported that positive memories of

the deceased are associated with effective bereavement-coping in family members (Ando,

Morita, Miyashita, Sanjo, Kira et al., 2010). In a related vein, Nwoye (2005) argues that

pathological grief is rare in most African cultures, as the indigenous grief rituals and

processes are specifically aimed at healing the memories of the deceased. Memories are

edited, rearranged and repositioned in order for the bereaved person to make sense of life

without the deceased's physical presence. Conversely, however, this process is described

to happen early on in the bereavement process, rather than later as described by

participants. It is thinkable that this cultural difference at least partly accounts for

difficulties with bereavement-coping in Western cultures. This would need to be examined

further.

A further adaptive coping strategy entailed talking about one's bereavement, with some

women explaining how this had proved useful for them:

> *We worked our way through the tragedy and by continuing to talk about it and as*
>
> *ever the what ifs etc.*

(Yellow Fern, page 4, lines 98-99)

Advising another participant how to cope with feelings of sadness, participant Red Daisy

wrote:

> *Talk, talk and talk again - to anyone who will listen. Write down all the negative*
>
> *things and then burn the paper.*

(Page 2, lines 40-42)

For Red Daisy, not just talking about her feelings proved useful, but also writing these feelings down, with herself being the only reader. The advice to 'burn the paper' afterwards may be part of a cathartic process, whereby the negative feelings are committed to paper and subsequently removed or destroyed symbolically. Expressive writing (Pennebaker and Beall, 1986) has been found to have this type of effect. One participant referred to the reading of a particular poem as helpful:

> *A friend sent me this* [poem] *when my Dad passed away, and when the sadness overwhelms me I try to read it and try to take in the message I'm not quite there yet but I try.*

(Yellow Blossom, page 2, lines 33-35)

For this woman, the reading of the poem and the message it conveyed was a source of comfort, rather than writing down her own feelings. In a sense, her feelings were vicariously expressed through the poem.

However, despite such adaptive ways of coping, it appeared that, although some losses participants reported had occurred many years ago, they appeared to still significantly affect them to the present day. Such losses were associated with maladaptive coping. This was the case for unexpected as well as expected deaths.

White Jasmine wrote about coping poorly with the unexpected death of her baby:

> *My son died suddenly and I was plunged into terrible emotional pain that at times threatened to overwhelm me although after 20 yrs i have managed to work through the grief I had never managed to get rid of the anxiety that comes from realising life is not safe and tragic things happen to me I wonder if this acute anxiety has played a role in my development of breast cancer.*

(White Jasmine, page 1, lines 16-21)

The participant's deliberation on whether the loss of her child was related to her development of breast cancer is corroborated by the literature, with two major register studies detecting a link between the loss of a young child and an increased breast-cancer

risk as well as overall cancer risk (Lambe, Cerrato, Askling and Hsieh, 2004; Li, Johansen and Olsen, 2002; Li, Johansen, Hansen and Olsen, 2002).

Another participant reported an emotional response after writing about her stillborn child on the 'Art for Wellbeing' message board:

> *Have just finished introducing myself and posting a picture to reflect my sad memory. I chose my baby girl because she is frequently in my thoughts and I have many regrets about it. Its brought a lump to my throat, my heart is pounding and my eyes feel gritty with unshed tears... out of all my bereavements this one still hurts and causes me pain. I still miss both my in-laws and my darling Dad but my baby still hurts the most.*

(Pink Fern, page 19, lines 388-393)

Here too, although the stillbirth had occurred over 20 years ago, it was still painful for Pink Fern to think and talk about. The physical reactions she described mirror the symptoms of emotional suppression and repressive coping as described in Chapter Two, whereby individuals exhibit inner physiological arousal (e.g. increased heart rate) while externally presenting a calm surface. This constitutes a potentially maladaptive coping strategy due to the increase in breast-cancer risk this behaviour has been linked to.

For both White Jasmine and Pink Fern, the deaths of their children had been unexpected. However, another woman described how even an expected death – the death of her husband – could be associated with maladaptive coping:

> *My major bereavement was 10 years ago, on Christmas Eve, when my beloved husband died. Not that it was unexpected, I had been expecting his death many times in the previous 25 years since his first heart attack.* […] *I thought I would handle his death well when it occurred. I'm afraid I didn't!*

(Purple Daisy, page 2, lines 47-53)

Whether expected or unexpected, participants often felt that they had been coping poorly with these significant losses. Red Ivy believed that this was an inherent part of her personality:

> *I recognise that I've not always coped well with loss, and understand that my depression has been linked to similar life changing effects.*

> (Page 2, lines 30-31)

She thus believed that her depression was the result of difficulties with adjusting to major losses.

Another woman described her reaction to the deaths of three work colleagues:

> *In one year at work* […] *I lost three close colleagues in very close succession and did not handle it particularly well.*

> (Purple Ivy, page 1, lines 11-12)

Pink Fern was more specific about coping with her father's death, describing how she did not cry:

> *If I am honest I think everything is deep inside me. When I lost my Dad I thought I would cry and keep crying...I didn't, I shed a few tears when in the ICU holding his hand and in church but nothing like I expected I would or felt I should.. we were close.*

> (Page 2, lines 28-31)

Pink Fern's account elucidates her perception that her response to her father's death was the result of suppressed feelings of sorrow. She believed she should have expressed her feelings more than she did.

It is important to note that for some participants, grieving was not just restricted to the loss of another person or living being. For example, Red Daisy explained how she grieved for

the loss of a life that was independent and unburdened by the responsibility of caring for her terminally ill mother:

> *I'm* […] *caring 24/7 for my Mum who has Alzheimer's and quite a few mobility problems. I had been caring 'from a distance' but after she had two falls last December I had to take the decision to move in with her permanently.* […] *Although not a bereavement in the accepted sense I do feel that I am going through a grieving process mourning the loss of the life I had.* […] *To be truthful I found the death of my father easier to accept in many ways, and whilst I was angry with him for leaving us I didn't feel such an overwhelming sense of loss as I do now.*

(Page 1, lines 4-20)

For Red Daisy, her changed life resulted in grieving for the loss of her former life, and perhaps the loss of a former independent self. Her response to her changed situation could be viewed by means of self-discrepancy theory (Higgins, 1987), whereby a discrepancy between the actual self (i.e. the persona caring for her mother) and the ideal self (i.e. an independent woman free of obligations) makes an individual vulnerable to dejection-related emotions (disappointment and dissatisfaction). It stands to reason that the distress caused by this discrepancy could be ameliorated by the individual coming to accept her new, changed self.

Another participant recounted how caring for her son, who suffered from muscular dystrophy, left her grieving for the life she felt that he should have had:

> *My experience of the grieving process is* […] *grieving for the life my son should have had if he didn't have this hellish disease. I don't think you ever get over the diagnosis* […]*.*

(Yellow Daisy, page 1, lines 23-25)

Yet another woman told of how, recovering from a hysterectomy, the disappearance of post-operation pain left her with a sense of loss:

> *Am I well... no not yet. I think I'm feeling a bit resentful of that, because even though there is no pain which I have been so used to, almost like my constant companion like a family member, invisible twin....and now it's gone.*

<div align="right">(Orange Daisy, page 3, lines 65-68)</div>

It seemed as though she had become so accustomed to the pain that once it ceased, she perceived it as a loss to be mourned, rather than a welcome relief.

Anticipatory grief was also written about by a woman who was grieving for a loss that she had not yet experienced, but was worried might happen. Green Rose, whose son was due to be deployed to Afghanistan, wrote:

> *I have chosen to share this poem by Grace Ellery Channing. It reminds me of how I feel about my son who is in the army and due to go to Afghanistan in a few months. I am not coping very well and it makes me sad because he is so young and I keep crying when I see all those coffins carrying (mostly) young men.*

<div align="right">(Page 1, lines 19-23)</div>

This illustrates how a loss which has not happened can still be very real and distressful to an individual. The reality of the mere threat of a loss has also been established for spouses of terminally ill people (Duke, 1998) and individuals living with repeated threats of hurricane destruction (Green, 2006).

1.2.1 Sub-Theme 1a: Avoidance

Many women described how they had been avoiding confronting their loss. Avoidant coping may be associated with positive outcomes in the short term, especially when there are events involved that cannot be changed, such as severe illness (Kazak and Meadows, 1989; cited in Seiffge-Krenke, 2004). Yet it is a coping strategy that appears to become maladaptive in the long term (Seiffge-Krenke, 2004). Furthermore, as detailed in Chapter Two, avoidant coping has been associated with an increased risk of developing breast cancer.

Avoidance was perceived by all those who reported using this strategy as a negative way of dealing with their experience. One participant explained how avoidance prevented her from focusing on her own needs:

> *When mum died I was the 'strong' one sorting everything out aged 19. Went straight from her death in August into Uni in September into world of work and never looked back until 10 years on. During both school and Uni I was kind of a social worker/problem solver for many of my friends dealing with various issues rather than focusing my efforts on myself (which in hindsight I really should have done!).*

> (Orange Holly, page 4, lines 70-75)

In a similar vein, Red Rose believed that her avoidant coping with her miscarriage had not been a positive way of dealing with the event:

> *I was quite young at the time* [of miscarriage] *and I dealt with it by trying to replace the baby I had lost as to me it was essential to be pregnant at the time the baby I lost would have been born. I was pregnant again very soon after and pregnant at the time when it would have been born, but in hindsight I'm not sure it was the right thing to do.*

> (Page 3, lines 44-48)

Another woman felt uneasy about not wishing to attend her father's funeral:

> *I have really been considering not attending* [my father's] *funeral, does that sound terrible?*

> (Purple Jasmine, page 9, lines 210-211)

White Jasmine explained how she had used avoidant coping following the death of her young child. She believed that this had had a negative impact on her health, resulting in the development of breast cancer:

> *I feel that I have been quite good at showing most feelings but grief I felt if I let go it might consume me. I remember after* [my son's] *funeral 19yrs ago feeling that I*

> *was going to run from the pain as fast as I could, it could of caught up with me in*
>
> *the form of breast cancer.*

<div align="right">

(Page 1, lines 23-26)

</div>

White Fern's experience is confirmed by the findings of Cooper and Farragher's (1992; 1993) quasi-prospective study, indicating an association between avoidant coping strategies and breast-cancer development, as discussed in Chapter Two.

For another participant, avoidance entailed not attending her mother's funeral and choosing not to know where she was buried:

> *I did not go to* [my mother's] *funeral and to this day I do not know where she is*
>
> *buried or even if it was a cremation. I have never been able to ask. I know that*
>
> *sound silly but whenever I try to ask the question I bottle out of it.*

<div align="right">

(Green Fern, page 3, lines 58-61)

</div>

Apart from coping with bereavement, avoidance was also reported in two instances as a form of dealing with other traumatic events. Red Blossom wrote about her experience of childhood sexual abuse:

> *I don't feel I've fully dealt with* [the sexual abuse] *yet. For a few years I just blocked*
>
> *it all out so there are still parts of my past I just don't remember.*

<div align="right">

(Page 3, lines 68-69)

</div>

Red Blossom's response to these traumatic events correspond to findings suggesting that individuals reporting sexual abuse are more likely to use avoidant coping strategies than those reporting other types of stressful life events (Bal, van Oost, De Bourdeaudhuij and Crombez, 2003). In this context, avoidant coping has been shown to lead to an increase in PTSD symptoms, indicating its maladaptive properties (Pineles, Mostoufi, Ready, Street, Griffin et al., 2011).

White Fern detailed how she had suffered a breast-cancer recurrence after years in remission, and described how she avoided being confronted with the topic of breast cancer:

<div align="right">

497

</div>

> [My mother] *keeps telling me every little detail of her* [friend's] *problems, how the cancer is spreading and what treatment she is having. I know she needs someone to talk to* […] *but emotionally I just cannot give her the support she needs with this. I just sit there screaming inside, I really don't want to know. In the end I just asked her to go* […] *and I could tell she was upset but the whole thing had really upset me* […].

<div align="right">(Page 14, lines 323-327)</div>

Similar to Red Blossom, White Fern seemed to use avoidance as a protective mechanism, as she felt unable to confront the reality of her illness. The above two examples hence show how avoidance was used to deal with stressful life events other than bereavement. Nevertheless, it could be argued that both Red Blossom and White Fern had suffered a loss of sorts, Red Blossom losing the innocence of childhood through sexual abuse, and White Fern losing her place in the 'remission society' (Frank, 1997) with the recurrence of her breast cancer.

Altogether, avoidance was experienced as a maladaptive coping strategy, which bore perceived negative psychological and physical health effects consistent with findings in the literature.

1.2.2 Sub-Theme 1b: Getting On with Things

Another bereavement-coping strategy emerging from women's accounts was that of 'getting on with things'. Participants described how they tried to carry on with their lives as normal in the wake of their loved one's death. Some women viewed this as a normal and useful way of dealing with bereavement, as the following statement shows:

> *I find the best thing to do is to just get on with it. If I break down that is not going to help my husband and son to cope.*

<div align="right">(Yellow Daisy, page 3, lines 73-74)</div>

Similarly, Pink Blossom wrote:

> *It all seems quite a blur now but I think I just got on with things and when it all got too much I would have a little cry.*

<div align="right">498</div>

(Page 2, lines 22-23)

Most of the participants familiar with this strategy, however, did not feel that 'getting on with things' was a desirable way of dealing with bereavement. Pink Fern wrote about coping with her stillbirth 20 years ago:

> *Things were so different back then people didn't know how to help with the grieving process. It usually ended up with people being told to get on with their lives and not talk about it. My Dad died last year and my Mum seems not to want to talk about him at all and she is getting rid of things of his... I know she isn't wiping him out of her life but it does seem like that at the moment.*

(Page 4, lines 80-85)

Getting on with one's life and not talking about one's loss seemed to Pink Fern an outdated way of dealing with bereavement, advocated by an older generation who were apparently unaware of the benefits of emotional disclosure. For her, however, this form of coping was perceived to be inappropriate. It has been argued that the loss of a child is one of the most dramatic events a person can experience in life, and that mourning for a dead child never ceases (Rubin, 1993; cited in Znoj and Keller, 2002). Furthermore, as mentioned above, it has been associated with an increased risk of breast cancer. This highlights the importance of dealing constructively with such a grave loss.

Another participant made clear that getting on with her life following her loss led to her suppressing her negative emotions, which proved stressful in the long run:

> *My life has been a rollercoaster, and until now I have managed to carry on by stuffing it all down inside and getting on with it, probably because I had the children to look after.*

(Orange Rose, page 5, lines 85-88)

White Fern had had a comparable experience following her husband's death:

> *I was very young, I didn't know how to deal with* [my husband's death]*, I just tried to get on with my life.* […] *For a year I just existed, went through the motions.*

499

(Page 2, lines 43-47)

For these women, 'getting on with things' was felt to be either the product of an inability to cope more constructively with their bereavement, or a form of avoidant coping. Although some participants thought this to be the normal way of dealing with bereavement, others made clear that this strategy had had no beneficial effects for them.

1.2.3 Sub-Theme 1c: Acceptance and Adjustment

Acceptance and adjustment emerged as a further common bereavement coping strategy. Participants related how they attempted to attempted to accept their loss and adjust to their changed lives. As Pink Fern stated,

> *You can't change what has happened, so* [it is] *not worth dwelling on it.*

(Page 23, lines 477-478)

Participant White Fern took a similar approach:

> *Maybe I have lost the ability to be really angry in the sense of shouting and getting upset, because I feel now that I just accept situations for what they are. I cannot change things, so I just allow myself to be swept away by things.*

(Page 6, lines 143-148)

These statements reflect a fatalistic view, in line with the concept of an external locus of control (Rotter, 1954), where individuals are less likely to assume that they can control the events that affect them. Although one would expect this to be adaptive in coping with events one cannot change anyway, an external locus of control has in fact been shown to be a maladaptive way of coping with bereavement (Rubinstein, 2004; Stroebe, Stroebe and Domittner, 1988).

Taking a somewhat more constructive approach, Red Rose, sharing a photograph of a cot, attempted to reframe her loss, highlighting the positive outcome:

> *A sad moment in my life was 26 years ago when I had a miscarriage […]. This photo reminds me of the baby I didn't have. Although had I had the baby I lost I wouldn't have my son.*

(Page 2, lines 35-39)

Here, Red Rose tried to view her situation in a more positive light. Situational redefinition is a coping strategy that is positively associated with self-motivation and optimism, and is as such adaptive. However, it appears to be negatively related to emotional release (Ferguson and Cox, 1997), indicating that individuals who tend to reappraise stressful situations positively are also less likely to express negative emotions. As outlined in Chapter Two, the suppression of negative emotions can be maladaptive in the long term, and has been linked to breast cancer (e.g. Greer and Morris, 1978; Grossarth-Maticek, Eysenck, Boyle, Heeb, Costa et al., 2000).

Accepting one's loss was not always easy, as the following statement made by Pink Fern shows:

> *Spent a lot of yesterday thinking of my baby and my Dad… why are there so many "If's" to life. I know I can't change things so why do I keep wishing so hard I could. I keep telling* [my husband] *he can't change things that have happened why can't I accept it…silly isn't it.*

(Page 22, lines 457-460)

Hence, acceptance was challenging and difficult to accomplish, because it conflicted with Pink Fern's desire to change outcomes that could not be changed. Positive acceptance is an important component of the five stages-of-grief model proposed by Kübler-Ross (1969), whereby the individual gradually comes to terms with their bereavement or their

501

own mortality, although, as pointed out in Chapter Two, this model has received criticism for its stage-approach (e.g. Bonanno, 2009).

Apart from acceptance, some women recounted how they got through the death of a loved one by adjusting to their changed lives. Sometimes women actively tried to adjust to a changed life, and sometimes their grief diminished as time passed:

> *How did I deal with* [my grandfather's death] *in the end.... I didn't, I just learned a new way of life.*

> (Blue Daisy, page 2, lines 27-28)

White Fern also felt that the passage of time helped in the grief process:

> *I don't think I could have done anything differently, you just have to let time heal.*

> (Page 2, lines 50-51)

Others, however, did not believe that the old adage of 'time healing all' was true:

> *The sadness never really goes away, does it? One merely accommodates it into one's daily living. "Time heals", they say, but I disagree. The passage of time just gives one space in which one can accommodate the disaster.*

> (Purple Daisy, page 3, lines 57-60)

Yellow Fern, too, believed that the passage of time merely diminished the pain of being bereaved:

> *We were eventually able to grieve and move forward - the hurt and anger never go away only diminish and become more tolerable.*

> (Page 5, lines 99-101)

Orange Holly had a similar point of view:

> *I wouldn't necessarily say time heals all; rather the memory of the pain fades away.*

These quotes reflect most women's perception that the pain and grief associated with bereavement were ever-present and merely diminished over time, rather than disappearing completely. This viewpoint is consistent with Frijda's (1988) assertion that the adage of time healing all is a myth. According to Frijda, what accounts for the emotion supposedly diminishing over time is repeated exposure to the emotional event: the individual gradually adapts as they experience the emotion again and again. However, Frijda went on to explain that when individuals are confronted with stimuli reminding them of a traumatic event (e.g. an item belonging to the deceased is stumbled upon by chance), the emotions may be experienced as poignantly as they were at the time the event occurred, which shows that these feelings do not disappear over time.

1.2.4 Sub-Theme 1d: Not Getting the Chance to Say Good-Bye

Several participants told of their regrets over not having been able to speak to their loved one before they died. Thus, they did not get the chance to say good-bye to them or to talk about any important matters they had on their minds.

> *My Gran had been ill a few months before she died, and […] unfortunately when she came out of hospital I never got chance to see her before she died so I had all emotions of guilt/anger and sadness.*

Purple Holly wrote about her mother's death, which occurred when she was young:

> *My father forbade that my brother and I should talk to* [my mother] *about cancer or death, so we all put up a pretence that nothing was happening. Consequently, I never had the chance to talk about things or at least to say goodbye.*

The women who wrote about this perceived lack of closure felt that it made it more difficult for them to cope with their bereavement. In line with this, White Fern explained how she believed that her presence at her father's death bed as he passed away made it easier for her to cope, because it enabled her to gain the closure she needed:

> *My dad was taken ill in 2001 and died 10 weeks later of liver cancer - which was a terrible blow as we were very close. I did cry but what helped me through this was being there when he died, he hung on for us getting there, and then passed away about 15 minutes later. I held his hand as he slipped away, it was all very peaceful and I was so glad I had been there it was good closure for me.*

(Page 1, lines 17-22)

One participant proposed that it was normal for bereaved individuals to feel distraught at not being present as their loved ones died:

> [My father] *didn't wait for me to get to the hospital before he died and I was so angry with him for leaving before I got there, but I think that this is a 'normal' feeling for most people when someone they love dies.*

(Red Daisy, page 3, lines 54-57)

Hence, women believed it to be beneficial to their grieving process to be present as a person close to them died, but they also recognised that gaining closure was not always possible. Similar findings were reported in a qualitative study by Bennett and Vidal-Hall (2000) involving widows. The authors pointed out that there is a lack of research discussing the importance of saying good-bye, or how 'unfinished business' impacts on the grieving process. The present findings lay additional emphasis on the significance of this issue. Still, although Browning (2002) too points out the importance of attaining some form of closure, he asserts that rather than saying good-bye to the deceased and thus attempting to sever the emotional bond to the loved one, it is important to be able to say good-bye to the grief itself, thereby acknowledging a continued bond to the deceased that is free of grief.

1.2.5 Sub-Theme 1e: Lack of Opportunities to Grieve

Another sub-theme emerging from participants' writings related to the lack of opportunities they had had to grieve for their losses. A variety of reasons were given. Some saw themselves faced with the practicalities of organising the funeral as well as emotionally supporting their family, which left them with little time to grieve. As participant Purple Jasmine expressed:

> *I know I'm not the only one to have organized a funeral but it is stressful.*
>
> (Page 11, line 256)

Pink Fern, remembering her in-laws passing away, wrote about the stress involved in organising their funerals:

> […] *my* [mother-in-law] *died suddenly in 2001 and I didn't have time to grieve as I was supporting my husband and boys, we were very close to her. My* [father-in-law] *died after battling cancer in 2009, again I supported my husband and boys through all the arrangements for the funeral and then for the 18 months while the house was sorted and sold... I didn't seem to have time to cry or think about it.* […] *We were very close and I honestly don't think I have grieved for him. We had a mad dash to the hospital to see him in the IC Unit and there I comforted my mum and brother as well as staying with my dad right to the end. After that there was the funeral arrangements to make, and my boys needed me…they were close to their grandad. Then my brother was taken seriously ill… I guess grieving has been put on hold.*
>
> (Page 5, lines 14-25)

A similar experience was reported by White Rose:

> *I never really spoke to anyone and felt at the funeral I had to be brave for other people and be a support to Aunties/Uncles, which didn't give me time to grieve.*

(Page 2, lines 26-28)

These women felt that they had to support their family members through their grief, but it came at the expense of them coping effectively with their own grief.

Other women faced financial worries as a result of their spouse, who was the main breadwinner, passing away. Yellow Fern was among these women:

> *My most recent serious worry was when my husband died, there are so many things to deal with but my major concern was that I may not be able to stay in my current home. To be faced with your income being halved but still have to meet all the usual household bills.*

(Page 6, lines 125-128)

White Fern, remembering her husband's death shortly after the birth of their first child, wrote:

> *When I lost my husband I also had to give up my home as I had just had a baby and couldn't work, obviously as he was also young he had no real pension. Fortunately I had my parents to bale me out and offer me a home for me and my baby, but I do remember being worried about how I would cope.*

(Page 9, lines 190-194)

For these women, the financial problems resulting from the death of their spouse thus posed a hindrance to adaptively coping with their loss.

Apart from financial issues, extraordinary circumstances surrounding the deceased's death were mentioned as posing a hindrance towards grieving properly. Yellow Fern wrote about the mysterious circumstances surrounding the death (possibly through murder) of her son:

> […] *this was a devastating and traumatic time for the family. Post mortems, inquest and much more over a period of four months - so much going on and little time for everything to sink in or grieve.*

(Page 4, lines 85-87)

Another participant shared the story of her sister's death, who she believed had received poor treatment from the health professionals responsible for her care:

> […] *my sister, who suffered from cerebral palsy, died from complications of a stroke, under the most awful circumstances in the hospital. Due to my husband's diagnosis, I haven't been able to redress this, except for a five page letter of complaint and a postponed chance to meet with all the clinicians involved. I know I haven't probably mourned her death.*

(Purple Holly, page 1, lines 13-18)

It is well documented that individuals who lose loved ones unexpectedly (e.g. through homicide) endure particularly profound grief, and are at a greater risk of maladaptive coping; this is especially the case for parental bereavement (Kashka and Beard, 1999; Znoj and Keller, 2002). Furthermore, it has been found that active leave-taking through post-funeral rituals can aid coping with bereavement (Bolton and Camp, 1989). It has been postulated that individuals need time to work through their grief and adjust to their loss (Engel, 1964; Morita, Hirai, Miyashita, Sato, Tsuneto et al., 2010).

Although most participants felt that the lack of time they had had to mourn their loved one's death had had negative effects on their coping, one woman remarked that she felt it was not unusual to be denied this opportunity:

> *The best time to deal with grief is immediately. I think few people get that luxury.*

(White Jasmine, page 2, lines 31-32)

Still, regardless of the reasons given, not having the opportunity to grieve was generally perceived to be a hindrance to coping constructively with bereavement.

1.2.6 Theme 1 Summary

Women wrote about using a wide range of bereavement coping strategies. Some of these were adaptive and perceived as positive and helpful ways of managing their emotions. Others seemed to avoid confronting their loss, or have difficulty dealing with it. Seemingly

adaptive ways of coping, such as acceptance and adjustment, proved difficult. Several participants expressed the need to achieve closure, but this being thwarted by the missed opportunity of saying good-bye to their loved ones who had passed away. Others commented on their lack of time to grieve properly, because they felt that they had to support family members and/or take care of funeral arrangements. Overall, a mixed picture emerged of participants' abilities to cope, but it became evident that many felt that they needed support with the bereavement-coping process.

1.3 Theme 2: Coping with Stress

The second theme concerned coping with stress. Participants described how they coped with stressful situations and life events, and which stress-coping resources they were able to recognise and draw on. Three sub-themes surfaced*: Remaining Positive, Social Support as a Stress Buffer*, and *Laughter and Humour for Stress Reduction.*

The functions of the stress-coping styles participants described can be broadly grouped into *emotional regulation*, relating to the management of emotions associated with a stressor; *approach coping*, relating to confronting the actual problem; *reappraisa*l, relating to redefining the situation in a more positive way; and *avoidance*, relating to avoiding confrontation of the stressor. This categorisation is in line with Cox and Ferguson's (1997) proposed functional dimensions of coping, which build on and extend Lazarus and Folkman's (1984) distinction between emotion-focused and problem-focused coping, a distinction which has been criticised for being too simplistic as it is unable to account for the wide range of coping functions observable in human beings (Carver, Scheier and Weintraub, 1989).

Some women engaged in approach coping. They had written about ongoing stressors at the beginning of the CEPB; in the course of the programme, they reported being able to

identify the source of their stress and attempted to actively find a solution to the problem. For example, White Rose wrote about discovering the root of her stress:

> *Recent events have made me realise it is work that causes most of my stress.* […] *We are moving to another area so we can have same size house but half the mortgage. This means that I can stop working and plan to spend a year finishing my studies, getting my confidence back and becoming stress free, or at least less stress. I feel my main priority now is getting my health sorted and I've found this* [intervention programme] *fascinating. It's made me realise how bad stress can be, and sometimes there is nothing you can do about it, but where you can, it's worth doing it.*

(Page 7, lines 147-164)

It seemed as though participating in the intervention programme contributed to White Rose recognising the usefulness of approach coping and attempting to use it in situations where this was possible.

Approaching the end of the intervention programme, Green Rose, who had been writing about ongoing financial problems, deliberated a potential solution:

> *I am* […] *beginning to wonder if it's worth us selling this house and buying a smaller one, so we can have a bit more money. A bit difficult, as it's not going to sell easily, but at least we have that option.*

(Page 4, line 91-94)

Similar to White Rose, she displayed a shift towards approach coping.

Another participant described her strategy for dealing with a stressful situation:

> *As a young woman I worried about everything as the young are wont to do! As I grew older I realised that there was no point in worrying about things that I couldn't change - like the world economy or climate change and that gave me the impetus to only worry about things that I can influence/change. Now if I have a worry I write it down in detail - leave it for a day and then read it over. If the solution to the*

> *problem is in my own hands - then I put the problem on the 'to do' list with the*
>
> *solution written alongside.*

<div align="right">(Red Daisy, page 5, line 101-104)</div>

These women thus actively confronted the stressor or stressors and tried to find a solution, which often happened in the course of the intervention: women found solutions to problems while blogging on the project Web site, or discussing their situation on the message boards. Active confrontation tends to be an adaptive coping strategy, with findings indicating that using approach rather than avoidance coping is associated with better adjustment to a problematic situation (Ebata and Moos, 1991), in addition to increased well-being (Lapierre and Allen, 2006).

However, it must be conceded that not all situations allow for an active confrontation of the stressor. Sometimes a stressful situation cannot be resolved through immediate action. Where it was felt that a problem could not be solved, several participants wrote of how they accepted the situation in order to cope effectively. Acceptance was used as a way of reducing the emotional distress caused by a problematic situation for which there appeared to be no immediate resolution. As Red Daisy explained,

> *If the worry is something over which I have little or no control - I consign the written*
>
> *problem to the wastebin and place my worry in God's hands. The secret is*
>
> *knowing the difference between those worries that I can solve and those that no*
>
> *amount of worrying about on my part will ever solve.*

<div align="right">(Page 5, line 112-115)</div>

Similarly, another woman spoke of her battle with cancer and acceptance as a way of coping with the stress caused by her illness:

> *One thing is for certain - once you have had cancer, it affects you in one way or*
>
> *another for the rest of your life. There is no getting away from it - only acceptance*
>
> *and doing the best you can.*

(Orange Holly, page 30, lines 640-642)

As discussed above in relation to coping with bereavement, acceptance, although generally viewed as an adaptive form of coping, could also be challenging to accomplish, which is reflected in the fact that not many participants reported using this strategy.

Other coping strategies aimed at regulating the negative emotions associated with a stressor were also described. Thus, some participants explained how they released built-up tension caused by stressful situations in different ways. Exercise or other physical activity was mentioned by two participants as a stress-reduction method:

> *Pilates is now my main release and I usually come out feeling like I have had a good work out and feel less tense.*

(Pink Fern, page 12, lines 228-229)

Similarly, Purple Ivy explained:

> […] *I don't know that I easily see the symptoms of stress in myself but I have been working in a very busy job with long hours for pretty much all my working life but I love it and mostly feel enriched by it. I also take regular exercise which I know defrays the negative physical effects of adrenaline in the system.*

(Page 6, lines 139-146)

There is a considerable body of literature examining the stress-reducing benefits of exercise. For example, in a 10-week aerobic exercise programme, Anshel (1996) found that exercisers responded to acute stress with more positive affect, lower stressor task heart rate, reduced systolic blood pressure, and better motor performance compared to the control group. Exercise has also been shown to decrease state anxiety over time (Cox, Thomas, Hinton and Donahue, 2004), as well as reducing depression (Craft and

Landers, 1998). Thus, exercising could be considered to be an adaptive way of coping with stress.

Some described activities such as listening to music, reading, spending time with their pets, or trying to take things 'one day at a time'. As one participant wrote:

> *I love Nirvana, I feel their music can accentuate any mood I'm in e.g. lift me up when I'm already happy or send me further down when I'm feeling low.*

> (Red Blossom, page 2, lines 42-43)

Certain types of music appear to have health benefits such as facilitating blood pressure recovery after stress (Chafin, Roy, Gerin and Christenfeld, 2004) and decreasing anxiety levels in a preoperative setting (Trappe, 2010). It is interesting to note that Red Blossom experienced the mood-amplifying effect of the band Nirvana's music on her mood as positive, even though sometimes her negative emotions were exacerbated. This shows how the experience of music as pleasant or unpleasant is very subjective to the individual. Pink Blossom enjoyed spending time with her pets:

> *I find my pets are great stress relievers.*

> (Page 3, lines 65-66)

For others, reading was a way of reducing stress, as Pink Fern remarked:

> *Reading is definitely an escape for me and it's the one thing I don't get to do often enough.*

> (Page 8, lines 601-602)

Both of these pastimes have been examined in terms of their stress-reducing properties. Reading has been shown to be an effective coping mechanism to provide stress relief and aid escapism (Usherwood and Toyne, 2002). Similarly, pet owners appear to exhibit lower resting heart rates and blood pressure, and to recover quicker from laboratory stressors,

than non-pet owners; this effect is even stronger when the pet is present (Allen, Blascovich and Mendes, 2002). Furthermore, a stress-buffering effect has been demonstrated for dog owners interacting with their dog (Barker, Knisely, McCain, Schubert and Pandurangi, 2010).

Some women spoke of 'taking things one day at a time', describing their efforts to deal with a situation in small, manageable steps. Orange Iris used this coping strategy following her son's attempted suicide:

> [My son] *broke down and admitted he had tried to kill himself* […] *I coped by taking one day at a time and keeping him busy.*

(Page 5, lines 95-105)

Yellow Fern also found 'taking one day at a time' useful in adjusting to life after the death of her husband:

At the moment no major worries only my venture into a long train journey on my own for the first time without my husband - as they say - take one day at a time.

(Yellow Fern, page 6, lines 132-134)

Thus, both women found it helpful to take an unrushed approach to their changed lives, focusing on getting through one day at a time.

Apart from reporting their own coping strategies, on one occasion a participant approached the facilitator for concrete advice on how to reduce tension. She was provided with instructions how to perform relaxation exercises, which she perceived as helpful:

> *Thanks for the* [relaxation exercises]. *When I find the time to do them they seem to help, especially the breathing one.*

(Pink Fern, page 24, lines 512-513)

This participant was thus able to make use of the advice offered by the researcher, which in turn helped alleviate her stress.

However, some women reported avoidant strategies, telling of how they deliberately avoided confronting the stressor. Thus, one participant avoided dealing with her mother's death by throwing herself into academic work:

> *I coped* [with my mother's death] *by getting as much praise as I could at school.*

(Purple Jasmine, page 4, line 79)

Another woman used avoidant coping as a way of dealing with her cancer treatment:

> *I know I have not really faced up to the reality of cancer and I am still in the coping stage, as my treatment is not yet over.*

(Green Fern, page 2, lines 40-42)

Keeping busy and occupying one's time with activities unrelated to the stressor was also mentioned by several women, including Purple Fern:

> […] *keeping busy helps, if I have time on my hands then I get a little less positive and think what if, but don't let myself go any further.*

(Page 3, lines 32-34)

Similarly, Yellow Fern described how she was trying to keep busy to avoid dealing with a stressful situation:

> *Everyone has kept telling me that I am doing too much so I have tried to do less but I feel the need to be doing something.*

(Page 7, lines 168-169)

Red Daisy found her new role of caring for her mother, who had Alzheimer's disease, very challenging, describing how she wished to disengage from the situation:

> *I feel as though I'd just like to go to bed, pull the duvet over my head and stay there for ever. Everything is just too much trouble - I know the feeling will pass (it has before) but right now I just want to cry into my pillow with frustration and the unfairness of it all.*

(Page 9, lines 214-218)

As discussed above in relation to bereavement, avoidant coping has been shown to be a maladaptive strategy in the long-term, with negative consequences for psychological and physical health.

Others professed that they struggled to cope in the face of an overwhelmingly stressful situation. White Daisy found it difficult to cope with her mother's breast cancer diagnosis:

> *Last November, my mum was diagnosed with breast cancer and had a mastectomy.* […] *Her illness has hit me hard and I am buckling with the stress. I worry about her a lot!*

(Page 1, lines 11-14)

Red Blossom was worried about several upcoming job interviews:

> *I don't deal with stress very well so all these interviews means I'm on a very high anxiety level.*

(Page 23, lines 386-387)

These women seemed to have no clear coping strategy, adaptive or maladaptive, and this left them feeling extremely anxious and overwhelmed. Yellow Jasmine was in a similar position, and wrote how she felt that she had to keep up the pretence of coping well, when in fact the opposite was the case:

> *When you give an impression of coping with things, of being confident, of being able to cope, then people always expect that of you regardless of what situation you find yourself in. It's very tough as you have set the bar very high and find yourself in a very vulnerable situation if you let your guard down or seem to be not coping!*

(Page 3, lines 63-67)

She found herself faced with the dual challenge of struggling to manage a stressful situation while feeling under pressure to appear to others as though she was coping well.

To summarise, although adaptive stress-coping strategies were reported by a number of participants, it appeared as though many women had difficulties in recognising potential stress-coping resources they possessed and then utilising these. Particularly, long-term stressful situations such as chronic illness or caring for a chronically ill family member seemed to be associated with the feeling of coping inadequately. This corresponds to the exhaustion stage of the General Adaptation Syndrome as described by Selye (1956), whereby the body's stress-coping resources are gradually depleted as a stressor persists, which has damaging effects on the organism. The detrimental effects of struggling to cope with a long-term stressor highlight the need for such individuals receiving support and guidance to effectively use their coping resources.

1.3.1 Sub-Theme 2a: Remaining Positive

A common coping strategy emerging from participants' writings was that of maintaining a positive frame of mind when faced with stressful events. This was especially true for those who had experienced, or were experiencing, life-threatening illness. Remaining positive was seen as a beneficial coping strategy for a variety of reasons. Some believed that for them a positive attitude was linked to improved physical health, and therefore a heightened chance of overcoming their illness. White Rose was one of the participants who advocated this belief:

> *I firmly believe in positive mental attitude to fight viruses etc. and if your grieving someone from however long ago that you never really get over it affects your health.*

<div align="right">(Page 8, lines 171-173)</div>

Yellow Jasmine felt that a positive attitude might be beneficial to her father's health, who was suffering from cancer:

> *I decided that I must keep positive in the hope that everyone else would and that maybe being positive might in some crazy way keep my Dad alive for a longer period of time. They do say that it's mind over matter - don't they?*

<div align="right">(Page 7, lines 168-171)</div>

For others, being positive reflected their gratefulness for the positive aspects of their life:

> *I am lucky that I am a very positive person who tries to count my blessings and I think this is one of the things which really helps.*

<div align="right">(Green Rose, page 5, lines 98-99)</div>

Green Daisy also felt that she generally had a good quality of life:

> *It really isn't all bad and I have a nice life apart from those stresses.*

<div align="right">(Green Daisy, page 2, lines 26-27)</div>

A few women were in remission from cancer and voiced how grateful they were for having survived. For them, remaining positive provided a way of coping with the fear of the cancer returning. Purple Fern wrote:

> *I try not to worry about the cancer coming back as I could make myself very unhappy, It could come back but I will deal with that when and if it ever does. I have a second chance and am grabbing it with both hands.*

<div align="right">(Page 1, lines 19-22)</div>

Such newly found zest for life was also reflected in Purple Ivy's words:

<div align="right">517</div>

I'm up for keeping going on the inner healing path as I would like to get to be more whole regardless of my physical health. I'm up for life and life in abundance in the here and now for however long that happens to be.

(Page 11, lines 256-258)

One participant asserted that stressful life events presented challenges through which one could achieve personal growth:

I often think that these times that are sent to try us make us stronger.

(Yellow Fern, page 6, lines 138-139)

This reasoning is in line with the coping strategy of situational redefinition (Cox and Ferguson, 1997). As mentioned above, situational redefinition is positively associated with self-motivation and optimism, and negatively associated with emotional release.

Yet, remaining positive also seemed to be a coping strategy which was difficult to implement, as Red Blossom explained:

I should be feeling quite happy as I've just got a job and I started the training yesterday but I can't help feeling this job will turn out to be a disaster, I guess I'm a natural pessimist.

(Page 12, lines 245-247)

Yellow Fern felt similarly:

I suppose this will get better and I will just have to be patient and work through all these feelings - easier said than done.

(Page 9, lines 217-219)

Though these women wished to see their situations in a more positive light, they found it difficult to do so.

Overall, maintaining a positive frame of mind, although challenging for some, was an important coping strategy used by a number of participants to deal with adverse life events, especially life-threatening illness.

1.3.2 Sub-Theme 2b: Social Support

Social support functioned as a source of emotional comfort and served as a stress buffer for many participants. It seemed to be an extremely important element of coping with stress, regardless of whether women actually felt supported or not.

A number of women described how they received emotional social support from close friends and family when they were experiencing stressful events. White Fern valued the support she received from her environment:

> *I have been lucky with friends and family who are happy to help and share any worries I have.*

(Page 8, lines173-174)

Green Fern treasured the support her husband gave her:

> *My husband has been brilliant, he has shown me how to laugh again and loves me no matter what, I know I am very lucky to have him and my children.*

(Page 2, lines 36-38)

Purple Jasmine stated how she believed it was important to confide in good friends:

> *I am one of those people that enjoys sitting down with perhaps a good friend one I have known for a number of years and opening my heart to them. Some may have the opinion that I am foolish to do so but a problem shared is a problem halved as the saying goes.*

(Page 20, lines 471-474)

Some participants thus had high perceived emotional social support. Another common way of utilising available social support involved socialising. Rather than talking about

one's problems, this presented a way of taking one's mind off the stressful situation, and therefore proved a useful way of buffering stress. As Yellow Jasmine described:

> *Went to a party at my sister's on Sat night.* […] *I really enjoyed it - first time in ages that I have felt normal.*

<div align="right">(Page 9, lines 217-219)</div>

Yellow Daisy enjoyed spending time with her son to help combat stress:

> *What helps* [cope with stress] *is to spend time with my son - he has a fantastic sense of humour and is very bright.* […] *doing things together as a family helps.*

<div align="right">(Page 4, lines 80-81)</div>

Another woman found opportunities to socialise at her place of work:

> *I do find going to work and talking and laughing with my colleagues helps me too.*

<div align="right">(Orange Rose, page 7, lines 129-130)</div>

Apart from writing about the social support available to them in their immediate environment, as well as receiving supportive messages from the facilitator, some participants also provided and received social support from each other while interacting on the project Web site. Several women made efforts to reach out to other participants and offer them emotional support through their message board postings. Pink Fern commented on another participant's posting:

> *Hello White Fern, I'm Pink Fern. I wanted to say to you how very sorry I am for your loss. I can't imagine how you coped with it all. It does sound like you had a wonderful support system around you. I am so glad you have found someone else he sounds to be a lovely man and good friend.*

<div align="right">(Page 2, lines 39-42)</div>

White Fern reached out to her fellow group members in a similar way:

> *Hi Yellow Fern and Green Fern. So so sorry for your losses. They are both extremely sad.*

<div align="right">(Page 6, lines 120-121)</div>

Yellow Fern thanked another woman for the support she had given her, and tried to reciprocate:

> *Thank you for your message, you certainly must have had a tough time.*

(Yellow Fern, page 6, lines 137-138)

Warm, supportive messages and offering mutual support seem to be characteristics often found in Internet support groups (Sullivan, 2003; Winefield, 2006). Furthermore, some users tend to assume the role of 'volunteer emotion workers', giving advice and support rather than receiving, and thus facilitating communication (Winefield, 2006). In the present study, however, such behaviour was observed in only two of the nine intervention groups. In the remaining groups, supportive interaction between group members was less common.

A number of participants lamented the fact that they were not getting enough social support from their immediate environment. The types of support they appeared to be lacking were both practical and emotional in nature. Where practical social support was insufficient, women remarked that their family members did not help them with their day-to-day tasks such as household chores, and that the responsibility therefore fell on them alone. This was the case for Green Rose:

> *My stepson does nothing to help and my daughter can't do much because she is feeling so ill.*

(Page 6, lines 136-137)

Red Daisy also had trouble receiving the practical support she needed from her family:

> *I'm still expected to 'take charge' when, in reality, it would be nice if someone else took charge for a while, gave me some time to myself and told me what to do.*

(Page 9, lines 197-199)

Similarly, emotional support was absent or lacking:

> *I feel that there is no-one I can talk to, and am realising that this isn't helping my*
>
> *health.* […] *I have tried talking to* [my husband] *about* [being stressed] *but he*
>
> *doesn't want to listen.*

(White Rose, page 7, lines 129-130)

Blue Daisy suffered from a chronic health problem that she found difficult to cope with, and complained about the lack of support from her husband:

> *I have been ill before, and* [my husband] *has had no sympathy for me only his*
>
> *needs which have to be met or he sulks. I was diagnosed with fibromyalgia 15*
>
> *years ago, he looked it up on the web and told me I was some sort of lunatic!*

(Page 3, lines 52-55)

Some women wished to reach out to other people whom they thought would understand them, but felt that there was no opportunity. Blue Daisy recounted how her son, a psychologist, was not offering her any support despite her debilitating illness:

> [My] *son is a psychologist, working in palliative care!! I thought he would be the*
>
> *most sympathetic and caring of my illness…but instead I have received nothing*
>
> *but nastiness...*

(Page 3, lines 68-70)

In another instance Yellow Daisy, whose son suffered from Duchenne Muscular Dystrophy, told of how she wished to meet other parents in a similar situation, but found no opportunity to do so:

> *I sometimes think that it would have been nice to meet up with the parents of the*
>
> *other boys* [with Duchenne Muscular Dystrophy] *but none of them will let us*
>
> *parents go with them (the parents stay in a separate part of the hospice and the*
>
> *boys needn't even see us). I guess they are worried we might ruin their street*
>
> *cred!*

522

(Page 5, lines 117-120)

Yellow Daisy evidently had the need to meet others in a similar situation to her and exchange experiences – this need may have been met by attending a self-help group for carers.

Then there were some women who, although having social support available to them in their immediate social environment, did not feel able to harness this support. Red Blossom wrote:

> [This] *picture* […] *reminds me of how I feel when my depression is at its worst: there are people around but they just feel out of reach.*

(Page 1, lines 26-27)

Another woman, who was in remission from leukaemia, was due to undergo a biopsy, which she felt very anxious about:

> *I am snappy with family although I try not to be, talking about it makes* [the impending bone marrow test] *real and I don't want that either.*

(Purple Fern, page 1, lines 26-27)

White Fern too had in the past refrained from confiding her worries to others:

> *I went on worrying* [about my finances] *for about 2 months and didn't tell anyone, not even my husband.*

(Page 8, lines 178-180)

The emotional support available to individuals has been demonstrated to have a much stronger influence on mental health than the support which is actually received (Dunkel-Schetter and Bennett, 1990; Wethington and Kessler, 1986). Still, it appears that although social support was potentially available to these women, it did not do much to act as a stress buffer. Perhaps this was due to the perceived quality of the available support being inadequate, or reservations regarding 'troubling' others with one's own problems. For example, it was felt by one woman that others had their own problems to contend with, and she therefore did not want to burden them with her own concerns:

> *I do have the support of family and friends but in this world today everyone is so*
>
> *busy - working and their own families to look after I tend to not want to burden*
>
> *them with my problems.*

(Yellow Fern, page 7, lines 178-180)

Similarly, Red Ivy related how her lack of social support stemmed from her tendency to focus on supporting others, rather than letting them know what she needed in order to feel supported herself:

> *All of my friends turn to me for help, I'm the strong coping one. I'm balanced and*
>
> *logical and can usually find answers to the questions & problems.* […] *I think if*
>
> *you're seen as someone who's a leader & copes in a crisis then people tend to*
>
> *bring there problems to you too.*

(Page 2, lines 44-48)

Commenting on one of the autobiographical accounts of breast-cancer sufferers, she further explained:

> *I have spent all my life, even during my cancer treatment, being the strong*
>
> *one. The one who is supporting others. I was the one who did the fixing, and never*
>
> *asked for help even when I needed it. I guess I was just someone who in the*
>
> *outside just coped, while inside I was falling apart.*

(Page 2, lines 36-39)

For this reason, she could relate to the experience of "breastfeeding everyone" but neglecting her own needs, as expressed in the account. This is a feature typical of the 'breast-cancer prone' personality (Temoshok and Dreher, 1992). It is also consistent with Iwamitsu et al. (2005), who have pointed out that a lack of social support is associated with the 'cancer-prone' characteristics of a tendency to suppress negative emotions and to be overly appeasing, co-operative and self-sacrificing. These characteristics reduce the likelihood of individuals receiving support from their environment, because they do not ask for help and appear to be totally self-sufficient.

524

In sum, although a number of participants reported sufficient levels of emotional social support, there were also a significant number of women who appeared not to be receiving the social support they needed. This was either because their efforts to reach out to others had been rebuffed, or because they did not seem to benefit from the potential stress-buffering effects of available support.

1.3.3 Sub-Theme 2c: Laughter and Humour for Stress Reduction

The third sub-theme of coping with stress concerned laughter and humour as ways of relieving stress. In the context of participating on the 'Laughter for Wellbeing' message board, many women expressed how important laughter and humour were to them. They seemed to derive these from different sources. For some, laughter featured in the time they spent with their grandchildren, as Red Lily explained:

> *My own granddaughter is a source of amusement* […]. *She is coming up for 2 and does some really funny things sometimes which has us all in stitches.*

> (Page 6, lines 134-136)

Red Daisy enjoyed laughter while spending time with her great-nephews:

> *When all else fails I try to spend time with my great-nephews* […] *- nothing beats play and laughter to release my own inner child.*

> (Page 3, lines 48-50)

Humorous media such as books, pictures or films also provided sources of stress reduction:

> *Jack Nicholson is an excellent actor and seems to be able to turn his hand to most things. I feel he doesn't take himself too seriously, which is brilliant! If we can't laugh at ourselves what else is there to laugh at!*

> (Red Lily, page 8, lines 159-161)

Pink Fern preferred reading:

I think I am more likely to laugh while reading a book or listening to an audio tape than when I watch TV.

(Page 13, lines 244-245)

Red Blossom, on the other hand, collected humorous pictures:

My computer is full of pictures I find amusing! I save them to show to friends or to look at where I need cheering up (I even printed a few to put on my walls!).

(Page 7, lines 149-151)

Funny memories were also important to some:

Dad has been gone a year tomorrow and I still laugh at things he bought me... and as for jokes he told they were terrible but you roared at them.

(Pink Fern, page 13, 254-256)

Similarly, White Fern wrote:

[…] we are lucky to have so many good times to remember aren't we.

(White Fern, page 11, lines 245-246)

A few participants prided themselves on having a good sense of humour, which appeared to help them get through difficult times and stressful situations. Blue Daisy was one of these women:

[…] one thing I have is a sense of humour and optimism! "Things can only get better", can't get any worse!

(Page 2, lines 35-36)

Purple Daisy described how she had mastered a recent stressful situation with humour:

Not a good week. This house is rapidly becoming a "money pit!", and my resolve to maintain it is weakening fast! […] I just started to laugh, got my coat and car keys, and went shopping! Needless to say, a shopping session in [town] *does absolutely nothing to attend to a shabby hall and staircase, and even less for a new radiator, but what the He**, there are no pockets in a shroud! […] Can't live without my shopping expeditions, or my sense of humour!*

526

(Page 2, lines 14-31)

White Fern emphasised the importance of being able to laugh at oneself:

> *I do laugh a lot, I seem to be surrounded by people who have what is known as 'black humour' and can find something funny in almost anything, I am sure that this has helped me through some pretty tough times. I also think more importantly, that I can laugh at myself* […].

(Page 9, lines 208-212)

The usefulness of laughter and humour to combat stress has been documented in the literature (Buckman, 1994; Fry and Salameh, 1987; Kuiper and Martin, 1998; Seaward, 1992; Wooten, 1996). It is notable that a number of participants were able to recognise and utilise this coping strategy of their own accord.

Yet, there were a significant number of women who admitted that they found it difficult to laugh or enjoy humour when faced with stressful life events. Red Daisy was caring for her mother who suffered from Alzheimer's disease, and explained her difficulties in laughing:

> *I don't find there's much to laugh about lately. I can just about raise a smile now and then, but if I'm honest I can't remember the last time I had a good, old fashioned belly laugh. For one thing humour passes Mum by these days and there's no fun in laughing on your own - humour is always better shared.*

(Page 17, lines 387-392)

Two other women recounted how physical or psychological factors prevented them from being able to enjoy humour and laughter:

> *I know laughter is the 'best medicine' however, because of my depression, there are times when I find it impossible to laugh, even at things which I find funny.*

(Red Blossom, page 8, lines 160-161)

With her intermittent difficulties in experiencing pleasure in the form humour and laughter, Red Blossom most likely exhibited a typical symptom of a major depressive episode (American Psychiatric Association [*DSM-IV-TR*], 2000).

Likewise, Purple Fern found it difficult to laugh due to her current health problems:

> *I have to admit there has not been too much laughter due to being so ill but things are on the change and getting back to normal, yet again it's trying to put a brave face on it all and laugh even when you don't feel like it as I […] feel I am letting them down not to feel happy that I survived* [cancer]*, I do but its the long drag back to health that gets you down and laughter is not very high on your list of things to do!*

(Page 4, lines 50-55)

Regrettably, Purple Fern gave low priority to laughter and humour, even though this has been shown to lead to improvements related to immune system function, such as improvement in natural killer cell activity (Bennett and Lengacher, 2006b; Seaward, 1992;) and thus promote recovery from illness.

Still, some of those who found it difficult to laugh felt that humour and laughter were important, and some resolved to try and incorporate laughter into their daily lives, such as Red Blossom:

> *I've learnt to not stop trying though, if one thing doesn't make me laugh then I'm hopeful something else will.*

(Page 8, lines 162-163)

Another participant, during the course of the CEPB, wrote about her decision to integrate laughter into her daily life, in the form of laughing exercises:

> *I think I will start laughing exercises each morning, we've been given the ability for a reason, and I may as well use it more often, don't want my face to get fixed with a frown and a downward mouth as you see in some elderly people. It'll release those endorphins (I think) and strengthen my immune system (I hope!).*

(Purple Holly, page 9, lines 193-197)

On the whole, most participants regarded the enjoyment of laughter and humour as an important part of life and as a good way of relieving stress, even those who found it difficult to enjoy laughter. Their beliefs about the beneficial effects of laughter were consistent with findings in the literature. For some, participation in the 'Laughter for Wellbeing' element of the CEPB served as a reminder of the potential for laughter and humour to enhance their quality of life.

1.3.4 Theme 2 Summary

Participants described adaptive coping strategies involving emotional regulation, approach of the stressor, or reappraisal. Maladaptive coping in the form of avoidance was also engaged in. Furthermore, a significant number of participants admitted to difficulties coping with current stressful life events. Many exhibited optimism and a positive frame of mind. A good social support network to buffer the effects of stress, as well as the enjoyment of laughter and humour were seen to be important elements of stress reduction. Yet, not every woman had these stress-coping resources available to them, or, if present, was able to draw on them. Overall, coping styles and abilities were diverse; still, those who reported maladaptive strategies or a perceived inability to cope seemed most in need of adaptive ways of stress reduction.

1.4 Theme 3: 'Breast-Cancer Prone' Characteristics

As part of the third theme found in participants' accounts, patterns emerged in line with the concept of the 'breast-cancer prone' personality, encompassing Type C and Type I traits and behaviour patterns. Three such characteristics emerged as sub-themes: *Difficulties in Experiencing or Expressing Anger, Self-Sacrifice,* and *Perceived Helplessness.*

In line with typical Type C behaviour, some participants reported experiencing negative feelings but keeping these feelings concealed from others, or maintaining a calm façade despite inner turmoil. One woman wrote about her difficulties confiding in other people:

> *I have always had difficulty in confiding to people usually taking the stance of working through things on my own.* [It] *seemed appropriate at the time - now I am not so sure.*

> (Yellow Fern, page 9, lines 234-248)

Another participant described the discrepancy between the face she presented to the outside world and her private, inner self which she concealed from others:

> *I put on a confident happier exterior but when I'm on my own I cry a lot because I'm actually the opposite.*

> (White Rose, page 9, lines 177-178)

Hiding persistent feelings of worry was another behaviour described by several women, such as Yellow Daisy:

> *I worry every day, although I try to keep it buried.*

> (Page 3, line 61)

Orange Iris experienced worry in a similar way:

> *I am always worrying!* […] *I try to fight it all the time and 'chillax' but I am not very good at it! though I am quite good at keeping it to myself!*

> (Page 5, lines 90-92)

Pink Fern also tended to hide feelings of worry:

> *I never look worried, haha. I feel like the swan, cool and calm on top while all is going like the clappers underneath.*

> (Page 11, lines 206-208)

Keeping negative feelings such as worry and sadness concealed from others and presenting a calm or happy exterior is a mannerism which has been described as typical for the Type C personality (Temoshok and Dreher, 1992).

Apart from keeping negative emotions and worries to themselves and maintaining a calm façade, some women also reported a lack of assertiveness or ability to stand up for themselves, another attribute in line with the 'Type C' personality. This was the case for Blue Daisy:

> *Sticking up for myself is not an option really, because I never win an argument and* [my husband] *always makes out he is the victim.*

(Page 6, lines 135-137)

Green Rose also lacked assertiveness:

> *I am* […] *inclined not to stand up for myself in difficult situations.*

(Page 9, line 195)

A lack of assertiveness is another Type C feature (Hosaka, Fukunishi, Aoki, Rahe and Solomon, 1999) which has been linked to an increased risk of developing cancer (Temoshok, 1987).

The presence of such features clearly shows that the CEPB was warranted. In fact, two participants were either considering changing 'breast-cancer prone' behaviour patterns, or had already done so. Thus, Purple Ivy wrote about a gym session with a personal trainer:

> *Maybe I'll have to be gently assertive and use those lovely "I" phrases to explain to* [my] *personal trainer that the shift of gears was just a tad too much* […].

(Page 19, lines 407-412)

Orange Holly explained that she had already successfully abandoned her tendency to suppress negative emotions:

> […] *most people view me as a strong, assertive, woman who normally has a smile on her face despite what stressful situations may be going on in my life at the time. I used to suppress things as described but that hasn't been true for the past 7*

> *years or so as I made a conscious decision not to do so and become more open*
>
> *with people about my feelings / thoughts.*

<div align="right">(Page 3, lines 58-61)</div>

Orange Holly's experience is consistent with the notion that 'breast-cancer prone' personality traits, such as emotional suppression, are open to change (Eysenck, 1994). However, it must be emphasised that it was not the primary focus of the CEPB to permanently change personality traits, as the evidence overwhelmingly points towards personality being a stable construct (McCrae and Costa, 1994). Rather, one of its aims was to ameliorate the negative effects of 'breast-cancer-prone' personality traits on individuals' wellbeing by encouraging them to engage in emotional expression within a 'safe' (i.e. anonymous) setting.

A further 'breast-cancer prone' behaviour pattern that became evident was that of being overly compliant and considerate towards others. Pink Fern remembered being this way since her early childhood, but then defying her parents by entering into a relationship that they did not approve of:

> *For as long as I can remember I was a "good girl" did as I was told, didn't answer*
>
> *back. Then I met* [my husband] *and we got serious.*

<div align="right">(Page 25, lines 532-533)</div>

Purple Ivy described her personality in a similar way:

> […] *I have* […] *been the good girl, nice girl and not done anger and so on.*

<div align="right">(Page 2, lines 43-44)</div>

Overall, a variety of behaviours in line with the 'breast-cancer prone' personality were described. However, three characteristics emerged that were reported particularly often by participants – these are detailed as sub-themes below.

1.4.1 Sub-Theme 3a: Difficulties in Experiencing or Expressing Anger

A significant number of women talked about their difficulties in either feeling angry or in expressing their anger. For them, anger was either an emotion which they did not remember experiencing very often, or one they did experience regularly but felt the need to keep under control. For example, this was the case for White Rose and Red Daisy:

> *I don't really get angry very often.*

> (Red Rose, page 2, line 32)

> […] *these days I don't get angry very often.*

> (Red Daisy, page 3, line 52)

Green Rose felt that anger was an unimportant emotion to her, but at the same time suspected that her inability to get angry may not be a desirable trait:

> […] *I don't really get angry. I am not sure why as there have been plenty of things which have made me angry, but it's not a significant emotion for me. Perhaps it's a problem and I should get angry more often!*

> (Page 2, lines 39-41)

Another woman did experience anger but was unable to express it:

> *I remember at times when I have been full of anger I could not express wondering where it would go*

> (White Jasmine, page 2, lines 43-44)

She explained how she had learned to keep her anger under control at a very young age, and was made to believe that anger was a 'sinful' emotion:

> *I was raised in a very Christian home anger was sinful I've been told are family don't do anger so I find it difficult to deal with especially after my marriage broke up and I was left alone to bring up my children while my ex got on with his life I have learned in recent years that anger is ok and have managed to find coping*

mechanisms but I know that I still suppress a lot of feelings of anger and I cant

bring myself to be honest with people who have hurt me.

(White Jasmine, page 2, lines 39-40)

Purple Jasmine had learned to avoid conflict as a child, witnessing violence in her family:

When I was young I used to shy away from confrontation, keeping my feelings of

anger under control, even though I saw a lot of violence in my family.

(Page 2, lines 36-38)

Another woman had learned to control her anger in her childhood, in order to prevent getting into confrontations with adults:

[…] had to learn at an early age to keep my temper under control, otherwise it

controlled me and got me into trouble!

(Red Daisy, page 3, lines 52-53)

These participants' accounts illustrate how for them suppression of anger was a learned behaviour, motivated by the 'reward' of escaping punishment through their parents or other authority figures. In operant conditioning terms, this would constitute passive avoidance learning (Skinner, 1953). As this behaviour pattern had been learned early on, it would have most likely been difficult to change.

Other women wrote about conscious efforts to 'bottle up' their anger. Pink Fern often did this in confrontations with her husband:

I don't tend to get angry very often or have one main anger situation. In the last 2

years I have frequently got angry at my husband...not the screaming shouting sort

but […] I tend to bottle it up and simmer away then let off steam on my own.

(Page 7, lines 148-151)

Red Rose made clear that she had not always bottled up her anger – this was in fact a fairly recent development:

> *These days I don't really get angry as in having a rant and shouting a lot. I'm a lot more mellow than I used to be. I think I probably bottle it up more.*

<div align="right">(Page 3, lines 50-51)</div>

Similar to the participants who reported becoming more assertive in the course of their adult life, Red Rose's account of expressing her anger less shows that certain aspects of personality may indeed be open to change, as posited by Eysenck (1994).

Two women explained how, rather than expressing their anger, they often directed it inward at themselves. Green Daisy wrote about her divorce:

> *I am more angry* [at myself] *for staying with* [my ex-husband] *for so long before we eventually split up.*

<div align="right">(Page 2, lines 38-39)</div>

For Red Daisy, directing anger inward was a regular occurrence:

> *I get angry when I feel frustrated by my situation, but it's anger directed towards myself and that only leads to self-pity and chocolate!*

<div align="right">(Page 3, lines 63-64)</div>

Directing anger inward corresponds to the tendency to express emotions inward rather than outward, as observed in Bleiker's (1995) prospective study of breast-cancer patients.

The cost of not expressing one's anger seemed to be decreased physical wellbeing. One participant described how she believed that suppressed anger had resulted in her physical health problems:

> *With the shoulder pain I either use a cold pack or do a few exercises. I know they are probably caused by pent up anger...*

<div align="right">(Pink Fern, page 9, lines 178-180)</div>

Her experience clearly highlights the connection between emotional and physical health, with suppressed anger manifesting itself in physical pain.

Altogether, an inability to experience anger or a difficulty in expressing anger seemed to be a common characteristic among the participants and clearly showed that an intervention involving the facilitation of emotional expression, such as the CEPB, was warranted for them.

1.4.2 Sub-Theme 3b: Self-Sacrifice

Another 'breast-cancer prone' behaviour pattern which emerged was that of self-sacrifice, or putting others' needs before one's own, to benefit spouses, partners, children or other family members. Different motivations were at the root of this self-sacrifice. Some women explained that they felt the need to be strong and support family members in the wake of a diagnosis of a terminal illness, or for family members coping with an illness, as the following quote exemplifies:

> *When Dad was diagnosed in November I fell apart on the inside but knew that I had to be strong on the outside for my Mum, Dad, brother and sisters.*

(Yellow Jasmine, page 7, lines 166-168)

Later in the programme, she stated:

> *Well I don't know what the next few months will bring but I know that I've got to be strong for Mum and Dad in particular.*

(Yellow Jasmine, page 12, lines 269-270)

Pink Fern also felt the need to be strong for a loved one – in her case, it was her husband who had been diagnosed with a brain tumour:

> *My hubby needs me to be strong at the moment and hopefully for a good long time yet. He is the one with all the problems and needs supporting. Which I must do for him.*

(Page 20, lines 407-409)

Setting one's own needs aside to benefit family members who were suffering was thus a common occurrence. Where this type of self-sacrificing behaviour was described in health-related autobiographical accounts, many women were able to recognise this characteristic in themselves, and thus related to the protagonists of these accounts. As Purple Holly commented:

> *The story that stood out for me was Olivia Newton-John's, as it's the closest that relates to me and my situation, with regard to giving out without holding anything back for myself.*

> (Page 6, lines 125-127)

Part of being strong for others was the tendency not to share one's own problems with one's family members, in order to protect them. In this vein, White Fern detailed how she hid her cancer diagnosis from her mother:

> *I've not told my mum that I still have cancer to try and protect her, she thinks I am well and on the road to recovery* […].

> (Page 15, lines 331-333)

Keeping this distressful knowledge to herself posed a considerable strain on her, and she may have benefited from sharing her troubles with her mother. Still, White Fern was willing to endure the strain in order to avoid distressing her mother.

Another chronically ill participant avoided asking her adult sons for support, in order to not inconvenience them:

> *I wasn't about to ask for help as I didn't want to be a burden on* [my sons]*...after all I am not their responsibility...*

> (Blue Daisy, page 5, lines 105-106)

It is likely that this resolve not to ask for help and support from the people around them posed a considerable strain on women. In fact, not all participants were comfortable with putting others' needs before their own. Some seemed to feel under pressure to do so, but

were unhappy with the situation. Blue Daisy made this clear in a blog entry where she reflected on her relationship with her husband:

[My husband's] *needs* […] *have to be met or he sulks.*

(Page 3, line 53)

She thus seemed to feel manipulated into taking care of her spouse's needs due to the threat of passive-aggressive behaviour if she failed to do so. White Rose similarly felt under pressure to take care of others, while nobody seemed to feel the need to reciprocate her behaviour:

I have felt for a long time that people come to me with their problems. I don't mind, I enjoy helping people and don't like seeing friends and family upset or down. But I've also felt that because I'm seen as a rock by everyone, I have no-one to go to with my problems. If I try to approach anyone about my issues I feel I am being selfish and people aren't interested in helping me.

(White Rose, page 9, lines 180-185)

Having read an autobiographical account, Yellow Jasmine reflected on why some people felt the need to be strong for others:

I can really empathise with [the protagonist] *as I can see a lot of her in me. I know that we all "pretend" to be ok at times but because of our jobs or home life some of us find the need to "pretend" more than others.* […] *people expect us to be strong or confident - maybe it's because we are close to vulnerable people around us who are desperate for us to be strong as they find it difficult to be strong. Sometimes we do feel like crying out for help but where do you go or who do you go to when people around you have an expectation of your behaviour and character?*

(Page 2, lines 43-52)

She felt that it was due to external circumstances that some individuals felt the need to put on a brave face and be strong for others, rather than due to personality factors. Another participant saw her own self-sacrificing behaviour reflected in an autobiographical account:

> *Like* [the protagonist] *I think I am breastfeeding everyone else and perhaps it's time to put me first. Trouble is I haven't got a clue how to do it!*
>
> (Green Rose, page 9, lines 201-203)

This participant's quote reflected that she was in need of support to change her behaviour patterns. In terms of the transtheoretical model of behaviour change (Prochaska and DiClemente, 1983), she was at the 'contemplation stage' where she began to recognise that her behaviour was problematic. Prochaska and Velicer (1997) suggest matching interventions to the individual's current stage of change. In order to facilitate the transition from the contemplation to the preparation stage, emotional arousal in the form of experiencing and expressing feelings about one's problems and solutions has been proposed (Prochaska, James, Norcross and DiClemente, 1995). Participants such as Green Rose engaged in this both by taking part in the 'Art and Laughter for Wellbeing' element of the intervention, and in their blogs.

Similar to the suppression of anger described above, some participants were aware that their habit of putting others first had been formed at an early age. For example, Purple Holly reflected on her caring, self-sacrificing behaviour:

> *Even though I was the youngest, I was brought up to look after people, so didn't have much of a carefree childhood.*
>
> (Page 3, lines 68-69)

It is thinkable that such a learned behaviour acquired at an early age would be difficult to change at a later age.

For some women, their self-sacrificing behaviour had reached the point where it appeared to be having negative effects on their well-being. They found their caring role very stressful, and sometimes experienced fatigue as a result:

> *My grandchildren are the light of my life and they give me and my husband so much pleasure, although they are hard work sometimes. Sometimes I feel like I need a break and then I feel I should be grateful for all the things I have got so I feel guilty.*
>
> (Green Rose, page 3, lines 68-72)

Yellow Blossom found taking care of her family extremely demanding:

> […] *my mum's health is not so good at times as she has rheumatoid arthritis which means she needs help with shopping and she doesn't drive, I find I am driving over to take her out and trying to fit in everything else as my job is demanding and I also have my family to take care of, it's very stressful and I am very tired a lot of the time.*
>
> (Page 1, lines 9-14)

While these individuals felt dissatisfied with their self-sacrificing role, other women related how they were making conscious efforts to change this pattern and think of themselves more, such as Purple Ivy:

> […] *I was diagnosed* [with breast cancer] *and as a result the whole world then revolved around me taking care of me and allowing others to do so to and the long term result of this is that whilst balance is coming back I will not go back to old ways.*
>
> (Page 3, lines 61-64)

Purple Ivy's account shows that it required a health problem in the form of breast cancer for her to recognise the importance of looking after herself. Furthermore, she believed that

her behaviour had played a role in her contracting breast cancer. Putting it in terms of the health belief model (Rosenstock, 1966), the breast-cancer diagnosis served as a cue to action, instigating behaviour change. Primary prevention of breast cancer (i.e. preventing its development) is usually preferable to secondary prevention (treating it in its early stages to prevent significant morbidity) or tertiary prevention (managing the disease by reducing its negative impact on the patient as well as reducing disease-related complications), due to the reduced risk of mortality associated with primary prevention (e.g. Andersen and Cacioppo, 1990). Therefore, it most likely would have been more beneficial for Purple Ivy to come to this realisation at an earlier point.

Orange Rose too felt that it was time to change her behaviour:

> […] *now* [my children are] *grown up* […] *they need me less and less. I've been forced to think about my own needs for a change, and it's been a scary thing to do, and churned up a lot of anxiety. If I can get through this, I think I will finally know who I am and what I want, instead of just trying to be what I think everyone else wants of me.*

<div align="right">(Page 5, lines 89-93)</div>

Her experience shows that it was not an easy process for her to change old behaviour patterns, although she saw it to be a necessary and positive step.

Although a few women recognised the need to take more care of themselves, the majority of those who reported self-sacrificing behaviour either felt that this was a natural way to behave, or simply did not know how to change. As Pink Fern put it,

> […] *people say I am* [strong]. *But I don't think I am. I just have to get on with things, and take care of the ones I love.*

<div align="right">(Page 3, lines 397-398)</div>

An essential part of taking care of others involved hiding negative emotions as a way of protecting the people close to them. Some reported experiencing negative emotions such

as fear, worry or sorrow, but hiding these from their loved ones in order not to burden

them. One woman wrote about her father's death:

> *Reading other people's sad memories brought back to me how I felt after Dad died*
>
> *(21 years ago) and made me realise that, at the time, I didn't show much grief.*
>
> *Probably because I was trying to be strong for my Mother and Sister.*
>
> (Red Daisy, page 8, lines 189-192)

Purple Fern described how she hid her feelings from her children:

> […] *maybe it's being a Mum and always being strong for your children and being*
>
> *there for them,* […] *I have never been good at expressing myself so find it easier*
>
> *to just hide behind myself and carry on as usual, thinking about it I am not sure my*
>
> *children have ever seen me cry other than funerals. Am I odd?*
>
> (Page 5, lines 61-65)

Other women concealed physical discomfort from their family members, such as Green

Rose:

> *I feel so exhausted, but then I feel guilty for feeling exhausted and I feel that I*
>
> *should be happy and upbeat so that's what I'm pretending to be with my family.*
>
> (Page 6, lines 137-140)

Thus, rather than unburdening themselves, these participants preferred to hide their

negative emotions and discomfort, despite the possibility that sharing them with others

may have provided relief.

When women did put their own needs first, profound guilt was often the consequence.

This was very much the product of not living up to one's or others' expectations of oneself

or believing that one was not fulfilling others' needs appropriately. At the beginning of the

programme, one participant told of how she had left her husband and children, a decision

she was still guilt-ridden about:

> *6 years ago I left my family home and moved 250 miles away to live apart from my loved ones, I left behind a husband and three children. […] My guilt stems from the fact that I could never make it better for* [my children] *even when I should have and could have improved their lives by actually being there I wouldn't make that change, always claiming self preservation as the reason for staying so removed. I still have overwhelming moments of crushing guilt, that I just cannot cope with, I have somehow learned to live with them, I just seem to push them to one side and get on with things knowing that if I didn't I would become totally frozen.*

(Orange Daisy, page 1, lines 18-51)

Although this participant clarified that she was clinically depressed at the time and felt incapable of taking care of her family, the guilt associated with this action, which involved putting her own needs before that of her children, was debilitating for the participant and caused her much suffering.

White Rose also felt that she was not living up to others' expectations, particularly those of her family and friends:

> *I* […] *feel guilty about not ringing people as much as I should.*

(Page 3, lines 51-52)

White Fern's guilt was even more pervasive and affected her in many areas of her life:

> *My husband always says I was born guilty! I basically feel guilty 24/7. […] I feel like I have a 10 ton weight on my shoulders the whole time...I feel bad if I leave the dogs too long....if my son has to get his own tea.....if favourite shirts aren't washed and ironed....if I don't have time to hoover before I go to work .....if I don't have peoples favourite foods in...oh the list is endless - like I say born guilty, I've just learnt to live with this feeling of needing to make sure everyone's alright and has*

> *got what they need. Sometimes* […] *I try to do what's right for me but it just feels*
>
> *wrong and makes me feel bad.*

<div align="right">(White Fern, page 7, lines 152-167)</div>

Her account illustrates how her guilt was related to not putting her family's needs before

her own at all times. Although she acknowledged that it was necessary to put her own

needs first at least occasionally, she was unable to do so without experiencing profound

guilt.

The belief that self-sacrifice is essential in relationships with others is another feature

typical to the Type C personality (Temoshok and Dreher, 1992), and potentially

contributes towards negative health consequences.

Red Ivy related how her breast cancer had been a wake-up call and led to the realisation

that she was unhappy in her marriage and intended to leave. This left her feeling as

though she had "failed":

> *I* […] *feel guilty for "failing" in my marriage. I never married expecting it to be*
>
> *anything other than forever, but then I never expected cancer either!*

<div align="right">(Page 4, lines 79-80)</div>

Thus, the decision to leave her marriage and pay attention to her needs by seeking her

own happiness made her feel guilty. Guilt was for these participants related to not fulfilling

others' or their own expectations of themselves, and not being self-sacrificing enough,

which is in line with key Type C traits (Temoshok and Dreher, 1992).

To summarise, self-sacrificing behaviour, a typical feature of the 'breast-cancer prone'

personality, was reported by a significant number of participants. Although some

recognised that this behaviour was affecting or had affected their physical and/or

emotional health negatively, only a few felt that they had been able to change their

<div align="right">544</div>

behaviour. Some were contemplating changing but did not know how to go about it. For these individuals, the emotional expression they engaged in as part of the intervention potentially served to instigate the preparation for change (Prochaska et al., 1995).

1.4.3 Sub-Theme 3c: Perceived Helplessness

The final major 'breast-cancer prone' characteristic emerging from participants' accounts was perceived helplessness. Many women described the feeling that events in their life were beyond their control, and that there was little or nothing they could do to ameliorate the situation. Blue Daisy, in the context of describing her oppressive relationship with her husband, wrote:

> *Sooooo much more bad stuff happening in my life, all of which it seems is out of my control... how do I change it. Fed up with thinking about it.... so apathy takes over. Just slink back into shell like a little snail.*

(Page 7, lines 157-159)

White Rose was unhappy in her job, and explained:

> *I get very wound up because I feel I have no control in the situation and have to work at the moment because my husband is unemployed.*

(Page 2, lines 36-38)

Purple Jasmine, reflecting on her difficult childhood, wrote:
> *The best way I can describe my feelings is to say that I felt a victim and had no control over what was happening within the family.*

(Page 2, lines 38-40)

All three participants believed that the events in their lives were beyond their control, which resulted in perceived helplessness, feeling as though one were the victim of circumstance and had little or no power to make changes in one's life. This is in

accordance with the concept of the 'cancer prone' Type I personality, characterised by feelings of helplessness and hopelessness leading to depression (Grossarth-Maticek, 1980).

Feelings of helplessness extended into areas of life such as improving one's health. Green Rose felt unable exercise due to external circumstances:

> *I feel so frustrated as I am trying to be more healthy - I've lost weight and want to exercise, but every time I do something seems to happen - a few weeks ago it was a piece of glass in my foot and prior to that the weather was rubbish.*

> (Page 3, lines 55-58)

Another participant described how coping with her son's inherited disorder left her feeling helpless:

> […] *I don't see anyone outside the family and talking I find does not help - the only thing that will help is a cure for muscular dystrophy and that isn't going to happen any time soon.*

> (Yellow Daisy, page 3, lines 68-70)

White Rose wrote about her ambivalent relationship with her husband, whom she held responsible for her situation:

> *Sometimes I feel like* [my husband]*'s ruined my life, and think of leaving him, and then other days he can be really sweet and I love him to bits.*

> (White Rose, page 7, lines 139-141)

The concept of the helpless Type I personality could be linked to an external locus of control (Rotter, 1954). Furthermore, it is likely that helpless and hopeless individuals have low self-efficacy (Bandura, 1977), that is, they are likely to perceive their own competence as low. Having an external locus of control has been found to be associated with less

voluntary physical activity than having an internal locus of control (Sonstroem and Walker, 1973). Similar findings have been reported for low self-efficacy and exercise (McAuley and Jacobson, 1991), as well as health behaviours in general (Conner and Norman, 2005). It is thinkable that the propensity of the Type I personality to develop cancer is linked to an external locus of control and low self-efficacy, which renders individuals less likely to engage in positive health behaviours, thereby increasing their cancer risk. However, this would need to be investigated further.

1.4.4 Theme 3 Summary

A number of 'breast-cancer prone' characteristics from both the Type C and the Type I personality constructs emerged from participants' accounts. Apart from a variety of typical 'breast-cancer prone' traits such as the suppression and concealment of negative emotions, lack of assertiveness, and over-compliance, many women reported difficulty in experiencing or expressing anger, self-sacrificing behaviour with profound feelings of guilt where this behaviour was not maintained, and feelings of helplessness. Some of these characteristics were also described by the protagonists of the health-related autobiographical accounts women had been asked to read as part of the intervention, and hence a large proportion of participants purported that they were able to identify with these protagonists. Of those participants who recognised the potential negative consequences of their 'breast-cancer prone' behaviour, only a few reported being either in the process of abandoning, or having already abandoned these patterns. In terms of the transtheoretical model, most women were either at the precontemplation or contemplation stage of behaviour change, which made it clear that there was a need for a stage-matched intervention, as suggested by Prochaska and Velicer (1997).

1.5 Theme 4: The Role of Psychological Factors in Health and Illness

The fourth theme emerging from the data encompassed participants' beliefs regarding the role of psychological factors in the development of health and illness. Here, two sub-themes surfaced: *Perceived Physical Symptoms of Stress* and *Scepticism.*

In the early weeks of the intervention, one participant expressed surprise at the idea of a connection between emotional suppression and physical health:

> *I never realised that suppressing your negative emotions could actually make you susceptible to illness.*

(Green Rose, page 9, lines 197-198)

Her incredulity regarding this notion is not surprising, given the dominance of the biomedical model in our society (Engel, 1977), with its emphasis on biological processes (van Wersch, Forshaw and Cartwright, 2009). Still, many women seemed to believe that psychological and physical health were connected, and that psychological problems could impact on one's physical health negatively. White Jasmine stated this at the very beginning of the programme:

> *I believe that emotions play a big role in our physical well being especially if at some level they are unresolved.*

(Page 1, lines 15-16)

Another participant explained her beliefs with regards to stress and breast cancer specifically:

> *It may be possible that stress and breast cancer are connected. Any stress that's experienced must have some affect* [sic] *on our body, unless we are lucky enough to find an outlet.*

(Purple Holly, page 5, lines 100-102)

Orange Rose felt that emotional suppression was linked to physical problems:

> *I definitely think suppressing your feelings can have a physical effect. All that stress and tension has to come out somehow, and if you're working hard and trying to be all things to all people it can be hard to admit you're unhappy even to yourself.*

> (Page 8, lines 40-43)

Purple Ivy presented rather detailed and elaborate ideas about the mechanisms underlying this connection:

> *I do believe stress is* […] *highly toxic to the body as it is known in long term situations to effect every system of the body and can have a marked effect on the immune system making it less able to fight any thing including cells that are turning cancerous. I think sudden shocks can also have the same stressing effect on the body's systems too. So in essence I think stress could well be a contributing factor to cancer getting a hold but not the one and only.*

> (Purple Ivy, page 3, lines 70-76)

Thus, she had elaborate ideas on the potential pathways to cancer development through psychological factors having suppressing effects on the immune system, while simultaneously allowing for other contributing factors. This view is in line with current findings in psychoneuroimmunological research, as outlined in Chapter Three.

As well as being aware of the relevance of psychosocial factors in the aetiology of breast cancer, some women suggested that more effort should be concentrated on applying this knowledge to health interventions. Yellow Jasmine stated:

> *Maybe if there was more help for people with real stress then possibly there may be less cases of cancer. Of course there are lots of contributing factors to*

> *someone getting cancer and not just stress but it would be good to help to alleviate*
>
> *that problem from someone's life.*

<div align="right">(Page 5, lines 102-105)</div>

While Yellow Jasmine's focus was on the primary prevention of cancer, which fits with

Grossarth-Maticek's (2008) recommendations to target psychosocial factors (e.g. stress)

in preventive cancer interventions, Purple Holly thought it useful to take a holistic

approach to secondary prevention:

> *I really do think it about healing the whole of oneself, not just the isolated part in*
>
> *question. Louise Hay does say that disease, or as she calls it, dis-ease in the*
>
> *body, is caused by our attitude to life and language.*

<div align="right">(Page 9, lines 176-179)</div>

Another participant shared this view with regards to psychosomatic complaints:

> *IF 60 to 80% of the things that people go to their GPs for are psychosomatic (I'm*
>
> *using that in the true sense of the word) then this is an area that neeeeeeeeeeds*
>
> *so much more understanding and is clearly an area where the holistic approach*
>
> *may appear to have success due to the effect of people feeling listened too and*
>
> *so on and so on.*

<div align="right">(Purple Ivy, page 14, lines 283-287)</div>

These participants advocated the importance of paying attention to psychological

variables in the prevention and treatment of physical illnesses. In part, this notion

stemmed from first-hand experience of how psychological problems could influence

physical wellbeing, and vice versa. For example, Green Rose explained how she believed that her weight problems were linked to stress:

> *My health isn't good and I have problems with my weight and I think this is linked to excessive stress in the past.*

<div align="right">(Page 8, lines 183-185)</div>

Another woman felt that her high blood pressure was attributable to her stressful life circumstances caring for her ill mother:

> […] *for the first time that I can ever recall my blood pressure was up and this I can only put down to the stress of caring for my Mum.*

<div align="right">(Red Daisy, page 7, lines 150-152)</div>

Green Rose's experience of poor health and weight problems has been corroborated by the finding that chronic stress can induce increased comfort food intake and body weight gain in stressed or depressed individuals (Dallman, Pecoraro, Acana, la Fleur, Gomez et al., 2003). Furthermore, it has been found that high life stress, in combination with high cardiovascular responsivity to stressors and a family history of hypertension is related to elevated blood pressure (Light, Girdler, Sherwood, Bragdon, Brownley et al., 1999).

Poor health also occurred after being bereaved. Thus, Purple Jasmine recounted the symptoms she experienced after her mother's death:

> *I remember enjoying good health up till the time of Mum's death, then I suffered sore throats and colds a lot. I do believe there is a connection between loss and physical and mental wellbeing.*

<div align="right">(Page 1, lines 24-27)</div>

But these effects were not passively accepted by all women. A few individuals reported taking active steps to relieve physical symptoms by trying to improve their psychological wellbeing. White Fern, for example, wrote about her efforts to reduce stress and thereby improve her physical health:

> *I am trying to structure my days with a little work and a little relaxation to try and help my physical health.*

> (Page 20, lines 408-409)

Purple Holly also engaged in stress management in the form of guided imagery, in order to aid recovery from rheumatoid arthritis.

> *Listened to a healing CD last night and did some imaginative mental work on my* [rheumatoid arthritis]. *I've got myself into remission before and for 16 years, I can do it again.*

> (Page 8, lines 152-154)

Thus, not only did many women recognise the potential impact of their psychological health on their physical health, but a few were also attempting to improve their physical wellbeing by targeting their psychological health. Nevertheless, this still only constituted secondary prevention, rather than trying to prevent physical illness from occurring in the first place.

As many had experienced the significance of the connectedness of psychological and physical health themselves, it was not surprising that a lot of participants could identify with the protagonists of the autobiographical accounts presented to them as part of the CEPB. These women felt that the accounts accurately reflected what they themselves believed about the relationship between physical and psychological health. Green Rose affirmed this:

> *I think that Patty's cancer could be linked to suppressed emotions. I think that when you are really deep down scared of something you do clam up and keep it inside and that isn't good for you.*

> (Page 9, lines 191-193)

This view was shared by Purple Holly:

> *Who's to say whether it is possible or not? The mind works in mysterious ways and is extremely powerful. It seems to me that if Patty feels she has in some way suppressed her feelings and as a result developed cancer, then she has. I guess what each of these emotional stories is showing, that given the right circumstances, anyone can get cancer, and not necessarily from a bereavement […].*

> (Page 3, lines 50-56)

Pink Jasmine's experience resembled that of the protagonist Patty Coldwell very closely:

> *Oh yes, I recognised myself* [in Patty Coldwell's story]*! I too was diagnosed with breast cancer at the age of 47, and have often wondered since if it was either a punishment for my sins or a reaction to the stressful events leading up to it.*

> (Page 1, lines 23-26)

Yellow Jasmine speculated that Patty had been living a dual life, with an 'inner' and an 'outer' self:

> *I think that it is really sad when a person can't be themselves all of the time. […] As with lots of people Patty has experienced living a dual life - the outwards Patty and the inner Patty. This kind of lifestyle isn't healthy as it puts too much pressure on the person being the "two people". [...] I do believe that her lifestyle could have contributed to her illness. Her mind and body have been under tremendous strain*

for a long time and she hasn't been able to find inner peace with herself and her

own feelings.

(Page 2, lines 35-44)

Her distinction between inner and outer self can be found in Goffman's (1959) distinction between public and private self as part of self-presentation theory, or in Levinas' (1968; cited in van Wersch, Forshaw and Cartwright, 2009) concept of the 'en-soi' (inner self) and 'pour-soi' (social self). It is thinkable that the discrepancy between inner and outer self would be particularly strong for the 'breast-cancer prone' individual, who is concerned about hiding her true emotions from others, to appease and conform to others' expectations. It is likely that this discrepancy could lead to considerable psychological discomfort in the long run.

The connection between psychosocial factors and ill health had also been witnessed in family members who had been affected by physical illnesses, which participants believed had been triggered by psychological issues. Such was the case for Red Lily's sister-in-law:

My brother's first wife died as a result of cancer. She was a busy teacher & deputy

head of her dept. She was told that everyone had the potential to develop cancer

and that it merely needs a trigger, either stress or long term ill health.

(Page 1, lines 7-10)

For Green Rose's daughter, on the other hand, physical illness had led to psychological problems:

[My daughter] *has been through a lot in her life and I can see how these things*

might have led to her depression, although I think a lot of it is because she is

[physically] *ill.*

(Page 7, lines 156-158)

Regardless of the nature of the relationship, a connection between physical health and psychosocial factors seemed plausible to most participants, and some had experienced the extent of this relationship first-hand. Nevertheless, it also became clear that for some it took a personal experience in the form of physical symptoms or illness to become aware of this connection. As mentioned earlier, it is generally more desirable to prevent a health problem from occurring in the first place; if awareness is only raised once a physical illness has actually occurred, it may be too late to intervene. Therefore, it seems more advantageous to be aware of the potential negative health effects of psychosocial risk factors such as stress and emotional suppression, and to seek to make changes in accordance with reducing these risk factors, before ill health occurs. In that sense, intervention came late for some participants, because they had already developed a health problem.

1.5.1 Sub-Theme 4a: Perceived Physical Symptoms of Stress

As part of relating their own experiences of the way physical and psychological health were connected, many women reported suffering from physical symptoms of stress. These were perceived to be caused by difficult or traumatic life events women had experienced, or were currently experiencing. The symptoms women wrote about included fatigue, bowel problems, skin problems, and slow recovery after surgery.

Green Rose was taking care of her grandchildren, which was a stressful situation and left her feeling tired:

> *I still don't feel all that well - I'm really tired and eating the wrong things and I also feel anxious as my husbands company have not yet renewed his contract and they need to do this by the end of May.*

(Page 6, lines 126-129)

For Blue Daisy, it was clear that her slow recovery after surgery was stress-related:

> [I] *had a hysterectomy last year. I have not recovered well. Mainly through stress and anxiety.*

> (Page 1, lines 7-8)

Eczema and bowel problems for Yellow Jasmine were triggered by her father's cancer diagnosis:

> *Still having trouble with my bowels - I'm sure it's all the worry about Mum and Dad.* […] *My legs have flared up again too. After Dad had been diagnosed with lung cancer in November my legs went all blotchy and itchy.*

> (Page 10, lines 223-227)

The loss of her husband, a particularly stressful type of life event, was for Yellow Fern connected to the development of hypertension:

> *My grieving process has not been without incident, after a light headed/dizzy episode and following many investigations I needed to have a pacemaker fitted then two wakes later after another such episode I was diagnosed with high Blood Pressure, with medication this is now stabilised. All this with no previous symptoms!!*

> (Page 1, lines 22-26)

In this sense, stress was either seen as being responsible for entirely new health problems, or exacerbating existing conditions. This was the case for Pink Fern, who suffered with asthma, eczema and migraines:

> […] *With stress my asthma and eczema get worse...usually after all is over with and I tend to get a few migraines. I think its coz I worry mainly about hubby now.*

> (Page 11, lines 215-217)

For another woman, a throat problem was aggravated by stress:

> *I am conscious that stress makes the throat problem worse, and I am hoping that trying to relax and calm down will aid my recovery, but it is very difficult.*

> (Orange Rose, page 7, lines 125-127)

Evidence for a connection between stress and the symptoms described by participants can be found in the literature. Both asthma and bowel problems have been linked to stress (Bienenstock, 2002). Regarding eczema, it has been established that psychosocial stress is an influencing factor on its progression (Kupfer, Gieler, Braun, Niemeier, Huzler et al., 2001). It is therefore possible that for both participants the physical symptoms were manifestations of stress.

Contributing a photograph of a worried-looking woman on the 'Art for Wellbeing' message board, White Rose wrote:

> *I chose this picture for worry* […] *because it represents me, as someone who worries a lot. Last year I was worrying a lot because my health was not good due to stress at work, and husband was unemployed. I was worried about how to pay the mortgage and bills, I was worried about my husband because the longer he was out of work the more I worried he wouldn't get a job. I ended up very ill by the end of the year and I wonder if this was caused by the worrying I did.*

> (Page 3, lines 56-64)

She apparently regarded uncertainties in life as a major source of stress, which in turn led to health problems.

Altogether, a sizeable number of participants seemed to believe that stressful life events played a large role in one's physical wellbeing, recounting experiences which seemed to support this idea. The symptoms experienced by women to be physical manifestations of stress largely reflected current findings in the literature.

1.5.2 Sub-Theme 4b: Scepticism

Despite many participants being convinced of the existence of a connection between physical and psychological health, and having experienced the same first-hand, a number of participants voiced their scepticism or ambivalence at the notion of a causal link between psychosocial variables and illness. Purple Ivy, for example, did not believe these to have played a major role in the aetiology of her breast cancer:

> *I do not think the emotional trauma is the sole or even the main reason for my having breast cancer*.

(Page 1, lines 24-26)

Another participant questioned the direction of the relationship, rather than the existence of the relationship itself:

> *I think it unlikely that cancer growth is linked to or exacerbated by physical stress, as a "scientist" somehow that doesn't sit right with me* […]*. On the other side of the fence though I do think that a positive attitude can be a strong support in getting better.*

(Red Ivy, page 2, lines 25-29)

Still, it was clear that although she very much subscribed to the biomedical concept of health and illness, she allowed for the influence of a positive attitude on recovery. This is in line with the concept of the 'fighting spirit' as described above, which has been found to be associated with an increased chance of survival in breast cancer (Greer et al., 1979).

White Rose too was sceptical of a possible connection between breast cancer and stress:

> *This is interesting that all the cancer patients* [in these autobiographical accounts] *found they suffered stress before their diagnosis, but this could be a coincidence. The majority of people have stress in their lives and could relate that to their cancer, although it does say specifically within the last 18-24 month time frame.*

(Page 10, lines 221-224)

In contrast, Purple Ivy believed the aetiology of illness to be multifactorial and complex, encompassing both physical and psychological variables:

> *I do believe that sudden stresses or long-term ongoing heightened stress does have a known damaging effect on the immune system and thereby rendering it less able to defend against developing cancer cells. I suspect stress is quote a causative factor but not everybody who is stressed gets cancer, they get other things like heart disease or strokes or thyroid problems or diabetes etc.*

(Page 6, lines 128-133)

Similarly, commenting on a health-related autobiographical account, Orange Holly wrote:

> *Although it may be technically possible that the level of mental stress arising for an abrupt death of a very close loved one may be a contributory factor to physical health; I think there are so many different factors at play in relation to cancer (e.g. physical health to start, family history, etc.) that we aren't provided with in this story to make a valid judgement as to whether this was the biggest factor or not. I believe that if there was continued mental stress over the years prior to the breast cancer diagnosis then I would concede that there could be a contributory factor (although not necessarily all arising from the death of her husband).*

(Page 2, lines 27-36)

Both of these women presented a sophisticated understanding of the potentially complex interplay of psychosocial factors with physical risk factors in the aetiology of breast cancer. This complexity has also been postulated by Grossarth-Maticek and colleagues (Grossarth-Maticek, 1980; Grossarth-Maticek, Eysenck and Vetter, 1988; Eysenck, 1988,

1991; Eysenck, Grossarth-Maticek and Everitt, 1991; Grossarth-Maticek, Eysenck and Boyle, 1994).

Altogether, none of the participants outright discounted the possibility of a causal link between psychological factors and illness, yet it appeared to be a dubious idea that some found difficult to accept. A few proposed that the relationships between these factors were much more complex than they appeared to be presented in the autobiographical accounts.

1.5.3 Theme 4 Summary

Opinions on the role of psychological factors in the aetiology of health and illness were mixed. Many supported this concept, writing about how they believed the connection between physical and psychological health had become evident in their own lives. For some, this entailed experiencing physical symptoms of psychological stress. It is important to emphasise that participants' symptoms were all self-reported. It is possible that they themselves were not fully aware of whether psychosocial factors led to physical illness, or whether psychosocial problems were the result of physical illness. Furthermore, from their accounts any pre-existing physical risk factors were unclear. Echoing these doubts, a number of participants voiced their scepticism regarding the role of psychosocial factors in the aetiology of illness, usually questioning the presence of a causal connection. Yet, some of these women were willing to admit that they believed there was some sort of a connection, even if its nature was unclear to them.

Despite these caveats, it seems the most likely that the true nature of the relationship between psychosocial and physical health is complex and multi-factorial, which was suggested by a few participants and corresponds to Grossarth-Maticek and colleagues' diathesis-stress theory of disease as discussed in Chapter Three. This awareness of the complex relationships between risk factors is unusual, as articles in the media geared

towards laypeople tend to simplify the cancer-mind connection. It seems that women need to be informed better about these intricate relationships. A multifaceted model of breast cancer is more likely to be convincing for those sceptical of a causal connection between breast cancer and psychosocial factors, than a simplistic model which ignores these relationships.

1.6 Theme 5: Experiences with Health-Care Professionals

Participants wrote about their experiences with health-care professionals and governmental agencies in the context of using services for the treatment of physical and/or psychological problems, as well as seeking financial or job seeker support. The experiences reported included positive as well as negative perceptions. Here, two sub-themes emerged: *Provision of Support* and *Experiences of Psychotherapy or Counselling*.

1.6.1 Sub-Theme 5a: Provision of Support

A number of women related their experiences of receiving informational, emotional or practical support from health services or governmental agencies. Some of these experiences were positive, but many were negative. The negative experiences were felt to have been very distressful.

Some women related past experiences with health services, where they believed they had not been supported adequately, leaving them to feel left alone and finding it hard to cope. At the very beginning of her participation in the programme, Pink Fern wrote about having a stillbirth:

> *I was 26 weeks pregnant and miscarried* […]. *Hubby and I were knocked for 6 and tried to support each other through it. Things were very different back then, there wasn't the support system there is now and we just had to get on with our lives.*
>
> (Page 1, lines 8-11)

Pink Fern went on to express her belief that this lack of support could impact on the grieving process:

> *Now you get to stay with your baby, wash and dress them and take photos... that might sound a bit unpleasant but I so wish I could have held her for more than the few minutes I got. I am not surprised we have trouble grieving.*
>
> (Page 5, lines 104-107)

She implied that there was more support and help to manage the grieving process available nowadays for women who had miscarried.

Feeling left alone by health-care professionals was not an isolated experience. Remembering her husband's sudden death following the birth of their baby, White Fern wrote:

> *The help available 20 years ago was rubbish. The nursing staff ushered me into a room away from everyone so as not to upset the other new mums, then they insisted I went straight home with a new born baby, it was 11 o'clock at night!* […] *I had no help from social services, health visitor or the council re housing. If it hadn't been for my parents and* [parents-in-law] *I dread to think how I would have coped.*
>
> (Page 4, lines 83-90)

White Fern had had to rely on her social-support network to cope with this life-changing event; fortunately she had had familial support available to her. But, similar to Pink Fern, White Fern too suggested that the available support had increased in the recent years:

> *I now work with families and children and I know there is a lot more* [help] *out there now than there was before, thank goodness.*

562

(Page 4, lines 92-93)

But it was not just the available support that had increased in women's perceptions. One woman's positive impressions included the NHS' efficient management of her cancer treatment:

> *Who says the NHS moves slowly? I've found during my entire cancer journey thus far that they have been absolutely brilliant and made efforts to keep things moving as quickly possible at all times.*

(Orange Holly, page 30, lines 633-635)

Orange Holly's experience of the quick and efficient treatment of her cancer seems to be in line with the NHS Operating Framework guideline of quick GP referral for urgent referrals where cancer is suspected (Department of Health, 2011).

Yet, it seemed that negative experiences were still common. Some wrote of their ongoing struggle with seemingly insensitive health-care professionals, which left them with a lack of emotional support. This was the case for Yellow Daisy, whose son suffered from Duchenne Muscular Dystrophy:

> *I still feel anger towards the unfeeling consultant who diagnosed* [my son]. *"Its muscular dystrophy, its very serious I need blood lift him onto the bed." End of conversation.*

(Page 2, lines 47-49)

Thus, she felt that the devastating news of her son's illness could have been delivered more sensitively by the consultant.

Even Orange Holly's experience of her cancer treatment had negative aspects. She wrote about her hospital visit:

> [At the hospital I] *felt very much like a piece of cattle being shooed in and out again and was quite upset about it and remained so for the remainder of the day.*

(Orange Holly, page 19, lines 428-430)

She clearly felt dehumanised by the hospital treatment she had received. Her and the other women's dissatisfaction with their treatment is echoed by findings indicating that most patients, particularly those who are either psychosocially vulnerable or feeling unwell, prefer a patient-centred consultation style (Dowsett, Saul, Butow, Dunn, Findlow et al., 2000; Ogden, Ambrose, Khadra, Manthri, Simons et al., 2002). This includes clear communication by the health care professional and a partnership between doctor and patient, rather than a patriarchal relationship (Little, Everitt, Williamson, Warner, Moore et al., 2001).

The experience of inadequate support extended into information provision (or lack thereof) by health-care professionals or governmental agencies. Participants felt that they had many questions about their medical treatment, or needed information on how to access health services, but that this information was not always given to them. As White Fern, who had been diagnosed with cancer, explained:

> *I just have so many unanswered questions, which nobody can answer, but they swill around in my mind at night whilst everyone else is asleep.*

(Page 12, lines 268-270)

Another participant, who suffered from Eating Disorder Not Otherwise Specified (EDNOS), related her fruitless search for help:

> *I have tried searching for local support groups and I've had no luck, there just doesn't seem to be any help in the local area for me.*

(Red Blossom, page 17, lines 330-331)

Some also reported a lack of support from governmental agencies such as the Job Centre or Social Services. Yellow Daisy vented her frustrations regarding the unfavourable way she felt the recipients of state benefits were treated:

> *I worry very much about the government demonisation of those of us who survive*
>
> *(I won't say live) on benefits.*

(Page 3, lines 64-66)

Red Blossom had had negative experiences with the Job Centre:

> *I'm feeling quite angry today but that's mostly due to stress and problems with the*
>
> *Jobcentre.* […] *The Jobcentre are now making me sign-on weekly and telling me I*
>
> *have to travel up to 90 minutes to get to a job. I know this is the same for everyone*
>
> *but they don't take any individual circumstances into account.*

(Page 18, lines 361-362)

One participant explained how a mistake on the part of the hospital in the medical treatment of her mother had left her mother disabled, and that, in spite of this, no financial assistance was rendered by the government:

> *Social services been in but said if* [my mother] *needs help she'll have to pay for it.*
>
> *Sounds rubbish really when the hospital made the mistake in the first place!*

(Yellow Jasmine, page 9, lines 210-212)

All these women felt treated unjustly by the system, which seemed insensitive to individual needs. A more caring, empathic approach was not just desirable in the context of medical care, but also with regards to dealings with Social Services or the Jobcentre.

A number of women had approached health-care providers for support with emotional problems, but felt that these were not being addressed appropriately. White Rose, who had been diagnosed with cancer, sought help for her emotional problems from her GP, but felt misunderstood:

> *I am still crying at anything, and have numbed myself to all emotions at the*
>
> *moment. I mentioned this to GP and he said I'll get through it, he'll make sure I do.*
>
> *He wants to sort my hormones out first. I feel as if no-one understands.*

Similarly, Red Blossom felt that she was not receiving the help she needed with her EDNOS:

> *I have* [EDNOS] *but my local* [Eating Disorders] *team have said they're not willing to work with me and my GP won't help me either; he just supplies me with anti-depressants and that's it.*

Both women were dissatisfied with their GPs' readiness to prescribe medication, which did not address the root of their problems. Their statements reflect their disappointment with the biomedical approach taken towards the treatment of their emotional problems. In the biomedical paradigm, which has its basis in reductionism and mind-body dualism, the focus is on the disease rather than the individual, which can result in the objectification of the patient (Helman, 2001). It stands to reason that this type of objectification could be overcome by an embodied, patient-centred approach, whereby the individual is recognised to be their embodied self (Marlock and Weiss, 2006), and their personal needs are acknowledged and attended to. The negative aspects of patient objectification would need to be highlighted in any patient-consultation training given to health-care professionals.

1.6.2 Sub-Theme 5b: Experiences of Psychotherapy or Counselling

A few participants had had prior experiences with interventions designed to improve psychological wellbeing. Some had attended psychotherapy or counselling sessions. These were largely experienced as positive and helpful in terms of gaining a better understanding of oneself. Purple Holly, for example, had attended psychotherapy sessions in the wake of her divorce:

> *I managed to talk to a psychotherapist after the collapse of my first marriage* […].

> (Page 1, lines 26-27)

Purple Jasmine also had experience of psychotherapy:

> *I have had talking therapy in the late nineties* [...].

> (Page 10, lines 225-226)

Orange Holly elaborated on her counselling experience, emphasising the usefulness of the counselling sessions:

> *I was diagnosed as clinically depressed and was on meds for a year. Had a*
> *wonderful counsellor and through the year worked through the grief that I hadn't*
> *worked through all those years before. It's thanks to that that I am aware of my*
> *coping mechanisms, triggers, etc. now :)*

> (Page 25, lines 560-564)

While these women were not currently in psychotherapy or counselling, one participant stated that she still attended counselling sessions, and had in fact trained as a counsellor herself:

> *I have found counselling a useful tool and still attend therapy sessions once a*
> *month I am now a qualified counsellor myself and have done some bereavement*
> *counselling myself.*

> (White Jasmine, page 1, lines 11-13)

Yet, despite these positive experiences, Red Blossom related how, for her, support had come at the wrong time:

> *I'm angry because I've just been given a counselling session. I've been on the*
> *waiting list for months and it's annoying that I've finally reached the top when I've*
> *now got a job because 1. I may not actually be able to attend the sessions and 2.*

> *they may bring up painful memories that could make my depression relapse. This isn't the first time my counselling/therapy sessions have come at the wrong time. Previously I'd been waiting for therapy and they finally gave me sessions when I'd started a new job then I had to quit the therapy because the therapist thought she was putting me at risk too much. Then later on I started therapy again, but they only gave it to me after my partner left; if they'd given me therapy before then he might not have left me because I would've been dealing with my issues.*

(Page 11, lines 252-263)

For this participant, the timing of the intervention was important – at the time when she felt she needed it most, support was inaccessible, but when it was offered to her later, she no longer required it. Again, similar to the experiences described above, the health-care system had failed to meet the individual's specific needs, despite the Department of Health's (2009) pledge to provide more individualised services in the UK.

1.6.3 Theme 5 Summary

Participants reported a variety of experiences with health-care professionals, some of which occurred in the wake of their bereavement and some which took place in the context of managing a severe illness. Those who wrote about negative experiences commented on the lack of emotional support and lack of sensitivity displayed by specific professionals, as well as the general lack of support, or inadequacy of support, available in coping with their loss. A few women had come into contact with psychotherapy or counselling services, and on the whole had felt adequately supported by these services, although one participant lamented her inability to access the counselling at the time she needed it. On the whole, it became evident that women felt their individual needs inadequately addressed by health-care professionals, the NHS and other government bodies. These experiences highlight the importance of interventions being tailored to an individual's requirements, with a stronger emphasis on emotional support, sensitivity and

greater attention being paid to treating core problems rather than pure pharmacological amelioration of symptoms.

1.7 Theme 6: Experiences of the CEPB

The final theme emerging from participants' accounts involved their experiences of the CEPB. Most women described which aspects of the programme they found useful and beneficial, and which less so. Two sub-themes surfaced here: *Expectations of the Programme* and *Benefits and Drawbacks*.

During as well as towards the end of the programme, many women commented on both its perceived beneficial as well as problematic facets. Regarding the programme's benefits, some participants stated that certain elements had helped them reflect on their own lives and put things into perspective. As White Rose, who had participated both in 'Art and Laughter for Wellbeing' as well as reading autobiographical accounts of breast-cancer sufferers, put it:

> *Most of the* [health-related autobiographical accounts] *I've been able to relate to because of recently recovering from cancer. It's made me look at my life over the last 18-24 months and realise it's been one of the most stressful in my life and I wonder if that has contributed if not caused my cancer. It has also made me reflect on my life and I am currently in the process of making life changes to have a less stressful life because health is far more important.*

(Page 11, lines 232-238)

White Rose's resolve to take stress-reducing measures in order to improve her health and quality of life as a result of the programme is a desirable outcome and in line with the aims of the intervention.

569

Pink Fern, who too had participated both in 'Art and Laughter for Wellbeing' as well as reading autobiographical accounts, also felt that her participation in the programme had helped her put things into perspective, which she was grateful for:

> *Now the 8 weeks have gone by quickly I wanted to officially say thank you to* [the researcher] *for helping me put things in order in my head. I have enjoyed the past 8 weeks and have definitely gained something from it. Sometimes it made me really sad and upset but other times it made me accept things I hadn't done. Having an outsider tell me things I think I knew has put things in perspective.*

(Page 3, lines 51-56)

A shift in perspective had also occurred for Yellow Jasmine, who had taken part in the intervention condition which only entailed reading autobiographical accounts:

> *The whole experience of this emotional health exercise has definitely been very emotional for me. It has had me in tears sometimes when I have been answering - a good thing maybe when you feel it's better to let it out than hold it in! It has made me realise how privileged I am to have such good friends and family.* […] *I have total respect and admiration for the people in the group or in the health stories who have battled through and are able to talk about their experiences in the hope of helping others. I feel quite humbled when I read what they have gone through.*

(Page 6, lines 131-140)

Both Pink Fern and Yellow Jasmine described feeling upset as a result of certain issues discussed on the programme, but overall they experienced an improvement at the end of the intervention. This corresponds to findings by Pennebaker and Seagal (1999), who suggested that writing about traumatic experiences tends to make people feel unhappier in the hours after writing. However, they also emphasised that these emotions can be viewed as appropriate to the topics the individuals are confronting, which are usually

570

traumatic in nature. Pennebaker and colleagues' research on expressive writing discovered that usually when questionnaires were administered to participants at least two weeks after the studies, participants in the experimental group reported being as happy, or happier than, controls. It thus appears that worsening of negative emotions is only a temporary effect, which is to be expected when confronting distressing and traumatic memories. It should therefore not interpreted as a negative outcome.

White Fern who, like White Rose and Pink Fern, had taken part in all elements of the intervention, stated that taking part in the CEPB had resulted in a shift of focus on living, rather than dying, as well as thinking more about her own needs:

> *I have enjoyed doing the project, it has helped me focus on living and not dying, and help me reflect on what I need and not what I want. Thank you.*

> (Page 21, lines 449-451)

This shift in focus from dying towards living in White Fern could be viewed as a shift from hopelessness towards hopefulness. As mentioned above, hopelessness, one of the features of the 'breast-cancer prone' personality, has been found to be associated with shorter survival times in breast cancer than the presence of a 'fighting spirit' (Greer, Morris and Pettingale, 1979), while a positive outlook on a difficult situation tends to have psychological benefits because it acts as a stress buffer (Eschleman, Bowling and Alarcon, 2010). Therefore, White Fern's change in focus is most likely to be associated with positive health outcomes, in addition to psychological benefits.

Purple Holly, who had been in the autobiographical accounts-only condition, reflected on the usefulness of the programme in that it made her more aware of taking care of herself:

> *I don't think it has made me think differently about health and illness, but more aware of taking care of myself, talking more openly about things, and more importantly, letting go of issues that necessarily don't need to take up thought time. Overall it's made me more aware, for which I'm very grateful.*

571

> *I'm sorry the programme has come to an end as I've got a lot out of it, even though*
>
> *I may not have been as prolific as other Hollies!*

(Page 6, lines 128-131)

Taking more care of oneself and talking more openly about issues are both outcomes that correspond to a reduction in 'breast-cancer prone' behaviours, namely self-sacrifice and emotional suppression. Therefore, it is likely that these outcomes for Purple Holly were associated with not only psychological improvements, but also beneficial health outcomes.

It was also felt by some that the programme was helping or had helped with venting negative emotions and improving emotional wellbeing. As Pink Fern explained during the programme:

> *Just had to let you know that laughter does work.* [Laughter] *has certainly made*
>
> *me feel so much better and lifted my mood. When all this is over will have to try*
>
> *and remember that, thx xxx*

(Page 31, lines 661-667)

Pink Fern's experience of the benefits of laughter is mirrored by findings in the literature, indicating that a sense of humour is related to improved mood status when faced with stressful life events (Martin and Lefcourt, 1983). Unfortunately, it is unknown whether Pink Fern applied this stress-reduction technique in the long run, after the end of the study.

Like many other participants, Purple Holly had used her blog to write about issues that worried her, and felt that the process of writing them down helped her to let go of these worries:

> *I'd never would have thought to write a blog and it's such a good idea to offload the*
>
> *little niggles that need letting go. What am I going to do now? I feel as if I'm ending*
>
> *a therapy session!! lol*

(Page 17, lines 294-297)

Both women's favourable experiences correspond to the aim of the CEPB to aid the improvement of psychological wellbeing by encouraging the expression of negative emotions, and to assist with stress reduction through the use of humour.

Purple Ivy, who had been part of the autobiographical accounts-only condition, explained how she believed that interventions focusing on the connection between emotional and physical health should become part of the services offered by the NHS:

> […] *it seems to me that there is money in research for new drugs, new treatments, the kind of thing that is all bells and whistles, that will make the drug company a fortune as and when it works but there is not so much money out there for research into already known drugs like aspirin (a big long term randomised, placebo controlled trial is needed but no-one will fund it because no-one will make anything out of it in the long run except those whose lives are saved of course), or foods, or the role of emotions because there is no money in the outcomes. Actually in the whole area of emotions it could even end up costing more because our dear old NHS* […] *would then have to look to helping people with emotional need, psychological need much earlier. I so do think the role of emotional health is under recognised and I suppose getting the recognition is a start, with a view to putting programmes in place for the long term.*
>
> (Page 14, lines 273-286)

Despite these positive comments, one woman talked about barriers to participation. These involved the perception that other members were not active enough, and being too tired to create any postings:

> *When I first joined up for this I came onto the site and found that nobody else had posted, so this put me off a bit. By the time I come home from work, I am so tired that I haven't got the energy to think about some of the topics on here.*

<div align="right">(Red Rose, page 1, lines 8-9)</div>

Barriers towards participating in an online forum in the form of fatigue and physical unwellness have also been reported by other studies (Im and Chee, 2006; Im, 2006). In the present study, however, this was only reported by one participant. On the whole, participants' experiences of the programme were predominantly reported as positive.

1.7.1 Sub-Theme 6a: Expectations

At the beginning of the programme, many participants wrote about their expectations of the CEPB. Primarily, these entailed hopes of receiving support as well as helping others in a similar situation. Where individuals expected to gain something from the programme, they hoped to receive support with stress-coping or bereavement-coping. Red Daisy had recently become a full-time carer for her elderly mother and wrote:

> *Perhaps I can pick up some tips on coping with my changed life from reading of the experiences of others visiting this forum.*

<div align="right">(Page 1, lines 22-23)</div>

Another participant hoped to get the opportunity to talk about losing her father:
> *There was much I needed to say to my father in the last few months of his life, that because of his terrible condition, heart failure and kidney problems I could not bring myself to add to his hurt. Taking part in this project may help me in that respect. I can at least get a few things off my chest.*

<div align="right">(Purple Jasmine, page 2, lines 40-43)</div>

Pink Blossom wished to come to terms with her grandmother's death:
> *I was very close to* [my grandmother] *and I know I have never fully come to terms with her death. Maybe contributing to this research will help.*

<div align="right">(Page 1, lines 9-11)</div>

Although many women had signed up for the programme with the hope of obtaining support with their grieving process or with stress coping, two women voiced their desire to help others in a similar situation to theirs through their participation. Yellow Jasmine explained:

> *I'm looking forward to taking part in this research and maybe helping others in the future.*

<div align="right">(Page 1, lines 16-17)</div>

Yellow Blossom stated similarly:

> *I hope taking part in this might help as other people will understand more about the effects of bereavement.*

<div align="right">(Page 1, lines 14-15)</div>

These women hoped that their contributions would help lead to new knowledge, which would be of benefit for others in the long run.

It was grieving for her late husband that Yellow Fern needed support with, but she hoped to extend the same support to others:

> *My reason for joining this project is to help me through the grieving process and hopefully I may be able to support others in the same or different circumstances.*

<div align="right">(Page 2, lines 31-33)</div>

Thus, the expected benefits of the CEPB included both giving and receiving support. As mentioned above, it has been observed in research on Internet support forums that some users tend to give advice and support rather than receiving it, thereby facilitating communication among group members (Winefield, 2006). There appears to be a desire

<div align="right">575</div>

for some individuals to support others, which is clearly a valuable asset for a programme designed to increase social support.

1.7.2 Sub-Theme 6b: Benefits and Drawbacks

During the course of the programme, most participants reflected on the perceived benefits which the blogs and message boards held for them. Perceived benefits comprised of the interaction with the facilitator, privacy, and facilitating reflection and decision-making. Perceived drawbacks concerned the discussion of negative emotional issues leading to a temporary increase in emotional discomfort.

The interaction with the facilitator (i.e. the author of the present thesis), through her contribution of replies and comments to all blog and message board postings, was perceived as helpful by some participants. One woman commented on the facilitator's contributions to her blog:

> *I have quite enjoyed writing this diary and I have found the* [facilitator's] *comments quite useful and thought provoking!*
>
> (Orange Iris, page 13, lines 278-279)

Similarly, Red Blossom found the facilitator's comments on her blog postings useful:
> *Thank you for all your responses to my blog, it's been really helpful to know that someone was willing to listen to me and offer helpful advice.*
>
> (Page 26, lines 415-416)

The advice and support offered by the facilitator during the course of the intervention seemed to be useful to participants. For example, in response to advice offered by the facilitator to access the social support available in her environment, Green Rose wrote:
> *Thank you for your note* [facilitator]. *I will see if I can go out with a friend*.

Another participant wrote about her father dying on the penultimate day of the intervention. After the facilitator had offered to keep her blog available for a longer period of time, she responded:

> *Thank you for keeping the blog open for me for a bit longer. My dad's funeral is on Thursday*.

As outlined in Chapter Six, the facilitator's interaction with participants was based on Roger's (1951) core conditions of person-centred therapy. Among these are the principles of therapist-congruence, whereby the therapist is deeply involved in and draws on her own experiences to facilitate the relationship; unconditional positive regard, which entails that the therapist accepts the client unconditionally, facilitating self-regard in the client; and therapist empathic understanding, which means that the therapist has an empathic understanding of the client's internal frame of reference. Lambert and Barley (2001) claimed that core conditions such as empathy, warmth, and the therapeutic relationship have been shown to correlate more highly with clients' outcome than specialised treatment interventions. This underlines the importance of a good therapeutic relationship when considering a particular client's experience of an intervention. It is possible that the interaction between facilitator and participants was perceived as helpful due to the facilitator's adherence to person-centred principles.

A further positive aspect mentioned by participants was privacy. One woman explained that she had kept a public blog in the past, but preferred the fact that the blog she was keeping on the CEPB Web site was private:

> *I think I do prefer that this blog is private. I find it very hard to express myself in person (especially about personal issues) but I feel I can explain my thinking better*

> *in writing. However if I knew that my friends and family might read it then I*
>
> *definitely wouldn't be honest in what I was writing; I always find I'm trying to hide*
>
> *my true self from them.*

(Red Blossom, page 11, lines 222-226)

She thus felt that the privacy of her blog, with only the facilitator and herself being able to read the entries, allowed her to express herself more freely and honestly. As pointed out above, the discrepancy between private self and social self is likely to be high in an individual with a 'breast-cancer prone' personality. Red Blossom's blog afforded her with an opportunity to reveal more of her private self to the facilitator, which in turn enabled the facilitator to foster a therapeutic relationship with her.

The third perceived positive element constituted the blogs' and message boards' potential to aid reflection and decision-making. Blog and message-board postings appeared to help participants see situations in a different light, and make difficult decisions which they had been mulling over for a while. Towards the end of the programme, Pink Fern reflected on the experience:

> *All of the emotions have made me think a lot... sometimes upsetting me and other*
>
> *times putting things into perspective… It also made me realise that no matter how*
>
> *bad things seem to have been or are for me there are others out there for whom*
>
> *things are way way worse, it's been a kinda kick in the pants… […] Have enjoyed*
>
> *the questions and can't believe that it's nearly all over...*

(Page 30, lines 636-646)

Red Ivy's participation in the programme seemed to have facilitated the decision to leave her marriage:

> *I have explored my options for leaving our home, and plan to make a new start*
>
> *next month. […] I feel strong & galvanised in my decisions, and just hope I don't hit*

> *too many hurdles along the way dealing with the paperwork and finances. Wish*
>
> *me luck...*

<div align="right">(Page 1, lines 22-23 and page 4, lines 82-84)</div>

The same was the case for Blue Daisy:

> *I have made plans to move out and divorce [my husband]... this operation has*
>
> *given me a life changing experience where I realise I only have 1 life and I need to*
>
> *live it...*

<div align="right">(Blue Daisy, page 3, lines 50-52)</div>

Both women had blogged about their ongoing marital problems. During the course of the programme, they made life-changing decisions. Although it is not clear whether they actually carried out their plans, it is possible that making these decisions alone was beneficial, in that it gave them with hope for the future.

Despite these perceived positive aspects there were also some perceived drawbacks. Mainly, as mentioned earlier, some women felt that writing about emotional events such as bereavement temporarily worsened their emotional wellbeing. After posting on the 'Art and Laughter for Wellbeing' message board, White Daisy wrote:

> *Have just written about the song that makes me emotional on the other part of the*
>
> *site and it has made my emotions go a bit frazzled.*

<div align="right">(Page 2, lines 37-39)</div>

Pink Blossom had written about losing her grandmother, which left her feeling sad:

> *Have just completed my first responses and feel a little sad now. Am going to visit*
>
> *my grandmother's grave tomorrow and plant some flowers around it.*

<div align="right">(Page 4, lines 87-88)</div>

While participating in 'Laughter for Wellbeing', Red Daisy found it difficult to contribute a humorous anecdote, as participants had been asked to do. She found that this worsened her mood:

<div align="right">579</div>

> *Just thinking about trying to find something funny to report has had the opposite effect and pulled me even further down this week as it's made me realise just how long it is since I found anything even mildly amusing.*

> (Page 17, lines 392-394)

In a similar vein, two women explained how they avoided blogging when they were already experiencing negative emotions, because they felt that this would exacerbate their negative feelings:

> *I had put off posting this week as I was really wanting to be more positive* […]*.*

> (Green Rose, page 6, line 120)

Pink Fern remarked similarly:

> *Sorry not to have been blogging like I should…stuck my head in the sand and waited for things here to improve.*

> (Page 29, lines 691-692)

Orange Daisy avoided contributing a personal memory relating to anger, because she was concerned that this would exacerbate her existing feelings of anger:

> *I deliberately didn't post last week because the subject was Anger and I've been so cross just lately its unreal. And every time I come on here and start writing the words seem to spew from my fingertips rather like now! So here I stop for today.*

> (Page 3, lines 55-58)

Thus, there were some temporary negative effects associated with emotional expression through blogging and message board postings. This is most likely due to the temporary deterioration observed in individuals who write about traumatic and distressful events, as described above. Still, it did not deter these participants from returning to the Web site to continue their participation, indicating that overall the perceived benefits most likely outweighed the discomfort experienced following their contributions. Overall, more positive effects were reported than negative ones, indicating that blogging and participating in the message board discussions seemed to benefit participants on the whole.

1.7.3 Theme 6 Summary

Participants generally experienced their participation in the intervention programme positively, recounting how it helped them put situations into perspective, vent negative emotions and thus improve emotional wellbeing. Their interaction with the researcher as well as with each other was experienced as positive and helpful, highlighting the importance of a strong therapeutic relationship in the person-centred sense. Barriers to participation were nevertheless also mentioned by one participant, concerning health problems and low energy levels which prevented her from visiting the CEPB Web site more often. These barriers have also been observed in previous studies. Several benefits as well as drawbacks of participating in message board discussions and blogging were pointed out. On the whole, however, both forms of participation were perceived as helpful.

1.8 Conclusions and Implications

Participants brought a variety of bereavement-coping and stress-coping strategies with them into the CEPB. Not all of these were adaptive, and a significant proportion of women admitted to not coping well with bereavement and/or stressful life events. Furthermore, only few women were trying to abandon or had successfully abandoned the 'breast-cancer prone' patterns they reported. The combination of these factors made it clear that the intervention was warranted and that these women needed support in dealing with distressful events effectively. In line with this, despite the initial exacerbation of emotional distress mentioned by several participants, they generally experienced their participation in the CEPB positively. The programme achieved its intended aim of allowing women to vent negative emotions and thereby improve emotional wellbeing. Despite the relatively large number of participants with whom the researcher had to interact simultaneously, a therapeutic relationship developed with many women. However, it is thinkable that having more than one facilitator on the programme would have allowed for more participants to form such a therapeutic relationship, and thus benefit more. Future studies may need to

have more than one facilitator, in order to be able to devote more time and resources to individual participants.

Some women mentioned fatigue acting as a barrier to more frequent participation. This has also been observed in previous Internet forum studies. However, it is unknown if there were other factors preventing women from participating more. This is especially true for those who dropped out or who never participated after being emailed their log-in details.

The mixed views of the connection between psychological and physical health that emerged make it clear that women needed to receive more and better-quality information about the complex relationships between breast-cancer risk factors. Few women were aware of the multifaceted complexity of the aetiology of this disease. Instead, they either endorsed or critiqued a simplistic cause-and-effect relationship. The researcher made efforts to inform participants of the current level of knowledge in this area. Still, it seems that paradoxically, the autobiographical accounts, which intended to educate women about the role of psychosocial factors in breast-cancer development, actually seemed to convey a simplistic relationship to many participants: the protagonists of these accounts often described their breast cancer to be attributable to a few psychosocial variables, without acknowledging potential physical risk factors. It may have been prudent to provide a more balanced view by, for example, interspersing these autobiographical accounts with accounts that made explicit mention of physical risk factors.

The dissatisfaction which women reported with the care they had received from health-care professionals, be it in the wake of being bereaved or a diagnosis of severe illness, draws attention to the need for more emotional support, empathic understanding and sensitivity in professionals' consultation styles. A patient-centred consultation style is much more likely to lead to good communication and greater patient-satisfaction than a doctor-centred style (e.g. Jenkins and Fallowfield, 2002), and thus to higher-quality care.

More work needs to be carried out to educate and train health-care professionals in communicating with patients in an empathic way. Health psychologists need to get much more involved in both designing and delivering such training.

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Appendix H: Paper Copy of Online Member-Checking Questionnaire

Dear Madam,

Last year, you took part in the 8 week Emotional Health programme, developed by Judith Eberhardt, PhD student at Teesside University.

I am currently writing up the results of the study, and have come up with a number of topics or themes which were common among participants. I would like to ask you to look at these and indicate if you can relate to or identify with any aspects of each theme. This is important because I need to check how well these results reflect participants' experiences. It should only take 5-10 minutes.

The answers you give will only be seen by me, the researcher of this study, and will remain completely confidential. Your name will be removed and replaced by an identification number for further data analyses, which will be anonymous.

If you decide at a later stage that you would prefer to withdraw your answers, you can email me at: j.eberhardt@tees.ac.uk.

Thank you very much for your time and effort.

All the best,

Judith Eberhardt, MSc, PhD Student
School of Social Sciences and Law, University of Teesside, Borough Road, Middlesbrough TS1 3BA

1. Consent
    ( ) I hereby confirm that I am a woman aged 18 years or older and that I live in the UK. I consent to taking part in this study. I am aware that I can withdraw from the study at any time.

2. Could you please provide your email address here (please ensure that it is the same email address that you used to sign up for the project):

    _____

3. Please type your email address again:

    _____

4. If you remember, please type the personal flower name that you were assigned for the programme (e.g. "Red Rose", "Blue Holly", etc.)

    _____

Below you will find descriptions of 8 themes I found while analysing the message board and blog posts all participants created. I would like to ask you to look at these and indicate if you can relate to or identify with each one of these descriptions. Thanks!

5. Coping with bereavement

Many women described different ways of coping with losing their loved ones.

Some of these ways of coping were seen as helpful, while others were not.

Some women said that they did things to help them avoid cope with their loss. Others tried to carry on as normal in the wake of their loved one's death, or to accept their loss. Some said that they felt empty inside.

Getting used to life without their loved one was difficult for some. One big regret that some women felt was that they did not get the chance to say good-bye to the person who passed away. Then, there were some who described a lack of opportunity to grieve their loss, because they had so many other things to attend to (e.g. organising the funeral, selling their house).

Can you relate to any aspects of this description?
      ( ) Yes
      ( ) No
      ( ) Maybe

6. Do you have any other comments?

      _____
      _____
      _____
      _____
      _____

7. Stress Coping

Most women described how they coped with stressful situations and life events. For some, maintaining a positive frame of mind, even when faced with stressful events, helped. Others said that they had support from friends and family when times got tough. Many women expressed how important laughter and humour were to them. However, some women described difficulties coping with stress and at times felt overwhelmed.

Can you relate to any aspects of this description?
      ( ) Yes
      ( ) No
      ( ) Maybe

8. Do you have any other comments?

        _____
        _____
        _____
        _____
        _____

9. Traumatic Childhood Events

Distressful childhood events were reported by some participants, which included events such as sexual abuse and the loss of a parent or grandparent. Some women's parents had demanded or encouraged them to keep their negative emotions to themselves when they were children; these emotions mainly included anger and sadness.

Can you relate to any aspects of this description?
        ( ) Yes
        ( ) No
        ( ) Maybe

10. Do you have any other comments?

        _____
        _____
        _____
        _____
        _____

11. Personality

In many participants' descriptions of themselves, distinctive personality patterns emerged. These included difficulties with getting angry or expressing anger, feeling guilty much of the time, putting others' needs before one's own, and feeling helpless and unable to change certain life situations.

 Can you relate to any aspects of this description?
        ( ) Yes
        ( ) No
        ( ) Maybe

12. Do you have any other comments?

        _____
        _____
        _____
        _____
        _____

13. The role of psychological factors in health and illness

Participants had different beliefs regarding the role of psychological factors in the development of health and illness. Some were sceptical if there really was a connection between emotional and physical health. Others did believe in this connection and even reported how they experienced physical problems as a result of emotional stress.

Can you relate to any aspects of this description?
     ( ) Yes
     ( ) No
     ( ) Maybe

14. Do you have any other comments?

     _____
     _____
     _____
     _____
     _____

15. Advantages and disadvantages of being a woman

Some women wrote about the experience of being a woman, and how they believed that certain aspects of being a woman influenced how they experienced the world. There were positive and negative sides to being a woman. While femininity had positive aspects such as nurturing and caring for others, it was also felt that women often occupied a secondary role, particularly in the family hierarchy or workplace.

Can you relate to any aspects of this description?
     ( ) Yes
     ( ) No
     ( ) Maybe

16. Do you have any other comments?

     _____
     _____
     _____
     _____
     _____

17. Experiences with health care professionals (GPs, consultants, counsellors etc.)

Many women wrote about their experiences with health care professionals and governmental agencies in the context of using services for the treatment of physical and/or psychological problems as well as seeking financial or job seeker support. Positive and negative experiences were talked about. Some women felt that they did not receive enough support from health care professionals in dealing with severe illness, bereavement or mental health problems. Others felt well supported.

Can you relate to any aspects of this description?
     ( ) Yes
     ( ) No
     ( ) Maybe

18. Do you have any other comments?

_____
_____
_____
_____
_____

19**.** Experiences of the Emotional Health programme

Most participants commented on their experience of this programme, describing which aspects of the programme they found useful and beneficial, and which less so. At the beginning of the programme, many participants wrote about what they expected of the intervention. Some women hoped to receive support in coping with bereavement, as well as helping others in a similar situation. During the course of the programme, most women commented on the aspects of the programme that they liked, and those they didn't like. Some women described how they enjoyed interacting with the researcher, the privacy of the blog, and the way in which the programme helped them to think about and become aware of certain issues in their lives. Some also talked about how they sometimes felt temporarily worse after writing about an emotional experience.

Can you relate to any aspects of this description?
     ( ) Yes
     ( ) No
     ( ) Maybe

20. Do you have any other comments?

_____
_____
_____
_____
_____

Thank you very much for your effort and time to participate in my study and complete the questionnaire. If, for any reason you feel you would like to discuss certain issues from this questionnaire or the programme with me, then please do not hesitate to email j.eberhardt@tees.ac.uk.

Appendix I: Dissemination of Project

Abstract of Guest Lecture for MSc Health Psychology Module 'Current Issues in Health Psychology, Teesside University, November 2009 (See Appendix J for Full Lecture)

Psychosocial Factors of Breast Cancer

Guest lecture by Judith Eberhardt

Research increasingly points to psychosocial factors as being influential in the aetiology and progression of cancer generally, and breast cancer in particular. What role can health psychology play on this important issue?

Suggested reading:

Greer, S. and Morris, T. (1978). Study of psychological factors in breast cancer – problems of method. *Social Science and Medicine, 12,* 129-134.

Greer, S., Morris, T. and Pettingale, K.W. (1979). Psychological response to breast cancer: effect on outcome. *Lancet, 2,* 785-787.

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Abstract of Poster Presented at Vitae Public Engagement Competition in Newcastle-upon-Tyne, April 2010, and at Teesside University Subject Enrichment Conference, June 2010 (See Appendix J for Poster)

Improving Women's Emotional Health through the Internet – a New Approach to Preventing Illness?

In my PhD project, I am examining links between emotional and physical health in women. There is scientific evidence to suggest that emotional health and physical health are connected. For example, bereavement (having lost someone close to you) has been linked to the development of breast cancer. Other factors, such as not talking about one's feelings when sad or angry, stressful life events, not dealing well with stress, and not receiving enough support from other people, have also been linked to poor physical health and conditions such as breast cancer. In my project, I am developing an online programme for women in the UK aged 18 or older, who have experienced the death of a loved one (it could be a family member, a friend or a pet) and would like to share their experiences with other women and me, the researcher. All women will take part in the programme through the Internet, on a website designed for this project. It will involve elements designed to improve women's emotional wellbeing (e.g. art and laughter for wellbeing, expressive writing). The aim of the programme is to enhance women's emotional wellbeing, which will hopefully contribute positively to their physical and overall wellbeing.

Abstract Accepted for 24th European Health Psychology Conference in Cluj, Romania, September 2010 (author was unable to present)

Poster presentation: The effects of an electronic bereavement coping enhancement programme on the psychosocial breast cancer risk profile of bereaved women

Objectives: The occurrence of and inadequate coping with stressful life events such as bereavement, certain personality features, and low social support have been associated with breast cancer. However, there is a lack of studies targeting these factors simultaneously as a strategy for breast cancer prevention. The present study aims to evaluate the effects of an electronic bereavement coping enhancement programme on the psychosocial breast cancer risk profile of bereaved women.

Methods: two hundred and sixteen participants will complete a psychological screening form. A 3×2 independent measures randomised controlled trial will be carried out. Independent variables are reading (or not reading) health-related autobiographical accounts, and participation in an online psychological group intervention (art-and-laughter for wellbeing, laughter-and-art for wellbeing, or no intervention). Dependent variables are bereavement coping, stressful life events coping, presence of certain personality features, and level of social support.

Results: Three feasibility studies were carried out to assess validity, reliability of scales, usability of the psychological screening form and project website, and bereavement coping. Seventy-eight percent of participants had experienced bereavement, of which 33% reported maladaptive coping.

Conclusion: There is a clear need for an intervention targeting psychological factors in breast cancer development. Results of the study will be presented.

Abstract of Presentation for Social Futures Institute Seminar, Teesside University, April 2011 (See Appendix J for Full Presentation)

The Development of an Electronic Bereavement-Coping-Enhancement-Programme as Part of Breast-Cancer Prevention

Despite the evidence supporting the role of psychosocial factors in the development of cancer, prevention tends to focus exclusively on physical risk factors. The occurrence of stressful life events (in general and bereavement in particular), maladaptive coping with stressful life events, Type C personality features, and low social support have been consistently linked to breast cancer. There is a lack of studies targeting these factors simultaneously as a strategy for breast cancer prevention. Recently, digital media have become an important tool of communication in health care, providing a strong rationale for online interventions. Another previously unexplored way of raising awareness of psychosocial risk factors is the reading of autobiographical accounts of people who have suffered from breast cancer. The aim of the present study is to evaluate the effects of an electronic bereavement coping enhancement programme and reading autobiographical accounts, on bereaved women's psychological profile.

Appendix J: Contents of the CD-ROM

File/Folder Name	Description
\content analysis \content analysis\pre.pdf \content analysis\post.pdf \content analysis\followup.pdf	Coded coping styles, measured before intervention, after intervention and at follow-up
\control group questionnaires \control group questionnaires\ pre.pdf \control group questionnaires post.pdf \control group questionnaires\ followup.pdf	Questionnaires administered to control group before intervention, after intervention and at follow-up
\dissemination	Material relating to dissemination of project: presentations and poster
\dropout questionnaire \dropout questionnaire\questionnaire.pdf	Questionnaire administered to participants who dropped out during the intervention
\pilot study 1 face validity \pilot study 1 face validity\face validity.pdf	Data collected for establishing face validity of scales
\pilot study 2 questionnaires \pilot study 2 questionnaires\questionnaires.pdf	Version A and Version B of the psychological screening tool used in pilot study 2
\pilot study 3 questionnaire3 \pilot study 3 questionnaire\questionnaire.pdf	Questionnaire used to evaluate intervention Web site in pilot study 3
\qualitative data \qualitative data\GROUP 1 \qualitative data\GROUP 2 \qualitative data\GROUP 3 \qualitative data\GROUP 4 \qualitative data\GROUP 5 \qualitative data\GROUP 6 \qualitative data\GROUP 7 \qualitative data\GROUP 8 \qualitative data\GROUP 9	Raw data collected from intervention group participants through blogs and message board postings, organised by intervention group
\quantitative data \quantitative data\data files \quantitative data\followup analysis \quantitative data\internal consistency \quantitative data\postintervention analysis	Raw data files and SPSS output for post-intervention analysis, follow-up analysis, and analysis of internal consistency of scales
\reflexive diary and bracketing \reflexive diary and bracketing\diary.pdf	Reflexive diary kept during the intervention and bracketing carried out before the intervention
\removed themes \removed themes\being a woman.pdf \removed themes\traumatic childhood events.pdf	Themes removed from thematic analysis following member checking
\Web site \Web site\links.pdf \Web site\pages \Web site\posting tutorial.pdf	Materials used on intervention Web site List of links provided to participants Copies of the main pages of all sub-sites in HTML format Tutorial displayed on intervention Web site, showing participants how to create and respond to postings