

Breast Self-Examination: The Effects of Autobiographical Accounts and a Multimedia Support Programme on Women's Knowledge, Beliefs and Behaviour

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Declaration

During my registration as a candidate for a PhD, I hereby declare that this thesis is entirely my own work, and has not been submitted to any other institution as part of any award.

Abstract

Each year more than 44,000 women are diagnosed with breast cancer and more than 12,000 of these die from the disease. These mortality rates are relatively high compared to the rest of Europe (Berrino et al., 2007; Mayor, 2003), which in part is due to the advanced stage of the disease at first presentation (McCready et al., 2005; Sant et al., 2003). Regular breast self-examination (BSE) can facilitate early detection (Cancer Research UK, 2008), yet it is not widespread. Identifying the motivational and contextual factors is likely to lead to the development of effective interventions as part of being 'breast-aware'. This is particularly important given that mammography screening may not be effective (Crossing & Mansezewicz, 2003) or recommended for younger women (Cancer Research UK, 2008) and that BSE may be beneficial in offering women the opportunity to create a positive relationship with their body. This study considered the utility of a proposed Extended Health Belief Model (E-HBM) as a framework for understanding women's knowledge, beliefs and behaviour. It sought to develop a new way to provide guidance and to encourage BSE by investigating the effect of autobiographical accounts of breast-cancer patients and a multimedia BSE support programme comparing video-enhanced or static guided instructions. The study adopted a 2x2 mixed methods design and 60 white British women aged between 19 and 67 participated. Analysis of Covariance revealed an interaction effect of autobiographical accounts and BSE support on BSE frequency and proficiency and regression analyses examined the utility of the E-HBM, with confidence being the main predictor. Moreover, thematic analysis elicited five themes; Previous Experience, BSE Irregularity, Perceived Susceptibility, Coping Style and The Usability of the 5 Step Model of BSE. The study concludes that the 5-step technique encourages BSE through creating a more pleasant experience, as women form an improved relationship with their breasts. Both the video-enhanced and static BSE supports are effective in terms of encouraging BSE and the effect of autobiographical accounts appears to be dependent on the type support. The practical implications and direction for future BSE interventions are discussed.

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Abbreviations

ACS	American Cancer Society
ANCOVA	analysis of covariance
ANOVA	analysis of variance
BAAPS	British Association of Aesthetic Plastic Surgeon's
BSE	breast self-examination
CBE	clinical breast exam
DHA	Defensive high-anxious
E-HBM	extended Health Belief Model
GHLC	God Health Locus of Control
HA	High-anxious
HBM	Health Belief Model
HBMS	Health Belief Model Scale
HLC	Health Locus of Control
IES	Impact of Events Scale
IMIQ	Implicit Models of Illness Questionnaire
IPQ	Illness Perception Questionnaire
IPQ-R	Revised Illness Perception Questionnaire
IPQ-RH	Revised Illness Perception Questionnaire Healthy Edition
LA	Low-anxious
M-C	Marlowe-Crowne Social Desirability Scale
MHLC	Multidimensional Health Locus of Control
NABCO	National Alliance of Breast Cancer Organisations
NSSQ	Norbeck Social Support Questionnaire
R	Repressors
RIES	Revised Impact of Events Scale
STAI	State Trait Anxiety Inventory

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CHAPTER ONE

Introduction

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1.0 Chapter Overview

Breast cancer remains a problem within the UK, with each year more than 12,000 women dying from the disease. Early detection aided by screening, decreases the mortality associated with breast cancer (Green & Taplin, 2003) and allows for more treatment choices if breast cancer is found (Allen, Van Groningen, Barksdale & McCarthy, 2010). Breast self-examination (BSE) is one of the means to aid the early detection of breast cancer but at present it remains a matter of controversy. This chapter provides an overview of breast cancer and current breast-cancer screening guidelines and discusses the utility of BSE. Following this, the current study's aims and rationale are presented and an overview of the subsequent thesis chapters is provided.

1.1 Breast Cancer and Breast Screening: an Overview

The incidence of breast cancer across the world has tripled in the past thirty years and is expected to double again by 2030. In 2008 there were 1.4 million new cases of breast cancer and 460,000 deaths (Smith, 2011). Breast cancer is the most common cancer in women in the UK (McPherson, Steel & Dixon, 2000). Each year more than 47,000 women are diagnosed and more than 12,000 of these die from the disease. The lifetime risk of developing breast cancer in the UK has risen to one in eight and there are 1 million new cases in the world each year (Cancer Research UK, 2008; McPherson et al., 2000; Wise, 2011). The risk of breast cancer has an age incidence increasing dramatically after the menopause; however, 8,000 women are diagnosed under the age of 50 each year (Cancer Research UK, 2008).

Despite improvements in both detection and treatment methods, breast-cancer rates have increased more than 50% in the last twenty years and 12% in the last ten (Cancer Research UK, 2008). Lifestyle factors and having a family history of the disease increase the risk of developing breast cancer (Smith, 2011) and the 'million women study'

estimated that 11% of breast cancers in the UK are caused by alcohol and 7% accounted for by obesity (Travis, Reeves, Green, Bull, Tipper, Baker et al., 2010). With the rising obesity and hazardous drinking rates in the UK (The NHS Information Centre, 2011) and the fact that people are living longer than ever before, breast-cancer rates may be expected to rise further.

The mortality rates in the UK are relatively high compared to the rest of Europe (Berrino, Sant, Rosso, Lasota, Coebergh & Santaquiliani et al., 2007; Mayor, 2003), which in part is due to the advanced stage of the disease at first presentation (McCready, Littlewood & Jenkinson, 2005; Sant, Allermani, Capocaccia, Hakulinen, Aareleid, Coebergh et al., 2003). It is well documented that early presentation of breast cancer improves the outcome (Hermon & Beral, 1995; DoH 2000; Mayor, 2003) and it is also a remit of the National Health Cancer Plan (DoH, 2000) to detect cancers earlier by raising public awareness. Although more women do consult earlier with breast cancer than other cancers, there is evidence to show that women are still not breast-aware (Bailey, 2000; DoH, 2000). Early detection aided by screening, decreases the mortality associated with breast cancer (Green & Taplin, 2003) and allows for more treatment choices if breast cancer is found (Allen et al., 2010).

Screening for breast cancer can encompass breast awareness, BSE, clinical breast exams (CBE) and mammography. None of the screening tests are 100% sensitive in detecting breast cancer, suggesting a recommendation for a combination of these techniques to be used in the screening process. In the UK, women are encouraged to be breast-aware from the age of 18, when the majority of female breasts have undergone mature development, and are invited to attend routine mammograms every three years as part of the National Screening Programme from the age of 50 to 70 years. Although the incidence of breast cancer is lower among women under 50 years of age, tumours that are found in younger women tend to be more aggressive and are associated with lower

survival rates (Kothari & Fentiman, 2002; Kroman, Jensen, Wohlfahrt, Mourridsen, Anderson & Melbye et al., 2000; Shannon & Smith, 2003). As a result, other detection methods are required for younger women. The American Cancer Society (2009) recommends younger women examine their breasts regularly so that they can become familiar with how they look and feel normally, and as a result any changes can be more readily detected and reported. Similarly, the American Congress Obstetricians Gynaecologists (2009) recommends the use of BSE as a tool for breast-cancer screening, stating that palpable lesions can be detected through BSE. However, in the UK, a strategy of breast awareness is recommended whereby women are encouraged to become familiar with their own breasts through looking and feeling for any changes from normal and reporting any obvious changes promptly (Austoker, 2003). These changes women are advised to look and feel for are depicted in figure 1.



Image removed

*Figure 1: Breast changes to look and feel for. Taken from *Your Breasts, Your Health: A Quick Guide to Being Breast Aware* (p.5-7), by Breast Cancer Care, 2011.*

Breast awareness, as a concept, is not always clear due to its confusion with BSE; BSE being the mechanistic examination of the breasts to detect an abnormality and breast awareness referring to a general examination with no structure or routine. Rather than ritually checking their breasts at a specific time according to a set technique, following breast awareness, women are encouraged to take convenient opportunities such as bathing or dressing to become familiar with their breasts (Austoker, 2003). Regular BSE according to the 5-step model (a structured BSE guide consisting of five specific steps incorporating both looking and touching the breasts in particular ways as presented in Appendix 6) has been promoted by breast-cancer campaigns in the past as one of the means to the early detection of breast cancer and to give individuals the best chance to fight the disease and, according to the US National Breast Cancer Foundation (2009), up to 70% of breast cancers are found by women performing their own BSE.

BSE is an in-expensive, non-invasive procedure that can be performed by non-medically trained individuals without the aid of expensive machinery (Elmore, Armstrong, Lehman & Fletcher, 2005; Kearney & Murray, 2009), and, in doing so, women can gain a sense of control over their own health (Allen et al., 2010). Likewise, BSE may be beneficial as part of breast awareness, in increasing a woman's awareness of their breasts and providing them with the opportunity to form an improved relationship with their breasts.

Despite these recommendations and the benefit of BSE as part of breast awareness it has been documented that regular BSE is not practised frequently (Cancer Research UK, 2008; Manasciewicz, 2003) for reasons such as lack of time, a perception that the procedure is complicated to perform, the fear of finding a lump, women's lack of confidence in the accuracy in their technique and women's lack of understanding what they were looking for (Agars & McMurray, 1993; Williams, Mahoney & Williams, 1998).

1.2 The Utility of Breast Self-examination

The medical profession have called the utility of BSE into question because findings from retrospective studies have not shown the expected benefits of the procedure (e.g. Semiglazov, Moiseyenko, Manikhas, Protsenko, Kharikova, Popova et al., 1999; Semiglazov, Moiseyenko, Protsenko & Kharikova, 1996; Semiglazov, Sagaidak, Moiseyenko & Mikhailov, 1993; Thomas, Gao, Ray, Wang, Allison, Chen et al., 2002; Thomas, Self, Allison, Tao, Mahloch, Ray et al., 1997; UK Trial of Early Detection of Breast Cancer Group, 1993, 1999). These studies conducted large trials within the UK, Russia and Shanghai, China, and failed to provide evidence of reduced breast-cancer mortality. Moreover, BSE did not appear to affect the survival rate or stage of detection and it resulted in more benign biopsies in the intervention groups.

The UK trial was part of a larger trial looking at mammography and CBE screening too and one of the goals of the trial was to assess the effect of BSE promotion on mortality. The trial recruited approximately 190,000 women, aged 45-64 years, from the patient lists of general practitioners in eight geographic areas. It was non-randomised and population based. In the BSE intervention part, women in the cities of Nottingham and Huddersfield were invited to one BSE class. Results released after 16 years of follow-up did not show a reduction in mortality for the BSE groups.

The WHO/Russia trial recruited approximately 193,000 women, aged 40-64 years, from two large cities (Moscow and St Petersburg) and randomised them, by cluster, into the intervention and control groups. The women in the intervention groups received standardised BSE education in groups at their workplace (Moscow) or at their routine annual check-up (St Petersburg). The primary goal of the study was to evaluate the impact of BSE on mortality. Results released after a 12-year follow-up (St Petersburg only) did not demonstrate a significant reduction in mortality associated with BSE.

The Shanghai trial randomised over 266,000 women aged 31-64 years, by factory or employment, into the BSE or control groups. The women within the BSE group received BSE instruction, reinforcement and competency checks. The goal was to assess the effect of BSE instruction on mortality. After 11-year follow-up, there was no significant difference in the mortality rate of women in the BSE group compared with the control group.

The results of these trials were widely reported in the academic and lay literature as evidence that BSE does not have any benefit for women's health and may even harm women by causing unnecessary diagnostic follow-up and anxiety. On this basis, UK health authorities omitted systematic BSE from their breast-cancer campaign and instead promote the 'be breast aware campaign' (NHS, 2011).

However, these studies suffer from several methodological flaws relating to the study population, the generalisability of their findings and the potential for exposure misclassification, all of which may limit the interpretation of the results (Kearney & Murray, 2009; Varghese, Wilson, Penberthy & Smith, 2006). None of the trials evaluated the practice of BSE on breast-cancer mortality, instead the effect of BSE teaching and encouragement was evaluated (Kearney & Murray, 2009). Only the China trial was truly randomised and therefore, confounding variables, such as difference in breast-cancer incidence and treatment rates may have influenced the results in the UK and Russia trials.

Further problems are posed when considering the BSE instruction employed in the trials. BSE instruction was poor in the UK and Russia trials; only one class was offered to the UK women, and these classes were poorly attended (31% and 53% of the women invited attended in the two communities studied) and in the Russia trial, only the women in the St Petersburg group received any individual instruction in BSE. Moreover, for both the UK and Russia trials, reinforcement in the teaching of BSE was poor or did not occur at all. All three trials were based on the premise that instruction or encouragement would result in

good BSE but practice was not measured in any of the trials. Expecting to see breast-cancer mortality rates drop significantly after teaching women BSE (sometimes only once) may be quite optimistic and unlikely (Kearney & Murray, 2009).

Furthermore, the researchers had to rely on self-report measures which are subject to report bias. Despite the measurement of the competency of BSE practice within the China trial, it is not possible to determine if women did BSE proficiently at home or even engaged in it at all. Moreover, breast cancers found by the Chinese women during BSE were classified separately from those found by women 'accidentally' such as while they were bathing or dressing (Thomas et al., 2002). This poses a problem considering these 'accidental' finds may have been facilitated by BSE. As a result of the study BSE, the women within the China trial may have become more familiar with how they look and feel normally and this may have allowed them to detect changes 'accidentally' whilst bathing or dressing. Without the knowledge and increased awareness gained through BSE, such changes may not have been so readily noticed. Classifying BSE and 'accidental finds' as two separate behaviours may have greatly diminished the ability to show a mortality reduction (Kearney & Murray, 2009).

Moreover, compliance to BSE practice was low or not measured sufficiently within all three trials. In the UK community, in which this was evaluated, less than one half (47%) reported to do BSE after one year. In Russia, only 18% of the women were practising BSE at four years and 34% were lost in the follow-up at nine years (Kearney & Murray, 2009) and in Shanghai only 49% of women were still attending supervised BSE sessions at year five. Perhaps the failure to find a reduction in mortality was a result of the women's lack of compliance with BSE.

Further problems are posed when one considers the majority of women in the Russia and China trials were premenopausal and as such would be expected to have higher mortality

rates (once the disease has developed) than older women (Ringash and Canadian Task Force on Preventive Health Care, 2001). Tumours found in younger women, although less common tend to be more aggressive and associated with lower survival rates (Kroman et al., 2000). The trials failure to find a reduction in mortality following BSE may have been impacted by the high rate of pre-menopausal women included within the trial.

Based on these methodological considerations it may be erroneous to abandon BSE as an efficacious method for the prevention of breast cancer. Indeed, China trial investigators themselves state in their published report that it should not be inferred from their trial that there “would be no reduction in risk of dying from breast cancer if women practise BSE competently and frequently” (Thomas et al., 2002). Given the low attendance, low compliance, young sample and high breast-cancer mortality rates, it has been suggested that studies would have to be very large, with a longer follow-up to detect even a small change in mortality (Kearney & Murray, 2009). Taking this into consideration, policy makers should not rely solely on data obtained from poor randomised controlled trials, and particularly not without considering the impact of any methodological weakness.

Moreover, whilst the currently adopted ‘be-breast-aware’ campaign holds strength in promoting awareness, it may be problematic considering that many women express concern over the accuracy of a procedure that involves just looking and feeling their breasts (Williams et al., 1998). Especially, considering that small and large breasts require a slightly different tactile examination and, without knowledge of this, large-breasted women may fail to examine their entire breasts and small-breasted women may express concern over apparent lumps which may simply be their rib bone. Women need a clearly structured or systematic approach which they can follow with ease and which gives them the confidence necessary to observe and examine their breasts correctly. The 5-step model of BSE may provide this confidence and was used in this study to promote, encourage and teach BSE.

Others have called for an end to the routine teaching of BSE, suggesting BSE is in fact harmful to those individuals engaging in it. Rather than reduce deaths, they argue it simply increases unnecessary biopsies and anxiety (Baxter, 2001). It does, however, need to be considered that a breast biopsy is not performed solely based upon the detection of a lump during BSE. A breast biopsy will likely only occur after a medical professional's evaluation, which will include at the least a thorough CBE and, in most cases, mammographic assessment (Varghese et al., 2006). Research suggests that women understand false alarms are an inevitable part of a larger programme to detect breast cancer early and one should not presume on their behalf that these harms are intolerable, given the aim of early detection (American Cancer Society, 2001). The potential harm is likely to be nominal within the overall scope of cancer prevention and should be minimised by women's appropriate consultation with their GP after detecting a breast change through BSE (Varghese et al., 2006). Furthermore, whilst it is apparent that mammography can provide a useful technique for most women engaging in it, it too is not free from problems. Its effectiveness among women under 50 years of age is a matter of controversy (Lechner, De Nooijer & De Vries, 2004; Vahabi, 2005). Its sensitivity may be lower in premenopausal women, making it a less effective screening test because of their dense breast tissue. On X rays, dense breast tissue appears white as does cancer, meaning a small tumour may go undiscovered. Thus, a greater proportion of breast cancers in younger women may not be detectable with screening mammograms alone. Moreover, high rates of false negative and false positive mammograms have been reported for women in their forties (Vahabi, 2005). As a result, additional tests to follow up these results may be needed and increased anxiety may result.

Cancer charities such as *breastcancer.org* have expressed their concern over guidelines recommending that women not perform BSE and further suggest that following such guidelines could seriously endanger women's health and lead to later detection of breast

cancer in some women (Weiss, 2008). Early detection is not only crucial to the survival of a patient but to her quality of life. Early detection for many could mean not having to lose a breast through mastectomy or not having to experience aggressive chemotherapy (Weiss, 2008). Le Geyte, Mant, Vessey, Jones and Yudkin, (1992) observed more than 600 women for six years and reported an increased survival of women regularly performing BSE. Likewise, other studies have reported that the performance of BSE may result in the detection of smaller primary tumours which, in turn, may allow more conservative surgery (Hill, White, Jolley & Mapperson, 1988; Koibuchi, Lino, Takei, Maemura, Horiguchi, Yokoe et al., 1998).

It should further be noted that NHS mammogram screening rounds take place every three years. Several studies have illustrated that in the period between breast-cancer screening rounds, a considerable number of new cancers are detected, the so-called interval cancers (Chart & Franssen, 1997; Hislop, Worth, Kan & Rousseau, 1997; Lechner et al., 2004). It can be assumed that BSE may be the only way that most women younger than 50 can determine that they have cancer and after this age BSE may detect the tumours that mammography did not pick up. Therefore, regular BSE may be an important tool, in order to self-detect cancers that have developed in younger women and in between mammogram rounds. Based on these considerations, it may be erroneous to abandon BSE as an efficacious method for prevention of breast cancer.

BSE is a complex procedure which is not easy to do properly according to both researchers and health professionals (Haji-Mahmodi, Montazeri, Jarvandi, Ebrahimi, Haghghat & Harirchi, 2002). This may be one reason for the controversy surrounding BSE. Another reason may be the heterogeneity in the way BSE is taught (Funke, Krause-Bergmann & Nave, 2008). Funke et al. (2008) suggest it is necessary not only to inform and to instruct women professionally and intensively, but also to ensure long-term

compliance. There is a need for BSE to be taught properly in order to understand what procedures are being performed and to understand fully the reliability of studies on BSE.

1.3 Rationale for the Current Study

Early detection aided by BSE can decrease the mortality associated with breast cancer and allow for more treatment choices if breast cancer is found. Yet regardless of health promotion, research (as discussed in the early stage of this chapter) highlights that not all women are assessing their breasts on a regular basis. For that reason, it is important to gain an understanding of women's knowledge, beliefs and behaviour related to breast cancer and BSE. A review of the literature surrounding BSE (presented in Chapter Two) indicates that worry/anxiety, coping style, illness representations, health locus of control (HLC) and social support may influence BSE behaviour and a model based on the Health Belief Model, but with these components incorporated to form an extended HBM (E-HBM) was developed. Consequently, a framework for understanding women's knowledge, beliefs about and behaviour related to breast cancer and BSE was formed to enhance the scientific understanding of a women's decision to engage in BSE or not.

Research (as discussed in the early stage of this chapter) and exploratory work (as discussed in Chapter Five) highlights a major issue preventing women from examining their breasts is their lack of knowledge regarding how to examine their breasts and a lack of confidence in their own ability to conduct a proficient exam. At present women are provided with little instruction to ensure a thorough breast exam, yet providing the necessary knowledge and education to perform BSE competently and confidently may encourage women to examine their breasts comprehensively and ensure long-term compliance. Although treatment success is high for cancers detected, opportunities to effectively identify and treat breast cancer may be lost when information about BSE is severely lacking or confusing to understand, or when current methods fail to provoke

interest within the female population. There is a need for BSE to be taught properly in order for women to understand what to do and to feel confident enough to do so, and this instruction needs to be provided in a clear and concise manner. Research (as discussed within Chapter Three) suggests that a multimedia BSE programme may elicit an interest in those women not currently engaging in BSE at all or regularly, and teach them the skills needed to perform BSE in a clearer and perhaps more enjoyable way.

Furthermore some women may neglect to examine their breasts because of a lack of perceived vulnerability to breast cancer or because of misconceptions connected to the disease. Viewing autobiographical accounts of breast-cancer patients may provide the motivation perhaps needed to engage in regular BSE. Through finding recognition within the stories women may become alerted to their own vulnerability to developing breast cancer and become motivated to take preventative action. If autobiographical accounts could alleviate some of the psychological barriers to performing BSE, then these might be an important tool that could be applied in breast-health promotion campaigns.

Finally, the past decade has seen a tremendous increase in Internet use and computer-mediated communication (Fox, Rainie, Larsen, Horrigan, Lenhart, Spooner et al., 2001; Nie & Erbring, 2000; Nie, Hillygus & Erbring, 2002), yet little is disseminated widely about the practical issues associated with their use and their effectiveness for data collection, especially within a research setting.

1.4 Aims of the Study

In line with this rationale and based on the previous literature discussed in this chapter and chapters two to four, this study had the following aims.

Aim 1: to enhance the understanding of women's knowledge, beliefs and behaviour regarding breast cancer and BSE both before and after an intervention within the framework of an extended HBM (E-HBM).

Aim 2: to explore the effects of viewing autobiographical accounts from breast-cancer patients on women's knowledge, beliefs and behaviour towards breast cancer and BSE.

Aim 3: to examine the usability and effectiveness of a novel multimedia BSE support programme, based on the 5-step BSE technique, and comparing video-enhanced or static guided instructions. Both methods aim to develop women's skills of using BSE techniques, as well as their knowledge through the use of performance enhancement tools, such as images within the static support or video and interactivity within the video-enhanced support.

Aim 4: to evaluate the effectiveness of online data collection and the use of blogs as a recording and communication tool.

The specific research questions and hypotheses for the current study based on these aims are described in Chapter Six.

1.5 Structure of the Thesis

The material in this thesis is organised into eight chapters. Following the introduction in Chapter One, Chapter Two provides an overview of the literature surrounding BSE and relevant variables associated with its practice. It identifies that, in addition to the Health Belief Model (HBM), worry/anxiety, coping style, illness representations, HLC and social support may be related to BSE practice and, therefore, proposes an extension of the Health Belief Model as a framework for understanding women's knowledge, beliefs about and behaviour related to breast cancer and BSE behaviour. Chapter Three reviews the literature surrounding autobiographical accounts, multimedia programmes and online data

collection. It considers the potential of autobiographical accounts and multimedia programmes in influencing women's beliefs and behaviour towards breast cancer and BSE, and explores the utility of conducting research within an online setting. Chapter Four presents an overview of the risk factors to breast cancer and demographic variables that may be important when considering BSE practice and considers the effect these may have on BSE behaviour. Chapter Five provides an overview of an exploratory qualitative study conducted in the early stages of the research and discusses the implications of the study findings, particularly in relation to the main study. The exploratory study provides positive feedback about the 5-Step BSE Technique that is the basis for the BSE material used in the main study, and highlights the utility of teaching or providing women with the necessary skills to perform BSE in order to increase and encourage BSE behaviour among all women. Chapter Six describes the method employed in the main study and presents the research questions, aims and rationale of the study. Chapter Seven presents the quantitative and qualitative outcomes of the study and considers the utility of the proposed extended Health Belief Model (E-HBM) to explain BSE. The E-HBM is amended based on the findings discussed in this chapter and a revised E-HBM is presented. Finally, Chapter Eight summarises and discusses the research findings in relation to relevant literature and highlights the contribution to knowledge and recommendations for future work.

1.6 Chapter Summary

Within this chapter, an overview of breast cancer and current breast-cancer screening guidelines was provided and the utility of BSE discussed. Breast cancer as an illness was introduced, and the lack of appropriate knowledge and successful interventions to encourage breast-screening highlighted. Following this, the current study's aims and rationale were presented and an overview of the subsequent thesis chapters provided.

CHAPTER TWO

Conceptual Framework

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2.0 Chapter Overview

If one could encourage women to regularly self-examine their breasts, more cases may be detected early and ultimately fewer may die from the disease. It is important therefore to gain an understanding of the psychosocial predictors of breast self-examination (BSE) among women. This chapter reviews the literature surrounding BSE and, based on this, proposes an extension of the Health Belief Model (HBM) as a framework for understanding women's knowledge, beliefs and behaviour regarding breast cancer and BSE behaviour.

2.1 The Health Belief Model

The HBM is a psychosocial model that attempts to explain the relationship between preventative health behaviour and health beliefs (Rosenstock, Strecher & Becker, 1988). It outlines six psychological dimensions that are believed to be important in the prediction of an individual's decision to perform a health-protective function (as depicted in Figure 2): perceived susceptibility, perceived seriousness, perceived benefits, perceived barriers, health motivation, and confidence (self-efficacy). According to the HBM, when individuals are faced with a potential threat to their health they consider their susceptibility to and the seriousness of the health threat and their belief that the health condition can be controlled or avoided. For example, women who perceive themselves to be susceptible to breast cancer and believe it to be a serious disease that can be controlled or avoided are more likely to be motivated to take action against it. Which action is pursued is seen to be a function of a cost-benefit analysis of the perceived benefits of, and perceived barriers to different actions. For example, women who believe that performing BSE has many benefits and there are few barriers to performing it are more likely to engage in regular BSE. In addition, a woman's degree of interest in or concern about her own health may also affect her willingness to perform BSE.

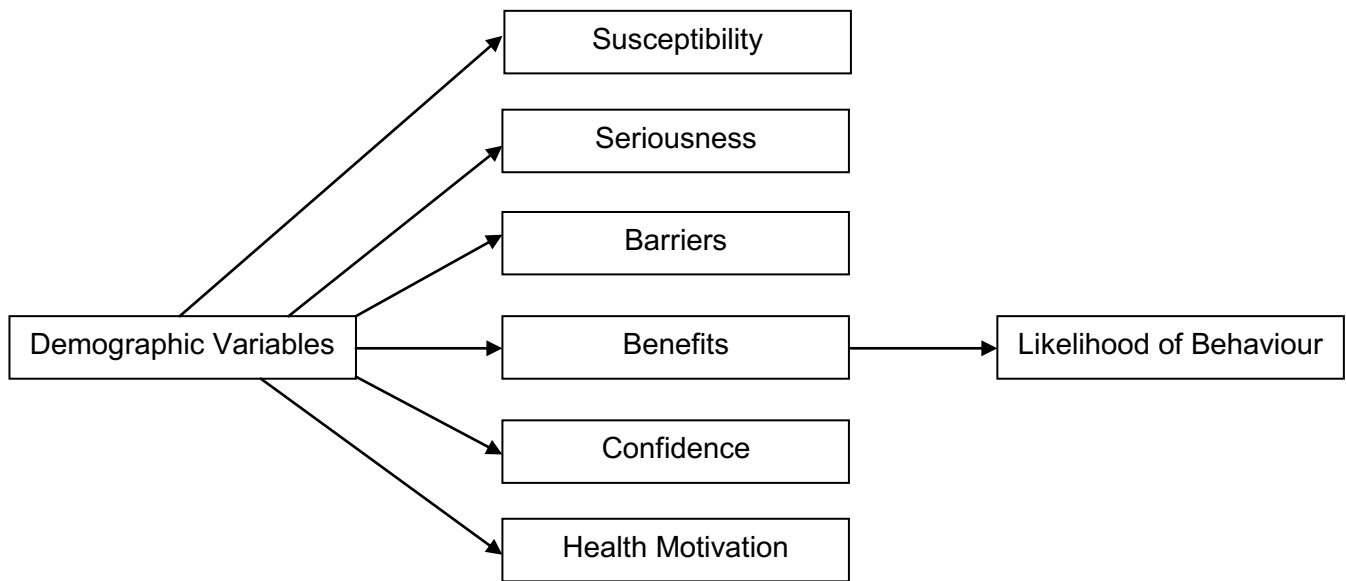


Figure 2: The Health Belief Model

The HBM has been used to successfully predict many health behaviours, including BSE in various populations (Calnan & Rutter, 1986; Champion, 1984; Foxall, Barron & Houfek, 1998; Karayurt, 2003; Lee, 2003; Lu, 2001; Norman & Brain, 2005; Petro-nustus & Mikhail, 2002; Ronis & Harel, 1989; Umeh & Rogan-Gibson, 2001) and research findings have indicated that all six dimensions of the model are significantly associated with BSE (Ashton, Karnilowicz & Fooks, 2001; Champion, 1993; Champion & Menon, 1997; Gray, 1990).

However, because the HBM is a psychosocial model, it accounts for only as much of the variance in health behaviours as can be explained by attitudes and beliefs that are obvious to and consciously evaluated by individuals. Other individual differences, such as demographic characteristics, personality factors, social support or previous health experiences, may also influence behaviour (Janz & Becker, 1984; Poss, 2001). This study takes this into account, considering the utility of an extension of the HBM. This extended model uses the components of the HBM as well as other constructs derived from relevant

literature (including anxiety, worry, coping style, illness representations, health locus of control and social support) to advance the scientific understanding of a woman's decision to engage or not engage in BSE.

2.2. Worry/Anxiety and Coping Style

Many women worry about breast cancer, which is hardly surprising given the attention that advocacy groups, celebrities, health professionals and the media have devoted to the disease (Blanchard, Erblich, Montgomery & Bovvbjerg, 2002; Burke, Olsen, Pinsky, Reynolds & Press, 2001). Some researchers have suggested that this worry may have benefits, promoting women to engage in self-protective behaviours such as BSE whilst others have proposed that this worry results in screening avoidance.

Studies targeting 'breast-cancer worry' (for example, Diefenbach, Miller & Daly, 1999; McCaul, Reid, Rathge & Martinson, 1996; McCaul, Schroeder & Reid 1996; McCaul, Branstetter, O'Donnell, Jacobson & Quinlan, 1998) have suggested that, worry is positively related to breast-cancer screening behaviour (BSE included). Rather than worry inhibiting screening, the opposite may be true, with women who report higher levels of worry reporting higher levels of screening behaviour (Diefenbach et al., 1999; McCaul et al., 1996a; McCaul et al., 1996b; McCaul et al., 1998). Similarly, McCaul et al. (1998) report that the level of self reported worry, baseline intrusive thoughts and daily self-monitoring thoughts all relate positively to reported BSE and intentions to perform BSE.

The generalisability of the findings in these studies is, however, questionable. One may suggest the sample of women used in these studies is unrepresentative of society in general. Diefenbach et al.'s (1999) sample of women was predominantly Caucasian, well-educated (either college or postgraduate level) and married. Whilst McCaul et al.'s (1996a; 1996b & 1998) samples consisted of both single and married women, they again failed to consider ethnicity and educational level. McCaul et al.'s (1996b) sample

consisted of predominately well-educated women (86.5%) and ethnicity was not noted, whilst McCaul et al. (1996a; 1998) failed to note both the educational level and ethnicity of their sample. This poses a problem given that a relationship between ethnicity (Champion & Menon, 1997; Foxall et al., 1998; Friedman, Moore, Webb & Puryear, 1999; Wardle, Steptoe, Smith, Groll-Knapp, Smith & Brodziak, 1995), educational level (Epstein, Lin, Audrain, Stefanek, Rimer & Lerman, 1997; Erblich, Bovberg, Valdimarsdottir, 2000; Friedman et al., 1999; Han, Wells & Primas, 2003; Madan, Barden, Beech, Fay, Sintich & Beech, 2000) and screening behaviour has been established.

Further problems are posed considering that half of McCaul et al.'s (1998) sample consisted of undergraduate psychology students and participants were rewarded for participating with either extra class credit or cash. This poses a problem with the individual's autonomy or freedom to choose whether or not they wish to participate, and the representativeness of the sample, again compromising the study's findings.

It is unclear whether the observed levels of worry or indeed its effect on screening behaviour would be similar to those exhibited by different groups of women and therefore generalisations must be limited to the particular group of women recruited for each of the studies. Indeed, McCaul et al. (1996a) themselves note that their sampling procedure may have missed those women who are most fearful of breast cancer, as such persons might not even consider participating in a study of this kind. It is important to note though, that women who may be considered to be the most fearful, those with high fear and a family history of breast cancer showed no hint of screening avoidance in their study.

Others have proposed that worry about breast cancer is problematic, both because of the distress it causes individuals and also because it causes screening avoidance (Kash, Holland, Halper & Miller, 1992; Lerman, Daly, Sands, Balshem, Lustbader & Heggan et al., 1993; Lerman, Kash & Stefanek, 1994). Using standardised instruments, Kash et al.

(1992) found that women who perceived their risk as high, had high anxiety and felt they could do little about developing breast cancer were less compliant with BSE, regular clinical breast examinations (CBE) and other preventative behaviours. Mean levels of psychological distress (measured using the Brief Symptom Inventory) among these women exceeded normal ranges by almost one standard deviation. Higher anxiety was directly related to poor attendance at a CBE and poor adherence to monthly BSE. Furthermore, the women in their study with the lowest levels of anxiety and perceived vulnerability were the ones who performed BSE monthly.

Similarly, but in relation to mammography, Lerman et al. (1993) found that psychological distress variables were associated strongly with non-adherence to age-specific screening guidelines. Women who did not adhere to mammography guidelines had significantly higher sum scores on the Intrusion Subscale as well as on several individual items. For example, 68% of women who had frequent intrusive thoughts about breast cancer adhered, as opposed to non-adherence in 83% of those who rarely or never had these thoughts. Also, adherers and non-adherers were distinguished by their responses to the items on breast-cancer worries: 59% of women who reported breast-cancer worries that interfered with their daily functioning adhered as opposed to 83% without such worries. It appears that serious breast-cancer worries (i.e., those which interfere with daily functioning) may pose a potent barrier to adherence to recommended screening guidelines. Women who had such worries in Lerman et al.'s (1993) study had an odds of mammography adherence that was about 2.5 times lower than that in women without such worries.

Any association between psychological distress and breast-cancer-screening practices may, however, vary depending on the psychological instrument used and the study population it is used on. Lerman et al. (1994) noted variations in this association in their study. Intrusive thoughts (as measured by the Revised Impact of Events Scale, RIES,

Horowitz, Wilner & Alverrez, 1979) showed an inverse association with mammography adherence; that is non-adherers had higher levels of intrusive thoughts than women who had adhered. Contrastingly, women who had not had a mammogram in the past year had lower levels of breast-cancer worries compared to those who had received one.

Interestingly, none of the generalised distress measures (i.e. Brief Symptom Inventory, Mental Health Inventory, or Profile of Mood States) were found to relate to mammography adherence. In relation to BSE, Lerman et al. (1994) found two psychological variables to be associated with BSE frequency. Levels of generalised psychological distress were highest among women who never practised BSE or practised less than once a month, compared with women who practised once per month or more. By contrast, levels of intrusive breast-cancer thoughts were highest among women who practised excessively.

It does, however, need to be considered that the different psychological instruments were employed on a varied sample of women. The authors recruited three samples of women from three different cancer centres and therefore the variation between the methods employed to recruit these women (i.e. self-referred versus population-based) as well as between and within sample variation made it difficult to draw conclusions about the associations between psychological factors and screening behaviour.

Moreover, similar methodological considerations as discussed previously for the positive 'worry/anxiety' relationship also need to be considered for these studies. The samples of women making up these studies were predominately white, well educated and had a family history of breast cancer. Again, this poses a problem given the relationship between ethnicity (Champion & Menon, 1997; Foxall et al., 1998; Friedman et al., 1999; Wardle et al., 1995), educational level (Epstein et al., 1997; Erlich et al., 2000; Friedman et al., 1999; Han et al., 2003; Madan et al., 2000) and screening behaviour.

Likewise, women who are at increased risk for breast cancer due to their family history may experience worry or anxiety differently from women with less risk. Indeed, Lerman et

al. (1994) revealed that the majority of the women in their study reported their perceived risk to be higher than average. Furthermore, the women in Lerman et al.'s (1993;1994) studies had family members living with breast cancer at the time of the study and thus may have been distracted from concerns about their personal breast-cancer risk because of the emotional and practical demands of having an affected relative. This is supported, in part, by Lerman et al.'s (1993) finding that rates of adherence were significantly lower among women who had a relative diagnosed within the past year. These considerations limit the interpretation of these studies.

Another point worth considering for both the positive and negative association studies is that most researchers have measured worry on a single occasion in the context of breast cancer, for example before or after screening. These are not everyday occurrences and responses in such contexts may exaggerate the worry that women commonly experience (McCaul et al., 1998). Daily self-monitoring may tell us more about the thoughts that cause women to worry and how much they worry over time and may also provide more detailed information about relationships between worry and other variables – relationships that may be affected by the measurement context, perhaps resulting in a clearer idea of the worry-screening relationship.

Similarly, a descriptive study can address the methodological questions raised by the diverse 'worry' measures employed in this area. Investigators have used different measures of worry, including scales formed from a few investigator invented items and scales with better known psychometric properties (e.g. Kash et al., 1992; Lerman et al., 1993; Lerman et al., 1994). Researchers have also used measures that emphasise thought (for example, the RIES, Horowitz et al., 1979), but also measures that focus on affect (for example anxiety). The literature on cancer-related fear, worry, or anxiety and screening behaviour is frequently contradictory, perhaps because of the diverse measures in the field. It is important to know how these scales relate to each other, how stable the

scale measurements are over time, whether they predict day-to-day worries and how they relate to screening behaviour.

McCaul et al. (1998) from a purely descriptive perspective provided results about the content of thought on breast cancer and what prompts these thoughts. They suggested that most thoughts about breast-cancer centred on risk, both one's own and the risk of family members and friends. Those thoughts about risk, which the women reported to be somewhat bothersome, extended less frequently to even more emotionally compelling thoughts about fear of cancer, death from cancer and the prevalence of breast cancer. On average, participants recorded seven thoughts during the week, although as noted by McCaul et al. (1998), this is probably overstated, as the study itself served as a frequent prompt of breast-cancer thoughts and indeed thoughts connected to the study made up 22% of the 'breast-cancer' thoughts. Still, participants noted many other potent cues, including the media, just talking with others or observing others with cancer. McCaul et al. concluded this high frequency of thinking about breast cancer, although exaggerated by the study itself, likely reflects the daily experience of many women confronted with many triggers to thinking about the disease.

McCaul et al. (1998) further addressed issues in 'worry' measurement. Specifically, they reported baseline summary judgment measures of worry to be significantly related to self-monitoring and phone interview measures and highlighted a distinction between worry as affect and intrusive thoughts. It was the specific worry items that best predicted the bothersome of thoughts; the intrusive thoughts questionnaire was the best predictor of the number of thoughts. Furthermore, the authors stated that worry reporting is not highly related to trait anxiety and suggested that the worry judgement measures represent fair measures of worry that women experience daily about breast cancer per se.

Rather than the existence of a simple positive or negative association, others have alternatively suggested breast-cancer worries may exhibit a curvilinear relationship (Anderson, Smith, Meischke, Bowen & Urban, 2003; Lerman, Trock, Rimer, Jepson, Brody & Boyce, 1991). Lerman et al. (1991) suggested that women's reports of the impact of their breast-cancer worries exhibit a curvilinear relationship, suggesting women with moderate levels of worry are more likely to practise monthly BSE than women with either high or low levels. Further support for such a relationship is provided in a more recent study (Anderson et al., 2003), in which again intermediate levels of worry appear to be associated with modestly increased levels of screening use, over very low or very high levels of worry. Based on this finding, one may suggest that, while some level of concern about one's risk can be a motivator of screening use, high levels of worry provoke denial or other psychological effort to reduce distress, and these may prevent very worried women from engaging in screening behaviour

The interpretation of these results, however, needs to be taken with caution. Firstly, Lerman et al. (1991) assess breast-cancer worry using two items and BSE frequency by a single item. If instead validated scales had been used the reliability with which these constructs were measured may have improved. Secondly, the slopes of the curves hypothesised by Anderson et al.'s (2003) graphical data display are fairly flat. The differences in screening behaviour may not be statistically significant for those women in the high worry group, or of practical significance for the women in the moderate worry group. Therefore, limited conclusions of the presence of such a curvilinear relationship can only be drawn.

Research conducted over the past fifteen years has produced contradictory evidence concerning whether cancer worry facilitates or inhibits breast-cancer screening behaviours (BSE included), with evidence supporting both relationships (Consedine, Magai, Krivoshekova, Ryzewicz & Neugut, 2004a; Hay, Buckley & Ostroff, 2005). A number of

methodological issues may be contributing to these inconsistent findings. There has been wide variation in the way distress has been defined and measured across studies. Studies that have measured mild breast-cancer concerns/worries (e.g. “during the past month, how often have you thought/worried about your chances of developing breast cancer?”) have typically found that such concerns are associated with positive screening behaviour (Diefenbach et al., 1999; McCaul et al., 1996a; McCaul et al., 1996b; McCaul et al., 1998). In contrast, studies that have measured more severe cancer-related worries, (e.g. “during the past month, how often have your thoughts about breast cancer impacted on your mood?”) or cancer-related symptoms (e.g. the impact of events scale) have typically found that such distress is associated with negative screening behaviour (Kash et al., 1992; Lerman et al., 1993, 1994). Finally, studies that have measured general distress have found an association (Kash et al., 1992) or contrastingly no association with screening adherence (Diefenbach et al., 1999). Similarly, Davey (1993), in a methodological study of worry questionnaires, concluded that content-based worry (for example worry about a particular area, such as breast cancer) is constructive worrying whilst contrastingly, general worry, is more highly related to general anxiety and more predictive of avoidance coping. It appears the association between distress and screening behaviour may be partially dependent upon the type of distress that is measured (Lerman & Schwartz, 1993).

A further difficulty in interpreting the literature is the lack of prospective studies. In the vast majority of past studies, researchers have focused on the association between current distress, worry or anxiety and previous screening behaviour. Therefore, much of the data comes from cross-sectional designs and caution needs to be taken when interpreting the results. Regardless of the direction of any obtained relationship, such designs preclude strong conclusions about the motivating effects of worry, because screening itself can influence emotionality. Thus, for example, a positive relationship between worry and

screening behaviour could indicate that worry encourages action or that engaging in screening promotes worry thus making cross-sectional data difficult to interpret. Furthermore women's thoughts, knowledge and screening behaviour would be expected to change over time and should be examined longitudinally.

The two prospective studies that are available on the relationship between screening and worry (Diefenbach et al., 1999; Schwartz, Taylor & Willard, 2003) are, however, equally conflicted, with one suggesting improved screening at intermediate levels of worry (Diefenbach et al., 1999) and the other suggesting a negative relation between worry and screening behaviours (Schwartz et al., 2003). According to theory health messages (such as recommendations for breast-cancer screening) are processed both at a cognitive level and at an affective level (Diefenbach & Leventhal 1992; Leventhal, Diefenbach & Leventhal, 1992; Miller & Diefenbach, 1998). The specific cognitions and affects that are activated determine whether health messages facilitate or undermine health-related behaviours. In line with this, Diefenbach et al. (1999; in a self-referred sample of women attending a clinic for women at increased risk for breast cancer) found that specific worry about breast cancer assessed at baseline with the variables of prior screening use, perceived vulnerability, and general distress controlled, in addition to older age-predicted mammography adherence 12 months later. General anxiety, however, was found to be unrelated to a subsequent decision to undergo mammography.

Schwartz et al. (2003) sought to extend the results reported by Diefenbach et al. (1999) by prospectively evaluating the association between multiple distress measures (mild cancer worry, moderate cancer worry, cancer-specific distress and general distress) and mammogram use among a non-self referred sample of first-degree relatives of breast-cancer patients. Variables that independently distinguished women who received a mammogram from those who did not were; having had a mammogram in the past,

moderate cancer worries, and general distress. Specifically, women who had attended a mammogram in the previous year and those who reported less distress and cancer worry were more likely to obtain a mammogram in the 12 months following the baseline assessment. No significant association however was found between cancer-specific distress (as measured by the IES), mild worries and mammogram use. This may be due to two things. Firstly, although a valid and reliable measure of cancer-specific distress (Thewes, Meiser & Hickie, 2001), the IES has been shown to be highly skewed among women at risk for breast cancer (Cella, Hughes, Peterman, Chang, Peshkin, Schwartz et al., 2002; Halbert, Schwartz, Wenzel, Narod, Peshkin & Cella et al., 2004; Schwartz, Taylor, Willard, Siegel, Lamdan & Moran, 1996). This was certainly the case in this study, with 50% of the participants scoring at or close to zero on this measure. The authors do indeed address this issue by dichotomising scores on the IES, however as they themselves note it is possible that their failure to detect an association between the IES and mammography may have been related to the skewed distribution on this measure and their decision to dichotomise it (Schwartz et al., 2003). Secondly, in terms of mild worry, the measure used was slightly different from those used in previous research. The frequency of thoughts about breast cancer was assessed rather than the frequency of worries about breast cancer and as such may have measured participant's awareness of risk rather than the degree of worry they experienced.

The literature on cancer-related fear, worry, or anxiety and screening behaviour is growing. However, results are frequently contradictory, making it difficult to coherently interpret and thus develop practical solutions and interventions. The most salient problem confronting researchers interested in the role of emotions in screening behaviour is that they cannot determine exactly what women are afraid of, or how these diverse fear components relate to one another or to screening behaviour, with much research leaving the object of women's fear unspecified (Consedine et al., 2004a). Women's fears

surrounding breast cancer are likely to encompass many things, but evidently include fear of a breast-cancer diagnosis (Aro, de Koning, Absetz & Schreck, 2001; Austin, Ahmad, McNally, Steward, 2002; Bloom, Hayes, Saunders & Flatt, 1987; Ciatto, Cecchini, Isu, Maggi & Camelli, 1992; Friedman, Webb, Weinberg, Lane & Cooper, 1995), fear of the medical establishment (Bloom et al., 1987; Miller & Hailey, 1994; Vernon, Laville & Jackson, 1990), non-specific 'cancer worry' (Caplan, Helzlsouer, Shapiro, Wesley & Edwards, 1996; Consedine et al., 2004a; Edwards & Jones, 2000; Lagerlund, Hedin, Sparen, Thurfell & Lambe, 2000) and general anxiety (Edwards & Jones, 2000; Lauver & Chang, 1991) or phobia (Desai, Bruce & Kasl, 1999). It appears identifying which elements of cancer and the screening process that women are most afraid of and how this relates to subsequent screening behaviour is important.

Consedine et al. (2004a) offered a preliminary framework for organising how diverse fears and anxieties may relate to screening behaviour. Within this, they identified three distinct sources of anxiety: (a) fear of screening components, (b) fear of screening outcomes, and (c) undifferentiated cancer fear. Although these components are empirically separable, they suggested that they are likely to interact with each other. Noting this, Consedine et al. (2004a) suggested fear has diverse effects on screening behaviour, although they noted a generally inverse relation between fear specificity and likelihood of screening. In terms of screening outcome, the available results seem to suggest that undifferentiated fear or anxiety regarding getting cancer may generally be facilitative of screening, at least where the fear occurs within manageable limits and the target population has access to, and some faith in, the efficacy of the available screening procedures (Consedine et al., 2004a). Indeed, studies investigating non-specific worry and screening behaviour have tended to demonstrate a positive relationship (Consedine, Magai & Neugut, 2004b; Lagerlund, Hedin, Sparen, Thurfell & Lambe, 2000; Lauver & Chang, 1991; McCaul et al., 1998; McCaul et al., 1996a; McCaul et al., 1996b).

Conversely, however, fear of the medical establishment and fear that the procedure will prove embarrassing seem likely to deter screening, as does a fear of a breast-cancer diagnosis (Consedine et al., 2004a). Fear of negative outcomes appear to occupy a middle ground in terms of its impact on screening behaviour and as such, its role in generating or inhibiting screening behaviour may depend on the relationship between this type of fear and other fears (Consedine et al., 2004a). Consedine et al. suggest that more specific cancer-related worries enable and encourage coping strategies that do not involve screening and thus do not generate the same impulse to act that more generalized cancer worries do.

In many cases, specific fears may be about components of the screening process itself. For component-specific fears, Consedine et al. (2004a) suggested avoiding screening situations will reduce anxiety and the individual may be less likely to screen. In contrast, where the anxiety is about cancer itself or is more dispersed, they suggested that the feelings are more difficult to pin down and avoid. Acting to reduce this generalized cancer worry may, in many cases, involve engaging in a screening behaviour as individuals seek to reduce their anxiety (Consedine et al., 2004a). Whilst Consedine et al.'s (2004a) interpretations seem to offer an insightful framework into the relationship between worry and screening behaviours, these interpretations need to be taken as preliminary. More research into which aspects of cancer and the cancer screening process are clearly defined is needed. Without knowing the sources of women's fears, and their relationship to behaviour, providers and health professionals will be inevitably ill informed and interventions likely to be unsuccessful.

Similarly, examining the levels of cancer worry experienced by women might resolve the inconsistent role of cancer worry with regard to screening behaviour. In a study by Diefenbach et al. (1999) cancer worry was at a moderate level whereas the cancer worry

reported in Lerman et al.'s (1990, 1993) studies was at a level that interfered with daily functioning. Whereas moderate levels appear to motivate screening, high levels of screening may actually inhibit screening behaviour. Research tends to assume that the relationship between fear/anxiety/worry and screening behaviour is linear when, in fact, there are some grounds to suspect that the relationship may be more complex (Consedine et al., 2004a). It may be, for example, that moderate levels of anxiety induce preventive care behaviours (Diefenbach et al., 1999; McCaul et al., 1996a; McCaul et al., 1996b; McCaul et al., 1998), while too little promotes inactivity and too much (Lerman et al., 1990, 1993) promotes avoidance of both the anxiety and the settings that elicit it. Whilst there is, a lack of evidentiary support for this assumption, one recent study of 6512 predominantly Caucasian (97%) women demonstrated that women who described moderate levels of worry were more likely to have an annual mammogram than those who reported mild or severe levels (Anderson et al., 2003). The same may be true for BSE.

A further point that may need to be considered when interpreting the literature into screening behaviour and worry/anxiety is the component of breast-cancer screening investigated. It may be that the two components of breast-screening (mammography and BSE) may be quite different because BSE is largely under a woman's personal control, whereas mammograms are mediated by a woman's GP and by variables such as access. Indeed encouragement by GPs was an important factor influencing a women's intention to attend a mammogram (Lerman et al., 1991). Furthermore, as BSE is recommended monthly rather than yearly, it has the potential to generate more anxiety. In contrast, yearly mammograms have potential reassurance value, with previous research suggesting many women obtain mammograms to achieve peace of mind (Rimer, Kasper-Keintz, Kessler, Engstrom & Rosan, 1989).

Nevertheless, one thing the research does seem to agree on is the existence of a relationship between worry/anxiety and BSE. Whether the relationship is facilitating or

inhibitory, however, remains a matter of controversy. It appears that in order to gain a full understanding one must clearly define which aspect of worry/anxiety is of interest (whether it be general anxiety or worry connected to cancer or cancer-screening) and how this is to be measured. Taking this into consideration, the current study uses a general trait anxiety measure in the form of the STAI and a more specific measure in the form of a breast-cancer-worry scale. Secondly, it is possible that variables other than the ones assessed in the majority of these studies may moderate the impact of worry on screening. For example research has pointed to the role of individual differences in health information processing (Miller, Shoda & Hurley, 1996) as well as to the role of cultural beliefs on health-care use (Kleinman, 1980). Similarly, both ethnicity (Champion & Menon, 1997; Foxall et al., 1998; Friedman et al., 1999; Wardle et al., 1995) and educational level (Epstein et al., 1997; Erlich et al., 2000; Friedman et al., 1999; Han et al., 2003; Madan et al., 2000) may have an impact on the screening behaviour witnessed in such studies. This study considers this and attempts to control for such variables.

A more recent meta-analysis conducted by Hay, McCaul and Magnan (2006) supports the contention that breast-cancer worry is associated with a stronger likelihood of screening, and that this conclusion holds regardless of how cancer worry is measured or whether the screening outcome was BSE or mammography. Given these results, it may be suggested that arguments stating that worry generally inhibits screening behaviour are unsupported and that indeed the opposite conclusion better fits the results. Although the worry-screening relationship reported is small in terms of total variance explained, Hay et al. (2006) suggest it could have real practical importance in terms of worry increasing screening.

It is apparent from the literature that a relationship between BSE and worry does exist. Similarly, it seems plausible that women must cope with anxiety related to possibly finding an abnormality if they are to perform BSE monthly as recommended. Effectively managing

the anxiety related to BSE practice and how the individual goes about doing this (their coping style) may in turn affect their BSE behaviour. Therefore, this study includes worry/anxiety and coping style in its extension of the HBM.

Effectively managing the anxiety related to BSE practice may be more arduous for women with high trait anxiety because their trait anxiety level is reflective of habitual difficulties in managing anxiety. They may have limited capacity to tolerate the added emotional arousal induced by the threat of BSE practice. Women with low anxiety, however, may be better able to tolerate the added emotional arousal but not be motivated to perform BSE.

Not all highly anxious persons are aware of their anxiety. Based on the Freudian concept of repressive defences (Freud, 1957), repressive coping style is a personality trait by which persons habitually use strategies outside of their awareness to avoid negative affect and impulses that are threatening to the self (Weinberger, 1990). As a result, repressive copers experience high levels of trait anxiety but self-report low levels. Improvements in the operationalisation of repressive coping allow the researcher to differentiate between persons who are truly low anxious and those who repress their anxiety (Weinberger, 1990). By administering a measure of trait anxiety together with a measure of defensiveness (such as the Marlowe-Crowne Scale, Crowne & Marlowe, 1960), four coping-style groups can be differentiated: (1) Repressors, (2) True Highly Anxious, (3) Defensive Highly Anxious and (4) True Lowly Anxious. Women who self-report low trait anxiety due to defensive coping are categorised as Repressors and women who report this low trait anxiety but without defensiveness are categorised as True Lowly Anxious. With regards to high anxiety, women who report high trait anxiety without defensiveness are categorised as True Highly Anxious and those who report high trait anxiety which persists despite their use of defensiveness are categorised as Defensive Highly Anxious. These groups can further be used to explore coping style and how it relates to BSE thoughts and behaviour (Crowne & Marlowe, 1960).

Research into BSE and coping style particularly is limited. However, one such study into the area demonstrates a potential link to BSE. Kreitler, Chaitchik and Kreitler, (1990) examined repressive coping in two groups of women: one attending a free breast-screening clinic and the other electing not to participate in the free screening, and found compared with non-attendees, attendees scored higher on repressive coping. Although repressive copers avoid threatening information (Linden, Paulhus & Dobson, 1986), repressive attendees may not have expected to receive threatening information. Repressors' use of defensiveness to cope with anxiety may alter their perceptions of personal susceptibility to breast cancer, thus decreasing perceptions of threat and keeping anxiety related to screening behaviours at more manageable levels.

Similarly, Barron, Houfek and Foxall (1997) found that coping style did predict women's practice of BSE, in terms of both frequency and proficiency. Moreover, coping style predicted the following HBM components: barriers, confidence, seriousness and susceptibility, but not benefits or general motivation. Their results further indicated that True Highly Anxious women and women with True Low Anxiety reported practising BSE significantly less often than did Repressive and Defensive Highly Anxious women. This decreased BSE frequency may be a way for the Highly Anxious women to avoid the anxiety associated with BSE practice. Additionally this decreased BSE frequency in the women with True Low Anxiety may be the result of them not feeling the need to perform BSE regularly, perhaps due to their low anxiety. More specifically when compared to True Highly Anxious women, Repressors viewed cancer less seriously, perceived fewer barriers to BSE practice, were more confident in performing BSE and practised BSE more frequently (Barron et al., 1997). By perceiving cancer less seriously and the self as capable of detecting abnormalities, repressors may be managing their perceptions of threat related to BSE practice.

Although the women categorised as Defensive Highly Anxious women practised BSE significantly more often than did true Highly Anxious women and True Low Anxious women, they did not differ from Repressors. Furthermore, Defensive Highly Anxious women perceived cancer more seriously and saw themselves as more susceptible than did Repressors. It may be that trait anxiety is more influential in determining perceptions (i.e. seriousness and susceptibility); whereas defensiveness may help women cope with the actual performance of BSE. Furthermore, the Defensive Highly Anxious women perceived themselves as the most susceptible group to breast cancer and were similar to True Highly Anxious women in their perceptions of the seriousness of breast cancer. Moreover, repressors reported the least seriousness and susceptibility of the four groups.

Coping style can predict women's practice of BSE, in terms of both proficiency and frequency (Barron et al., 1997). Similarly each of the different coping styles differentiated by Crowne and Marlowe (1960) were related to different BSE thoughts and behaviours. By understanding one's coping style, BSE thoughts and behaviour may be predicted and interventions designed to target this. These findings and those discussed for worry/anxiety support the importance of incorporating anxiety/worry and coping style into the extension of the HBM. By doing so one may be able to explain BSE thoughts and behaviours more fully and gain a greater scientific understanding of the reasons why some women choose to engage in BSE and others do not. Similarly one may further use this to explain why some interventions are effective in some women but perhaps not as effective in others and may allow the design of interventions to encourage BSE which target a women's coping style.

2.3 Illness Representations

The onset of illness gives rise to a range of problems which can vary from person to person. Research has shown that in order to make sense of and respond to these

problems, patients create their own models or representations of their illness. The most influential theoretical framework adopted in this work is the self-regulation model of Leventhal and colleagues, who have proposed that patients' illness representations are based around distinct components which in turn determine coping (Leventhal, Nerenz & Steele, 1984; Leventhal & Diefenbach, 1991).

This model proposes that people have representations of illness (or illness cognitions), which are used for interpreting bodily changes and planning their health and illness behaviour. Early research identified five components within the cognitive representation of illness: identity (the label a person uses to describe the illness and the symptoms they view as being part of the disease), cause (the individual's personal ideas about the aetiology and likely cause or causes of the disease), timeline (likely duration of the health problem and expectations about the course of the illness), consequences (the individual's beliefs about illness severity and the likely impact upon physical, emotional, psychological, social, and economic functioning), and cure/control, (the extent to which individuals believe that their condition is curable or at least controllable).

The model suggests that people are active processors of information. Illness representations are derived from a number of sources, for example, personal experiences, past experiences with illness and information obtained in contact with other people, from the social environment, and from friends, relatives and health professionals, as well as the media and culture. Such representations can be highly idiosyncratic and very different from the medical view of illness. This may explain why, despite the medical reasons to engage in BSE, people do not.

Several studies using a variety of methods across a range of clinical conditions have confirmed the consistency and validity of the five representation dimensions (Baumann, Cameron, Zimmerman & Leventhal, 1989; Heijmans & de Ridder, 1998; Schiaffino & Cea,

1995; Skelton & Croyle, 1991), and the dimensions have been shown to have important implications for how patients conceptualise and cope with their condition (Leventhal et al., 1984). Moreover, extensive semi-structured interviews, open-ended questionnaire investigations, and factor-analytic studies have established that illness representations are multidimensional and have a common content across illness (Turk, Rudy & Salovey, 1986; Weinman, Petrie, Moss-Morris & Horne, 1996).

Early research investigating the content of illness representations largely involved open-ended interviews, but as knowledge has grown and Leventhal's self-regulatory model has become more widely used, more objective measures have been developed. Factor-analytic studies have resulted in the development of generic measures of illness representations such as the Implicit Models of Illness Questionnaire (IMIQ, Turk et al., 1986) and the Illness Perception Questionnaire (IPQ, Weinman et al., 1996). The IPQ was developed to provide a quantitative assessment of the five components of the illness representation (identity, consequences, timeline, control/cure and cause in Leventhal's self-regulatory model; Leventhal et al., 1984; Leventhal, Benyamini, Brownlee, Diefenbach, Leventhal & Patrick-Miller et al., 1997).

More recently the IPQ has been revised and new dimensions added (IPQ-R, Moss-Morris, Weinman, Petrie, Horne, Cameron & Buick, 2002). The illness coherence scale was added in order to better evaluate the overall meaning of the illness for a particular patient. In addition, the content of the original cure/control component from the IPQ was viewed by Horne (1997) as confounding sets of beliefs about personal abilities to control the illness and the efficacy of treatment to cure or manage the illness. These set of beliefs are therefore treated separately in the IPQ-R as the personal control and treatment control scales. Furthermore, the timeline dimension was differentiated into beliefs about the relative chronicity of the illness (acute/chronic) and beliefs about the fluctuation in symptoms and temporal changeability of the illness (cyclical). One important aspect of the

IPQ-R was the inclusion of a measure of emotional representations, which was related to the cognitive components of illness representations. In the study of Moss-Morris et al. (2002) the dimensions exhibited a characteristic and theoretically predictable pattern of inter-relationships, which was also found across studies of chronic illness in a recent meta-analysis (Hagger & Orbell, 2003). The new and revised IPQ-R appears to show logical inter-relationships. Beliefs in treatment and personal control and a sense of illness coherence were inversely related to pessimistic beliefs about the timeline and consequences of the illness as well as to negative emotional representations. The more positive beliefs of control and coherence were also inter-correlated, as were the more negative beliefs and emotional representations. There was also positive relationship between the attribution factors and illness identity and psychological and risk factor attributions were related to an increased sense of personal and treatment control (Moss-Morris et al., 2002). Furthermore, illness-specific measures, when factor analysed seem to cluster about the original dimensions derived by Leventhal, Meyer & Nerenz (1980), and this was congruent across different illnesses (for example Hagger & Orbell, 2003). Based on this one can suggest the IPQ-R provides a comprehensive and psychometrically assessment of the key components of patient's perceptions of illness.

The majority of the studies in this area have focused on the illness perceptions of patients and it is not known whether these perceptions also exist in healthy individuals and if they have the same structure and pattern of inter-relationships. There is evidence that healthy people are quite knowledgeable about factors which may affect health and quality of life as well as preventable measures to avoid disease (Figueiras & Alves, 2007), yet some individuals still avoid acting on this knowledge and engaging in self-protective behaviours such as BSE.

Illness representations of cancer may comprise of inaccurate information, misconceptions or negative conceptualisations of the disease and this may affect how individuals view and

engage in self-protective behaviours. In an Irish study of public attitudes and beliefs about cancer (Spiers, McElwee, Fleming & O’Gorman, 1999), the word cancer was associated with inevitable death, terror, suffering, devastation, shock, incurability, unfairness and helplessness. Similarly, in an American study assessing layperson’s perceptions of cancer (Katz, Hass, Parisi, Astone, McEvaddy & Lucido, 1987), cancer was described as the most painful condition, less understood medically and less preventable than heart disease, diabetes or AIDS. Breast cancer in particular, had strong social representations due to its severe implications of women’s appearance, attractiveness and self-image (Lantz & Booth, 1998). Additionally, Buick (1997) explored illness perceptions in breast-cancer patients and laypersons and found that physically healthy women had stronger beliefs concerning the role of internal/self blame and chance causal attributions than did the breast-cancer patients. Moreover, laywomen’s perceptions of the duration and impact of treatment of breast cancer were overestimated compared with that of radiation cancer patients and the healthy women underestimated cure/control possibilities as compared with that of radiation patients.

Physically healthy women seem to hold stronger beliefs concerning the role of environmental factors in causing breast cancer (Anagnostopoulos & Spanea, 2004; Buick & Petrie, 2002). Buick and Petrie (2002) found healthy women were less likely to perceive treatment for breast cancer as a cure or control for the disease and similarly Anagnostopoulos and Spanea, (2004) found physically healthy women also overestimated the consequences that breast cancer can have on patients and held less strong beliefs for cure/control of breast cancer. Similarly, Meyerowitz, Williams and Gessner, (1987) found that healthy individuals rated cancer as significantly less controllable than a fictitious disease that was described in exactly the same way as cancer.

Healthy women’s representations of breast cancer are worth exploring because inaccurate representations may have an effect on health protective behaviours.

Exaggerated or negative perceptions of breast cancer appear to be related to coping behaviours and illness outcomes (Hagger & Orbell, 2003) and may be largely responsible for healthy women's failure to adhere to appropriate preventative and early detection behaviours. One qualitative study (Savage & Clarke, 1998), demonstrated non-screeners for breast cancer were more likely than screeners to comment that they would have symptoms if they had breast cancer. With regard to the treatment/cure of breast cancer, the screeners mentioned more people who had been cured, while the non-screeners spoke about not having treatment if they had cancer. Understanding healthy women's perceptions of breast cancer may be useful for the promotion of preventive health activities such as BSE.

Layperson's perception of cancer may be negatively affected by the social construction of breast cancer, which in turn is heavily influenced and shaped by lay literature and the media (Lupton, 1994; Thorne & Murray, 2000). In an analysis of the articles on breast cancer that appeared in popular magazines, Burke et al. (2001) noted distorted, exaggerated or inaccurate messages about breast cancer. Breast cancer was portrayed as a disease primarily affecting young women and causing early death, abandonment of young children, and posing a major threat to marriage and dating. Therefore, the social and cultural context of breast cancer may negatively affect laypersons' perceptions of cancer. Laywomen's screening behaviour may serve to mitigate the emotional impact of these negative perceptions of cancer and regulate the worry and threat posed by them. Screeners, by performing mammography, CBE or BSE are presented with the rather threatening prospect of breast-cancer detection, and they may engage in defensive attribution that serves to protect them from possible future derogation or blame. Taking this into consideration, illness representations may influence how healthy individuals perceive and adopt health related behaviours (such as BSE).

There is extensive literature concerning people's health beliefs and their relation to various health behaviours. However, most studies have examined illness-specific beliefs and behaviours within specific groups of patients or groups at risk from a particular illness (Hughner & Kleine, 2004). There has been much less focus on how healthy people think about health and illness, and how their ways of thinking relate to health related behaviours.

Research into this area is limited, but initial findings are encouraging. Results from Figueiras and Alves (2007), with the development of a new version of the IPQ-R for use with healthy individuals, show illness representations account for a small but significant proportion of variance in attitudes towards preventative behaviours and intention to adopt them. Cognitive dimensions such as illness coherence, psychological attributions, chronic timeline and the perception of the consequences explained some variance in these attitudes and intention, suggesting that independent of the experience of illness, these representations may influence health-related behaviours in healthy individuals. More specifically, a stronger emotional representation was positively associated with identity, a more chronic and cyclical timeline, more serious consequences and a less coherent illness model, but negatively associated with control beliefs (personal and treatment). A stronger belief in treatment control was associated with less perceived consequences, a less chronic timeline and a smaller number of symptoms associated with the illness. The causal attribution factors were not found to be related to emotional representation of the illness (a result which is contrary to the relationship found in different groups of patients, Moss-Morris et al., 2002). However, they showed a positive association with control beliefs and with the illness coherence dimension, suggesting that healthy people's causal attributions for a disease may influence their personal control and treatment beliefs, and may help them to make sense of the illness.

Further research is needed in order to explain whether the illness perceptions of healthy individuals may predict behaviours using longitudinal designs, but initial findings are encouraging and suggest the potential effect it may have. Based on this potential, this study includes illness representations in its extension of the HBM.

2.4 Health Locus of Control

Variables that may contribute to a woman's perception of her risk of breast cancer such as health locus of control (HLC; Rowe, Montgomery, Duberstein & Bovbjerg, 2005) are important because their contributions to perceived risk may subsequently lead to differences among women's adherence to screening techniques like BSE. HLC, an individual difference construct derived from social learning theory (Rotter, 1954), is the general expectancy that one's behaviour either is or is not directly related to one's health outcome. HLC has been widely used to measure individuals' health beliefs and can be defined as the perception of what controls an individual's health (Wallston, Wallston, Kaplan & Maides 1976). The major dimensions of the HLC are internal and external. That is individuals' perceptions of the source of their power to change particular life events may be attributed to internal factors or external factors (Wallston, Wallston & DeVellis, 1978). Individuals with an internal HLC believe that their own actions determine the consequences of their health outcomes and individuals with an external HLC believe what happens to them is essentially out of their control and caused by someone or something external to themselves. The dimension of external control is further divided into powerful others and chance. People with a powerful other HLC believe that powerful others determine their health whereas people with a chance HLC orientation believe that their health is determined by fate, luck or chance (Wallston et al., 1978). These beliefs generally form early in life as a result of early childhood experiences with illness in one's family and may remain relatively stable across time (Lau, 1982). However, as Arakenan

(1980) suggests, new social learning experiences may, over time, alter previous experiences and change the locus of control.

Perhaps the most important development of the HLC construct has been towards a multidimensional conceptualisation of control. Wallston et al.'s (1978) introduction of the Multidimensional Health Locus of Control Scale (MHLC) was a significant contribution to this development in terms of sources and control (Baken & Stephens, 2005) and this scale has since been used extensively to investigate the relationship between HLC and health behaviours.

According to Hussey and Gilhland (1989), research suggests that internally orientated individuals are more likely to be (1) health-orientated and have a desire for physical well-being and (2) more likely to comply with recommended health regimens. Similarly, a sense of internal control has been related to actions to improve health (Lau, 1988).

Studies investigating HLC among the general public have shown a significant relationship of HLC to their health-related behaviours (O'Hea, Grothe, Bodenlos, Boudreaux, White & Brantley, 2005). Individuals with higher internal control are more likely to abstain from smoking and binge drinking and engage in exercise, and more likely to adhere to preventative medicine practices including inoculation, dental care and preventative screening (Booth-Butterfield, Anderson & Booth-Butterfield, 2000; Brown & Steele, 1999; Lau, 1988; Schlenk & Hart, 1984; Wallston & Wallston, 1981; Wasseem, 1991).

A number of researchers have explored the relationship between HLC and health-promotion behaviour and results have been equivocal. Laffrey and Isenberg (1983) examined three factors assumed to be associated with participation in physical activity (internal HLC, value placed on health, and perceived importance of exercise) and found internal HLC to be uncorrelated with any of the other variables. Similarly, Zindler-Wemet and Weiss (1987) found that when age, education, social support, health status, work role

and health values were entered as covariates in analysis of variance procedures, no relationship was found between HLC and health behaviour.

Other researchers, however, report more positive results. In a study of faculty women, Lakm (1988) found positive correlations between a measure of an individual's willingness to undertake self-care activities, and both internal HLC and health values. Significant negative correlations were observed between a belief in chance and self-care activities. It does, however, need to be noted when interpreting these results that, although the correlations show HLC to be associated with health behaviours, the researchers failed to take into account through regression analysis the effect of health values and health status, although these variables correlated positively with health behaviours. In a similar study, Brown, Muhlenkamp, Fox and Osborn (1983) used regression analysis and found that the combined effect of MHLC and health values accounted for a significant amount of the variance in total health-promotion activities with chance HLC emerging as the most important predictor. However, caution is again required, as the researchers did not indicate the degree of correlation between health values and HLC measures (Orbele, 1991).

Research further indicates that HLC may be related to compliance with therapeutic regimens (Harrigan, Faro, Van Puttle & Stoler, 1987; Hussey & Gilhland, 1989; Shilhinger, 1983) and a number of researchers have explored this relationship. Balsmeyer (1984) found the hypertension clinic patients who adhered to a medical regime to reduce blood pressure scored significantly higher for internal HLC than the non-adherent patients. Similarly, Kerr (1986) found that a significantly greater number of participants with higher internal HLC scores had lowered blood pressure at the end of a three-month therapeutic regimen, and those with a high chance HLC scores were least successful in lowering their blood pressure. Moreover, multiple regression analysis showed that the HLC variables explained 9% of the variance in lowered blood pressure.

Contrasting results, however, were found when investigating the relationship between HLC and weight loss (Gierszewski, 1983). Gierszewski (1983) compared the means of internal and powerful others HLC and internal and chance HLC, and found that the means were in the opposite direction to that expected. Internals demonstrated less weight loss/more weight gain than either externals/powerful others or externals/chance. It appears that HLC is somewhat effective as a predictor of compliance to a therapeutic regime. Surprisingly, external HLC seems to be more positively associated with compliance than does internal HLC, an observation that is generally contrary to expectations. Perhaps, HLC is mediated by the context within which it is being studied. Health behaviours vary in a number of ways. These include whether they are risk-enhancing (e.g. smoking) or health-promoting (e.g. regular exercise) activities, whether they are carried out primarily for health purposes (e.g. BSE) or are determined by multiple health and non-health factors (e.g. alcohol consumption), and whether or not they have strong cultural determinants (e.g. dietary habits, Steptoe & Wardle, 2001). Some of the inconsistencies in the literature may have arisen through comparing HLC to different health behaviours in different samples.

Studies of preventive and treatment practices related to cancer have found varying results. One would expect people high in internal control to perform screening behaviours that have a strong personal control component such as BSE and pay more attention to information about health issues (Redeker, 1989; Toner & Manuck, 1979; Wallston et al., 1976) and indeed some research suggests this to be true.

Bundek, Marks and Richardson (1993) examined the HLC beliefs of elderly Hispanic women in relation to BSE frequency. As hypothesised, they found holding a belief that health outcomes are controlled by oneself (internal HLC) was positively related to screening behaviours over which one has a high degree of personal control, such as the

frequency of BSE. Internal HLC was further related to attention to health-related information. Not only may holding an internal HLC give an individual the belief they can control their own health but it may further encourage this individual to learn about the benefits of this control, perhaps more so than individuals with external HLC. Thus individuals with an internal HLC may be more aware of the benefits of BSE due to their increased attention to BSE related information and this, along with their belief that they are able to control their health, may encourage them to examine their breasts.

Further support is offered in the earlier work of Hallal (1982). Hallal (1982) examined 207 women and found a positive relationship between internal HLC and ever performing BSE. It does, however, need to be noted that whilst a positive relationship was found it was non-significant; $r(205) = 0.117$, $p < 0.05$, limiting any conclusions. A significant negative relationship however was found between control by powerful others and ever performing BSE, that is those women with a high external HLC were more likely to have never performed BSE.

Similar findings, however, were not replicated in the later work of Bundek et al. (1993). They, instead, found that both internal and powerful others HLC were positively related to frequency of BSE, with internal HLC producing much stronger effects. This discrepancy between Hallal (1982) and Bundek et al. (1993) may be explained, in part, by differences in the measures of BSE frequency. Hallal (1982) used a dichotomous measure (ever versus never) that produced a highly skewed distribution (80% versus 20%). Moreover, the 'ever' group included women who performed BSE monthly as well as those who performed it less than once a year. Taking this into consideration Hallal's (1982) results may not reflect the precise manner in which frequency of BSE relates to a particular health control dimension.

Bundek et al.'s (1993) findings strongly suggested that the dimension of internal control is the most critical in predicting screening practices that have a strong component of personal control. Further support for this contention is highlighted in the earlier work of Redeker (1989), who similarly to Bundek et al. (1993), also used relatively sensitive measures of BSE frequency. Redeker (1989) administered the MHLC scale to a sample of non-Hispanic women and found that those who had never practised BSE tended to have a lower internal control than did those who had performed BSE three or more times a year. Beliefs about powerful others, however, were not examined by Redeker (1989).

More recently, Rowe et al. (2005) examined the relationship between HLC and perceived breast-cancer risk in 66 women (51.5% White and 48.5% other: Black, Hispanic, Asian or Indian). They found that internal HLC was significantly and positively related to the perceived likelihood of remaining free of breast cancer. It appears that internal HLC may play a role in a woman's perceived risk for breast cancer in that women who believe that they can control their own health through their own behaviour may be more likely to report a lower perception of risk than women who believe that others or chance control their health. This perception of risk may further influence screening behaviour in that women who perceive no risk of breast cancer may see no reason to engage in BSE.

Moreover, there is evidence to suggest that internal and external HLC beliefs moderate the process of coping with health-related risks and adverse events. For example Masters and Wallston (2005) presented a correlation analysis of data from a student sample showing links between HLC beliefs and specific coping styles. In particular, internal HLC beliefs were related to active coping and positive reframing, whereas external HLC beliefs were related to coping strategies of behavioural disengagement, emotional support and self-distraction. This may be important when considering women may need to cope with anxiety related to the possibility of finding an abnormality if they are to perform BSE

regularly. If coping style is indeed important for BSE then HLC and how this relates to coping style may also be important.

Similarly, by noting an individual's HLC, one may be able to identify whether their orientation is related more strongly to belief in internal control or to control by powerful others or chance. Using this information as a guideline, one could tailor advice about BSE behaviour that is in line with the individual's existing HLC orientations. For example, this might involve stressing the self-initiated nature of BSE for those with high internal control and stressing compliance with medical professional's recommendations regarding BSE for those who measure high in control by powerful others. Appropriate modifications may be further made for those who measure high in both internal and external HLC based on this. By doing this, one may be able to increase the extent to which women perform necessary BSE. Indeed, support for this contention is apparent in relation to mammographic screening. Williams-Piehota, Schneider, Pizzaro, Mowad and Salovey (2004) administered persuasive messages to promote mammography among women who were callers to a cancer information service. To ensure this intervention would be proactive, the messages were only given to those who did not have cancer themselves. The rates of obtaining a mammogram at six and twelve months later were then compared between callers who had received internally or externally orientated message. The rates were higher for each message type when it matched the caller's primarily internal or external health HLC beliefs than when it did not. Thus it appears when confronted with a serious health risk or problem an individual's HLC beliefs affects their propensity for an adaptive response.

It is apparent from the literature that indeed a relationship may exist between an individual's HLC and their health-related behaviours. However, most of the studies attempting to correlate MHLC scores with measures of health behaviour have failed to find evidence for strong associations between any of the three MHLC subscales and

behaviour, particularly when looking at a single behaviour. In fact, the bivariate correlations seldom exceeded 0.30 signifying that MHLC beliefs explained less than 10 percent of the variance in any particular health behaviour (Wallston, 1992).

Steptoe and Wardle (2001) argued that these inconsistent and small associations found between MHLC scores may be due to the relatively small sample sizes employed in most of the studies, and to an over reliance on the Pearson product-moment correlation as the measure of statistical association. They administered the MHLC scale (form B) along with a measure of 10 health behaviours to over 7000 university students in 18 European countries. When analysing their data using partial correlations (controlling for age, sex and country), they found that internal HLC scores were positively associated with six of the behaviours, chance HLC scores were negatively associated with six of the behaviours and powerful others HLC scores were positively associated with three and negatively associated with two of the health behaviours. As with many other studies, the correlations although statistically significant, were small, accounting for no more than a small percent of shared variance between HLC and health behaviours. When Steptoe and Wardle analysed their data, however, they found a striking difference on health behaviour for individuals in the top quartile on a MHLC dimension compared to individuals in the lowest quartile. For example, an individual in the highest quartile on the internal HLC subscale was 77% more likely to exercise than someone in the lowest quartile. Not only did their analysis control for age, sex and country, but they also controlled for the other HLC dimensions. Although Steptoe and Wardle failed to explore BSE, similar findings may occur when doing so. Rather than abandoning HLC altogether, new statistical approaches might be necessary to establish the validity of the MHLC.

Furthermore, when considering the low correlations of past studies one must note that just because there is not a strong correlation between a MHLC score and a measure of health behaviour does not mean that the MHLC is an invalid scale (Wallston, 2005), or that HLC

is not important in explaining health behaviour; instead HLC beliefs alone play a modest role in explaining behaviour. In order to gain a full understanding of health behaviour one may need to consider several variables. This study considers this and rather than just exploring HLC in relation to BSE independently it includes HLC in its extension of the HBM. This extended HBM explores the potential effect of HLC on both BSE thoughts and behaviour and it is envisaged that by investigating such a relationship a women's decision to engage or not engage in BSE may be further understood. This in turn, may be subsequently used to aid the promotion of BSE.

One external source of HLC that has not received sufficient attention is that of religion or 'supreme beings' such as God (Wallston, Malcarne, Flores, Hansdottir, Smith, Stein et al., 1999). According to the UK 2001 census 77 percent of the British population believe in God or another 'supreme being'. If or how these beliefs affect an individual's perceived control in relation to their health and subsequently their health related behaviour may be important.

God health locus of control (GHLC) has been defined as the degree to which one believes that God has ultimate control over their health (Wallston et al., 1999). People with an internal HLC believe that they have control over the situations and outcomes connected to their health whereas people with an external HLC believe an external force controls their health, for example powerful others, chance or indeed God. To date GHLC particularly amongst white women has received little attention, with research tending to focus on GHLC in African-American women (Kinney, Emery, Dudley & Croyle, 2002) and consisting of methodological flawed studies. Kinney et al. (2002) examined the relationship between GHLC and breast-screening behaviours amongst African-American women at high risk for breast cancer and found women with high GHLC levels were less likely to adhere to CBE and mammography recommendations than those with lower GHLC scores. Perhaps such women believe that God will alleviate breast-cancer

symptoms (Coward, 2005) and there is nothing they can do. They leave their health in God's hands. Conversely this was not the case for adherence to BSE; women with a higher GHLC were more likely to adhere to BSE. It appears adherence to CBE and mammography may be affected by different factors than those that influence performance of BSE.

One must however note the small sample size (52 women) and the high risk status of these women limit the generalisability of this study's findings. More research is needed across different populations and with larger sample sizes before any firm conclusions regarding GHLC and breast-screening can be established. Whilst African-American women's beliefs in God and its affect on screening behaviours may indeed differ to that of white British women the research nevertheless suggests the potential affect GHLC may have on breast-screening behaviours such as BSE. Taking this into consideration this study explored the relationship between GHLC and women's beliefs and behaviour towards BSE.

2.5 Social Support

Social support is defined as the exchange of resources between at least two individuals, the provider and the recipient with the intention of improving the well-being of the recipient (Kahn, 1979). These resources offer information or tangible material that leads the individual to believe they are loved and cared for, esteemed and valued, and belong to a network of communication and mutual obligation (Cobb, 1976). The mechanism of social support can be explained in a three-fold manner (Maxwell, 1982; Komproe, Rijken, Ros, Winnubst & Hart, 1997). Social support acts to decrease the perception of stress (Cassel, 1976) to serve as a buffer for stress (Cobb, 1976) and to have a direct impact on health behaviours. It is through this direct impact that social support may be related to the health behaviour BSE.

The links between social support, positive health outcomes and well-being are well established and individuals who have social and community ties have lower morbidity and mortality rates than those who lack social support (House, Landis & Umberson, 1988). Furthermore compared with men, women appear to be more influenced to perform positive health behaviours when they have adequate supportive relationships (Molinari, Ahern & Hendryx, 1998).

Numerous studies reported the beneficial impact of social support on women's psychological well-being and coping abilities through every stage of breast cancer (Hoskins, Baker, Sherman, Bohlander, Bookbinder, Budin et al., 1996; Lungton, 1997; Maunsell, Brisson & Deschenes, 1995; Northouse, Latern & Reddy, 1995). However, because much breast health depends on a women's decision to adhere to screening guidelines, factors that underlie these decisions must also be understood. Participation in cancer-screening programmes requires that women are aware of the recommended screening guidelines, perceive a benefit from early cancer detection and tolerate the potential threat posed by positive screening outcomes (Flax & Earp, 1999; Reppucci, Woolard & Fried, 1999). It is assumed that higher levels of social support would influence breast-cancer screening behaviour in many ways. Social support provides women with more assistance to overcome barriers, it provides women with more opportunities to learn about the value of BSE and, finally, it influences personal risk perception through information that becomes available to the individuals and advice offered by influential others (Katapodi, Facione, Miaskowski, Dodd & Waters, 2002). Thus one may presume that women with higher levels of social support are more likely to engage in BSE than those with lower levels.

Empirical evidence supporting positive effects of social support on women's breast-screening practices has been mixed. Women who have undergone mammograms have been shown to report higher levels of social support than women who have not (Fite,

Frank & Curtin, 1996). Similarly, in a randomised control Taylor, Thompson, Montano, Mahloch, Johnson & Li, (1998) examined predisposing, enabling and reinforcing factors for seeking mammograms (in a sample of inner-city women of different ethnic groups, aged 50 and over), and found reinforcing factors for mammogram use included whether their physicians, family or friends had advised the women to have a mammogram. However, another study showed that emotional support and instrumental support were not significantly related to the use of mammography or CBE in a sample of black women (Kang, Bloom & Romano, 1994). Similarly, in a large study of older women, social support was shown to be just marginally related to regular breast-cancer screening (Allen, Sorenson, Stoddard, Peterson & Colditz, 1999).

It does, however, need to be considered that these studies focus on mammography and CBE. It may be that these two components of breast-screening may be quite different from BSE because BSE is largely under a women's personal control, whereas mammograms and CBE are conducted by health professionals, and mediated by a woman's GP and by healthcare variables such as access. Furthermore, as BSE is recommended monthly rather than yearly, it may require a different level of social support to the contrasting yearly mammograms and less frequent CBE. Indeed Katapodi et al. (2002) report no difference in mammography participation rates in relation to social support, although social support has been shown to be related to BSE behaviour (Laughter, Kean, Drear, Espanza, Hortobagy, Judkins et al., 1981; Lierman, Kasprzyk & Benoliel, 1991; Wagle, Komorita & Lu, 1997). The authors themselves note that the lack of a significant finding may be a result of the small proportion (just 6%) of women in the sample who reported never having a mammogram. Nevertheless, it highlights the potential for differences to exist between BSE and mammography.

Few studies have focused specifically on the influence of social support on BSE, particularly across a varied age range. However, those that have demonstrate its potential

effect on BSE. Higher self-reported levels of social support have been shown to be significantly associated with greater adherence to screening guidelines for BSE among a multicultural sample (Katapodi et al., 2002) in women 55 years of age and older (Lierman et al., 1991; Wagle et al., 1997) and in younger women aged 35-55 (Laughter et al., 1981).

Further support for this contention is apparent through the exploration of the relationship between social support and repeated breast-cancer screening among a large (N= 55,278) national sample of post-menopausal women (Messina, Lane, Glanz, West, Taylor, Frishman & Powell, 2004). More specifically, lower levels of either emotional/informational support or positive social interactions, but not tangible support or affection, were found to be significantly and independently associated with less frequent use of mammography, CBE and BSE.

It is, however, important to be cautious with generalising such results. Katapodi et al.'s (2002) sample was recruited through leaders in community settings and therefore one can assume that the women in the sample already had established at least some relationships within their community and that the recruitment procedure probably excluded women with the lowest levels of social support. Indeed the authors themselves noted a skewed distribution of the social support scores, with the majority of women reporting high levels of social support. Similar limitations can be noted when considering the participants in Wagle et al.'s (1997) study. The sample was drawn from a clinic where women presented themselves for annual physical examinations; thus, a relatively high performance in BSE may be expected in such women. Indeed, the authors noted a 64% performance rate of BSE in their study, a level much higher than the average of 25-33% for all age groups (American Cancer Society, 1996; Wagle et al., 1997).

One must further note that unlike Wagle et al. (1997), Katapodi et al. (2002), used a social support scale that emphasised the extent to which basic social support is present for women, rather than a scale that emphasised the size of the support network and its actual structure, like the Norbeck Social Support Questionnaire (Norbeck, Lindsey & Carrieri, 1983). Although the scale used by Katapodi et al. (2002) was able to assess the presence of a basic social support network, it was unable to examine whether the members of a support network might influence adherence to breast-cancer screening guidelines, perhaps limiting any conclusions that can be drawn from the data. In order to gain a more detailed understanding of a women's social support network it may be more desirable to employ a scale emphasising the size and structure of social support. This study considers this with the use of the Norbeck Social Support Questionnaire.

Furthermore, individual resources (for example, higher education and greater household income) are thought to have direct positive effects on the use of cancer-screening (Hsia, Kemper, Kiefe, Zapka, Sofaer, Pettinger et al., 2000). These may also mitigate the effects of a lack of social support on the adoption of preventative health behaviour. On the basis of their meta-analytic reviews, Smith, Fernengel, Holcroft and Gerald (1994) and Vitaliano, Scanlan, Zhang, Savage, Brummett & Barefoot et al. (2001) raised the question of whether other variables moderated the impact of social support among different groups. Individuals with less income and education may draw more value from social support than individuals with more of these resources, with those with a higher income and education having the means to provide for their own needs and thus depending less on the support of others. Likewise, more affluent people may be more competent at finding or 'buying' adequate social support and are likely to be members of diverse groups that entail a wider variety of resources. Thus, a larger network of social support resources may be available to them. If this is indeed true, one may need to consider levels of social support along with educational level and income in order to fully understand a woman's thoughts and

behaviour towards BSE. Similarly one may need to consider the education and income of a particular woman or group of women before designing interventions to encourage BSE.

Vitaliano et al. (2001) and later Messina et al. (2004) tested this 'added-value hypothesis' and found that social support was more health promoting and holds more value for people with lower incomes than for those with higher incomes (Vitaliano et al., 2001; Messina et al., 2004). Similarly, having less than a college education was significantly associated with lower odds of annual mammography and CBE, but increased odds of monthly BSE (Messina et al., 2004).

Moreover, when investigating screening behaviours generally, a relationship between both ethnicity (Champion & Menon, 1997; Foxall et al 1998; Friedman et al., 1999; Wardle et al., 1995), age, (Funke, Krause-Bergmann, Pabstr & Nave, 2008; Lauver & Angerame, 1990, Nemcek, 1989; Persson, Svensson & Ek, 1997) and educational level (Epstein et al., 1997; Erblich et al., 2000; Freidman et al., 1999; Han et al., 2003; Madan et al., 2000) and screening behaviour (BSE included) has been established. Despite this relationship only Katapodi et al. (2002) stratified their sample for age, income and education and the other studies' samples (Messina et al., 2004; Wagle et al., 1997) consisted of predominately educated and when income is noted; more economically advantaged women (Messina et al., 2004). Similarly, all of the studies' samples consisted of predominately white women, again limiting the generalisability of the findings. Screening behaviour and socially defined constructs such as social support appear to differ among different cultures and circumstances. Indeed, Katapodi et al. (2002) note that high levels of social support were most evident in the wealthiest and most highly educated women in their sample and that social support further differed significantly by educational level. Women who had only grade-school education reported significantly lower social support compared to those with high-school education or graduate-school education. Therefore, the findings of these studies may not apply to other samples and as such caution needs to

be taken when interpreting the results. Further to this, because social support was measured at baseline, the status of social support at the time of screening was unknown. Consequently, the studies discussed could not examine whether social support as measured at baseline were related to changes in breast-cancer screening over time.

Despite these methodological considerations, one may suggest that a relationship between social support and BSE exists and this provides evidence to support the assumption that women with more social support are more likely to adhere to recommended breast-cancer screening guidelines. Although the mechanisms through which social support promotes BSE behaviours are unclear, one explanation is that women who are entangled in social networks have greater motivation and feel more obliged to engage in positive health-care practices than do women with less social support (Hubbard, Muhlenkamp & Brown, 1984).

Indeed some support for this idea is offered by the example of the success of micro-lending schemes in poor communities for example Bangladesh. Micro-lending in this context refers to the practice of granting small loans to those in need. The Grameen Bank of Bangladesh, founded in 1976 by Muhammad Yunus, was the first to implement a peer-group micro-lending programme which provides low-income entrepreneurs access to capital. The structure of the programme involves groups of entrepreneurs forming 'lending circles.' An entrepreneur's access to financing is dependent on the timely repayment of existing loans by their lending circle and on their active participation in the lending circle. The available loan size increases over time, conditional on the timely payment of previous loans to the lending circle (Hossain, 1988; Yunus, 2010). This micro-lending programme is not based on any collateral or legally enforceable contracts; instead it is based on trust (Yunus, 2010). The success of this programme in Bangladesh, with a 98% loan repayment rate, has been widely publicised and has resulted in many Third World countries and low-income communities in North America implementing similar

programmes. The existence and success of these micro-lending programmes can be explained simply: first-time entrepreneurs know they will not receive further funds if they default and the schemes are usually run by small communities so there is social pressure to repay (See Besley & Coate, 1995; Ghosh & Ray, 1994; Stiglitz, 1990; Townsend, 1994; Varian, 1990).

These micro-lending principles may be applicable to other areas of behaviour, for example BSE. Similarly, women within strong social networks may feel social pressure to examine their breasts, especially if the other women in the social network are doing so.

Additionally, social support may provide more assistance for women to overcome potential barriers to BSE and may provide women with more opportunities to learn about the value of BSE. It is apparent from the literature discussed that indeed a relationship exists between social support and BSE. Taking this point into consideration, social support was included in the extension of the HBM for this study and it was assumed that a significant relationship would occur between level of social support and adherence to breast-cancer screening guidelines.

2.6 Proposed Extension of the Health Belief Model (E-HBM)

Based on the literature discussed, this study proposes an extension of the HBM by including worry/anxiety, coping style, illness representations, HLC and social support as components within the model. Incorporating these components into the HBM enhances the scientific understanding of a women's decision to engage in BSE or not because a wider range of psychologically plausible factors is used to explain variance in the health-protection behaviour of BSE. This enhanced understanding is essential to the success of any intervention designed to encourage BSE. Therefore, this study considers the utility of the extended HBM as a framework for understanding women's knowledge, beliefs and behaviour regarding breast cancer and BSE behaviour. This study proposes that

worry/anxiety, coping style, illness representations, HLC and social support may form the extension of the HBM (see Figure 3).

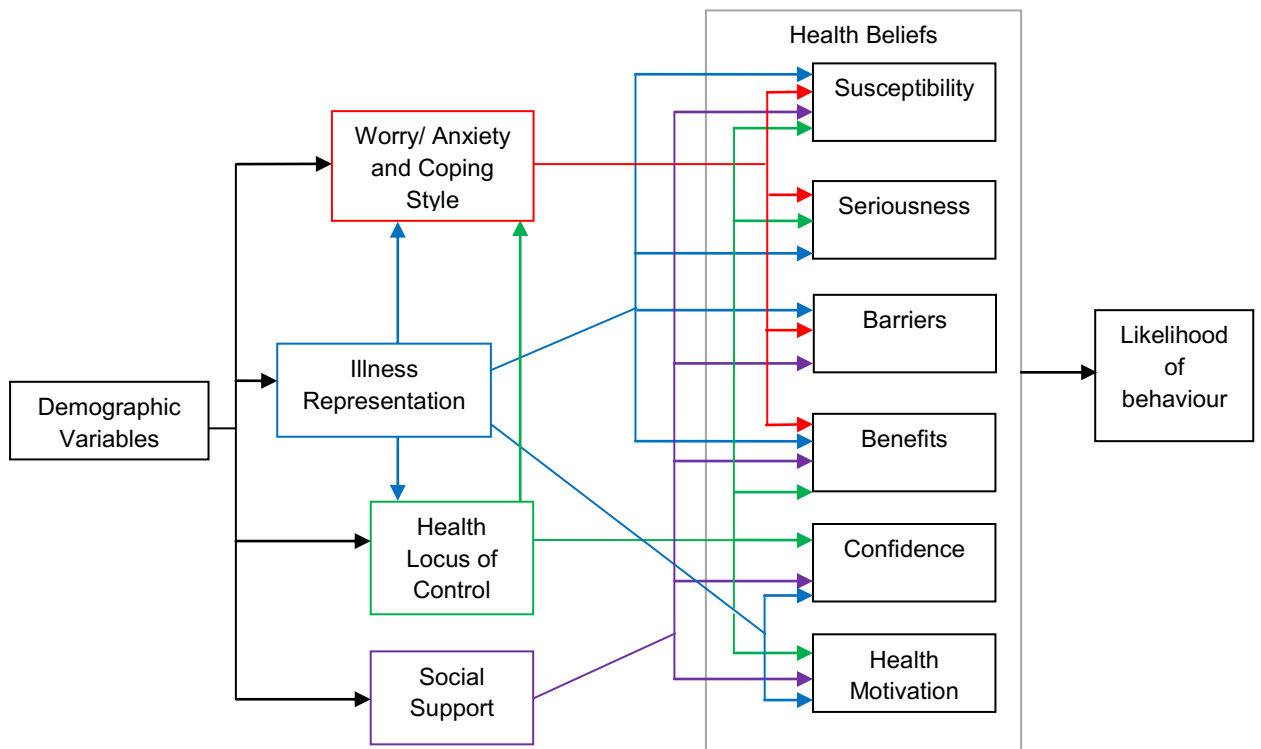


Figure 3. Proposed Extended Health Belief Model

Worry/Anxiety and Coping Style

How susceptible to breast cancer a woman believes herself to be may depend on her levels of worry/anxiety about breast cancer. Similarly, how serious she views breast cancer to be may again be dependent on this level of worry/anxiety. For example, worrying about breast cancer may make women more aware of the seriousness of breast cancer and their own susceptibility to the disease, which in turn may encourage them to engage in the self-protective behaviours such as BSE (Diefenbach et al., 1999; McCaul et al., 1996a, McCaul et al., 1996b; McCaul et al., 1998).

Women need to cope with this anxiety if they are to perform BSE. How they do this, their coping style may determine whether they engage in BSE (Barron et al., 1997). For example, some women may choose to manage the anxiety by avoiding BSE altogether whilst others may attempt to deal with this anxiety by engaging in BSE. This anxiety and, in turn, how a woman copes with this anxiety may further affect how she views the barriers and benefits of BSE. For example, if a woman is anxious about the possibility of finding an abnormality in her BSE she may decide to manage this anxiety by avoiding BSE altogether. Alternatively, women anxious about breast cancer itself may decide to manage this anxiety by engaging in BSE. The reassurance benefits that BSE can bring may help these women manage this anxiety. The barrier-benefit analysis of the perceived benefits and barriers to BSE may, at least in part, be influenced by a woman's level of worry/anxiety and their coping style.

Social Support

Social support may affect BSE in four ways. Firstly, women who have more social support may be more motivated and feel more obliged to engage in BSE (Hubbard et al., 1984). Similarly, women with strong social networks may feel social pressure to examine their breasts, especially if other women in the social network are.

Secondly, social support may give women the confidence that they are capable of performing BSE. For example if other people within a woman's social group are engaging in BSE, the woman may recognise they too are capable of performing BSE.

Thirdly, social support may provide women with assistance to overcome the barriers to BSE (Katapodi et al., 2002). For example, a barrier to BSE may be embarrassment but if a woman's friends or family are examining their breasts and the woman is aware of this, this may, in turn, reduce their feeling of embarrassment and perhaps influence the barrier-

benefit analysis. Similarly, social support may provide more opportunities for women to learn about the value of BSE, again perhaps influencing the barrier-benefit analysis.

Fourthly, social support may influence the personal risk perception (or susceptibility) through information that becomes available to the women and advice offered by influential others (Katapodi et al., 2002).

Illness Representations

Illness representations of breast cancer may comprise of inaccurate information, misconceptions or negative conceptualisations of the disease (Anagnostopoulous & Spanea, 2004; Buick, 1997; Buick & Petrie, 2002; Katz et al., 1987; Spiers et al., 1999). This, in turn, may affect the level of anxiety or worry women experience, how a woman perceives the seriousness of and their own susceptibility to, breast cancer (Burke et al., 2001), their barrier-benefit analysis of the perceived benefits and barriers to BSE, and how capable this woman believes she is at performing BSE. Similarly, these illness representations may influence women's health motivation and may provide women with prompts to practise or not practise BSE. Further to this, illness representations may influence to what extent a woman believes herself to be in control of her health.

Health Locus of Control (HLC)

HLC may affect components of the HBM and subsequently BSE in five ways. Firstly, HLC may determine how susceptible a woman believes they are to breast cancer and indeed how severe they view breast cancer to be.

Secondly, HLC may influence how beneficial a woman believes BSE to be. Internally orientated women, that is, those believing they are in control of their health may be more positive towards BSE. Similarly, those with an external locus of control, that is, those believing their health is essentially out of their control may fail to see the benefits of BSE.

Typically, it is expected that people high in internal control are more likely to perform screening behaviours that have a strong personal control component such as BSE (Redeker, 1989; Toner & Manuck, 1979; Wallston et al., 1976).

Thirdly, HLC may influence how motivated a woman is to health matters generally. Research suggests that generally those with an internal locus of control may pay more attention to information about health issues (Redeker, 1989; Toner & Manuck, 1979; Wallston et al., 1976) than externally orientated individuals.

Fourthly, HLC may influence a woman's confidence in their ability to implement health-protective behaviours such as BSE and indeed in her ability to control or manage their health. This in turn may encourage or discourage this woman from examining their breasts.

Fifthly, HLC may also influence worry/anxiety and coping style. A woman's HLC may influence her level of worry or anxiety in relation to breast cancer and BSE. Furthermore, internal and external HLC beliefs may influence the process of coping with health-related risks, as is required in order to implement BSE (Masters & Wallston, 2005).

2.7 Conclusion

The HBM has been used to successfully predict many health behaviours including BSE, but it only accounts for as much of the variance in health behaviours as can be explained by the model's components. A review of the literature highlighted five constructs associated with BSE practice that were not considered within the HBM components: worry/anxiety, coping style, illness representations, HLC and social support. By extending the HBM to include these five constructs it was proposed that an increased understanding of a woman's decision to engage or not engage in BSE would be gained; understanding of which is essential for the success of any intervention encouraging BSE. This study aimed

to explore this proposed extension of the HBM and considered its utility as a model to further explain women's knowledge, beliefs and behaviour regarding breast cancer and BSE.

2.8 Chapter Summary

Within this chapter the literature surrounding BSE and variables associated with its practice was reviewed and an extension of the Health Belief Model (E-HBM) proposed in which worry/anxiety, coping style, illness representations, HLC and social support were incorporated. By incorporating these variables within the existing HBM, this chapter presented a framework for understanding women's knowledge, beliefs and behaviour regarding breast cancer and BSE behaviour more completely.

CHAPTER THREE

The Use of Multimedia, Autobiographical Accounts and Online Data Collection within a Research Setting

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3.0 Chapter Overview

The use of multimedia programmes and the internet has become widespread, with much communication now taking place within this setting and using the medium of multimedia. Likewise, autobiographical accounts have become popular in recent years, with the area of breast cancer receiving much attention. This chapter reviews the literature surrounding autobiographical accounts, multimedia programmes and online data collection, and considers the potential of autobiographical accounts and multimedia programmes in influencing women's beliefs and behaviour towards breast cancer and breast self-examination (BSE), and the utility of conducting research within an online setting.

3.1 Multimedia BSE Programme

It is well documented that an early presentation of breast cancer improves the outcome (Hermon & Beral, 1995; DoH, 2000; Mayor, 2003), but this early presentation, especially for those women not routinely invited for a mammogram, may depend on their ability and desire to examine their breasts. Research indicates some women avoid BSE because of a perception that the procedure is complicated to perform, the fear of finding a lump, a lack of confidence in the accuracy of their technique and a lack of understanding what to look for (Agars & McMurray, 1993; Williams, Mahoney & Williams, 1998). Moreover, exploratory work conducted in the early stages of this project (see Chapter 5) concluded that in some women this fear surrounding BSE and breast cancer generally may stem from a lack of knowledge and education. Providing women with the necessary knowledge and education to perform BSE may encourage women to examine their breasts and may ensure they examine their breasts comprehensively. Women need a clearly structured or systematic approach which they can follow with ease and which gives them the confidence necessary to observe and examine their breasts correctly.

Regular BSE according to the 5-step model (a structured BSE guide consisting of five specific steps incorporating both looking and touching the breasts in particular ways as presented in Appendix 6) has been promoted by breast-cancer campaigns in the past (*www.breastcancer.org, 2009*) as a comprehensive method of BSE and may provide the confidence and knowledge required for BSE. Indeed, exploratory work conducted in the early stages of this project (reported in Chapter 5 of this thesis) demonstrated that when provided with a set of detailed examination guidelines (as given in the 5-step BSE technique) women become more positive and enthusiastic towards BSE. Particularly, the women in this exploratory study felt the 5-step technique was something that could be a useful teaching tool that could improve their current BSE techniques and aid the actual BSE process when used as a step-by-step guide. Furthermore, for some of those not engaging in BSE, the steps provided them with the necessary knowledge to start examining their breasts; many of those not currently examining felt that this knowledge would enable and encourage them to do so. Therefore, it appears that a major obstacle preventing BSE performance in women is their lack of knowledge and skills. It is expected that when they have developed or acquired these women can move away from an avoidance-coping strategy and can, instead, be encouraged to engage in BSE regularly. It is therefore important to determine how women can develop the required knowledge and skills in an appropriate and successful manner.

Research on BSE training demonstrates that instruction and training in BSE is well received by most women and that they can be trained to improve the accuracy of their examination technique and to enhance their perception that they have the skills to successfully examine their breasts (Leight & Leslie, 1998; Stefanek, Wilcox & Huelskamp, 1992; Strickland, Feigl, Upchurch, King, Pierce & Grevstad et al., 1997; Valdez, Banerjee, Fernandez & Ackerson, 2001). This study explores two BSE teaching materials namely a

video-enhanced and a static presentation of the 5-step model (Appendices 13 and 14 present these teaching materials).

The term multimedia may mean different things to different people in different settings. For the purpose of this discussion multimedia is defined as the presentation of material through printed or spoken text, static graphics and animation or video.

There is a growing body of evidence that demonstrates the beneficial effects of multimedia on learning (Mayer, 2001). In certain circumstances, cognitive theorists and researchers have demonstrated improved learning outcomes with the use of multimedia tools (Wilijer & Catton, 2003). Mayer (2001) has created several learning experiments and shown that multimedia works – that is at least in the case of scientific explanations, adding illustrations to text or adding animation to narration can help students to better understand the presented explanation (Mayer, 2001). This too may be true for the learning of BSE.

Multimedia learning materials that are designed in the light of how the human mind works are more likely to lead to meaningful learning than those that are not (Mayer, 2001). A cognitive theory of multimedia learning (illustrated visually in Figure 4) assumes that the human information-processing system includes dual channels for visual/pictorial and auditory/verbal processing, that each channel has limited capacity for processing, and that active learning entails carrying out a coordinated set of cognitive processes during learning. According to this theory, for meaningful learning to occur in a multimedia environment, the learner must engage in five cognitive processes: (1) selecting relevant words from the presented text or narration for processing in verbal working memory, (2) selecting relevant images from the printed illustrations for processing in visual working memory, (3) organising the selected words into a coherent verbal representation, (4) organising selected images into a coherent visual representation, and (5) integrating the visual and verbal representations and prior knowledge.

Image removed

*Figure 4: An illustration of the cognitive theory of multimedia learning. Source: *Multimedia Learning* (p.44), by R.E. Mayer (Ed.), 2001, New York: Cambridge University.*

These processes do not necessarily occur in linear order, so a learner might move from process to process in many different ways. Successful learning from media requires that a learner coordinates and monitors these five processes (Mayer, 2001). When words and pictures are both presented, individuals have an opportunity to construct verbal and pictorial mental models and to build connections between them. When words alone are presented, an individual has the opportunity to build a verbal mental model but are less likely to build a pictorial mental model and make connections between the verbal and pictorial mental models. Based on this principle, the multimedia BSE support materials used in this study presented both verbal and pictorial material. More specifically, pictures and text were presented within the static BSE support, and video and text within the video-enhanced BSE support.

Digital media have become an important and powerful tool of communication in health (Wong 2006), and the provision of health-care information can be greatly enhanced by the use of electronic multimedia information programmes (Dionisio, Bui, Johnson, Thompson & Sinha, 2002). An electronic multimedia programme is a computer-based application that combines text, sound and graphics, video and interactivity, which serve to reinforce and

complement one another to facilitate learning. Electronic multimedia programmes presently offer the most comprehensive method of information provision and address several of the shortcomings associated with other media such as printed informational sheets (Flynn, van Schaik, van Wersch, Ahmed & Chadwick, 2004). They allow a particular user to dictate the pace, type and the order that information is viewed within the programme and can engage the user's interest perhaps more than a static paper version would. Moreover, they can be shaped to reach the target audience (O'Donnell, Doval, Duran & O'Donnell, 1995), can provide women with substantial information and practical advice in a short period of time (Thomas, Daley, Perryman & Stockdan, 2000), and can be presented to otherwise unreachable audiences in 'teachable moments' (Yancey & Walden, 1994; Yancey, Tanjasiri, Klein & Tunder, 1995).

Research into multimedia BSE programmes is limited, but initial findings are encouraging. Multimedia video programmes have been linked to an increase in BSE proficiency, increased confidence in performing BSE, increased knowledge about breast cancer and an initiation of adaptive coping responses (Fry and Prentice-Dunn, 2006; Wood, 1996). Wood (1996) explored the efficacy of using video self-instruction kits (containing an instructional video, printed educational materials, a miniature lump model and BSE skill checks) to increase BSE proficiency and knowledge about breast cancer in women aged 60 years and over. The effectiveness of this intervention was demonstrated in terms of increased knowledge about breast cancer and increased proficiency in BSE skills and lump detection. In this entirely self-taught educational programme using video-instruction, participants apparently learned the basic skills and knowledge needed and retained this throughout the second testing. The significant improvement in skill scores indicated that exposure to the intervention was effective in teaching the steps of BSE and the more complicated task of using the skills to find hidden lumps in the simulation models. Not only

did these women demonstrate improved skill, but they were able to use the skills to find lumps, the main objective in performing BSE.

Similarly, positive results of educational BSE interventions have also been demonstrated in younger women. Fry and Prentice-Dunn (2006) explored the effect of an educational intervention targeting breast cancer on the coping styles of college students. Participating in the intervention group significantly reduced the use of avoidance, hopelessness and fatalistic religiosity in response to information about breast cancer and led to higher behavioural intentions and more rational problem solving than occurred in the control condition. Furthermore after three months, intervention participants reported higher confidence in performing BSE and a trend towards at least irregular BSE compared with control participants. Whilst it does need to be noted that both groups reported similar incorporations of BSE into their routine and a similar consistency of BSE performance, this may be due to the dichotomous measure used not being sufficiently sensitive. Measuring the actual frequency of BSE may have provided a clearer picture of the intervention's impact. Despite this, it appears that an educational intervention such as this can initiate adaptive coping and decrease maladaptive responses at least over a short-term period and this can encourage positive BSE behaviour.

It does, however, need to be noted that the authors in both studies presented information in several formats and therefore participants may have behaved differently from how they would have done if simply presented with a multimedia video BSE programme. Wood (1996) employed an instructional video, printed educational material, a miniature lump model and BSE-skill checks, whilst Fry and Prentice-Dunn's (2006) intervention contained an essay, testimonial video and group discussions. Individuals, therefore, had several opportunities to learn about BSE and perhaps this led to a deeper processing of the information than would have occurred when presented with information in one format, for

example a multimedia BSE video programme. Indeed, Fry and Prentice-Dunn note that their study indicates that all components played a substantive role in altering attitudes towards BSE. Nevertheless, the studies demonstrate that when BSE information is presented in an appropriate manner, it has the potential to encourage BSE. Furthermore, positive results have been demonstrated when comparing a multimedia training programme with a pamphlet (Reis, Trockel, King & Remmert, 2004) and a video-taped programme with no intervention (Janda, Stanek, Newman, Obermair, Trimmel, 2002).

Reis et al. (2004) examined the effectiveness of a computer-based training lesson on BSE compared to a standard pamphlet in 58 women within a community-based health centre. The lesson addressed the following topics: (1) the benefits of BSE with three moving video testimonies from women and one from a health-care professional on the value of BSE, (2) how to perform BSE with information on the signs of breast cancer and an interactive session with a breast model, (3) what to do if a lump is found, and (4) fourteen frequently asked questions about breast care and breast cancer with answers. A positive impact of this brief interactive intervention was demonstrated, with women in the intervention group reporting an increase in self-efficacy to perform BSE following the 20-minute computer programme.

Similarly, Janda et al. (2002) investigated the effect of a video-taped BSE education session on actual BSE behaviour in the pre-menopausal women patients of five specialists in obstetrics and gynaecology in Austria. The video-taped BSE session consisted of a 15-minute video addressing the following topics: breast-cancer incidence, screening methods for early detection and the benefits of BSE and how to perform BSE correctly, including a woman performing BSE and explaining all her movements confidently. The video also presented guidelines about necessary actions to be taken if a change in the breasts was noticed. Women receiving the videotaped BSE intervention

performed BSE more often than those who did not at a three-month follow-up. This occurred despite a lower baseline frequency of BSE reported by these women at the start of the study. It appears watching another woman performing BSE and coping well may reduce the uncertainty surrounding BSE, give women the confidence that they too can examine their breasts, and thus alleviate the psychological barriers to performing BSE correctly.

It is, however, worth noting that significant increases in BSE frequency and confidence between baseline and follow-up were also recorded in the women not receiving the video. As the authors themselves recognise, one reason for this increased health-related behaviour may be that the study population is already receptive to screening recommendations. Breast-cancer screening is widely promoted by cancer organisations and therefore the vast majority of the female population may know screening methods such as BSE exist (Janda, Obermair, Haidinger, Waldhoer & Vutuc, 2000; Newcomb, Weiss, Storer, Scholers, Young & Vorgt, 1991). Responding to a questionnaire on BSE, or just being asked to participate in the study may have been sufficient for the control group women to reconsider BSE. However, the increase in BSE adherence was significantly stronger in the group that viewed the video, suggesting the video nevertheless encouraged increased BSE performance.

Although treatment success is high for cancers detected, unfortunately opportunities to effectively detect and treat breast cancer may be being lost because information about BSE is severely lacking or confusing to understand or because current methods fail to create interest within the female population. BSE is a complicated procedure which is not easy to do properly according to both researchers and health professionals (Haji-Mahmodi, Montazeri, Jarvandi, Ebrahimi, Haghghat & Harirchi, 2002). There is a need for BSE to be taught properly in order for women to understand what to do and to feel

confident enough to do so. There may be a better and more efficient way for providers to teach BSE (American Cancer Society, 2001) and this better way may be through the use of a multimedia programme. The research reviewed in this section suggests that a multimedia BSE programme may elicit an interest in those women not currently engaging in BSE at all or regularly and can teach them the skills needed to perform BSE in a clearer and perhaps more enjoyable way. Therefore, this study aimed to achieve an improvement in women's BSE through the development and the use of a multimedia BSE support programme, comparing static and video-enhanced formats of the support.

3.2 Autobiographical Accounts

Autobiographical accounts of illness and disorders have enjoyed high popularity in the past decade. There has been a surge of various kinds of publications about all sorts of conditions and written from the point of view of all those concerned with the condition. Research suggests that individuals with diseases such as breast cancer are increasingly using online media to engage in health-related social networking, provide support and share stories (Fox, Purcell & Pew, 2010; Rodgers & Chen, 2005). Further to this, a growing number of cancer organisations (for example the American Legacy Foundation 2011, the American Cancer Society, 2011, and the Lance Armstrong Foundation, Live strong, 2011) are starting to use patients' accounts as communication devices, to learn about cancer, deal with a diagnosis, provide inspiration, support and hope, and raise public awareness. The American Legacy Foundation's Legacy for Health "Letters" campaign features farewell letters of four women battling terminal tobacco-related cancers, with the goal of raising public awareness of the dangers of smoking and encouraging people to quit, the American Cancer Society's "Stories of Hope" series offers a repository of video-taped survivors' stories across different cancer topics, intended to provide inspiration, hope, and support and in their "Survivor Interviews" series, The Lance

Armstrong Foundation Live Strong features 200 video-taped cancer narratives of men, women, and caregivers and invites people to watch the survivors' stories to learn about cancer, to deal with a diagnosis and to hear firsthand about their experiences.

At present there is a large amount of autobiographies written by breast-cancer patients and survivors available but little is known about the potential effects these may have on those viewing them, particularly in relation to BSE. Research using autobiographical accounts has tended to focus on individuals who have already developed cancer (Bellizi, Blank & Oakes, 2006), and the potential preventive function of such accounts neglected. However, initial research findings demonstrate autobiographical accounts can be beneficial in promoting breast-screening, particularly that of mammography and BSE (Erwin, Spatz, Stotts, Hollenberg & Deloney, 1996; Erwin, Spatz, Stotts & Hollenberg, 1999). Findings from the Witness Project, a community and church based programme aimed at increasing mammography and BSE, among low-income African-American women in rural Arkansas and in which, local breast and cervical cancer survivors talk about their cancer experiences to small groups of women in churches and other community settings, demonstrated that self-reported mammography and BSE use increased following the project (Erwin et al., 1996, 1999). One possible explanation, of the autobiographical accounts effectiveness in encouraging positive breast-screening behaviours is that the direct experience of cancer of the women within the accounts makes them a credible source of information. Moreover, due to the local nature of the women within the accounts, women may be more able to identify with them and perceive themselves as being vulnerable to breast cancer, and able to engage in breast-screening methods because these women are able to. Indeed, a qualitative evaluation of the programme highlighted that the Witness role models were trusted and seen as truthful largely because they were perceived as having similar cultural values (Bailey, Erwin &

Belin, 2000). Whilst the results of the witness project are limited, in their focus of African-American women and considering, the ethnic differences demonstrated within the breast-screening literature (Champion & Menon, 1997; Foxall, Barron & Houfek, 1998; Friedman, Moore, Webb & Puryear, 1999; Wardle, Steptoe, Smith, Groll-Knapp, Smith & Brodziak, 1995), the findings nevertheless highlight the potential preventative function of autobiographical accounts.

The theory of self-efficacy (Bandura, 1997) may provide a framework for understanding the potential role of autobiographical accounts in breast health-promotion. The theory is derived from social learning theory which encompasses the areas of developing competencies, motivational influences and self-regulation of behaviour. Self-efficacy focuses on one's expectations and beliefs about their ability to competently perform specific actions that will consequently produce desired outcomes. According to this theory individual self-efficacy beliefs are constructed from four principle informational sources: enactive mastery experience, vicarious experiences, verbal persuasion, and physiological and affective states. Ultimately, an individual will choose to engage in a specific behaviour if they believe they are competent in performing the behaviour and that it will have a positive outcome or consequence (Bandura, 1997). Vicarious experience using models can serve as an effective tool for promoting self-efficacy beliefs in others (Bandura, 1997). Through watching the autobiographical accounts women may identify with the women, within the accounts and perceive themselves as also capable of making decisions and performing specific practices related to their own breast health.

Observing women discussing the importance of breast awareness and how they themselves discovered breast cancer through methods such as BSE may highlight that breast awareness is relevant to them and that they too are capable of engaging in breast-screening methods such as BSE. Similarly, observing women discussing their experience

of breast cancer and coping well may reduce the uncertainty surrounding breast cancer and therefore alleviate some of the psychological barriers to performing BSE.

Furthermore, observing a person of similar age discussing their experience of breast cancer may highlight their own vulnerability to the disease and give them the motivation they perhaps need to engage in BSE. When diagnosed with an illness people become very motivated to change their behaviour (Alfano, Day, Katz, Herndon, Bittoni, Oliveri et al., 2009; Mullens, McCaul, Erickson & Sandgren, 2004; Rabin & Pinto, 2005), but by then it may be too late. Instead of waiting until a person becomes ill, autobiographical accounts may serve a preventative function and almost simulate this diagnosis, giving them the motivation needed.

The term 'teachable moment' describes naturally occurring life transitions or health events that have the potential to motivate individuals to spontaneously adopt risk-reducing or health-protective behaviours (McBride, Emmons & Lipkus, 2003). Researchers suggest that a cancer diagnosis can be a 'teachable moment' (Demark-Wahnefried, Aziz, Rowland & Pinto, 2005; Ganz, 2005) in that the diagnosis of cancer itself often represents an event that prompts spontaneous changes in health behaviours among cancer patients and survivors (Demark-Wahnefried et al., 2005; Park, Edmondson, Fenster & Blank, 2008). Perhaps viewing autobiographical accounts may provide this 'teachable moment' too and prompt the women to not only think differently about breast cancer and BSE, but encourage them to adopt BSE. Indeed, research suggests breast-cancer survivors report a much higher level of BSE (76%, Trask, Pahl & Begeman, 2008) than is typically reported in the general population, most likely because of their breast-cancer diagnosis. Perhaps a similar increase in BSE may be produced through simulating this motivational response with the autobiographical accounts.

Furthermore, through the autobiographical accounts women may be educated about breast cancer and the experience of breast cancer, perhaps dismissing myths and misconceptions, some of which may be preventing BSE. Moreover, these accounts may highlight that there is life after breast cancer: it does not have to result in death and, indeed, there can be some positive aspects to being diagnosed. Observing women speaking positively about their experience of breast cancer may alleviate some of the concerns the women have, perhaps concerns that are preventing them from engaging in BSE.

Autobiographical accounts may serve a preventative function through highlighting an individual's own vulnerability to developing breast cancer and alleviating some of the psychological barriers to performing BSE, both of which may in turn encourage BSE. This study aimed to explore this preventative function, comparing BSE beliefs and behaviour with and without the viewing of autobiographical accounts.

3.3 Online Data Collection and Blog Communication

With the recent advances in computer technology and access to the Internet, patients and medical professionals are increasingly turning to the use of computers to obtain and deliver patient-centred care information (Fotheringham, Owies, Leslie & Owen, 2000; Gustafson, Bosworth, Hawkins, Boberg & Bricker, 1992; U.S. Department of Health and Human Services, 2000; Institute of Medicine, 2002). The use of web-based interventions broadens the reach and increases the translation of these patient education tools into practice in all settings (Fleisher, Buzaglo, Colins, Millard, Miller & Eglestonet al., 2008).

As the use of the Internet increases (according to recent estimates over 65% of people in the UK are using the internet at home [National Statistics, 2009] and many of these may have looked on line for health information), the opportunity for broad dissemination of

proven interventions is ripe. Moreover, web-based approaches provide a communication channel that is easily accessible for most people, through their home, work or local libraries. The Science Panel on Interactive Communication and Health (Health Gov, 1999; Robinson, Patrick, Eng & Gustafson, 1998) suggest the value of interactive health communication in improving knowledge and health-behaviour skills (Lewis, 1999). Specifically, patients with cancer commonly use the Internet to access disease and treatment-related information (Chen & Siu, 2001; Street, 2003; Metz, Devine, DeNittis, Jones, Hampshire, Goldwein & Whittington, 2003; Monnier, Laken & Carter, 2002; Aspden & Katz, 2001; Fogel, Albert, Schnabel, Ditkoff & Neugut, 2002; Eysenbach, 2003) and report receiving some benefit of finding health information and support on line (LaCoursiere, Knobf & McCorkle, 2005). Furthermore, there is evidence for high acceptance of multimedia interactive programmes to enhance treatment decision-making among prostate-cancer patients (Diefenbach & Butz, 2004), and for the effectiveness of a web-based intervention on behavioural outcomes (Wantland, Portillo, Holzemer, Slaughter & McGhee, 2004).

The use of electronic data collection methods in a research project allows people in different geographic areas to communicate and exchange their experiences and opinions without long-distance travel. Studies in which electronic data collection methods have been used have demonstrated the feasibility of these methods, the richness of electronically collected data, the informative and prompt responses of research participants and decreased human errors; for example, options are available to prevent participants from proceeding within the study if they have failed to respond to all of the questions or items (Curl & Robinson, 1994; Fawcett & Buhle, 1995; Lakeman, 1997; Stanton, 1998).

Among various electronic data collection methods, message boards (online forums) are prominent in terms of allowing asynchronous interactions through which participants can (anonymously, if appropriate) join in discussions at their convenience, unlike other methods requesting synchronous interactions (for example chat groups). Asynchronous online forums have been reported to be observable, relatively easy to use, accessible and safe (Anderson & Kanuka, 1997; Hsiung, 2000). Furthermore, they have been reported to provide a more facilitating forum for some people to discuss sensitive personal health issues and have been suggested as a feasible alternative to traditional face-to-face focus groups (Campbell, Meier, Carr, Enga, James & Reedy et al, 2001). The effectiveness of the emotional and informational support that online forums provide has been reported (Hsiung, 2000) and the same may apply to personal blogs.

Internet-based health information can enable people to interact with many others despite constraints of distance. Computer provided information may be expected to become an important factor that affects health-behaviour. Indeed, the Internet is used by breast-cancer support groups as a new way to seek health information and become empowered through the use of technology (Klemm & Nolan, 1988). This too may be true for BSE. The Internet allows for two-way communication, so that women may express their fear of finding a lump or confusion with BSE, and discuss and solve such problems through cyberspace, in a more pleasant and (if appropriate) anonymous manner.

Despite these positive aspects of computer-mediated communication, little is disseminated widely about the practical issues of using it for data collection, especially in a research setting. In the past decade there has been a tremendous increase in Internet use and computer-mediated communication (Fox, Rainie, Larsen, Horrigan, Lenhart, Spooner et al., 2001; Nie & Erbring, 2000; Nie, Hillygus & Erbring, 2002) and, as an increasing amount of communicative activity takes place through this new medium, it is of

interest to evaluate it within a research setting. Consequently, this study explores online data collection and the potential of blogs as a recording and communication tool.

3.4 Conclusion

Providing women with the necessary knowledge and education to perform BSE may encourage them to examine their breasts comprehensively. Although treatment success is high for cancers detected, unfortunately opportunities to effectively identify and treat breast cancer may be lost when information about BSE is severely lacking or confusing to understand, or when current methods fail to provoke the interest of the female population. A multimedia support BSE programme may offer a more concise, efficient and interesting method of BSE guidance and may provide women with the skills needed to perform proficient breast exams in a clearer and more enjoyable way. This study aimed to examine this through the development of a novel multimedia BSE support programme based on the 5-step BSE technique. The support aimed to develop women's skills of using BSE-techniques, as well as their knowledge through the use of performance enhancement tools, such as images within the static version and video and interactivity within the video-enhanced.

Furthermore, some women may neglect to examine their breasts because of a lack of perceived vulnerability to breast cancer or because of misconceptions connected to the disease. Viewing autobiographical accounts of breast-cancer patients may provide the motivation the women perhaps need to examine their breasts. By finding recognition in the stories, the women's own vulnerability to developing breast cancer may be alerted and this in turn may motivate them to take preventative action. If autobiographical accounts could alleviate some of the psychological barriers to performing BSE then they may serve as an important tool that could be applied in breast-health-promotion campaigns. This study aimed to explore the effects of viewing autobiographical accounts from breast-

cancer patients on women's knowledge, beliefs about and behaviour related to breast cancer and BSE.

Finally, despite the positive aspects of computer-mediated communication, little is disseminated widely about the practical issues of use for data collection, especially in a research setting. The past decade has seen a tremendous increase in Internet use and computer-mediated communication (Fox et al., 2001; Nie & Erbring, 2000; Nie et al., 2002); nonetheless, research evaluating these initiatives is still sparse. Taking this into consideration, this study aimed to explore and evaluate the effectiveness of online data collection and the use of blogs as a recording and communication tool.

3.5 Chapter Summary

In this chapter, the literature surrounding multimedia programmes, autobiographical accounts and online data collection was reviewed. The potential of autobiographical accounts and multimedia programmes in influencing women's beliefs about and behaviour related to breast cancer and BSE was examined. Finally, the utility of conducting research within an online setting was considered and the need for more research surrounding the practical issues of online data collection highlighted.

CHAPTER FOUR

Breast-cancer Risk Factors and Demographics Related to BSE Practice

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4.0 Chapter Overview

Breast-cancer risk factors and demographic characteristics may be important when considering breast self-examination (BSE) practice. They may heighten an individual's level of perceived risk of breast cancer and may influence their thoughts and behaviour towards BSE. This chapter presents an overview of the risk factors to breast cancer and demographic variables that may be important when considering BSE practice; and considers the effect these may have on BSE behaviour.

4.1 Risk Factors for Breast Cancer

Whether persons view themselves at risk for breast cancer may influence their decisions to engage BSE or not. Risk factors may heighten individuals' perception of their risk of breast cancer and encourage them to examine their breasts or alternatively this awareness may cause the individual to become anxious and avoid BSE altogether. Genetics, family history, gynaecological history, and demographic and environmental factors influence the risks of developing cancer. More specifically, research has established the following risk factors to be associated with breast cancer; gender, age, family history, age at menarche and menopause, oral contraception usage and breast tissue density.

4.1.1 Gender and Age

Being female is the most important factor for breast cancer with the risk for females being 100 times that of males (Medline Plus, 2005). Second to gender is age; with advanced age, cells have naturally undergone more divisions and can be replicated in an uncontrolled fashion, leading to dysplasia (or abnormal development) of breast cells. Following this, the incidence of breast cancer increases with age; doubling about every 10 years until the menopause, when the rate of increase slows dramatically (McPherson, Steel & Dixon, 2000).

4.1.2 Family History

Up to 10% of breast cancer in Western countries is due to genetic predisposition.

Breast-cancer susceptibility is generally inherited as an autosomal dominant with limited penetrance. This means that it can be transmitted through either sex and that some family members may transmit the abnormal gene without developing cancer themselves. It is not yet known how many breast-cancer genes there may be. Two breast-cancer genes, BRCA1 and BRCA2, which are located on the long arms of chromosomes 17 and 13 respectively, have been identified and account for a substantial proportion of very high risk families; in other words those with four or more breast cancers among close relatives.

Most breast cancers that are due to a genetic mutation occur before the age of 65, and a woman with a strong family history of breast cancer of early onset who is still unaffected at 65 has probably not inherited the genetic mutation (McPherson et al., 2000). The lifetime breast-cancer risk in a woman carrying BRCA1 or BRCA2 is 40 to 65% and if an individual carries either of these genes, there is a 50% chance that her offspring will inherit these genes (Staton, Kurian, Cobb, Mills & Ford, 2008).

Breast-cancer risk is increased for women having a first-degree biological relative (mother, sister, or daughter) or a second-degree relative (grandmother, aunt, or niece) with the disease (McPherson et al., 2000; Paley, 2001). A woman's risk of breast cancer is two or more times greater if she has a first-degree relative (mother, sister, or daughter) who developed the disease before the age of 50, and the younger the relative when she developed breast cancer the greater the risk. For example, a woman whose sister developed breast cancer aged 30-39 has a cumulative risk of 10% of developing the disease herself by age 65, but that risk is only 5% (close to the population risk) if the sister was aged 50-54 at diagnosis. The risk increases by between four and six times if two first-degree relatives develop the disease. For example, a woman with two affected relatives, one who was aged under 50 at diagnosis, has a 25% chance of developing breast cancer

by the age of 65. In general terms, the more biological relatives with breast cancer; especially relatives who were diagnosed before the age of 50, the higher a woman's breast-cancer risk (McPherson et al., 2000).

4.1.3 Age at Menarche and Menopause

A thorough gynaecological history can help determine an individual's risk of breast cancer. Both the age at menarche and the age of menopause influence breast-cancer risk due to the increased time that the body is exposed to Oestrogen (Phipps, Malone, Porter, Daling & Li, 2008). Women who start menstruating early in life or who have a late menopause have an increased risk of developing breast cancer. According to Paley (2001), females who start menarche between the ages of 11 and 14 carry an increased risk of breast cancer of up to 30% compared to those whose onset of menses occurs at 16 years of age. A woman's age at menopause can also affect breast-cancer risk. Women who have a natural menopause after the age of 55 are twice as likely to develop breast cancer as women who experience the menopause before the age of 55 (McPherson et al., 2000; Paley, 2001).

4.1.4 Oral Contraceptive Use

While women are taking oral contraceptives and for 10 years after stopping these agents, there is a small increase in the relative risk of developing breast cancer but there is no significantly increased risk of having breast cancer diagnosed 10 or more years following cessation of the oral contraceptive agent. Cancers diagnosed in women taking the oral contraceptive are less likely to be advanced clinically than those diagnosed in women who have never used these agents. Duration of use, age at first use, dose and type of hormone within the contraceptives appear to have no significant effect on breast-cancer risk. Women who begin use before the age of 20 appear to have a higher relative risk than women who begin oral contraceptive use at an older age. This higher relative risk applies

at an age when the incidence of breast cancer is, however, very low (McPherson et al., 2000).

4.1.5 Breast Tissue Density

Women with mammographically dense breast tissue have an increased risk of developing breast cancer. Studies using quantitative methods for defining breast density report a 4 to 6 times increase in relative risk in women with the most dense breasts compared with those with little tissue density (Korde, Calzone & Zujewski, 2004). The determinants of breast tissue density are not fully defined but include age, oestrogen exposure and family history (Korde et al., 2004). Furthermore, having dense breast tissue can pose problems during mammogram assessment due to its similar appearance to breast cancer; therefore, some cancers in dense breast tissue may be undiscovered. Those women aware of this issue may subsequently view breast cancer and BSE differently and place a higher value on BSE.

An individual's perceived risk may depend on the number of these breast-cancer risk factors relevant to themselves. This study considers this, noting the risk factors relevant to each of the study individuals and exploring the potential effect of these risk factors on their beliefs and behaviours towards breast cancer and BSE and subsequent BSE behaviour.

4.2 Demographics Related to BSE Practice

Similarly, and perhaps more important, ethnicity, age and educational level have been linked to BSE behaviour. Research suggests women's BSE behaviour depends on the ethnic group they belong to, their age and finally their level of school education.

4.2.1 BSE and Ethnicity

Ethnic-minority women, in particular, tend to examine their breasts the least (Calle, Flanders, Thun & Martin, 1993; Estrada, Trevino & Ray, 1990; Giuliano, Papenfuss, de

Guernsey de Zapien, Tilousi & Nuvayestewa, 1998), and this may result in their lower survival and higher mortality rates compared to Caucasian women. Chen, Correa, Kurman, Wu, Eley and Austin (1994) suggest that approximately 75% of the racial differences in breast-cancer survival rates may be explained by the stage at diagnosis, specific characteristics of the tumour, the presence of additional illness and socio-demographic factors.

The frequency of BSE performance varies across ethnic and racial groups (Champion & Menon, 1997; Foxall, Barron & Houfek, 1998; Friedman, Moore, Webb & Puryear, 1999; Wardle, Steptoe, Smith, Groll-Knapp, Koller, Smith & Brodziak, 1995) although there are exceptions (Douglass, Bartolucci, Waterbor & Sirles 1995) and the findings are complex. Statistics related to breast-cancer incidence, mortality and survival reveal a disparity between Caucasian and African-American women. Even though the incidence of breast cancer is 20% higher in Caucasian women than in African-American women, African-American women experience higher mortality and lower survival rates (NABCO, National Alliance of Breast Cancer Organizations, 1995; American Cancer Society, 1996). Furthermore African-American women are more likely than Caucasian women to be diagnosed with larger tumours that are at more advanced stages (Ghafoor, Jemal, Ward, Cokkinides, Smith & Thun, 2003; Li, Malone & Daling, 2003). The survival rate is almost 98% for women diagnosed with the earliest stage of breast cancer but only 26% for women diagnosed with the most advanced stage (American Cancer Society, 2005). This disparity may be due to different screening behaviours among differing ethnic groups.

Breast-cancer screening is essential to detect any abnormality or tumour at the earliest stage possible and it may be that a difference in this screening behaviour exists between Caucasian and African-American women. This may explain the increased advanced stage of breast cancer in African-American women, which in turn may cause the higher mortality and lower survival rates for this group of women. Indeed evidence suggests that early

detection would significantly reduce the mortality and morbidity numbers of African-American women (Frisby, 2002). Moreover it has been suggested that for these women to survive at rates comparable to Caucasian women, the health-care system and mass media need to provide information to African-American women to motivate them to conduct examinations earlier and to seek medical assistance so that the disease might be detected at an earlier stage (El-Tamer, Homel & Wait, 1999).

Researchers have examined a wide variety of factors that may serve as barriers to breast-cancer screening in African-American women. Psychological responses such as fear, fatalism and misperceptions about the disease have been identified as personal factors that inhibit them from participating in cancer-related health-promotion behaviours (Cardwell & Collier, 1981; Long, 1993). Other research into breast cancer specifically identifies a lack of knowledge about breast cancer and breast-cancer screening, fear of finding a cancerous lump and distrust in the health-care system and providers as major barriers to screening (Long, 1993; Phillips & Wilbur, 1995). Furthermore, factors such as beliefs in the efficacy of disease prevention behaviours, perceived threats and feelings of personal susceptibility, and methods of the communication of cancer-related information have also been cited as influences of health-promotion behaviours among black women (Denniston, 1981). More recent literature on mammography use in the African-American population identifies some very specific barriers that may work to prevent engagement in regular mammography. These include: spirituality, concern about the discomfort associated with mammograms and other preventative measures, misconceptions and a lack of factual knowledge about breast cancer, negative feelings related to death, fear and loss of breasts and/or hair and perceived non-susceptibility (Burnett, Steakley & Tefft, 1995; Clarke-Tasker, 1993; Frisby, 2002; Price, Desmond, Slenker, Smith & Stewart, 1992; Royak-Schaler, DeVellis & Emerson, 1995). Such barriers may also be relevant when explaining BSE behaviour.

Contrastingly, several studies have shown that women from minority groups report more-frequent BSE than their majority counterparts (Foxall et al., 1998; Freidman, Webb & Weinberg, Lane & Cooper, 1995; Morrison, 1996). For example, African-Americans have reported more frequent BSE than Caucasians (Celentano & Holtzman, 1983; Douglass et al., 1995; Epstein, Lin, Audrain, Stefanek, Rimer & Lerman, 1997; Hughes, Lerman & Lustbader, 1996; Harris, Miller & Davis, 2003). Similarly, others have found that more African-American or non-white women than Caucasian women practised BSE monthly (Celentano & Holtzman, 1983; Dickson, Paesons, Greaves, Jackson, Kronenfeld, Ward et al., 1986; Douglass et al., 1995) with the percentage of African-American women practising BSE monthly ranging between 38.2% and 41%, compared to between 28.7% and 31% for Caucasian women (Douglass et al., 1995; Vernon, Vogel, Halabi, Jackson, Lundy & Peters, 1992).

Likewise, other studies suggest that Hispanic and Native American women may also differ in this regard, showing that Hispanic, Native American and African-American women practise BSE more frequently than white women (Friedman et al., 1995; Foxall, Barron & Houfek, 2001). More specifically, Foxall et al. (2001) found Hispanic women practised BSE significantly more often than Caucasian women, whereas Native American women practised significantly more often than Caucasian and African-American women. Of particular note was that African-American, Hispanic and Native American women practised BSE more than once a month, with Native American women reporting a mean of 53 BSEs within the previous year. This increased BSE practice may be related to greater concern and anxiety about personal risk of breast cancer (Hughes et al., 1996). Indeed, Foxall et al.'s (2001) findings offer support for this assumption demonstrating that Native American women reported more anxiety than Caucasian and African-American women, and Hispanic women reported more anxiety than African-American women. Hispanic

women also perceived greater risk for breast cancer than Caucasian and African-American women.

Conversely, however, some studies have shown Hispanic women to be less likely to report having conducted BSE (Vernon et al, 1992), and have found no differences in BSE frequency between Hispanic and Black women (Ganesan, Teklehaimanot, Akhtar, Wijegaranatre, Thadepalli & Ganesan, 2000). Similarly Kaplan, Weinberg, Small and Herndon (1991) noted that Caucasian women performed monthly BSE more frequently than non-white women. Reports of studies related to breast-screening, particularly BSE, appear inconsistent. Whilst it does need to be noted Kaplan et al. did not report whether their finding was statistically significant and their sample was limited to relatives of women with breast cancer, which in itself may have an effect on BSE behaviour there is nevertheless evidence to suggest ethnicity influences breast-cancer screening, just perhaps how remains unclear.

Several community surveys reveal that Asian-American women, have lower adherence to breast-cancer screening than their Caucasian counterparts (Hiatt, Pasick, Perez-Stable, McPhee, Engelstad, Lee et al., 1996; Jenkins & Kagawa-Singer, 1994). Hiatt and colleagues (Hiatt et al., 1996) surveyed Caucasian, African-American, Latina and Asian-American women aged 18-74 and found that Chinese and Vietnamese women have the lowest rates of first-time utilisation and recent utilisation of mammography, clinical breast exams (CBE) and BSE. Moreover, there is evidence to suggest Chinese-American women report significantly lower perceived susceptibility than Caucasian women and recognise the high benefits of carrying out breast-cancer screening behaviour (mammograms in the case of this study, Lee-Lin, 2008).

Research has identified barriers to breast-cancer screening in the general population, include lower income, lower education, minority status, older age, lack of knowledge

regarding screening guidelines, absence of symptoms, lack of recommendation from a health professional, poorer access to health-care, poor memory, pain, embarrassment, fear and anxiety (Calle et al., 1993; Epstein et al., 1997; Friedman, Nelson, Webb, Hoffman & Baer, 1994; Fox, Murata & Stein, 1991). In addition to these common barriers, ethnic minorities may encounter cultural barriers to breast-cancer screening (Morisky, Fox, Murata & Stein, 1989; Richardson, Marks, Solis, Collins, Birbab & Hisserich, 1987), which in turn may affect their behaviour.

Culture plays an important role in shaping one's beliefs about health and illness (Tang, Solomon & McCracken, 2000). With regard to Chinese culture, beliefs about health and illness are not only conceptualised differently from those in Western culture, but also may conflict with the Western health-care paradigm. Cultural beliefs that may contribute to the delay or failure to participate in cancer-screening include: (a) the use of Eastern approaches to medicine (Lum, 1995); (b) a lack of prevention orientation for health-care services (Lum, 1995); (c) modesty around sexuality, reproductive organs, and the body (Lum, 1995); and (d) reliance on family when seeking medical care (Seow, Straughan, Emmanuel, Tan & Lee, 1997).

The use of Eastern approaches to promote health and prevent illness may act as a barrier to cancer-screening. Eastern approaches to treatment typically include non-invasive and natural remedies such as herbal medicine, whilst Western approaches use more invasive or chemically based therapies such as surgery or drugs (Tang et al., 2000). Historically, Chinese people sought traditional healers such as herbalists and acupuncturists to treat illness before considering Western approaches to treatment (Kraut, 1990). Therefore, one may presume Chinese women who retain their traditional beliefs about health may be less likely to seek Western cancer-screening procedures. Indeed research suggests compared to Caucasian people, Asian-Americans are less likely to have had a physical examination

in the past year (Boult & Boult, 1995) and Chinese people tend to use medical services only when experiencing acute illness or pain (Garcia & Lee, 1989).

Although culture can play a pivotal role in shaping health beliefs, it does not automatically determine health-behaviours. The extent to which individuals adhere to their cultural beliefs when engaging in health-behaviours may also be a function of acculturation. Acculturation refers to the process by which an individual's attitudes, beliefs and behaviour become more congruent with that of the dominant society (Tang et al., 2000). Tang, Solomon, Yeh and Worden (1999) examined Asian-American women's cultural beliefs to breast-cancer screening and found those who endorsed more modesty were less likely to have ever performed BSE. Furthermore, the study revealed a positive relationship between acculturation and participation in initial breast-cancer screening, but not for acculturation and breast-cancer screening adherence. It would appear that a Chinese-American woman's level of acculturation is a better predictor of initiation to breast-cancer screening behaviour than of adherence to screening after initial participation. Once introduced into the Western health-care system, acculturation may no longer serve as an important determinant of continued screening.

Similarly, among Latin-American women, the level of acculturation and their specific cultural attitudes and beliefs have been found to be positively associated with breast-cancer screening behaviour (O'Malley, Kerner, Johnson & Mandelblatt, 1999; Suarez, 1994; Laws & Mayo, 1998). This too may be true for other ethnic groups. The level of acculturation amongst the particular population of women in question may influence their subsequent BSE behaviour.

Further conflicting findings are demonstrated in a study by Fletcher, Morgan, O'Malley, Earp, and Degnan, (1989) who reported no relationship between ethnicity and BSE, and from another by Burnett et al. (1995), who found no significant differences in mean

intention scores to perform BSE among Caucasian, African-American, and Hispanic women. The findings of these studies are however limited in that the sample consisted of women over 40 and they assessed intent rather than actual BSE practice. Intentions do not always lead to actual behaviour and may differ considerably.

Nevertheless, a relatively large body of research does suggest that there may be differences within major ethnic groups regarding BSE but the nature of this relationship between ethnicity and breast-cancer screening appears to depend on the ethnic group studied and the screening technique examined. Reconciling discrepant screening-rate findings is complex, and more research is needed before any firm conclusions can be made (Magai, Consedine, Conway, Neugut & Culver, 2004) and at present the inconsistent and conflicting nature of the results prevent one from concluding what differences do indeed exist between the various ethnic groups and why this is the case. Nevertheless, it is apparent that women from different ethnic backgrounds adopt differing screening behaviours. Thus this controls for this, matching women in each of the four experimental groups on ethnicity.

4.2.2 BSE and Age

BSE Practice in Young Women

Women's views vary depending on their life experiences and perceptions and so it is difficult to generalise how women of different ages or in different stages of their lives feel about BSE. Nevertheless, it may be fair to presume the views of younger women differ from those of older women. BSE is of particular relevance to women younger than 50 years due to the infrequency of CBE and the controversy surrounding the effectiveness of mammography in younger women (Crossing & Manaszewicz, 2003). Although these women are at a reduced risk of developing breast cancer than those older than 50 years, tumours that do develop in these younger women are likely to be more aggressive and

have a lower overall survival rate than those found later in life (National Breast Cancer Council, Australia, 2001). For these women, early detection through BSE is important (Crossing & Manaszewicz, 2003), yet they may not realise this due to being young.

Furthermore, it has been shown that young women who perform BSE familiarise themselves with their breast anatomy and this familiarisation assists them in identifying future breast abnormalities. It is also important in establishing health practices that will be particularly helpful when they are older and thus in a greater breast-cancer risk age group (over 45 years; Goldbloom, 1985; Mamon & Zapka, 1986). Moreover, BSE is very important for the detection and monitoring of numerous benign breast complaints which can occur in many age groups (for example cysts, fibro adenomas, diffuse nodularity, mastalgia and abscesses). These conditions, although not life-threatening can be distressing and painful if they are not carefully monitored and subsequently treated appropriately (Fox, Walker, Heys, Ah-See & Eremin, 1997). Moreover, past research has also suggested that mammogram attendance (which is suitable for older women) is associated with practising BSE (Rodriguez, Plasencia & Schroeder, 1995). Thus, one can presume that by encouraging BSE in young women it may, in turn, encourage them to continue their breast-screening in later life and adopt all the relevant breast-screening practices available to them, further adding to the rationale for investigating and encouraging BSE in younger age groups.

Previous breast-cancer research has identified two distinct groups of women: those who are overly worried and feel that they are at a high risk of getting breast cancer, and those who think that it is not going to happen to them (Bryan, 2001; d'Agincourt-Canning, 2006; Epstein, 1997; Siegel, Gluhoski & Gorey, 1999). The general perception is that younger women fall into the latter. Younger women tend to not consider themselves at risk for developing breast cancer, as they believe it is a problem that affects older women (Breast Cancer Network Australia, 1998). Research suggests one of the main reasons that young

women do not perceive themselves to be at risk for breast cancer stems from a very low level of knowledge and understanding about the disease (Paul, 1999; Vahabi, 2005).

Considering this, whilst, mammography is not an accurate screening tool for young women, it is important that young women are targeted for breast-health education programmes. These programmes need to provide information about what is normal and abnormal, explore young women's current knowledge and beliefs, and raise awareness (Baum, Saunders & Meredith, 1994; Vahabi, 2005).

A recent qualitative study by Johnson and Dickson-Swift (2008) explores the knowledge and beliefs in young women 20-25 years and provides more insight into their perceptions of breast cancer and screening behaviours. The young women in their study had very low levels of knowledge about breast cancer and the issues surrounding the disease and this spanned across all areas including what breast cancer is, contributing factors for the development of breast cancer, the risk factors, own personal risk, and who is most affected and why (Johnson & Dickson-Swift, 2008). Likewise, other studies have found that women tend only to be able to identify two main risk factors: age and family history (Bryan, 2001; Epstein, 1997; Siegel et al., 1999; Williams, Clarke & Savage, 2002). These were also the only two risk factors that the participants of Johnson and Dickson-Swift's (2008) study could identify with some confidence. Indeed, this may be why younger women feel less at risk for breast cancer and subsequently feel less need to adopt screening behaviours such as BSE.

There is a significant difference in the perception of risk and the effect that it has on BSE between age groups (Bryan, 2001). Older women, who have a higher perception of risk, are more likely to undertake regular BSE whereas no correlation was found between young women's BSE and their perceived risk (Bryan, 2001). This could be because it is well known by women that the risk of breast cancer increases with age and young women do not feel that they are at risk until they reach an older age. The findings of Johnson and

Dickson-Swift's (2008) offer support for this contention, with the participants in their study reporting they felt that they were not at risk of breast cancer and subsequently saw no need to undertake regular BSE.

Moreover, overall practice rates in young women as reported by previous studies are generally low (Budden, 1995; Cromer, Frankel, Hayes & Brown, 1992; Hailey, 1986; Pitts, McMaster & Wilson, 1991; Wardle, Steptoe, Smith, Groll-Knapp, Koller & Smith, 1995) and significantly lower when compared to the practice of older women (Persson, Svensson & Ek, 1997). Al-Qattan, Al-Saleh, Al-Mussallam & Masoud (2008) compared 357 women performing BSE with 609 women not performing BSE to determine the potential association of age with BSE. The mean age of those practising BSE was 33.4 years (+- 8.9 years) whereas it was 30.5 years (+- 8.5 years) for those who did not and this difference was found to be significant. This finding offers further support for the contention that the older women are, the more likely they are to perform BSE. Moreover, the study further highlighted that women who thought the best age to start BSE was 40 years and above were less likely to practise BSE than those who thought 20 years and above was the best age to start, and the majority of the sample thought the best age to start BSE was 30 years or above (Al-Qattan et al., 2008). It may be this belief that prevents younger women from engaging in BSE and encourages older women to start examining their breasts.

BSE Practice in Older Women

In the United Kingdom, where the age standardised incidence and mortality is the highest in the world there are more than 14,000 deaths each year, and the incidence is increasing particularly among women aged 50-64 years (McPherson et al., 2000). Women aged 50 years and over are routinely invited for a mammogram every three years and so may be more aware of their breast-health generally and its importance. Alternatively, they may

feel there is no need for BSE and instead think that attending their mammographic screening will be enough. Similarly, the elderly population may not feel it is relevant because of their increasing age.

Persson et al. (1997) examined the BSE practice in women aged between 25-80 years of age, and found a larger proportion of middle-aged women (45-64 years of age) and older women (65-80 years of age) practised BSE compared to women aged 25-44 years. The ethnicity of the sample was varied and included women from Europe, Asia, Africa, South America and the Middle East; but all the women were residing in Sweden at the time of the study. Of those women who actually carried out the examination, their frequency of BSE was also related to their age group. Middle-aged and older women practised BSE more than once a month to a greater extent than did the younger women, who practised BSE less than once a month. Furthermore, middle-aged women accounted for about half of those who answered that they perform BSE once a month. The study demonstrates that age constitutes a predictor of whether or not BSE is practised and this applied to all the women included in the study. Similarly, this tendency for middle-aged and older women to practise BSE more frequently than younger (aged 25-44 years) women is further supported by Lauver and Angerame (1990), Funke, Krause-Bergmann, Pabstr and Nave (2008) and Nemcek (1989).

While the proportion of women who practised BSE (in Persson's et al., 1997 study) was larger in the age group 45-64 years, the number of women who did so was smaller in the age group 65-80 years. Indeed, a difference in the beliefs regarding BSE can be expected between not just old and young women, but between middle-aged and older women too. Similarly, Persson et al. (1997) noted a difference between the older and younger women in their study, but in terms of those wishing to take part in an interview about BSE. The older women (65-80 years of age) in their study did not want to be interviewed to the same degree as the younger women (45-64 years of age). It appears something is

preventing this group of women from wanting to talk about and perform BSE in a similar way to women in a younger age group. One possible explanation for this is that the subject of BSE is too sensitive to talk about for this older age group and subsequently too embarrassing for them to examine their breasts. It may be that from a general point of view, older women do not think they can contribute anything to interviews regarding BSE and in this case they may feel embarrassed to talk about BSE. Similarly, they may feel embarrassed to perform BSE or seek guidance about BSE, guidance which they may need in order to implement the BSE procedure. Past research, however, indicates that embarrassment is not a barrier for older women to perform BSE (Baker, 1988) and this explanation would fail to explain why some older women do engage in BSE and engage more than much younger women (aged 25-44 years, Persson et al., 1997). It is also possible that the younger women (aged 45-64) are more aware of breast-cancer prevention, since mammography screening generally comprises these ages, making them more willing to agree to an interview regarding BSE, be more readily available to receive information regarding BSE, and subsequently engage in BSE.

As women age they are at greater risk for developing breast cancer, yet they are less likely to receive routine screening when compared with younger (aged 45-64) women (Persson et al., 1997). Previous researchers have concluded that older women are less likely to practise BSE, have CBE or receive mammograms than younger women (Bernstein, Mutschler & Bernstein, 2000; Burack, George & Gurney, 2000; Mandelblatt, Gold & O'Malley, 1999; McCarthy, Burns, Freund, Ash, Schwartz, Marwill et al., 2000). Furthermore, these inadequate screening practices have resulted in serious outcomes. In a study of mammography use and the stage of breast cancer at diagnosis, women 67 years and older who were non-users of routine mammography screening were diagnosed significantly more often at Stage two breast cancer and subsequently were at higher risk of dying from the disease than regularly screened women (Rawl, Champion, Menon &

Foster, 2000). Those who had never had a mammogram were three times more likely to have advanced-stage breast cancer and die from the disease when compared with those receiving regular screening, and in women aged over 85 years, the risk of late-stage breast cancer rose to seven times greater than in those regularly receiving mammograms. It was concluded that regular mammography screening would reduce the incidence of late-stage diagnosis and subsequent mortality from breast cancer among women 67 years and older. This indeed may also be true for BSE.

As women in the older population are less likely to receive regular breast-cancer screening despite the availability of screening services, there is a need for innovative educational interventions aimed at reaching older women. In order for these interventions to be successful, a greater understanding of BSE beliefs and behaviours in this age group is needed.

Whilst much of the research supports the age differences discussed, this is not true for all the studies into this area. Age has been shown to have a positive relationship (Cole & Gorman, 1984), a negative relationship (Celentano & Holtzman, 1983; Dorsay, Cuneo, Somkin & Tekawa, 1988; Yelland, Rice, Ward, Bain, Siskind & Schofield, 1991) or no relationship at all (Champion, 1992; Clarke & Sandier, 1989; Gray, 1990; Olson & Mitchell, 1989). Nevertheless, a relatively large body of research does suggest that differences between the different age groups regarding BSE exist and, indeed, it seems plausible that a relationship between BSE behaviour and age can be found. The nature of this relationship, however, appears to depend on the age group studied and the screening technique examined.

Whilst most research suggests that younger women (aged 18-44) perform BSE the least and middle-aged women (aged 45-64) the most, with older women (aged 65 onwards) somewhere in between, the conflicting nature of other studies prevents one from

concluding what differences do indeed exist between young, middle-aged and older women and why these differences exist. Nevertheless, it is apparent that for whatever reason, women of different ages think about and adopt screening behaviours differently. Thus, this study controls for this, matching women in each of the four experimental groups on age.

4.2.3 BSE and Educational Level

Previous research has claimed that women in academic environments are likely to be at the forefront of any major changes in health practices because of their greater exposure to information and resources (Pitts et al., 1991). Following this assumption, one may suggest that those with a higher education will be more aware of the importance of breast-screening behaviours and subsequently engage in them more than their less educated counterparts.

Indeed, this is true for both black and white women in relation to mammographic screening. Results from Han, Wells and Primas' (2003) study suggest that white women with less than 2 years of education were 1.72 times more likely to be non-users of mammography than white women with more than 12 years of education, and black women without 12 years of education were 5.6 times more likely to be non-users of mammography than black women with more than 12 years of education. Moreover, higher education has been positively associated with higher screening behaviours for CBE and mammography in women from six ethnic groups (African-American, US born white, English speaking Caribbean, Haitian, Dominican, and Eastern European; Consedine, Magai & Neugut, 2004b).

However, education has shown a more complex relationship with BSE frequency. Some studies have found a positive relationship between education and BSE (Abdel-Fattah, Zaki, Bassili, El-Shazly & Tognoni, 2000; Canbulat & Uzun, 2008; Freidman, Moore,

Webb & Puryear, 1999; Karayurt & Dramali, 2007; Kudadjie-Gyamfi, Consedine, Magai, Gillespie & Pierre-Louis, 2005; Madan, Barden, Beech, Fay, Sintich & Beech, 2000; Seif & Aziz, 2000), while others have indicated the reverse (Funke et al., 2008) or no relation at all (Balogun & Owoaje, 2005; Bennett, Lawrence, Fleischmann, Gifford & Slack, 1983; Chen, 2009).

Friedman et al. (1999) examined breast-cancer screening among women in a general hospital psychiatry clinic and found women who performed monthly BSE were more likely to be educated, more confident in performing BSE and to have had monthly BSE recommended by a doctor than those who did not. However, since the ethnic composition of the sample was predominately African-American and Caucasian psychiatry patients, the generalisability of the findings may be limited to psychiatry patients belonging to these two ethnic groups.

Similar findings have, however, been produced when examining BSE practice in non-psychiatry patients. Madan et al. (2000) examined monthly BSE compliance rates amongst women attending a breast-health clinic and found that women who had completed high school had lower BSE non-compliance rates, (16%) compared to those who had not completed high school, (33%). The ethnic composition of this sample, however, may again limit the generalisability of the findings. Although the sample was not confined to African-American and Caucasian as in Friedman et al.'s study, the sample predominately consisted of these ethnic groups, with 95% of the population belonging to African-American or Caucasian groups. Similarly, the study population included women that were actively taking part in their own health by attending the breast-health centre for a routine screening evaluation. These women may be more motivated to engage in BSE than the general population and, indeed, the authors themselves noted a high rate of BSE compliance in their study population (Madan et al., 2000).

Further support for a positive relationship is offered when looking at the BSE practice of women in Turkey. Karayurt and Dramali (2007) examined BSE practice amongst women living in one of the health-centre areas located in Izmir (West Turkey) whilst Canbulat and Uzun (2008) examined female health workers in Erzurum (East Turkey). A higher frequency of BSE practice amongst high-school-graduate (equivalent to UK A levels) and university-graduate women was demonstrated in women generally (Karayurt & Dramali, 2007) and, similarly, the female health workers performed BSE at higher rates than the general population (Canbulat & Uzun, 2008), perhaps because of their increased education level. All the women included in Canbulat and Uzun's sample held at least a high-school graduate level of education. Moreover, those with a higher level of education (physicians) performed BSE more regularly than women with a lower level of education (nurses or midwives). Further to this, physicians' health motivation, perceived BSE benefits and perceived BSE self-efficacy were higher than that of nurses and midwives, perhaps due to their higher levels of education. It appears that educational level may not only affect BSE behaviour directly, but the beliefs surrounding the behaviour too. However, once again, these findings are limited to these particular groups of women as no demographic data regarding individual ethnicity was provided by the authors of these two studies.

When considering the generalisability of these studies' findings to other ethnic groups, one needs to note that similar significant relationships between BSE and educational level have been found in women across varying ethnic groups. For example, Kudadjie-Gyamfi et al. (2005) examined BSE practices among women from six ethnic groups (European-American, African-American, Eastern Europeans, Haitian, Dominican and English speaking Caribbean) and found that education significantly predicted BSE adherence, regardless of ethnicity, with women with more than a high-school education being almost twice as likely to perform BSE than women with less education. With regards to the

relationship between education and BSE, it may be suggested that ethnicity may not be an influential moderating factor.

BSE has further been found to be positively associated with higher education level in newly diagnosed breast-cancer patients in Egypt (Abdel-Fattah et al., 2000). Although a low level of the patients reported any BSE (10.4%) and even fewer practised it monthly (2.7%), when compared to similar studies in Europe and the USA (O'Malley & Fletcher, 1987; Persson, Johansson & Ek, 1995; Wardle et al., 1995), the levels were comparable to figures reported from Saudia Arabia (Kashgari & Ibrahim, 1996). Thus, one can assume that this low frequency can be attributed to cultural and educational variations.

Moreover, education has been linked to BSE knowledge and accuracy. University graduates have been found to have a greater degree of knowledge of BSE and be more likely to achieve a satisfactory level of BSE practice than secondary-school graduates (Seif & Aziz, 2000). Rather than focus on BSE frequency, Seif and Aziz (2000) assessed the technique and methods used by the women when examining their breasts. This assessment included questions on different positions, sites to be examined, abnormal signs to look for, methods of palpation and warning signs to be urgently reported. BSE was judged satisfactory if a score of 50% or greater was achieved. Following this, their results indicated a higher percentage of the university-graduates (90.1%) achieved a satisfactory level of BSE practice than those graduated from secondary school (74.5%). Whilst again the sample limited the generalisability of the study, given it only consisted of Egyptian women, it nevertheless highlighted the potential effect education level can have on not only BSE frequency but on the quality of BSE practice too.

Awareness of BSE has been further found to be related to educational attainment within female traders in Nigeria (Balogun & Owoaje, 2005). No association however, was demonstrated between level of education and practice of BSE within this study. This

discrepancy in part, may be explained by the very low level of BSE (18.1 %) amongst these women. Their level of BSE was much lower than the levels reported amongst women in other areas of Nigeria. Studies conducted in Port-Harcourt and Lagos revealed higher levels of BSE practice of 72% and 63%, respectively (Jebbin & Adotey, 2004; Odusanya, 2001), perhaps due to higher levels of education in the women in those studies.

Furthermore, in contrast to previous studies, Balogun and Owoaje, (2005) used a dichotomous measure (do versus don't) that produced a highly skewed distribution (18.1% versus 81.9%). Thus the 'do' group is likely to have included women who performed BSE monthly as well as those who performed it less than once a year. Taking this into consideration their results may not reflect the precise manner in which educational level may be related to BSE practice.

Nevertheless, equally conflicting results are produced when exploring BSE frequency in more detail. In contrast to the positive studies discussed previously, Bennett et al. (1983) examined BSE practice in patients and staff from a Boston hospital and failed to show any association between BSE practice and education level. Although women with a higher level of education reported more BSE practice than did less educated women, their BSE was infrequent and the percentage of women who practised BSE monthly was essentially the same across education levels. It does, however, need to be noted that the authors compared women who had completed college or had an advanced degree with those with less schooling. Their less-schooling category consisted of women with high-school level education as well as elementary-level. The difference between elementary level and high school may be quite diverse in terms of education level and should, the authors have included high-school education in their 'educated' group, different results might have been found when comparing this to elementary-level education alone.

Further support for a lack of relationship has been offered through the exploration of BSE practice in Chinese immigrant women in the US. Chen (2009) examined Chinese women living in different areas of New York and found no relationship between education levels (achieved in the United States or Asia) and BSE practices. This may, however, be explained, at least in part by the women's lack of knowledge regarding how to navigate the American health-care system. Chinese women who have not learned to navigate the health-care system and who do not know where and how to find a physician who will provide breast-care services (mammograms, CBE's or BSE instruction) and information may not be able to engage in effective BSE practice, no matter how many years of formal education they have. Alternatively, others have further found lower education level to be related to regular BSE. Funke et al. (2008) examined BSE in German women attending a breast-health seminar and found women with a lower degree of education examined their breasts more often on a monthly basis than women with a higher degree of education. However, this finding is unusual in the literature and perhaps may have been influenced by the attendance of a breast-health seminar. The seminar included a lecture about breast cancer and BSE according to a 5-point plan of breast awareness (knowing what is normal, looking at and feeling the breasts, knowing what changes to look for and what to do if a change is found), after which the women were given the opportunity to feel nodules within silicon models to get an idea what different textures and nodules in the breast feel like. Following this, individual training of BSE was offered by a gynaecologist in a separate room, while a female social educator offered a talk on the importance of compliance in carrying out BSE regularly, breast cancer in general as well as the anxiety associated with it. After three to four hours, the teaching was completed by another talk emphasising the importance and impact of breast awareness (including BSE) on breast-cancer detection. Special workbooks and booklets about breast cancer and its diagnosis as well as flyers for the bathroom explaining BSE were handed out at the end of the seminar. It was only after

this that the women were given a questionnaire asking them to report on their breast-screening behaviour over the past two years. Perhaps the seminar's emphasis on the importance and usefulness of BSE influenced the BSE practice reported by the women.

Further to this, BSE practice for each of the three educational levels is not reported and it is unclear how the authors reach their conclusion of "women with a lower degree of education examined their breasts more often on a monthly basis than women with a higher degree". It is unclear whether they compare the lowest educational group with the highest or compare the three groups with each other. The education of the women in the study's sample was predominately high-school level or less (49% had nine years at secondary school and 40% had ten years of schooling equivalent to less than UK GCSE and UK GCSE level respectively). Only 11.3% of the sample held an education level equivalent to UK A-levels and none held higher qualifications. A problem is therefore posed if comparing the lowest and highest education group with each other. Perhaps the inverse relationship of education and BSE demonstrated in this study is due to the few women with an education above a high-school level in the sample and the lack of women with higher qualifications. Alternatively those with a lower education may be perhaps more compliant to advice given by 'figures of authority' in this case health-care professionals and this may have resulted in their increased BSE practice.

Much of the research investigating BSE and education level relies on the use of self-report measures and therefore caution is needed regarding the reliance of self-report data.

Sometimes patients respond in a socially desirable manner when answering questions about screening behaviour (Friedman et al., 1999). Thus a limitation of all these studies is their reliance on self-reporting BSE behaviour. Many women interviewed may not be completely honest regarding BSE, especially in the setting of a psychiatry outpatient clinic (for example Friedman et al., 1999) and breast-health centre (for example Madan et al., 2000) or when belonging to a patient or health-care staff group (for example Abdel-Fattah

et al., 2000; Bennett et al., 1983; Canbulat & Uzun, 2008). However, whilst it is difficult to determine whether an individual is engaging in BSE from their self-report, studies examining the validity of self-reporting mammography have found a high rate of agreement between self-reports and medical records (Fulton-Kehoe, Berg & Lane 1992; King, Rimer, Trock, Balshem & Engstrom, 1990). It may be fair to assume women self-report about BSE and mammography in a similar manner.

Despite the potentially complex relationship between level of education and BSE it can be suggested that women from different educational backgrounds may engage in BSE behaviour differently. Thus, this study controls for this, matching each of the four experimental participant groups on education level.

4.3 Conclusion

An individual's perception of their own risk to breast cancer may influence their thoughts surrounding breast cancer and BSE and their subsequent BSE behaviour. Existing research has established gender, age, family history, age at menarche and menopause, oral contraception usage and breast tissue density as risk factors associated with breast cancer. Following this, individuals with a history relevant to these risk factors and who are aware of their risk based on these factors may perceive themselves as high risk. Likewise, those without such a history may perceive themselves as low risk. To take this factor into consideration, participants were asked to provide detailed demographic data including these risk factors.

Similarly, research suggests age, educational level and ethnicity are related to BSE practice. The nature of the relationship between these demographic variables and BSE appears to be complex, and the conflicting and inconsistent nature of the results prevents one from concluding the nature of the differences between the various demographic groups. Nevertheless, it is apparent that women from different ethnic and educational

backgrounds may adopt different screening behaviour. Likewise, it is apparent that women of different ages think about and adopt BSE differently. Whilst the impact of ethnicity was minimised within the current study due to the limited variation in ethnicity of the sample, age and educational level varied. This study controlled for the potential effects of age and education, through an attempt to match each of the four experimental groups on age and educational level.

4.4 Chapter Summary

In this chapter an overview of the risk factors to breast cancer and demographic variables that may be important when considering BSE practice was presented and the effect these may have on BSE behaviour considered. It was demonstrated that women of different ages and from different ethnic and educational backgrounds may think about and adopt BSE differently. Likewise, it was proposed that if aware of these risk factors, individuals with a history relevant to breast-cancer risk factors may perceive themselves as high risk and likewise, those without such a history may perceive themselves at low risk and this, in turn, may influence their thoughts surrounding breast cancer and BSE and their subsequent BSE behaviour.

CHAPTER FIVE

Exploratory Work

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5.0 Chapter Overview

This chapter provides an overview of an exploratory qualitative study conducted in the early stages of the research and discusses the implications of the study findings, particularly in relation to the main study. The exploratory study provides positive feedback about the 5-step BSE technique that is the basis for the breast self-examination (BSE) material used in the main study, and highlights the potential utility of teaching or providing women with the necessary skills to perform BSE in order to increase and encourage BSE behaviour among all women.

5.1 Introduction

As previously discussed within Chapter 1, regular BSE can facilitate early detection (Cancer Research UK, 2008), yet it is not practised regularly for reasons such as a lack of time, a perception that the procedure is difficult to perform, the fear of finding a lump, women's lack of confidence in the accuracy of their technique and women's lack of understanding what they were looking for (Agars & McMurray, 1993; Williams, Mahoney & Williams, 1998). Considering this, it appears that women may need a clearly structured approach which they can follow with ease, and which gives them the confidence necessary to observe and examine their breasts regularly and proficiently. The 5-step BSE technique, a structured guide consisting of five specific steps incorporating both looking and touching the breasts in particular ways to ensure a thorough breast exam has been recommended by breast-cancer charities in the past, and may provide this confidence and be a valuable BSE support tool. This exploratory study aimed to explore women's knowledge, beliefs and behaviour towards breast cancer, BSE and the 5-step technique, and in doing so explore the utility of this technique as a BSE support tool for use in the main study.

5.2. Method

5.2.1 Research Design

A phenomenological framework was selected as the most suitable theoretical framework due to the exploratory nature of the study. A phenomenological framework is well suited for research in which it is important to understand several individual's common or shared experiences of a phenomenon (Cresswell, 2007) and this study aimed to explore and understand women's knowledge, beliefs and behaviour towards breast cancer and BSE. Following this framework and in order to remain consistent to its theoretical commitment, qualitative methodology, particularly that of the semi-structured interview was employed (Smith & Osborn 2003). This technique served as a prompt and gave direction whilst not restricting the topics covered and allowed respondents to discuss their thoughts, feelings and experiences, a central theme of phenomenology.

5.2.2 Sample

Inclusion criteria for the sample were (1) being female, (2) being a UK resident, (3) being aged 18 years or over and (4) competent with the English Language. Exclusion criteria were (1) inability to provide informed consent, (2) currently having or receiving treatment for breast cancer and (3) current major psychiatric illness.

Eight white British women aged between 18 to 51 years (mean = 33 years, SD = 13.55) from the North-east of England were invited to participate in a 20-minute semi-structured interview. The highest education qualification obtained by the women was GCSE qualifications (1), college certificate/A-levels (3) and university degree (4). Table 1 presents a detailed overview of the demographic characteristics of the sample.

Table 1

Demographic Characteristics of the Exploratory Study Sample

P	Ethnic Origin	Age	Highest Educational Qualification Obtained	Marital Status	No of children	Religion	Immediate Family History of Breast Cancer
1	White British	51	College certificate/ a levels	Married	2	Christian	Mother
2	White British	23	College certificate/ a levels	Co-habiting	1	Christian	-
3	White British	23	University Degree	Single	0	Christian	-
4	White British	50	University Degree	Married	2	Christian	-
5	White British	21	School	Co-habiting	0	Christian	-
6	White British	18	College certificate/A levels	Single	0	Christian	Grand-mother
7	White British	35	University Degree	Single	0	Christian	-
8	White British	43	University Degree	Single	0	Christian	Aunt

5.2.3 Materials

The semi-structured interview guide included six questions on BSE generally and seven questions on the 5-step BSE procedure specifically. If the women were unaware of the 5-step BSE technique they were given time to view the procedure (as presented in Appendix 6) prior to answering the second set of questions. Tables 2 and 3 present a detailed interview guide. The interview included open and closed questions and was formulated to give the respondents opportunities to provide the researcher with their own insights into BSE and the 5-step procedure.

Table 2

Exploratory Study Interview Guide: BSE Generally

1	Have you ever examined your breasts?		
2	If so, how often?	If no, have you ever in the past?	
3	Can you describe your current breast self-examination behaviour?	Can you explain why you don't currently examine your breasts?	Can you explain why you have never examined your breasts?
4	How do you examine your breasts?	How in the past did you examine your breasts?	-
5	How do you find examining your breasts?	How did you find examining your breasts?	How do you think you would find examining your breasts?
6	What do you think about breast self-examination generally?		

Table 3

Exploratory Study Interview Guide: The 5-step BSE Procedure

1	Have you ever heard of the 5-step model for breast self-examination?	
	If they had heard of the model they were asked:	If they had not heard of the model they were given time to view the model and then asked:
2	Can you describe to me what it entails?	
3	Have you ever tried it?	
4	If yes, can you describe to me how you found it?	If no, can you describe to me why not?
5	Are there any of the steps that you find harder or easier than others?	Are there any of the steps that you think you would find harder or easier than others?
6	Do you currently follow the steps described in the model when examining your breasts? Why?	- Looking at this model does it make you feel differently about your current method of breast self-examination? Why?
7	What do you think about this model generally?	

5.2.4 Procedure

Participants gave their informed consent and were made aware that they could withdraw from the study at any time. Data collection involved the use of a demographic form and a face-to-face semi-structured interview. Interviews were conducted in locations convenient to respondents and were audio taped for later analysis. Data was transcribed in full and read and re-read, in order to ensure sufficient immersion in the data.

5.3 Data Analysis and Interpretation

Following thematic analysis, each transcript was read several times until an overall sense of the data was obtained and it was possible to start making notes describing any striking issues. Once this process was completed for the whole transcript, further review enabled the naming of initial themes by the process of abstraction (Fade, 2004).

Three initial themes regarding BSE generally and a further three regarding the 5-step model of BSE were extracted and listed. Possible connections between these themes were then explored in order to cluster them together in a meaningful way and this in turn produced a clear understanding of the central themes. This process was performed on all the individual transcripts, individually before an attempt was made to compare and contrast them with each other to produce a set of themes that represent all the individuals participating in the study.

5.3.1 Data Analysis and Interpretation – BSE generally

Despite expressing knowledge of the potential benefits of BSE, none of the women interviewed examined their breasts regularly and one had never engaged in BSE. When asked their reasoning behind this avoidance of BSE three themes arose from the data.

Theme 1: Negative associations.

Breast cancer and subsequently BSE appeared to be viewed very negatively.

Subtheme 1.1: Negative association of breast cancer

A recurring concern of the women in the study was the serious and frightening nature of breast cancer. This concern consequently resulted in them expressing their fear of getting breast cancer. For these women breast cancer is a serious and horrible condition that

people die from. They seem to neglect the potential for breast cancer to be treated and cured, and tend to simply focus on the negative connotations of breast cancer.

“I know it’s a serious disease and you can die from it etc” (P3).

“It’s a serious disease and people die from it, so yeah it’s frightening. I’d be scared if I thought I had it” (P5).

“Breast cancer is a horrible disease and people really suffer, I wouldn’t want to go through that” (P6).

Subtheme 1.2: Negative associations of BSE

Similarly, the uncertainty examining breasts can bring is of major concern for these women. This concern is further strengthened by their belief if they examine their breasts they will find something. They seem to neglect that they may not find anything and instead focus on examination resulting in the discovery of a lump or some other indicator of breast cancer.

“The thought of finding a lump and it turning out to be cancer is scary” (P4).

“It would worry me if I found anything. And I don’t know if it’s worth that” (P1).

“If I examine my breasts I might find something and I don’t want that” (P8).

They are further concerned over the accuracy of the examination of their breasts. For these women their lack of knowledge about what to actually do when they examine their breasts and their uncertainty of what finding something means caused them real concern.

“I think it’s quite difficult cos I don’t really know much about it I suppose” (P2).

“I don’t know how to do it properly” (P7).

“... so now I’m thinking if I ever do get a lump am I gonna know whether it’s just that or something to worry about” (P4).

Theme 2: Influential Factors

Furthermore these negative associations of both breast cancer and BSE seemed to be influenced by age, past experience and the experience of other people close to them.

Subtheme 2.1: Age

Breast cancer was seen to be influenced by age. It was seen as something only experienced by older people. Age appeared to affect both beliefs and behaviour. All the younger women (aged 18-23 years) in the study expressed their lack of risk and, whilst they did hold negative beliefs about breast cancer and BSE, these beliefs seemed to be less strong than those of the older (35-51 years) women. Consequently they reported examining their breasts less than the older women in the study. Similarly those that attempted BSE or have done so in the past tended to be typically older.

“I think it’s probably cos I’m younger” (P2).

“I guess if I was older I’d think about it a bit more and be a bit more concerned. I know it’s bad but I’m young” (P6).

Subtheme 2.2: Past Experience

The women’s past experience (or lack of it) also appears to influence their beliefs and response to BSE. The negative associations of breast cancer and BSE are further strengthened for those who have examined their breasts in the past and found a lump for it to turn out to be nothing. Two of the women interviewed described their experience of finding a lump and this appears to have shaped and influenced their present BSE

behaviour. As a result of this past experience one avoids thinking about and actually examining their breasts altogether and the other is concerned about their BSE accuracy.

“Because I’ve found a lump in the past and it worries you. Its more trouble being worried, its more trouble than it’s worth” (P1).

“I found a lump not long back and I went to the doctors. So I went to the doctors and she like examined me and she said I can tell why you think you’ve found a lump cos one of your boobs is a lot lumpier than the other one. So she sent me off to the hospital to erm have a mammogram and that so I went ‘n’ I got examined there and he said exactly the same... so now I’m sort of thinking if I ever do get a lump how am I gonna know whether it’s just that or something to worry about” (P4).

Furthermore, those who have no experience of breast cancer, whether it be finding a lump or general experience, express concern over this lack of experience. They find discussing breast cancer and BSE quite difficult because of this lack of experience and knowledge.

“I don’t really know anything about it. Like no one I know has had breast cancer or whatever. So erm, I guess I worry about what I know, like do I know enough if you get me” (P3).

“I think it’s quite difficult cos I don’t really know much about it I suppose” (P2).

Subtheme 2.3: Experience of others

Those who had family members or friends that have been through the disease, seemed to think about the disease more and consequently expressed a greater fear.

“My mother had breast cancer and she subsequently died of it so it’s always been something in the forefront of my mind I guess” (P1).

Likewise a lack of others' experience can also be influential. Whilst those without any experience of breast cancer expressed less concern than those with, they still expressed similar negative associations of both breast cancer and BSE just perhaps not as strongly.

"I know it's a serious disease and that but like I don't know anyone personally that's been affected by it. But then I suppose I'm probably quite lucky for that. I'd say I worry somewhat but not where it overtakes my life or anything. It's not something I think about every day, but sometimes, like when you see something on the tele or whatever I think mmm maybe I should, like it comes into my mind a bit more" (P5).

Theme 3: Coping Style

All the women chose to cope with the fear surrounding breast cancer and BSE by not performing breast exams and not thinking about it. Whether because of fear of breast cancer itself, or fear of finding a problem through BSE or the actual process of examining their breasts, the outcome was the same. The fear seems to be too much for them to cope with.

"It's just sometimes it overtakes your life and it's all you can think about. And I don't want to live like that. I don't want to worry I'd rather just not know" (P1).

"When I think about it, it's just not worth it" (P8).

"I wouldn't like doing it, like I wouldn't feel comfortable and I'd maybe be a little embarrassed. I don't really know what to do" (P3).

"I don't really know what to do properly" (P2).

To summarise, these women appear to use avoidance-coping by avoiding thinking about both breast cancer and BSE and by avoiding performing BSE itself. This avoidance

appears to be linked to the women's lack of knowledge surrounding breast cancer and BSE.

5.3.2 Data Analysis and Interpretation - The 5-step BSE Model

When asked if they knew or had heard of the 5-step model of BSE only two of the eight women participating in the study had. Furthermore, despite being aware of the existence of the 5-step model they were still unsure about what the model actually entails and had not previously attempted to follow this technique. Following the presentation of detailed instructions on the five steps, the eight women discussed their thoughts and feelings regarding it, from which three themes arose from the data.

Theme 1: Lack of knowledge

The majority of women had not heard of the 5-step model and those who had did not know what it entailed. When asked if it was this lack of knowledge that had prevented them from attempting the 5-step model in the past, all but one of the women reported it was. For this one woman several factors influenced her decision not to engage in the technique described by the model, including embarrassment of BSE generally, lack of knowledge and the lack of desire to partake in BSE.

"It's not something I really like doing anyways, like I don't really feel comfortable doing so but I suppose if I wanted to I could follow it, if the instructions were there and that I guess I'd maybe give it a try" (P3).

However, she did note that if she had the desire to engage in BSE in the future the 5-step technique is something she would consider.

"I mean I suppose if I wanted to do it, it would be a good way to start. Like it would help you realise what to do" (P3).

Furthermore, when shown the model, all the women reported they could, if they were provided with detailed instructions and if they actually wanted to, follow the steps quite easily.

“I think it seems pretty straightforward” (P2).

“I think it should be quite easy I think” (P4).

Theme 2: Generation of new ideas

For those women who had examined their breasts before, the introduction of the steps brought new ideas and techniques they hadn't thought about or attempted before.

“I don't think I go as far as what they say. I only go round there and I use the same pressure everywhere where it says use different pressures and really erm I never stand and look in the mirror I never do that I just lie down and have a feel” (P4).

“I don't really do it like that now, I just kind of have a feel about you know, I've never really thought about doing those different shapes. And I don't do different pressures. Like I said I just feel around” (P5).

They believed they were not as thorough as the steps suggested or as they perhaps felt they should have been and that by following the steps they could improve their examination.

“I don't think I've maybe been as thorough” (P1).

“I guess before when I've done it I haven't really thought about those kind of things it talks about and I maybe should of” (P5).

“Erm well I don't do it like that now, but I guess if you did do it like that it would be better. I mean you'd probably have a better chance of finding something” (P7).

Particularly, they seemed to neglect looking at the breasts instead focusing on touching alone, and during this touching they neglected to use different pressures as the 5-step technique advises.

“I use the same pressure everywhere where it says use different pressures and really erm I never stand and look in the mirror I never do that” (P4).

For most this neglect was not deliberate rather they simply were not aware they should be doing it.

“I guess when I’ve done it before I haven’t really thought about what I was doing. I just kind of had a feel about” (P1).

Whilst some noted the steps are common sense they still felt it was useful to be shown, taught and given these steps to follow particularly those surrounding the different pressures and parts of the breast to touch.

“I think it’s pretty much common sense really I suppose, but then it’s useful as well too. I mean it’s useful to have kind of like steps to follow. You know something you can measure what you’re doing up against if you get me” (P7).

Theme 3: Usefulness of pictorial representations

The pictorial representations of the steps were found to be particularly useful for the women and it was expressed that their inclusion aided not only the understanding of the steps, but would allow them to skim through the steps picking up what was going on through the pictures – something they felt to be particularly useful especially once the steps were familiar.

“You could even just skim through it and pick it up from the pictures” (P2).

“I think the pictures really help you get the gist of what’s going on” (P6).

Overall, the women were very positive towards the 5-step method. It was something they felt that could be a useful teaching tool that could improve their current examination techniques and something which could aid the actual examination process when used as a step-by-step guide. Furthermore, for some of those not engaging in BSE, the steps provided them with the necessary knowledge to start, something which many of those not currently examining felt would enable and encourage them to do so.

5.4 Conclusion

To conclude, data analysis revealed three themes regarding BSE generally, and three regarding the 5-step model of BSE. Table 4 provides a summary table of these themes.

Table 4

Summary of Exploratory Work Themes

Themes Relating to BSE Generally

Theme 1: Negative Associations

Subtheme 1.1: Negative Associations of Breast Cancer

Subtheme 1.2: Negative Associations of BSE

Theme 2: Influential Factors

Subtheme 2.1: Age

Subtheme 2.2 Past experience

Subtheme 2.3: Experience of Others

Theme 3: Coping Style

Themes Relating to the 5-Step BSE Technique

Theme 1: Lack of Knowledge

Theme 2: Generation of New Ideas

Theme 3: Usefulness of Pictorial Representations

From these themes it appears, breast cancer and BSE can be a frightening concept for some women, with which they can only cope with by adopting an avoidance strategy. This fear appears to stem from a lack of knowledge and education and results in the women avoiding regular BSE. However, when provided with a set of detailed examination guidelines (as given in the 5-step BSE technique) women become more positive and enthusiastic about BSE. Particularly, the women in this study felt the 5-step technique was something that could be a useful teaching tool that could improve their current BSE techniques and aid the actual self-examination process when used as a step-by-step guide. Furthermore, the steps provided some of those not engaging in BSE with the necessary knowledge to start. Many of those not currently examining, felt that this knowledge would enable and encourage them to examine their breasts regularly.

This study suggests that a major obstacle preventing BSE performance in women is their lack of knowledge and when given this knowledge, women can move away from an avoidance-coping strategy and instead be encouraged to engage in BSE regularly. This study highlights the utility of teaching or providing women with the necessary skills to perform BSE in order to increase and encourage BSE behaviour among all women and forms the basis for the inclusion of the 5-step BSE technique employed in the main study. Likewise, this study confirms the potential influence of age, past experience and the experience of others on both breast cancer and beliefs regarding BSE and subsequent behaviour, and highlights the need for these variables to be considered when seeking a scientific understanding of a women's decision to engage or not engage in BSE.

5.5 Chapter Summary

Within this chapter an overview of an exploratory qualitative study conducted in the early stages of the research was presented and implications of this study's findings considered. The utility of teaching or providing women with the necessary skills and knowledge to

perform BSE was highlighted and the positivity of the 5-Step BSE technique demonstrated. Finally, the informative nature of the study, particularly in relation to the materials used in the main study was discussed.

CHAPTER SIX

Rationale, Aims and Method

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6.0 Chapter Overview

This chapter describes the method employed and presents the research questions, aims and rationale of the study.

6.1 Rationale for Current Study

If one could encourage women to regularly self-examine their breasts (BSE), breast awareness might enhance, leading to more cases of breast cancer being detected early and ultimately less mortality. However, regardless of health-promotion, research (as discussed in previous chapters) highlights that not all women are assessing their breasts on a regular basis. For that reason, it is important to gain an understanding of the psychosocial predictors of BSE among women. A review of the literature surrounding BSE indicated that worry/anxiety, coping style, illness representations, health locus of control and social support may influence BSE behaviour. These components are incorporated into the Health Belief Model (HBM) to form an extension of the HBM, (E-HBM).

Consequently, a framework for understanding women's knowledge, beliefs and behaviour regarding breast cancer and BSE behaviour is produced to enhance the scientific understanding of a women's decision to engage in BSE or not. This is seen as essential to guarantee the success of any intervention designed to encourage BSE and is likely to lead to the development of effective interventions to promote regular BSE as part of being 'breast-aware'. This is particularly important given that mammography screening may not be effective (Crossing & Mansezewicz, 2003) or recommended for younger women (Cancer Research UK, 2009) and that BSE may be beneficial in offering women the opportunity to create a positive relationship with their body.

Likewise, providing women with the necessary knowledge and education to perform BSE may encourage women to examine their breasts comprehensively. Although treatment

success is high for cancers detected, unfortunately opportunities to effectively identify and treat breast cancer may be lost when information about BSE is severely lacking or confusing to understand, or when current methods fail to elicit the interest and curiosity of the female population. There may be a better and more efficient way for providers to teach BSE (American Cancer Society, 2001) than is currently the case and one of which may be through the use of a multimedia BSE support programme. Such a method might give women the skills needed to perform BSE in a clearer and perhaps more enjoyable way.

Furthermore some women may neglect to examine their breasts because of a lack of perceived vulnerability to breast cancer or because of misconceptions connected to the disease. Viewing autobiographical accounts of breast-cancer patients may function as a wake-up call by finding recognition in the stories which might alert an individual's own vulnerability to developing breast cancer and motivate women to take preventative action. If autobiographical accounts could alleviate some of the psychological barriers to performing BSE, then these might be an important tool that could be applied in breast health-promotion campaigns.

Finally, despite the positive aspects of computer-mediated communication, little is disseminated widely about the practical issues of use for data collection, especially in a research setting. The past decade has seen a tremendous increase in internet use and computer-mediated communication (Fox et al., 2001; Nie & Erbring, 2000; Nie, Hillygus & Erbring, 2002); nonetheless research evaluating these initiatives is still sparse. It is therefore important to explore the effectiveness of computer-mediated communication within a research setting.

6.2 Aims, Research Questions and Hypotheses

In line with this rationale and based on the previous literature discussed in earlier chapters this study had the following aims.

Aim 1: to enhance the understanding of women's knowledge, beliefs and behaviour regarding breast cancer and BSE both before and after an intervention within the framework of an extended HBM (E-HBM).

Research Question Related to Aim 1

Does worry/anxiety, coping style, illness representations, health locus of control and social support influence BSE beliefs and behaviour?

Hypotheses

H1.1: The level of worry/anxiety experienced by a woman and how they choose to cope with this predicts the HBM components susceptibility, seriousness, barriers and benefits.

H1.2: Women who have more social support are more motivated and feel more obliged to engage in BSE.

H1.3: Women who have more social support have more confidence that they are capable of performing BSE.

H1.4: Social support predicts the HBM component susceptibility.

H1.5: Women who have more social support are less likely to experience barriers to BSE.

H1.6: Women who have more social support are more aware of the benefits of BSE.

H1.7: Illness representations predict the HBM components; susceptibility, seriousness, barriers, benefits, health motivation and confidence.

H1.8: Illness representations predict the level of anxiety or worry women experience.

H1.9: Illness representations predict an individual's health locus of control.

H1.10: Health locus of control predicts the HBM components susceptibility, health motivation and confidence.

H1.11: Internally orientated individuals are more likely to see the benefits of BSE.

H1.12: Externally orientated individuals are less likely to see the benefits of BSE.

H1.13: Health locus of control predicts worry/anxiety and coping style.

H1.14: BSE frequency and proficiency can be predicted with the original HBM components: susceptibility, seriousness, benefits, barriers, confidence and health motivation and the additional E-HBM components worry, anxiety, coping style, illness representations, health locus of control and social support.

Aim 2: to explore the effects of viewing autobiographical accounts from breast-cancer patients on women's knowledge, beliefs and behaviour towards breast cancer and BSE.

Research Question Related to Aim 2

Do observing autobiographical accounts affect women's knowledge, beliefs and behaviours towards breast cancer and BSE?

Hypothesis

H2: Those women observing autobiographical accounts differ in terms of knowledge, beliefs and behaviour to those women not observing autobiographical accounts.

Aim 3: to examine the usability and effectiveness of a novel multimedia BSE support programme, based on the 5-step BSE technique, and comparing video-enhanced or static

guided instructions. Both methods aim to develop women's skills of using BSE techniques, as well as their knowledge through the use of performance enhancement tools, such as images within the static support or video and interactivity within the video-enhanced support.

Research Question Related to Aim 3

Does the method of BSE instruction affect women's knowledge, beliefs and behaviours towards BSE?

Hypothesis

H3: Women's knowledge, beliefs and behaviour BSE differ depending on their version of multimedia BSE support.

Aim 4: to evaluate the effectiveness of online data collection and the use of blogs as a recording and communication tool.

Research Question Related to Aim 4

How effective is the use of online data collection and blogs as a recording and communication tool?

6.3 System Design and Development

A questionnaire, BSE programme and a study website was designed and developed specifically for the study.

6.3.1 Questionnaire Design and Development

A review of the literature surrounding BSE highlighted five variables associated with BSE, worry/anxiety, coping style, illness representations, health locus of control and social support. Following this an extension of the HBM in order to include these variables as

components within the model was proposed. A further review of the literature highlighted the most commonly used instruments to measure these variables, and after examining their validity, reliability and relevance to the current study it was decided the following instruments would be used.

- (1) *Health Beliefs*: Health Belief Model Scale (Champion, 1984;1993)
- (2) *Breast Cancer Worry*: Breast Cancer Worries Scale (McCaul, Branstetter, O'Donnell, Jacobson and Quinlan, 1998)
- (3) *General Trait Anxiety*: State Trait Anxiety Inventory – Trait Subsection (Spielberger, Gorsuch, & Lushene, 1964)
- (4) *Health Locus of Control*: Multidimensional Health Locus of Control Scale (Wallston, Wallston & DeVellis, 1978) and the God Locus of Health Control Scale (Wallston, Malcarne, Flores, Hansdottir, Smith, Stein et al., 1999)
- (5) *Illness Perceptions and Representations*: Illness Perception Questionnaire Revised Healthy Edition (Figueiras & Alves, 2007)
- (6) *Social Support*: Norbeck Social Support Questionnaire (Norbeck, Lindsey & Carrieri, 1983)
- (7) *Coping Style*: Marlowe-Crowne Social Desirability Scale (M-C) (Crowne & Marlowe, 1960) in conjunction with the Trait Subscale of the State Trait Anxiety Inventory (Spielberger, Gorsuch, & Lushene, 1964).

In addition to the variables discussed, it was felt that demographic characteristics, BSE frequency and proficiency and technology acceptance should be considered.

Demographic characteristics provide more data about the sample and allow the

exploration of the effect of breast-cancer risk factors, and the demographics of education, age and ethnicity on BSE. BSE proficiency and frequency was measured using the BSE Frequency/Proficiency Questionnaire (Champion, 1989, 1990) and was included to explore participants' BSE behaviour at the start and end of the study, identifying any changes. Finally, as technology was a major aspect of the current study due to the studies online nature it was decided to examine participants' views on this technology. The nature of the study required participants to complete online questionnaires, access a study website, complete an online blog, and view video-enhanced and static material displayed via a study website. Taking this into consideration participants' views on the Internet, websites, and blogs were reported using the Brief Technology Acceptance Questionnaire (Venkatesh, Morris, Davis, Davis, & Walton, 2003; Venkatesh & Speier, 2000).

These existing instruments along with a 16-item demographic data questionnaire were inputted into the web survey tool Survey Gizmo. Survey Gizmo was selected for its apparent ease of use and because of the wide range of questionnaire formats included within the tool. Survey Gizmo allowed the application of over 20 different question types which ensured all the instruments within the questionnaire could remain in the same format as they would be in their original paper versions.

Questionnaire Pilot Study

In order to preliminarily assess the questionnaire that was to be used in the main study and to determine whether the questions were comprehensible and suitable to potential participants, a pilot study was conducted with 32 women aged between 18 to 65 years of age (Mean = 33.78 years; SD = 14.09). It was anticipated that these women would have similar characteristics as the women in the main study. Appendix 1 provides a more detailed description of the demographic characteristics of the pilot sample.

The participants were asked the following nine questions in order to assess the length of time taken to complete the questionnaire, how easy it was to complete, what questions (if any) were problematic or satisfying.

1. How long approximately (in minutes) did it take you to complete the questionnaire?
2. How did you find completing the questionnaire? (Very difficult/ difficult/ neither easy nor difficult/ easy/ very easy).
3. Was it possible for you to complete every question? (Yes or No)
If no: what questions did you find you were unable to complete?
If no: why were you unable to complete it?
4. Completing the questionnaire was easy (strongly disagree/ disagree/ neutral/ agree/ strongly agree).
5. Becoming skilful at completing the questionnaire was easy (strongly disagree/ disagree/ neutral/ agree/ strongly agree).
6. The questionnaire was easy to navigate (strongly disagree/ disagree/ neutral/ agree/ strongly agree).
7. I found completing the questionnaire enjoyable (strongly disagree/ disagree/ neutral/ agree/ strongly agree).
8. The actual process of completing the questionnaire was pleasant (strongly disagree/ disagree/ neutral/ agree/ strongly agree).
9. I had fun completing the questionnaire (strongly disagree/ disagree/ neutral/ agree/ strongly agree).

Following this, participants were also given the opportunity to communicate further comments and suggestions for improvements.

Results

Participants' responses to the questions were collated and any highlighted problems within the questionnaire were noted and solutions offered. Appendices 2 and 3 provide a breakdown of the raw data and Table 5 Provides a summary of the participants' responses.

Table 5

Questionnaire Pilot: Summary of the Participant's Responses

<i>Q1: How long approx (in minutes) did it take you to complete the questionnaire?</i>	<i>Q2: How did you find completing the questionnaire</i>	<i>Q3: Was it possible to complete all questions?</i>	<i>Q4: Completing the questionnaire was easy</i>	<i>Q5: Becoming skilful at completing the questionnaire was easy</i>
Mean 38 minutes	Difficult 13%	Yes 84%	Disagree 13%	Disagree 6%
SD 13.70	Neither 53%	No 16%	Neutral 31%	Neutral 31%
	Easy 25%		Agree 44%	Agree 56%
	Very Easy 9%		Strongly agree 13%	Strongly agree 6%
<i>Q6: The questionnaire was easy to navigate</i>	<i>Q7: I found completing the questionnaire enjoyable</i>	<i>Q8: The actual process of completing the questionnaire was pleasant</i>	<i>Q9: I had fun completing the questionnaire</i>	
Agree 69%	Disagree 6%	Disagree 3%	Disagree 18%	
Strongly agree 31%	Neutral 59%	Neutral 53%	Neutral 63%	
	Agree 34%	Agree 41%	Agree 19%	
		Strongly agree 3%		

Time taken to complete

On average participants reported completion of the questionnaire took approximately 38 minutes (SD = 13.70). These results were used to inform participants in the main study about the length of time they could expect completion to take.

Ease of completion

Most of the women completed all the questions (27 of the 32). Of the five women for whom completion was problematic; four were unable to answer all the questions mainly because these were not relevant to them; for example, they had not lost anyone close to them in the past year, had never had a family member with breast cancer or because their medical and family history was not available to them (i.e. adopted).

The fifth participant indicated a problem connected to the survey design itself, indicating confusion over some of the question's wording. The wording of these questions was adapted to prevent this confusion in the final study.

The majority of the participants found completing the questionnaire to be neither easy nor difficult (17) or easy (8). Similarly when asked to show their level of agreement with the statement "completing the questionnaire was easy" only four of the thirty two participants disagreed. Furthermore when asked to show their level of agreement with the statements "becoming skilful at completing the questionnaire was easy" and "the questionnaire was easy to navigate" only two disagreed with the first and all the participants either agreed or strongly agreed with the second. This suggested that the current set-up of the questionnaire was suitable for the main study and with a slight wording adjustment to a few of the questions all participants should find it possible to complete the questionnaire in the main study.

Experience of completion

When asked to show their level of agreement with the statements "I found completing the questionnaire enjoyable", "The actual process of completing the questionnaire was pleasant" and "I had fun completing the questionnaire" most participants selected neutral

or agree, suggesting the completion of the questionnaire is not an unpleasant experience for the participants and for a few even an enjoyable one.

In addition to the set questions participants were also given the opportunity to provide further comments and suggestions for improvements. Eight of the participants took up this opportunity and comments related to confusion over the wording of the questions and suggestions to include more background information before the questions were offered.

Based on the participants' comments, changes to the questionnaire were made as follows;

(1) Demographic Questionnaire

Breast tissue question

"I also found the description of breast tissue as "dense" quite difficult to relate to, though am unsure what other descriptions might be used" (P1)

In an attempt to solve this problem dense was changed to firm.

Breast-cancer family history question

"I was also unable to fully answer any questions regarding medical history of blood relatives as none are available to me" (P1).

To solve this problem a further response option was added to the questionnaire – family history not available.

(2) Norbeck Social Support Questionnaire

“In the section about the people close to you that could help etc, was slightly unsure if my answers should have been reflective of how much they would want to help if they were able, or how much they were actually able to help taking into account how far they lived, financial situations etc. For example, my sister, she, would want to help me a great amount if I was confined to bed, or needed money or a trip to the doctors etc, however she lives in the south of England studying and lives on a student budget, so would only be able to help me a moderate amount” (P1).

Although one participant did find this question slightly confusing it was felt that adding more information could affect reliability and validity. Since the remainder of the participants had no problems with this it was instead decided to leave the question in its original form and measure this variable generally.

(3) STAI - Question 19

“Even though I had to tick an answer as I would otherwise have been unable to continue, I was unsure as to the meaning of the question asking “Am I a steady person” as I was unsure of the context and meaning” (P1).

To solve this problem steady was replaced with stable.

(4) Marlowe-Crowne Social Desirability Scale

“I don't have a car so in the question regarding would I do all the safety checks before a long journey I can only give the answer based on what I assume I would do in that situation, not what I actually do” (P1).

To make this question clearer, the item was amended to “I never make a long trip without checking the safety of my car (If you do not have a car please answer what you believe you would do if you did have one).

(5) General question considerations

“The questionnaire was great and covered all the major points, though it might be worth having a few boxes like this for people to elaborate on their answers. I wouldn't say I found the questionnaire easy, due to the nature of the topic - My knowledge in this area is limited and I think that was why I didn't find it easy. I liked that the questionnaire was online, that made it much easier to complete. Your questions certainly made me think and I liked your links with the consent form, they were useful and informative” (P3).

“I think there are some leading questions” (P4)

“I answered neutral for the thing I was unsure about. I hope this was the right thing to do” (P20)

“A few questions seemed to ask the same thing in a different form of words. This may be necessary as a control, but I found it a little confusing - but then it may just be me! It made me feel very good listing my support network - and very blessed” (P15).

“Didn't understand the significance of some of the questions. May be give people more background to the reasoning of the questions may have helped” (P10).

“I think there should be a "don't know" box on the questions that range from agree to disagree as well as neutral, as sometimes I feel neutral was not appropriate to answer some of the questions” (P42).

“I wouldn't put "never" in a question - it is such a strong word, maybe 'I would not' instead of 'I would never'- but I know how research wants you to word questions appropriately i.e. whether you agree or disagree! Also, it has made me wonder about breast cancer now - I would love to read the research/results once they are published” (P41).

Whilst these points were considered, no changes were made. As the questionnaire was constructed from existing psychological instruments it was felt that adding or changing the questions themselves or the question responses could affect reliability and validity.

It was concluded that the questionnaire held no major problems and was suitable to be used in the main study after the wording adjustments discussed above. Appendices 4 and 5 provide a copy of the pre-intervention and post-intervention questionnaires.

6.3.2 Design of Multimedia-Enhanced BSE Programme

Regular BSE according to the 5-step model (a structured BSE guide consisting of five specific steps incorporating both looking and touching the breasts in particular ways) (see Appendix 6) has been promoted by breast-cancer campaigns in the past (breastcancer.org, 2009) as a comprehensive method. Furthermore as demonstrated in the earlier exploratory work, the 5-step technique can be a useful teaching tool that improves current techniques, aids the actual self-examination process when used as a step-by-step guide, and offers necessary knowledge for women who examine their breasts for the first time.

Consequently, it was decided that the BSE educational materials should incorporate this technique. An instructional video provided by Aetna Inteli-health, with medical content reviewed by the Harvard Medical School Faculty was selected to form the video aspect of the video-enhanced BSE support programme.

Similarly the text of both versions of the multimedia BSE support programme was based on instructions provided by Aetna Inteli-health but with the incorporation of some further information regarding BSE for different breast sizes and a description of lymph nodes. This additional information was added to provide the women with more information and thus aid them in their examination. Appendix 7 provides the text based BSE instructions used in the study.

The sound from the video within the video-enhanced version was removed to enable a more accurate comparison with the static version of the BSE instructions. Following this,

both versions of the BSE instruction material were identical in content; the only difference was the way in which this content was presented; pictures and text in the static version and video and text in the video-enhanced version.

6.3.3 Selection of Autobiographical Accounts

Health Talk Online is the award winning website of the DIPEX charity and the information contained on the website is based on qualitative research into patients' experiences, led by experts at the University of Oxford. The site contains videos of the interviews of more than 2,000 peoples' experience of health and illness and 53 on breast cancer per se. Twelve accounts were selected to be used in the study and these covered a range of ages and issues. The women in the accounts ranged in age from 18 to 70 at the time of diagnosis (Mean = 41.92 years; SD =14.16) and 19 to 70 at the time of the creation of the autobiographical account (Mean = 44.17 years; SD =13.86). It was important to ensure that the widest age range possible was displayed to ensure women in the main study could identify with the women in the accounts.

The accounts were further selected to ensure they covered a range of issues connected to breast cancer; risk factors for breast cancer, the importance of breast awareness, finding a lump, the diagnosis and initial reaction, the reaction of others, the experience including positive aspects, coping with cancer, and life after cancer. It was hypothesised that observing women discussing the importance of breast awareness and how they themselves discovered breast cancer through methods such as BSE may highlight the relevance of breast awareness. Similarly, observing women discussing their experience of breast cancer and coping well may reduce the uncertainty surrounding breast cancer and alleviate some of the psychological barriers to performing BSE. Furthermore, through the autobiographical accounts women may be educated about breast cancer, possibly

dismissing myths and misconceptions, some of which may be inhibiting their engagement in BSE. Appendix 8 presents the autobiographical accounts used.

6.3.4 Website Development

The website needed to be designed in such a way to ensure only those participating in the research could be in contact with the site, and access information solely for their assigned group. By hosting the site on the university network, entry to the site could be restricted. In order to access the university network, individuals needed a university account and permission to be granted by the university. Following this, the study website was created using the website development tool Microsoft SharePoint.

Five pages were produced within the site: a general study homepage and a homepage for each of the four participant groups. Appendix 9 presents screenshots of the website design. These pages were password-protected and access was controlled to ensure participants could only enter the general group page and their study group homepage. When attempting to access the pages, participants were prompted to enter their username and password. Each participant was allocated a unique username and access was controlled for each participant individually.

The general study homepage displayed information about the study and the researcher's contact details. In addition to this information, links to each of the four group homepages were provided on the left-hand side of the page. Each of the group homepages displayed information about the study specific to their group and links to the pre-and post-intervention questionnaires. Links to the study materials that participants needed to complete the study were provided on the left-hand side of the page.

All the group homepages provided a link to pages within the site containing blog guideline questions (see Appendix 10), researcher's contact details (see Appendix 11) and a task summary table (see Appendix 12). The homepages for Groups 1 and 2 provided a link to

a page displaying static BSE instructions (see Appendix 13) and the homepages for Groups 3 and 4 provided a link to page displaying the video-enhanced BSE instructions (see Appendix 14). In addition, the homepages for Groups 1 and 3 provided a link to a page containing links to the autobiographical account videos (see Appendix 15).

Furthermore, a personal blog was created for each individual within the site (see Appendix 16). This was developed as a sub-site within the site and could be accessed via a link on the left-hand side of the page or by going to the following address

<https://unity2.tees.ac.uk/schools/SSSL/breastselfexamination/groupX/BlogPY> (where X

was the relevant group number and Y the participant's number). All participants were provided with the web address to access their personal blog at the start of the study to ensure accessing the blog was as easy as possible. Likewise, the blog was constructed to ensure participants could use it with no difficulty. Unnecessary headings and content approval were removed and instructions on blog creation were provided as a welcome message within the blog. To ensure confidentiality the blog was password-protected.

Development Challenges and Decisions to Overcome These

During the creation of the study website, a few development challenges arose; these and the decisions that were made to overcome these are described below.

Participants needed to have an associate university account created to access the site. In order for this to occur, university regulations required the completion of an associate application form for each person requiring access to the site. Thus, to get account permission to create an account for each of the participants a form needed to be sent to them, signed and returned to the university. Furthermore, the site usernames created for these accounts incorporate the individual's real name. This posed problems considering the anonymous nature of the study.

To resolve this problem permission was granted from the university to create a batch of temporary accounts. These were anonymous in that they did not display the individual's name within the site; instead, their username was numerical and they did not require a signature from each individual participant; instead, the researcher was able to sign on their behalf.

Microsoft SharePoint allows the user to embed videos within the site and as a general rule any file playable by a standard Microsoft video player is compatible. Unfortunately, the format of the BSE video file did not allow the video to be added to the site in its original form. The video needed to be first downloaded from its original source <http://www.wonderhowto.com/how-to-perform-breast-self-examination-check-for-lumps-5366/view> and then converted into an AVI file. Once converted it was necessary to save the file on the university network drive. Following this the file was then ready to be embedded into the site coding. This entire process needed to be completed separately for each of the five parts of the video; looking, feeling using circular lying down, feeling using line lying down, feeling using circular standing and feeling using line standing. Once completed, five frames streaming the video were displayed on a page within the site. Text-based instructions were then placed next to each of these frames to complete the BSE video-enhanced instructions.

Website Pilot Study

In order to preliminarily assess the website designed for this study and to determine whether any modifications needed to be made before its use in the study, a pilot study was conducted in which 16 women aged between 18 and 51 (Mean = 27.19 years; SD = 8.30) were asked to view the website and give feedback. The main study had four participant groups and therefore the website was designed so to have four distinct sub-sites (one for each of these participant groups). Pilot participants were randomly assigned

to one of these four study groups and asked to view and rate their group sub-site accordingly. It was anticipated that these women would have similar characteristics as the women in the main study. Appendix 17 provides a more detailed description of the demographic characteristics of the pilot sample.

All participants were asked to view their respective sub-sites in the same way as they would if they were participating in the study. Therefore and in order to test all aspects of the site, they were asked to complete the following tasks.

- (1) Read all the study information displayed on the site.
- (2) Follow the link to the pre-and post-intervention questionnaires (they were not asked to complete the questionnaires, just check the link directing to the questionnaires was working correctly).
- (3) View BSE instructions (Those in Groups 1 and 2 were provided with a static version of the BSE instructions and those in Groups 3 and 4 were provided with a video-enhanced version of the BSE instructions).
- (4) Write a message within a personal blog provided by the site.

In addition to this, those in Groups 1 and 3 were also asked to view a series of breast-cancer patient autobiographical accounts in video form.

Following this, all the pilot participants were asked to complete a feedback questionnaire. This questionnaire asked for feedback on all aspects of the website and included questions on the following: website welcome page, website group page, personal blog, BSE technique and the entire website. Table 6 provides a full list of these questions and responses and Appendices 18 and 19 present a breakdown of the raw data.

Results

Table 6

Website Pilot Study: Summary of the Questions Asked and Participant Responses

Question	Response				
Website Welcome Page					
	Very Easy	Easy	Neither	Difficult	Very Difficult
How did you find accessing the study website?	25%	56%	9%	-	-
How did you find reading the information on the website?	19%	56%	25%	-	-
Was the study information displayed on this page sufficient?	Yes 100%	No -			
	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
Using the website was easy	25%	63%	13%	-	-
Becoming skilful at using the website was easy	19%	63%	19%	-	-
The website was easy to navigate	19%	75%	-	6%	-
I found using the website enjoyable	19%	25%	56%	-	-
The actual process of using the website was pleasant	13%	50%	38%	-	-
I had fun using the website	13%	25%	56%	6%	-
Website Group Page					
	Very Easy	Easy	Neither	Difficult	Very Difficult
How did you find accessing the study website group page?	19%	69%	6%	6%	-
How did you find reading the information on this page	19%	69%	6%	-	6%
Was the study information displayed on this page sufficient?	Yes 100%	No -			
Was it clear from reading this page when and what tasks you would be required to do as a participant?	94%	6%			

Did the link to the pre-intervention and post-intervention questionnaire work for you?	100%	-			
Were you able to access and read the autobiographical accounts? (This only applied to those in Groups 1 & 3).	100%	-			
Were you able to access and read/view the BSE instructions ok?	94%	6%			
	Strongly Agree	Agree	Neither	Disagree	Strongly Disagree
Using the website was easy	31%	50%	13%	6%	-
Becoming skilful at using the website was easy	19%	63%	13%	6%	-
The website was easy to navigate	25%	63%	-	6%	6%
I found using the website enjoyable	13%	44%	38%	6%	-
The actual process of using the website was pleasant	6%	44%	50%	-	-
I had fun using the website	13%	25%	50%	13%	-
Website Group Page - Personal Blog					
	Very Easy	Easy	Neither	Difficult	Very Difficult
How did you find accessing the blog?	19%	69%	13%	-	-
How did you find reading the blog?	19%	63%	19%	-	-
How did you find writing in the blog?	19%	63%	19%	-	-
	Yes	No			
Do you think the blog instructions are sufficient to read and write within the blog?	100%	-			
Do you think the 'questions to help you write your blog' are sufficient to do this?	100%	-			
	Strongly Agree	Agree	Neither	Disagree	Strongly Disagree
Writing a blog was easy	25%	56%	19%	-	-
Becoming skilful at writing a blog was easy	13%	56%	31%	-	-

The blog was easy to navigate	25%	69%	6%	-	-
I found writing a blog enjoyable	6%	69%	25%	-	-
The actual process of writing a blog was pleasant	-	75%	25%	-	-
I had fun writing a blog	-	56%	38%	6%	-
Website Group Page – Breast Self-examination Technique					
	Yes	No			
Written Instructions					
Was the procedure described clear and easy to understand?	100%	-			
Do you think it would be possible for you to complete the steps using those written instructions supplied?	100%	-			
Video & Accompanying Text					
Was the procedure shown in the video and accompanying text clear and easy to understand?	88%	13%			
Do you think it would be possible for you to complete the steps using those instructions supplied in the video and accompanying text?	88%	13%			
Website Entire Site					
	Strongly Agree	Agree	Neither	Disagree	Strongly Disagree
Using the website was easy	25%	50%	25%	-	-
Becoming skilful at using the website was easy	19%	69%	25%	-	-
The website was easy to navigate	19%	63%	19%	-	-
I found using the website enjoyable	19%	44%	38%	-	-
The actual process of using the website was pleasant	6%	56%	38%	-	-
I had fun using the website	13%	38%	50%	-	-

Website Welcome Page

No problems were found with the website welcome page. All the women reported the study information displayed on this page to be sufficient and none found accessing or reading this information to be difficult. Most of the women found using the website to be easy and not an unpleasant or un-enjoyable experience.

When asked for further comments or suggestions for improvements three of the women took up this opportunity reporting;

“I was concerned at first about using the site but once I got into it and realised what I was doing I found it easy” (P9).

“Would have preferred to have accessed my group homepage straightaway, and to have found the welcome information incorporated there, perhaps as a link. The information displayed is sufficient, however I have found that the text is too lengthy and a bit off putting, regarding keeping on with the study, as it feels there are many different stages involved and a great amount of my time will be required” (P16).

This point was taken into consideration and for the main study the site was adapted to enable participants to access their group homepage immediately. In addition to this, the text was reduced and a link to a summary table was added.

“Maybe larger links to different pages” (P13)

Unfortunately there was no facility within the site to change the size of the links to the different pages.

Website Group Page

Most of the women found accessing the study group page and reading the information displayed on this page to be easy. The information displayed on this page was judged by

all the women to be sufficient and for most it was clear from reading this page when and what tasks they would be required to do as a participant. The links to the pre-and-post-intervention questionnaires worked fine for all the women and those given the autobiographical accounts to view similarly had no problems.

Problems however were experienced for one woman; she expressed difficulty in accessing the group page, found reading the information on this page to be very difficult and thought it was not clear from reading this information what was required to do as a participant. When asked to explain this, she reported;

“Some of the welcome page information is repeated, which is a bit tiring and repetitive, also the links on the right hand side displaying all the different weeks are overwhelming. I felt that I would have to put too much energy into this” (P16).

“Felt confused with regard to the order of tasks and what exactly I would have to do. Would have preferred a personalised table (where I could write my name for example and receive a welcome note with my name), where the timeline of tasks to be taken would be stated more clearly and all the text could be accessed by clicking on the title of the task (having it displayed is again too much). Also it is unclear how tasks and weeks connect together, if I understood this right then I would have liked for example end of week 2 – now go to task 3 and so on and so forth” (P16).

The welcome page and these links were removed for the final study. Instead participants accessed their group homepage immediately, and were provided with a link to this summary table. Further to this, the table was updated to allow participants to personalise their table to themselves and print out for their own reference and the information within the table was stated more clearly to ensure participants were aware of how the tasks and weeks connected together.

Overall most of the women had no difficulty accessing and using the site. Furthermore it was reported using the website was not an unpleasant experience for any of the women, and only one of the women reported using the website to be un-enjoyable (P16). This was most likely due to the access and reading issues discussed above.

When asked for further comments or suggestions for improvements two of the women took up this opportunity reporting;

“Merge welcome page information with each group’s homepage information and create a visually accessible line of tasks to be taken, without displaying all the text, just to get an overall idea of where things begin, what’s involved, where everything ends, and then click on each one of them to access the task information/instructions. Also merge tasks and weeks together as appropriate (e.g. end of 2nd week/do task 3, end of fourth week/do task three etc)” (P16)

As discussed previously the site was amended, taking this point into consideration.

“More detailed links to the different sections of the video autobiographies perhaps. It is unclear why the footage is divided at first, could maybe be made clearer by headings such as “Diagnosis” “Initial reaction” etc for each individual. Just being picky though, I really like this section” (P13).

Taking this point into consideration, headings were added to the autobiographical accounts, describing the theme of each of them. For example risk factors, the diagnosis and life after cancer.

Personal blog

None of the women found accessing, reading or writing within the blog to be difficult and most reported this to be easy or very easy. The blog instructions and questions to help

write the blog were judged by all the women to be sufficient and for most writing within and navigating the blog was an easy, pleasant and enjoyable process.

When asked for further comments or suggestions for improvements one of the women took up this opportunity reporting;

“Would have liked information to have been organised/presented in a differently and not just a list of questions (perhaps have a picture of a girl in the middle where I could type my name in and have bubbles with different colours all around me, where I would be asking myself those same questions instead of someone else asking me” “I quite enjoyed accessing that as there is minimal information included which gave me more confidence as a user” (P16).

Unfortunately the site set-up did not allow the blog to be amended to enable this suggestion to be inputted. However as only one participant expressed a desire for the blog to be presented differently, and this was purely due to their preference, not because they were unable to complete the blog in the original form, it was felt the blog could be left unchanged.

Breast Self-examination Technique

With regards to the BSE support all the women given the static support could view them problem free and expressed that they felt the procedure described to be clear to understand and that it would be possible for them to examine their breasts using these instructions.

Whilst most of the women given the video-enhanced support could access and view this fine, one woman however experienced a problem getting the video to play. It appears however this was due to her virus protection software, rather than a problem with the video itself. Once this particular woman updated her virus protection software the video

worked with no problems. All the women were able to view the video-enhanced BSE support (and indeed this women once the problem was resolved) expressed they felt the procedure shown to be clear and easy to understand and it would be possible for them to examine their breasts using it.

When asked for further comments or suggestions for improvements two of the women took up this opportunity reporting;

“Just a really minor wording issue, I thought the description of the breast tissue to be like orange segments a very good and useful description, but it was suggested afterwards this might seem “scary”, I would maybe use a different word, maybe “unusual” as suggesting something might be scary can often make a person wary of something before doing it and might seem a bit intimidating, “pink elephant” syndrome kind of thing so I’d maybe avoid the word scary” (P13).

Taking this point into consideration the word scary was replaced with unusual within the final study BSE instructions.

“Found videos more useful, instructions are too lengthy and would not go on to read them, perhaps have accompanying text but not show it, maybe as a link, as the lengthy text would put me off watching the videos, would feel it would take me ages to do the self-examination” (P16).

Unfortunately due to the nature of the study the accompanying text needed to be displayed in order to allow the static and video-enhanced BSE versions to be truly compared with each other.

Entire Website

Overall none of the women found using the website to be a difficult, unpleasant or un-enjoyable process suggesting, that after the amendments discussed the site was ready for the main study.

6.4 Method

6.4.1 Design

The study adopted a mixed methods 2×2 independent measures design (Independent Variable 1 = patient information: viewing or not viewing autobiographical account, Independent Variable 2 = multimedia BSE performance support: BSE with the static BSE support or with the video-enhanced BSE support). The qualitative and quantitative outcomes of the study were: (1) quality of BSE support; (2) health beliefs; (3) experience of BSE at an individual and group level; (4) evaluation of computer-mediated communication within a research setting.

6.4.2 Participants

A volunteer sample of 60 women, mean age 37.72 years (SD = 13.734), with ages ranging from 19 to 67 were recruited to participate in the study. The majority of the women were from the North-east of England (54). The other women resided in the North-west (2), Yorkshire and Humberside (2), West Midlands (1) and South-east (1) regions of England.

The highest education qualification obtained by the women was primary education (1), GCSE qualifications (7), college certificate/A-levels (20) university degree (18), and postgraduate qualifications (14). All the women in the study were of white ethnic origin. Tables 7 and 8 present a more detailed description of the age and educational level of the participants in each group and Appendix 20 provides a more detailed description of the demographic characteristics of the sample.

Table 7

Participant's Age per Group

	Group 1	Group 2	Group 3	Group 4
n	15	15	15	15
Age Range	19-66	21-60	20-67	19-55
Mean	38.4	38.93	36.07	37.47
SD	15.69	12.76	15.42	11.95

Table 8

Participants Highest Educational Level Achieved per Group

	Group 1	Group 2	Group 3	Group 4
n	15	15	15	15
Primary	0	0	1	0
GCSE	2	3	0	3
College/A level	4	3	5	7
Degree	5	5	5	4
Post graduate Award/ Masters/ PhD	4	4	4	1

Inclusion criteria included: (1) aged 18 or over; (2) female; and (3) proficient at English Language to Cambridge level 6. Exclusion criteria included (1) an inability to provide informed consent; (2) current diagnosis or receiving treatment for breast cancer; (3) and current major psychiatric illness.

6.4.3 Summary of Materials

The study materials received depended on their participant group and were distributed via the study website. All participants were provided with a list of points and questions to aid

them with the completion of their blog (see Appendix 10). These were designed as a starting point and participants were encouraged to make notes within their blog about any thoughts, feelings and experiences connected to breast cancer, BSE and the study itself as they progressed through the study.

Half the participants were provided with a static version of the BSE instructions (see Appendix 13) and half were provided with the video-enhanced version of the BSE instructions (see Appendix 14). All the information was identical in both versions; the only difference was the way it was presented: pictures and text in the static version and video and text in the video-enhanced version.

Half the participants were asked to view 12 autobiographical accounts of breast-cancer patients, provided by Health Talk Online (see Appendix 8). These were divided into six sets and participants were asked to view Set One in Week One, Set Two in Week Two and so on.

6.4.4 Description of Instruments

A pre-and post-intervention questionnaire were designed specifically for this study (see Appendices 4 and 5). The pre-intervention questionnaire consisted of 10 sections: 1. Demographic Data, 2. Brief Technology Acceptance Questionnaire, 3. BSE Proficiency and Frequency Questionnaire, 4. Health Belief Model Scale, 5. Breast Cancer Worries Scale, 6. State Trait Anxiety Inventory, 7. Multidimensional Health Locus of Control Scale, 8. Illness Perception Questionnaire, 9. Norbeck Social Support Scale, and 10. Marlowe-Crowne Social Desirability Scale. The post-intervention questionnaire was similar to the pre-intervention questionnaire; except the demographic data was replaced with study evaluation questions and the God Health Locus on Control (GHLC) was incorporated into the Multidimensional Health Locus of Control Scale. In retrospect, the GHLC would have

been included in both the pre-intervention and post-intervention questionnaires, but unfortunately its existence was discovered after the pre-intervention questionnaire had been administered.

More information about the psychological instruments included in the pre-intervention and post-intervention questionnaire follows and Cronbach alpha coefficients for each questionnaire and their sub items are presented in Table 9.

Table 9

Study Questionnaire Cronbach Alpha Coefficients

Instrument	Cronbach Alpha Coefficient	
	Pre-Intervention	Post-Intervention
Brief Technology Acceptance Questionnaire		
<i>Intrinsic Motivation for Websites</i>	0.89	0.96
<i>Performance Expectancy for Websites</i>	0.89	0.87
<i>Perceived Ease of Use of Websites</i>	0.82	0.80
<i>Facilitating Conditions for Websites</i>	0.78	0.62
<i>Intrinsic Motivation for Blogs</i>	0.99	0.94
<i>Performance Expectancy for Blogs</i>	0.98	0.95
<i>Perceived Ease of Use of Blogs</i>	0.96	0.81
<i>Facilitating Conditions for Blogs</i>	0.77	0.68
BSE Frequency/Proficiency Questionnaire		
<i>Proficiency Scale</i>	0.43	0.71
Health Belief Model Scale		
<i>Barriers</i>	0.81	0.82
<i>Benefits</i>	0.80	0.90
<i>Confidence</i>	0.87	0.94
<i>Health Motivation</i>	0.68	0.73
<i>Seriousness</i>	0.76	0.79
<i>Susceptibility</i>	0.96	0.92
Breast Cancer Worries Scale	0.73	0.81
State Trait Anxiety Inventory	0.95	0.93
Multidimensional Health Locus of Control Scale		
<i>Internal</i>	0.71	0.70
<i>Chance</i>	0.48	0.62
<i>Powerful Others</i>	0.64	0.68
GOD Health Locus of Control Scale	-	0.99
Illness Perception Questionnaire Revised Healthy		

<i>Edition</i>		
<i>Identity</i>	0.61	0.41
<i>Timeline Acute/Chronic</i>	0.79	0.72
<i>Timeline Cyclical</i>	0.55	0.72
<i>Consequence</i>	0.53	0.78
<i>Personal Control</i>	0.70	0.78
<i>Treatment Control</i>	0.67	0.83
<i>Illness Coherence</i>	0.80	0.91
<i>Emotional Representation</i>	0.83	0.89
<i>Risk Factors</i>	0.78	0.88
<i>Psychological Attribution</i>	0.92	0.92
 <i>Norbeck Social Support Questionnaire</i>		
<i>Affection</i>	1.00	0.99
<i>Affirmation</i>	0.99	0.99
 <i>Marlowe-Crowne Social Desirability Scale</i>		
	0.68	0.46

Demographic Questionnaire

A 16-item questionnaire was used to gather demographic data about the participants. This was designed to measure variables labelled as breast-cancer risk factors and those connected with BSE behaviour. These included age, ethnicity, marital status, number of children, highest education qualification obtained, employment status, area of employment, length of unemployment (if applicable), religious orientation, details about contraceptive pill usage, stage of menstruation (i.e. menopausal or non-menopausal), age at start of menstruation, family and friend breast-cancer history, bra size and density of breast tissue. Participants were also asked to note the region they currently live in to provide more data about the sample.

Brief Technology Acceptance Questionnaire

A 26-item questionnaire was used to measure technology acceptance of websites, and blogs using scales that have previously been developed and validated. Three items were used to measure intrinsic motivation (Venkatesh & Speier, 2000), four items were used to measure performance expectancy (Venkatesh, Morris, Davis, Davis, & Walton, 2003), three items were used to measure perceived ease of use (Venkatesh et al., 2003) and three items were used to measure facilitating conditions (Venkatesh et al., 2003). Scale ratings were averaged to create a mean scale score and ranged from 1 to 5, with higher scores reflecting greater levels of the concept.

In addition, participants were also asked within the questionnaire, when they started using websites, when they first felt confident using websites and how often and for how many hours they use the Internet. This was to provide information on participants' general Internet use.

BSE Frequency/Proficiency Questionnaire

A modified version of the BSE Frequency/Proficiency Questionnaire (Champion, 1989, 1990) was used to measure the self-report of BSE frequency and knowledge of BSE technique. One item addressed the number of times a respondent performed BSE during the past 12 months and constituted the frequency measure in this study. Participants responded by selecting a number from 0 to 12. Women, who practised BSE more than 12 times per year were instructed to select "more than 12 times".

Eleven items addressed respondents' knowledge of the BSE technique and constituted the proficiency measure in this study. All eleven items reflected current American Cancer Society (ACS) recommendations for BSE performance and encompassed all aspects of the 5-step BSE technique.

Nine items used a 4-point scale to assess the degree to which respondents were consistent in applying certain techniques when performing BSE. One item used a 3-point scale to assess the part of the hand used in performing BSE (1. Palm of hand; 2. Tips of fingers; or 3. Flat part of your fingers) and a further item used a 5-point scale to assess the hand used to examine the breast (1. Either hand; 2. Right hand for right breast, left hand for left breast; 3. Left hand for both breasts; 4. Right hand for both breasts; and 5. Right hand for left breast, left hand for right breast).

Item scores of the proficiency scale were totalled. Possible total scores ranged from 11 to 44, with higher scores reflecting greater proficiency. Proficiency items were based on current recommendations for BSE performance given by the ACS and 5-step BSE technique guidelines (Breast cancer.org), thus supporting the content validity of the scale.

Health Belief Model Scale

The 42-item Health Belief Model Scale (HBMS) (Champion, 1984; 1993) was applied to measure health beliefs towards BSE. The HBMS has a 5-point Likert scale to measure attitudes and beliefs about breast cancer, BSE practice and health motivation. The scale was originally developed in 1984 and revised more recently in 1993. The items were divided into six scales: (1) perceived susceptibility to breast cancer (5 items); (2) seriousness of breast cancer (7 items); (3) barriers to BSE practice (7 items); (4) benefits to BSE (5 items); (5) confidence in performing BSE (11 items); and (6) general health motivation (7 items). Scale ratings were averaged to create a mean scale score ranging from 1 to 5, with higher scores reflecting greater levels of the concept (e.g. perceived susceptibility).

Content validity for the HBMS has been established by expert judges: factor analysis confirmed the existence of six independent factors. Standardised multiple regression have

demonstrated that the six scales of the HBMS explain 24% of the variance in BSE practice (Champion, 1993), thus supporting the predictive validity of the instrument.

Breast Cancer Worries Scale

Four questions borrowed from McCaul, Branstetter, O'Donnell, Jacobson and Quinlan, (1998) addressed breast-cancer worry: (1) "How often do you worry about breast cancer?" (1 = not at all; 5 = almost all the time), (2) "How many days out of the last seven did you worry about breast cancer?" (0-7), (3) "Does breast-cancer worry affect your mood?" (1 = not at all; 5 = almost all the time), and (4) "Does breast-cancer worry affect your performance of daily activities?" (1 = not at all; 5 = almost all the time). Following McCaul et al., (1998) these items were standardised and averaged to form the Breast Cancer Worries Scale.

State Trait Anxiety Inventory

The STAI is a validated 40-item self-report assessment device which includes separate measures of state and trait anxiety. The original STAI form was constructed by Charles D. Spielberger, Richard L. Gorsuch, and Robert E. Lushene in 1964. Various reliability and validity tests have been conducted on the STAI and have provided sufficient evidence that the STAI is an appropriate and adequate measure for studying anxiety in research and clinical settings (Sesti, 2000). For the purpose of this study the trait items were used to evaluate the more general and long standing quality of trait anxiety. The trait STAI subscale contained 20-items and used a 4-point Likert scale ranging from 1 (almost never) to 4 (almost always) to record participants responses to the scale. Nine items related to the absence of anxiety and were reversed scored. Item scores were added and scores ranged from 20 to 40, with higher scores reflecting greater Trait anxiety.

Multidimensional Health Locus of Control Scale

The Multidimensional Locus of Control Scale (MHLC) is an 18-item instrument that measures three dimensions of control as they pertain to health (Wallston, Wallston & DeVellis, 1978). The dimensions assessed are Internal Health Locus of Control (e.g., “If I get sick it is my own behaviour which determines how soon I get well again”), Powerful Others Health Locus of Control (e.g., “Whenever I don’t feel well, I should consult a medically trained professional”), and Chance Health Locus of Control (e.g., “No matter what I do, if I am going to get sick, I will get sick”). A 6-point Likert type scale ranging from 1 (strongly disagree) to 6 (strongly agree) was used to record responses on the MHLC. Each dimension had six items that produced a range of scores of 6 to 36 per scale. The instrument is the most widely used locus of control scale specific to health and has demonstrated good reliability and validity in both general and medical populations, with coefficient alphas for the dimensions ranging between 0.67 to 0.77 (Wallston et al., 1978; Wallston, Wallston, Smith & Dobbins, 1987).

GOD Health Locus of Control Scale (GHLC)

The extent of the belief that God exerts control over one’s health state was measured by the God Health Locus of Control Scale, (GHLC; Wallston, Malcarne, Flores, Hansdottir, Smith, & Stein et al., 1999). This measure was developed as an adjunct to the MHLC scale to better understand cognitions about external sources of control over illness. As in the MHLC, the GHLC too consisted of a 6-point Likert type scale ranging from 1 (strongly disagree) to 6 (strongly agree) to record GHLC responses. All were keyed in the same direction, with a high score indicating a high belief in God as a locus of control. The item scores were summed for a possible total score of 6-36. The GHLC scale score is positively related to religiosity and generally not correlated with other MHLC subscales

(Wallston et al., 1999). Internal consistency has been acceptable in prior studies, with scores ranging from 0.87-0.94 (Wallston et al., 1999).

Illness Perception Questionnaire Revised Healthy Edition

The Illness Perception Questionnaire (IPQ) was developed to provide a quantitative assessment of the five components of the illness representation (identity, consequences, timeline, control/cure and cause in Leventhal's self-regulatory model (Leventhal, Nerenz, & Steele, 1984; Leventhal et al., 1997). The recent publication of the Revised Illness Perception Questionnaire (IPQ-R) (Moss-Morris et al., 2002), represented an advancement in theory and measurement of the constructs. New dimensions were included, such as the illness coherence scale in order to better evaluate the overall meaning of the illness for a patient. In addition, the content of the original cure/control component from the IPQ was viewed by Horne (1997) as confounding sets of beliefs about personal abilities to control the illness and the efficacy of treatment to cure or manage the illness. These sets of beliefs were therefore treated separately in the IPQ-R as the personal control and treatment control scales. Also, the timeline dimension was differentiated into beliefs about the relative chronicity of the illness (timeline acute/chronic) and beliefs about the fluctuation in symptoms and temporal changeability of the illness (timeline cyclical). One important aspect of the IPQ-R was the inclusion of a measure of emotional representations, which was related to the cognitive components of illness representations. In the study of Moss-Morris et al. (2002), the constructs exhibited a characteristic and theoretically predictable pattern of interrelationships, which was also found across studies of chronic illness in a recent meta-analysis (Hagger & Orbell, 2003). Furthermore, illness-specific measures, even when factor-analysed, seem to cluster about the original dimensions derived by Leventhal et al. (1980), and this is congruent across different illnesses (e.g. Hagger & Orbell, 2005). More recently, the IPQ-R has been

adapted to assess the illness representations of 'healthy' individuals in relation to different illness perceptions (IPQ-RH, Figueiras & Alves, 2007). For the purpose of this study breast-cancer-specific illness perceptions replaced general illness perceptions.

The IPQ-RH (Figueiras & Alves, 2007) is divided into three sections with the identity and causal dimensions presented separately from the remaining others. In the first section the identity scale is presented with a list of commonly known symptoms and participants are asked whether or not they believe the symptom to be related to the illness (1 – yes; 0 – no). The sum of the yes-rated items forms the identity subscale of this version. For the purpose of this study six commonly known symptoms related to breast cancer were presented. In the following section, consequences, timeline acute/chronic, timeline cyclical, illness coherence, personal control, treatment control, and emotional representation of the IPQ-R were rated on the original 5-point Likert type scale: from strongly disagree to strongly agree. In this version, the wording of the IPQ-R items was adapted for healthy individuals (e.g., "My illness is a serious condition" in the original version becomes "This illness is a serious condition" in the adapted version). For the purpose of this study "This illness" became "Breast cancer". The causal attributions dimensions were presented as a separate section which uses the same Likert-type scale. The test–retest data of this version shows that this scale has acceptable levels of stability over three weeks (Figueiras & Alves, 2007). Data from their Principle Component Analysis provides further empirical support for the theoretically derived dimensions of patients' illness representations in healthy populations.

Norbeck Social Support Questionnaire

Social support was measured by the Norbeck Social Support Questionnaire (NSSQ) (Norbeck, Lindsey & Carrieri, 1983). The NSSQ measured social support as functional support consisting of affect, affirmation, and aid; convoy or support network properties of

size; duration of relationships and frequency of contact; and losses of network including recent losses, quantity of loss and quality of loss and is considered to be a reliable measure of a person's social support network (Rock, Green, Wise, & Rock, 1984).

The NSSQ consisted of a series of half pages that were visually aligned with the individual's social network. Individuals indicated by initials persons who were significant to them, the nature of their relationship and then ranked on a 5-point Likert scale, eight questions about the type and degree of social support received from each individual listed. For questions 1 to 6, the scale ranged from 0 (not at all) to 4 (a great deal), for question 7, the scale ranged from 1 (less than 6 months) to 5 (more than 5 years) and for question 8, the scale ranged from 1 (once a year or less) to 5 (daily).

The responses were totalled to yield a score for each functional subscale of affection (question 1 and 2), affirmation (question 3 and 4) and aid (question 5 and 6). These items were then added to form a total functional social support score. Emotional support was calculated by adding the responses to questions 1 to 4 and tangible support was calculated by adding the responses to questions 5 and 6. The number of entries made on the network list was noted to form the social support network size measure and these ranged from 1 to 24. The total network score was calculated by adding the number listed, with the total score for questions 7 and 8. The quantity of social support losses during the past 12 months was determined and quality was assessed by a 5-point scale with scores ranging from 1 (none at all) to 5 (a great deal).

A high degree of test-retest reliability and internal consistency of the functional components has been established in past studies (Wagle, Komorita, & Lu, 1997). Construct validity has been demonstrated, and concurrent validity obtained through a significant correlation with the Cohen and Lazarus Social Support Questionnaire and

Brandt and Weinart's Personal Resource Questionnaire (Norbeck, Lindsey, & Carrieri, 1981; Norbeck et al., 1983).

Consultation of a correlation matrix revealed high correlations (0.814 - 0.992) between components of the social support questionnaire within the current study, suggesting perhaps all components of the questionnaire were not needed and the questionnaire may be reduced. Following this, principle component analysis revealed a two components solution whereby simply including affection and affirmation measures of social support, would explain 92.263% of the total variance. Thus it was decided for the purpose of this study, social support would be investigated with these two components.

Marlowe-Crowne Social Desirability Scale

Coping style was measured using the Marlowe-Crowne Social Desirability Scale (M-C) (Crowne & Marlowe, 1960) in conjunction with the Trait Subscale of the State Trait Anxiety Inventory. Weinberger, Schwartz and Davidson (1979) proposed a four-fold classification of individual coping styles: repressors (R, low anxiety and high defensiveness), low-anxious (LA, low anxiety and low defensiveness), high-anxious (HA, high anxiety and low defensiveness) and defensive high-anxious (DHA, high anxiety and high defensiveness).

The M-C is a 33-item scale originally designed to measure socially desirable behaviours. The total score can range from 0 to 33, with higher scores reflecting greater defensiveness. Weinberger and others (Jamner et al., 1988; Weinberger, 1990, Weinberger, Schwartz & Davidson, 1979) concluded that the M-C measures the individual difference of defensiveness and when coupled with an anxiety measure can differentiate between R, LA, HA and DHA coping styles. For the purpose of this study a medium split was implemented to distinguish high and low scores. Participants who scored 16.5 or less on the M-C were categorised as low defensive and those who scored higher than 16.5 were categorised as high defensive. Similarly those scoring 40 or less on the STAI (Trait

subscale) were categorised as low trait anxiety and those scoring above 40 were categorised as high anxiety.

Study Evaluation Questions

At the end of the study participants were asked to provide some further information about their BSE over the course of the study and if their views regarding breast self-examination had changed as a result of the study. Although participants were asked to examine their breasts six times over the course of the study, it was anticipated that not all the women would do this. Thus it was important to note how many times the women had actually examined their breasts over the course of the study. Likewise it was of interest to note the reasons for this lack of BSE in these women.

Nine questions were used to examine participants BSE over the course of the study, and these consisted of open and closed questions to provide the opportunity for participants to answer the questions in their own words and give more information if they should wish.

The questions were as follows;

1. Please describe if and how your awareness of your breasts has changed over the course of this study.
2. As part of this study you were asked to examine your breasts six times over a three month period. Were you able to do this? If no please try to describe why and how many times you examined your breasts?
3. Please describe how you found examining your breasts over the course of this study.
4. Were you able to follow all aspects of the examination procedure with ease?
5. Did you enjoy following the instructions to examine your breasts? Please discuss why.

6. Please discuss what you think about the breast self-examination technique you have been doing.
7. Please describe what you think about breast self-examination generally.
8. Has, the way you think about breast self-examination generally changed throughout the study? If so please try to describe how and why?
9. Do you have any further comments or thoughts connected to the study?

A follow-up questionnaire was designed for use in this study, asking participants to report the frequency of their BSE since the end of the study, and to provide reasoning should BSE have not occurred. The framework of this questionnaire was as follows;

Follow-up Questionnaire

1. Since the end of the study have you continued to examine your breasts?
If so; how often do you examine your breasts?
If no; please describe why you have been unable to or chosen not to examine your breasts.

6.4.5 Power Analysis

Prospective power analyses using the statistical software program Sample Power were conducted to determine the required sample size needed to detect a small, medium and large effect of autobiographical accounts and BSE support on BSE for a significance level of 0.05 (see Appendix 21 for a more detailed explanation of the power analysis calculations). It was important to ensure that the sample size of the study was sufficient to detect at least a large effect of each independent variable (autobiographical accounts viewed or not viewed and type of BSE support) and the interaction between these variables. This condition was met as the actual sample included 15 participants per each

of the four study groups (totalling 60) and this exceeded the sample size needed to detect a large effect ($N = 56$).

6.4.6 Procedure

A website was designed specifically for this study and displayed information about the study and all the study materials. Following informed consent, each participant was provided with a username and password to gain access to this site and their own personal blogs and a participant number to identify them during the study. Participant's age, ethnicity and highest educational level obtained was noted and they were assigned to one of four groups based on this. This was to ensure, each of the four groups were comparable on age, ethnicity and highest educational level obtained.

Group 1 received autobiographical accounts and the static BSE procedure, Group 2 received no autobiographical account and the static BSE procedure, Group 3 received autobiographical accounts and the video-enhanced BSE procedure, and Group 4 received no autobiographical accounts and the video-enhanced BSE procedure.

All groups were asked to complete a pre-intervention questionnaire at the start of the study (see Appendix 4) and a post-intervention questionnaire at the end (see Appendix 5) via the website. In addition, for three months participants were invited to examine their breasts fortnightly using the BSE instructions provided to them and report in their blogs on the frequency and usability of the BSE procedure. Similarly, all groups were asked to have a daily awareness of their breasts – no structured procedure was given to enable this; instead, participants were asked to just be aware of how their breasts looked and felt (for example looking at their breasts whilst getting dressed or undressed and touching them whilst getting a bath or shower). Again, they were asked to report in their blogs how they found this. Each participant was assigned her own personal blog and this was only

accessible to her and the researcher. A set of questions and points were given to each of the participants via the study website to aid with this blog-writing process.

Those participants assigned to Groups 1 and 3 were additionally asked to view a set of videos of women talking about their experience of breast cancer (autobiographical accounts).

Following completion of the study, a follow-up questionnaire was administered four months after the end of the intervention, asking participants to report the frequency of their BSE since the end of the study. If participants had not examined their breasts since the end of the study they were further asked to provide reasoning for this.

6.4.7 Recruitment and Data Collection

Participants were recruited through advertisements on websites related to women's and adolescents' health issues, social networking sites, at the local college and university, radio interviews and through stories about the research in the local press. Seventy women started the study, but 60 completed the study. Analysis of variance (ANOVA) and Chi square analyses were conducted on this data depending on the nature of the data, interval or nominal level, to discover if drop-out participants and those that completed the study differed on the demographic characteristics noted within the pre-intervention questionnaire. The women were compared in terms of age, educational level, ethnicity, marital status, number of children, employment status, area of employment, length of unemployment (if applicable), religious orientation, details about contraceptive pill usage, stage of menstruation (i.e. menopausal or non-menopausal), age at start of menstruation, family and friend breast-cancer history, bra size and density of breast tissue.

The analyses revealed no differences between the women in terms of age, educational level and ethnicity and most of the other demographic characteristics noted. However they

did reveal a significant difference in terms of length of contraceptive pill use, $F(1, 65) = 8.330$, $p < 0.01$, with drop-out participants reporting longer pill usage than completing participants. Further analyses also revealed no difference between drop-out participants and those that completed the study in terms of pre-intervention BSE frequency and proficiency.

As technology was a major aspect of the current study due to the study's online nature, participants were further compared with drop-out participants in terms of their views on the Internet, websites and blogs. ANOVA analyses revealed no significant differences between the women on all aspects of the brief technology acceptance questionnaire.

Based on these analyses, it was concluded that the drop-out women were not significantly different to the participants who completed the study in terms of these demographic characteristics, BSE frequency and proficiency and technology views.

6.4.8 Trustworthiness of Data

The trustworthiness of the qualitative data produced within this study was considered following Lincoln and Guba (1985). According to Lincoln and Guba (1985) trustworthiness of a research study is important in evaluating its worth and involves establishing credibility, transferability, dependability and confirmability. *Credibility* refers to an evaluation of whether or not the research findings represent a 'credible' conceptual interpretation of the data drawn from the participants' original data. *Transferability* refers to the degree to which the findings of this inquiry can apply or transfer beyond the bounds of the project. *Dependability* is an assessment of the quality of the integrated processes of data collection, data analysis, and theory generation. *Confirmability* is a measure of how well the inquiries' findings are supported by the data collected (Lincoln & Guba, 1985).

To increase the likelihood that credible findings and interpretations were produced the following techniques were engaged in.

1. *Prolonged Engagement and Persistent Observation*

The BSE intervention and data collection process took place over a 3-month period and therefore it may be suggested that sufficient time was invested to learn and understand the participants' beliefs and behaviour and ensure credible findings were produced. The longitudinal nature of the study allowed the researcher to become orientated to the situation and thus appreciate and understand the context fully and gave participants the opportunity to become comfortable disclosing their thoughts and feelings towards BSE, some of which may have been potentially sensitive information. Furthermore, the regular disclosure of the participants' thoughts within their blogs allowed for the identification of the most relevant characteristics of the situation and context, increasing the credibility of the findings further.

2. *Methodological Triangulation*

Two methods were implemented to facilitate data collection. Participants were asked to complete blogs throughout the study and an end of study questionnaire. Following, Webb et al. (1966) it was assumed that by confirming the study's results with two different measurement processes at different times throughout the study, that the uncertainty of any interpretations made would be greatly reduced and the credibility of the findings increased. Through using two different methods, it was envisaged that the study could overcome the weakness and problems associated with single method data collection.

3. Member checks

Participants were given the opportunity to verify the interpretations and conclusions drawn from the data analysis of the blogs and end of study questions. A description of each of the themes drawn from the data analysis were provided to participants and they were asked to rate their ability to relate to the theme on a scale of 1 to 3; true for me (1), not true for me (2) and not sure (3). All participants were asked to complete the questionnaire but only 40 did so. The responses for those participants who completed the questionnaire were collated and Tables 10 - 14 present a summary of their responses.

Table 10

Participants Ability to Relate to Theme 1: Previous Experience

	Subtheme 1	Subtheme 2	Subtheme 3
True for me	29 (73%)	35 (88%)	28 (70%)
Not true for me	8 (20%)	3 (8%)	10 (25%)
Not sure	3 (8%)	2 (5%)	2 (5%)
Total	40	40	40

Table 11

Participants Ability to Relate to Theme 2: BSE Irregularity

	Subtheme 1	Subtheme 2
True for me	35 (88%)	33 (83%)
Not true for me	5 (13%)	6 (15%)
Not sure	0 (0%)	1 (3%)
Total	40	40

Table 12

Participants Ability to Relate to Theme 3: Perceived Susceptibility

	Subtheme 1	Subtheme 2
True for me	38 (95%)	38 (95%)
Not true for me	2 (5%)	2 (5%)
Not sure	0 (0%)	0 (0%)
Total	40	40

Table 13

Participants Ability to Relate to Theme 4: Coping Style

	Subtheme 1	Subtheme 2
True for me	21 (53%)	27 (68%)
Not true for me	15 (38%)	8 (20 %)
Not sure	4 (10%)	5 (13%)
Total	40	40

Table 14

Participants Ability to Relate to Theme 5: The Usability of the 5-Step Model of BSE

	Subtheme 1	Subtheme 2	Subtheme 3	Subtheme 4	Subtheme 5	Subtheme 6
True for me	39 (98%)	37 (93%)	39 (98%)	36 (90%)	38 (95%)	40 (100%)
Not true for me	0 (0%)	2 (5%)	1 (23%)	1 (3%)	0 (0%)	0 (0%)
Not sure	1 (3%)	1 (3%)	0 (0%)	3 (8%)	2 (5%)	0 (0%)
Total	40	40	40	40	40	40

The majority of the participants were able to relate to Themes 1, 2, 3 and 5.

However less reported finding both statements for Theme 4 to be true for them.

This was most likely because the statements refer to two different coping styles, and individuals may relate to just one of the coping styles. Indeed 53% related to an avoidance coping style and 68% to a proactive coping style.

It was suggested from these results, that the themes drawn from the data analysis were representative of the majority of the participants that completed this questionnaire. This increased the credibility of the findings, and confirmed that the findings are representative of the women participating in this study.

4. *Reflective Journal*

To further establish credibility within the findings of the study, and with the additional aim of establishing transferability, dependability and confirmability a reflective journal was kept for the duration of the study (See Appendix 22). Within this journal, reference was made to the logistics of the study and to the methodological decisions and the accompanying rationales for these decisions. Furthermore the journal recorded a reflection of the researcher's own values and interests connected to the study and the decisions made as the study progressed. Qualitative research is inherently an interpretive process and it was felt through the completion of this journal, transparency could be achieved and any opinions, thoughts and feelings connected to the study acknowledged. This was important to ensure that the findings of the study were consistent and could be repeated at a later date and that they have applicability in other contexts. Moreover, it was felt that the completion of the journal increased the confirmability of the findings and ensured the findings were credible.

Finally, to increase the transferability of the findings, the data was collected from two sources; blogs and a questionnaire. Lincoln and Guba (1985) state that if the original researcher presents enough description data to allow comparison then the problem of applicability is solved. Collecting data from the blogs and questionnaire produced a wealth of descriptive data regarding the women's thoughts, feelings and behaviour towards BSE

and the quotes taken from the participant's blogs and questionnaires provided thick descriptions regarding each of the themes that arose within this study.

6.4.9 Ethical Considerations

The study strictly adhered to the ethical principles and guidelines published by the British Psychological Society.

Ethical clearance was gained from the Teesside University Ethics Committee (see Appendix 23). Information about the study was provided to prospective participants via www.breast-aware.co.uk (see Appendix 24). Those interested in taking part followed a link from this page to complete an online consent form (see Appendix 25).

Confidentiality was maintained at all times; participants were provided with a username and password unique to them and were identified with a participant number to maintain their anonymity. The study website was protected with security protection software and participants were only able to access their group home page and information relevant to themselves. Confidentiality was further respected by the storage of data in locked filing cabinets and password protected PCs situated in secure offices at Teesside University.

6.5 Chapter Summary

Within this chapter, the research questions, aims and rationale of the study were presented and a description of the method employed in the main study provided. The design and development of the study questionnaires, multimedia BSE support programme (both static and video-enhanced versions), web blog, the autobiographical accounts and the study website were discussed and an overview of the development 'challenges' and decisions made to overcome these provided. The results of the pilot work and the impact of these in informing the main study was highlighted and the data collection process for both the qualitative and quantitative data was described in detail. Finally, the recruitment

process, trustworthiness of the data collected and the ethical considerations associated with the research were considered.

CHAPTER SEVEN

Results (1): Examination of the Effect of Autobiographical Accounts and BSE Support

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7.0 Chapter Overview

To aid clarity, material relating to the results of this thesis is presented in four separate chapters, chapters 7-10. This chapter, the first of these four examines the frequency and proficiency of women's breast exams pre and post-intervention, and considers the effect of autobiographical accounts and BSE support on both the engagement of BSE and the health beliefs associated. Participants' responses to the pre-intervention and post-intervention structured questionnaire were analysed quantitatively and the SPSS outputs for these analyses are presented in Appendix 26.

7.1. BSE Frequency and Proficiency and Levels of Anxiety, Worry and Confidence Before and After Intervention

All participants were asked to examine their breasts six times over a three-month period and 45 did. The demographic characteristics of those who did and did not were compared and analysed. Analysis of variance (ANOVA) and chi square analyses revealed no difference in demographics between the women in terms of age and educational level and all of the other demographics noted within the pre-intervention questionnaire.

Before the study intervention, 15 of the participants reported not to examine their breasts. Of the 45 that did, their BSE frequency varied from once to more than 12 times over the past year, and their scores on BSE proficiency ranged from 18 to 33. BSE recommendations advise women to examine their breasts on a monthly basis (American Cancer Society, 2009; American College of Obstetricians and Gynaecologists, 2009), totalling 12 examinations over a year period. Based on this participants were asked to report the frequency of their BSE by selecting a number from 0 to 12. Those who practised BSE more than 12 times per year were instructed to select "more than 12 times". Following the intervention, as perhaps could be expected due to the nature of the study,

all participants who had previously reported less than 12 breast exams over the past year reported an increase in the frequency of their BSE, and those that had reported more than 12 times, again reported more than 12 breast exams. A follow-up questionnaire was administrated four months after the end of the intervention, asking participants to report the frequency of their BSE since the end of the study. Thirty-nine participants completed this, and of these 35 reported examining their breasts on a regular basis: 3 daily, 6 weekly, 10 fortnightly, 13 monthly, 3 every 6 weeks. Those participants, who reported no BSE since the end of the study, stated this was because they had forgotten or not been prompted to do so. In regards to BSE proficiency, most ($n = 53$) of the women reported an increase in proficiency following the intervention and two reported scores identical to those reported at the start of the study. The five women who reported decreased proficiency reported scores that had only been reduced by one or two points.

Participant's BSE frequency and proficiency were noted. Descriptive statistics for pre-and post-intervention BSE frequency and proficiency are presented in Table 15. ANOVA summary tables are presented in Table 16 for BSE frequency and Table 17 for BSE proficiency.

Table 15

Descriptive Statistics for Pre-and Post-Intervention BSE

	Mean	SD	N		Mean	SD	N
Pre- Intervention BSE Frequency	4.67	4.66	60	Pre- Intervention BSE Proficiency	19.77	11.01	60
Post- Intervention BSE Frequency	7.80	3.98	60	Post- Intervention BSE Proficiency	30.52	5.65	60

Table 16

ANOVA Summary Table for BSE Frequency

<i>Test of Within subjects Effects</i>						
Source	SS	df	MS	F	p	ϵ^2
Time	294.53	1	294.53	53.48	<0.001	0.12
Time × BSE Support	1.63	1	1.63	0.30	0.58	0.00
Time × Autobiographical Accounts	1.63	1	1.63	0.30	0.58	0.00
Time × Autobiographical Accounts × BSE Support	4.80	1	4.80	0.87	0.35	0.00
Error (Time)	308.40	56	56.00			
<i>Test of Between subjects Effects</i>						
Source	SS	df	MS	F	p	ϵ^2
BSE Support	0.30	1	0.30	0.01	0.92	0.00
Autobiographical Accounts	0.30	1	0.30	0.01	0.92	0.00
BSE Support × Autobiographical Accounts	128.13	1	128.13	4.06	< 0.05	0.04
Error	1769.73	56	0.30			

Table 17

ANOVA Summary Table for BSE Proficiency

<i>Test of Within subjects Effects</i>						
Source	SS	df	MS	F	p	ε^2
Time	3466.88	1	3466.88	58.47	< 0.001	0.27
Time × BSE Support	16.88	1	16.88	0.29	0.60	0.00
Time × Autobiographical Accounts	49.41	1	49.41	0.83	0.37	0.00
Time × Autobiographical Accounts × BSE Support	14.01	1	14.01	0.24	0.63	0.00
Error (Time)	3320.33	56	59.29			
<i>Test of Between subjects Effects</i>						
Source	SS	df	MS	F	p	ε^2
BSE Support	541.88	1	541.88	6.81	0.01	0.04
Autobiographical Accounts	102.68	1	102.68	1.29	0.26	0.00
BSE Support × Autobiographical Accounts	525.01	1	525.01	6.59	0.01	0.04
Error	4459.53	56	79.64			

Mixed (2) × 2 × 2 analysis of variance (ANOVA) were conducted for both BSE frequency and proficiency, to establish if participants' BSE frequency and proficiency after the intervention differed from their scores before. The analyses revealed a significant difference between pre-intervention and post-intervention measures, with participants reporting higher scores post-intervention for BSE frequency $F(1, 56) = 53.48, p < 0.01, \varepsilon^2 = 0.12$, and proficiency $F(1, 56) = 58.47, p < 0.01, \varepsilon^2 = 0.27$.

No interaction effect of time and BSE support on BSE frequency, $F(1, 56) = 0.30, p = 0.58, \varepsilon^2 = 0.00$ and proficiency, $F(1, 56) = 0.29, p = 0.60, \varepsilon^2 = 0.00$ or no interaction effect of time and autobiographical accounts on BSE frequency, $F(1, 56) = 0.30, p = 0.58, \varepsilon^2 = 0.00$ and proficiency, $F(1, 56) = 0.83, p = 0.37, \varepsilon^2 = 0.00$, was, however, demonstrated. Similarly, the analyses further revealed no interaction effect of time, BSE

support and autobiographical accounts on BSE frequency, $F(1, 56) = 0.87, p = 0.35, \varepsilon^2 = 0.00$, or proficiency, $F(1, 56) = 0.24, p = 0.63, \varepsilon^2 = 0.00$. It appears post-intervention BSE frequency and proficiency is higher than pre-intervention regardless of whether the BSE support was static or video-enhanced and whether autobiographical accounts were viewed or not viewed.

Mixed ANOVA's were further conducted for anxiety and worry, to explore if participants' level of anxiety and worry changed over the course of the study. ANOVA summary tables are presented in Table 18 for anxiety and Table 19 for worry.

Table 18

ANOVA Summary Table for Anxiety

<i>Test of Within subjects Effects</i>						
Source	SS	df	MS	F	p	ε^2
Time	60.21	1	60.21	2.88	0.10	0.00
Time × BSE Support	14.01	1	14.01	0.67	0.42	0.00
Time × Autobiographical Accounts	8.00	1	8.01	0.38	0.54	0.00
Time × Autobiographical Accounts BSE Support	1.01	1	1.01	0.05	0.83	0.00
Error (Time)	1171.27	56	20.92			
<i>Test of Between subjects Effects</i>						
Source	SS	df	MS	F	p	ε^2
BSE Support	1197.01	1	1197.01	6.73	0.01	0.08
Autobiographical Accounts	238.01	1	238.01	1.34	0.25	0.00
BSE Support × Autobiographical Accounts	891.08	1	891.08	5.01	0.03	0.05
Error	9954.33	56	177.76			

Table 19

ANOVA Summary Table for Worry

<i>Test of Within subjects Effects</i>						
Source	SS	Df	MS	F	p	ε^2
Time	0.41	1	0.41	1.80	0.19	0.00
Time × BSE Support	0.25	1	0.25	1.11	0.30	0.00
Time × Autobiographical Accounts	0.02	1	0.02	0.08	0.78	0.00
Time × Autobiographical Accounts × BSE Support	0.03	1	0.03	0.15	0.70	0.00
Error (Time)	12.72	56	0.23			
<i>Test of Between subjects Effects</i>						
Source	SS	Df	MS	F	p	ε^2
BSE Support	2.00	1	2.00	2.54	0.12	0.02
Autobiographical Accounts	2.85	1	2.85	3.61	0.06	0.03
BSE Support × Autobiographical Accounts	0.83	1	0.83	1.05	0.31	0.00
Error	44.22	56	0.79			

The analyses revealed no significant difference between the pre-intervention and post-intervention anxiety, $F(1, 56) = 2.88$, $p = 0.10$, $\varepsilon^2 = 0.00$ and worry, $F(1, 56) = 1.80$, $p = 0.19$, $\varepsilon^2 = 0.00$, measures. Moreover, the analyses revealed no interaction effect of time and BSE support on anxiety, $F(1, 56) = 0.67$, $p = 0.42$, $\varepsilon^2 = 0.00$ and worry, $F(1, 56) = 1.11$, $p = 0.30$, $\varepsilon^2 = 0.00$, or no interaction effect of time and autobiographical accounts on anxiety, $F(1, 56) = 0.38$, $p = 0.54$, $\varepsilon^2 = 0.00$ and worry, $F(1, 56) = 0.08$, $p = 0.78$, $\varepsilon^2 = 0.00$. Similarly, the analyses further revealed no interaction effect of time, BSE support and autobiographical accounts on anxiety, $F(1, 56) = 0.05$, $p = 0.83$, $\varepsilon^2 = 0.00$, or worry, $F(1, 56) = 0.15$, $p = 0.70$, $\varepsilon^2 = 0.00$. It appears that the women's levels of anxiety and worry did not change as a result of being part of the study and examining their breasts.

Finally, mixed ANOVA's were conducted for confidence, to explore if participants' level of confidence changed over time. The descriptive characteristics and an ANOVA summary table are presented in Tables 20 and 21.

Table 20

Descriptive Statistics for Pre-and Post-Intervention Confidence Scores

	Mean	SD	N
Pre-Intervention Confidence	2.83	0.64	60
Post-Intervention Confidence	3.55	0.70	60

Table 21

ANOVA Summary Table for Confidence

<i>Test of Within subjects Effects</i>						
Source	SS	df	MS	F	p	ϵ^2
Time	15.80	1	15.80	80.70	<0.001	0.23
Time × BSE Support	0.10	1	0.10	0.49	0.49	0.00
Time × Autobiographical Accounts	0.19	1	0.19	0.99	0.32	0.00
Time × Autobiographical Accounts × BSE Support	0.18	1	0.18	0.94	0.34	0.00
Error (Time)	10.96	56	0.20			
<i>Test of Between subjects Effects</i>						
Source	SS	df	MS	F	p	ϵ^2
BSE Support	0.37	1	0.37	0.59	0.44	0.00
Autobiographical Accounts	0.18	1	0.18	0.29	0.60	0.00
BSE Support × Autobiographical Accounts	6.16	1	6.16	9.88	< 0.01	0.09
Error	34.90	56	0.62			

In relation to confidence, the analyses revealed a significant difference between pre-intervention confidence scores and post-intervention measures with participants reporting higher scores post-intervention, $F(1, 56) = 80.70$, $p < 0.001$, $\epsilon^2 = 0.23$. No interaction

effect of time and BSE support, $F(1, 56) = 0.49, p = 0.49, \varepsilon^2 = 0.00$ or time and autobiographical accounts, $F(1, 56) = 0.99, p = 0.32, \varepsilon^2 = 0.00$, on confidence was, however, demonstrated. Similarly, the analyses further revealed no interaction effect of time, BSE support and autobiographical accounts on confidence, $F(1, 56) = 0.94, p = 0.34, \varepsilon^2 = 0.00$. It appears post-intervention confidence scores are higher than pre-intervention scores, regardless of whether the BSE support was static or video-enhanced and whether autobiographical accounts were viewed or not viewed.

7.2 A Comparison of the Group Demographic Characteristics

The demographic characteristics of the women in each of the groups were compared and analysed. ANOVA and chi square analyses revealed no difference in demographics between the groups in terms of their demographic characteristics. Furthermore, ANOVA revealed no difference between the groups on any component of the E-HBM or in terms of BSE frequency and proficiency at the start of the study. Thus, it was concluded that any difference in BSE frequency or proficiency at the end of the study was most likely a result of the study interventions.

7.3 Influence of Autobiographical Accounts and BSE support on BSE Frequency and Proficiency

Participants' responses to the pre-intervention and post-intervention questionnaires were then used to perform a series of analysis of covariance (ANCOVA)'s to explore if viewing autobiographical accounts and the type of Multimedia BSE support used affected women's knowledge, beliefs and behaviour towards breast cancer and BSE. A 2×2 ANCOVA with pre-intervention scores included as a covariate was conducted for BSE frequency and proficiency to establish if autobiographical accounts and type of BSE support influenced the frequency and proficiency of BSE at the end of study. The

descriptive characteristics of these analyses and ANCOVA summary tables are presented in Tables 22 and 23 for BSE frequency and Tables 24 and 25 for BSE proficiency.

Table 22

Descriptive Statistics for Post-Intervention BSE Frequency by Study Group

Study Material	Adjusted Mean	SE	<i>n</i>
Autobiographical Accounts + Video-enhanced BSE Support	7.10	0.71	15
No Autobiographical Accounts + Video-enhanced BSE Support	8.91	0.71	15
Autobiographical Accounts + Static BSE Support	8.17	0.71	15
No Autobiographical Accounts + Static BSE Support	7.02	0.71	15

Table 23

ANCOVA Summary Table for BSE Frequency

Source	SS	<i>df</i>	<i>MS</i>	<i>F</i>	<i>p</i>	η^2
Pre-BSE Freq	432.03	1	432.03	57.90	< 0.001	0.45
BSE Support	2.55	1	2.55	0.34	0.56	0.00
Autobiographical Accounts	1.64	1	1.64	0.22	0.64	0.00
BSE Support × Autobiographical Accounts	31.84	1	31.84	4.27	0.04	0.03
Error	410.37	55	7.46			

Table 24
Descriptive Statistics for Post-Intervention BSE Proficiency by Study Group

Study Material	Adjusted Mean	SE	<i>n</i>
Autobiographical Accounts + Video-enhanced BSE Support	30.65	1.33	15
No Autobiographical Accounts + Video-enhanced BSE Support	33.43	1.35	15
Autobiographical Accounts + Static BSE Support	30.66	1.33	15
No Autobiographical Accounts + Static BSE Support	27.32	1.40	15

Table 25
ANCOVA Summary Table for BSE Proficiency

Source	SS	<i>df</i>	<i>MS</i>	<i>F</i>	<i>p</i>	ε^2
Pre BSE Prof	432.03	1	432.03	57.90	< 0.001	0.01
BSE Support	131.30	1	131.31	4.96	0.03	0.06
Autobiographical Accounts	1.17	1	1.17	0.04	0.84	0.00
BSE Support × Autobiographical Accounts	132.75	1	132.75	5.01	0.03	0.06
Error	456.93	55	26.49			

There was no effect of viewing autobiographical accounts on BSE frequency $F(1, 55) = 0.22, p = 0.64, \varepsilon^2 = 0.00$, and proficiency, $F(1, 55) = 0.04, p = 0.84, \varepsilon^2 = 0.00$, when holding constant BSE frequency and proficiency scores at the start of the study. Similarly, there was no effect of BSE support on BSE frequency when holding constant pre-intervention BSE frequency, $F(1, 55) = 0.34, p = 0.56, \varepsilon^2 = 0.00$. Whilst there was an effect of BSE support on BSE proficiency when holding constant BSE proficiency score at the start of the study $F(1, 55) = 4.96, p < 0.05, \varepsilon^2 = 0.06$, the presence of an interaction effect prevents any conclusions been drawn. There was a significant interaction effect of autobiographical accounts and BSE support on BSE frequency, $F(1, 55) = 4.27, p < 0.05$,

$\varepsilon^2 = 0.03$, and proficiency, $F(1, 55) = 5.01, p < 0.05, \varepsilon^2 = 0.06$, when holding constant BSE frequency and proficiency at the start of the study.

Following this, simple-effect analyses were conducted to explore these interaction effects further. ANCOVA's were conducted for the static BSE support and video-enhanced BSE support separately with autobiographical accounts as the predictor and for autobiographical accounts and no autobiographical separately with type of BSE support as the predictor. Pre-intervention BSE scores were included within the analyses as covariates.

In relation to BSE frequency the analyses revealed that, when the video-enhanced BSE support was used there was a significant effect of autobiographical accounts on BSE frequency, $F(1, 27) = 4.51, p < 0.05, \varepsilon^2 = 0.05$, but when the static support was used there was no significant effect of autobiographical accounts, $F(1, 27) = 0.90, p = 0.35, \varepsilon^2 = 0.00$. It appears viewing an autobiographical account or not has an effect on BSE frequency when the type of BSE support is the video-enhanced version, with not viewing autobiographical accounts resulting in higher BSE frequency than viewing autobiographical accounts.

In relation to BSE proficiency, the analyses revealed that, when no autobiographical account was viewed there was a significant effect of BSE support on BSE proficiency, $F(1, 27) = 10.63, p < 0.01, \varepsilon^2 = 0.20$, but when autobiographical accounts were viewed there was no significant effect of BSE support, $F(1, 27) = 0.00, p = 1.00, \varepsilon^2 = 0.00$. It appears the type of BSE support has an effect on BSE proficiency when no autobiographical account is viewed with the video-enhanced BSE support resulting in higher proficiency scores than static BSE support.

Participants were further asked to report the number of times they had examined their breasts over the course of the study. Although all of the women were asked to examine their breasts six times over a three-month study period, as discussed previously, only 45 of the women reported they did. It was therefore of interest to establish if viewing autobiographical accounts, or the type of multimedia BSE support given, influenced the frequency of breast exams during the study. As study BSE could only be measured at the end, BSE frequency recorded at the start of the study was included as a covariate. The descriptive characteristics of this analysis are presented in Table 26 and an ANCOVA summary table is presented in Table 27.

Table 26

Descriptive Characteristics for Study BSE by Study Group

Study Material	Adjusted Mean	SE	n
Autobiographical Accounts + Video-enhanced BSE Support	4.26	0.36	15
No Autobiographical Accounts + Video-enhanced BSE Support	5.82	0.36	15
Autobiographical Accounts + Static BSE Support	5.58	0.36	15
No Autobiographical Accounts + Static BSE Support	5.01	0.36	15

Table 27

ANCOVA Summary Table for Study BSE

Source	SS	df	MS	F	p	ϵ^2
Pre BSE Freq	9.12	1	9.12	4.67	0.04	0.05
BSE Support	0.98	1	0.98	0.50	0.48	0.05
Autobiographical Accounts	3.68	1	3.68	1.88	0.18	0.01
BSE Support × Autobiographical Accounts	16.21	1	16.21	8.31	< 0.01	0.10
Error	107.29	55	1.95			

ANCOVA revealed that whilst there was no effect of viewing autobiographical accounts, $F(1, 55) = 1.88, p = 0.18, \epsilon^2 = 0.01$, or the type of BSE support used, $F(1, 55) = 0.50, p = 0.48, \epsilon^2 = 0.05$, there was a significant interaction effect of autobiographical accounts and BSE support on study BSE, $F(1, 55) = 8.31, p < 0.01, \epsilon^2 = 0.10$. Following this, simple-effect analyses were again conducted to explore this interaction effect further. ANCOVA was conducted firstly for the static BSE support and video-enhanced support separately with autobiographical accounts as the predictor. The analyses revealed that when the video-enhanced support was used there was a significant effect of autobiographical accounts on study BSE, $F(1, 27) = 7.76, p < 0.05, \epsilon^2 = 0.16$, but when the static support was used there was no significant effect of autobiographical accounts, $F(1, 27) = 1.58, p = 0.21, \epsilon^2 = 0.02$. More specifically, lower frequency scores for study BSE were reported when autobiographical accounts were viewed and the type of BSE support video-enhanced.

ANCOVA was then conducted for autobiographical accounts viewed and autobiographical accounts not viewed separately with type of multimedia BSE support as the predictor. The analyses revealed that, when autobiographical accounts were viewed there was a significant effect of type of BSE support on study BSE, $F(1, 27) = 4.67, p < 0.05, \epsilon^2 = 0.09$, but when autobiographical accounts were not viewed there was no significant effect of type of BSE support, $F(1, 27) = 3.86, p = 0.60, \epsilon^2 = 0.09$. More specifically, higher frequency scores for study BSE were reported when the static BSE support was used. It appears a complex interactive relationship of autobiographical accounts and type of BSE support in relation to study BSE frequency may exist, with highest study BSE scores reported when no autobiographical accounts were viewed and the video-enhanced support was used; and lowest study BSE scores reported when autobiographical accounts were viewed and the video-enhanced support was used.

7.4 Influence of Autobiographical Accounts and BSE Support on Health Beliefs Connected to Breast Cancer and BSE

A 2×2 ANCOVA with pre-intervention scores included as a covariate was conducted on each of the HBM and E-HBM variables to establish if autobiographical accounts and the type of multimedia BSE support influenced health beliefs connected to breast cancer and BSE at the end of the study. In relation to the HBM components, the analyses revealed an effect of viewing autobiographical accounts on barriers and an interaction effect of viewing autobiographical accounts and the type of BSE support on confidence. No effect of viewing autobiographical accounts or type of BSE support was, however, found for the other components of the HBM. The descriptive characteristics of these analyses and ANCOVA summary tables are presented in Tables 28 and 29 for the HBM component barriers and Tables 30 and 31 for the HBM component confidence.

Table 28
Descriptive Characteristics for Post-Intervention Barriers Score by Study Group

Study Material	Adjusted Mean	SE	n
Autobiographical Accounts + Video-enhanced BSE Support	2.50	0.11	15
No Autobiographical Accounts + Video-enhanced BSE Support	2.15	0.10	15
Autobiographical Accounts + Static BSE Support	2.28	0.10	15
No Autobiographical Accounts + Static BSE Support	2.17	0.10	15

Table 29

ANCOVA Summary Table for Barriers

Source	SS	df	MS	F	p	ϵ^2
Pre Barrier Score	8.01	1	8.01	51.10	< 0.001	0.40
BSE Support	0.13	1	0.13	0.83	0.37	0.00
Autobiographical Accounts	0.79	1	0.79	5.05	0.03	0.03
BSE Support × Autobiographical Accounts	0.22	1	0.22	1.38	0.25	0.00
Error	8.62	55	0.16			

Table 30

Descriptive Characteristics for Post-Intervention Confidence Score by Study Group

Study Material	Adjusted Mean	SE	n
Autobiographical Accounts + Video-enhanced BSE Support	3.42	0.15	15
No Autobiographical Accounts + Video-enhanced BSE Support	3.83	0.15	15
Autobiographical Accounts + Static BSE Support	3.60	0.15	15
No Autobiographical Accounts + Static BSE Support	3.37	0.15	15

Table 31

ANCOVA Summary Table for Confidence

Source	SS	df	MS	F	p	ϵ^2
Pre Confidence Score	6.71	1	6.71	20.73	< 0.001	0.22
BSE Support	0.28	1	0.28	0.86	0.36	0.00
Autobiographical Accounts	0.12	1	0.12	0.38	0.54	0.00
BSE Support × Autobiographical Accounts	1.41	1	1.41	4.45	0.04	0.04
Error	17.81	55	0.32			

As illustrated within the summary tables presented, ANCOVA revealed there was a significant effect of autobiographical accounts on barriers when holding constant HBM barrier scores at the start of the study, $F(1, 55) = 5.05, p < 0.05, \epsilon^2 = 0.03$, with those viewing autobiographical accounts reporting higher barrier scores than those not viewing autobiographical accounts. ANCOVA further revealed a significant interaction effect of autobiographical accounts and BSE support on HBM confidence when holding constant HBM confidence scores at the start of the study, $F(1, 55) = 4.35, p < 0.05, \epsilon^2 = 0.04$.

Following this, simple-effect analyses were conducted to explore these interaction effects further. ANCOVA were conducted for the static and video-enhanced versions of the multimedia BSE support separately with autobiographical accounts as the predictor and for autobiographical accounts and no autobiographical account separately with type of BSE support as the predictor. Pre-intervention scores on confidence were included within the analyses as a covariate. The analyses revealed no significant effect of autobiographical accounts when BSE support was static, $F(1, 27) = 1.68, p = 0.21, \epsilon^2 = 0.02$ or video-enhanced $F(1, 27) = 3.01, p = 0.09, \epsilon^2 = 0.05$, and no significant effect of BSE support when autobiographical accounts were viewed, $F(1, 27) = 0.32, p = 0.58, \epsilon^2 = 0.00$. The analyses did, however, reveal a significant effect of BSE support when no autobiographical accounts were viewed on confidence, $F(1, 27) = 5.80, p < 0.05, \epsilon^2 = 0.10$, with women in the video-enhanced group reporting higher confidence scores.

In relation to the additional E-HBM components, the analyses revealed an effect of viewing autobiographical accounts on powerful others HLC and the illness representation component personal control, an effect of BSE support on social support affirmation, and an interaction effect of viewing autobiographical accounts and type of BSE support on the illness representation components timeline cyclical and psychological attribution. No effect of viewing autobiographical accounts or type of BSE support was however found for the

other components of the E-HBM. The descriptive characteristics of these analyses and ANCOVA summary tables are presented in Tables 32 to 41.

Table 32

Descriptive Characteristics for Post-Intervention Powerful Others HLC Score by Study Group

Study Material	Adjusted Mean	SE	n
Autobiographical Accounts + Video-enhanced BSE Support	18.60	0.84	15
No Autobiographical Accounts + Video-enhanced BSE Support	14.78	0.82	15
Autobiographical Accounts + Static BSE Support	15.93	0.85	15
No Autobiographical Accounts + Static BSE Support	15.49	0.82	15

Table 33

ANCOVA Summary Table for Powerful Others HLC

Source	SS	df	MS	F	p	ξ^2
Pre Powerful Others HLC Score	368.26	1	368.26	36.23	< 0.001	0.32
BSE Support	13.99	1	13.99	1.38	0.25	0.00
Autobiographical Accounts	67.78	1	67.78	6.67	0.01	0.05
BSE Support × Autobiographical Accounts	40.52	1	40.52	3.99	0.05	0.03
Error	559.076	55	10.17			

Table 34

Descriptive Characteristics for Post-Intervention Personal Control Score by Study Group

Study Material	Adjusted Mean	SE	n
Autobiographical Accounts + Video-enhanced BSE Support	3.35	0.16	15
No Autobiographical Accounts + Video-enhanced BSE Support	2.94	0.16	15
Autobiographical Accounts + Static BSE Support	3.47	0.16	15
No Autobiographical Accounts + Static BSE Support	3.14	0.16	15

Table 35

ANCOVA Summary Table for Personal Control

Source	SS	df	MS	F	p	ϵ^2
Pre Personal Control Score	5.94	1	5.94	16.83	< 0.001	0.18
BSE Support	0.33	1	0.325	0.92	0.34	0.00
Autobiographical Accounts	2.03	1	2.03	5.75	0.02	0.05
BSE Support × Autobiographical Accounts	0.02	1	0.02	0.07	0.79	0.00
Error	19.41	55				

Table 36

Descriptive Characteristics for Post-Intervention Social Support Affirmation Score by Study Group

Study Material	Adjusted Mean	SE	n
Autobiographical Accounts + Video-enhanced BSE Support	50.40	3.64	15
No Autobiographical Accounts + Video-enhanced BSE Support	55.63	3.67	15
Autobiographical Accounts + Static BSE Support	49.36	3.58	15
No Autobiographical Accounts + Static BSE Support	42.15	3.60	15

Table 37

ANCOVA Summary Table for Social Support Affirmation

Source	SS	df	MS	F	p	ϵ^2
Pre Social Support Affirmation Score	29336.71	1	29336.71	153.4	< 0.001	0.61
BSE Support	789.60	1	780.60	4.13	< 0.05	0.01
Autobiographical Accounts	14.37	1	14.37	0.08	0.79	0.00
BSE Support × Autobiographical Accounts	526.47	1	526.47	2.75	0.10	0.01
Error	10518.49	55	191.25			

Table 38

Descriptive Characteristics for Post-Intervention Timeline Cyclical Score by Study Group

Study Material	Adjusted Mean	SE	n
Autobiographical Accounts + Video-enhanced BSE Support	3.15	0.15	15
No Autobiographical Accounts + Video-enhanced BSE Support	3.54	0.15	15
Autobiographical Accounts + Static BSE Support	3.30	0.15	15
No Autobiographical Accounts + Static BSE Support	3.07	0.15	15

Table 39

ANCOVA Summary Table for Timeline Cyclical

Source	SS	df	MS	F	p	η^2
Pre Time Control Score	7.72	1	7.72	22.48	< 0.001	0.25
BSE Support	0.36	1	0.36	1.04	0.31	0.00
Autobiographical Accounts	0.09	1	0.09	0.26	0.61	0.00
BSE Support × Autobiographical Accounts	1.41	1	1.41	4.10	< 0.05	0.04
Error	18.89	55	0.34			

Table 40

Descriptive Characteristics for Post-Intervention Psychological Attribution Score by Study Group

Study Material	Adjusted Mean	SE	n
Autobiographical Accounts + Video-enhanced BSE Support	2.60	0.16	15
No Autobiographical Accounts + Video-enhanced BSE Support	2.21	0.16	15
Autobiographical Accounts + Static BSE Support	2.08	0.16	15
No Autobiographical Accounts + Static BSE Support	2.31	0.16	15

Table 41
ANCOVA Summary Table for Psychological Attribution

Source	SS	df	MS	F	p	ϵ^2
Pre Psychological Attribution Score	16.26	1	16.26	45.07	< 0.001	0.42
BSE Support	0.67	1	0.67	1.85	0.18	0.01
Autobiographical Accounts	0.09	1	0.09	0.26	0.61	0.00
BSE Support × Autobiographical Accounts	1.46	1	1.46	4.04	< 0.05	0.03
Error	19.84	55	0.36			

As illustrated within the summary tables presented, ANCOVA revealed significant effects on powerful others HLC, social support affirmation, and the illness representations timeline cyclical, personal control and psychological attribution. Firstly, there was a significant effect of autobiographical accounts on powerful others HLC, $F(1, 55) = 6.67$, $p < 0.05$, $\epsilon^2 = 0.05$, and the illness representation personal control, $F(1, 55) = 5.75$, $p < 0.05$, $\epsilon^2 = 0.05$. The women who had viewed the autobiographical accounts reported higher personal control and higher powerful others HLC than those who had not viewed the accounts. Secondly, there was a significant effect of type of BSE support on social support affirmation, $F(1, 55) = 4.13$, $p < 0.05$, $\epsilon^2 = 0.01$. The women who had viewed the video-enhanced BSE support scored higher on social support affirmation.

Lastly, there was also a significant interaction effect of autobiographical accounts and type of BSE support on the illness representations timeline cyclical, $F(1, 55) = 4.10$, $p < 0.05$, $\epsilon^2 = 0.04$ and psychological attribution, $F(1, 55) = 4.04$, $p < 0.05$, $\epsilon^2 = 0.03$. Following this, simple-effect analyses were conducted to explore these interaction effects further.

ANCOVA were conducted for the static and video-enhanced versions of the multimedia BSE support separately with autobiographical accounts as the predictor and for autobiographical accounts and no autobiographical account separately with type of BSE

support as the predictor. Pre-intervention scores on the E-HBM variables were included within the analyses as covariates.

The analyses revealed no significant effect for both timeline cyclical and psychological attribution. There was no significant effect of the video-enhanced support and autobiographical accounts on timeline cyclical $F(1, 27) = 2.92, p = 0.10, \epsilon^2 = 0.03$, and psychological attribution $F(1, 27) = 0.08, p = 0.78, \epsilon^2 = 0.00$, and there was no significant effect of the static BSE support and autobiographical accounts on timeline cyclical, $F(1, 27) = 0.47, p = 0.50, \epsilon^2 = 0.00$, and psychological attribution, $F(1, 27) = 0.91, p = 0.35, \epsilon^2 = 0.00$. Similarly, there was no significant effect of autobiographical account viewed and BSE support on timeline cyclical, $F(1, 27) = 0.59, p = 0.45, \epsilon^2 = 0.00$, and psychological attribution, $F(1, 27) = 0.30, p = 0.59, \epsilon^2 = 0.00$, and there was no effect of no autobiographical account viewed and BSE support on timeline cyclical, $F(1, 27) = 3.78, p = 0.06, \epsilon^2 = 0.07$, and psychological attribution, $F(1, 27) = 0.74, p = 0.40, \epsilon^2 = 0.00$. This lack of significant results within the simple-effect analyses may be due to a reduction in the power of the sample as a result of halving the sample size.

7.5 Conclusion

To conclude, it appears the 5-step BSE technique was useful in encouraging and maintaining a thorough and regular breast exam with the women reporting higher scores after the intervention for both BSE frequency and proficiency. The women's levels of anxiety and worry did not change as a result of being part of the study and examining their breasts, instead the women reported increased levels of confidence regarding BSE. The video-enhanced BSE support did not seem to hold any advantages over the static version in terms of BSE frequency, and in relation to both frequency and proficiency; any effect of viewing autobiographical accounts appears to depend on if the BSE support is static or

video-enhanced. However, in relation to BSE proficiency, the video-enhanced BSE support did seem to hold an advantage over the static version, with those women receiving the video-enhanced support reporting more proficient post-intervention breast exams than those receiving the static support.

In relation to the women's health beliefs, those women who had viewed the autobiographical accounts reported higher barrier scores, higher personal control and higher powerful others HLC than those who had not viewed the autobiographical accounts. In relation to BSE support, the women who had viewed the video-enhanced BSE support scored higher on social support affirmation. Finally, BSE support in combination with autobiographical accounts seemed to have an effect on confidence, timeline cyclical and psychological attribution. Women receiving the video-enhanced support and who had not viewed autobiographical accounts reported higher confidence scores and, whilst no significant results were found following simple-effect analyses, after consideration of the difference in effect sizes within these analyses it was proposed that if the sample size was to increase a significant effect of video-enhanced support and autobiographical accounts on both timeline cyclical and psychological attribution may be expected. Finally, the analyses revealed no effect of autobiographical accounts on the remainder of the health beliefs components.

7.6 Chapter Summary

This chapter, the first of four chapters relating to the results of this thesis, presented the quantitative outcomes of the study in relation to autobiographical accounts and BSE support. It examined the increased frequency and proficiency of women's breast exams from pre to post-intervention, and considered the effect of autobiographical accounts and BSE support on both the engagement of BSE and the health beliefs associated.

CHAPTER EIGHT

Results (2): Support for the Proposed Extended Health Belief Model (E-HBM)

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8.0 Chapter Overview

This chapter, the second of four results chapters considers the utility of the proposed E-HBM to explain BSE behaviour. The E-HBM is amended based on the findings discussed in this chapter and an update of the E-HBM is presented.

8.1 Support for Proposed Extended Health Belief Model

Participants' responses to the pre-intervention questionnaire were used to consider the utility of the proposed Extended Health Belief Model (E-HBM) as presented in Figure 3.

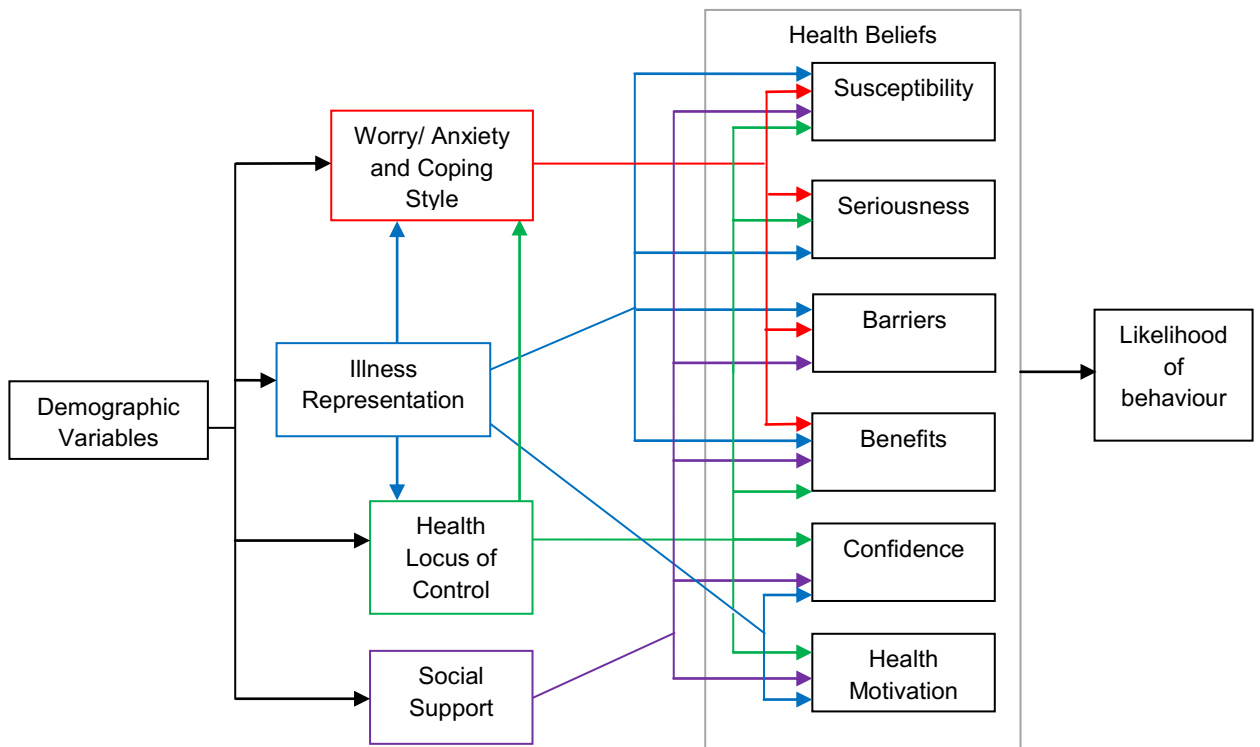


Figure 3. *Proposed Extended Health Belief Model*

According to the proposed E-HBM, demographic characteristics predict the components of the model and participants' responses to the pre-intervention questionnaire were used to analyse this potential relationship. The predictive utility of these demographic

characteristics in relation to worry, anxiety, coping style, illness representations, HLC, social support, the original components of the HBM and BSE frequency and proficiency was considered with a series of multiple-regression analyses. Summary tables of these multiple regression analyses are presented in Appendix 27. Bivariate Correlation or multiple regression depending on the nature of the data (nominal: regression or correlation when nominal with two categories, interval: correlation) highlighted which demographic characteristics were significantly related to each of the model's components and this informed which variables to include within the series of regression analyses. Demographic characteristic data of a nominal level was dummy-coded before its inclusion within the regression and hierarchical multiple regression was conducted to include these dummy coded variables.

In relation to the E-HBM components the analyses offered support for the utility of age, family history, age started the menstrual cycle, age started the menopause, employment status, cup size and number of children in predicting anxiety, powerful others HLC, and the illness representations identity, risk factors and consequences. More specifically, in relation to anxiety hierarchical multiple-regression indicated that the predictors, age and family history explained 27% of the variance $R^2 = 0.27$, $F(3^1, 56) = 6.73$, $p < 0.01$. Age, $sr^2 = 0.06$, $p < 0.05$ and family history, $sr^2 = 0.18$, $p < 0.01$ significantly predicted anxiety. In relation to powerful others HLC, multiple regression indicated that the predictor set for powerful others (including number of children, age started the menopause and breast-cancer history of non-blood relatives and friends), explained 80% of the variance, $R^2 = 0.80$, $F(3^2, 7^3) = 9.39$, $p < 0.01$; however, only the predictors, number of children and age

¹ When dummy coded family history has 2 dummy variables

² Additional variable(s) within predictor set were not found to be significant.

³ These demographic characteristics were not relevant to all of the participants. For this analysis $n = 11$.

started menopause were found to be significant. Number of children $sr^2 = 0.34$, $p < 0.05$ and started the menopause $sr^2 = 0.60$, $p < 0.01$ significantly predicted powerful others HLC. In relation to the illness representation component identity, hierarchical multiple-regression indicated that two predictors, age started the menstrual cycle and family history explained 18% of the variance, $R^2 = 0.18$, $F(3^1, 56) = 4.02$, $p < 0.01$. Age started the menstrual cycle, $sr^2 = 0.07$, $p < 0.05$ and family history, $sr^2 = 0.11$, $p < 0.05$ significantly predicted identity. In relation to the illness representation component risk factors, multiple-regression indicated that the predictor set for risk factors (including employment status and education), explained 27% of the variance, $R^2 = 0.27$, $F(8^4, 51) = 2.32$, $p < 0.05$; however, only the predictor risk employment status was found to be significant. Employment status significantly predicted risk factors, $sr^2 = 0.25$, $p < 0.01$.

In relation to the illness representation component consequences, regression indicated that one predictor, cup size explained 30% of the variance, $R^2 = 0.30$, $F(10^5, 49) = 2.08$, $p < 0.05$. Cup size significantly predicted consequences, $sr^2 = 0.30$, $p < 0.05$. Moreover, in relation to the original HBM components, the analyses offered support for the utility of family history, cup size, education and type of employment in predicting susceptibility, health motivation and barriers. More specifically, hierarchical regression indicated, in relation to susceptibility, two predictors family history and cup size explained 43% of the variance, $R^2 = 0.43$, $F(12^6, 47) = 2.94$, $p < 0.01$. Family history, $sr^2 = 0.10$, $p < 0.05$ and cup size, $sr^2 = 0.32$, $p < 0.05$, significantly predicted susceptibility. In relation to health motivation regression indicated one predictor, education explained 18% of the variance, $R^2 = 0.18$, $F(4^7, 55) = 2.94$, $p < 0.05$. Education significantly predicted health motivation

⁴ When dummy coded education and employment status each have 4 dummy variables.

⁵ When dummy coded cup size has 10 dummy variables.

⁶ When dummy coded family history has 2 dummy variables and cup size has 10.

⁷ When dummy coded education has 4 dummy variables.

$sr^2 = 0.18$, $p < 0.05$. In relation to barriers, regression indicated that one predictor, type of employment explained 48% of the variance, $R^2 = 0.48$, $F(12^8, 31) = 2.39$, $p < 0.05$. Type of employment significantly predicted barriers, $sr^2 = 0.48$, $p < 0.05$.

Finally, in relation to BSE frequency multiple-regression indicated that the predictor set for frequency (including age and age started the menstrual cycle), explained 25% of the variance, $R^2 = 0.25$, $F(2, 59) = 9.42$, $p < 0.01$, however only the predictor age was found to be significant. Age significantly predicted BSE frequency, $sr^2 = 0.18$, $p < 0.01$. No support however was offered for a predictive relationship between any of the demographic characteristics and BSE proficiency.

Consultation of the descriptive statistics provides more detailed information regarding the direction of this predictive relationship between the demographic characteristics and the E-HBM model. Descriptive statistics for reported anxiety, powerful others HLC, identity, risk factors, consequences, susceptibility, health motivation, barriers and BSE frequency scores by demographic group are presented in Appendix 27.

It appears women with no children, and women who started the menopause at a later age, express higher levels of 'powerful others' HLC and younger women and those with no family history of breast cancer report higher levels of trait anxiety. In relation to the original HBM components it appears that, individuals with a higher level of achieved education are more motivated towards their health, women with larger breasts and women with a family history of breast cancer feel more susceptible to breast cancer and those in a health or nursing area of employment report the lowest level of barriers towards BSE. Finally in relation to BSE specifically, it appears older women report more frequent breast exams than younger woman.

⁸ When dummy coded type of employment has 12 dummy variables

In addition to the predictive utility of demographic characteristics, according to the model, worry, anxiety, coping style, illness representations and health locus of control predict components of the HBM and these in turn predict BSE. Based on this proposed E-HBM, 14 hypotheses were derived (See Chapter 6) and then considered following the examination of a correlation matrix and the results of multiple-regression analyses. A correlation matrix highlighted which E-HBM variables (worry, anxiety, coping style, social support, illness representations and HLC) were significantly correlated with each other and each of the HBM components and which of these were significantly correlated with BSE frequency and proficiency. Variables with significant correlations were included within the multiple-regression analyses.

Multiple-regression analyses were conducted for each of the HBM components using all the variables that had significant correlations to establish if indeed the E-HBM variables predicted any of the HBM components, and other E-HBM variables where appropriate. The correlation matrix revealed the E-HBM variables anxiety, worry and HLC were correlated with illness representations; thus, multiple-regression analyses were conducted for worry, anxiety and HLC using the illness representation components that had significant correlations. Finally, multiple-regression analyses were conducted for BSE frequency and proficiency using the E-HBM variables and the HBM components that had significant correlations to establish if indeed the proposed E-HBM (Figure 3) predicted BSE frequency and/or proficiency. Tables 42 to 55 present summary tables of these multiple-regression analyses.

Table 42

Standard Multiple Regression of Worry, Emotional Representations (Emotion Rep), Internal HLC, Powerful Others HLC (Powerful HLC) on the HBM Component Susceptibility (Suscept)

Variables	Suscept (DV)	Worry	Emotion Rep	Internal HLC	Powerful HLC	<i>b</i>	β	sr^2
Worry	0.37					0.31	0.23	0.04
Emotion Rep	0.40	0.38				0.27	0.25	0.05 *
Internal HLC	- 0.31	- 0.20	- 0.17			- 0.04	- 0.19	0.03
Powerful HLC	0.33	0.04	0.11	- 0.12		0.05	0.27	0.07 *
						Constant <i>a</i> = 1.54		
Means	2.60	1.38	2.89	24.65	15.33			$R^2 = 0.33$
Standard Deviation	0.81	0.61	0.74	4.05	4.21			Adjusted $R^2 = 0.28$
								** $R = 0.58$

* $p < 0.05$. ** $p < 0.01$.

Table 43

Standard Multiple Regression of Personal Control, Internal HLC and Chance HLC on the HBM Component Health Motivation

Variables	Health Motivation (DV)	Personal Control	Internal HLC	Chance HLC	<i>b</i>	β	sr^2
Personal Control	0.26				0.05	0.07	0.00
Internal HLC	0.30	0.41			0.01	0.10	0.00
Chance HLC	- 0.46	- 0.36	- 0.43		- 0.05	- 0.39	0.12 **
Constant <i>a</i> = 4.18							
Means	3.74	3.04	24.65	18.82	$R^2 = 0.23$		
Standard Deviations	0.48	0.75	4.05	3.95	Adjusted $R^2 = 0.19$		
							** $R = 0.48$

* $p < 0.05$. ** $p < 0.01$.

Table 44

Standard Multiple Regression of Internal HLC, Risk Factors, Psychological Attribution (Psy Attribution) and Personal Control on the HBM Component Benefit

Variables	Benefit (DV)	Internal HLC	Risk Factors	Psy Attribution	Personal Control	<i>b</i>	β	<i>sr</i> ²
Internal HLC	0.27					0.01	0.80	0.01
Risk Factors	0.27	0.19				0.14	0.13	0.01
Psy. Attribution	0.27	0.21	0.44			0.08	0.10	0.01
Personal Control	0.45	0.41	0.24	0.26		0.27	0.36	0.10 **
						Constant <i>a</i> = 1.84		
Means	3.57	24.65	3.05	2.16	3.04	<i>R</i> ² = 0.24		
Standard Deviations	0.58	4.05	0.50	0.73	0.75	Adjusted <i>R</i> ² = 0.19		
						** <i>R</i> = 0.49		

* *p* < 0.05. ** *p* < 0.01.

Table 45

Standard Multiple Regression of Anxiety, Worry, Consequences (Conseq) and Emotional Representation (Emotion Rep) on the HBM Component Seriousness

Variables	Serious (DV)	Anxiety	Worry	Conseq	Emotion Rep	B	β	sr^2
Anxiety	0.26					0.00	0.05	0.00
Worry	0.36	0.10				0.17	0.17	0.02
Conseq	0.31	-0.02	0.03			0.26	0.21	0.04
Emotion Rep	0.59	0.44	0.38	0.19		0.37	0.46	0.14 **
Constant a = 0.69								
Means	3.12	40.68	1.38	3.98	2.89			$R^2=0.41$
Standard Deviations	0.59	11.29	0.61	0.48	0.74			Adjusted $R^2=0.36$

** $R=0.64$

* $p < 0.05$. ** $p < 0.01$.

Table 46

Standard Multiple Regression of Illness Coherence and Internal HLC on the HBM Component Barriers

Variables	Barriers (DV)	Illness Coherence	Internal HLC	B	β	sr^2
Illness Coherence	0.28			0.14	0.22	0.05
Internal HLC	-0.27	-0.27		-0.03	-0.21	0.04
Constant a = 2.58						
Means	2.31	2.79	24.65			$R^2 = 0.12$
Standard Deviations	0.51	0.85	4.05			Adjusted $R^2 = 0.90$
						$**R = 0.35$

* $p < 0.05$. ** $p < 0.01$.

Table 47

Standard Multiple Regression of Illness Coherence and Emotional Representation on the HBM Component Confidence

Variables	Confidence (DV)	Illness Coherence	Emotional Representations	b	β	sr^2
Illness Coherence	-0.30			-0.17	-0.23	0.04
Emotional Representations	-0.27	0.45		-0.14	-0.16	0.02
Constant a = 3.71						
Means	2.83	2.79	2.89			$R^2 = 0.11$
Standard Deviations	0.64	0.85	0.74			Adjusted $R^2 = 0.08$
						$**R = 0.34$

* $p < 0.05$. ** $p < 0.01$.

Table 48

Standard Multiple Regression of Illness Coherence on Coping Style

Variables	Coping Style (DV)	Illness Coherence	<i>b</i>	β	sr^2
Illness Coherence	0.28		0.40	0.28	0.08 *
Constant <i>a</i> = 1.12					
Means	2.22	2.79			$R^2 = 0.08$
Standard Deviations	1.20	0.85			Adjusted $R^2 = 0.06$
$**R = 0.28$					

* $p < 0.05$. ** $p < 0.01$.

Table 49

Standard Multiple Regression of Treatment Control and Emotional Representations on Worry

Variables	Worry (DV)	Treatment Control	Emotional Representations	<i>b</i>	β	sr^2
Treatment Control	- 0.29			- 0.29	- 0.30	0.09 *
Emotional Representations	0.38	0.38		0.32	0.39	0.15 **
Constant <i>a</i> = 1.45						
Means	1.38	3.47	2.89			$R^2 = 0.23$
Standard Deviations	0.61	0.63	0.74			Adjusted $R^2 = 0.21$
$**R = 0.48$						

* $p < 0.05$. ** $p < 0.01$.

Table 50

Standard Multiple Regression of Emotional Representations and Illness Coherence on Anxiety

Variables	Worry (DV)	Emotional Representations	Illness Coherence	<i>b</i>	β	sr^2
Emotional Representations	0.44			5.49	0.36	0.10 **
Illness Coherence	0.33	0.45		2.30	0.17	0.02
				Constant <i>a</i> = 18.43		
Means	40.68	2.89	2.79			$R^2 = 0.21$
Standard deviations	11.29	0.74	0.85			Adjusted $R^2 = 0.19$
						** $R = 0.46$

* $p < 0.05$. ** $p < 0.01$.

Table 51
*Standard Multiple Regression of Personal Control, Treatment Control and Illness
 Coherence on Internal HLC*

Variables	Internal HLC (DV)	Personal Control	Treatment Control	Illness Coherence	<i>b</i>	β	<i>sr</i> ²
Personal Control	0.41				1.61	0.30	0.07 *
Treatment Control	0.34	0.40			1.47	0.23	0.04
Illness Coherence	-0.27	- 0.10	0.03		1.21	- 0.25	0.06 *
					Constant <i>a</i> = 18.04		
Means	24.65	3.04	3.47	2.79	<i>R</i> ² = 0.27		
Standard Deviations	4.05	0.75	0.63	0.85	Adjusted <i>R</i> ² = 0.23		
					** <i>R</i> = 0.52		

* *p* < 0.05. ** *p* < 0.01.

Table 52

Standard Multiple Regression of Personal Control and Illness Coherence on Chance HLC

Variables	Chance HLC (DV)	Personal Control	Illness Coherence	<i>b</i>	β	sr^2
Personal Control	- 0.36			- 1.74	- 0.33	0.11**
Illness Coherence	0.35	-0.10		1.46	0.31	0.10 *
				Constant <i>a</i> = 20.04		
Means	18.82	3.04	2.79			$R^2 = 0.23$
Standard Deviations	3.95	0.75	0.85			Adjusted $R^2 = 0.20$
						** $R = 0.48$

* $p < 0.05$. ** $p < 0.01$.

Table 53

Standard Multiple Regression of Timeline Acute/Chronic and Risk Factors on Powerful Others HLC

Variables	Powerful Others HLC (DV)	Timeline Acute/Chronic	Risk Factors	<i>b</i>	β	sr^2
Timeline Acute/Chronic	0.33			2.61	0.28	0.07 *
Risk Factors	0.26	0.31		1.43	0.17	0.03
				Constant <i>a</i> = 4.43		
Means	15.33	2.51	3.05			$R^2 = 0.14$
Standard Deviations	4.21	0.45	0.50			Adjusted $R^2 = 0.11$
						** $R = 0.37$

* $p < 0.05$. ** $p < 0.01$.

Table 54

Standard Multiple Regression of Confidence and Illness Coherence on BSE Frequency

Variables	Frequency (DV)	Confidence	Illness Coherence	<i>b</i>	β	sr^2
Confidence	0.47			3.02	0.41	0.15 **
Illness Coherence	-0.32	-0.30		-1.08	-0.20	0.04
				Constant <i>a</i> = -0.84		
Means	4.67	2.83	2.79	$R^2 = 0.26$		
Standard Deviations	4.66	0.64	0.85	Adjusted $R^2 = 0.23$		
						** <i>R</i> = 0.51

* $p < 0.05$. ** $p < 0.01$.

Table 55

Standard Multiple Regression of Confidence and Emotional Representation on BSE

Proficiency

Variables	Proficiency (DV)	Confidence	Emotional Representations	<i>b</i>	β	sr^2
Confidence	0.49			7.36	0.43	0.17 **
Emotional Representations	-0.35	-0.27		-3.47	-0.23	0.05
				Constant <i>a</i> = 8.96		
Means	19.77	2.83	2.89	$R^2 = 0.29$		
Standard Deviations	11.01	0.64	0.74	Adjusted $R^2 = 0.26$		
						** <i>R</i> = 0.54

* $p < 0.05$. ** $p < 0.01$.

Based on the results of these multiple-regression analyses, the proposed E-HBM was amended and updated to produce an E-HBM reflecting the study's findings. Figures 5 and

6 present this updated model. The figures first present the diagram in full and then follow with a presentation of worry/anxiety and coping style, illness representations, HLC and social support separately. For ease of reading demographics are presented in detail within the first diagram and then grouped as demographic characteristics thereafter. The results of these multiple-regression analyses are presented with the hypotheses they relate to following the presentation of the E-HBM.

In relation to the illness representations components, emotional representations predicted the HBM components susceptibility and seriousness and personal control predicted the HBM component benefits. In relation to HLC, the analyses revealed chance HLC predicted the HBM component health motivation and powerful others HLC predicted the HBM component susceptibility. Whilst no predictive relationships were found between coping style, worry, anxiety and social support and any of the HBM components, the analyses did reveal a relationship between illness representations and coping style, worry, anxiety and HLC. More specifically, emotional representations predicted worry and anxiety, illness coherence predicted coping style and internal and chance HLC, personal control predicted internal and chance HLC, treatment control predicted worry, and timeline acute/chronic predicted powerful others HLC. Finally, in relation to BSE the analyses revealed the only component to predict BSE frequency and proficiency was the HBM component confidence.

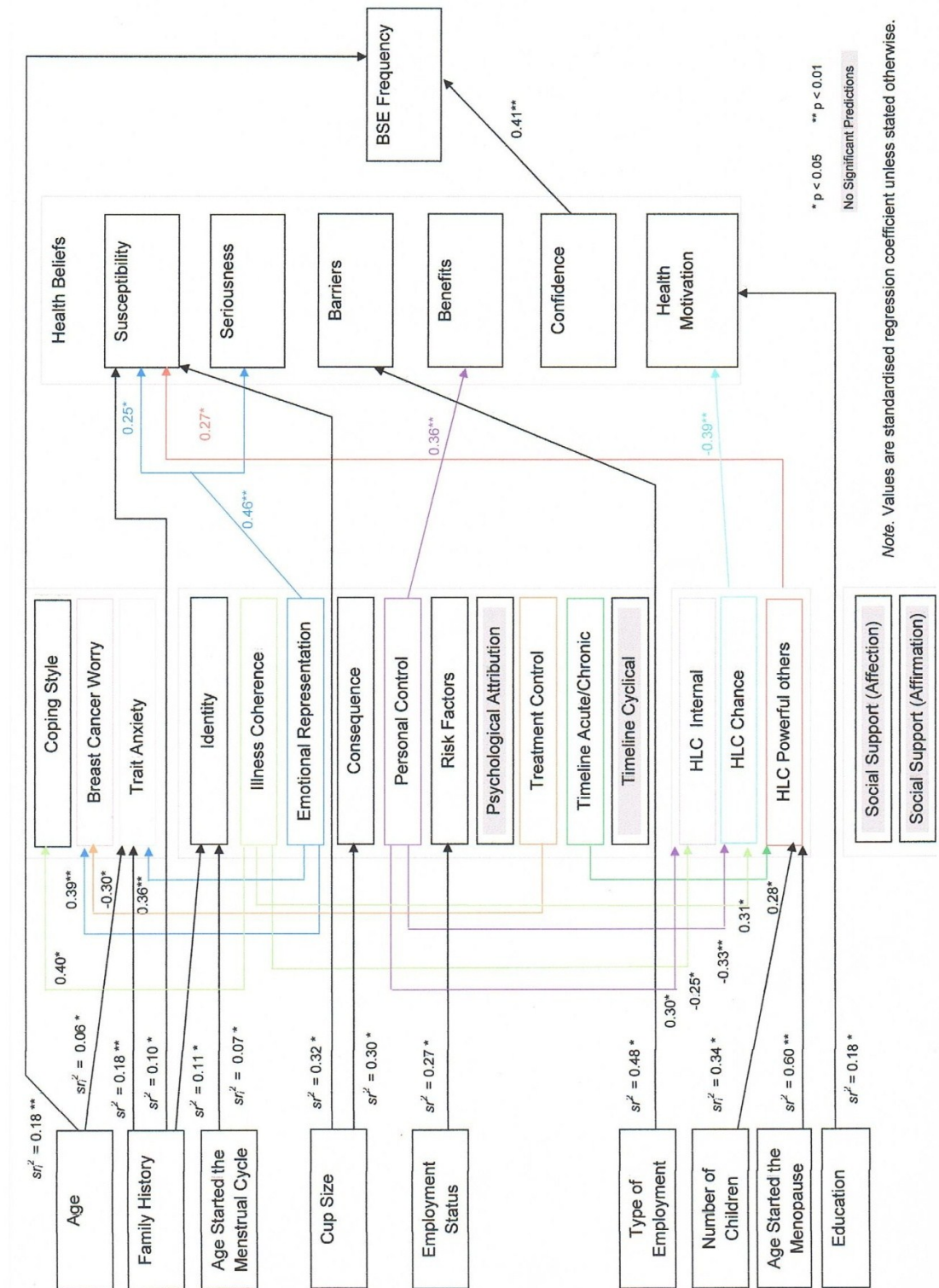


Figure 5. E-HBM Based on Study's Findings for BSE Frequency Pre-Intervention (Including Detailed Demographic Characteristics)

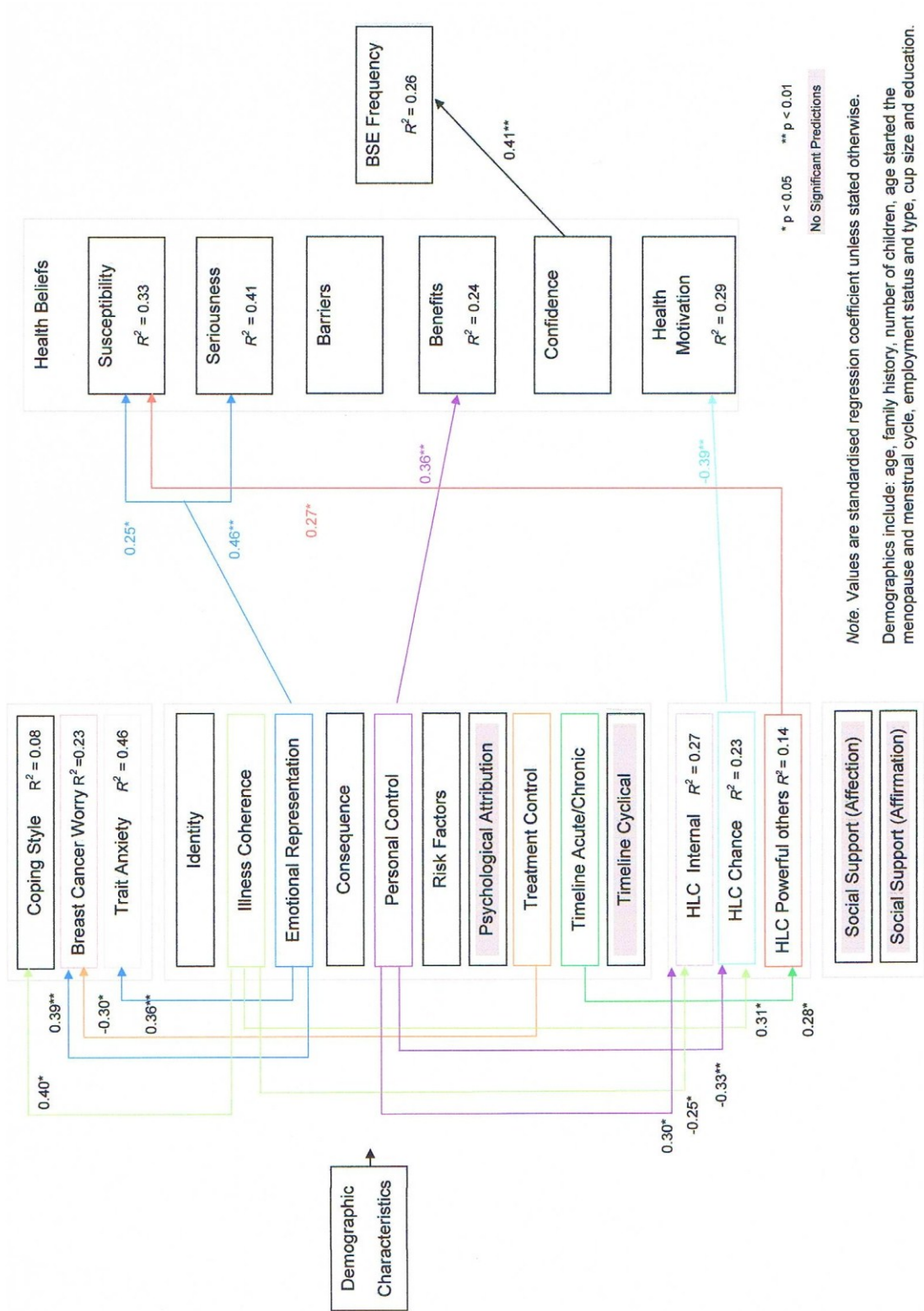


Figure 5a. E-HBM Based on Study's Findings for BSE Frequency Pre-Intervention

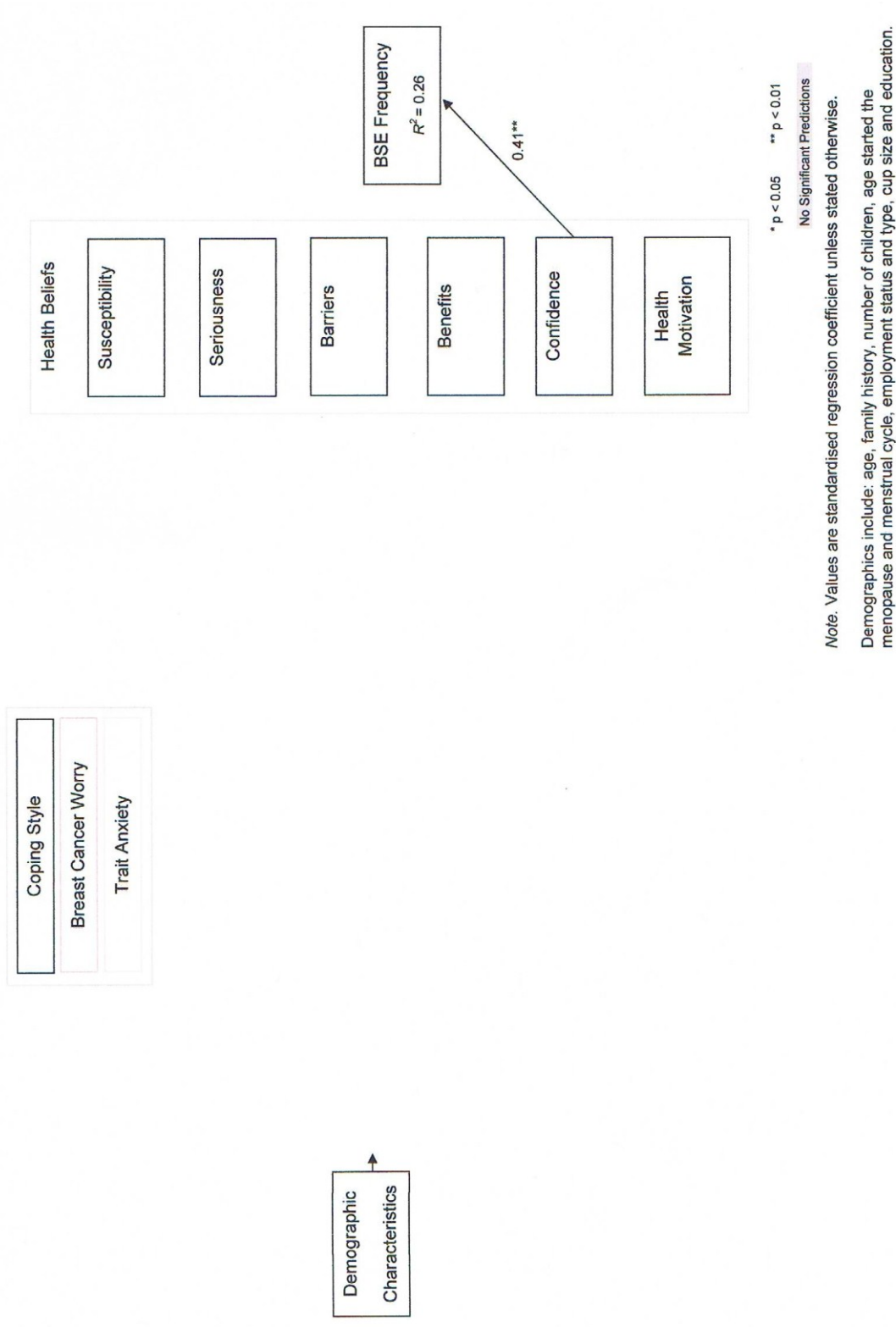


Figure 5b. E-HBM Based on Study's Findings for BSE Frequency Pre-Intervention – Worry/Anxiety and Coping Style.

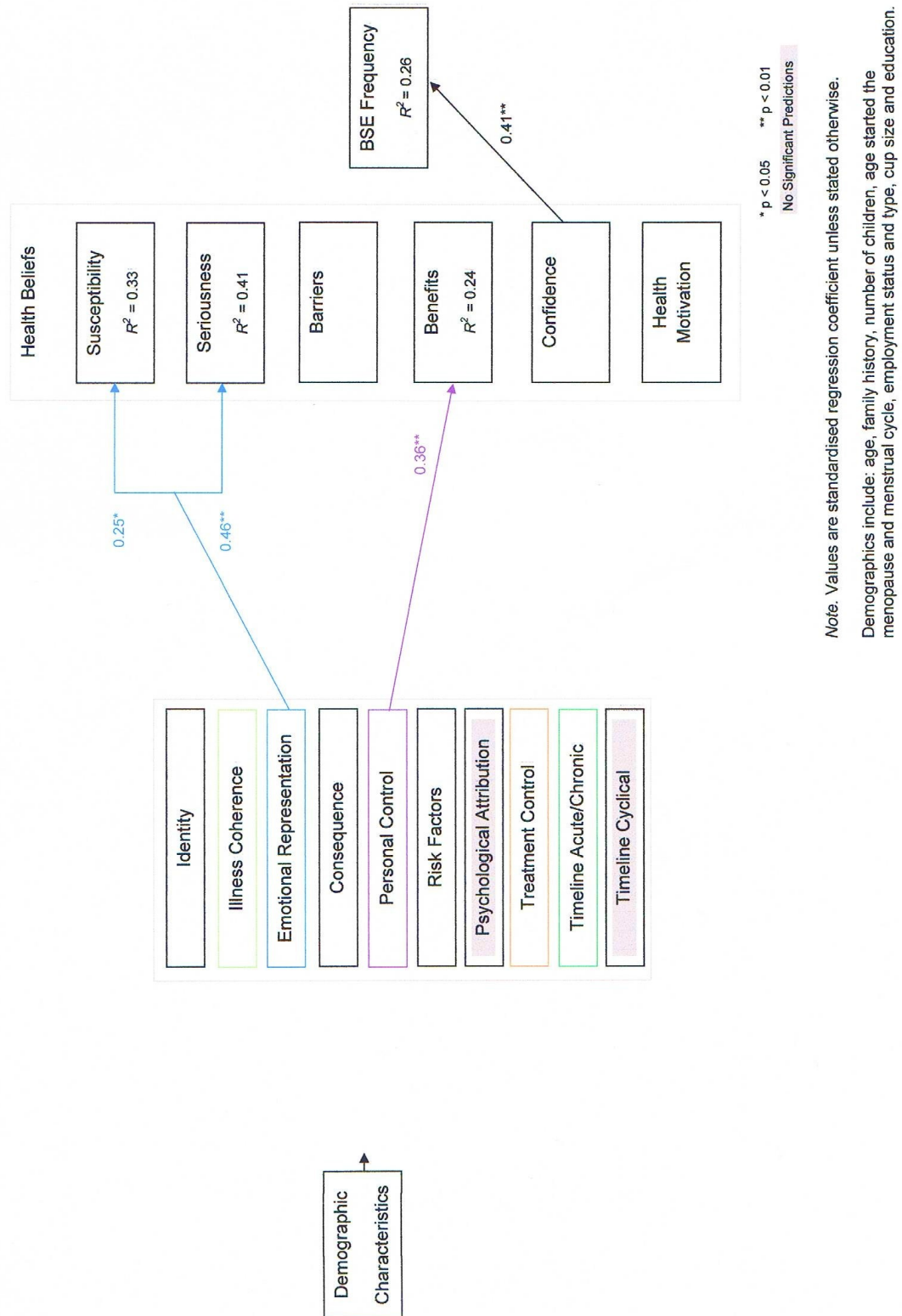


Figure 5c. E-HBM Based on Study's Findings for BSE Frequency Pre-Intervention – Illness representations.

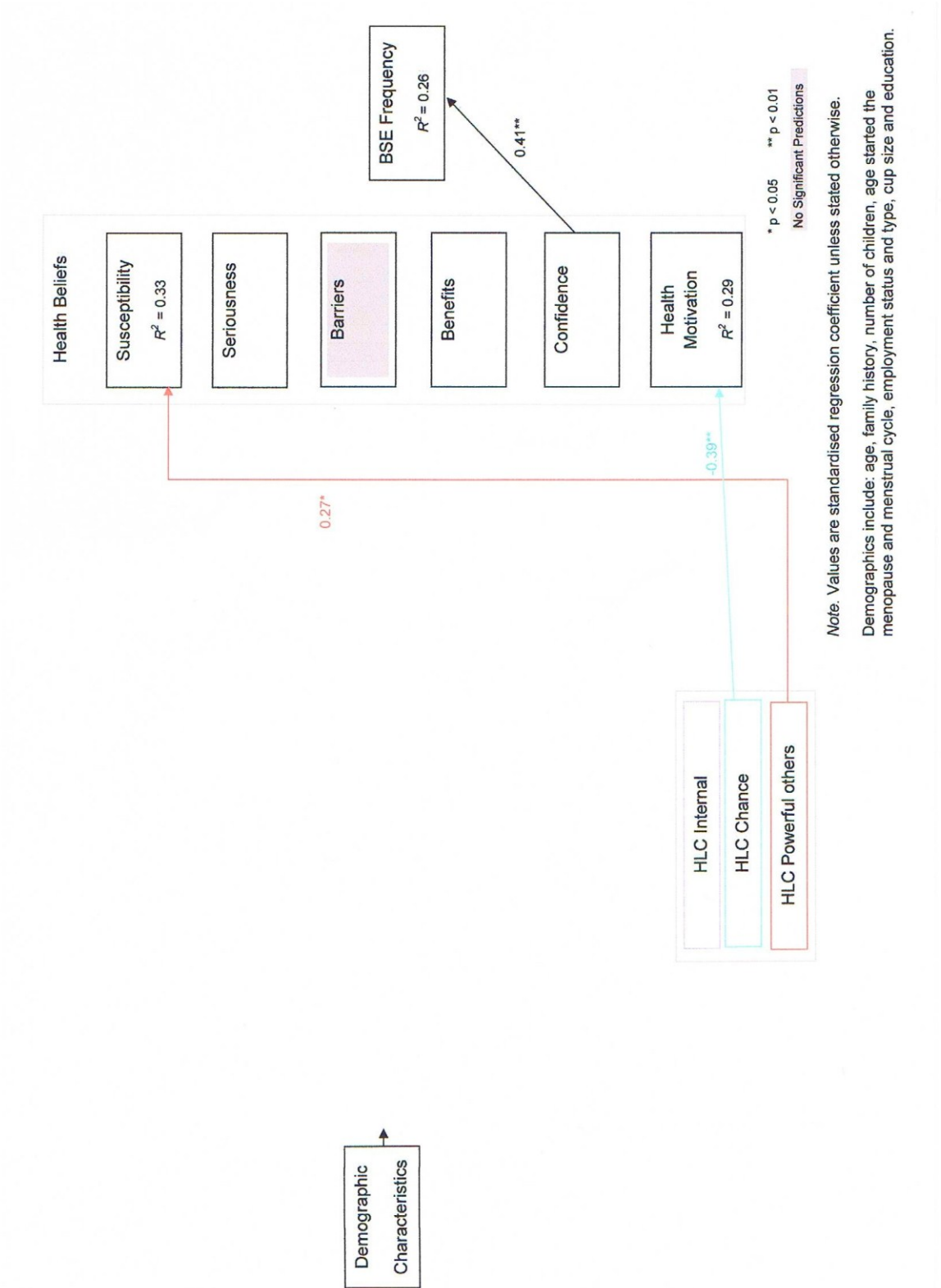


Figure 5d. E-HBM Based on Study's Findings for BSE Frequency Pre-Intervention – Health Locus of Control.

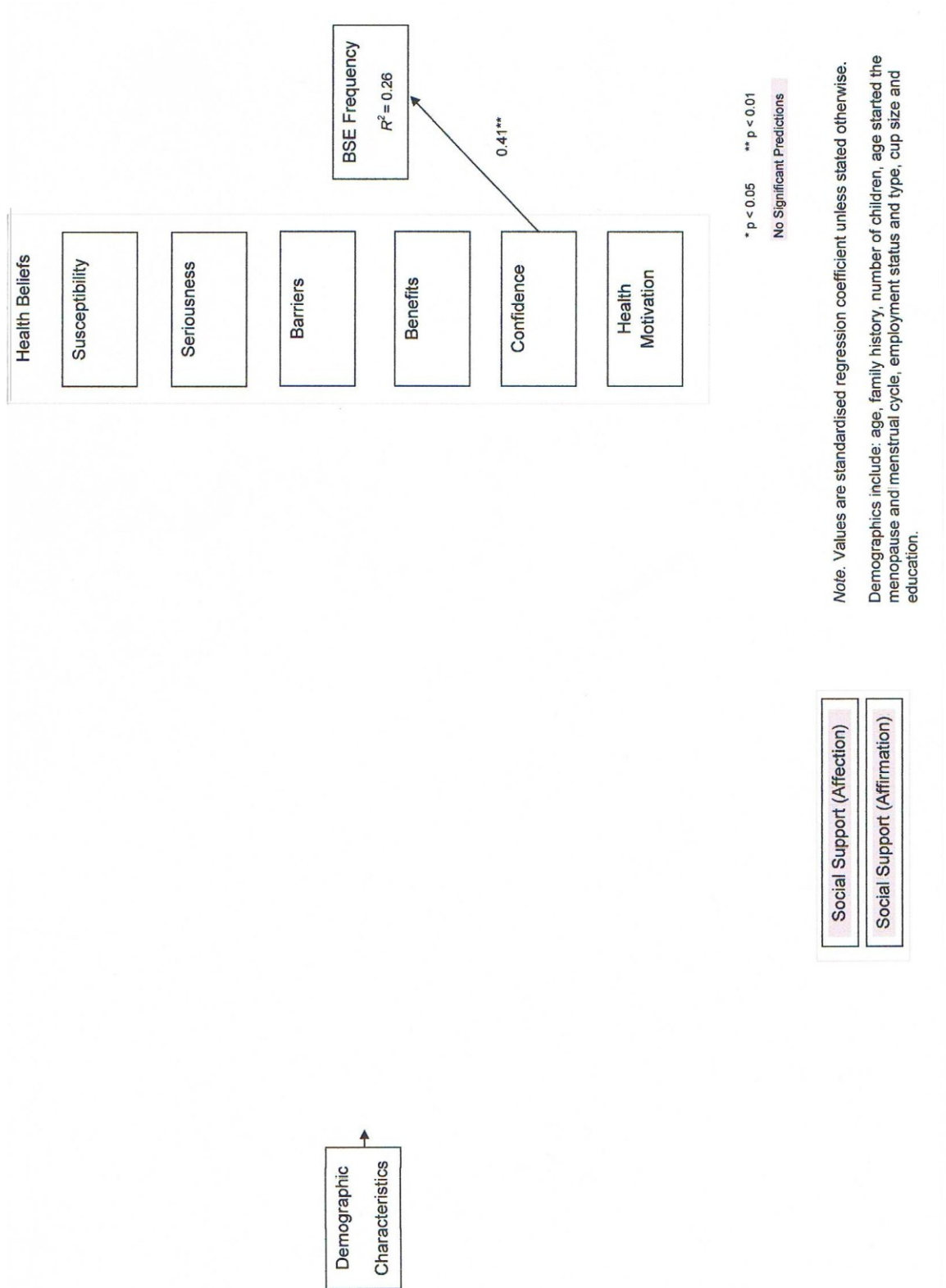


Figure 5e. E-HBM Based on Study's Findings for BSE Frequency Pre-Intervention - Social Support

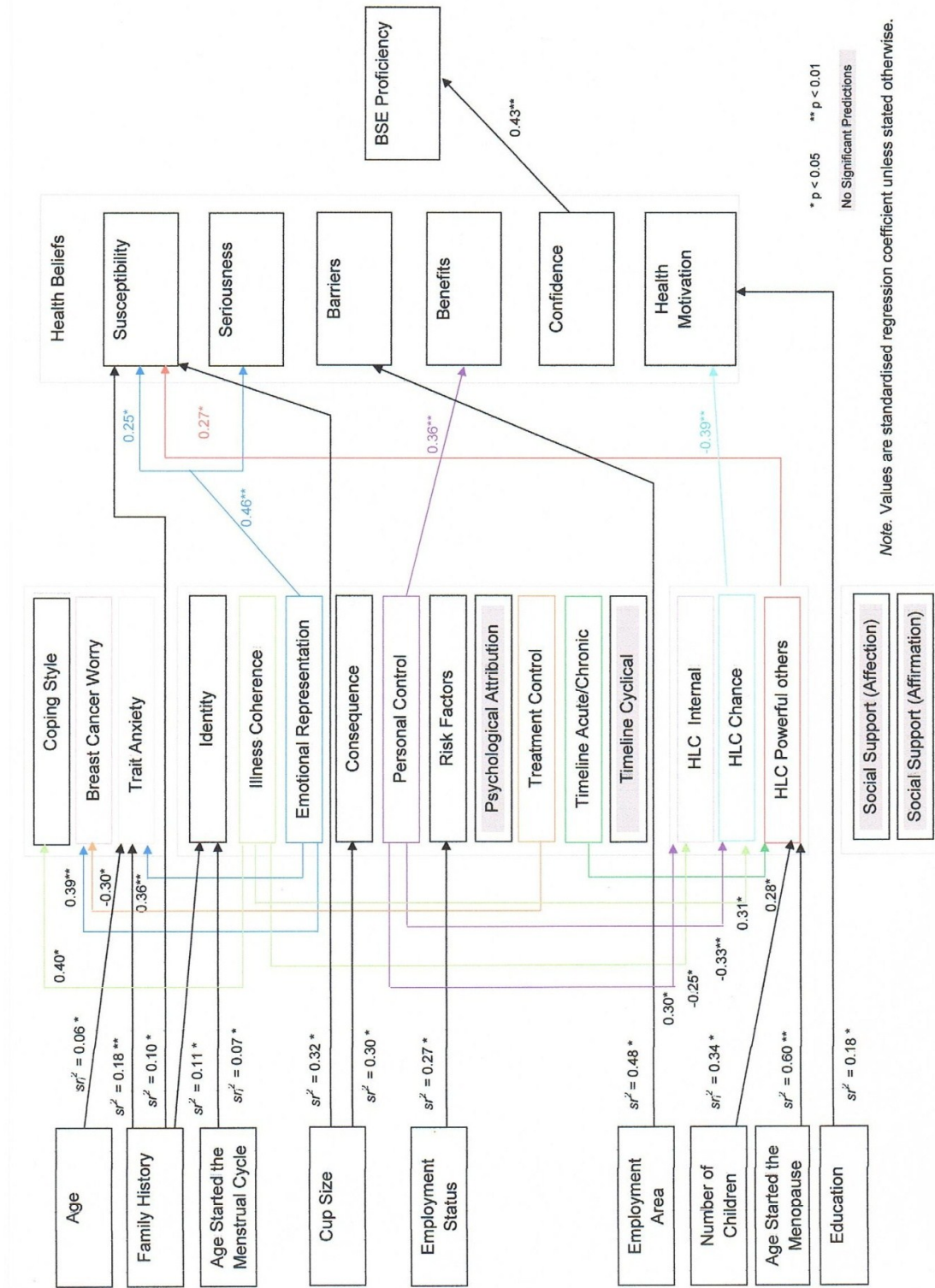


Figure 6. E-HBM Based on Study's Findings for BSE Proficiency Pre-Intervention (Including Detailed Demographic Characteristics)

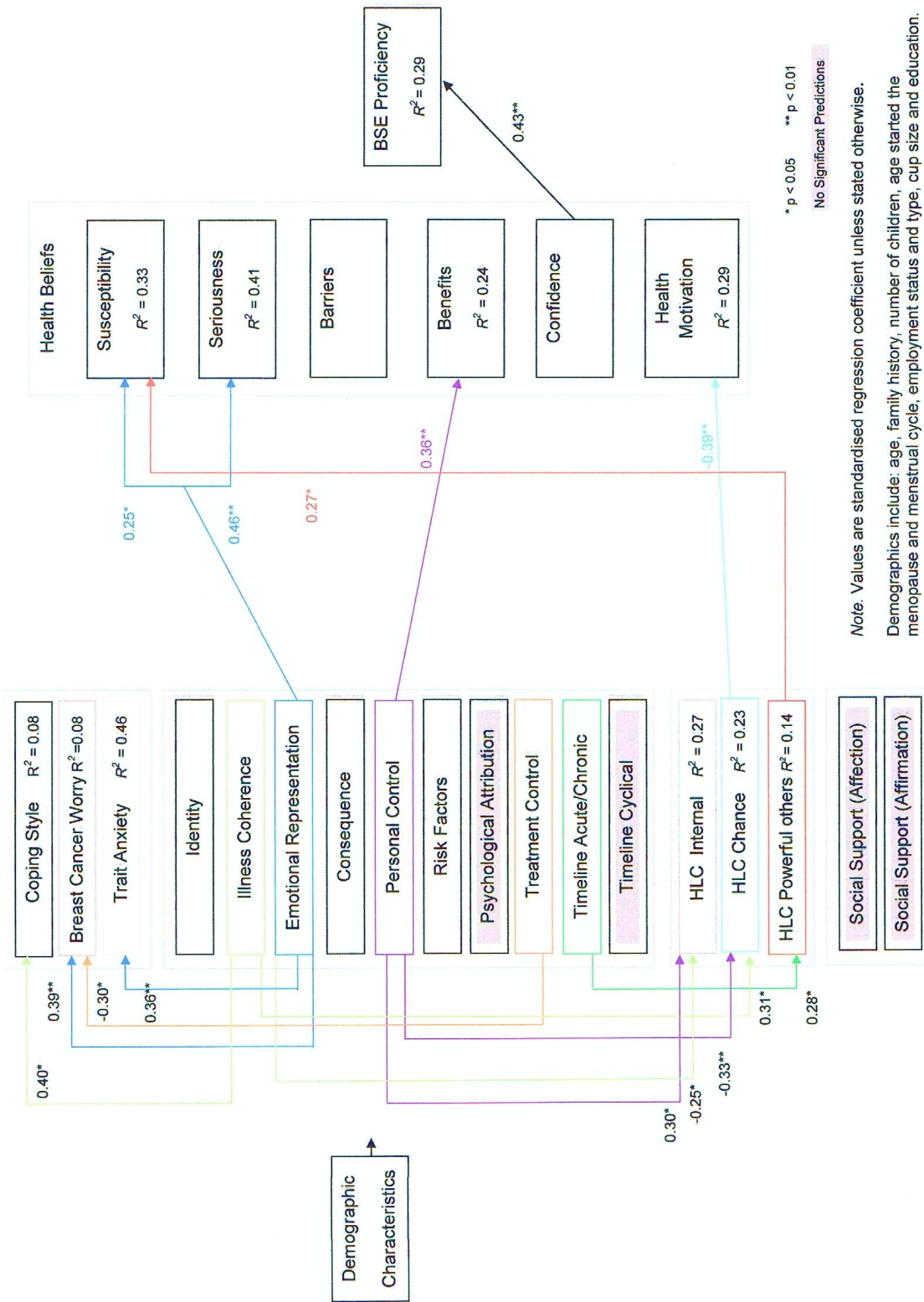


Figure 6a. E-HBM Based on Study's Findings for BSE Proficiency Pre-Intervention

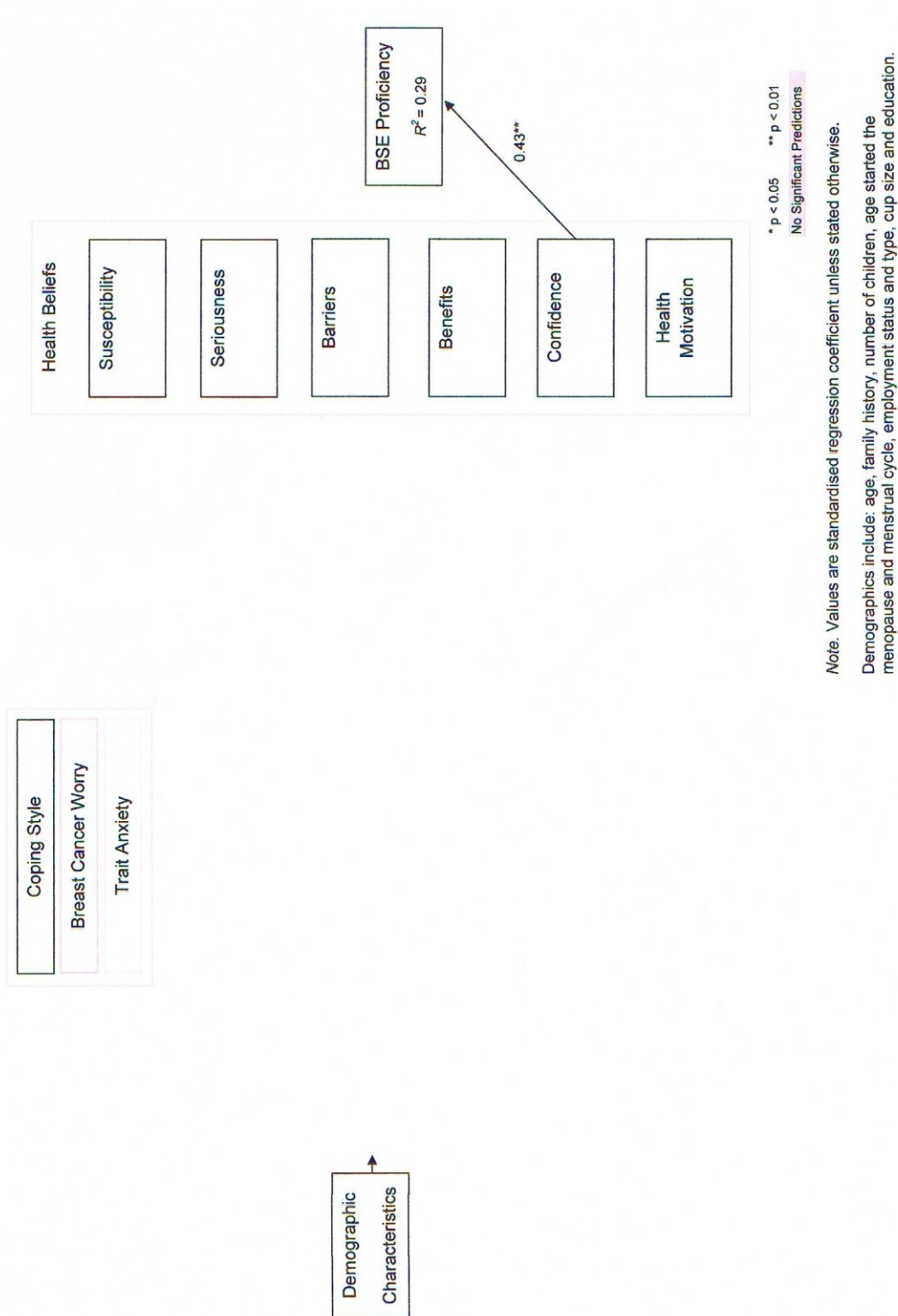


Figure 6b. E-HBM Based on Study's Findings for BSE Proficiency Pre-Intervention – Worry/Anxiety and Coping Style.

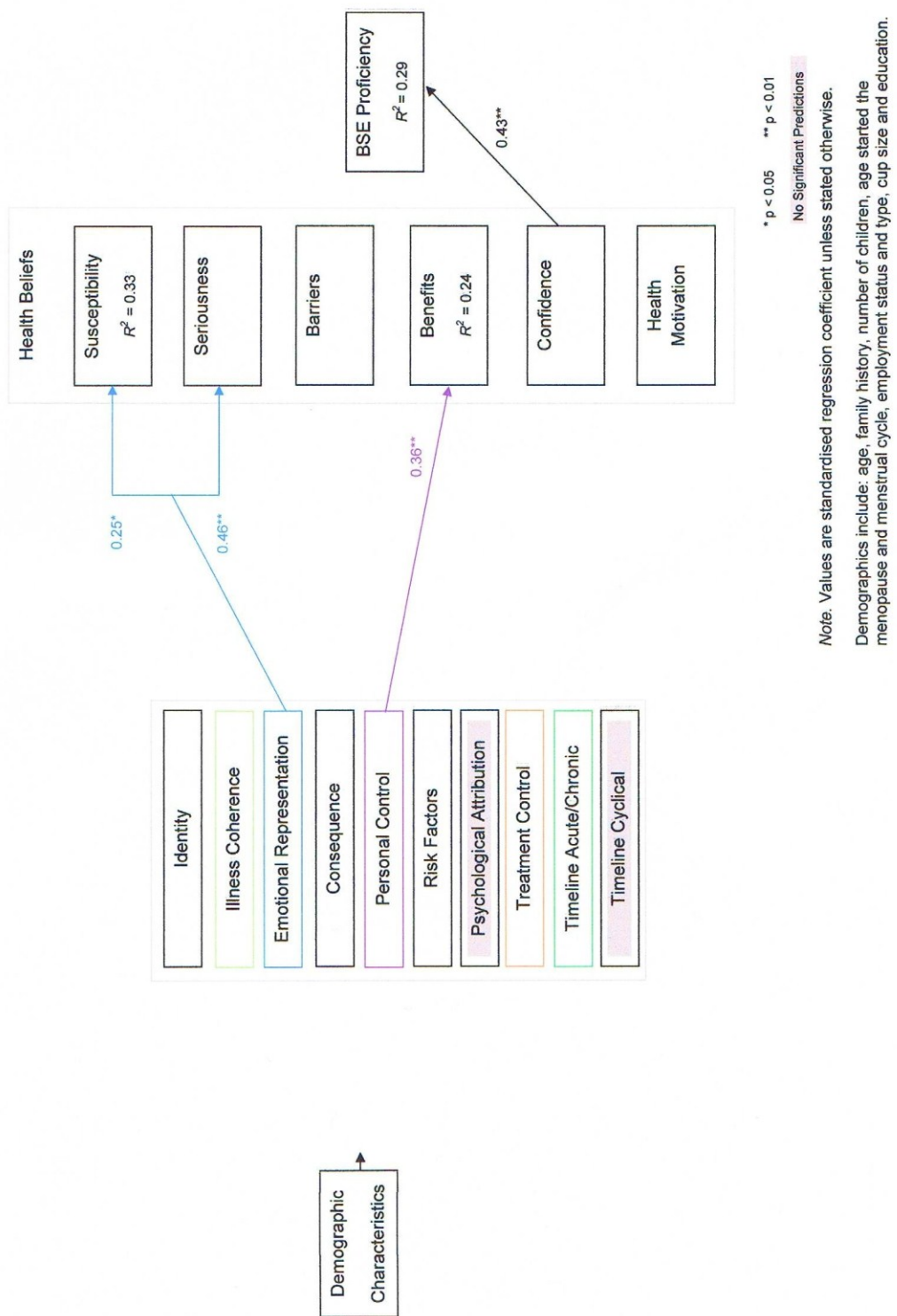


Figure 6c. E-HBM Based on Study's Findings for BSE Proficiency Pre-Intervention – Illness representations.

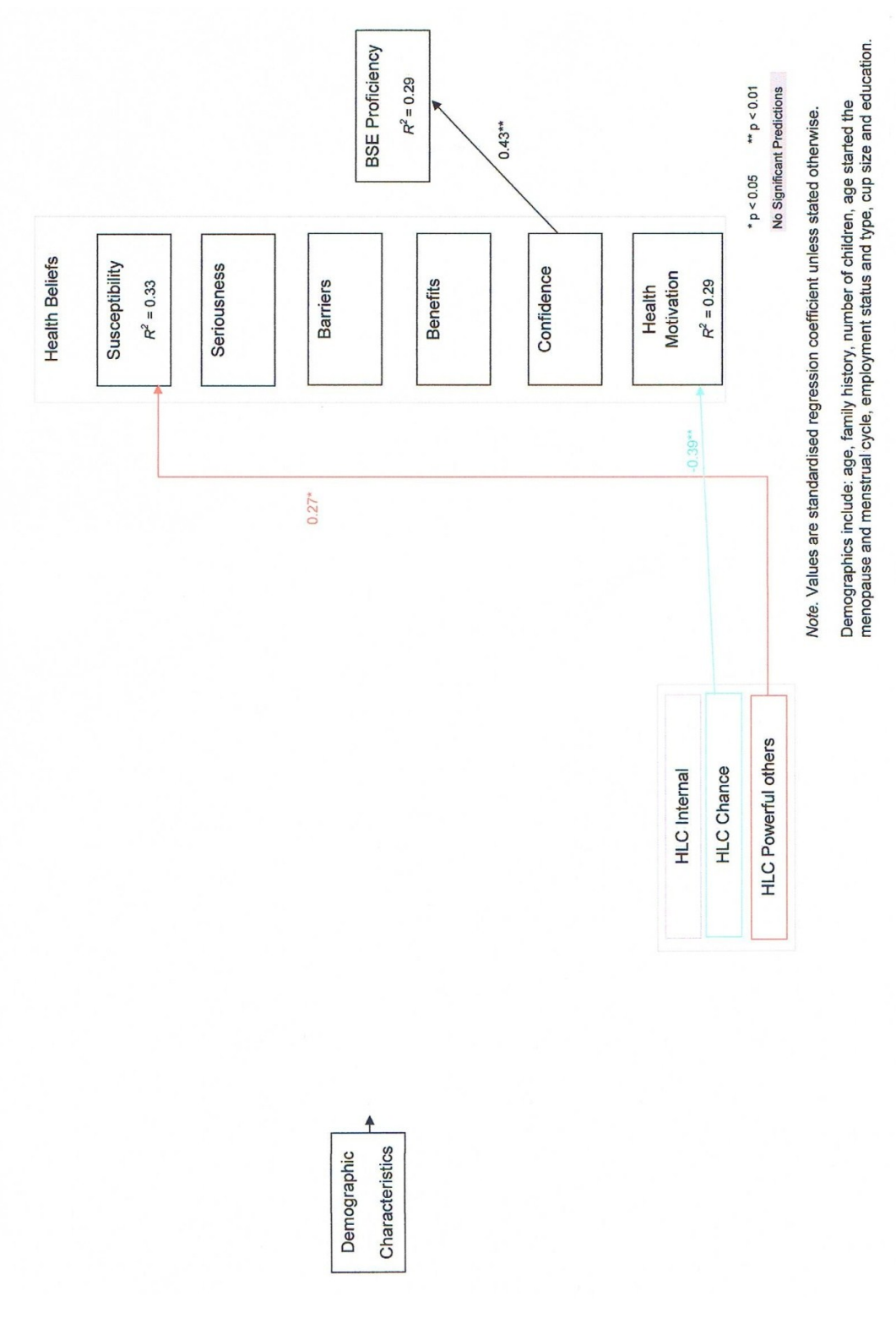


Figure 6d. E-HBM Based on Study's Findings for BSE Proficiency Pre-Intervention – Health Locus of Control.

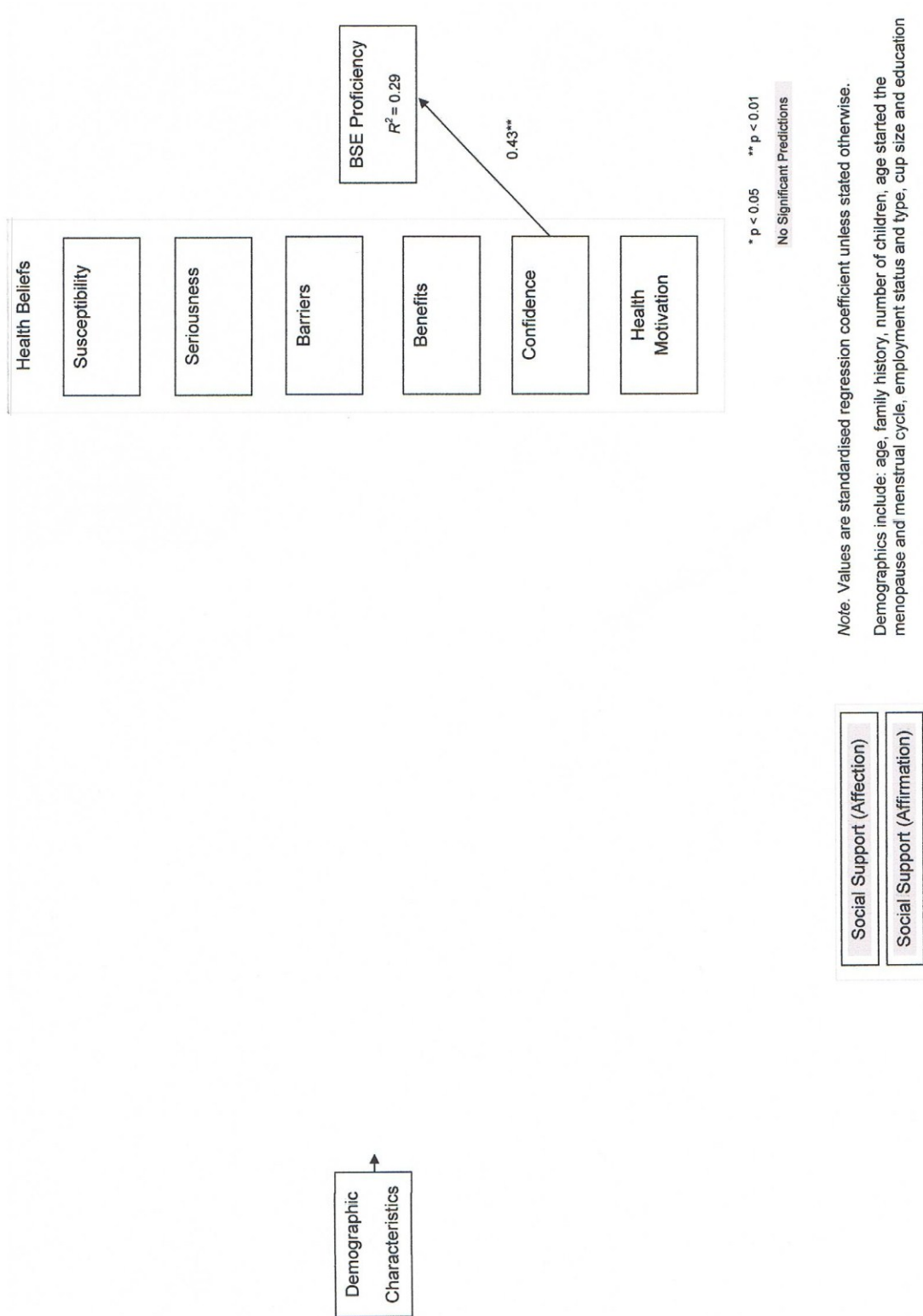


Figure 6e. E-HBM Based on Study's Findings for BSE Proficiency Pre-Intervention - Social Support

The hypotheses based on the proposed E-HBM, and the results of multiple-regression to test these analyses were as follows: (Figures 5 and 6 present the updated E-HBM based on the study's findings).

H1: The level of worry/anxiety experienced by a woman and how she chose to cope significantly predicts the HBM component susceptibility, seriousness, barriers and benefits.

Anxiety, worry and coping style did not significantly predict the HBM components susceptibility, seriousness, barriers and benefits.

H2 and H3: Women who have more social support are more motivated to engage in BSE and have more confidence that they are capable of performing BSE.

Social support did not significantly predict the HBM components health motivation and confidence.

H4: Social support significantly predicts the HBM component susceptibility.

Social support did not significantly predict the HBM component susceptibility.

H5: Women who have more social support are less likely to experience barriers to BSE.

Social support did not significantly predict the HBM component barriers.

H6: Women who have more social support are more aware of the benefits of BSE.

Social support did not significantly predict the HBM component benefits.

H7: Illness representations significantly predict the HBM components susceptibility, seriousness, barriers, benefits, health motivation and confidence.

Two components of illness representations, personal control and emotional representation were found to significantly predict the HBM components benefits and susceptibility and seriousness, respectively. In relation to the HBM component benefits, multiple-regression indicated that the predictor set for benefits (including internal HLC and the illness representation components risk factors, psychological attribution and personal control), explained 24% of the variance, $R^2 = 0.24$, $F(4, 55) = 4.38$, $p < 0.01$; however, only the predictor personal control was found to be significant. Personal control significantly predicted benefits, $sr^2 = 0.10$, $\beta = 0.36$, $t(55) = 2.69$, $p < 0.01$.

In relation to the HBM component seriousness, multiple-regression indicated that the predictor set for seriousness (including anxiety, worry and the illness representation components consequences and emotional representations), explained 41% of the variance, $R^2 = 0.41$, $F(4, 55) = 9.43$, $p < 0.01$, however only the predictor emotional representation was found to be significant. Emotional representation significantly predicted seriousness, $sr^2 = 0.14$, $\beta = 0.46$, $t(55) = 3.60$, $p < 0.01$.

In relation to the HBM component susceptibility, multiple-regression indicated that the predictor set for susceptibility (including worry, emotional representations, and internal and powerful others HLC), explained 33% of the variance, $R^2 = 0.33$, $F(4, 55) = 6.84$, $p < 0.01$, however only the predictors emotional representation and powerful others HLC were found to be significant. Emotional representation significantly predicted susceptibility, $sr^2 = 0.05$, $\beta = 0.25$, $t(55) = 2.05$, $p < 0.05$.

H8: Illness representations predict the level of anxiety or worry women experience.

Three components of illness representations, emotional representation, illness coherence and treatment control, were found to significantly predict worry and/or anxiety and coping style. In relation to worry, multiple-regression indicated that two predictors, emotional

representation and treatment control, explained 23% of the variance, $R^2 = 0.23$, $F(2, 57) = 8.71$, $p < 0.01$. Emotional representation significantly predicted worry, $sr^2 = 0.15$, $\beta = 0.39$, $t(57) = 3.37$, $p < 0.01$, as did treatment control, $sr^2 = 0.09$, $\beta = -0.30$, $t(57) = -2.59$, $p < 0.05$.

In relation to anxiety, the predictor set for anxiety (including the illness representation components emotional representations and illness coherence), explained 21% of the variance, $R^2 = 0.21$, $F(2, 57) = 7.75$, $p < 0.01$, however only the predictor emotional representation was found to be significant. Emotional representation predicted anxiety, $sr^2 = 0.10$, $\beta = 0.36$, $t(57) = 2.72$, $p < 0.01$.

In relation to coping style, one predictor illness coherence, explained 8% of the variance, $R^2 = 0.08$, $F(1, 58) = 4.94$, $p < 0.05$. Illness coherence predicted coping style, $sr^2 = 0.08$, $\beta = 0.28$, $t(58) = 2.22$, $p < 0.05$.

H9: Illness representations significantly predict an individual's health locus of control.

In relation to internal HLC, multiple-regression indicated that the predictor set for internal HLC (including the illness representation components personal control, treatment control and illness coherence), explained 27% of the variance, $R^2 = 0.27$, $F(3, 56) = 6.87$, $p < 0.01$, however only the predictors personal control and illness coherence were found to be significant. Personal control significantly predicted internal HLC, $sr^2 = 0.07$, $\beta = 0.30$, $t(56) = 2.37$, $p < 0.05$, as did illness coherence, $sr^2 = 0.06$, $\beta = -0.25$, $t(56) = -2.19$, $p < 0.05$.

In relation to chance HLC, multiple-regression indicated that two predictors, personal control and illness coherence explained 23% of the variance, $R^2 = 0.23$, $F(2, 57) = 8.42$, $p < 0.01$. Personal control significantly predicted chance HLC, $sr^2 = 0.11$, $\beta = -0.33$, $t(57) = -2.83$, $p < 0.01$, as did illness coherence, $sr^2 = 0.10$, $\beta = 0.31$, $t(57) = 2.68$, $p < 0.05$.

Finally, in relation to powerful others HLC, multiple-regression indicated that the predictor set for powerful others HLC (including the illness representation components timeline acute/chronic and risk factors), explained 14% of the variance, $R^2 = 0.14$, $F(2, 57) = 4.47$, $p < 0.05$, however only the predictor timeline acute/chronic was found to be significant. Timeline acute/chronic significantly predicted powerful others HLC, $sr^2 = 0.07$, $\beta = 0.28$, $t(57) = 2.15$, $p < 0.05$.

H10: Health locus of control significantly predicts the HBM component; susceptibility, health motivation and confidence.

In relation to the HBM component health motivation, multiple-regression indicated that the predictor set for health motivation (including personal control and internal and chance HLC), explained 23% of the variance, $R^2 = 0.23$, $F(3, 56) = 5.50$, $p < 0.01$, however only the predictor chance HLC was found to be significant. Chance HLC significantly predicted health motivation, $sr^2 = 0.12$, $\beta = -0.39$, $t(56) = -2.91$, $p < 0.01$.

In relation to the HBM component susceptibility, multiple-regression indicated that the predictor set for susceptibility (including worry, emotional representations and internal and powerful others HLC), explained 33% of the variance, $R^2 = 0.33$, $F(4, 55) = 6.84$, $p < 0.01$, however only the predictors powerful others HLC and the illness representation component emotional representations were found to be significant. Powerful others HLC significantly predicted susceptibility, $sr^2 = 0.07$, $\beta = 0.27$, $t(55) = 2.42$, $p < 0.05$. However, none of the HLC orientations predicted confidence.

H11 and H12: Internally orientated individuals are significantly more likely to see the benefits of BSE and externally orientated individuals are significantly less likely to see the benefits of BSE.

HLC did not significantly predict benefits.

H13: Health locus of control significantly predicts worry/anxiety and coping style.

HLC did not significantly predict worry, anxiety or coping style.

H14: BSE frequency and proficiency can be predicted with the original HBM components; susceptibility, seriousness, benefits, barriers, confidence and health motivation and the additional E-HBM components worry, anxiety, coping style, illness representations, health locus of control and social support.

In relation to BSE frequency, multiple-regression indicated that the predictor set for BSE frequency (including confidence and illness coherence), explained, 26% of the variance, $R^2 = 0.26$, $F(2, 57) = 9.96$, $p < 0.01$, however only the predictor confidence was found to be significant. Confidence significantly predicted BSE frequency, $sr^2 = 0.15$, $\beta = 0.41$, $t(57) = 3.45$, $p < 0.01$. Similarly, in relation to BSE proficiency, multiple-regression indicated that the predictor set for BSE proficiency (including confidence and emotional representations), explained 29% of the variance, $R^2 = 0.29$, $F(2, 57) = 11.50$, $p < 0.01$, however only the predictor confidence was found to be significant. Confidence significantly predicted BSE proficiency, $sr^2 = 0.17$, $\beta = 0.43$, $t(57) = 3.67$, $p < 0.01$.

However, none of the other HBM components were found to significantly predict BSE frequency and proficiency and in relation to the additional E-HBM components, worry, anxiety, coping style, HLC, social support and illness representations none significantly predicted BSE frequency or proficiency.

Furthermore, as a measure of God HLC was not included within the pre-intervention questionnaire, it could not be considered in relation to the E-HBM and within the regression analyses that considered the E-HBM hypotheses. Whilst religion is included within the measure of powerful others HLC, and this was included within the pre-intervention and post-intervention questionnaire it does not provide any detail regarding

who 'powerful others' are for a particular individual. In retrospect the GHLC would have been included in both the pre-and post-intervention questionnaires, but unfortunately its existence was discovered after implementation of the pre-intervention questionnaire.

However, regression analyses were conducted using post-intervention scores to explore the effect God HLC may have had if pre-intervention measures had been available within the current study. Following the examination of a correlation matrix, in which significant correlations between post-intervention God HLC and E-HBM variables were highlighted, multiple regression analyses were conducted for each of the significant variables within the matrix. Summary tables of these multiple regression analyses are presented in Appendix 27.

After considering other significant predictors, only significant results were found for powerful others HLC. More specifically, the analyses revealed post-intervention God HLC (in addition to chance HLC and the illness representation risk factors) significantly predicted post-intervention powerful others HLC. Multiple-regression indicated that the predictor set for powerful others HLC explained 34% of the variance, $R^2 = 0.39$, $F(4, 55) = 8.74$, $p < 0.001$, however only the predictors God HLC, chance HLC and risk factors were found to be significant. God HLC significantly predicted powerful others HLC, $\beta = 0.06$, $t(55) = 2.28$, $p < 0.05$. This is perhaps unsurprising given religion is included within powerful others HLC. No relationship however, was found for the remainder of the HBM and E-HBM components and BSE frequency and proficiency.

8.2 Conclusion

To conclude, the predictive utility of demographic characteristics in relation to components of the E-HBM was confirmed with a series of multiple-regression analyses and further detail regarding these predictive relationships was provided following consultation of the

descriptive statistics. It appears women with no children, and women who started the menopause at a later age, express higher levels of 'powerful others' HLC and younger women and those without a family history of breast cancer report higher levels of trait anxiety. In relation to the original HBM components, it appears that individuals with a higher level of achieved education are more motivated towards their health, that women with larger breasts and women with a family history of breast cancer feel more susceptible to breast cancer and those in a health or nursing area of employment report the lowest level of barriers towards BSE. Finally, in relation to BSE specifically, it appears older women report more frequent breast exams than younger women.

It appears some demographic characteristics are related to health beliefs surrounding breast cancer and BSE, and the frequency of which BSE is engaged in; therefore, these characteristics should be considered when exploring BSE.

It was hypothesised that worry/anxiety, coping style, HLC, illness representations, social support and the HBM components would predict BSE behaviour. This however, was not found to be true in the current study. Instead, with other variables held constant only confidence was a significant predictor of BSE frequency and proficiency pre-intervention. It appears that the other components of the HBM and worry/anxiety, coping style, HLC, social support and illness representation may not be important in understanding BSE proficiency and frequency directly but that a more complex relationship may exist. Figures 5 and 6 present the extended HBM based on the study's results.

8.3 Chapter Summary

This chapter, the second of four chapters relating to results of this thesis, presented the quantitative outcomes of the study in relation to the E-HBM. The utility of the proposed E-

HBM to explain BSE was considered and the E-HBM was updated based on the findings discussed in this chapter. Figures 5 and 6 present this updated model.

CHAPTER NINE

Results (3): Autobiographical Accounts, BSE Support and the Extended Health Belief Model (E-HBM)

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9.0 Chapter Overview

This chapter, the third of four results chapters considers autobiographical accounts and BSE support in relation to the proposed E-HBM. Following this, the model is developed further to include the effect of autobiographical accounts and BSE support on BSE frequency and proficiency.

9.1 Autobiographical Accounts, BSE Support and the Extended Health Belief Model

Further ANCOVAs were conducted to explore if viewing autobiographical accounts and the type of BSE support used, had an effect on BSE frequency and proficiency after taking into account the potential effect of the women's level of confidence and the frequency and proficiency of their breast exams before the intervention. Previous ANCOVAs demonstrated a significant effect of pre-intervention BSE frequency and proficiency on post-intervention BSE frequency and proficiency, respectively, and previous multiple-regression analyses revealed that the HBM component confidence was the only variable to directly predict pre-intervention BSE frequency and proficiency. However, whilst pre-intervention confidence scores predicted pre-intervention BSE frequency and proficiency, ANCOVA revealed after considering pre-intervention BSE and confidence scores, post-intervention confidence only has an effect on post-intervention BSE proficiency. ANCOVA summary tables are presented in Table 56 for BSE frequency and Table 57 for BSE proficiency.

Table 56

ANCOVA Summary Table for Post-Intervention BSE Frequency

Source	SS	df	MS	F	p	η^2
Pre BSE Frequency	267.01	1	267.06	36.11	< 0.001	0.28
Pre Confidence	18.52	1	18.52	2.50	0.12	0.01
Post Confidence	194.34	23	8.452	1.14	0.36	0.20
Error	251.44	34	7.40			

Table 57
ANCOVA Summary Table for Post-Intervention BSE Proficiency

Source	SS	df	MS	F	p	ϵ^2
Pre BSE Proficiency	0.11	1	0.11	0.01	0.94	0.00
Pre Confidence	28.16	1	28.16	1.45	0.24	0.00
Post Confidence	1041.31	23	45.27	2.33	0.01	0.54
Error	661.13	34	19.45			

As highlighted within the ANCOVA summary tables, there was an effect of post-intervention confidence on post-intervention BSE proficiency when holding constant pre-intervention BSE proficiency and confidence, $F(1, 34) = 2.33, p < 0.05, \epsilon^2 = 0.54$. No effect, however, was found on post-intervention frequency, $F(1, 34) = 1.14, p = 0.36, \epsilon^2 = 0.20$. Following this, it was decided in order to explore the effect of BSE support and autobiographical accounts on BSE fully; pre-intervention measures of BSE frequency or proficiency and confidence should be included within the analyses as covariates. Moreover, as analyses revealed a significant effect of post-intervention confidence on post-intervention BSE proficiency, post-intervention measures of confidence should further be included as a covariate within the proficiency analysis. The descriptive characteristics and ANCOVA summary tables are presented in Tables 58 and 59 for proficiency and, 60 and 61 for frequency.

Table 58
Descriptive Statistics for Post-Intervention BSE Proficiency by Study Group

Study Material	Adjusted Mean	SE	<i>n</i>
Autobiographical Accounts + Video-enhanced BSE Support	31.46	1.11	15
No Autobiographical Accounts + Video-enhanced BSE Support	31.99	1.14	15
Autobiographical Accounts + Static BSE Support	30.38	1.11	15
No Autobiographical Accounts + Static BSE Support	28.24	1.16	15

Table 59
ANCOVA Summary Table for BSE Post-Intervention Proficiency

Source	SS	df	MS	F	p	ϵ^2
Pre BSE Proficiency	22.32	1	22.32	1.25	0.27	0.00
Pre Confidence	100.58	1	100.58	5.65	0.02	0.04
Post Confidence	513.36	1	513.36	28.84	0.00	0.26
Autobiographical Accounts	9.39	1	9.39	0.53	0.47	0.00
BSE Support	81.29	1	81.29	4.57	0.04	0.03
Autobiographical Accounts × BSE Support	22.58	1	22.58	1.27	0.27	0.00
Error	943.30	53	17.80			

Table 60

Descriptive Statistics for Post-Intervention BSE Frequency by Study Group

Study Material	Adjusted Mean	SE	<i>n</i>
Autobiographical Accounts + Video-enhanced BSE Support	7.10	0.71	15
No Autobiographical Accounts + Video-enhanced BSE Support	8.92	0.72	15
Autobiographical Accounts + Static BSE Support	8.19	0.73	15
No Autobiographical Accounts + Static BSE Support	6.99	0.73	15

Table 61

ANCOVA Summary Table for Post-Intervention BSE Frequency

Source	SS	df	MS	F	p	ϵ^2
Pre BSE Frequency	354.18	1	354.18	46.63	< 0.001	0.37
Pre Confidence	0.24	1	.24	0.03	0.86	0.00
Autobiographical Accounts	1.45	1	1.45	0.19	0.66	0.00
BSE Support	2.63	1	2.63	0.35	0.56	0.00
Autobiographical Accounts × BSE Support	31.24	1	31.24	4.11	< 0.05	0.03
Error	410.13	54	7.60			

Following this, the analyses revealed a significant effect of BSE support on BSE proficiency, $F(1, 53) = 4.57, p < 0.05, \epsilon^2 = 0.03$, with higher proficiency reported in the video-enhanced BSE support group; and a significant interaction effect of autobiographical accounts and BSE support on BSE frequency, $F(1, 54) = 4.11, p < 0.05, \epsilon^2 = 0.03$, with the highest BSE frequency reported by those receiving the video-enhanced BSE support and not viewing the autobiographical accounts. No significant results were, however, demonstrated for BSE support on BSE frequency, $F(1, 54) = 0.35, p = 0.56, \epsilon^2 =$

0.00, autobiographical accounts on BSE proficiency, $F(1, 53) = 0.53, p = 0.47, \varepsilon^2 = 0.00$ or an interaction effect of autobiographical accounts and BSE support on BSE proficiency, $F(1, 53) = 1.27, p = 0.27, \varepsilon^2 = 0.00$.

It appears after consideration of the effect of pre-intervention BSE frequency and pre-intervention confidence, there is a significant interaction effect of autobiographical accounts and BSE support on post-intervention BSE frequency. Moreover, it appears after consideration of the effect of pre-intervention BSE proficiency and pre-intervention and post-intervention confidence, there is an effect of BSE support on post-intervention BSE proficiency. To consider these relationships in relation to the E-HBM and to further establish if their relationship was direct or if indeed mediation was present, further ANCOVAs were conducted with BSE proficiency. Baron and Kenny (1986) suggest four steps must be taken to establish that a mediated relationship exists, and the analyses were conducted in accordance with these. ANCOVA summary tables are presented in Tables 62, 63 and 64. As previous analyses revealed a significant effect of pre-intervention confidence on BSE proficiency (see Table 59), this was further included within these analyses as a covariate to ensure any effects reported were not as a result of this.

Table 62
ANCOVA Summary Table for Post-Intervention BSE Proficiency: Mediation Analysis Step 1

Source	SS	df	MS	F	P	ε^2
Pre BSE Proficiency	38.62	1		1.43	0.24	0.01
Pre Confidence	0.27	1		0.01	0.92	0.00
Autobiographical Accounts	1.08	1	1.08	0.04	0.84	0.00
BSE Support	131.51	1	131.51	4.88	0.03	0.06
Autobiographical Accounts × BSE Support	123.71	1	123.71	4.59	0.04	0.05
Error	1456.66	54	26.975			

Table 63

ANCOVA Summary Table for Post-Intervention Confidence: Mediation Analysis Step 2

Source	SS	df	MS	F	P	ϵ^2
Pre BSE Proficiency	0.08	1	0.08	0.23	0.63	0.00
Pre Confidence	4.84	1	4.84	14.74	< 0.001	0.15
Autobiographical Accounts	0.14	1	0.14	0.44	0.51	0.00
BSE Support	0.20	1	0.20	0.61	0.44	0.00
Autobiographical Accounts × BSE Support	1.33	1	1.32	4.04	< 0.05	0.03
Error	17.73	54	0.33			

Table 64

ANCOVA Summary Table for Post-Intervention BSE Proficiency when Holding Constant Post-Intervention Confidence: Mediation Analysis Step 3

Source	SS	df	MS	F	P	ϵ^2
Pre BSE Proficiency	22.32	1	22.32	1.25	0.27	0.00
Pre Confidence	100.58	1	100.58	5.65	0.02	0.04
Post Confidence	513.36	1	513.36	28.84	< 0.001	0.26
Autobiographical Accounts	9.39	1	9.39	0.53	0.47	0.00
BSE Support	81.29	1	81.29	4.57	0.04	0.03
Autobiographical Accounts × BSE Support	22.58	1	22.58	1.27	0.27	0.00
Error	943.30	53	17.80			

Mediation Step 1: Show X (autobiographical accounts and/or BSE support) is a significant predictor of Y (post-intervention BSE proficiency)

The analyses revealed a significant effect of BSE support, $F(1, 54) = 4.88, p < 0.05, \epsilon^2 = 0.06$, and a significant interaction effect of autobiographical accounts and BSE support, $F(1, 54) = 4.59, p < 0.05, \epsilon^2 = 0.05$, on BSE proficiency.

Mediation Step 2: Show X (autobiographical accounts and/or BSE support) is a significant predictor of M (post-intervention confidence)

The analyses revealed a significant interaction effect of autobiographical accounts and BSE support on post-intervention confidence, $F(1, 54) = 4.04, p < 0.05, \epsilon^2 = 0.03$.

However, no significant effect of BSE support on post-intervention confidence was demonstrated, $F(1, 54) = 0.61, p = 0.44, \epsilon^2 = 0.00$, so the main effect of BSE support could not be mediated.

Mediation Steps 3 and 4: Show M (post-intervention confidence) is a significant predictor of Y (post-intervention BSE proficiency) when we control for X (autobiographical accounts and/or BSE support)

The analyses revealed a significant effect of post-intervention confidence on BSE post-intervention proficiency when holding constant the interaction effect of autobiographical accounts and BSE support, $F(1, 53) = 28.84, p < 0.001, \epsilon^2 = 0.26$. Moreover, the analysis demonstrated the interaction of autobiographical accounts and BSE support ceased to be significant, $F(1, 53) = 1.27, p = 0.27, \epsilon^2 = 0.00$. Therefore, full mediation was present: post-intervention confidence mediated the interaction effect of autobiographical accounts and BSE support on post-intervention BSE proficiency.

In relation to BSE support, the analyses revealed BSE support remained significant, $F(1, 53) = 4.57, p < 0.05, \epsilon^2 = 0.03$. However, due to the lack of a significant finding within Step 2, partial mediation was not present within the relationship between BSE support, confidence and BSE proficiency, and, instead, it was concluded BSE support has a direct effect on post-intervention BSE proficiency.

Following the results of these series of analyses, the E-HBM was developed further to include the potential effect of autobiographical accounts and BSE support in relation to BSE frequency and proficiency. Figure 7 illustrates the predictors of post-intervention frequency and Figure 8 illustrates the predictors for post-intervention proficiency.

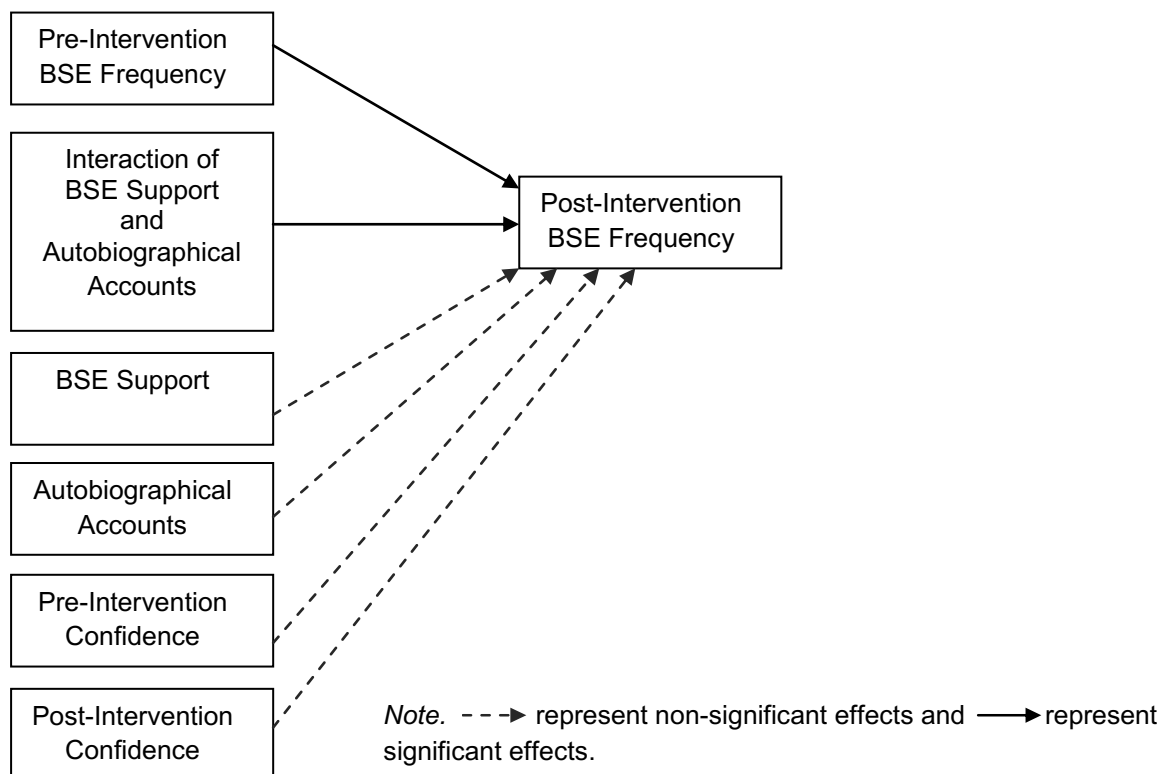


Figure 7. Model Illustrating the Predictors of Post-Intervention BSE Frequency.

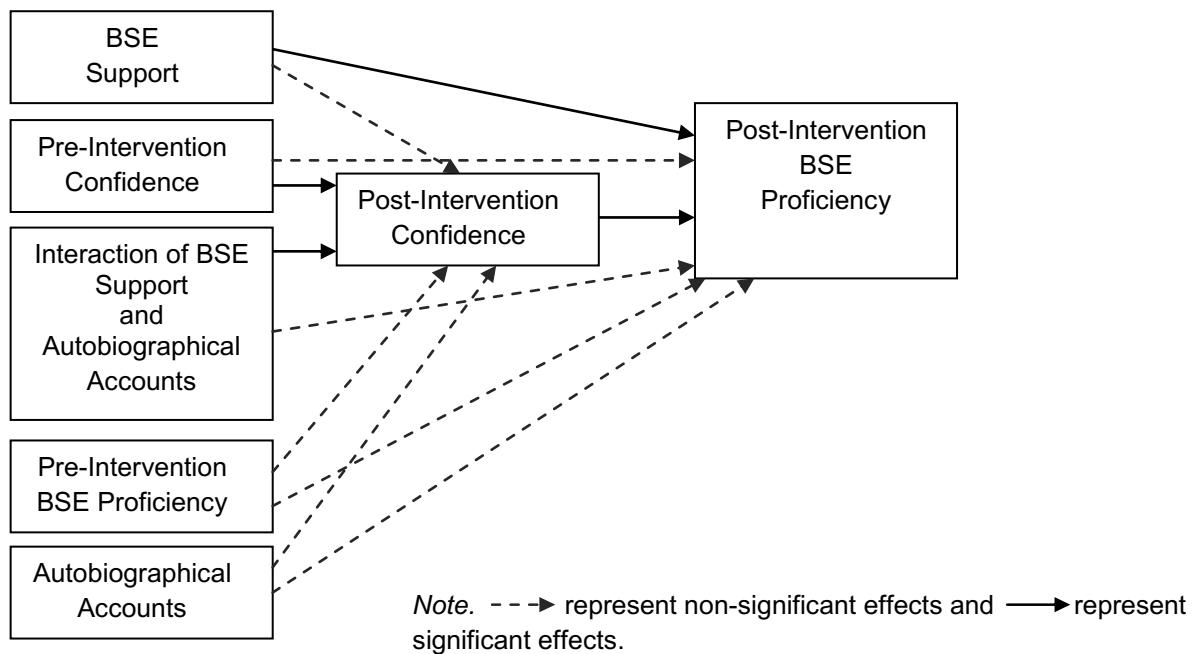


Figure 8. Model Illustrating the Predictors of Post-Intervention BSE Proficiency

It appears after considering a range of covariate effects, that post-intervention confidence mediates the interaction effect of autobiographical accounts and BSE support on post-intervention BSE proficiency and that a direct relationship exists between BSE support and proficiency. In relation to BSE frequency, it appears a direct relationship exists in which, an interaction of autobiographical accounts and BSE support (in addition to pre-intervention BSE frequency) predicts post-intervention BSE frequency.

9.2 Conclusion

To conclude, it appears after considering the effects of a range of covariates, that post-intervention confidence mediates the interaction effect of autobiographical accounts and BSE support on post-intervention BSE proficiency and that a direct relationship exists between BSE support and proficiency. In relation to BSE frequency, a direct relationship exists in which an interaction of autobiographical accounts and BSE support (in addition to

pre-intervention BSE frequency) predicts post-intervention BSE frequency. Figures 7 and 8 provide an illustration of these findings.

9.3 Chapter Summary

This chapter, the third of four chapters relating to results of this thesis, presented the quantitative outcomes of the study in relation to the incorporation of autobiographical accounts and BSE support within the E-HBM. Analyses were conducted to explore if and how autobiographical accounts and the type of BSE support can be incorporated into the E-HBM as presented in Figures 5 and 6. Following this, the E-HBM was developed further to include the effect of autobiographical accounts and BSE support on BSE frequency and proficiency. Figures 7 and 8 present this development of the E-HBM.

CHAPTER TEN

Results (4): Qualitative Data Analysis and Interpretation

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10.0 Chapter Overview

This chapter, the fourth of four results chapters presents the qualitative outcomes of the study. Participants' completed blog and end-of-study open-questionnaire responses are analysed qualitatively and five themes relating to women's beliefs and behaviour surrounding BSE are presented. The utility of conducting research within an online setting and the use of blogs as a recording and communication tool is further explored and an evaluation presented.

10.1 Qualitative Data Analysis and Interpretation

Participants' completed blogs and end-of-study open-questionnaire responses were analysed qualitatively using thematic analysis. Although some researchers claim thematic analysis is a generic tool used across varying methodologies (see, for example, Boyatzis, 1998; Ryan & Bernard, 2000), others argue it is "...a method in its own right" (Braun & Clarke, 2006, p. 78). This thesis follows Braun and Clarke (2006) and used thematic analysis "...as a method for identifying, analysing and reporting patterns (themes) within data" (p.79). Thematic analysis as described by Braun and Clarke (2006) was considered suitable for the exploratory purposes of this study because of the method's flexibility and descriptive rather than interpretive function. This made it preferable to other methods such as Interpretative Phenomenological Analysis (IPA) and Grounded Theory. Moreover, thematic analysis can offer a thick description of the data set and results produced by this method of analysis are generally accessible to the general public. This was important to increase the transferability of the findings, ensure the themes could be reflected back to participants to check for a degree of concurrence and to enable the effective dissemination of the study's findings to the general public.

Each blog and questionnaire transcript was read several times until an overall sense of the data was obtained and it was possible to start making notes describing any striking

issues. Once this process was completed, further review enabled the naming of initial themes by the process of abstraction (Fade, 2004). This process was repeated for each transcript and selected themes were compared and contrasted for all participants' transcripts to validate and elaborate existing themes.

Five initial themes regarding women's beliefs and behaviour surrounding BSE were extracted and listed: Previous Experience, BSE Irregularity, Perceived Susceptibility, Coping Style and the Usability of the 5-Step Model of BSE. Appendix 28 presents transcripts of the qualitative data in full. Possible connections between these themes were then explored in order to cluster them together in a meaningful way and this, in turn, produced a clear understanding of the central themes. This process was performed on all the individual transcripts, before an attempt was made to compare and contrast them with each other to produce a set of themes that were consistent across all the transcripts and represented all the individuals participating in the study. Participants were given the opportunity to verify the themes taken from the data analysis. Detailed findings from this theme verification process are presented in Chapter Six (Section 6.4.8) but to summarise the majority of those that responded to this process, reported being able to relate to the themes and feeling the themes were true for them.

10.2 Theme 1: Previous Experience

Past experience of breast cancer and BSE seemed to influence both thoughts and behaviour connected to BSE.

Subtheme 1: Past BSE

Past BSE provided reassurance for some women.

“Right breast has been quite sensitive over the last week but this is usual (have had this checked out in past and am aware of changes in tenderness during monthly cycle)” (P79 Blog, Lines 14-15).*

However, for others it caused anxiety.

“I already have anxieties about self examination due to lumpy breasts” (P17 Questionnaire, Line 17).

“Feel anxious in the lead up to the examination” (P47 Blog, Lines 96-97).

“When I have tried examining my breasts in the past it has caused me to be anxious” (P17 Blog, Lines 6-7).

This anxiety caused some to question their ability to examine their breasts comprehensively.

“In the past, when examining my breasts, I did worry that I had a lump in my right breast, and got sent for a mammogram. This came back clear, but when the doctor examined my breasts she said that she could see why I had thought that I had found a lump due to the texture of my right breast being a lot lumpier than that in my left breast. This sometimes causes me to worry that I did have a small lump in my right breast, that I would not find it early on due to the lumpy texture that I have” (P9 Blog, Lines 6-12).

“When I have tried examining my breasts in the past it has caused me to be anxious as I have felt lumpiness and not known whether these are actual lumps or the natural lumpiness of my breasts” (P17 Blog, Lines 6-8).

*One hundred and ten women signed up for the study but of these 40 did not proceed past completing the consent form. However, all the women who completed the consent form were given a participant number resulting in some of the women who did participate in the study holding participant numbers greater than 70.

However, for others the anxiety associated with BSE was too much to cope with and they instead avoided BSE.

“It probably all stems down to finding a lump years ago and it frightened me even though in the end it was nothing untoward. It is the most horrible feeling and seems to take ages from going to doctors; hospital and getting results and you always think the worst. Since then it has put me off checking even though I know it is in your best interest and can end up saving your life as early detection is better” (P47 Blog, Lines 99-103).

Contrastingly, having a regular history of finding non-cancerous lumps can provide reassurance and almost seem to normalise the situation. One woman discussed her experience of regularly finding non-cancerous lumps and whilst she still gets them checked, she experiences much less anxiety than the first time she found one.

“Over the previous five years I have found lumps in my left breast on average every twelve months. Each time these lumps have been cysts which have been 'drained' each time I have attended the breast clinic at North Tees. I'm not sure why I get them so often, but I associate them with the coil as they have coincided with my use of the coil. The first time I found a lump I was extremely frightened - I immediately thought it was breast cancer. I have now found these lumps so frequently over the years, that I no longer think of cancer. I assume the lump is another cyst. However, saying that, there is always 1% of me thinks this time might be different” (P34 Blog, Lines 6-13).

Whilst taking part in the study this same woman found a lump in her breast and her documentation of how this affected her provides an insight into the experience of finding a

lump. It was the shock of finding an additional lump in her right breast that caused greatest concern.

“I was expecting the doctor to confirm the lump in the left breast. I did not feel anxious or worried about this prior to the doctor’s appt this morning as this has been the breast which in the past I have always found the lumps/cysts... I wasn’t expecting the doc to find anything in the right breast and this has made me feel surprisingly odd. After leaving the doctors ...I was aware that I was filling up. I continued to feel subdued and a bit weepy (although I have not cried) all day. I’m not sure or confident that the lump in the right breast is the same old cyst” (P34 Blog, Lines 29-37).

It appears unexpectedness can cause the greatest anxiety.

“During the build up to the appointment although I was fairly certain that the lumps were cysts, I knew at the back of my mind were negative thoughts that this time may be different. Particularly as this time I didn’t find the lump in my right breast myself” (P34 Blog, Lines 41-44).

Subtheme 2: Experience of Seeking Advice from Medical Professionals

Furthermore, the experience of seeking advice for a breast lump or abnormality from a medical professional seems to influence future BSE behaviour. Two of the women reported negative experiences with the medical profession and this discouraged them from seeking advice for problems in the future.

“I became much more breast aware last year when I was experiencing symptoms other than a lump (tingling behind the nipple and pain with or without pressure applied to the area). I did feel incredibly frustrated at the time as it took 3 doctor’s

visits to get a referral to be checked, and the process from first doctor's appointment to the results stating 'no significant abnormality' took approximately 3 months. It left me with a feeling of 'why did I bother?' which is the last thing any woman with breast symptoms should be thinking" (P82 Blog, Lines 15-21)

"After doing my own breast examinations in the past I have been to my GP for a check up due to being anxious and they have usually said it was fine, on one occasion I was referred to the hospital for a biopsy to make sure. This makes me more hesitant about doing breast examinations as I feel the resulting use of GPs time and the use of a hospital appointment unnecessarily due to my anxiety is a waste and should be used by people who really do have problems" (P17 Blog, Lines 9-14).

Perhaps women need to be reassured by health professionals that they are not wasting time or resources if they find they are cancer-free and rather than if it is better to check any change or abnormality they are unsure about.

Subtheme 3: Experience of others

Having a family member or friend who has experienced breast cancer seemed to influence interest in BSE and the study itself.

"This is a very special study and takes a very special person to run this study to help better lives of people with the disease and help people detect it. I have had loved ones with this illness and if this study helps one person to catch it early or get a person and their family through their illness it will help hugely" (P96 Blog, Lines 79-82).

"I was interested in participating in this study because I lost a friend to breast cancer ten years ago. She was only 38" (P34 Blog, Lines 4-5).

“It’s incredibly important. I lost my mum to secondary breast cancer (she’d been clear from breast cancer for a number of years), and although it was found too late and was untreatable, I’m very aware that if she hadn’t examined herself and found the lump at the start she probably would have died sooner than she did. She was one of the unlucky ones, but lives are saved by doing this and I can’t stress highly enough how important I feel it is” (P82 Questionnaire, Lines 20-25).

It encouraged some of the women to start examining their breasts and highlighted and strengthened the importance of BSE in others.

“Over the course of this study, a family member who had been clear of breast cancer for a long time has undergone treatment for secondary cancer ... The treatment has unfortunately been unsuccessful. This has only re-iterated the importance of catching any abnormalities as early as possible in the hope that it is not too late for treatment to be successful, and I am thankful that due to this study I am now performing regular checks on myself” (P38 Questionnaire, Lines 37-43).

“I’ve been doing breast examinations ever since my mum was diagnosed with breast cancer around 15 years ago” (P82 Blog, Lines 3-4).

It appeared knowing someone with a history of breast cancer encouraged an increased awareness of, and interest in, both breast cancer and BSE. Moreover, this interest seemed to provide motivation to seek out more information about breast-cancer prevention and for some encouraged BSE. However for others it was not always enough to encourage regular BSE.

I also know that I should do breast exams, and I have done in a desultory way over the years” (P11 Blog, Lines 7-8).

Whilst an awareness of the need for BSE was apparent, it appears personal experience may be more influential in encouraging regular BSE.

“I think I’ll also become more interested in BSE as I get older as there is a history of breast cancer in my family. I know that BSE is important because of my family history but I just don’t see myself at risk of breast cancer at the moment. Maybe when I’m older or if I had a scare or something” (P50 Blog, Lines 40-43)

However, this is not always true and for some having a family member with breast cancer was enough to encourage BSE.

“I’ve been doing breast examinations ever since my mum was diagnosed with breast cancer around 15 years ago” (P82 Blog, Lines 3-4).

Perhaps, the strength of the family history influence depends on the individual in question, the strength of the experience or the relationship between themselves and the person with breast cancer. Indeed one woman was in the centre of her mother’s experience of breast cancer and as a result of the experience a strong bond was formed.

“I was living with my parents at the time my mum was diagnosed, I helped take care of her through radio and chemotherapy, and I wonder sometimes if it hadn’t happened whether our relationship would have been as strong as it was. We’d had difficulties before her diagnosis, but the day we found out it was like the slate was wiped clean and we just started all over again. I think we both appreciated the one silver lining that came from it” (P82 Blog, Lines 40-45).

10.3 Theme 2: BSE Irregularity

BSE was viewed positively by all the women participating in the study and all had the intention to engage in it. However, this intention did not always lead to BSE behaviour and most found it difficult to regularly examine their breasts.

“I think that breast self examination is incredibly important and beneficial. However busy lives mean it is sometimes difficult to remember to do the examination regularly despite good intentions” (P17 Questionnaire, Lines 29-31).

Fifteen women were unable to complete the six breast exams they were asked to do as part of the study, and when asked to provide reasoning for this most reported lack of time or routine and forgetfulness. Whilst the other women did do the required breast exams, they still expressed concern over the regularity in which they engaged with BSE, providing similar reasoning for this.

Subtheme 1: Non-Salient Cognitions of BSE

All the women expressed a desire to examine their breasts but the non-salient nature of BSE failed to encourage examination and for many it was a challenge to remember to engage in their self-examining behaviour.

“Everyday life takes away my need to be aware” (P66 Blog, Lines 86-87).

“If it came into my mind in the shower I’d do it, but I never set any time aside though I often felt I should” (P82 Blog, Lines 5-6).

“I was determined to stick to doing an examination every 2 weeks... however this only lasted for a few days and then I stopped doing it. It wasn’t a conscious decision to stop I just started to forget to do it” (P17 Blog, Lines 49-53).

It appears BSE is not something most women think about regularly.

“If I am very truthful, I have found that to do the breast examination is not something that comes into my mind as often as it should do, and without realising it, quite a lot of time goes by from one examination to the next, just due to the demands of everyday life” (P9 Blog, Lines 36-39).

“It’s just hard to remember to do. When you’re busy and got loads to do it’s kind of the last thing you think about doing. I know once you get into the habit of doing it every week it’ll be easy to remember to do it, it’s just actually getting round to starting the habit” (P50 Blog, Lines 30-33).

Instead, there is a need for it to be incorporated into behaviours they are already actively engaging in on a regular basis. One woman expressed an increased awareness in her breasts due to the nice weather and her sunbathing activities and another due to shopping for a bikini.

“I have perhaps been more aware of my breasts and their appearance and feel as I have been doing a lot more moisturising than usual. This may sound ridiculous but because of the nice weather I sat in the garden in my bikini and even though I used a factor 40 I still have a canny tan and because I want to prolong it I have been moisturising. Through this I have been looking at my breasts and touching them - more superficially because of tan maintenance - but I am sure that if there had been any changes in my breasts that I would have noticed” (P66 Blog, Lines 20-26).

“I’ve been continuing to be more aware of my breasts, more so recently as I was trying to find a bikini/ tankini top” (P77 Blog, Lines 42-43).

However, it is unknown whether this increased awareness would continue once the women no longer engage in these activities.

“I have been observing my breasts regularly and this has become part of a routine but whether or not this is due to the nice weather and wearing of skimpier clothing and bikinis I am not sure. If in the cold winter when I race to get dressed and wear layers upon layers I will be as observant I am unsure” (P66 Blog, Lines 43-46).

Indeed, the same woman reported a reduction in her awareness once she could no longer sunbathe.

“As the weather has not been so warm I haven’t been moisturising as much which doesn’t help with my awareness” (P66 Blog Lines 63-68).

Similarly, other women expressed a need for BSE to be incorporated into their current routine.

“I will now have to work out how to incorporate this into my routine. Probably after a bath fortnightly” (P79 Blog, Lines 6-7).

Moreover, incorporating BSE into their current routine appeared to make the examination process easier and assured the women it is possible to examine their breasts regularly.

“I did my examination last night but did it in two parts. I did the standing up bit when in the shower and when I went to bed did the laid down part there. I found this to be easier and I could probably do the examination when standing on a more regular basis by incorporating it as part of my bathing routine” (P66 Blog, Lines 28-31).

It appears the success of encouraging regular BSE is dependent on how readily it can be included into a woman’s current routine.

“Fortnightly checks have fast become my normal routine – so much so that I’ve forgotten to blog about them. I guess that shows I’ve truly moved on from checking for the sake of the research to checking for the sake of me. Breakthrough” (P42 Blog, Lines 49-52).

Over the course of the study, the implementation of regular BSE became more routine for many of the women participating in the study and this enabled them to examine their breasts on a more regular basis.

“I have got into a good routine of regular examination and feel my technique has improved” (P24 Questionnaire, Lines 4-5).

“I continue to regularly check my breasts, usually whilst I’m in the bath” (P34 Blog, Line 117).

“After the first week it becomes normal in your weekly routine” (P96 Blog, Lines 106-107).

Subtheme 2: Need for prompts

Moreover, due to the non-salient nature of BSE, most of the women expressed a need to be prompted to examine their breasts. Some women prompted themselves.

“Even though I know I have to be aware of my breasts I need to prompt myself regarding the awareness” (P66 Blog, Lines 18-19).

However, for others, health-promotion activities or the research study itself served as a prompt.

“I think I have been more aware too as I have been having various other check-ups - eyesight test and a smear - so the checking has been more at the front of my mind” (P66 Blog, Lines 46-48).

“I have found it easier to remember to do my breast examinations because I felt I had to fulfil my commitment to the study” (P64 Questionnaire, Lines 4-5)

Moreover, it appears autobiographical accounts may also serve as a prompt to encourage BSE.

“I have watched the videos and found them quite upsetting. I particularly related to the 19 year old girl who had the same family history of breast cancer that I have... This has given me the motivation to keep up to date with the examinations” (P17 Blog, Lines 59-63).

Whilst these prompts encouraged the initial engagement of BSE, it appears they may also serve as a prompt to encourage long-term compliance to BSE.

“If I was not involved in this research I would not be committed to performing breast self examination with such regularity. I know that after the research project is over I will continue but there are thousands of people out there (not just women) who need to be self examining their breasts in order to become more familiar with what is normal for them - and ultimately to be able to detect changes as they occur, allowing them to get changes checked as early as possible and ultimately, perhaps save their lives” (P62 Blog, Lines 31-36).

“I think the study has made me feel breast self examination is more important than I previously thought. I guess I half heartedly examined before where now I think

about it more. The breast cancer accounts really helped with this and made me realise how important examining is” (P20 Questionnaire, Lines 30-33).

10.4 Theme 3: Perceived Susceptibility

For most of the women participating in the study breast cancer was seen as something any woman of any age can experience and that women should take control of their health and examine their breasts on a regular basis to control for the disease.

“I feel it is a must for all women” (P9 Questionnaire, Line 22).

“I feel breast self examination is something all women should be aware of and do regularly” (P93 Questionnaire, Lines 20-21).

“I think it should be taught to children at a young age” (P81 Questionnaire, Line 38).

Whilst many of the women neglected to discuss their own perceived susceptibility to breast cancer per se, a few did discuss their own personal risk. For these women age and family history seemed to be influential.

Subtheme 1: Age as a Risk Factor to Breast Cancer

One of the younger women in this study expressed her lack of concern regarding breast cancer and BSE due to her young age.

“I don’t think it is particularly important for me to develop the habit of doing it cos I’m only 20. I know this is stupid as young people can get it too, you just don’t think its common and you definitely don’t think it’ll happen to you. This is a very naive idea, I understand this. In a magazine there was an article on young women who had survived breast cancer – all these women were in their 20-30s so it does

make you realise it could happen to you. I think as I start to get older I will become more involved with BSE as I think my health and looking after it will be important to me, where as now I kind of take it very much for granted. I think I'll also become more involved in BSE as I get older as there is a history of breast cancer in my family" (P 50 Blog, Lines 33-41).

Whilst she was aware that young women can develop breast cancer, she neglected to apply this to herself and instead there was a sense of optimistic bias. However, this was not confirmed by the other young women participating in the study. They neglected to discuss their susceptibility on an individual level and instead focused on breast cancer as a disease that needs to be considered regardless of age.

"I think it's important in helping ensure breast cancer is found early" (P37 Questionnaire, Line 18).

"I think it's important as it can be the difference between life and death" (P67 Questionnaire, Line 21)

Moreover, for one of the young women BSE was so important that she encouraged her friends to examine their breasts too.

"I wrote a public blog yesterday about breast self-examination to make my female friends aware they should be doing it and many thanked me for the advice" (P77 Blog, Lines 68-69).

Perhaps surprisingly, despite Participant 50's thoughts that BSE would become important when she ages, this woman still expressed a need for BSE to be taught to younger women.

“So people know what’s normal I think BSE should be taught in schools. If this was done it would become a habit from a young age so would just be carried out like brushing your teeth” (P50 Blog, Lines 65-67)

It appears, whilst BSE may be viewed as of greater importance the older a woman becomes, younger women still have the desire to examine their breasts. Perhaps in some women this desire is just weaker.

Subtheme 2: Family History as a Risk Factor of Breast Cancer

Rather than simply encouraging an interest in BSE and the study itself, (Theme 1), having a family member who had experienced breast cancer seemed to further influence the women’s personal perceived susceptibility to breast cancer. A family history of breast cancer was a well known risk factor amongst the women and for most their thoughts and behaviour were influenced by this. Those with a family history of breast cancer expressed greater concern about the disease and subsequently viewed BSE as of great importance.

“For me breast examination is essential because of my family history (mum and maternal great aunt)” (P82 Blog, Lines 13-14).

Whilst, those without a family history expressed less concern about breast cancer and less interest in BSE.

“Recently my daughters were discussing how they don't really feel that cancer is something that they worry about, due to there being no-one having this illness in our family, and that they are more likely to worry about Alzheimer’s as a threat to them and I wonder if subconsciously I feel this as well and this is the reason that I am not as pro-active in carrying out the examinations as often as I should” (P9 Blog, Lines 40-44).

“I previously thought because no one in my family has ever suffered from breast cancer that it really wasn’t a worry for me, which to a point it isn’t now but I am no longer ignorant and will make sure I give myself regular checks” (P81 Questionnaire, Lines 7-9).

Likewise, others reported to feel less vulnerable to breast cancer and consequently view BSE as irrelevant to them because of a lack of family history.

“It’s surprising when you get talking to people how many have the same attitude to breast cancer and the fear of it and how some people think it doesn’t apply to them because they haven’t had relatives with breast cancer so they are not at risk” (P47 Blog, Lines 83-85).

It appeared family history was perhaps the most well known or considered risk factor for breast cancer among these women. Moreover, the women’s personal perceived risk of breast cancer seemed to be determined by this, and those at increased risk due to their family history were more positive and proactive towards BSE. It is, however, worth noting, as discussed previously, that similar thoughts and behaviour were reported by women without a personal family history to breast cancer, but who had experience of a friend with breast cancer. A woman’s perceived risk of breast cancer may not simply be determined by blood relatives’ history of breast cancer, but rather any experience of breast cancer the woman has.

10.5 Theme 4: Coping Style

Subtheme 1: Avoidance

Fear seemed to be a central factor disengaging some women from regular BSE with some choosing to cope with this fear by avoiding BSE altogether.

“Finally plucked up the courage to do this as it scares me even though I know it is in my best interest. The thought of what you might find is scary as sometimes ignorance is bliss” (P47 Blog, Lines 3-4).

“I actually felt quite nervous before this breast examination. I’d put it in my diary to do every second Sunday. I didn’t have time on Sunday evening and forgot on Monday evening – I was adamant it wasn’t something I shouldn’t rush. But I wonder if on a subconscious level I was putting it off. I think this underlies why I haven’t been diligent in the past about a) doing a regular exam or b) ever learning how to do one properly. Because of what I might find. It seems ridiculous but I think there’s some truth in it for me. Even afterwards, when everything seemed normal I still didn’t feel reassured. I guess I realised it only means normal for now” (P42 Blog, Lines 22-30).

This fear was not connected to the BSE process itself but rather the fear of discovering a sign of breast cancer through the examination.

“I agree it’s in your own best interest to self examine because early detection is better it is just easier said than done when you have had relatives die of breast cancer” (P47 Blog, Lines 9-11).

“It might sound melodramatic but I think it’s about coming to terms with the reality of doing a regular breast exam – that every time I do it there is a chance I might find something. And yet, I need to remind myself that the more I do, that if I do find a lump or something unusual I’ll find it earlier than I would have otherwise” (P42 Blog, Lines 31-34).

It appears women can, however, move away from this avoidance and examine their breasts if provided with knowledge and support to make BSE more routine.

“I have gone from not doing any breast examination to regularly doing it now and I am always looking for changes in my breasts as having cancer is a big fear of mine due to having a friend that has had breast cancer” (P36 Questionnaire, Lines 28-30).

“I hope this has helped me overcome my fears a little and I continue to do the examination more frequently now the study has finished” (P47 Questionnaire, Lines 25-26).

Moreover, as BSE became more routine for the women, the process became easier and their negative feelings towards BSE seemed to decrease.

“Getting into the swing of this – I’m less nervous about the prospect of it and feeling more in control” (P42 Blog, Lines 36-37).

“Got easier over time in that I did not have to think through how to do it and didn’t indulge in so many negative thoughts about breast cancer just because I was doing the checks” (P64 Questionnaire, Lines 11-13).

“It feels less scary (because I might find something) and more empowering (because if I do, I’m more likely to find it early)” (P42 Questionnaire, Lines 24-25).

Further to this, some women expressed dislike at having to think about and look at their breasts and this made the engagement of BSE problematic.

“Looking in the mirror at my now old breasts is depressing in its own right. Maybe this will help me overcome that” (P64 Blog, Lines 7-8).

“I felt uncomfortable about looking at my breasts in the mirror because I don’t like my body very much but I focused on the task and tried not to think about my hang ups... it was easy to feel my breasts using the line technique and I felt ok about doing this because I wasn’t looking in the mirror anymore” (P77 Blog, Lines 29-31).

“I now force myself to look at my breasts each day after I shower and while in the shower I feel them to see if they feel any different. I say force myself because I don’t think it is a natural thing for a woman to look at her body in general – I find that a little vain. I do look at myself to check how I look in an outfit now and then but I’ve not looked closely at myself naked” (P62 Blog, Lines 9-13).

Perhaps the first step in encouraging BSE particularly for some women is to make them more comfortable simply looking at and thinking about their breasts. Indeed, over the course of the study this dislike seemed to become less problematic as looking and thinking about their breasts became normalised, and as a result BSE became more regular and pleasant.

“Since my last examination I have checked my breasts every morning and now and again after my evening bath. I think I am becoming obsessed with them. I really do not mind looking at myself in the mirror now. I must have steadily become used to it” (P62 Blog, Lines 26-29).

“I am more comfortable about thinking about them it’s not all wonder if they are diseased” (P64 Blog, Lines 41-42).

“I don’t feel so self-conscious about doing it anymore and I try to do it regularly” (P77 Questionnaire, Line 21).

Furthermore, it may be beneficial to promote BSE as an activity couples can engage in together, especially in those women for which fear is problematic. One of the women participating in the study expressed the positivity of involving her fiancé within her breast exams. Whilst she herself struggles with the thought of breast cancer and is uncertain whether she would be honest with herself if a change was to occur, she is reassured by the presence of her partner.

“My fiancé is also becoming more aware and checks on a regular basis as I always think he may be a little more honest if shape or colour did change or if a lump appeared as sometimes you just don’t want to admit to yourself that something could be wrong, especially something that could be so life threatening as breast cancer” (P96 Blog, Lines 38-42).

Subtheme 2: Proactive Coping

Instead of avoiding BSE, some of the women chose to cope with the anxiety surrounding BSE by facing the problem head on and examining their breasts. These women did not understand avoidance.

“I can remember many years ago – in the 60s perhaps – talking to my child minder about the new fangled mammograms and was amazed at her take on scans and other health examinations. She said I wouldn’t want to know. She wouldn’t be swayed by my argument that if its caught early it can be treated, and she has stayed in my mind because I am sure she wasn’t/isn’t the only one who feels like that” (P11 Blog, Lines 18-23).

Instead, they chose to deal with the threat by engaging in BSE, yet not letting it overtake their life. Instead, they viewed BSE as a regular part of everyday life and just something every woman should and needs to do.

“It’s a sensible thing to do, as are all available means of checking, smears, blood pressure checks etc” (P11 Questionnaire, Lines 20-21).

“I feel it’s a must for all women” (P9 Questionnaire, Line 22).

Similarly, they expressed that BSE, in addition to other health-protecting activities, was adequate. They did not believe in over-worrying.

“What also interests me is that although I’m surrounded by women with breast cancer, I’m not very anxious for myself. I have had a very healthy life so far, and because of my family history of heart disease (mother, father, sister all had heart attacks) I try to eat well and take exercise, and I hope I’m not complacent. I also hope that participating in this will not raise my anxiety levels. I don’t believe in meeting trouble half way” (P11 Blog, Lines 32-36).

Furthermore, for one of these women, humour appeared to be a useful coping mechanism. When faced with a negative situation she attempted to keep the situation positive, using humour to lighten the mood.

“I remember when my cousin’s prosthesis arrived and we called it breasts by post” (P11 Blog, Line 58).

Despite the women’s negative experiences with breast cancer or BSE they were determined not to let this over-concern them and instead remained positive.

“I remain positive about my own breast health. I know 1 in 9 women get breast cancer, but that means 8 in 9 don’t. I hope I’m one of the 8” (P11 Blog, Lines 93-94).

It appears this positive focus is important in not only encouraging the initiation of BSE, but of long-term compliance too. There appears to be a need for the positive outcomes of breast cancer to be promoted in order to displace some of the fear surrounding breast cancer and to enable women to examine their breasts regularly.

“I think BSE is a good idea because it means people are more aware of what are the symptoms of breast cancer so are more on the lookout. This means that lots of people may catch breast cancer in the earlier stages if they do get it meaning they have a greater chance of survival. If the number of people surviving breast cancer increases then so does the optimism of the disease – it means people who get it will have a more positive outlook of surviving as most people do survive. If the odds of survival are good as well it’ll encourage more people to be breast aware as they won’t be scared to find something cause they’ll know that finding something doesn’t have to mean death” (P50 Blog, Lines 56-63).

Two of the women asked to view autobiographical accounts as part of the study further highlighted this need for a positive focus.

“Set 5 autobiographical accounts demonstrate the positivity of those diagnosed with and/or have survived breast cancer, I feel this positivity should be promoted more to show that finding a lump and then having treatment/surgery is something which can be overcome and that not all patients diagnosed with breast cancer lose the fight. Sometimes a positive outlook can help fight it” (P62 Blog, Lines 52-56).

“The first woman’s accounts made me think more positively about breast cancer- that it’s something you can recover from and go on to lead a happy, normal life, even though it’s scary at the time” (P77 Blog, Lines 18-20).

Perhaps positive autobiographical accounts could be used as part of future BSE campaigns to facilitate a more positive outlook.

Subtheme 3: Instability of Coping Style

Coping style however, appears to be able to change depending on the situation. One of the women participating discovered a lump during the study and her account of her experience of this highlights the instability of her coping style. Initially, she appeared to adopt a proactive style, facing problems head on and expressing a desire to deal with situations that arise.

“I never take it for granted that the lumps I find are cysts, I always get them checked out as soon as possible” (P34 Blog, Lines 31-32).

However, once she discovered a lump and awaited confirmation regarding its status her behaviour changed and she instead avoided touching her breasts.

“Both my sister and I have spoken about how once the GP confirms the lump and refers you to the breast clinic 1) the lump starts to feel uncomfortable in ways it didn’t previously i.e. you are conscious of its presence, you can ‘feel it’ without touching it, it feels tender, like a bruise (is this psychological?), 2) you don’t examine yourself in the period of time between the GP and the breast clinic – it is although you know there is something there and you don’t want to keep on touching or feeling it” (P34 Blog, Lines 84-79).

Once she was given the all clear she again faced the anxiety head on and reverts back to her proactive coping style.

“After my lump last week and my sisters on-going experience I have researched cancer more thoroughly” (P34 Blog, Lines 90 -91).

She accepted her situation in that she was likely to regularly discover lumps and chose to deal with this.

“I know that I have large clusters of cysts in both breasts and that the ‘lumps’ will continue to become prominent. That I will be going back and forth to the breast clinic to have these cysts drained is something I think of as routine. Nevertheless, I am always very cautious to alert my GP as soon as I discover a ‘lump’ as there is always a tiny niggling thought on the back of my mind that this may be the time when it’s not simply a cyst” (P34 Blog, Lines 117-122).

Furthermore, she expressed her lack of understanding regarding those that adopt avoidance coping strategies.

“I have a friend who is terrified of getting breast cancer and does not check her breasts as a result of fear of finding a lump. I don’t understand this and don’t understand how women like this can overcome their fear and regularly examine their breasts. I asked my friend about bathing as I thought while she was washing she may naturally stumble across a lump. Her response was that she purposely used a bath mitt to avoid such a scenario. I don’t understand this type of avoidance” (P34 Blog, Lines 129-134).

10.6 Theme 5: The Usability of the 5-Step Model of BSE

All the women in the study were aware of the advantages to BSE and thought it was something all women should engage in.

“I think BSE is a good thing as it makes you more aware so things can be caught early. Also makes you more aware of what’s actually there already and is normal so you don’t jump to conclusions when it’s actually nothing and is perfectly normal. BSE also makes you more comfortable feeling and talking about your breasts so if you do find a problem you’re more confident to talk about it and go and see someone” (P50 Blog, Lines 7-12).

“I think it’s important in helping ensure breast cancer is found early” (P37 Questionnaire, Line 18).

However, most were unsure how to examine their breasts comprehensively and expressed concern over their own ability to discover signs of breast cancer.

“I have been concerned about breast cancer for a number of years and it worried me that I do not regularly check my breasts. This has always been because I do not really know what I am supposed to do and the leaflets from my GP practise have not been very helpful” (P17 Blog, Lines 3-6).

“I’ve been doing breast examinations since my mum was diagnosed with breast cancer around 15 years ago, but these were sporadic and I was never sure I was doing it right” (P82 Blog, Lines 3-5).

When I have tried examining my breasts in the past it has caused me to be anxious as I have felt lumpiness and not known whether these are actual lumps or the natural lumpiness of my breasts” (P17 Blog, Lines 6-8).

They expressed frustration at not being shown or given instructions by medical professionals and suggested that if provided with guidance regarding how to examine their breasts they would engage in BSE more regularly.

“It’s shocking really that I don’t know given how media aware I am and that I’ve never been shown by my doctor or family planning nurse, even though I went for my pill check-ups every 6 months for ten years” (P59 Blog, Lines 7-9)

“Earlier this year when I asked the nurse who did my smear about them (she was talking about weight, general health, breast examinations etc beforehand) she wasn’t very specific about how to do one. I would have appreciated her actually showing me (P42 Blog, Lines 15-18).

“I feel that if I know how to examine my breasts properly this would lead me to doing this on a regular basis without causing the anxiety that I have experienced in the past” (P17 Blog, Lines 14-16).

Moreover, they suggested a need for raised awareness regarding not only the benefits of BSE but how to examine your breasts.

“I think more should be done with campaigns and teaching to make people more aware of breast self examination and to help more people to do it on a regular basis” (P20 Questionnaire, Lines 24-25).

“I think it should be taught to children at a young age and I think that most of the problem is that most women just don’t know how to give themselves a proper examination which is why in many sad cases by the time they find out they have breast cancer is at a very late stage and makes the whole recovery process far more traumatic” (P81 Questionnaire, Lines 38-41).

“It is vital to educate and raise awareness of self-examination” (P34 Questionnaire, Lines 26-27).

Likewise, the women suggested that BSE information and training should be made more readily available within a public setting and should perhaps be made available within doctors’ surgeries, schools and youth groups.

“I think BSE should be taught in schools and people should be encouraged to get into the habit so they become comfortable talking about such issues and they develop a habit that they’ll continue all their life” (P50 Blog, Lines 76-78).

“I think women (and men although study is for women) should get information on how to check using the steps and shown if necessary when they go for check up or smear at the doctors and also younger individuals should be able to get guidance about how to check e.g. in youth clubs, schools and sport groups etc so that all generations are aware” (P96 Blog, Lines 69-72).

Subtheme 1: Usefulness of 5-step Technique

As part of the study, the women were provided with detailed instructions based on the 5-step technique of how to examine their breasts. All the women liked having these and they seemed to impact on the women’s BSE in a positive manner.

“I appreciated having clear guidance regarding how examinations should be done. It felt good to be in control of my health” (P29 Questionnaire, Lines 13-14).

“It is very important to know how to examine your breasts and it was nice being told this” (P70 Questionnaire, Line 13).

They appreciated having the instructions to follow and suggested following these made the process more enjoyable and productive.

“What was great was having some very detailed, specific instructions to work through” (P42 Blog, Line 8).

“I liked having the instructions to refer to and would give me the best chance of detecting any changes” (P93 Questionnaire, Lines 14-15).

“The instructions made it more enjoyable, as they made me feel like I actually know what I should be doing” (P67 Questionnaire, Lines 14-15).

Furthermore they expressed a need for these instructions to start examining their breasts or to improve their current BSE.

“I think the instructions are important so that you can see where you have gone wrong previously. Or simply to get a better idea of what to do exactly to ensure you are doing it correctly” (P62 Questionnaire, Lines 18-20).

“I enjoyed having the instructions, I think they are needed so you can compare what you have done previously and see how you can improve to make the exam better and make sure you examine everything” (P20 Questionnaire, Lines 16-18).

“I think there should be more information available to women telling them how to examine their breasts so they know they are doing it right. It is something that is so important” (P44 Questionnaire, Lines 21-23).

The positive nature of the BSE instructions was expressed by all of the women. For one of the women participating the 5-step instructions were so important and informative she gave the instructions to her family and friends.

“I am still enjoying taking part in this study and have passed on techniques I received to family and friends so with me knowing the technique it may help others detect a horrible illness early so it can be treat. Without being invited to do this

study myself, my family and friends would not know how to check correctly and may have missed an important step or sign” (P96 Blog, Lines 62-66).

Subtheme 2: Increased Self-efficacy

After been given the 5-step BSE technique instructions the women’s insecurities reduced and their self-efficacy increased.

“This is the first time I’ve felt confident in self examination” (P82 Blog, Line 46).

“The breast self-examination technique I tried tonight seemed very thorough. With it I feel much more confident that I know what to look and feel for” (P42 Blog, Lines 19-20).

“I feel much more confident in my ability to recognise changes in my breasts” (P82 Questionnaire, Line 4).

Moreover, this sense of self-efficacy continued to increase as the study progressed and they examined their breasts more.

“Now I know how to do it properly I am increasing in confidence of how to do it” (P77 Questionnaire, Line 9).

“I have got more used to the idea of examining myself instead of being self-conscious, my confidence has increased” (P62 Questionnaire, Lines 4-5).

“I feel less conscious and I guess it feels more natural to do it. I would say my confidence about what I’m doing has increased too” (P20 Questionnaire, Lines 4-6).

Furthermore, for a few of the women, following the 5-step BSE procedure created a sense of empowerment, as their sense of control over their own health increased.

“It certainly felt positive. In fact it was very empowering and I felt a sense of having started a new routine that I intend to keep” (P42 Blog, Lines 10-12).

“Quite empowered that I was checking myself” (P59 Questionnaire, Line 16).

“It’s good to make you feel you are being healthy and taking control of your health” (P100, Questionnaire, Line 18).

Subtheme 3: Straightforward Nature of the BSE Procedure

For most of the women the 5-step BSE procedure was easy to follow and understand, and provided the women with an informative step-by-step guide for examination.

“I found the procedure easy to follow and do” (P20 Questionnaire, Line 18).

“Found going through it step by step worked well” (P76 Blog, Lines 3-4).

“The instructions made it clear what I was supposed to do” (P44 Questionnaire, Line 13).

Moreover, for some the 5-step technique made the whole process of BSE a more positive and enjoyable experience.

“The instructions made it more enjoyable, as they made me feel like I actually know what I should be doing” (P67 Questionnaire, Lines 14-15).

“You feel better knowing you are following instructions and getting it right” (P34 Questionnaire, Lines 13-14).

“After completing a self-examination I feel very pleased with myself because it is not something you suddenly think of doing in normal day to day life” (P62 Blog, Lines 23-25).

Subtheme 4: Usefulness of pictures/video

The women expressed the advantageous nature of the pictures and videos in providing much needed reassurance regarding the accuracy of their BSE technique and clarification on aspects of the technique they were unsure about.

“I found the video easy to follow as you could see what you were supposed to be doing properly as when you just read instructions it doesn’t always sink in... having the video has been a personal help to me by reassuring and showing the correct technique which I feel has given me confidence to do by myself without the use of the video...even though I have remembered what to do there is always the video as back up if needed or to refresh your memory” (P47 Blog, Lines 5-6 and 78-82).

“Having photos and diagrams on the techniques makes it easier to understand what to do” (P50 Blog, Line 4).

Subtheme 5: Introduction of new ideas/techniques

Following the 5-step BSE technique, introduced the women to new ideas and ways to examine their breasts and provided the women with an increased understanding and knowledge regarding BSE.

“Before the course of this study I didn’t feel like I really had a good understanding or knowledge but now I feel this has changed and I do” (P67 Questionnaire, Lines 4-5).

“I am more aware of what to look for when examining” (P39 Questionnaire, Line 4).

“Due to the examination instructions, I now do different things to examine my breasts” (P9 Questionnaire, Line 4).

The technique encouraged a more thorough examination and provided guidance to ensure the entire area of the breast was examined.

“To be honest, following the instructions makes me feel like I’m doing a more thorough job and taking it more seriously” (P42 Blog, Lines 39-40).

“It has helped me to ensure I examined everywhere and not miss any part of my breast” (P20 Questionnaire, Lines 21-22).

Similarly, following the 5-step technique encouraged the women to check a larger area than they did before and highlighted areas they were previously unaware should be included in a breast exam.

“I now check a larger area” (P100 Questionnaire, Line 4).

“I examined the whole of my breast instead of just a little bit here and there” (P56 Questionnaire, Line 16).

“I hadn’t realised about checking the armpit area so this was new for me. The instructions were very clear though so I felt confident trying it out” (P77 Blog, Lines 33-35).

“I have examined my breasts before but just on an ad hoc basis when and if I felt like it and not covering the area as detailed” (P66 Blog, Lines 9-11).

Furthermore, the 5-step technique highlighted new positions which may enable a more efficient breast exam and aid the BSE process. Before the study some of the women were unaware of the advantages to examining your breasts both standing and lying down and of the benefits of raising your arm above your head during the examination. But over the course of the study these became part of their regular BSE routine.

“I’d never examined while laying down before” (P82 Blog, Lines 7-8).

“I realised I didn’t know that it was important to do a double test – upright and prone. I’ve noticed I’m now more deliberate about the examination when I’m lying down as it is considered a separate, rather than a part of my showering routine... I do examine my breasts more than I did – most days in the shower and looking as I dress, which I did before but now I do the lying down arm over head exam more than I used to” (P11 Blog, Lines 9-12 and 62-64).

Similarly, before the study, most of the women were unaware of the importance of including looking in their BSE routine.

“I have examined them on a regular basis for some time. However I would not normally look in the mirror or do the standing examination, but I felt OK doing this” (P9 Blog, Lines 4-6).

However, over the course of the study looking was introduced into their regular BSE routine and became a normal part of examining their breasts.

“I now examine my breasts more thoroughly. I do things I didn’t do before like looking in the mirror. Looking is now part of my routine as well as touching” (P93 Questionnaire, Lines 4-5).

“Spent a bit more time having a good look at breasts in the mirror- this is something that I didn’t do enough of before” (P79 Blog, Lines 17-18).

“I also pay more attention to them in the mirror or in the shower which certainly feels more empowering” (P42 Blog, Lines 46-47).

Subtheme 6: Easier with Practice/ Improvement Over Time

Over the course of the study the women reported finding the BSE process much easier to remember and follow.

"I found it much easier to do this time than the first time because it wasn't such a new thing to me" (P77 Blog, Lines 63-64).

"Because I've done it a few times it gets easier and quicker to do" (P50 Blog, Lines 45-46).

"Doing the examination does get easier and the different techniques are easily remembered" (P66 Blog, Lines 53-54).

I really only glanced at the written instructions to remind myself and make sure that there wasn't anything I had forgotten about, but I had remembered it all" (P17 Blog, Lines 102-104).

Likewise, their awareness of their breasts and the importance of BSE increased over the course of the study.

"Become more aware of what's normal for me and in general" (P50 Questionnaire, Line 4).

"It makes sense to me now as to why I need to do it" (P23 Questionnaire, Lines 26-27).

"I am more aware of the importance of self examination, as well as looking after myself to increase my chances of staying healthy" (P105 Questionnaire, Lines 4-5).

“It’s changed in that I am aware of how regular examination can make you more aware of even small changes” (P76 Questionnaire, Lines 25-26).

As a result of the study, most women formed an improved relationship with their breasts and for some this in turn reduced their concern about breast cancer.

“I am also now more familiar with the texture of my breasts which makes the whole thing less of an unknown” (P42 Blog, Lines 43-44).

“Since using these guidelines I automatically check daily and I understand now that about two weeks prior my breasts become swollen and hurt which I have been told is normal but I know to seek help if I find any suspicious lumps” (P30 Blog, Lines 8-11).

“I do find I think about my breasts more how they feel, if there’s tenderness, tissue changes, puckering etc. It feels natural to think about it and although it sounds morbid it’s not” (P82 Blog, Lines 34-36).

“I felt less at risk from developing cancer” (P68 Questionnaire, Line 13).

10.7 The Effectiveness of the use of Online Data Collection and Blogs as a Recording and Communication Tool

As a secondary aim, this study explored the utility of conducting research within an online setting and the use of blogs as a recording and communication tool. Qualitative data generated from participant’s completed blogs and end-of-study open-questionnaire responses and analyses comparing the demographic characteristics and responses to the Brief Technology Acceptance Questionnaire (BTAQ) of drop-out and completed participants and those who completed a blog and those who did not, were used to provide further detail regarding the online nature of the study and the use of blogs.

As previously highlighted, all data was collected on line. Participants were directed to complete online questionnaires and a blog via the study website, and the BSE instructions and links to the autobiographical videos were provided by this site. As previously discussed within Chapter Six (pilot work) highlighted no major problems with the site. Likewise, none of the main study participants reported problems connected to the access of the site or study materials. As further discussed in chapter six, 70 women started the study and 60 completed the study. ANOVA and chi square analyses were conducted, depending on the nature of the data (interval and nominal level, respectively) to discover if drop-out participants and those that completed the study differed on demographic characteristics, scores on the brief technology acceptance questionnaire (BTAQ) subscales and in terms of BSE frequency and proficiency at the start of the study. The analyses revealed no differences between the women in terms of BSE frequency and proficiency and their scores on the following BTAQ subscales; facilitating conditions for both websites and blogs, performance expectancy of both websites and blogs, intrinsic motivation towards websites and perceived ease of use of websites. Intrinsic motivation towards blogs and the perceived ease of use of blogs could not be compared across the women, as none of the drop-out participants had completed a blog previously, preventing them from completing the questions relating to these subscales. In relation to demographic characteristics, the analyses further revealed no differences between the women in terms of most of the demographic characteristics noted within the pre-intervention questionnaire. Whilst these did reveal a significant difference in terms of length of contraceptive pill use, $F(1, 65) = 8.33, p < 0.01$, with drop-out participants reporting longer pill usage than completed participants, it was noted that contraceptive pill use, although a risk factor of breast cancer per se, was not found to be related to the participants health beliefs and behaviour connected to breast cancer and BSE. Thus, it was concluded that the women's decision to drop-out of the study was unlikely influenced

by their demographic characteristics, their views on technology or their BSE frequency and proficiency. It appeared, the drop-out participants were similar to the women completing the study in terms of demographic characteristics and BTAQ responses, and that their decision to not participate in the study was likely influenced by one or more other factors.

Moreover, due to the lack of problems highlighted through pilot work it seems likely that, participants would have been able to complete the study if they had wanted to. The online nature of the study was effective in providing participants with the necessary information to take part in the study, but perhaps something else was preventing them from completing the study. Only two participants contacted the researcher asking to be withdrawn for personal reasons, the others simply did not continue with the study. This may suggest rather than not wanting to take part, the online nature of the study may have failed to prompt these women to remember to take part. Indeed, the women in the study discussed their problem in remembering to examine their breasts and their need for prompts; perhaps the same problem exists in relation to study participation. Perhaps the lack of face-to-face contact between the researcher and participants failed to remind participants about the study, and in turn, encourage full participation within the study. Likewise, the longitudinal nature of the study is likely to have facilitated subject attrition. Perhaps, there is a need for online longitudinal research to consider ways to encourage long-term compliance amongst the participants. Despite this, an 86% completion rate was demonstrated: the study collected completed responses for 60 out of the 70 participants that started the study.

Similar considerations may also apply when considering the use of online blogs as a recording tool. All the participants (N = 60) were asked to complete a blog for the duration of the study but only 26 (43%) did so. Pilot work highlighted no problems with the access

of the blog, and the reading and writing within it. Likewise, the blog instructions and questions to help write the blog were judged by all the women to be sufficient and, for most, writing within and navigating the blog was an easy, pleasant and enjoyable process. Following this, it was assumed that participants in the main study would experience the blog in a similarly positive way and perhaps other reasons may have influenced whether participants' completed their blog.

The demographic characteristics and responses to the BTAQ of those who completed blogs and those who did not complete a blog were compared and analysed. Analysis of variance (ANOVA) and chi square analyses were conducted depending on the nature of the data, nominal or interval. There was no difference in demographics between the women in terms of educational level, age and many of the demographics noted within the pre-intervention questionnaire (ethnicity, marital status, number of children, employment status, length of unemployment (if applicable), stage of menstruation, age started menopause (if applicable), family and friend breast-cancer history, bra size and density of breast tissue). Similarly no difference was found between the women in terms of technology acceptance. A significant difference, however, was found in terms of religion and contraceptive-pill use between those women who had completed the blog and those that had not. The percentage of participants that completed the blog did differ by religion, $\chi^2(2, n = 26) = 6.26, p < 0.05$ and contraceptive pill use $\chi^2(2, n = 26) = 6.20, p < 0.05$. As percentages, fewer women reporting a religious orientation and taking the contraceptive pill at present completed a blog. Whilst a significant difference was found in terms of religion and contraceptive pill use it is unlikely that this influenced their completion of the blog. It is more likely that women decided to not engage in the completion of the blogs for more personal reasons, for example a lack of time or forgetfulness. Indeed, within some participants' responses to the end-of-study questionnaire these issues were apparent.

Some of the women discussed their forgetfulness, lack of time and lack of privacy, and how this impacted on their participation in the study, particularly regarding completion of the blogs.

“Unfortunately due to work and/or university commitments I have been unable to take part in the blogs” (P65 Questionnaire, Lines 4-5).

“I think 3 months was rather a long time. I was very interested at the start, but then found myself forgetting to do the tasks – except the examinations themselves which I was doing before anyway” (P11 Questionnaire, Lines 26-28).

“I have 2 teenager daughters and a husband and I work full time, have been surprised to realise how little privacy I get-whenver I shut my bedroom door I always seem to be interrupted” (P58 Questionnaire, Lines 11-13).

Furthermore, it was suggested that completing a paper form of the blog of which they could copy into their blog at a later date would have been more beneficial.

“If there was a document I could have printed for the instructions and the blog entries I could have done this in my own time and entered it onto the blog at a convenient time” (P88 Questionnaire, Lines 29-30).

It appears for some of the women remembering and finding the time to complete the online blog was problematic. Moreover, it is apparent from the varying detail and quantity of the blog entries amongst those that did complete, that some women appeared to find keeping a blog much easier than others. Indeed one woman expressed her problem thinking what to write within her blog and another expressed her lack of interest because she did not have breast cancer.

“However I did start to find it difficult to think of what to say each time and suspect I may have rambled about unimportant issues. But I do commend the study itself and I’m glad I could be part of it, albeit not as fully as I would have liked” (P82 Questionnaire, Lines 32-35).

“It wasn’t in my interest to do a blog and I didn’t have the time, however if I was suffering from breast cancer I would definitely benefit from talking about it through a blog or forum with other sufferers and know I would make time for this” (P71 Questionnaire, Lines 24-26).

Whilst a wealth of information can be gained in the anonymous setting of an online blog, it appears the method does not suit everyone and this limitation needs to be considered when conducting online research. The online nature of the study was effective in providing all the information and materials needed for the women to complete the study and in encouraging regular and proficient BSE. Similarly, data collection through the use of online questionnaires was effective. In those women that completed the blogs, the blogs provided an insightful and informative view on the women’s beliefs and behaviour surrounding breast cancer, BSE and the study itself. It appears that the use of online data collection and blogs as a recording and communication tool can be an effective research method, but this effectiveness may be dependent on the topic area of interest and the participants involved.

10.8 Conclusion

To conclude, the qualitative responses highlighted that for most of the women participating in the study, breast cancer was seen as something any woman of any age can experience. They suggested that women should take control of their health and examine their breasts on a regular basis to control for the disease. Whilst many of the

women did not discuss their own perceived susceptibility to breast cancer, a few did. For these women, age and family history seemed to be influential.

Past experience of BSE, encounters with medical professionals before participation in the study and the experience of others outside the study influenced both thoughts and behaviour connected to BSE. This in turn encouraged some of the women to examine their breasts, but for others this past experience resulted in greater anxiety which, in turn, discouraged some from regular BSE. Nevertheless, BSE was viewed positively by all the women participating in the study and all had the intention to engage in it, but prior to the study most were unsure how to examine their breasts comprehensively and they expressed concern over their own ability to discover signs of breast cancer. They expressed frustration at not being shown or given instructions by medical professionals and suggested that, if provided with guidance regarding how to examine their breasts, they would examine more regularly.

Moreover, for many of the women it was a challenge to remember to engage in BSE. It appeared BSE is not something most women think about regularly; instead, there is a need for it to be incorporated into behaviours they are already actively engaging in on a regular basis. Over the course of the study, the women reported finding the BSE process easier to remember and follow, and their awareness of their breasts and BSE increased. They highlighted a need for the detailed guidance provided within the study BSE support and suggested that the support made the process of BSE a more positive and enjoyable experience. Furthermore, as a result of following the guidelines within the BSE support, the women's insecurities reduced and their confidence increased. This confidence continued to increase as the study progressed and they examined their breasts more.

As a result of the study, most women formed an improved relationship with their breasts, and for some this in turn reduced their concern about breast cancer. Likewise, the women

reported being more able to examine their breasts on a regular basis and they suggested that the BSE support encouraged a more thorough and proficient breast exam.

Finally, as a secondary aim, this study explored the utility of conducting research within an online setting and the use of blogs as a recording and communication tool. It is apparent from the current study, that the use of online data collection and blogs can be an effective research method but this effectiveness may be dependent on the topic area of interest and the participants involved.

10.9 Chapter Summary

This chapter, the fourth of four chapters relating to the results of this thesis, presented the qualitative outcomes of the study. Qualitative data derived from participant's completed blogs and end-of-study open-questionnaire responses was analysed and five themes were presented: Previous Experience, BSE Irregularity, Perceived Susceptibility, Coping Style and the Usability of the 5-step Model of BSE. The utility of conducting research within an online setting and the use of blogs as a recording and communication tool was considered and an evaluation of their use provided.

CHAPTER ELEVEN

Discussion and Conclusions

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11.0 Chapter Overview

This chapter summarises and discusses the research findings in relation to relevant literature. It also highlights the author's contribution to knowledge and their recommendations for future work.

11.1 Summary of Main Findings

This study was intended to explore the effect of autobiographical accounts of breast-cancer patients and a multimedia-enhanced BSE support programme on women's knowledge, beliefs and behaviours towards breast self-examination (BSE). More specifically the study aimed

- (1) to enhance the understanding of women's knowledge, beliefs and behaviour regarding breast cancer and BSE both before and after an intervention, within the framework of an extended HBM (E-HBM),
- (2) to explore the effects of viewing autobiographical accounts from breast-cancer patients on women's knowledge, beliefs and behaviour towards breast cancer and BSE,
- (3) to examine the usability and effectiveness of a novel multimedia BSE support programme, based on the 5-step BSE technique, and comparing video-enhanced and static guided instructions. Both methods aimed to develop women's skills of using BSE techniques, as well as their knowledge through the use of performance enhancement tools, such as images within the static support or video and interactivity within the video-enhanced support, and
- (4) to evaluate the effectiveness of online data collection and the use of blogs as a recording and communication tool between participating women and the researcher.

Based on these study aims, four research questions arose and were considered following data analysis.

11.2 Research Question 1

Following past research it was hypothesised that worry/anxiety, coping style, illness representations, health locus of control (HLC) and social support would influence the HBM components and in some cases each other, and these in turn would influence a women's decision to engage in BSE, and the proficiency with which they implemented their examination. This is depicted in Figure 3.

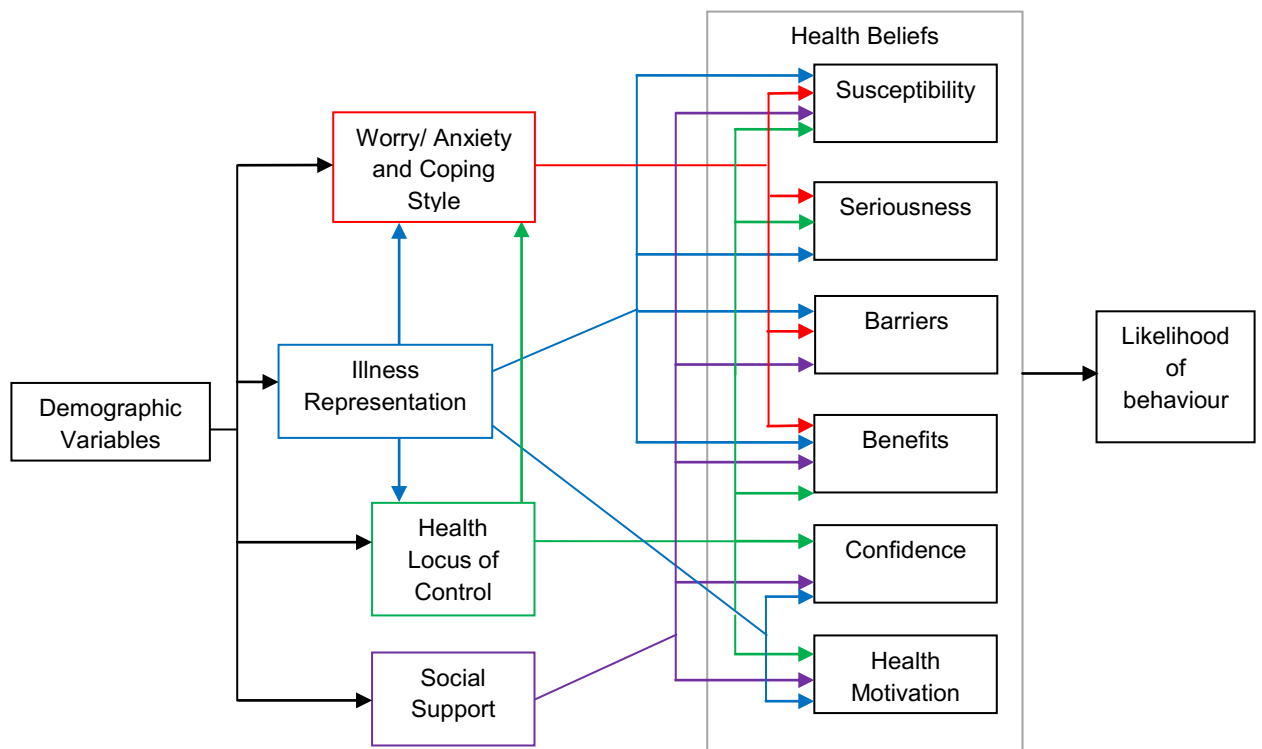


Figure 3. Proposed Extended Health Belief Model

However, the evidence presented in this thesis does not support all hypothesised relationships. Instead, only the HBM component confidence predicted both the frequency and proficiency of BSE and none of the E-HBM components influenced this. It appears, at

least within this study that the other components of the HBM and worry/anxiety, coping style, HLC, social support and illness representation components may not be important in understanding BSE proficiency and frequency directly but that a more complex relationship may exist. This is depicted in Figures 5 and 6.

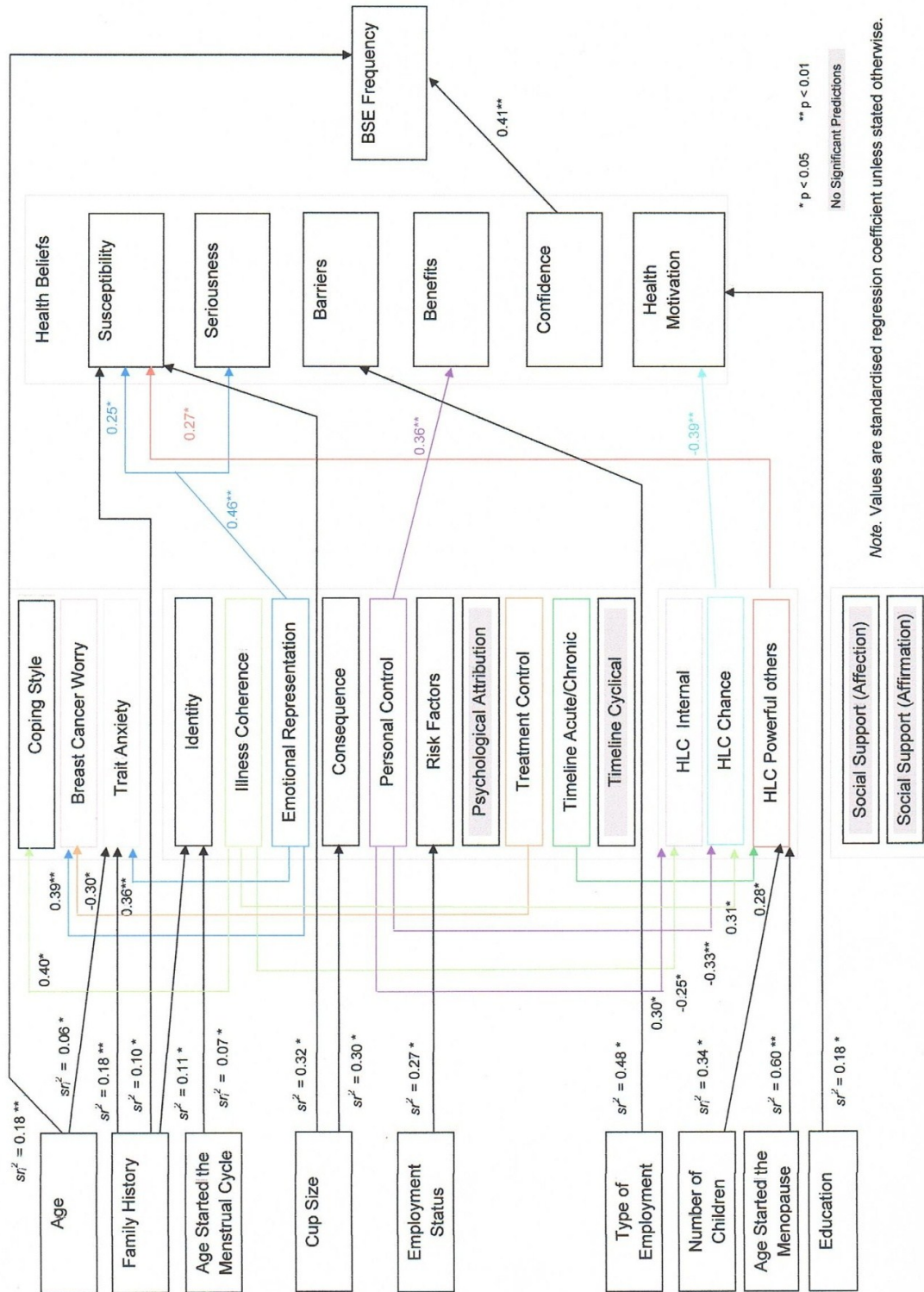


Figure 5. E-HBM Based on Study's Findings for BSE Frequency Pre-Intervention (Including Detailed Demographic Characteristics).

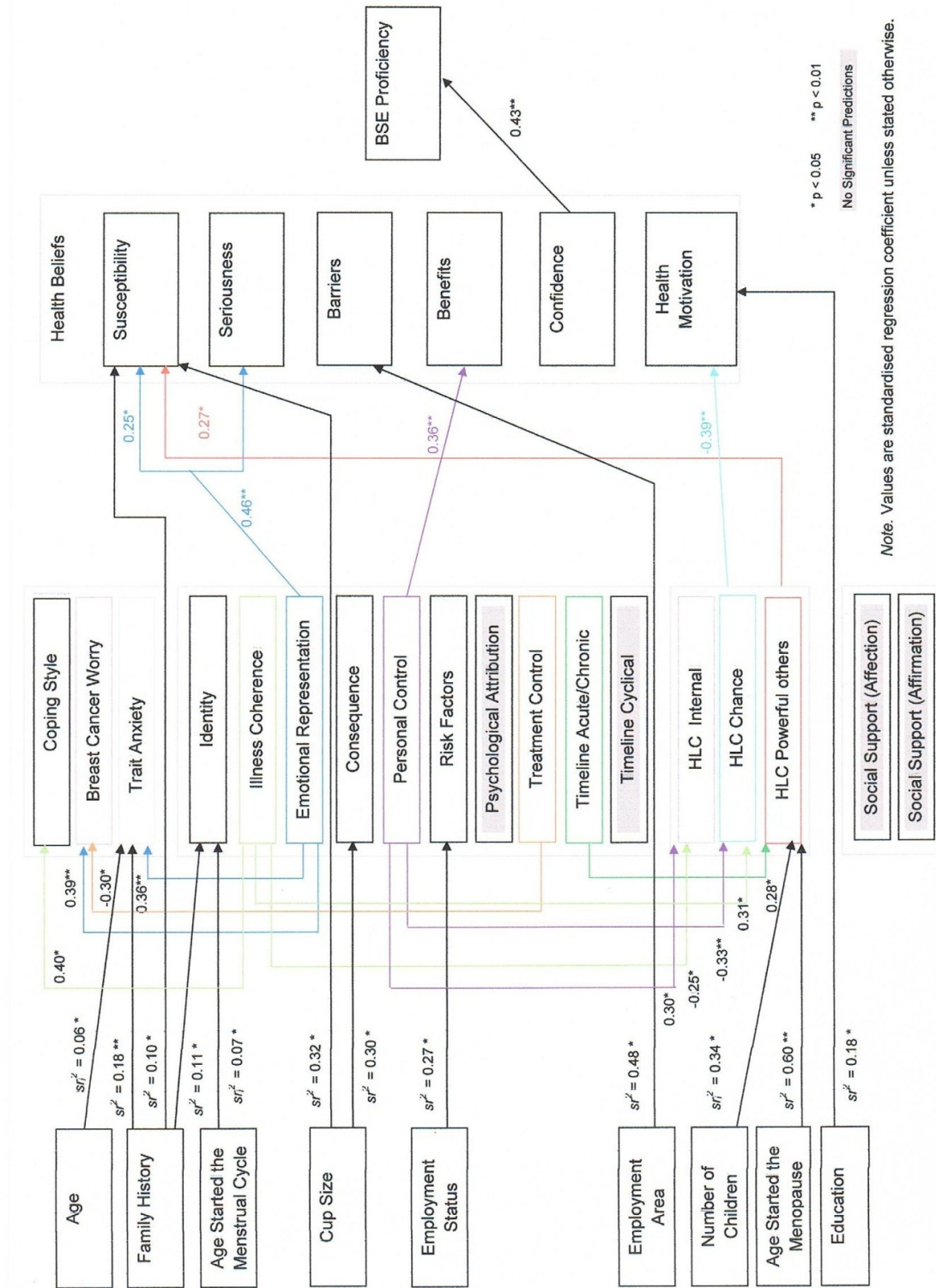


Figure 6. E-HBM Based on Study's Findings for BSE Proficiency Pre-Intervention (Including Detailed Demographic Characteristics)

11.2.1 Support for the Health Belief Model (HBM)

Whilst in line with past research (e.g. Alagna & Reddy, 1984; Ashton, Karnilowicz & Fooks, 2001; Chalmers & Luker, 1996; Champion, 1985, 1989; Erbllich, Bovbjerg & Valdimarsdottir, 2000; Friedman, Nelson, Webb, Hoffman & Baer, 1994; Hallal, 1982; Luszczynska & Schwarzer, 2003; Norman & Brain, 2005; Nystrom, 2000; Stenfaneek & Wilcox, 1991, Smiley, McMillan, Johnson, Ojeda, 2000), support was found for the predictive utility of confidence in relation to BSE frequency and proficiency, no such support was found for the remainder of the HBM components within the current study. In contrast to HBM theory (Champion, 1993), perceived susceptibility, seriousness, perceived benefits and barriers and health motivation did not significantly predict BSE.

The HBM has been used in the past to successfully predict many health behaviours, including BSE in various populations (Calnan & Rutter, 1986; Champion, 1984; Foxall, Barron & Houfek, 1998; Karayurt, 2003; Lee, 2003; Lu, 2001; Norman & Brain, 2005; Petro-nustus & Mikhail, 2002; Ronis & Harel, 1989; Umeh & Rogan-Gibson, 2001) and research findings have indicated that all six dimensions of the model are significantly associated with BSE (Ashton et al., 2001; Champion, 1993; Champion & Menon, 1997; Gray, 1990). One reason for the failure of the current study to find similar significant findings may be the small sample size employed in the current study. The effect sizes reported for the HBM components with the exception of confidence were very small, ranging from 0.0001 to 0.04 and as such the sample size may not have been sufficient to detect a significant effect. Indeed findings from power analysis (as presented in Appendix 21) suggest a larger sample size may have been needed for all the HBM components but confidence, and this may be why confidence was found to be the only significant predictor of both frequency and proficiency. The analysis further suggests given the effect sizes

reported a sample of 39,239 would be needed to find significant results for all the HBM components in relation to proficiency, and a sample of 15,692 in relation to frequency.

However, the effect sizes for health motivation, seriousness and barriers in relation to BSE frequency, and for health motivation, benefits in relation to BSE proficiency were so small that it would not be theoretically or practically useful to increase statistical power in order to detect these effects. In relation to the other HBM components however, larger effects were reported, and perhaps if a larger sample had been used within the current study significant associations may have been found for these components. Indeed, whilst no support was found for the utility of the HBM as a whole, in predicting BSE within the HBM questionnaire responses, qualitative responses drawn from the post-intervention questionnaire and the women's blogs offered some limited support.

According to the HBM, when individuals are faced with a potential threat to their health they consider their susceptibility to and the seriousness of the health threat and their belief that the health condition can be controlled or avoided. For example, women who perceive themselves to be susceptible to breast cancer and believe it to be a serious disease that can be controlled or avoided are more likely to be motivated to take action against it. Indeed, within the qualitative responses, it was apparent that the women were aware of the serious nature of breast cancer and many reported high levels of fear surrounding the possibility of discovering a sign of breast cancer through the breast exam. Whilst many of the women neglected to discuss their own perceived susceptibility to breast cancer per se, a few did. For these women perceived susceptibility to breast cancer was influenced by age and family history. One of the women expressed her lack of concern regarding breast cancer and BSE due to her young age and others discussed how their thoughts and feelings regarding breast cancer and BSE were influenced by their family history of breast cancer. Those with a family history of breast cancer expressed greater concern about the

disease and subsequently viewed BSE as of great importance. Likewise, those without a family history expressed less concern about and vulnerability to breast cancer and less interest in BSE. This is unsurprising, considering age and family history are well known risk factors for breast cancer (Bryan, 2001; Epstein, 1997; McPherson, Steel & Dixon, 2000; Paley, 2001; Siegel, Gluhoski & Gorey, 1999; Staton, Kurian, Cobb, Mills & Ford, 2008 Williams, Clarke & Savage, 2002). Likewise, representations of breast cancer within the literature overwhelmingly link the disease to hereditary risk factors (Stoppard, 1996) and research suggests family history and age are the only two risk factors that women can identify with confidence (Johnson & Dickson-Swift, 2008). As a result, some women believe they are not vulnerable to breast cancer because they have no family history (Salazar & Carter, 1994) or are of a young age (Johnson & Dickson-Swift, 2008; Paul, 1999; Vahabi, 2005).

Following the HBM further, which action is pursued is seen to be a function of a cost-benefit analysis of the perceived benefits of, and perceived barriers to different actions. For example, women who believe that performing BSE has many benefits and there are few barriers to performing it are more likely to engage in regular BSE. It was apparent within the qualitative responses that the women were aware of the benefits of BSE in noticing any changes early, and giving the individual the best chance to fight the disease, but barriers surrounding the fear of discovering breast cancer, dislike looking and thinking about their breasts, and the uncertainty of how to examine their breasts prevented them from examining their breasts on a regular basis.

These reported barriers are what could be expected given the relationship between BSE practice and confidence established within the literature (Alagna & Reddy, 1984; Ashton et al., 2001; Chalmers & Luker, 1996; Champion, 1985, 1989; Erblich et al., 2000; Friedman et al., 1994; Hallal, 1982; Luszczynska & Schwarzer, 2003; Norman & Brain,

2005; Nystrom, 2000; Stefanek & Wilcox, 1991, Smiley et al., 2000) and considering the negative connotations of breast cancer (Read, 1995; Saywell, Beattie & Henderson, 2000). It is not surprising that the women expressed fear surrounding the discovery of breast cancer through BSE, given that breast cancer is said to be the disease that women fear most (Read, 1995) and its profile within the media is higher than that of all other common cancers (Saywell et al., 2000). Likewise, past studies offer support for fear of breast cancer as a barrier to BSE (Aro, de Koning, Absetz & Schreck, 2001; Austin, Ahmad, McNally, 2002; Bloom, Hayes, Saunders & Flatt, 1987; Burton, 1995; Ciatto, Cecchini, Isu, Maggi & Camelli, 1992; Consedine, Magai, Krivoshekova, Ryzewicz & Neugut, 2004a; Friedman, Webb, Weinberg, Lane & Cooper, 1995).

Moreover, the women's dislike and discomfort surrounding looking at and thinking about their breasts is what could be expected, given BSE is more than simply a technique that needs to be done; it carries meaningful implications and unanswered questions (Lende & Lachiondo, 2009), especially considering that a woman's life may change based on what is found (Gibbs & Franks, 2002; Hallowell, 2006). Research suggests that women do not always like to talk about their breasts or look at pictures of them and when they think of breast health they think of breast cancer (Hughes, 1998). Likewise, women have often been taught to find shame in and feel alienation from their bodies, and this in turn may make the engagement of BSE unpleasant or uncomfortable (Boston & Louw, 1987; Fish & Wilkinson, 2003; Love, 1995). This was especially apparent in a qualitative study conducted over several months with a small sample (13) of women in Canada (Kearney, 2006). Through a series of interactive group discussions, the women explored the personal and social factors related to their practice of BSE and, in doing so, the study provided further insight in the meaning of BSE to women. Whilst the applicability of the study was limited due to the sample, similar themes arose to those of the current study. In a similar manner to the women who took part in the present study, the women described

BSE as a complex issue that may be related to the way women value themselves and are valued in society.

Much pressure is placed on women within current society to attain the ideal body and the Barbie doll with her slender body, narrow hips and large breasts typically epitomises this ideal (Frederick, Peplau & Lever, 2008). However, the proportions represented by Barbie are so extreme that only one out of every 100,000 women possesses this body type (Norton, Olds, Olive & Dank, 1996). This poses a problem, considering most women will not be able to attain this ideal and as a result may feel dissatisfied with their body. Indeed, the women within Kearney's (2006) study identified the idealised female body as that which is unattainable by most women: thin to the point of androgyny with well defined breasts. They felt that the breasts have been glorified as the fundamental representation of female sexuality and the perfect breast is freely displayed and welcomed in society and the media, whereas the imperfect is not. Furthermore, Kearney's sample of women discussed their tendency to take care of others before themselves and began to question why this was so. In doing this, they suggested an essential issue that may influence BSE is that women may not feel worthy of self-care if they do not conform to the narrow standards of the ideal female body.

Research further suggests many women are dissatisfied with their breasts and feel pressure to possess larger breasts (Forbes & Frederick, 2008; Forbes, Jobe & Revak, 2006; Harrison, 2003; Tantleff-Dunn & Thompson, 2000). Whilst these studies tend to focus on college women, limiting the generalisability of the findings to women in general, a more recent study offers support for breast dissatisfaction within women that holds true regardless of their age or body size. Fredrick and colleagues (2008) assessed the views regarding breast size and shape of a large (26,703) and diverse sample of women via an online survey and revealed that the majority of the women (70%) expressed discontent with their breasts. Moreover, recent estimates of the number of women seeking to change their breasts with surgical interventions further suggest this apparent breast dissatisfaction amongst women. According

to the British Association of Aesthetic Plastic Surgeon's (BAAPS) annual audit during 2010, 9,418 women underwent breast augmentation surgery and 4,218 women underwent breast reduction surgery, a rise of 10.3% for breast augmentation surgery and 2.3% for breast reduction surgery when compared with figures for 2009. It appears breast dissatisfaction is a current problem among UK women, and it may be an important issue when considering the practice of BSE. When faced with a procedure such as BSE that involves manually and visually scrutinising their body and familiarising themselves with any potential abnormalities, women who are less satisfied with their physical appearance and, indeed, their breasts may avoid any discomfort they feel regarding their body and avoid BSE (Chait, Thompson, Jacobsen, 2009). Indeed, for some of the women within the current study, their dislike and discomfort of their breasts made the engagement of BSE problematic. It appears that in order for women to examine their breasts comprehensively and regularly, women need to form an improved relationship with their body and breasts and become more comfortable looking at and touching themselves.

Finally, the HBM model suggests a woman's degree of interest in or concern about her own health may also affect her willingness to perform BSE. As could be expected given the nature of the study, all the women were interested in managing their own health and had the intention to engage in BSE, but other factors appeared to overcome this desire and prevent them from examining their breasts regularly.

Whilst the lack of statistical support for the predictive nature of the HBM, may be explained by the limited sample size employed within the current study, consideration of the women's qualitative responses provides an alternative explanation. At least for the women within this current study other factors were more important.

For most of the women participating in the study breast cancer was seen as something any woman of any age can experience and that women should take control of their health

and examine their breasts on a regular basis to control for their health regardless of age and family history. Within the current study there was a strong sense of BSE being of great importance for all women, with the majority of the women believing any woman of any age should examine their breasts regardless of how susceptible to breast cancer they believed themselves to be. This at least in part may explain why no relationship was found between the HBM component perceived susceptibility and BSE.

Furthermore, two central considerations that arose within the qualitative responses were, first the 'non-salient nature' of BSE and the need for prompts and, second, the uncertainty surrounding BSE. All the women expressed a desire to examine their breasts, but the 'non-salient nature' of BSE (as typified within qualitative Theme 2, Subtheme 1) failed to encourage them to examine their breasts and for many it was a challenge to remember to engage in BSE regularly. It appeared that BSE was not something most of the women thought about regularly, and instead they needed to be prompted to examine their breasts. Moreover, the women suggested a need for BSE to be incorporated into activities they were already actively engaging in. Whilst this is in line with past studies in which a similar need for prompts has been demonstrated and which have indicated that having a reminder to practise BSE was significantly associated with BSE practice (Agars & McMurray, 1993; Craun & Deffenbacher, 1987; Grady, 1984; Khokhar, 2009; Mayer & Fredenksen, 1986; Rutledge & Davis, 1988), no studies have yet to highlight explicitly the 'non-salient nature' of BSE and the impact on BSE behaviour accordingly.

Furthermore, prior to being given the study BSE support the women expressed their uncertainty surrounding how to examine their breasts comprehensively and expressed concern over the accuracy of their own ability to discover signs of breast cancer. This is what could be expected given that a lack of confidence in the accuracy of their examination technique and a lack of understanding what one was looking for have been

reported to prevent BSE in the past (Agars & McMurray, 1993; Williams, Mahoney & Williams, 1998). Likewise, this uncertainty is unsurprising given that BSE requires women to take responsibility for their own breast health and the lack of detailed guidance on how to examine currently offered by the UK health system.

Breast awareness rather than BSE is currently promoted within the UK. Following this rather than ritually checking their breasts at a specific time according to a set technique, women are encouraged to take convenient opportunities such as bathing or dressing to become familiar with their breasts (NHS, 2011). No detailed guidance is offered for this and whilst the currently adopted 'be breast-aware' campaign holds strength in promoting awareness, it may fail to reduce the uncertainty some women experience surrounding the examination. Many women express concern over the accuracy of their examination technique and a lack of understanding what to look for (Agars & McMurray, 1993; Williams et al., 1998) and exploratory work conducted within the current study highlighted a need for more detailed guidance on how to conduct a breast exam. In order to reduce this uncertainty and encourage breast exams women need more detailed BSE guidance. Indeed, as a result of having been given the BSE support the women within the current study reported that their uncertainty surrounding BSE decreased and they felt more able to examine their breasts comprehensively.

The lack of consideration of these factors with the HBM questionnaire may have limited the predictive utility of the model for the BSE of these women. Similarly, a lack of knowledge surrounding BSE and a lack of confidence in the women's ability to conduct a proficient exam was a second central consideration that arose within the qualitative responses. Moreover, this was a central factor of the HBM confidence items and may explain why confidence was the only HBM component to significantly predict BSE. All the women were aware of the advantageous nature of BSE and had the desire to examine

their breasts but most were unsure how to examine comprehensively and expressed concern over the accuracy of their own ability to discover signs of breast cancer. Furthermore, the women expressed frustration at not being shown or given instructions and suggested that, if provided with guidance regarding how to examine their breasts, they would examine more regularly. Indeed, after being provided with BSE support, the frequency and proficiency of the women's breast exams increased and they reported feeling more able to examine their breasts comprehensively. Moreover, confidence scores were significantly higher after the intervention, suggesting that providing women with guidance regarding how to examine their breasts may increase their confidence levels and in turn encourage more frequent and proficient BSE. Although the lack of a control group limits this interpretation, qualitative responses from the women within this study and past research offer additional support for this assumption (Fry & Prentice-Dunn, 2006; Secginli & Nahcivan, 2011). Whilst the educational interventions employed in both Fry and Prentice-Dunn (2006) and Secginli and Nahcivan (2011) were more complex than the one provided in the current study, they did similarly, provide detailed guidance regarding the BSE process. Within the first, the intervention consisted of a 12-page essay focusing on breast cancer and BSE, a group session discussing the themes of the essay, a 30-minute video focusing on breast-cancer survivors, a BSE instructional video and American Cancer Society shower cards and pamphlets demonstrating BSE and within the second, the intervention consisted of a teaching session and video on breast cancer and breast-screening methods (BSE, CBE and mammography), BSE video and card instructions, BSE instruction with a breast model, a booklet focusing on the importance of breast-screening, and a calendar that addressed key points about screening.

Following the intervention, the women within each of these studies reported higher confidence scores post-intervention when compared to women not receiving the educational intervention. Whilst the lack of qualitative data within these two studies

prevents one from gaining a complete understanding regarding how the participants responded to and how they viewed the BSE educational interventions, the current study provides an explanation within the women's qualitative responses. It appears that a woman's level of confidence in relation to BSE can be increased if provided with guidance on how to examine their breasts. Moreover, it is important to note that similarly positive results were reported in terms of increased confidence within the current study, yet the BSE intervention was less complex and time-consuming than those employed by past research. This is important considering women may be more likely to continue with BSE if they can incorporate it into their current routine, and given the benefits of a more straightforward intervention for health-promotion campaigns.

Considering these findings, perhaps the HBM components susceptibility, seriousness, benefits, barriers, and health motivation failed to predict BSE in these women because the HBM component confidence, the 'non-salient nature' of BSE and the uncertainty surrounding BSE were more important and influential factors for the BSE of the women in the current study.

11.2.2 Support for the Extended Health Belief Model (E-HBM)

Whilst no support was offered for the assumption that all the HBM components would predict BSE behaviour, some support was offered for the ability of the E-HBM components illness representations and HLC to predict the HBM components benefit, seriousness, susceptibility and health motivation. Following the results of this study, it appeared that a woman's feelings of susceptibility towards breast cancer and their belief in the seriousness of the disease may depend on their emotional representations of the disease. This seems likely, given that women may experience emotion-driven reactions to the health threat of breast cancer, and these in turn may determine how serious they view the disease to be and how susceptible they believe they are to the disease. The illness

representation emotional representations explored the emotional impact of breast cancer using items such as 'breast cancer makes me afraid' and produced results suggesting a predictive relationship between emotional representations and the HBM components susceptibility and seriousness, whereby a woman's level of emotional representation predicted their belief that they were susceptible to breast cancer and that breast cancer was a serious health threat. It appears those for whom breast cancer has a strong emotional impact subsequently believe they are more at risk of breast cancer and that the impact of the disease is serious.

This is what could be expected considering past studies have demonstrated the word cancer to be associated with death, terror, suffering, devastation, shock, incurability, unfairness and helplessness (Spiers, McElwee, Fleming & O'Gorman, 1999); all emotive words suggesting the serious nature of the disease and that breast cancer is said to be the disease women fear the most (Read, 1995). Whilst no detailed explanation is provided within the literature for this predictive relationship between emotional representations and susceptibility, it seems plausible that those women for whom breast cancer has a strong emotional impact may respond more emotionally and view themselves as more susceptible to breast cancer than perhaps those who have a less emotional reaction and instead weigh-up their susceptibility using factual information of breast cancer. In an analysis of the articles on breast cancer that appeared in popular magazines, Burke, Olsen, Pinsky, Reynolds and Press (2001) noted distorted, exaggerated or inaccurate messages about breast cancer, whereby breast cancer was portrayed as a disease primarily affecting young women and causing early death, abandonment of young children, and posing a major threat to marriage and dating. These messages all focused on areas that are likely to have a strong emotional impact on the women reading them and may lead women to believe they are more susceptible to breast cancer than they perhaps are. Moreover women who already have a negative and emotional representation

of breast cancer may relate to and be influenced by these messages more so than perhaps women with a less emotional and more factual representation of breast cancer.

The HBM component susceptibility was further found to be predicted by the HLC component 'powerful others', in that those individuals who believed 'powerful others' determined their health perceived themselves as being more susceptible to breast cancer. This is not surprising considering these individuals feel their health is not controlled by themselves and given past research in which internal HLC has been demonstrated to be significantly and positively related to the perceived likelihood of remaining free of breast cancer (Rowe, Montgomery, Duberstein & Bovberg, 2005). Whilst no effect of internal HLC was found in the current study, it does seem plausible that powerful others HLC, an external HLC orientation may produce opposite results. Perhaps the lack of control over their health, individuals with a 'powerful others' HLC believe they have, increases their feelings of susceptibility.

HLC was further found to be related to the HBM component health motivation, with higher scores on chance HLC predicting lower health motivation. This is not surprising considering those with a chance HLC orientation believe their health is a matter of luck or chance and cannot be controlled by themselves. Following this view, it may be fair to presume these individuals may fail to see the benefit of being engaged in health matters and trying to manage their health. Moreover this is perhaps what could be expected given the results of past research in which internal HLC was found to be related to attention to health related information (Bundek, Marks & Richardson, 1993; Redeker, 1989; Toner & Manuck, 1979; Wallston, Wallston, Kaplan & Maides, 1976) and actions to improve health (Lau, 1988); and considering research suggests internally orientated individuals are more likely to be health-orientated than externally orientated individuals (Hussey & Gilhland,

1989). Whilst no effect of internal HLC was found in the current study, it does seem plausible that chance HLC, an external HLC orientation may produce opposite results.

Following the results of this study further, the HBM component benefit was found to be predicted by the illness representation component personal control. Personal control examined the extent to which a person believes they have control over breast cancer using items such as 'I have the power to influence breast cancer' and whilst it was perhaps unexpected that this component was not found to be related to perceived susceptibility, the predictive relationship with the HBM components benefits may be explained through the consideration that not only may scoring higher on personal control give an individual the belief they can control their health but it may further encourage them to learn more about the benefits of this control.

Before the study, it was hypothesised HLC generally would predict the HBM components susceptibility, health motivation and confidence and indeed support was offered for 'powerful others' HLC in predicting susceptibility and chance HLC in predicting health motivation. However in addition to this it was also hypothesised that individuals with an internal HLC would be significantly more likely to see the benefits of BSE and those with an external HLC significantly would be less likely to see the benefits. No support was offered for these predictions within the current study and whilst this finding was perhaps unexpected given past research, (Bundek et al., 1993) in which positive relationships between HLC and BSE have been interpreted in terms of the HBM component benefits; it may be explained through a consideration of the women's qualitative responses. It was apparent from their responses, that all the women within the current study were aware of the benefits to BSE, as a result of personal experience and breast health-promotion campaigns. Following this, it may be proposed that HLC only has an effect on benefits, when individuals have to actively seek information regarding the health threat and

strategies to manage the threat. Given the attention that advocacy groups, celebrities, health professionals and the media have devoted to promoting the benefits of breast-screening, women regardless, of their HLC may have become aware of the benefits of BSE without having had to seek this information and this may explain why no effect of HLC in relation to the benefits of BSE was demonstrated within the current study.

In contrast to what could be expected given past research no support was further offered for the utility of worry/anxiety, coping style and social support in predicting BSE. Before the study, it was proposed that worry/anxiety and coping style would predict the HBM components seriousness, susceptibility, barriers and benefits, and that social support would predict the HBM components health motivation, confidence, susceptibility, barriers and benefits. In relation to worry it was proposed that how susceptible to breast cancer a woman believes herself to be and how serious she views breast cancer to be may depend on her levels of worry and anxiety. Similarly, it was further proposed that this anxiety or worry and, in turn, how she chooses to cope with this may further affect how she views the barriers and benefits of BSE. Whilst no statistical support was offered for this proposition, qualitative responses generated from the post-intervention questionnaire and the women's blogs offered some support for breast-cancer worry and coping style.

It was apparent within the responses, the impact worry about breast cancer had on the women's subsequent BSE behaviour. Fear of breast cancer seemed to be a central factor disengaging some women from regular BSE with some women choosing to cope with this fear by avoiding BSE altogether. However others instead of avoiding BSE chose to cope with the fear by facing the problem head on and examining their breasts. These women did not understand avoidance and instead chose to deal with the fear by remaining positive and focusing on the reassurance benefits that BSE could bring.

Research conducted over the past 15 years has produced contradictory evidence concerning whether cancer worry facilitates or inhibits breast-cancer screening behaviours (BSE included), with evidence supporting both relationships. Some researchers have suggested that this worry may have benefits, promoting women to engage in self-protective behaviours such as BSE (Diefenbach, Miller & Daly, 1999; McCaul, Reid, Rathge & Martinson, 1996; McCaul, Schroeder & Reid 1996; McCaul, Branstetter, O'Donnell, Jacobson & Quinlan, 1998) whilst others have proposed that worry about breast cancer is problematic, both because of the distress it causes individuals and also because it causes screening avoidance (Kash, Holland, Halper & Miller, 1992; Lerman, Daly, Sands, Balshem, Lustbader & Heggan et al., 1993; Lerman, Kash & Stefanek, 1994). Results within the literature are frequently contradictory, perhaps because of the diverse measures in the field. Investigators have used different measures of worry, including scales formed from a few investigator-invented items (e.g. McCaul et al., 1996a and 1996b) and scales with better known psychometric properties (e.g. Kash et al., 1992; Lerman et al., 1993; Lerman et al., 1994). It is important to know how these scales relate to each other, how stable the scale measurements are over time, and how they relate to screening behaviour.

In a similar manner to the current study McCaul et al. (1998), used a measure of general anxiety (using the trait subscale of the STAI) and a measure of breast-cancer worry (borrowed from McCaul et al., 1996a) and in line with the current study no significant association was reported between trait anxiety and BSE. However, in relation to breast-cancer worry contrasting results were demonstrated with the researchers reporting a positive significant association between the breast-cancer worry items and BSE. Whilst this lack of significant relationship within the current study is surprising given the results of McCaul et al. (1998), it does need to be noted that the representativeness of McCaul et al.'s sample was limited in that they failed to note both the educational level and ethnicity

of their sample. This poses problems given the established relationship between ethnicity (Champion & Menon, 1997; Foxall et al., 1998; Friedman, Moore, Webb & Puryear, 1999; Wardle, Steptoe, Smith, Groll-Knapp, Smith & Brodziak, 1995), educational level (Epstein, Lin, Audrain, Stefanek, Rimer & Lerman, 1997; Erblich, Bovberg & Valdimarsdottir, 2000; Friedman et al., 1999; Han, Wells & Primas, 2003; Madan, Barden, Beech, Fay, Sintich & Beech, 2000) and screening behaviour. Moreover further problems are posed considering that half of McCaul et al. (1998)'s sample consisted of undergraduate psychology students and participants were rewarded for participating with either extra class credit or cash. This poses a problem with the individual's autonomy or freedom to choose whether or not they wish to participate, and the representativeness of the sample, again compromising the study's findings. Perhaps the generalisations of McCaul et al.'s results must be limited to the particular group of women within their study. Whilst the differing results may be explained by considering the sample of women employed in the studies it is important to note support was offered for a relationship between breast-cancer worry and BSE within the qualitative accounts of the current study. Moreover the qualitative accounts offered support for both an inhibitory and facilitating relationship of worry on BSE.

Whilst there is a growing recognition of the impact of measurement type within the literature there is less focus on the impact coping style may have on producing conflicting findings. It became apparent within the current study that women can move away from avoidance and examine their breasts if provided with appropriate knowledge and support to make BSE more routine. Past research has demonstrated that following education about breast cancer and BSE, women reduce the use of avoidance, hopelessness and fatalistic religiosity in response to breast cancer and have higher behavioural intentions towards BSE and more rational problem solving compared with control condition (Fry & Prentice-Dunn, 2006) and indeed the same appeared to be true for the women with the current study. Prior to the study fear of breast cancer was a central factor disengaging

some of the women from regular BSE but after being given the BSE support they reported feeling much more able to examine their breasts. Moreover as BSE became more routine for these women, the process became easier and their negative feelings towards BSE seemed to decrease.

Furthermore, the current study demonstrated that at least within these women, general trait anxiety was not important in relation to BSE but rather the specific breast-cancer-related worry. One of the most salient problems confronting researchers interested in the role of emotions in screening behaviour to date is that they cannot determine exactly what women are afraid of, or how these diverse fear components relate to one another or to screening behaviour, with much research leaving the object of women's fear unspecified (Consedine et al., 2004a). The current study provided some light on this area, suggesting that in relation to BSE breast-cancer specific worry is more important than general trait anxiety.

Past research has suggested women's fears surrounding breast cancer is likely to encompass many things, but evidently includes fear of a breast-cancer diagnosis (Aro, de Koning, Absetz & Schreck, 2001; Austin, Ahmad, McNally, 2002; Bloom, Hayes, Saunders & Flatt, 1987; Ciatto et al., 1992; Friedman et al., 1995), fear of the medical establishment (Bloom et al., 1987; Miller & Hailey, 1994; Vernon, Laville & Jackson, 1990), non-specific 'cancer worry' (Caplan, Helzlsouer, Shapiro, Wesley & Edwards, 1996; Consedine et al., 2004a; Edwards & Jones, 2000; Lagerlund, Hedin, Sparen, Thurfell & Lambe, 2000) and general anxiety (Edwards & Jones, 2000; Lauver & Chang, 1991) or phobia (Desai, Bruce & Kasl, 1999). This, however, was not found to be true within the current study; instead the women's worry centred around the fear of a breast-cancer diagnosis.

Without knowing the sources of women's fears, and their relation to screening behaviour, providers and health professionals will be inevitably ill informed and interventions are

likely to be unsuccessful. The literature on cancer-related fear, worry, or anxiety and screening behaviour is frequently contradictory, possibly because of the diverse measures in the field and the lack of consideration of coping style. The qualitative responses within this current study address the methodological questions raised by the diverse “worry” measures employed in this area and whilst much more research is needed within this area, this study offers support for a relationship between BSE and breast-cancer worry that is dependent on the coping style employed. Past research highlights the impact of coping style on the engagement of BSE (Barron, Houfek & Foxall, 1997; Kreitler, Chaitchik & Kreitler, 1990) and whilst no association between coping style and BSE practice was demonstrated with the coping style scale, the importance of coping style was highlighted within the women’s qualitative accounts. This dependency on coping style may explain why the breast-cancer worries scale employed within the current study failed to predict the HBM components or indeed BSE directly and may offer an explanation for the inhibitory and facilitating relationship of worry highlighted within the qualitative accounts.

Similarly, in relation to social support it was proposed that how susceptible to breast cancer a woman believes herself to be may depend on her levels of social support. Moreover, it was further proposed that women who have more social support would be more motivated to engage in BSE, be more aware of the benefits to BSE and experience less barriers, and have more confidence that they are capable of performing BSE.

According to past research social support provides women with more assistance to overcome barriers, it provides women with more opportunities to learn about the value of BSE, and, it influences personal risk perception through information that becomes available to the individuals and advice offered by influential others (Katapodi, Facione, Miaskowski, Dodd & Waters, 2002). Moreover research has suggested that women who are entangled in social networks have greater motivation to engage in positive health-care practices than do women with less social support and that social support may give women

the confidence that they are capable of performing BSE (Hubbard, Muhlenkamp & Brown, 1984). Whilst no statistical support was offered for this proposition, qualitative responses generated from the post-intervention questionnaire and the women's blogs offered some limited support for the effect of social support on the HBM components benefits, health motivation and confidence.

Within the qualitative responses it was apparent that having a family member or friend who had experienced breast cancer seemed to influence interest in BSE and this interest seemed to provide motivation to seek out more information about breast-cancer prevention and highlighted the importance of BSE. This is expected given the findings of a recent qualitative study investigating the motivations and reasons for women attending a BSE training programme (Yang, Huang, Hsieh, Chung, Huang, Bih, 2010). Whilst this study was conducted with a small sample of Taiwanese women limiting the applicability of the findings to UK women, the women reported similar beliefs to the women within the current study. In a similar manner to the women within the current study a negative family history made the women more concerned about their breasts. Furthermore, many of the women expressed that their being conscious of the risk of breast cancer was influenced by their family and friends having had breast cancer and whilst almost all of the participants wanted to learn BSE, those with a family history of breast cancer especially expressed this desire (Yang et al., 2010).

Moreover, for some of the women within the current study, this impact of family history in-turn encouraged BSE, but for others it was not always enough to encourage regular examinations. This finding is in line with past research in which equally inconclusive findings have been demonstrated with some studies reporting an increase in BSE amongst women with a family history of breast cancer (Cohen 2002; Rutledge, Baresevick, Knobf & Bookbinder, 2001) and others reporting poor adherence to BSE

among women with such histories (Kash et al., 1992; Stefanek & Wilcox, 1991). The subjective experience of breast cancer may help explain the variation within the women's responses and indeed the inconsistencies within the BSE and family history literature, and may explain why the experience encouraged some of the women to examine their breasts and for others did not. The experience of breast cancer is likely to be very subjective and different from person to person, and perhaps its relationship with BSE is dependent on the individuals in question, the strength of the experience and the relationship between the individuals within the experience. Indeed, one woman was in the centre of her mum's experience of breast cancer and as a result a strong bond was formed. For her BSE was essential because of the experience of her and her mother.

Likewise, rather than their increased level of perceived risk as a result of a family history of breast cancer, the cancer-specific distress associated with this perceived risk may be the factor influencing BSE practice. This may explain why having a family history increased interest, motivation and breast exams in some women but not others. Indeed, support for this proposition is offered in past research (Audrain, Rimer, Cella, Stefanek, Garber, Pennanen et al., 1999). Audrain et al., (1999) compared the impact of a single session stress management coping intervention versus a general health counselling control condition on BSE adherence amongst relatives of newly diagnosed cancer patients and revealed that women with heightened cancer-specific distress were more likely to improve their BSE adherence following the intervention, but in general the intervention was not more effective than the control in promoting BSE adherence. Following this, the authors suggested that women with high levels of cancer-specific distress may have benefited from the intervention because it facilitated adjustment to the affected relatives diagnosis and concerns about their own personal risk. Moreover, they further suggested that perceptions of risk does not appear to moderate the effects of a stress management coping intervention on improvement in BSE adherence, and cancer-specific distress,

rather than perceived risk of breast cancer is the factor responsible for changes in BSE practice; women may perceive their risk as elevated, yet it is the distress surrounding the perceived personal risk that compromises BSE (Audrain et al., 1999). Indeed (as previously discussed) studies have found distress to be associated with screening avoidance (Kash et al., 1992; Lerman et al., 1993; Lerman et al., 1994) and linked coping style with the practice of BSE (Barron et al., 1997; Kreitler et al., 1990).

It should further be noted that support within the qualitative accounts was limited, and did not appear to be relevant to the HBM components susceptibility and barriers. This, in addition to the lack of significant results found within the social support questionnaire suggest it appears that whilst one should not rule out any relationship between social support and BSE, the relationship is perhaps not as important as the literature may suggest. Other factors, at least for the women within this study appeared to be more influential in encouraging BSE and this may at least in part explain the lack of a relationship between social support and BSE within the current study.

Before the study, it was further hypothesised that illness representations would predict the level of worry or anxiety the women experienced, and their HLC; and that HLC would predict the women's worry/anxiety and coping style. Whilst no support was offered for the assumption that HLC would predict worry/anxiety and coping style some support was offered for the ability of the illness representation components timeline acute/chronic, personal control, illness coherence, emotional representation and treatment control to predict worry, anxiety and coping style, and the HLC orientations chance and internal.

The illness representation personal control examined the extent to which a person believes they have control over breast cancer using items such as 'I have the power to influence breast cancer'. Personal control and HLC are two similar components, and the predictive relationship of personal control on HLC found in the current study seems

plausible. Higher levels of personal control predicted higher levels of internal HLC, and lower levels of chance HLC. This seems likely given that internally orientated individuals tend to believe they are in control of their health and chance orientated individuals do not, they believe their health is a matter of luck or chance. However considering the similar nature of personal control and HLC, it seems unexpected that different results were found for personal control and HLC in relation to the HBM components.

The results further offered support for the predictive utility of the illness representation component illness coherence in predicting coping style and HLC. This is perhaps what could be expected given that illness coherence examined the women's understanding of breast cancer using items such as 'breast cancer is a mystery to me' and that it seems plausible that in order to cope with the health threat of breast cancer individuals may need some understanding of breast cancer. Similarly, it seems likely, that in order to decide how in control of breast cancer they feel they are individuals may again need some understanding of breast cancer. This may explain the predictive relationship between illness coherence and HLC. More specifically, higher levels of illness coherence predicted internal HLC and lower levels of illness coherence predicted chance HLC. This may be explained by considering the possibility that individuals with a greater understanding of breast cancer may be more aware of the advantages to screening and be more aware of the possible ways breast-cancer can be prevented and treat; resulting in them feeling more in control of their health.

The results further highlighted that the illness representation component emotional representation predicted the level of anxiety and worry the women reported. This is what could be expected given that it seems likely that woman who experience emotion driven reactions to the health threat of breast cancer may worry about breast cancer more. Similarly anxious individuals may be more prone to experience emotion driven reactions.

The level of worry the women reported was also found to be predicted by the illness representation treatment control. More specifically, higher scores on treatment control were associated with lower levels of worry. This is unsurprising, considering treatment control examined the extent to which a person believed breast cancer could be treated (using items such as the negative effects of this illness can be prevented or avoided by treatment) and it seems plausible that individuals who believe breast cancer can be treated tend to worry less, than those who do not.

Finally, the illness representation timeline acute/chronic was found to predict powerful others HLC, with higher scores on timeline acute/chronic predicting higher levels of 'powerful others' HLC. Timeline acute/chronic examined how long the women believed breast cancer would last using items, such as breast cancer is likely to be permanent rather than temporary and whilst no explanation within the literature is offered for its predictive utility in regards to 'powerful others' HLC one suggestion may be that believing breast cancer is likely to last for a long time or be a permanent condition may cause the individual to feel they are not in control of their health.

Research focusing on illness representations particularly in relation to thoughts and behaviour related to BSE is limited. Most studies have examined illness-specific beliefs and behaviours within specific groups of patients or groups at risk from a particular illness and there has been much less focus on how healthy people think about health and illness, and how their ways of thinking relate to health related behaviours. More recently, especially following the development of a new version of the IPQ-R for use with healthy individuals (Figueiras & Alves, 2007) research has started to focus on the illness representations of healthy individuals but as yet no research has explored the IPQ-R items particularly in relation to BSE and the associated health beliefs. It is apparent within the current study, the potential effect the illness representations; personal control, illness

coherence, emotional representation, treatment control and timeline acute/chronic can have on women's levels of worry, anxiety, coping style, and the HLC orientations chance and internal and the impact these may have on subsequent BSE behaviour. Taking this into consideration, there is a need for future research to explore this further.

Whilst support was offered for the HBM component confidence in predicting the frequency and proficiency of the women's breast exams, it appears that the other components of the HBM and E-HBM may not be important in understanding BSE proficiency and frequency directly but that a more complex relationship may exist. Although more women do consult earlier with breast cancer than other cancers, there is evidence to show that women are still not breast-aware (Bailey, 2000; Cancer Research UK, 2008; DoH, 2000; Manasciewicz, 2003). Understanding the reasoning behind some women's desire to examine their breasts and others desire not to, is likely to help health-care professionals develop more effective screening programmes and encourage more women to engage in BSE. Although the study failed to confirm the predictive utility of the proposed E-HBM in relation to the frequency and proficiency of BSE, support was offered for a more complex theoretical framework as presented in Figures 5 and 6. Future research should explore the predictive utility of this framework further and within a larger sample of women.

11.2.3 Relationship of Demographic Characteristics and Health Beliefs and Behaviour Connected to Breast Cancer and BSE

Detailed demographic information was collected from the participants at the start of the study and this allowed for the exploration of the influence of their demographic characteristics in relation to their health beliefs and behaviour connected to breast cancer and BSE. Whilst this exploration suggested no relationship between the participants' demographic characteristics and their subsequent breast exam in terms of proficiency a relationship was demonstrated between the participants' ages and the frequency of their

breast exams. More specifically, the older women reported more frequent breast exams when compared to the younger woman. This is what could be expected considering a major risk factor to breast cancer is age, with the incidence of breast cancer increasing with age (McPherson et al., 2000; Paley, 2001). If aware of this risk factor to breast cancer, it may be proposed that individuals falling into this increased risk group may be more concerned with breast cancer and subsequently more concerned with screening practices such as BSE.

In relation to components of the HBM, the study revealed a relationship between education, bra cup size, family history and employment type; and the HBM components health motivation, susceptibility and barriers. More specifically, individuals with a higher level of achieved education were more motivated towards their health. This is what could be expected given past research, whereby higher educated physician's reported higher health motivation than the lesser educated nurses and midwives, (Canbulat and Uzun, 2008); and considering previous research has claimed that women in academic environments are likely to be at the forefront of any major changes in health practices because of their greater exposure to information and resources (Pitts, McMaster & Wilson, 1991).

Moreover, the results suggested that women with larger breasts and women with a family history of breast cancer felt more susceptible to breast cancer. This is unsurprising given that having a family history of breast-cancer increases an individual's likelihood of getting breast cancer (McPherson et al., 2000; Paley, 2001). Likewise research indicates those with a family history of breast cancer perceive heightened susceptibility to breast cancer (Alagna, Morokoff, Bevet & Reddy, 1987; Evans, Burnell & Hopwood, 1993; Lerman, Lustbader, Rimer, Daly, Miller & Sands, 1995; Lloyd, Watson, Waites, Meyer, Eeles, Ebbs & Tylee, 1996). Whilst it is unclear why the women with larger breasts felt more at risk of

breast cancer, one explanation may be that these women have a more negative relationship with their breasts. Indeed, research has linked breast dissatisfaction with psychological distress, including feelings of embarrassment and self-consciousness, lack of self-confidence and diminished self-esteem, and doubts about one's femininity, (Cline, 1990; Grant, 1996). Perhaps breast dissatisfaction can further influence a women's perception of the risk of breast cancer. Likewise, past difficulties examining their breasts may have reduced their confidence in their ability to find any signs of breast cancer.

Breast exams on larger breasts typically need more time due to the larger area to examine and require more care to ensure the entire breast area is examined. This extra time and care may impact on the women's level of confidence in the ability of their breast exam to discover any signs of breast cancer and their feelings of control over the disease, resulting in the women experiencing a great perceived susceptibility to breast cancer.

Furthermore, research has suggested women with larger breasts may be at increased risk for advanced breast cancer as a result of a larger tumour size at presentation or the increased susceptibility to lymph node positivity (Egan, Newcomb, Titus-Ernstoff, Trentham-Dietz, Baron, Willet, 1999; Hall, Coates, Uhler, Brinton, Gammon, Brogan, 1999; Hall, Newman, Millikan & Moorman, 2000; Hasenburg, Grothey, Jaspers, Gitsch & Spatling, 2000; Hoe, Mullee, Royle, Guyer & Taylor, 1993; Hsieh & Trichopoulos, 1991; Kusano, Trichopoulos, Terry, Chen, Willett, Michels, 2006). Although the evidence for this increased risk is controversial, and based on studies with methodological flaws (most of the studies within the area are case control or cohort studies, the definition of what size constitutes a large breast has not been defined within most of these studies and the methodology employed for measuring the size of the breasts has tended to vary including measures of mammographic volume, the size of mastectomy specimen and self-reported cup-size) this increased risk has been reported within the lay literature (for example The Independent, Dobson, 2005). As a result, the women within the current study may have

been exposed to these news stories highlighting a potential increased risk of breast cancer for themselves and this in turn may have increased their feelings of susceptibility to breast cancer.

In relation to barriers the study revealed those women in a health or nursing area of employment reported the lowest level of barriers towards BSE. This is unsurprising given these women may be exposed to breast awareness campaigns within their workplace and be more aware of the benefits to BSE due to their work environment; and given past research whereby nursing students reported low barriers to BSE (Budden, 1999).

Although the study's generalisability is limited given the sample only consisted of younger (40 years and under) Australian nursing students, it in addition to the findings of the current study offers limited support for this interpretation. Moreover, current UK guidelines within the NHS Cancer Plan (DoH, 2000) and the Royal College of Nursing Review (2002) encourage and emphasise the role of nursing professionals in providing information and guidance on breast awareness. Through being exposed to and providing this information and guidance these women may become more positive to breast awareness and in turn BSE and as a result perceive fewer barriers to examining their breasts.

In relation to the E-HBM components breast-cancer worry, anxiety and HLC, the study revealed a relationship between marital status and breast-cancer worry, family history and anxiety; and marital status, number of children, age started menopause, and, HLC. More specifically, women with no children, and women who started the menopause at a later age, expressed higher levels of 'powerful others' HLC. That is, they believed 'powerful others' determined their health. Additionally the results suggested younger women and those without a family history of breast cancer reported higher levels of trait anxiety, and the women who classified their marital status as co-habiting expressed higher levels of

'chance' HLC. Whilst no explanation is offered within the current study for these relationships, it is perhaps an area future research could explore further.

Finally, in relation to illness representations the study revealed a relationship between, age started menstrual cycle, family history of breast cancer, employment status and cup size; and identity, illness coherence, risk factors and consequences. More specifically, individuals who reported starting the menstrual cycle at an older age were more able to identify the common symptoms of breast cancer than those who started at a younger age; and those with a family history of breast cancer were less able to identify the symptoms than those without a history. It is unknown why the women who started the menstrual cycle at an older age were more able to identify breast-cancer symptoms given that the reverse may be expected to be true when considering risk factors to breast cancer.

According to Paley, (2001) women who started menstruating between the ages 11 and 14 carry an increased risk of breast cancer of up to 30% compared to those whose onset of menses occurs at a later age. If aware of this breast-cancer risk factor, it may be proposed that individuals falling into that increased risk age group may be more concerned with breast cancer and as such more aware of breast-cancer symptoms.

Similarly, surprisingly results were found in relation to family history and identity. Following this risk factor idea, one may propose that those with a family history of breast cancer may be more concerned with breast cancer and aware of the symptoms. Likewise, they may have witnessed firsthand, their family member displaying some of the symptoms of breast cancer and considering this would be expected to be more aware of the symptoms than someone without this history.

Moreover, individuals who were self employed were more aware of the risk factors to breast cancer and those with a F cup bra size reported the lowest consequences of breast cancer and those with a E cup reported the highest consequences of breast cancer (with

varying levels of consequences reported amongst the other cup sizes). Whilst no explanation can be offered for this relationship in the current study especially given the random spread of consequence scores amongst the bra cup sizes, this is an area future research could explore further.

It is important to note the relationship between these demographic characteristics and BSE frequency, and the HBM and E-HBM components highlighted in the current study. Whilst no difference was found in terms of these demographic characteristics between the women in each of the four study groups, future research should note the impact these demographic characteristics could have and consider this within their analyses.

11.3 Research Questions 2 and 3

Before the study, it was proposed that some women may neglect to examine their breasts because of a lack of perceived vulnerability to breast cancer or because of misconceptions connected to the disease and through viewing the autobiographical accounts they may become alerted to their own vulnerability to developing breast cancer and become motivated to take preventative action. Following this, it was hypothesised that those women observing autobiographical accounts would differ in terms of knowledge, beliefs and behaviour towards BSE when compared to those women not observing the autobiographical accounts.

Likewise, it was further proposed that although treatment success is high for cancers detected, opportunities to effectively detect and treat breast cancer may be being lost because of a lack of guidance within current breast awareness campaigns, information about BSE is severely lacking or confusing to understand or because current methods fail to elicit the interest and curiosity of the general female population. BSE is a complicated procedure which is not easy to do properly according to both researchers and health

professionals (Haji-Mahmoddi, Montazeri, Jarvandi, Ebrahimi, Haghghat & Harirchi, 2002) and it needs to be taught properly in order for women to understand what to do and to feel confident enough to do so. Moreover, it has been suggested there may be a better and more efficient way for providers to teach BSE (American Cancer Society, 2001). This study sought to develop a more efficient method of BSE instruction through the use of a multimedia-enhanced programme comparing static with video-enhanced support. It was proposed that through using a multimedia-enhanced programme the interest of women not engaging in BSE at all or regularly could be elicited and the skills needed to perform BSE could be taught in a clearer and perhaps more enjoyable way. This study aimed to achieve an improvement in women's BSE through the development and use of a multimedia BSE support programme, comparing static and video-enhanced formats of the support. Whilst both BSE supports aimed to develop women's skills of using BSE-techniques, as well as their knowledge, through the use of performance enhancement tools, it was hypothesised that women's knowledge, beliefs and behaviour BSE would differ depending on their type of multimedia BSE support perhaps as a result of the type of the performance enhancement tools used (images within the static version and interactivity and video within the video-enhanced).

11.3.1 Autobiographical Accounts, BSE Support and BSE Frequency and Proficiency

Whilst no support was offered for an increase in the frequency of BSE following viewing autobiographical accounts or BSE support alone, a significant interaction effect of autobiographical accounts and the type of BSE support (static or video-enhanced), was found. After exploring this interaction further, it appeared that autobiographical accounts only had an effect on the frequency of which the women examined their breasts when the BSE support employed was the video-enhanced version. More specifically, higher BSE frequency was reported from the women who had not viewed autobiographical accounts

and who had received the video-enhanced BSE support. In relation to BSE proficiency, however, the analyses revealed a significant effect of type of BSE support, and a significant interaction effect of autobiographical accounts and BSE support. Whilst the presence of an interaction effect limits any conclusions being drawn regarding BSE support alone, exploration of the interaction effect further suggested BSE support appears to only have an effect on BSE proficiency when no autobiographical account was viewed, with the women who had not viewed the autobiographical accounts and who had received the video-enhanced support resulting in higher proficiency scores. It appears a complex relationship may exist, and that any effect of autobiographical accounts may be dependent on the BSE support given.

Moreover, the results further suggested the HBM component confidence should be considered in this interactive relationship of BSE support and autobiographical accounts on BSE proficiency but not post-intervention frequency. It appears after considering the effects of a range of covariates, that post-intervention confidence mediates the interaction effect of autobiographical accounts and BSE support on post-intervention BSE proficiency and that a direct relationship exists between BSE support and proficiency, whereby increased proficiency is reported following the video-enhanced support. In relation to BSE frequency, however, it appears a direct relationship exists in which, an interaction of autobiographical accounts and BSE support (in addition to pre-intervention BSE frequency) predicts post-intervention BSE frequency. This is illustrated in Figures 7 and 8.

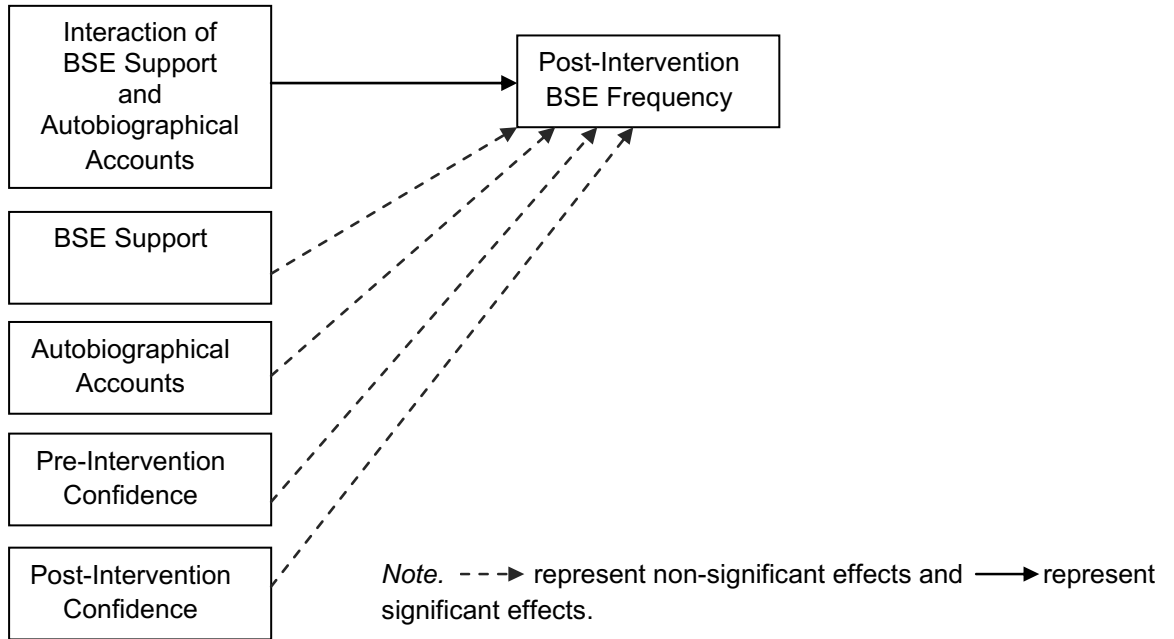


Figure 7. Model Illustrating the Predictors of Post-Intervention BSE Frequency

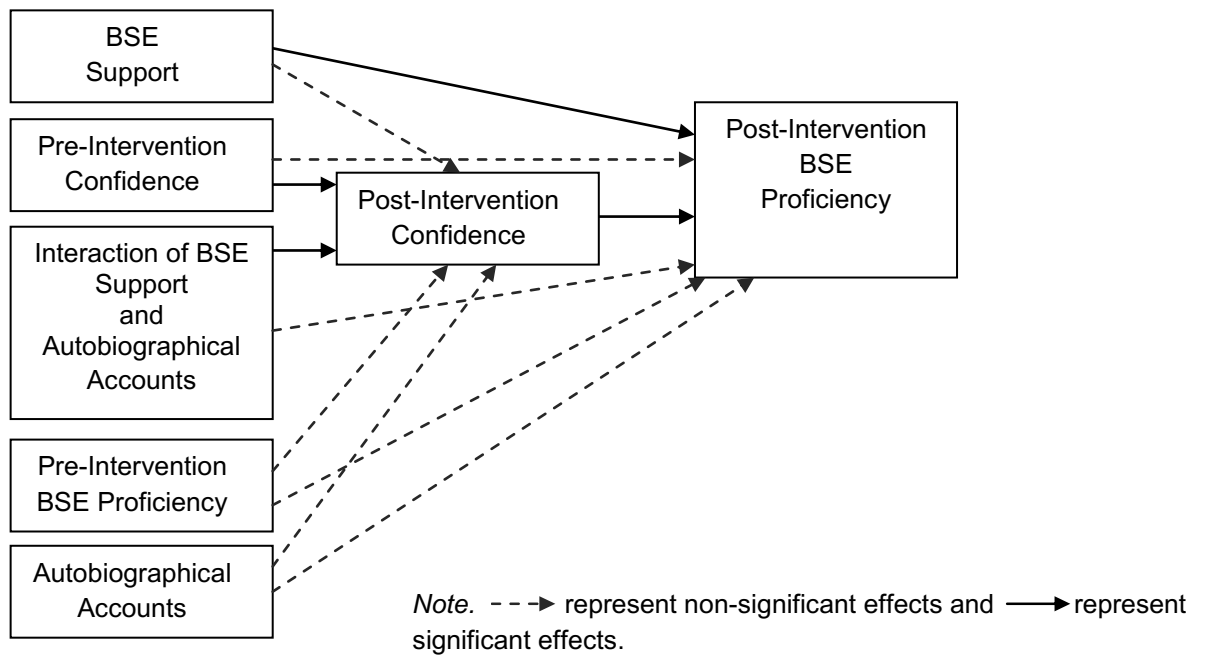


Figure 8. Model Illustrating the Predictors of Post-Intervention BSE Proficiency

It appears at least with regards to BSE proficiency, that BSE support and autobiographical accounts have an impact on the level of confidence women feel and this in turn influences the proficiency of their breast exams. Whilst this relationship seems plausible, considering that observing women discussing the importance of breast awareness and how they themselves discovered breast cancer through methods such as BSE may highlight to the women that they too are capable of engaging in breast-screening methods such as BSE; it is surprising that the results only revealed a significant effect of BSE support when, no autobiographical accounts were viewed, with women who had not viewed the accounts and had been given the video-enhanced BSE support reporting higher confidence scores. Whilst increased confidence following the video-enhanced support is expected given past research (Janda, Stanek, Newman, Obermair & Trimmel, 2002; Reis, Trockel, King, Remmert, 2004), in which increased self efficacy and confidence scores were reported following a video-enhanced programme, it is unknown why this only increased when no autobiographical account was viewed. The relationship between BSE, autobiographical accounts and BSE support (at least in terms of BSE proficiency) is more complex than originally proposed and appears to be mediated by the HBM component confidence. This is an area future research should explore further.

Nevertheless, the demonstration of an effect of BSE support when no autobiographical account was viewed on confidence is of particular importance considering a lack of confidence in the accuracy of their examination technique has been reported in the past to be a key barrier to BSE (Agars & McMurray, 1993) and given the predictive utility of confidence in relation to BSE within the current study and past research (Alagna & Reddy, 1984; Ashton et al., 2001; Chalmers & Luker, 1996; Champion, 1985, 1989; Erlich et al., 2000; Friedman et al., 1994; Hallal, 1982; Luszczynska & Schwarzer, 2003; Norman & Brain, 2005; Nystrom, 2000; Stefanek & Wilcox, 1991, Smiley et al., 2000). Moreover, qualitative responses generated from the women's blogs and questionnaire responses

further highlighted the importance of confidence in relation to BSE. BSE was viewed positively by all the women participating in the study and all had the intention to engage in it but most were unsure how to examine their breasts comprehensively and expressed concern over their own ability to discover signs of breast cancer.

Interventions that improve a women's level of confidence regarding BSE are likely to increase the frequency and proficiency with which they examine their breasts and are thus vital to ensure women are able to detect breast cancer at the earliest stage possible.

Early detection decreases the mortality associated with breast cancer (Green & Taplin, 2003), allows for more treatment choices if breast cancer is found (Allen, Van Groningen, Barksdale & McCarthy, 2010) and may increase the likelihood of not having to lose a breast through mastectomy or not having to experience aggressive chemotherapy (Weiss, 2008). Breast cancer remains a current problem within the UK, with each year more than 12,000 women dying from the disease and there is evidence to suggest that despite the benefits of BSE women do not examine their breasts regularly (Cancer Research UK, 2008; Manasciewicz, 2003). Thus, any intervention that is likely to encourage BSE is of great importance and interventions designed with women's beliefs surrounding BSE in mind are likely to be more successful. Considering that the women who had not viewed the autobiographical account and who had been given the video-enhanced BSE support reported higher confidence levels, perhaps future interventions should focus on providing women with access to this video-enhanced support.

However, whilst the video-enhanced support was successful in increasing women's confidence levels, it alone was not more successful than the static version in increasing the women's levels of BSE frequency. Indeed, qualitative responses drawn from the post-intervention questionnaire and the women's blogs highlighted the women were positive about both the static and video-enhanced BSE instructions and in line with Mayer (2001),

the women expressed the advantageous nature of the pictures within the static version and the video footage within the video-enhanced version in providing much needed reassurance regarding the accuracy of the BSE technique and clarification on aspects of the technique they were unsure about. The women further expressed frustration at not being shown or given instructions by medical professionals and suggested that if provided with guidance regarding how to examine their breasts they would examine more regularly. Indeed over the course of the study the women reported finding the BSE process much easier to remember and follow regardless of which BSE instruction method they were following and their awareness of their breasts and BSE increased. They suggested that the study BSE technique guidelines made the whole process of BSE a more positive and enjoyable experience and as a result of following the guidelines the women's insecurities reduced and their confidence increased and this confidence continued to increase as the study progressed and they examined their breasts more. Based on this positive impact of providing women with both the static and video-enhanced BSE support, perhaps, both the static and video-enhanced BSE support should be considered for BSE interventions. However, future BSE interventions should note that whilst, the video-enhanced support did not offer any advantage over the static support in terms of BSE frequency it offered an advantage in terms of BSE proficiency. Whilst all the women reported more proficient exams regardless of the BSE support they had received, proficiency scores for the women with the video-enhanced support were higher. It appears both BSE supports were effective in encouraging the women to examine their breasts frequently and proficiently but perhaps the video-enhanced support is more effective in terms of BSE proficiency.

Research on BSE training demonstrates that instruction and training in BSE is well received by most women and that they can be trained to improve the accuracy of their examination technique and to enhance their perception that they have the skills to successfully examine their breasts (Leight & Leslie, 1998; Stefanek, Wilcox & Huelskamp,

1992; Strickland, Feigl, Upchurch, King, Piercem Grevstadet et al., 1997; Valdez, Banerjee, Fernandez & Ackerson, 2001). Similarly, as a result of the current study most women formed an improved relationship with their breasts, and for some this in turn reduced their concern about breast cancer. Moreover, the frequency of which the women examined their breasts increased and for some this increased frequency remained four months after the study had ceased. In regards to BSE proficiency, the women suggested that the technique regardless of whether they were following the static or video-enhanced version encouraged a more thorough examination and provided guidance to ensure the entire breast area was examined. Following this, the women reported higher scores post-intervention for both BSE frequency and proficiency, and confidence.

It appears the 5-step BSE technique regardless of instruction method was useful in encouraging and maintaining a thorough and regular breast exam and that providing women with the necessary knowledge and education to perform BSE encourages women to examine their breasts and ensures they examine comprehensively. Likewise, whilst the video-enhanced support may be more beneficial in increasing women's levels of confidence surrounding BSE, both methods of support appear to increase confidence just perhaps the static less so than the video-enhanced support.

Given the success of the 5-step BSE technique there is a need for future interventions to incorporate the technique within their breast awareness campaigns, selecting whichever method (static or video-enhanced) is appropriate and/or accessible for the intervention environment. Furthermore, Breastlight, (a product that allows you to see inside your breasts through shining a powerful light through the breast tissue) is available within the current consumer market. Initial evaluations of the product in increasing breast awareness are encouraging and although research has yet to explore the utility of the product as a BSE promotion tool, initial findings are encouraging. Following a large scale study (1087

women) led by an independent market research company (Commissioned by PWB Health, 2008), Breastlight was revealed on the whole to be well received and understood. The majority of the women suggested the Breastlight was easy to use and after using the product women reporting regular checks of their breast increased from 44% to 76% and those reporting less frequent exams decreased from 34% to 8%. Moreover, the Breastlight improved the women's confidence in self-checking their breasts (80% were more confident after using the breast light). Initial evaluations of the Breastlight are positive and given its suggestive utility in increasing the confidence and frequency of breast exams future research should explore the potential of interventions incorporating both the Breastlight and the 5-step BSE technique.

11.3.2 Autobiographical Accounts, HBM and E-HBM

Whilst, analyses within this study failed to offer support for a positive effect of autobiographical accounts alone on the frequency and proficiency of BSE, and the HBM component confidence, support was offered for an effect on the HBM component barriers, personal control and powerful others HLC. With regards to personal control, the women who had viewed the autobiographical accounts reported higher levels of personal control than those who had not viewed the accounts. This is what could be expected given that it was hypothesised that through watching the autobiographical accounts women may identify with the women within the accounts, and perceive themselves as also capable of making decisions and performing specific practices related to their own breast health; and that observing women discussing the importance of breast awareness and how they themselves discovered breast cancer through methods such as BSE may highlight that breast awareness is relevant to them and that they too are capable of controlling the threat of breast cancer and engaging in breast-screening methods such as BSE.

However, with regards to 'powerful others' HLC and the HBM components barriers more surprising findings were obtained, in which after considering pre-intervention scores, the women who had viewed the autobiographical accounts reported higher barrier and higher 'powerful others' HLC scores than those who had not viewed the accounts. This was unexpected given that it was hypothesised that the accounts would reduce some of the barriers to BSE and that the women also reported higher levels of personal control. Personal control and powerful others HLC measure two very different levels of control; personal control examines the extent to which a person believes they have control over breast cancer and individuals with a powerful others HLC orientation believe that powerful others (for example doctors or God) determine their health. It is surprising that the women's scores were higher on both these variables following the autobiographical accounts, given these two items measure opposing levels of control.

The increased barriers score compared to those who had not viewed the autobiographical however, may at least in part be explained by considering that in viewing the autobiographical accounts, barriers to BSE may have become highlighted or become more relevant to the women. Whilst this increased barrier score could be taken as a negative effect of autobiographical accounts, it does need to be noted that this higher score in barriers to BSE, did not affect their subsequent BSE behaviour. Instead, as previously discussed, no effect of autobiographical accounts alone on BSE frequency and proficiency was demonstrated. Similarly one should further consider the positive responses of the women within the study towards the autobiographical accounts. Rather than preventing breast exams, qualitative data generated from the women suggested the autobiographical accounts highlighted the importance of BSE and increased their motivation to engage in BSE. Indeed this is what could be expected given that, research suggests narrative or autobiographical accounts reduce counter arguing (Kreuter, Holmes, Alcaraz, Kalesan, Rath & Richert et al., 2010; McQueen, Kreuter, Kalesan & Alcaraz, 2011)

and considering that reducing counter arguments can increase the persuasive nature of a message (Green & Brock, 2000; Slater & Rouner, 2002). It appears that viewing autobiographical accounts may reduce counter arguments to BSE and through this women may become more motivated or persuaded to engage in BSE.

Moreover, the qualitative responses drawn from the post-intervention questionnaire and the women's blogs suggested for some women the autobiographical accounts served as a prompt not only to encourage the initial engagement of BSE but long-term compliance. Before the study, it was proposed that viewing autobiographical accounts may function as a wake-up call and encourage BSE. Through finding recognition within the stories it was suggested that an individual's own vulnerability to developing breast cancer may be alerted, motivating this individual to take preventative action. Indeed, this was true for some of the women within the current study. Qualitative data generated from the women within the study highlighted their emotional responses to the autobiographical accounts, and how through this and their ability to relate to the women within the accounts the importance of BSE and their motivation to engage in BSE increased.

The ability to relate to the women within the accounts appears to be an important issue that needs consideration if wanting to apply autobiographical accounts within a health-promotion setting. It is apparent through the women's accounts that a particularly strong emotional response is generated when the women can recognise similarities between the women giving the autobiographical account and themselves. It is the emotional response facilitated through recognition that appears to motivate the women to examine their breasts. This is what could be expected given, past research has demonstrated the best predictor of a woman becoming engaged in and feeling positive towards a breast-cancer survivor's story was whether she liked the women and viewed her as similar to herself (Bailey, Erwin & Belin, 2000; Kreuter, Buskirk, Holnes, Clark, Robinson, Si et al., 2008)

and considering that identifying with the individual within the account is expected to increase empathy and cognitive rehearsal, decrease counter arguing and influence attitudes, perceived risk, perceived norms and behaviours (Dal Cin, Zanna & Fong, 2004; Hinyard & Kreuter, 2007; Moyer-Guse, 2008; Slater, 2002; Slater & Rouner, 2002). Likewise, research suggests emotions affect what individuals notice and remember (Dolan, 2002), in part because they evoke physiological reactions that add a dimension of experience (Kesinger, 2008). Considering this, autobiographical accounts that evoke strong emotions might therefore lead to greater recall. It appears that survivor stories and indeed autobiographical accounts may be most effective when viewers identify with the individual within the story or account and when strong emotions are evoked.

The term 'teachable moment' describes naturally occurring life transitions or health events that have the potential to motivate individuals to spontaneously adopt risk-reducing or health-protective behaviours (McBride, Emmons & Lipkus, 2003). Researchers suggest that a cancer diagnosis can be a 'teachable moment' (Demark-Wahnefried, Aziz, Rowland & Pinto, 2005; Ganz, 2005) in that the diagnosis of cancer itself often represents an event that prompts spontaneous changes in health behaviours among cancer patients and survivors (Denmark-Wahnefried et al., 2005; Park, Edmondson, Fenster & Blank, 2008). Breast-cancer survivors report a much higher level of BSE (76%, Trask, Pahl & Begeman, 2008) than is typically reported in the general population, most likely because of their breast-cancer diagnosis, their 'wake-up call'. Prior to the study it was suggested that viewing autobiographical accounts may provide this 'teachable moment' too and prompt the women to not only think differently about breast cancer and BSE, but encourage them to adopt BSE. Through simulating this 'wake-up call' with the autobiographical accounts it was proposed that a similar increase in BSE may be produced.

Whilst no support was offered for an increase in BSE as a result of viewing the autobiographical accounts, the women's levels of personal control increased, they reported becoming more motivated to examine their breasts and as a result of identifying with the women within the accounts, the importance of BSE increased. Moreover, it was highlighted within the qualitative accounts the positive influence these accounts can have, in promoting more positive representations surrounding breast cancer and BSE. Similarly, in line with the women within the current study a similar need for a positive focus regarding breast cancer has been suggested by physicians and breast-cancer patients (Heisey, Clemons, Granek, Fergus, Hum, Lord et al., 2011). Interviews with doctors and breast-cancer patients who were presented with symptoms at a later stage (12 weeks or more after self-detection) highlighted the advantageous nature of hopeful testimonials from women living with breast cancer in terms of 'demystifying' the disease and promoting the perception that breast cancer is curable and not a 'death sentence'. Whilst it does need to be noted the study's generalisability is limited in that it was conducted in Canada, and with physicians and breast-cancer patients whose views may differ to that of women generally, the findings in addition to those of the current study nevertheless suggest the positive effect viewing autobiographical accounts can have on women's feelings towards breast cancer and BSE and highlight the need for future research to explore this further.

11.3.3 BSE Support, HBM and E-HBM

Whilst analyses within this study failed to offer support for a positive effect of BSE support alone on the frequency of BSE, support was offered for an effect on level of affirmation social support, with the women who had viewed the video-enhanced enhanced BSE support reporting higher scores on affirmation social support than those who had viewed the static support. The affirmation social support measurement items addressed how much the women could confide in people within their social network and how much these people agreed with or supported the women's general actions and thoughts; and it is

unknown why after considering pre-intervention scores that viewing the video-enhanced BSE support resulted in higher scores. Whilst no explanation for this can be provided in the current study, it is perhaps an area of research that could be explored further.

11.3.4 Interaction of Autobiographical Accounts and BSE Support on HBM and E-HBM

In addition to the individual effects discussed, the results further revealed a significant interaction effect of autobiographical accounts and BSE support on the illness representations timeline cyclical and psychological attribution. Additional analyses revealed no further detail regarding the interaction of BSE support and autobiographical accounts on timeline cyclical and psychological attribution but consultation of the effect sizes suggested that if a larger sample size was employed one may expect a significant effect of video-enhanced support and autobiographical accounts on both timeline cyclical and psychological attribution. The illness representation timeline cyclical examined the unpredictable nature of breast cancer and the psychological attribution examined how much the women believed breast-cancer can be attributed to psychological factors for example stress or worry. It is unknown how or why levels of these two illness representations would be influenced by autobiographical accounts and BSE support. Perhaps a more complex relationship exists between these variables, and with further exploration more detail about this relationship may be uncovered.

Whilst the relationship between BSE support, autobiographical accounts and the components of the HBM and EHBMs is more complex than originally proposed, it should be noted that both the static and video-enhanced BSE supports were effective in encouraging and maintaining a more frequent and proficient breast exam within the women in the current study. Moreover, as a result of being given the supports the process of BSE became a more positive experience, and the women's relationship with their

breasts improved. At present little instruction is available for women regarding how to examine their breasts, yet it became apparent in the current study there is a great need for BSE instruction and guidance. Considering the advantageous nature of both BSE supports highlighted within the qualitative accounts and the complex relationship with autobiographical accounts and elements of the HBM and E-HBM demonstrated, there is a need for future research to explore autobiographical accounts and both BSE supports further and within a larger sample.

Some researchers have called for an end to the routine teaching of BSE, suggesting BSE is in fact harmful to those individuals engaging in it. Rather than reduce deaths, they have argued that BSE simply increases unnecessary biopsies and anxiety (Austoker, 2003; Baxter, 2001; Kosters & Gotzsche, 2003). Whilst it is unknown if unnecessary biopsies were produced as a result of the current study, anxiety and levels of breast-cancer related worry were found not to differ significantly from pre to post-intervention. It appears, in contrast to what some may suggest that the women's levels of anxiety and worry did not change as a result of being part of the study and examining their breasts and rather an improved relationship with their breasts was formed.

11.4 Research Question 4

Despite the positive aspects of computer-mediated communication, little is disseminated widely about the practical issues of use for data collection, especially in a research setting. This study sought to explore the practical implications of and effectiveness of computer-mediated communication within a breast health-promotion research setting. More specifically, this study examined the effectiveness of; conducting a research study within an online setting, displaying study information and materials on a specifically designed study website and the use of online questionnaires and blogs as a data recording tool.

Before the study, following Fleisher et al. (2008), it was assumed that the online nature of the study would broaden the reach of participants recruited for the study, enabling people in different geographic regions of the UK to participate without the need to travel, and in turn increase the representativeness of the sample. However, this was not successful for the current study and instead the women recruited were predominately from the North-east of England (54), with 6 residing in the North-west (2), Yorkshire and Humberside (2), West Midlands (1) and South-east (1) respectively. Rather than a problem associated with the online nature of the study, this may be a result of recruitment methods. Participants were recruited through advertisements on websites related to women's and adolescent's health issues, social networking sites, at the local college and university, radio interviews and through stories about the research in the local press. Whilst an effort was made to recruit from a wide area through websites and social networking sites; more interest may have been generated through local recruitment within the college and university, radio interviews and local press stories. Perhaps future studies should aim to recruit within a wider range of colleges and universities and through national radios and press stories.

Past studies in which electronic data collection methods have been used have demonstrated the feasibility of these methods, the richness of electronically collected data, the informative and prompt responses of research participants and decreased human errors (Curl & Robinson, 1994; Fawcett & Buhle, 1995; Lakeman, 1997; Stanton, 1998). Indeed, through the use of electronic questionnaires within the current study it was possible to ensure participants completed every question within the pre-and post-intervention questionnaires and this in turn ensured all participants' responses could be used. Furthermore through electronic questionnaires, responses were returned promptly and within a format that facilitated data analysis.

Before the study, it was assumed that the personal blogs would provide a more facilitating forum for some people to discuss sensitive personal health issues and be a feasible alternative to traditional face-to-face focus groups (Campbell, Meier, Carr, Enga, James, Reedy et al., 2001; Hsiung, 2000). This appeared to be true for some of the women but not all with only 43% of the women choosing to complete their blog for the duration of the study. Pilot work highlighted no problems associated with blog completion and it was assumed that participants in the main study would experience the blog in a similarly positive way. As previously discussed, no difference was found between the women who completed the blogs and those that did not in terms of age, educational level and most of the demographics noted with the pre-intervention questionnaire and on all aspects of the BTAQ questionnaire. A difference was found in terms of contraceptive pill use and religion, but whilst this difference may have influenced their completion of the blog, it is more likely that women decided to not engage in the completion of the blogs for more personal reasons, for example a lack of time or forgetfulness. Responses from the post-intervention questionnaire demonstrated for some of the women remembering and finding the time to complete the online blog was problematic and it was apparent from the varying detail and quantity of the blog entries amongst those that did complete, that some women appeared to find keeping a blog much easier than others. Indeed one woman expressed her problem thinking what to write within her blog and another expressed her lack of interest because she did not have breast cancer. Whilst a wealth of information can be gained within the anonymous setting of an online blog, it appears the method does not suit everyone and this limitation needs to be considered when conducting online research.

In the past decade there has been a tremendous increase in Internet use and computer-mediated communication (Fox, Raine, Larsen, Horrigan, Lenhart, Spooner et al., 2001; Nie & Erbring, 2000; Nie, Hillygus & Erbring, 2002) and, as an increasing amount of

communicative activity takes place through this new medium, it is important to evaluate it within a research setting. The current study offers a first step in this evaluation. The online nature of the study was effective in providing all the information and materials needed for women to complete the study and in encouraging regular and proficient BSE. Similarly, data collection through the use of online questionnaires was effective. In those women that completed the blogs, the blogs provided an insightful and informative view on the women's beliefs and behaviour surrounding breast cancer, BSE and the study itself. It appears the use of online data collection and blogs as a recording and communication tool can be an effective research method, but this effectiveness may be dependent on the topic area of interest and the participants involved.

11.5 Limitations of the Current Study

The present study had some limitations that should be noted. Firstly, the research was limited in its scope and applicability. The sample relied upon a small sample of white women predominately from the North-east of England, limiting the generalisability of the findings. Detailed demographics, however, were taken at the start of the study, and this allowed one to compare the sample with the general population on a number of demographic characteristics. The sample included women with and without a family and friend history of breast cancer and women who were menopausal and non menopausal. Within the sample there was a range of ages, educational levels, marital status', breast cup sizes, employment status', type of employment and contraceptive pill usage. Similarly, the sample included women who were Christian and women who had no religion, women with large and small breasts and women with dense and loose breast tissue. Given that an individual's perception of their own risk to breast cancer may influence their thoughts surrounding breast cancer and BSE and their subsequent BSE behaviour; and that demographic characteristics such as age, educational level and ethnicity have been linked

to BSE behaviour, it was important to note the samples variety within these demographic variables. The variation within the sample limited the effect of these demographic variables and improved the applicability of the sample. Moreover, no difference was found in each of the four study groups on any of these demographic characteristics.

Nevertheless, whilst a range of ages, educational level, family and friends history of breast cancer, menstrual state, marital status', breast cup size and density, employment status and type, contraceptive pill use and religion were included within the sample, the sample size and limited geographic area and ethnic diversity, limit the generalisability. There is a need for the findings to be replicated in a larger sample of women across a wider geographic area and within a more racially and ethnically diverse sample.

With regards to BSE frequency and proficiency at the start of the study, the majority of the women were not engaging in regular or proficient breast exams. Whilst this is what should be expected given the results of past research (Cancer Research UK, 2008; Manasciewicz, 2003), the study is unable to conclude if similar results would have been found with regular and proficient examiners.

Secondly, medical guidelines, advise women to examine their breasts on a monthly basis a few days after their period ends or for those experiencing menopause the same day each month (American Cancer Society, 2009; American College of Obstetricians and Gynaecologists, 2009) and to be aware of how their breasts look and feel generally at times that are convenient for the woman (NHS Cancer Screening Programmes, 2011). In contrast to this, however, women within the current study were asked to examine their breasts fortnightly and have a general daily awareness of their breasts when doing daily activities such as bathing or dressing. Fortnightly examinations were advised within the current study to give participants the opportunity to become comfortable with the BSE support they were following without having to expand the time frame of the study. There

was concern that three examinations would not give the women enough time to become comfortable with the BSE technique and expanding the study to a longer period than three months would increase subject attrition rates. The study, however, is not suggesting breast exams should be conducted more regularly than once a month unless the women wishes to do so, rather it suggests women should follow medical guidelines and examine once a month. Considering this, limits the interpretation of any findings from the current study and suggests a need for research that explores BSE using the BSE supports within the current study but on a monthly basis. With regards to breast awareness the study does, however, propose a daily awareness of how the breasts look and feel whilst doing other daily activities such as bathing or dressing. This is important to ensure being breast-aware becomes a normal part of a woman's routine.

Thirdly, the longitudinal online nature of the study is likely to have facilitated subject attrition and may have limited participant recruitment. Participants were recruited using a wide variety of methods; advertisements on websites related to women's and adolescents' health issues, social networking sites, at the local college and university, radio interviews and through stories about the research in the local press. One hundred and ten women expressed interest in participating within the current study, 70 begun data collection and 60 completed the study.

A comparison of the demographic characteristics of the 10 drop-out participants and the women who completed the study suggested the women were similar in terms of demographic characteristics, brief technology acceptance questionnaire responses and BSE frequency and proficiency at the start of the study. Thus, it appears their decision to not participate in the study was likely influenced by another factor. Moreover, due to the lack of problems highlighted through pilot work it seems likely that at least in methodological terms participants would have been able to complete the study if they had

wanted to. The online nature of the study was effective in providing participants with the necessary information to take part but perhaps something else was preventing them from completing the study. Only two participants contacted the researcher asking to be withdrawn for personal reasons, the others simply didn't continue any further with the study. This may suggest rather than not wanting to take part, the online nature of the study may have failed to prompt these women to remember to take part. Indeed the women in the study discuss their problem in remembering to examine their breasts and their need for prompts; perhaps the same can be said about taking part in the study. Perhaps the longitudinal nature of the research and the lack of face to face contact between the researcher and participants failed to remind participants about the study, and in turn, encourage full participation within the study. Future research should consider ways to encourage long-term compliance amongst participants within longitudinal online research.

Fourthly, the study employed a self-report measure of BSE. Generally, behavioural outcome measures are considered more accurate than self-report due to the possibility of misreporting. The women within the study may have misreported their BSE because they had forgotten how often or how they practised it, and/or wished to present a more socially desirable image. However, other more objective methods for BSE are not available. Furthermore, participants were asked to report the frequency of BSE at two time points within the study, at pre-and post-intervention. Thus it is likely, that if over-reporting did occur it would have occurred at both time points. As the current study was interested in the difference of BSE between these time points the problem of misreporting may not have been a major issue for the current study. Likewise, BSE proficiency was measured using eleven items that addressed respondents' knowledge of BSE and encompassed current ACS and the 5-step BSE technique recommendations for BSE performance. It was unlikely that participants would be able to score high on proficiency unless they had

some knowledge regarding BSE, suggesting misreporting for a socially desirable image was unlikely.

Participants were further asked to self-report their family history of breast cancer. This may have posed a problem considering that participants may not have been aware of their medical history or of relatives who have had breast cancer. Although an option was included within the pre-intervention questionnaire for the women for whom their family history was not available not all participants may have been aware they did not know their family history. However, it was the awareness of family history; their decision-making, not the actual history itself that was considered important in the current study. Following past research it was assumed that an individual needs to be aware of such history for their behaviour to be affected (Umeh & Jones, 2010).

Fifthly, due to ethical considerations it was considered unsuitable to advise women not to examine their breasts and as such no control was included within the current study. All participants were provided with a form of multimedia BSE support. Thus, it is impossible to say if increases in BSE occurred simply because they were taking part in the current study and not as a result of the BSE support they were given. However, it should be noted that qualitative responses drawn from the post-intervention questionnaire and the women's blogs highlighted the women's need for BSE support, and it was the lack of guidelines or instruction that prevented them from examining their breasts in the past. Whilst it is likely that the increased frequency and proficiency of the women's breast exams is a result of been given BSE support, the study is unable to conclude this comprehensively.

Sixthly, in line with most applications of the HBM (Sheeran & Abraham, 1996), the current study did not include 'cues to action' within the application of the HBM. This poses a problem considering 'cues to action' may be an important determinant of BSE behaviour. Past research has demonstrated sending women monthly prompts can increase BSE

performance (Craun & Deffenbacher, 1987; Khokhar, 2009) and instructing women to specify where and when they will perform BSE so that it is associated with an environmental cue has been shown to produce an increase in the incidence of BSE (Orbell, Hodgkins & Sheeran, 1997). Likewise, the women within the current study highlighted a need to be prompted to examine their breasts. Future work should incorporate 'cues to action' within the application of the HBM to examine the effect of prompts further.

Finally, the study only included a God HLC measure within the post-intervention questionnaire. Whilst religion is included with the measure of powerful others HLC, and this was included with the pre-and post-intervention questionnaire it does not provide any detail regarding who 'powerful others' are for a particular individual. In retrospect the GHLC would have been included in both the pre-and post-intervention questionnaires but unfortunately its existence was discovered after implementation of the pre-intervention questionnaire. Its lack of inclusion within the pre-intervention questionnaire limited data analysis, and prevented it from being considered in relation to the proposed E-HBM. Whilst it should be noted that the majority of the participants' scores on the questionnaire were low suggesting God HLC did not appear to be important for the participants within the current study, it was not possible to explore this fully. Future research should collect GHLC scores pre-and post-intervention to explore the potential effect of God HLC on beliefs and behaviour surrounding BSE.

11.6 Study Contribution to Knowledge and Direction for Future Research

Notwithstanding the above limitations, the present study's findings are of theoretical importance. Although the study failed to confirm the predictive utility of the proposed E-HBM in relation to the frequency and proficiency of BSE, support was offered for a more complex theoretical framework as depicted in Figures 5 and 6.

Understanding the behaviour and beliefs of women with regard to BSE is likely to help health-care professionals develop more effective screening programmes and evaluate the effectiveness of interventions. This study provided insight into women's thoughts and feelings surrounding breast cancer and BSE, and the influence these have on their BSE behaviour. Five themes arose within qualitative data generated from the women: Previous Experience; BSE Irregularity; Perceived Susceptibility; Coping Style; and the Usability of the 5-Step Model of BSE. These themes highlighted the need for not only improved guidance and support with BSE, but the need for recognition of the personal, psychological, social and cultural factors surrounding BSE. Taking this into consideration one may suggest that perhaps an embodied approach to breast-cancer screening is needed. Within an embodied approach three points are emphasised: (1) the importance of subjective experience to understanding why people do things; (2) the fact that screening is an embodied practice, something an individual does to their breast; and (3) the importance of viewing the body as meaningful and relational, not simply an object to be manipulated, screened or treated (Lende & Lachiondo, 2009).

Following this approach, an individual's feelings and experiences rather than simply what they think is important in deciding about screening. Past research indicates that when making decisions about screening women draw on everyday experiences, on metaphorical thought - not simply abstract knowledge and statistical calculations of risk, and their own personal histories (Coreil, Wilke & Pintado, 2004; Gibbs and Franks, 2002; Lock, 1998; Skott, 2002; Thomas, 2004). Indeed, the women in this current study discussed the importance of their past experience and the experience of those close to them in influencing how they think and feel about BSE. They discussed the negative connotations of, and fear surrounding breast cancer, and their relationships with their body and breasts and the impact these have on their screening behaviour.

Following past researchers (Csordas, 2002; Thomas-MacLean, 2004), it was apparent in the current study that the body, at least for these women, was not purely a biological system. Instead it held meaning. In general the health-care system focuses only on the mechanical, biological body and it is often assumed that individuals are able to cognitively distance themselves from their bodies, or disembodiment in the same way as the doctor does (MacLachlan, 1997). There appears to be little recognition that this is not an inherent ability (Lende & Lachiondo, 2009) but rather a learned process that doctors themselves undergo through everyday experiences that occur in medical school (Good, 1994).

Likewise, in preventative health, people are generally assumed to have this disembodied, biomedical worldview and subsequently researchers infer that once a woman learns the importance of screening, the impulse to engage in this behaviour will naturally arise (Lende & Lachiondo, 2009); that the woman can easily become an objective examiner of her body. It was apparent in the current study, that this is not always the case. Whilst all the women were aware of the importance of BSE, this did not always lead to regular breast exams. Instead, the women expressed discomfort about looking and thinking about their breasts and how this made the engagement of BSE problematic. Furthermore, the mortality rates in the UK are relatively high compared to the rest of Europe (Berrino, Sant, Rosso, Lasota, Coebergh & Santaquiliani et al., 2007; Mayor, 2003) and it is proposed that is in part due to the advanced stage of the disease at first presentation (McCready, Littlewood & Jenkinson, 2005; Sant, Allermani, Capocaccia, Hakulinen, Aareleid, Coebergh et al., 2003). Perhaps discomfort surrounding looking at and thinking about their breasts may be further responsible for this late presentation.

Further to this, there is little recognition that screening is not only a means to detect disease but also an active choice that bears on the meaning of one's self, particularly since one's very life might change based on what is found (Gibbs & Franks, 2002; Hallowell, 2006). This seemed a particular issue for the women in the current study. The

women discussed the anxiety surrounding BSE and their fear of discovering a lump or sign of breast cancer. Similarly, they suggested a need to come to terms with the possibility that they may discover a sign of breast cancer and the need to remind themselves of the advantages of an early diagnosis. Within preventative health, an embodied approach provides a focus on women's experiences, in particular how women relate to their bodies and the multiple meanings their bodies can have. BSE is more than simply a technique that needs to be done; it carries meaningful implications and unanswered questions (Lende & Lachiondo, 2009).

Current breast health-promotion campaigns tend to focus on providing information on the benefits of being breast-aware, but they tend to fail to go beyond increasing awareness. Likewise, current breast-screening interventions tend to focus on improved access, improved education and improved health-care services. However, these approaches neglect to address a major issue in breast cancer, how women relate to their bodies and how their experiences shape both their thoughts and behaviour surrounding BSE. As highlighted within this current study, BSE is individualistic and women seem to respond differently. Women have different past experiences, family histories, coping styles and relationships with their bodies and any interventions designed to encourage long-term BSE need to consider this. There is a need for more information on how to examine, but researchers must also consider how BSE impacts women. The current study highlighted the impact past experience, encounters with medical professionals and the experience of others can have on BSE, and the differing coping styles women employ in order to deal with the threat of breast cancer. Moreover, the study suggested that with appropriate support and encouragement to form an improved relationship with their body and make BSE more routine, regular BSE can be encouraged.

Findings from this current study may serve as a framework for developing future BSE interventions. A number of important practical implications can be drawn from the present findings. First, given that a major obstacle in BSE was the 'non-salient nature' of BSE failed to encourage BSE, interventions should seek to help women incorporate BSE into their everyday lives. Although all the women within the current study had the intention to engage in BSE, they found it a challenge to remember and for many there was a need to be prompted to examine their breasts. However, it became apparent as the study progressed that incorporating BSE into behaviours they were already actively engaging in on a regular basis made the process of BSE easier and, in turn, facilitated regular BSE. Similarly, many of the women expressed their need for BSE to be incorporated into their current routines.

Interventions should seek to help women identify a time, place and situation within their current routines in which they can perform BSE and encourage them to be consistent in this to promote regular BSE. Likewise, interventions should include prompts to encourage BSE compliance. Past research has demonstrated the positive impact of prompts on the engagement of BSE (Agars & McMurray, 1993; Craun & Deffenbacher, 1987; Grady, 1984; Khokhar, 2009; Mayer & Fredenksen, 1986; Rutledge & Davis, 1988) and qualitative responses from the women within the current study suggest the potential positive effect of prompting women to examine their breasts. With the recent advances in computer and mobile technology and access to the Internet and considering the current popularity surrounding mobile phones, applications for mobile phones and tablet devices, and social networking sites perhaps BSE prompts could utilise this new technology. A recent study conducted with women in Delhi (Khokhar, 2009), demonstrates the potential positive effect prompts via text message may have on the engagement of BSE and current breast exam applications highlight the opportunity for new ways to encourage and provide support for BSE. Within the Delhi study women were trained in BSE with the help

of a lecture, video, demonstration of the technique using a breast model, and a feedback demonstration and following training, short text message reminders, were sent to the women at monthly intervals according to their last menstrual period or in the case of menopausal women the first day of every month. The text messages reminded the women to do their breast exam and asked them to reply to the text stating whether they had done the exam or not. After the first two months of sending reminder messages, the practice of BSE significantly increased. Whilst much more research is needed within this area before a firm conclusion can be drawn, the Delhi study highlights the potential for BSE prompts that utilise current technology and the need for future research to explore this further.

Moreover, over the past two decades, mobile phones have evolved considerably in both function and design, from simple call and text devices to the more sophisticated smartphones. Mobile phones are now more prevalent than computers or internet access across the world (Kolko, Rose & Johnson, 2007; Donner, 2008), and according to data from the International Data Corporation (IDC) the worldwide market for smartphones has grown by 39% (IDC, 2010). These figures indicate that not only has the adoption of mobile phones become almost universal but also that the market is rapidly shifting towards phones that are in fact pocket computers. Unlike traditional phones, smartphones allow the user to access the internet and install, configure and run specialised applications of their choice. Utilising these current developments in technology allows interventions to not only deliver informational messages and reminders at scheduled times (as in the Delhi study) but to also make health-related information visible every time a user picks up their phone through 'glanceable displays'. Whilst the use of 'glanceable displays' has yet to be explored in relation to BSE, results from a study investigating its use in relation to physical activity (Consolvo, Klasnja, McDonald, Avrahami, Froehlich, LeGrand et al., 2008) suggests the potential impact of such displays in relation to health behaviour change. Through the use of a garden display on the background screen of the phone, users were

able to see at a glance how active they had been that week, how varied their activities had been and whether they had obtained their weekly goal. Different types of flowers represented different types of physical activity and the user got a flower for every activity they engaged in. The garden was automatically updated either when the sensing device detected an activity or when the user manually 'journalled' a new activity. If users met their weekly goals a large butterfly appeared in the garden. As the garden was visible each time the individual used their phone, they had frequent encounters with feedback about their physical activity. After 3-months individuals who had this background display maintained their level of physical activity over the course of the study – including the winter holiday season while the activity of individuals without the background display significantly decreased during this period (Consolvo et al., 2008). Study interviews revealed that viewing the garden display throughout the day kept physical activity in the front of the individuals' minds. It appears 'glanceable displays' may be a promising avenue for facilitating health behaviour change and perhaps one which should be explored in relation to BSE. Given the none-salient nature of BSE and the great need for prompts identified in the current study, it is important to find ways to enable women to remember to examine their breasts regularly. Perhaps the use of 'glanceable displays' is one of the means in which this could be done.

At the end of 2010, over 17,000 smartphone health applications were available for consumers to download in major application stores and it is estimated that 500 million people worldwide, out of a total of 1.4 billion smartphone users, will be using health-related smartphone applications by 2015 (Research2guidance, 2012). The effectiveness of smartphone applications to promote health protective behaviours such as BSE is an emerging field of research and one which needs to be explored further but the theory behind using these devices is encouraging. Unlike desktop computers or even laptops, mobile phones are nearly always with the person. Many individuals are rarely more than a

few feet away from their mobile phones and more often than not they are in an individual's hand, pocket or purse (Klasnja & Pratt, 2012). The fact that mobile phones are so close at hand makes it possible to reach people any time of the day quickly and easily, without any effort from the phone holder. Moreover individuals' relationships with their mobile phones are often deeply personal (Venta, Isomursu, Ahtinen & Ramiah, 2008). Mobile phones are typically customised with user-selected ringtones and notification sounds, with images of loved ones and with cases and decorations that express the owner's style. Moreover, mobile phones are also used for a range of activities throughout the day from planners, calendars and email to social networking, checking finances and playing games and as a result phones often contain highly personal information, including pictures, intimate text message and financial information (Klasnja & Pratt, 2012). This personal nature of mobile phones may reduce the barriers to the adoption of, and increase acceptance to phone-based health interventions by integrating forms of health education and health promotion with a tool that is already an integral part of an individual's daily routine and to which they often have a positive emotional attachment to.

Furthermore, the combination of smartphones technical capabilities and the proximity to their owners provides phones with a great deal of knowledge about the user's current situation (Fogg, 2007). Through embedded sensing, for example GPS location tracking and access to the phone user's calendar, contacts and other personal information, mobile phone applications can infer where the user is and what they are doing. This knowledge in turn makes it possible to create just-in-time interventions that provide users with information or support when the support is most needed or most useful (Intille, 2004; Patrick, Griswold, Raab & Intille, 2008). This may be particularly useful in relation the encouragement of BSE, in that not only may applications be used to provide support on how to conduct a breast exam but they may be programmed to do so at a time when it is convenient for the user to engage in BSE.

Despite the advantages of utilising mobile phone technology and the wide range of health related smartphone applications available, there is limited research into the effectiveness of these applications to promote health behaviour change, particularly in relation to BSE. The Your Man Reminder developed by Rethink Breast Cancer, a non-profit health group based in Canada is one of a number of applications related to BSE and demonstrates the potential impact such application may have on encouraging and promoting BSE. The application features a range of 'dream men' for women to choose from, including the 'boy next door', the 'sports jock' and the 'business man' and after choosing the preferred man, the application automatically alerts an individual on their smartphone each month, reminding them to check their breasts. In addition to reminding women to do a regular breast exam, developers also suggest the application can be something of a 'virtual cheerleader' for women providing the phone owner with inspirational messages, such as, 'any guy would be lucky to have you' in addition to 'give your breasts some TLC'. The application also has an 'education' feature in which the importance of early detection is stressed to the phone owner and as a way to motivate other women to check their breasts, the application also includes a sharing feature which will allow users to let others know when they have done their monthly check and encourage others to do so through social networking sites.

Whilst much more research is needed, particularly in relation to BSE initial findings are encouraging. Utilising current technology advances may allow breast health promotion campaigns to engage women in a new way and enable women to incorporate BSE into their current routine in an easier and perhaps more enjoyable manner. This is an area future research should explore further.

Second, given that fear seemed to be a central factor disengaging some women from regular BSE, there is a need for interventions to acknowledge this fear and provide

knowledge, support and encouragement to help women overcome this and make BSE more routine. As BSE became more routine for the women within the current study, the process became easier and their negative feelings towards BSE decreased.

Third, given the discomfort some women experience looking at and thinking about their breasts there is a need for interventions that focus on making women feel more comfortable looking, touching and thinking about their breasts and which make breast awareness become a normal part of a woman's life. This could be achieved by encouraging women to look and feel their breasts whilst engaging in their current everyday activities, for example whilst in the shower or bath, getting dressed or applying moisturiser. As being aware of their breasts becomes more normalised through their engagement in these regular activities, they may find the process of BSE becomes easier and more enjoyable. The current study highlighted the potential for women to form an improved relationship with their breasts. Over the course of the study, the dislike and discomfort they experienced with their breasts seemed to become less problematic as looking and thinking about their breasts became more normalised, and as result BSE became more pleasant and regular. Similarly, interventions could further address this issue through the promotion of BSE as an activity couples can engage in together. Within the current study, one of the women expressed the positivity of involving her fiancé within her breast exams. Whilst she herself struggled with the thought of breast cancer and was uncertain whether she would be honest with herself if a change was to occur she was reassured by the presence of her partner.

Fourth, as previously discussed, there is little recognition that screening is not only a means to detect disease, but also an active choice that bears on the meaning of one's self, particularly since one's very life might change based on what is found (Gibbs & Franks, 2002; Hallowell, 2006). Many women worry about breast cancer, which is hardly

surprising given the attention that advocacy groups, celebrities, health professionals and the media have devoted to the disease and the distorted, exaggerated or inaccurate messages about breast cancer that have been portrayed in popular magazines (Blanchard, Erblich, Montgomery & Bovbjerg, 2002; & Burke et al., 2001). Past research has found the word cancer to be associated with inevitable death, terror, suffering, devastation, shock, incurability, unfairness and helplessness and to be described as the most painful condition, less understood medically and less preventable than heart disease, diabetes or AIDS (Katz, Hass, Parisi, Astone, McEvaddy & Lucido, 1987; Spiers et al., 1999). Similarly, Meyerowitz, Williams and Gessner, (1987) found that healthy individuals rated cancer as significantly less controllable than a fictitious disease that was described in exactly the same way as cancer. Breast cancer in particular, has been found to have strong social representations due to its severe implications of women's appearance, attractiveness and self-image (Lantz & Booth, 1998). There is a need for interventions to focus on displacing some of the fear and negative connotations surrounding breast cancer, and promote the positive outcomes of breast cancer and indeed some of the women within this current study, expressed this need for a positive focus of breast cancer.

This could be facilitated through the use of autobiographical accounts from breast-cancer patients, in which a more positive outlook of breast cancer is focused on and whereby breast-cancer patients suggest there is life after breast cancer. Through the autobiographical accounts women may be educated about breast cancer and the experience of breast cancer, perhaps dismissing myths and misconceptions, some of which may be preventing BSE. Moreover, these accounts may highlight that there is life after breast cancer; it does not have to result in death and, indeed, there can be some positive aspects to being diagnosed. Observing women discussing their experience of breast cancer and coping well may reduce the uncertainty surrounding breast cancer and

therefore alleviate some of the psychological barriers to performing BSE. Some of the women asked to view autobiographical accounts within the current study, highlighted the positive influence these accounts can have, through their description of how the accounts made them feel more positive about breast cancer and in turn BSE. These women further suggested there is a need for this positivity to be promoted not only to encourage BSE but to help those with breast cancer fight the disease.

Fifth, at present little instruction is available for women regarding how to examine their breasts. Yet, it became apparent in the current study there is a great need for BSE instruction and guidance. This is of particular importance considering the lack of or poor BSE instruction employed within the UK, Russia and China trials (Semiglazov, Moiseyenko, Manikhas, Protsenko, Kharikova, Popova et al., 1999; Semiglazov, Moiseyenko, Protsenko, Kharikova, 1996; Semiglazov, Sagaidak, Moiseyenko & Mikhailov, 1993; Thomas, Gao, Ray, Wang, Allison, Chen et al., 2002; Thomas, Gao, Self, Allison, Tao, Mahloch et al., 1997; & UK Trial of Early Detection of Breast Cancer Group, 1993, 1999) and the influential nature of these trials on health-care policy. As highlighted within Chapter 1, the medical profession questioned the utility of BSE because findings from these trials failed to provide evidence for reduced breast-cancer mortality following BSE and on this basis UK health authorities omitted BSE from their breast-cancer campaign and instead promote breast awareness (NHS, 2011). This move towards breast awareness is problematic, considering it was based on studies within which BSE instruction was poor and considering the great need for BSE instruction and guidance demonstrated within the current study.

Moreover, all three trials were based in the premise that instruction would result in good BSE. This is problematic, considering the 'non-salient nature' of BSE and the need for prompts highlighted with the current study, and past research (Agars & McMurray, 1993;

Craun & Deffenbacher, 1987; Grady, 1984; Khokhar, 2009; Mayer & Fredenksen, 1986; Rutledge & Davis, 1988). As previously discussed, all the women within the current study expressed a desire to examine their breasts but the 'non-salient nature' of BSE failed to encourage examinations and for many it was a challenge to remember to engage in BSE regularly. It appeared that BSE was not something most of the women thought about regularly, and instead they needed to be prompted to examine their breasts. It is likely that the women within these trials may have experienced BSE in a similar manner and the lack of prompts provided within the trials may have prevented the women from engaging in regular BSE. Likewise, compliance to BSE practice was low or not measured sufficiently by all the researchers. In the UK community, in which this was evaluated, less than one half (47%) were doing BSE after 1 year. In Russia, only 18% of the women were practising BSE at 4 years and 34% were lost in the follow-up at 9 years (Kearney & Murray, 2009) and in Shanghai only 49% of women were attending supervised sessions at Year Five. This is particularly problematic considering it is necessary to not only inform and instruct women professionally and intensively on BSE, but to also ensure long-term compliance.

Based on these methodological considerations it may be erroneous to abandon BSE as an efficacious BSE screening method. There is a need for UK health authorities to not only promote breast awareness, but BSE too. Women need instruction and guidance on how to check and what changes to look for, and simply promoting breast awareness is not enough to enable women to do this. The current study highlighted the positive impact of providing BSE support and the utility of the 5-step BSE technique in encouraging and maintaining a thorough and regular breast exam. Interventions are needed in which detailed BSE guidelines based on the 5-step BSE technique are provided to women.

Sixth, in order to develop appropriate BSE screening behaviours, visual materials should be employed. In line with past research (Mayer, 2001), the women within the current study expressed the advantageous nature of the pictures within the static version and the video footage within the video-enhanced version in providing much needed reassurance regarding the accuracy of the BSE technique and clarification on aspects of the technique they were unsure about. Moreover, as both BSE supports (video-enhanced and static) include visual materials and were effective, interventions should choose whichever method is appropriate and/or accessible for the training environment.

Lastly, as the use of the Internet increases (according to recent estimates over 65% of people in the UK are using the internet at home [National Statistics, 2009] and many of these may have looked on line for health information), the opportunity for broad dissemination of proven interventions is ripe. Web-based approaches provide a communication channel that is easily accessible for most people, through their home, work or local libraries. There is evidence for the high acceptance of multimedia interactive programmes to enhance treatment decision-making among prostate-cancer patients (Diefenbach & Butz, 2004) and for the effectiveness of a Web-based intervention on behavioural outcomes (Wantland, Portillo, Holzemer, Slaughter & McGhee, 2004). Likewise, the online nature of the current study was effective in providing all the information and materials needed to encourage regular and proficient BSE. Future interventions should explore the nature of providing interventions within an online setting further.

11.7 Conclusion

As a result of the failure of three trials within the UK, Russia and China (Semiglazov et al., 1993; 1996; 1999; Thomas et al., 1997; 2002; & UK Trial of Early Detection of Breast Cancer Group, 1993; 1999) to provide evidence for reduced breast-cancer mortality

following BSE, the medical profession have questioned the utility of BSE and as a result, NHS guidelines at present no longer advocate BSE and instead promote breast awareness. This move towards breast awareness is problematic since it was based on the findings of methodologically flawed studies within which BSE instruction was poor and considering the great need for BSE instruction and guidance demonstrated within the current study. Women express concern over their own ability to discover signs of breast cancer and suggest a great need for guidance on how to examine their breasts thoroughly. Likewise, they express frustration at not been given advice about or been shown by health-care professionals how to examine their breasts and suggest the need for BSE training to be readily available. Women need instruction and guidance on how to check and what changes to look for, and simply promoting breast awareness is not enough to enable women to do this. There is a need for UK guidelines to revert back to past breast-screening guidelines and promote BSE, in addition to breast awareness. Moreover, given the discomfort some women experience looking at and thinking about their breasts there is a need for breast awareness to become more normalised. Women need to be encouraged to look and feel their breasts whilst engaging in their current everyday activities, for example whilst in the shower or bath, getting dressed or applying moisturiser to improve their relationship with their breasts.

Increasing and improving the rate of which BSE is engaged in and the proficiency of these exams depends largely on educating women on how to examine, increasing their level of confidence surrounding BSE and improving women's relationship with their breasts. Given the predictive utility of pre-intervention confidence in predicting both BSE frequency and proficiency at the start of the study, the increased levels of confidence reported post-study and the positivity of the 5-step BSE support in providing the guidance needed to conduct a more pleasant, comprehensive and proficient breast exam, interventions are needed in

which detailed BSE guidelines based on the 5-step BSE technique are provided to women. Both the static and the video-enhanced support were found to be effective in encouraging and maintaining a more frequent and proficient breast exam within the women in the current study and therefore interventions should select whichever method is appropriate and/or accessible for the training environment. Moreover, these interventions should utilise current advances in technology and investigate ways to prompt women to examine their breasts on a regular basis perhaps through mobile phone technology or social networking sites.

There is a need for future interventions to not only provide information regarding and instruction for BSE, but to help women overcome personal, psychological, social and cultural barriers that prevent BSE. Interventions, designed with this recognition of women's breasts and the role of personal, psychological, social and cultural factors in BSE in mind are likely to lead to the development of effective interventions to promote regular BSE as part of being 'breast-aware'. This is particularly important given that mammography screening may not be effective (Crossing & Mansezewicz, 2003) or recommended for younger women (Cancer Research UK, 2008), and that BSE may be beneficial as part of breast awareness, in increasing a woman's awareness of their breasts. Survival rates for breast cancer in the UK have improved over the last 20 years, such that eight out of ten breast-cancer patients now survive beyond 5 years (Cancer Research UK, 2008). Improving women's relationships with their breasts and increasing the detection of the early signs of breast cancer through the performance of BSE is likely to contribute to this trend.

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Enclosed DVD: Containing the following;

1. Data File of Complete Thesis and Appendices
2. Reflective Journal Data File
3. SPSS Output Files
4. Quantitative Data File
5. Qualitative Data File
6. Study Website
7. Video Footage for Video Enhanced BSE Support
8. Posters and Slides from Study Dissemination

Appendix 1: Participant Demographics for Questionnaire Pilot

Table A1.1

Demographic Data for Participants of Questionnaire Pilot

Participant Number	Age	Marital Status	Ethnic Origin
7	51	Married	White British
3	28	Married	White British
8	24	Single	White British
21	21	Single	White British
11	50	Married	White British
13	24	Co-habiting	White British
1	25	Single	White
9	32	Single	White
5	23	Single	White British
14	24	Co-habiting	White British
25	51	Married	White British
6	18	Single	White British
4	24	Co-habiting	White British
27	23	Single	White British
20	65	Married	White British
16	52	Married	White British
15	49	Married	White British
19	24	Co-habiting	White British
29	46	Married	White British
28	42	Divorced	White British
10	53	Married	White
2	20	Single	White British
17	25	Single	White British
30	19	Single	White British
41	24	Single	White British
37	48	Married	White British
44	49	Divorced	White British
42	20	Single	White British
35	55	Married	White British
32	24	Co-habiting	White British
36	24	Single	White British
33	24	Co-habiting	White British

Appendix 2: Questionnaire Pilot Study Quantitative Raw Data

Table A2.1

Responses to Questions 1 to 4.

Participant Number	Q1: Time to complete	Q2: How did you find completing the questionnaire	Q3: Was it possible to complete all questions?	Q4: Completing the questionnaire was easy
7	50	3	Yes	3
11	50	3	Yes	3
13	60	3	Yes	4
9	40	3	Yes	4
1	60	3	No	4
5	15	5	No	5
25	55	4	Yes	4
6	25	3	Yes	4
4	32	4	Yes	4
27	40	3	Yes	4
20	35	3	Yes	3
16	50	3	Yes	3
15	50	4	No	4
19	35	3	Yes	3
29	50	4	Yes	4
28	60	3	Yes	4
10	35	2	Yes	3
2	25	5	Yes	5
17	35	3	No	3
30	35	4	Yes	5
41	35	3	Yes	4
21	25	3	Yes	4
3	25	2	Yes	2
37	25	3	Yes	3
8	20	2	Yes	3
44	40	4	No	4
42	25	4	Yes	3
35	60	5	Yes	5
32	45	3	Yes	2
36	30	3	Yes	2
14	10	4	Yes	4
33	40	2	Yes	2

Table A2.2

Responses to Questions 5 to 9.

Participant Number	Q5: Becoming skilful at completing the questionnaire was easy	Q6: The questionnaire was easy to navigate	Q7: I found completing the questionnaire enjoyable	Q8: The actual process of completing the questionnaire was pleasant	Q9: I had fun completing the questionnaire
7	3	4	3	3	3
11	4	5	4	4	4
13	3	5	2	3	2
9	4	4	3	3	3
1	4	5	3	4	3
5	5	5	2	2	2
25	4	4	4	4	3
6	3	4	3	3	3
4	2	4	3	3	3
27	4	4	3	3	3
20	4	4	3	4	4
16	3	4	3	3	3
15	3	5	3	3	2
19	3	4	3	3	3
29	3	4	3	4	3
28	4	5	3	4	3
10	4	4	3	3	2
2	4	5	4	4	3
17	4	4	3	3	3
30	4	5	4	4	4
41	4	4	4	4	2
21	4	4	3	3	3
3	3	4	4	4	4
37	4	4	4	4	3
8	3	4	4	3	3
44	4	4	4	4	3
42	4	4	4	4	4
35	5	5	4	5	4
32	2	4	3	3	3
36	3	4	3	3	2
14	4	4	3	3	3
33	4	5	3	3	3

Appendix 3: Questionnaire Pilot Study Qualitative Responses

Table A3.1

Questions participants were unable to complete and why.

Participant Number	Q3a If no: what questions did you find you were unable to complete.	Q3b If no: why were you unable to complete it.
1	<p>Even though I had to tick an answer as I would otherwise have been unable to continue, I was unsure as to the meaning of the question asking "Am I a steady person" as I was unsure of the context and meaning.</p> <p>I also found the description of breast tissue as "dense" quite difficult to relate to, though am unsure what other descriptions might be used.</p> <p>I was also unable to fully answer any questions regarding medical history of blood relatives as none are available to me.</p> <p>Also I don't have a car so in the question regarding would I do all the safety checks before a long journey I can only give the answer based on what I assume I would do in that situation, not what I actually do.</p> <p>I also in the section about the people close to you that could help etc, was slightly unsure if my answers should have been reflective of how much they would want to help if they were able, or how much they were actually able to help taking into account how far they lived, financial situations etc. For example, my sister, HE, would WANT to help me a great amount if I was confined to bed, or needed money or a trip to the doctors etc, however she lives in the south of England studying and lives on a student budget, so would only be ABLE to help me a moderate amount.</p>	Oops sorry have written a small essay above explaining why.
5	About losing someone close to me in the past year	I have not lost anyone close to me in the past year
15	The questions about losing someone close.	Just because I hadn't!
17	Never had a member of my family suffer from breast cancer.	
44	Only questions that were not relevant to myself.	

Appendix 3

Table A3.2

Further comments

Participant Number	Further comments or suggestions for improvements
13	Overall the survey was easy to follow and complete.
4	I think there are some leading questions.
20	I answered neutral for thing I was unsure about. I hope this was the right thing to do!
15	A few questions seemed to ask the same thing in a different form of words. This may be necessary as a control, but I found it a little confusing - but then it may just be me! It made me feel very good listing my support network - and very blessed.
10	Didn't understand the significance of some of the questions. maybe give people more background to the reasoning of the questions may have helped
41	I wouldn't put "never" in a question - it is such a strong word, maybe 'I would not' instead of 'I would never'- but I know how qualitative research wants you to word questions appropriately i.e. whether you agree or disagree! Also, it has made me wonder about breast cancer now - I would love to read the research/results once they are published.
3	The questionnaire was great and covered all the major points, though It might be worth having a few boxes like this for people to elaborate on their answers. I wouldn't say I found the questionnaire easy, due to the nature of the topic - My knowledge in this area is limited and I think that was why I didn't find it easy. I liked that the questionnaire was online, that made it much easier to complete. Your questions certainly made me think and I liked your links with the consent form they were useful and informative.
42	I think there should be a "don't know" box on the questions that range from agree to disagree as well as neutral, as sometimes I feel neutral was not appropriate to answer some of the questions.

Appendix 4: Pre-Intervention Questionnaire

In order to ensure copyright restrictions are considered the full questionnaire is not available here, instead an example of the questions is presented. Full question items may be obtained by consulting the following references;

- (1) BTAQ: Brief Technology Acceptance Questionnaire (Venkatesh, Morris, Davis, Davis, & Walton, 2003; Venkatesh & Speier, 2000).
- (2) BSE P and F Q: BSE Frequency/Proficiency Questionnaire (Champion, 1989, 1990).
- (3) HBM: Health Beliefs: Health Belief Model Scale (Champion, 1984;1993).
- (4) BCWS: Breast Cancer Worry: Breast Cancer Worries Scale (McCaul, Branstetter, O'Donnell, Jacobson and Quinlan, 1998).
- (5) STAI: General Trait Anxiety: State Trait Anxiety Inventory – Trait Subsection (Spielberger, Gorsuch, & Lushene,1964).
- (6) MHLC: Health Locus of Control: Multidimensional Health Locus of Control Scale (Wallston, Wallston & DeVellis, 1978).
- (7) IPQ-RH: Illness Perceptions and Representations: Illness Perception Questionnaire Revised Healthy Edition (Figueiras & Alves, 2007).
- (8) Norbeck SS Q: Social Support: Norbeck Social Support Questionnaire (Norbeck, Lindsey & Carrieri, 1983).
- (9) M-C: Marlowe-Crowne Social Desirability Scale (M-C) (Crowne & Marlowe, 1960).

=====

Pre-study Questionnaire

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Pre- study Questionnaire - Welcome

=====

Thank you for agreeing to take the time to complete this questionnaire. The questionnaire has ten sections and answering the questions should take approximately 40 minutes. The questionnaire will start by asking you for some personal details (such as age, ethnic origin etc) and then follow with some questions designed to assess your thoughts and feelings regarding breast cancer, breast self-examination and health and illness.

I would be grateful if you could answer all the questions honestly. These questions are not a test and there are no right or wrong answers just your own views.

Appendix 4

Your responses will be kept anonymous and treated in confidence at all times.

=====

Demographic Details

=====

Please indicate your response to the following questions.

1. Participant No (This is the number allocated to yourself at the start of the study).
2. Sex
3. Age (in years)
4. Ethnic Origin
5. Other (please state)
6. Marital Status
7. No of children
8. Region You Currently Reside In
9. Other (please state)
10. Highest Education Qualification Obtained
11. Employment Status
12. If unemployed - what is the length of your unemployment?
 In Years _____
 In Months _____
13. If employed - what is your area of employment?
14. Religious Orientation
15. Contraceptive Pill
16. If you are currently taking it, how long have you been doing so for?
 In Years _____
 In Months _____
17. Are you currently... Menopausal or Non menopausal?
18. If menopausal; how old were you when you started the menopause?
 In Years _____

Appendix 4

19. Age at start of menstruation

In Years _____

20. Have any of your blood relatives had breast cancer

Yes

No

Family history not available

21. If Yes who? (Tick all that apply)

Grandmother

Mother

Sister

Daughter

Auntie

Cousin

Grandfather

Father

Brother

Son

Uncle

Other

22. Other (please state)

23. Have any of your non-blood relatives or friends had breast cancer?

Yes

No

24. If Yes who? (Type all that apply)

25. Bra Cup Size

26. Does your breast tissue feel ... loose or dense (firm)?

=====

BTAQ

=====

Please show your level of agreement with each of the following statements by selecting one response per statement only.

1. I would find a web site useful for finding information

- Strongly disagree
- Disagree
- Neutral
- Agree
- Strongly agree

2. Using a web site would enable me to accomplish tasks more quickly when finding information

- Strongly disagree
- Disagree
- Neutral
- Agree
- Strongly agree

3. Using a web site would enhance my effectiveness in finding information

- Strongly disagree
- Disagree
- Neutral
- Agree
- Strongly agree

=====

BSE P & F Q

=====

Please indicate your response to the following questions.

Appendix 4

1. Have you ever heard of breast self-examination?

- 1. Yes
- 2. No (Skip to the end of these questions)
- 3. Don't know

2. Have you ever done breast self-examination?

- 1. Yes
- 2. No (Skip to the end of these questions)
- 3. Don't know

3. During the past year how many times did you examine your breasts for breast cancer?

- 1. Examined 0 time
- 2. Examined 1 time
- 3. Examined 2 times
- 4. Examined 3 times
- 5. Examined 4 times
- 6. Examined 5 times
- 7. Examined 6 times
- 8. Examined 7 times
- 9. Examined 8 times
- 10. Examined 9 times
- 11. Examined 10 times
- 12. Examined 11 times
- 13. Examined 12 times
- 14. Examined more than 12 times

Please think about the last time you examined your breast when answering the next set of questions.

4. When doing breast self-examination, how do you feel your breasts? Do you use ...

- 1. The palm of your hand
- 2. The tips of your fingers

Appendix 4

3. The flat part of your fingers (pads)

5. When doing breast self-examination how many fingers do you use?

1. 1

2. 2

3. 3

4. 4

=====

HBM

=====

Please show your level of agreement with each of the following statements by selecting one response per statement only.

1. I know how to perform breast self-examination

Strongly disagree

Disagree

Neutral

Agree

Strongly agree

2. I am confident I can perform breast self-examination correctly

Strongly disagree

Disagree

Neutral

Agree

Strongly agree

3. If I were to develop breast cancer I would be able to find a lump by performing breast self-examination

Strongly disagree

Disagree

Neutral

Agree

Appendix 4

Strongly agree

4. I am able to find a breast lump if I practise breast self-examination alone

Strongly disagree

Disagree

Neutral

Agree

Strongly agree

=====

BCWS

=====

Please indicate your response to the following questions.

. 1. How often do you worry about breast cancer?

Not at all

Almost all the time

2. How many days out the last 7 did you worry about breast cancer?

0

1

2

3

4

5

6

7

3. Does breast cancer worry affect your mood?

Not at all

Appendix 4

()

()

()

() Almost all the time

4. Does breast cancer worry affect your performance of daily activities?

() Not at all

()

()

()

() Almost all the time

=====

STAI

=====

A number of statements which people have used to describe themselves are given below. Read each statement below and then select the appropriate response to indicate how you generally feel. Please select one response per statement only.

1. I feel pleasant

() Almost never

() Sometimes

() Often

() Almost always

2. I feel nervous and restless

() Almost never

() Sometimes

() Often

() Almost always

3. I feel satisfied with myself

() Almost never

() Sometimes

Appendix 4

Often

Almost always

=====

MHLC

=====

Please show your level of agreement with each of the following statements by selecting one response per statement only.

1. If I get sick, it is my own behaviour which determines how soon I get well again.

Strongly disagree

Moderately disagree

Slightly disagree

Slightly agree

Moderately agree

Strongly agree

2. No matter what I do, if I am going to get sick, I will get sick.

Strongly disagree

Moderately disagree

Slightly disagree

Slightly agree

Moderately agree

Strongly agree

3. Having regular contact with my doctor is the best way for me to avoid illness.

Strongly disagree

Moderately disagree

Slightly disagree

Slightly agree

Moderately agree

Strongly agree

4. Most things that affect my health happen to me by accident.

- Strongly disagree
- Moderately disagree
- Slightly disagree
- Slightly agree
- Moderately agree
- Strongly agree

=====

IPQ-RH

=====

Please indicate whether you believe the symptoms below are related to breast cancer

1. The presence of a lump or thickening in an area of the breast or armpit

- Yes
- No

2. Dimpling of the skin in the breast region

- Yes
- No

3. A change in the size or shape of a breast or nipple

- Yes
- No

4. A blood stained discharge from the nipple

- Yes
- No

5. A rash on a nipple or the surrounding area

- Yes
- No

6. Unusual pain in the breast

- Yes

Appendix 4

No

Please show your level of agreement with each of the following statements by selecting one response per statement only.

7. Breast cancer lasts for a short time

Strongly disagree

Disagree

Neutral

Agree

Strongly agree

8. Breast cancer lasts for a long time

Strongly disagree

Disagree

Neutral

Agree

Strongly agree

9. Breast cancer passes quickly

Strongly disagree

Disagree

Neutral

Agree

Strongly agree

=====

Norbeck SS Q

=====

Please list each significant person in your life in the first column. Consider all the persons who provide personal support for you or who are important to you.

Use only first names or initials, and then indicate their relationship to you in the second column, as in the following example;

Appendix 4

Example;

First Name or Initials	Relationship
1. Mary T	friend
2. Bob	brother
3. MT	mother

Use the following list to help you think of the people important to you, and list as many people as apply in your case;

Spouse or partner

Family members or relatives

Friends

Work or school associates

Neighbours

Health care providers

Counsellor or therapist

Minister/ priest/ rabbi

Other

You do not have to use all 24 spaces. Use as many spaces as you have important people in your life. When you have finished your list, you are ready to move onto questions 1 to 8 (columns 3 - 10)

For each person listed, please answer the questions by writing in the number that applies.

<u>For questions 1 - 6</u>	<u>For question 7</u>	<u>For question 8</u>
0 = not at all 1 = a little 2 = moderately 3 = quite a bit 4 = a great deal	1 = less than 6 months 2 = 6 to 12 months 3 = 1 to 2 years 4 = 2 to 5 years 5 = more than 5 years	5 = daily 4 = weekly 3 = monthly 2 = a few times a year 1 = once a year or less

Appendix 4

	First Name or Initials	Relationship	Question 1: How much does this person make you feel liked or loved?	Question 2: How much does this person make you feel respected or admired?	Question 3: How much can you confide in this person?	Question 4: How much does this person agree with or support your actions or thoughts?	Question 5: If you needed to borrow £10, a ride to the doctor, or some other immediate help, how much could this person usually help?
1	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
2	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
3	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
4	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
5	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
6	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
7	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
8	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
9	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
10	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
11	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
12	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
13	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
14	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
15	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

	First Name or Initials	Question 6: If you were confined to bed for several weeks, how much could this person help you?	Question 7: How long have you known this person?	Question 8: How frequently do you usually have contact with this person? (e.g phone calls, visits or letters)
1	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
2	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
3	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
4	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
5	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
6	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
7	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
8	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
9	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
10	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
11	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
12	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
13	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
14	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
15	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

During the past year, have you lost any important relationships due to moving, job change, divorce, separation, death or some other reason?

() No

() Yes

Appendix 4

If you have lost important relationships during this past year;

Please indicate the number of persons from each category you have lost.

Spouse or partner _____

Family members or relatives _____

Friends _____

Work or school associates _____

Neighbours _____

Health care provider's _____

Counsellor or therapist _____

Minister/priest/rabbi _____

Other _____

Overall how much of your support was provided by these people who are no longer available to you?

- None at all
- A little
- A moderate amount
- Quite a bit
- A great deal

=====

M - C

=====

Please indicate whether you believe the statement to be true for you by selecting either true or false for each of the following statements.

1. Before voting I thoroughly investigate the qualifications of all the candidates.

- True
- False

2. I never hesitate to go out of my way to help someone in trouble.

- True
- False

Appendix 4

3. It is sometimes hard for me to go on with my work if I am not encouraged.

True

False

4. I have never intensely disliked someone.

True

False

=====

Thank You!

=====

Thank you once again for taking the time to complete these questions.

Best Wishes

Nicola

Appendix 5: Post-Intervention Questionnaire

The post-intervention questionnaire was similar to the pre-intervention questionnaire but with the omission of the demographic section and the addition of 9 study evaluation questions and the incorporation of the GHLC subscale within the Multidimensional Health Locus of Control Scale and study evaluation questions.

19. If my health worsens, it is up to God to determine whether I will feel well again.

- Strongly disagree
- Moderately disagree
- Slightly disagree
- Slightly agree
- Moderately agree
- Strongly agree

20. Most things that affect my health happen because of God.

- Strongly disagree
- Moderately disagree
- Slightly disagree
- Slightly agree
- Moderately agree
- Strongly agree

21. God is directly responsible for my health getting better or worse.

- Strongly disagree
- Moderately disagree
- Slightly disagree
- Slightly agree
- Moderately agree
- Strongly agree

22. Whatever happens to my health is God's will.

- Strongly disagree
- Moderately disagree
- Slightly disagree
- Slightly agree
- Moderately agree
- Strongly agree

23. Whether or not my health improves is up to God.

- Strongly disagree
- Moderately disagree
- Slightly disagree
- Slightly agree
- Moderately agree
- Strongly agree

24. God is in control of my health.

- Strongly disagree
- Moderately disagree
- Slightly disagree

Appendix 5

- Slightly agree
- Moderately agree
- Strongly agree

=====
The Study
=====

1. Please describe if and how your awareness of your breasts has changed over the course of this study?

2. As part of this study you were asked to examine your breasts 6 times over a 3 month period. Were you able to do this?
 - Yes
 - No

If no please try to describe why

If no, how many times did you examine your breasts?

3. Please describe how you found examining your breasts over the course of this study

4. Were you able to follow all aspects of the examination procedure with ease?

5. Did you enjoy following the instructions to examine your breasts? Please discuss why

6. Please discuss what you think about the breast self-examination technique you have been doing

7. Please describe what you think about breast self-examination generally

8. Has, how you think about breast self-examination generally changed throughout the study. If so please try to describe how and why

9. Do you have any further comments or thoughts connected to the study?

=====
Thank you for taking part in the study
=====

You have now come to the end of the study. Thank you once again for taking the time to complete these questions. All the information gathered in this study will remain confidential and your identity will not be referred to in any written report following this study.

You have the right to withdraw your data anytime up until 1st October 2010 and can do so by emailing the researcher Nicola Smith at g7079216@live.tees.ac.uk. You can also withdraw your data by leaving or posting a letter to the researcher at the reception of the school of Social Sciences and Law, Teesside University, Middlesbrough, TS13BA. You do not need to provide your name if you wish to withdraw; please instead include your participant number.

Thank you very much for participating in this study and if you have any other questions or queries relating to this study please feel free to contact me at the above email address. Once all the results are ready they will be made available at www.breast-aware.co.uk This is expected to be in October 2011. If you would like me to email results of the study to you please leave your email address in the box below.

Thanks and Best Wishes Nicola

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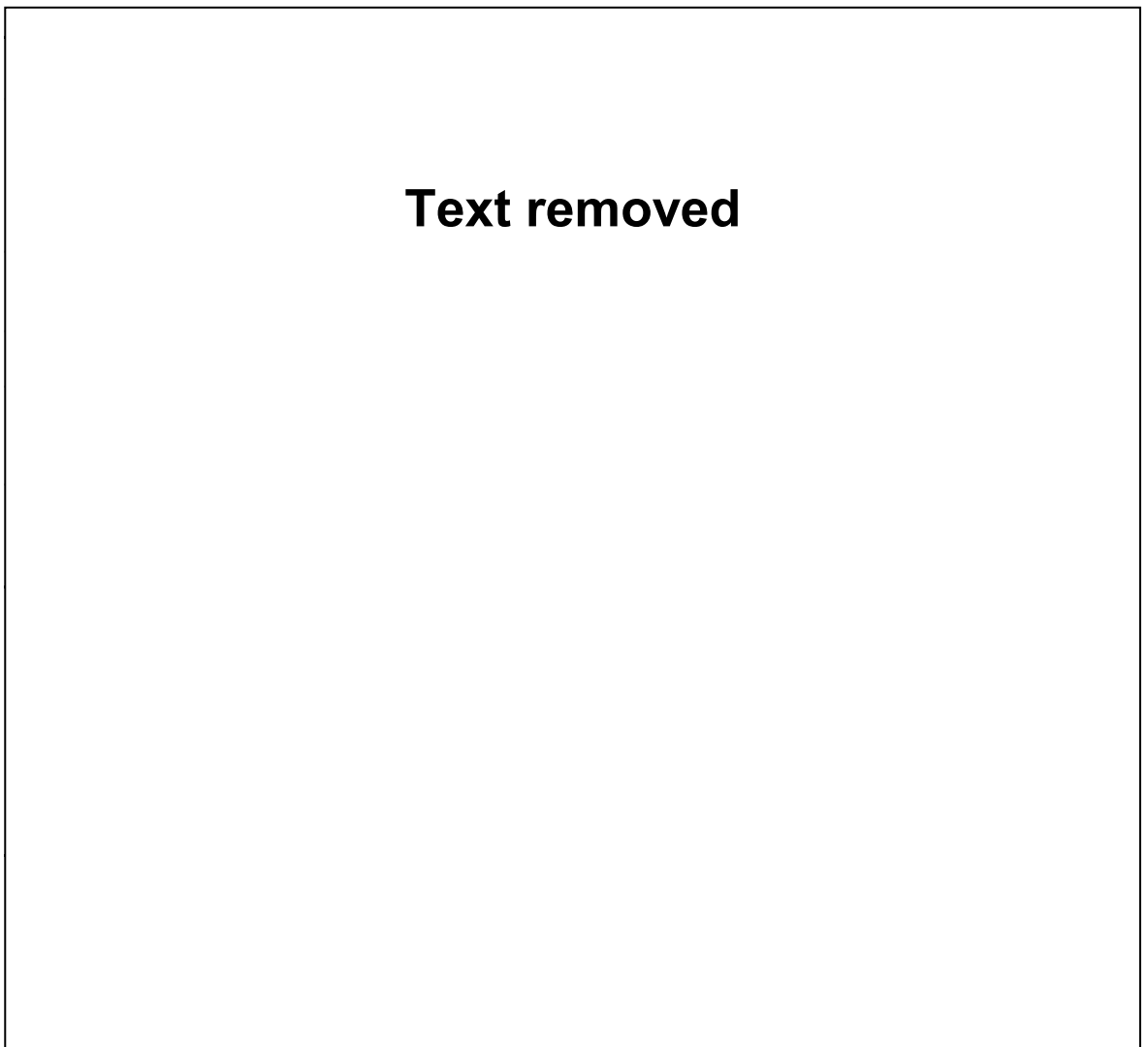
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Appendix 7: Text Based BSE Instructions

An instructional video provided by Aetna Intelli-health, with medical content reviewed by the Harvard Medical School Faculty was selected to form the video aspect of the programme. Similarly the text of the programme was based on instructions provided by Aetna Intelli-health but with the incorporation of some further information regarding BSE for different breast sizes and a description of lymph nodes. This additional information was added to provide the women with more information and thus aid them in their examination.

The text based BSE instructions used within both the static and multimedia support are presented below with the additional information highlight in red.

Looking



Feeling

The second part in performing a breast self-exam involves feeling your breasts.

Examining the breasts can be tricky for some women, particularly those with dense or firm breast tissue. The breast is constructed like an orange; you'll feel segments, and that can be scary but it is important to remember that is normal. You need to examine your breasts regularly to become familiar enough with your own body to know what is normal for you. Feeling your breasts regularly will allow you to do this.

It is also important to examine your breasts both standing up and laying down. Masses in the lower part of the breast may be more easily felt when lying down and masses in the upper part of the breast may be easier to detect whilst standing up and by examining your breasts in both positions you are giving yourself the best chance to find any possible problems. If you have large breasts you may need to spend longer examining your breasts than those women with smaller breasts. It is important that you cover the whole breast area including the breast itself, the surrounding area and the area between your breast and underarm including the underarm itself. To ensure you cover the whole area take your time and follow a definite pattern.

Text removed

Step 4 - Feeling Your Breasts Using the Circular Technique Whilst Lying Down

Text removed

Text removed

Lymph nodes are small rounded structures that are present at various points in the body including the armpit. Their function is to produce disease-fighting white blood cells and filter out harmful microorganisms and toxins. Breast cancer can cause the lymph nodes in the armpit to become enlarged when the breast itself seems perfectly normal so it is important to ensure you always include the armpit when examining your breasts. Most lymph nodes cannot be felt until they become swollen.

Text removed

Step 4 - Feeling Your Breasts Using the Line Technique Whilst Lying Down

Text removed

Lymph nodes are small rounded structures that are present at various points in the body including the armpit. Their function is to produce disease-fighting white blood cells and filter out harmful microorganisms and toxins. Breast cancer can cause the lymph nodes in the armpit to become enlarged when the breast itself seems perfectly normal so it is

important to ensure you always include the armpit when examining your breasts. Most lymph nodes cannot be felt until they become swollen.

Text removed

Step 5 - Feeling Your Breasts Using the Circular Technique Whilst Standing Up

Again you can choose to use either the circular or line technique to examine your breasts but this time standing up.

Text removed

Lymph nodes are small rounded structures that are present at various points in the body including the armpit. Their function is to produce disease-fighting white blood cells and filter out harmful microorganisms and toxins. Breast cancer can cause the lymph nodes in the armpit to become enlarged when the breast itself seems perfectly normal so it is important to ensure you always include the armpit when examining your breasts. Most lymph nodes cannot be felt until they become swollen.

Text removed

Step 5 - Feeling Your Breasts Using the Line Technique Whilst Standing Up

Text removed

Text removed

Lymph nodes are small rounded structures that are present at various points in the body including the armpit. Their function is to produce disease-fighting white blood cells and filter out harmful microorganisms and toxins. Breast cancer can cause the lymph nodes in the armpit to become enlarged when the breast itself seems perfectly normal so it is important to ensure you always include the armpit when examining your breasts. Most lymph nodes cannot be felt until they become swollen.

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Appendix 8: Autobiographical Accounts

Autobiographical Accounts Set 1

Woman 1 (Health talk online Breast Cancer Interview 2)

Age at Interview: 57

Age at Diagnosis: 54

Brief outline: Diagnosed with breast cancer in 1998. Had a lumpectomy and was given chemotherapy, radiotherapy and Tamoxifen.

Comments on the increased risk of developing breast cancer if other family members have had it.

I would like to know why we all get breast cancer, you know. I think we all go through, when we're diagnosed, you go through just about everything as to the reasons why. I have talked to the genetics department about whether in fact my daughter and my sister's two daughters are sort of, may well get breast tumours, and both of my sister and myself it was post-menopausal, so it wasn't, it wasn't sort of earlier than that. But evidently last, the year previously to when I spoke to them, they said that if there had been 3 members in the family that had had a breast tumour then they would've deemed us to be an at-risk category. But because of budget cuts they now had to increase it to four, which I thought was quite interesting (laughs). So all I can do about the girls in the family is that they should be checked regularly and I think I'd probably tell the whole world that they should be, all the women in the world that I meet that: "Have you examined your breasts? Do make sure that you do. "I do on a regular basis. And go for breast screening when it comes along as well."

Link to video

http://www.healthtalkonline.org/myflv.swf?myFlv=vid_bca02_DIC.flv

Describes switching off from the news of her diagnosis.

It was a very strange experience. I felt as though I was sitting in the corner by the window, it was rather like an out of body experience, and when I came back, you know, I came back to reality, I kept trying to put myself back in the seat I was in but I kept going back to the window again. I think everybody thought I was taking it very well, I was very controlled.

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And fortunately I had a friend with me again because at that point I switched off completely. I heard, I've always heard that people seeing a doctor can switch off from bad news, I actually didn't realise I'd done it but I'd had one sentence come out of him and I completely blanked.

Link to video

http://www.healthtalkonline.org/myflv.swf?myFlv=vid_bca02_DIP.flv

Explains that she now works part time to enable her to do more of the things she enjoys.

I felt great relief that I'd got through it and I wanted to get on with my life and I wanted to do all the things that I'd planned to do. I had, my lifetime dream was to go to Peru and Bolivia which I was going to do the previous year and had to cancel. And my goal was that, this was January when I finished, that I was going to go and do this in September, and I was going to get fit, and I was going to go and so I did. And I've been and I've done that (laughs) in fact. So that was a wonderful experience and I've done lots of things since. I think the one thing I have done is I stopped working full time and I'm now working in a job share so that I have more time for me, so I can go out and meet friends and do the things I want to because it makes you look at the world and your life in a different way.

Link to video

http://www.healthtalkonline.org/myflv.swf?myFlv=vid_bca02_LBC.flv

Woman 2 (Health talk online Breast Screening Interview 18)

Age at Interview: 39

Background: A medical secretary. Married with 2 children.

Brief outline: Discovered a lump at age 36, which was cancerous. Had treatment for invasive breast cancer. Now has annual mammograms.

She discusses finding a breast lump

What happened was I actually found the lump myself, I was in the shower at the time, and I found this lump because I did my own examinations, more or less every month I did

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them, it was a routine thing. I found the lump and I thought "oh my god, what is this". When I came out of the shower, I asked my husband to check it as well. He couldn't feel anything at all, so I went to work and I talked it over with a couple of girls. They basically just said "oh, could be a cyst and nothing more than that, but phone up the doctor and find out". So I did. I made an appointment, luckily I got an appointment very quickly with her, I explained to the receptionist what was going on. I went to the doctor explained that I had found a lump, she felt the lump and said "right, OK, we'll write a letter to the hospital", which she did.

Link to video

http://www.healthtalkonline.org/myflv.swf?myFlv=vid_BRSBS18_GBF.flv

She has all diagnostic tests done on one day but had to wait a few days to get the results

The doctor there that I saw, the Consultant, he did the ultrasound scan and he kept on saying "it doesn't look good" and I think from there, I more or less knew that I had cancer. But I still didn't want to believe it at the time, you know, he said "it just doesn't look good, it doesn't look good" and then he said "OK, I want you to go for a needle biopsy, a mammogram and see what they find there". But that couldn't be done until the afternoon, so we had to go back in the afternoon to the hospital and they told us to go back on Thursday to have the results. When we went back on the Thursday, in the room was sitting the doctor, the Macmillan Nurse, and there were some medical students there as well and I just looked and I thought "no, something doesn't seem right, it just doesn't" you know "not right at all". I spoke to my husband the day before on the Wednesday and I kept on saying to him "what do you think, what do you think?" and he was like, he's had an open mind all the way, you know, he wouldn't believe it, he said "I'm keeping an open mind"

Link to video

http://www.healthtalkonline.org/myflv.swf?myFlv=vid_BRSBS18_02_GBF.flv

Autobiographical Account's Set 2

Woman 3 (Health talk online Breast Cancer Interview 6)

Appendix 8

Age at Interview: 47

Age at Diagnosis: 44

Brief outline: Diagnosed with breast cancer in 1998. Had a lumpectomy and was given radiotherapy and Tamoxifen.

Advises women to be aware of any breast changes and comments on the effectiveness of treatment

And just as soon as you find anything that worries you, go to the doctor. It's not just a lump. It can be a skin change. A lot of women don't realise if they get puckering of the skin, or problems with nipples, that they should go and get them looked at. Because there are other ways of presenting itself other than an obvious lump. Not to be too afraid. Particularly if you know you've only got a small lump. Even a big lump in the long term can do very well, as it were, the patient can do very well. But I do think whatever your situation, and whatever you are told, even if you've got lymph node involvement, people still do very well. Things are improving all the time.

Link to video

http://www.healthtalkonline.org/myflv.swf?myFlv=vid_bca06_LMO.flv

Woman 4 (Health talk online Breast Cancer Interview 15)

Age at Interview: 19

Age at Diagnosis: 18

Brief outline: Diagnosed with breast cancer in 2000. Had a bilateral mastectomy and was given chemotherapy, radiotherapy, drugs for secondary cancer.

Describes her thoughts and feelings when diagnosed with cancer.

The fact is I was so shocked because I wasn't expecting it whatsoever that I didn't do anything. I just sat deadly still and I didn't know what to do. It was awful because no one was there and then they went out the room and they went into the office and they left me on my own in that little room and that's when I burst into tears. That's when, that's when the reality hit me. And you get all these things going through your mind you know. How long have I got? That was the first question you know. Is it terminal? Am I going to die, you know? What are my chances? You get all these thoughts. I think everybody must, you know, it's just, and you just, it was so much of a shock to me and I'm so young, I'd been so

fit for so long you know. And I'm not the one in the family that's the smoker. I do drink at the weekend but I don't drink excessively you know. I eat fairly healthily, I keep fit. So why me, what have I done, you know? So I thought: "Well I must've been a bit of a bad 'un in my past life." I must you know, I must've done something wrong." And I just, I wanted someone to blame really. And it's, you can't find anybody because no one's given you it, you know.

Link to video

http://www.healthtalkonline.org/myflv.swf?myFlv=vid_bca15_DIP.flv

Explains that malignant lumps are rare in young women and that she was referred to hospital when the lump she found had not gone away.

I don't know, I think I'd just got out the bath or something and I did used to, you know, check my breasts and things like that, but not as regularly as I should. Not as religiously as I should. They say do it every couple of weeks so you get familiar with them. And I found this lump and I thought: "Well what do I do about it? It's nothing. I'm only young, it can't be anything." So I went to my GP and she said basically: "It shouldn't be anything at all considering your age." I was 19 at the time. No, I was 18 at the time. Nineteen in August. So, 18 years old, you don't expect anything like that, and I don't think anybody does. She said: "Well come back to me in 2 weeks. It could just be your hormones playing up because you're so young. You're probably just having a bit of problems." So I went back in two weeks and it had not gone anyway so she - I think that sort of clicked something in her mind that something needed to be done. So she referred me to the breast clinic at the local hospital. So, I got an appointment for them and I went to see the doctor there. Again, he said: "You're so young it's likely to be absolutely nothing, a little cyst that needs draining." He said: "There's no real reason why we can give you a mammogram because they don't show up in younger people." And I thought: "Well that's not fair, they're not doing everything they can!" So he said: "We'll do a needle test and then we'll send you for an ultrasound as well."

Link to video

http://www.healthtalkonline.org/myflv.swf?myFlv=vid_bca15_DSD.flv

Describes reassuring her mother who felt that she, not her daughter, ought to have developed breast cancer.

I told her, and she just burst into tears. And I think it was a feeling of guilt more than anything from being away. And she felt like she wasn't there for me. And I think she also thought that if it was something to do with genetics, she should be the next in line for it, because my grandma had had it, my great grandma had had it, so it was obvious that it was her turn and it seems like it's skipped a generation. So she felt it should've been her. And I said to her: "Look, you can't say that because we're not even sure it's through the genes that I've got this. We don't know, there's no one to blame, and I'm certainly sure that I'll never blame anybody because it's nobody's fault. There's nothing you can do it about it. If it happens, you just have to deal with it. So I think that put her mind at rest a bit.

Link to video

http://www.healthtalkonline.org/myflv.swf?myFlv=vid_bca15_LIF.flv

Autobiographical Accounts Set 3

Woman 5 (Health talk online Breast Screening Interview 15)

Age at Interview: 43

Age at diagnosis: 42

Background: Does voluntary and freelance work in cancer services. Married with 2 adult children.

Brief outline: Discovered lump at age 42. All tests showed lump was benign. It was surgically removed and found to be cancerous. Had treatment for cancer.

Encourages younger women to be breast aware and not dismiss any unusual changes because they are too busy.

Well, anything you discover on your body that isn't natural or isn't, it shouldn't there, don't pretend, don't dismiss it, get it checked out. Because I know for a fact that if I had been, if I'd said, "oh well, it's just a lump, everything's clear, I can't be bothered. I'm too busy, I've got to go back to work" then I might not be here today telling you this. Because I know younger women who, with cancer that had moved so fast and, unfortunately, you know, they leave behind younger families because it just moves too fast. So don't, anything of concern, don't dismiss it. Get it checked out. We all get embarrassed, we don't, none of us like going to the doctors, but it's a very small price to pay. A very, very small price to pay. And, again, while it's there, you may dismiss it but it will be with you all the time and

getting rid of it will give you peace of mind. It will give you peace of mind. And, you know, your family deserve it and you deserve it. More than anything else, you deserve a peace of mind. Yes, it will give you peace of mind, knowing that you've got it checked out.

Link to video

http://www.healthtalkonline.org/myflv.swf?myFlv=vid_BRSBS15_IBX.flv

Women 6 (Health talk online Breast Cancer Interview 10)

Age at Interview: 27

Age at Diagnosis: 24

Brief outline: Diagnosed with breast cancer 1998, underwent a lumpectomy, chemotherapy and radiotherapy.

It does come up in different forms. You just, you know - all the issues, even when, you know, you sort of looking for jobs or, you know, you're thinking about insurance and pensions and everything. Suddenly you've got this thing. And like when I'd, I don't know, whenever you have to fill out a form about "have you had a serious illness?" and suddenly it's there. Whereas before everything was always: "No, no, no, no, no." And suddenly there's this thing there and it just changes, it changes everything. It changes the way people perceive you on paper. And yeah, it does change a lot so it definitely affects you. It affects your life even if, you know, you feel you're not thinking about it.

Link to video

http://www.healthtalkonline.org/myflv.swf?myFlv=vid_bca10_LBC.flv

Explains that breast cancer can be seen as just another illness rather than much worse than anything else.

I suppose that, yeah that you are, you know, you can come out the other side. That, you know, it isn't necessarily a death sentence. That you don't, you can treat it like another illness. It doesn't have to be this whole thing on its own that is much, much worse than anything else. And well if you can, if you can get past the fear of cancer - the initial being diagnosed with it - then actually you can look at it as if you had, you know, another illness which, there are other illness with the possibility of it being terminal, but with a very strong chance of it not being. And that, you know, they can offer you so much now that, you know, the medicine available is amazing, the treatment is amazing.

Link to video

http://www.healthtalkonline.org/myflv.swf?myFlv=vid_bca10_LMO.flv

Explains that her family were a great source of support and how she became closer to her father.

Yeah. I think I got through it because my family is great and great company. My mum I've always been close to, and dad, you know, we've been close, but suddenly I was really, you know, right there all the time. So I was, I was just like a child again, like a hundred per cent dependent, particularly during those weeks when I was really ill. And, you know, through all my teenage years I'd always been dashing off with my friends and everything, and suddenly I was at home a lot, all the time and just learnt to appreciate, you know, their company really. Just sitting in at night watching telly with them and everything, which I would never have done before. And I really enjoyed it and I love my parents' company now. I'm quite happy to go and sit round with them for the evening or afternoon and it's really, really nice going away on my own with my dad. I would never have done that before, that was lovely.

Link to video

http://www.healthtalkonline.org/myflv.swf?myFlv=vid_bca10_LSS.flv

Autobiographical Accounts Set 4

Women 7 (Health talk online Breast Cancer Interview 42)

Age at Interview: 52

Age at Diagnosis: 48

Brief outline: Diagnosed with inflammatory breast cancer in 1997. Was given chemotherapy, a mastectomy with reconstruction, followed by radiotherapy and Tamoxifen.

Explains that an inverted nipple alerted her to her illness.

I think the first time I became suspicious was I noticed that I had a lump in my breast, but I'd always had very lumpy breasts at my period times. And the first month I just totally ignored it. I thought: "Oh, I'm just imagining things." And I think it was half-way through the next month and I thought: "Mm, that's still there." I thought: "Well maybe I'm just about to

start my period again." So I ignored it again. And then one morning I was in the shower and I noticed that my nipple had inverted quite a bit, and I had always been told that breast cancer you would feel it as a tiny little pea-sized lump and mine definitely wasn't a tiny little pea sized lump. But I had also been told that if the nipple changed shape in any way you should always go and get it investigated.

Link to video

http://www.healthtalkonline.org/myflv.swf?myFlv=vid_bca42_DSD.flv

Explains that she asked her boss to tell colleagues about her illness, and that she received a lot of support.

When I went for the initial appointment and I phoned my immediate boss and I told her that it was cancer. And she said: "What do you want me to tell everybody?" I said: "Well tell them I've got a chest infection," and to wait until I'd been to the doctor's the second time. So I went, I went back the next night and I phoned [name] to confirm it and she said: "Well what do you want me to do?" I said: "Well just tell them." I said: "There's no point in keeping it a secret because it's going to come out, I can't hide it." So when I went back to work, I actually went back to work on the Friday, there was a bunch of flowers on my desk. And that was really touching, that brought the tears on. "And they were marvellous, they were really, really kind, they were very good and they just didn't, they didn't treat me any differently, which was good." And I suppose partly because I didn't, I didn't act any differently. I just got on with life and with my work, and did whatever was necessary.

Link to video

http://www.healthtalkonline.org/myflv.swf?myFlv=vid_bca42_LIO.flv

Recommends asking as many questions as necessary.

Stay calm. Be as positive as you possibly can. Go into interviews with written questions if necessary. Think about it hard before you go into your first interview after the staging. I'm only saying this in retrospect because I wish I had done that because I probably, if I'd sat down and thought about it, I might've had more questions. I mean I did have some. **And every time you go to see anybody, whether it's an oncologist or a surgeon, if there's anything at all, ask your question, Don't be fudged, don't be put off, ask your question. And if you don't understand the answer, ask again until you hear**

what you want to hear, or hear what you understand. Because if you want to know about it, the only way to do it is to ask.

Link to video

http://www.healthtalkonline.org/myflv.swf?myFlv=vid_bca42_LMO.flv

Women 8 (Health talk online Breast Cancer Interview 13)

Age at Interview: 41

Age at Diagnosis: 39

Brief outline: Diagnosed with breast cancer 1999. Underwent a mastectomy and was given chemotherapy, radiotherapy and Arimidex.

Comments that she fits into none of the risk factor categories and is critical about media reports on the causes of breast cancer.

Having found the information, having read the Imperial Cancer Care Book on breast cancer, which I really do think is highly informative. And you look at the risk factors. I didn't fit into any of them. So to me cancer is a nasty disease that can strike anyone. And yes, there are things that people can do to help themselves, such as not smoking (I gave up 11 years ago or so), but you certainly do need to start to help yourself once you are a victim of cancer. And to enable you to do that you need to have the correct information. You will find all sorts of things in the media which can be quite scare mongering, on hair dyes, on whether or not you breastfed, on whether or not you had terminations. I'm not sure that any of these things are factual. I would strongly suggest to people that they disregard them completely. Don't allow things to frighten and scare you. Stick with the experts. Stick with what it is you know. Ask the necessary questions if something, if you're overwhelmed by something, you think "that could be me" or perhaps, you know, "I shouldn't do that" or whatever. And I mainly have time to do or I've made time to do the things that I've wanted to do and that I've been putting on hold for years.

Link to video

http://www.healthtalkonline.org/myflv.swf?myFlv=vid_bca13_DIC.flv

Discusses some of the positive ways in which breast cancer had changed her life

And I do not think for a second that that life stops with cancer. In fact for me, in many respects, life began with cancer. I was only turned 40 when I was diagnosed with cancer and I had this thought in my head, as many women I'm sure do, that life begins at 40. And I had many plans of what I was going to do and what was going to change when I would come to 40. I think it would be fair and true to say that they may not have materialised if it were not for the fact that I was diagnosed with cancer. I can do, for instance I recently bought a guitar, I bought a keyboard, I want to learn how to play. I read a lot more than I have done in the past, I read more for pleasure. I get my housework done at an early time in the day. I look forward to my days. I plan my days which I've never had the opportunity to do before because it was chaos doing a full day's work, I worked for the County Council.

Link to video

http://www.healthtalkonline.org/myflv.swf?myFlv=vid_bca13_LBC.flv

Autobiographical Accounts Set 5

Women 9 (Health talk online Breast Cancer Interview 44)

Age at Interview: 34

Age at Diagnosis: 30

Brief outline: Diagnosed with breast cancer in 1997. Under went a lumpectomy and was given chemotherapy and radiotherapy.

Describes discovering a lump in her breast while she was pregnant.

About five months into the pregnancy I discovered a very small lump on my left breast. I wasn't overly concerned about it at all as there had been a history of breast lumps in my family. My mother had a double mastectomy in her early 30s due to several breast lumps that she'd developed which had been quite painful. And both my older sisters, one of whom is four years older than me and the other seven years older than me, had both had breast lumps as well. The lump that I discovered was very, very tiny at the time and I wasn't overly concerned at all. I went to the doctors that evening, the doctors fitted me in very quickly and examined the lump but again weren't overly concerned. At seven-and-a-half months I went back as the lump had got bigger and was referred to my local hospital at the breast care clinic. I had a needle biopsy taken from the breast and was called back

to get the results when I was absolutely shocked to find that it was breast cancer. All the way through we'd been very confident that I had nothing to worry about

Link to video

http://www.healthtalkonline.org/myflv.swf?myFlv=vid_bca44_DSD.flv

Explains how her husband's support and sense of humour helped them to cope better with her illness.

It's difficult thinking: "Well what will I be like?" because obviously your main concern is I just want the cancer taken away. I personally wouldn't have been too upset because I have a very strong healthy marriage and my husband said: "I don't care what you look like afterwards, you're still going to be you." And when my scar had healed my husband kissed my scar which was very, very important to me. But it's hard for men as well because, as much as they want to reassure you, and tell you that you are still the same person, it's difficult for them sometimes because they're going through it, although they're not the victim themselves, they're still upset, they're trying to reassure you, they're trying to be strong for you. I feel my relationship with my husband is a lot stronger. He's a very caring person, was absolutely wonderful through all the treatment. Kept a very good sense of humour through it as well. And my husband actually said to the breast care nurses when they were explaining all the treatment: "Will she be able to swim after this?" And she said: "Yes, I don't see why not." And he said: "Well that's a good job because she can't swim now." And humour is important you know, with anything. If you can laugh through it and laugh with each other, and sometimes laugh at the illness as well then, you know, laughter is the best medicine sometimes really.

Link to video

http://www.healthtalkonline.org/myflv.swf?myFlv=vid_bca44_LBI.flv

Women 10 (Health talk online Breast Cancer Interview 33)

Age at Interview: 56

Age at Diagnosis: 54

Brief outline: Diagnosed with breast cancer in 1999. Underwent a lumpectomy and was given Intra-operative radiotherapy and Tamoxifen.

Explains that knowledge about breast cancer can reduce the fear.

Well it is an emotionally draining and terrifying experience. But the emotion and the terror receded as I became more knowledgeable. So you combat that with empowering yourself with knowledge, getting to know and confronting what is happening to you. And that power takes away the fear and takes away the stress because when you're actively participating in your cure that solves that problem. But it isn't easy and there are times when you, you do crumble. But it is transient. The only important thing about hardship, my grandmother told me, is that it always passes on.

Link to video

http://www.healthtalkonline.org/myflv.swf?myFlv=vid_bca33_02_TFI.flv

Explains that, despite her doubts about future relationships, she has met a new partner.

And I felt and believed that the romance in my life was completely over, that I was never going to be desired or feel desirable or have any sense of desire myself. That I was going to have something awful done to my breast. I would not be a woman in that sense any more. But I was fortunate it was small it was a lumpectomy and in reality I have an almost indistinguishable scar in a very good position. It's about on the bra line, on the side, underneath my arm. And my right breast is very slightly smaller than my left breast, but with a good bra you just never notice it. You feel a sense of invasion and you go through a very bad patch of self doubt. But you come out the other side. And I have a very happy ever after story because as a result of my diagnosis I met the most wonderful man in the world who could cope with it because his wife died six years ago of lung cancer. And I've found a new partner for life and that's absolutely wonderful. So there was life after breast cancer.

Link to video

http://www.healthtalkonline.org/myflv.swf?myFlv=vid_bca33_LBI.flv

Describes how her family supported her and helped her to seek out more information about breast cancer.

There were some friends who scuttled away and I never heard anything from them because they couldn't cope with it. It was frightening, it was embarrassing. But my son and my immediate family were absolutely wonderful. My daughter-in-law bought for me

two of the brilliant books that I read and found such a help. And my son immediately gave me crash courses on how to use the internet. I didn't have a computer and you might say that the cancer experience has switched me on technologically-speaking. He took me to a video [internet] café and we went into the videos, and I wanted to look up intra-operative radiotherapy because it had been mentioned to me and there were reams of stuff on it. There's loads of stuff on tamoxifen, whatever you want to know you can find out.

Link to video

http://www.healthtalkonline.org/myflv.swf?myFlv=vid_bca33_LSS.flv

Autobiographical Accounts Set 6

Women 11 (Health talk online Breast Cancer Interview 23)

Age at Interview: 45

Age at Diagnosis: 44

Brief outline: Diagnosed with breast cancer in 2000. Underwent a mastectomy and was given chemotherapy and Tamoxifen.

Explains that she expected the news of her diagnosis and treated the illness as a minor interruption

I wasn't surprised. I did say to the surgeon: "That's exactly what I expected you to say. Now what are we going to do?" I don't think at the time I actually realised how severe cancer can be, not having had any close relatives suffer from cancer or you know anybody. But as you go through the treatment so you learn more. But I mean I never cried, never cried about it or, I'm too matter of fact I think for that. I just sort of thought: "Well, you've got it girl. Let's just get on with it. "Let's get this sorted, get the next 12 months over with and then get back on with your life," really. You just have to get on with it. You haven't got any option. It's happened but there's no point in asking why because nobody knows the answer to that. So you've got to just go through it and get on with it.

Link to video

http://www.healthtalkonline.org/myflv.swf?myFlv=vid_bca23_DIP.flv

Describes the tests she had to diagnose her cancer

Appendix 8

First I found a lump in my left breast. And for two weeks I ummed and ahed and was very undecided as to whether this was a lump or whether it was something I was imagining. But I'd got a week off work coming up so I decided to go to the doctor's. And the doctor referred me to the hospital. And within a fortnight I was at the hospital having a biopsy and a scan. Yes, I had a needle biopsy which involved the consultant putting a needle into the lump and taking a sample from the tissue. And I had a mammogram which is a little bit uncomfortable but not really painful. And I had an ultrasound scan. So I had those three tests done on the same day within about an hour or so.

And it was a needle biopsy? It was a needle biopsy. And then you had an ultrasound scan as well? Yes, yes. Can you say a little bit about that?

That's just a case of they pop the, a little bit of jelly onto your boob and run the camera over where the lump is, and try to get a picture of what's inside there.

Link to video

http://www.healthtalkonline.org/myflv.swf?myFlv=vid_bca23_DSD.flv

Explains that her husband was supportive and she is pleased with the appearance of her scar

When we came out of the hospital, my husband said: "Have you got any idea which operation you want to go for?" And I said: "I'm going for a full mastectomy." And his answer was: "I'm pleased to hear that." So he was totally in agreement with me, which was absolutely ideal.

What does the incision look like now, the scar now?

Brilliant, brilliant, it's very neat, very tidy, it's white and you just get used to it really. It's not ugly, it's a nice tidy job.

And do you mind looking at it?

No, not at all.

Do you mind your husband looking at it?

No not at all, no, no. When I first I had it done yes, I did feel deformed. And I think possibly some of that was because I'd had the infection. But when you're feeling better, then things are not so bad. So now that all the treatment is behind me, no I don't mind the scar.

Link to video

http://www.healthtalkonline.org/myflv.swf?myFlv=vid_bca23_LBI.flv

Explains why she enjoyed her hospital experience

So there was myself and another lady having it done that evening and we got to be quite friendly. We used to go wandering all over the hospital and I must admit, this sounds awful, but I really enjoyed my time in hospital. I had, this lady and myself, we became friends and we had a good time. We thoroughly enjoyed ourselves. We used to have cream cakes at midnight. And one night we went down to the ground floor where they've got a machine that does chips and beef burgers, and we had that. I mean it wasn't very nice but it was a little bit of an adventure for us I suppose. And I was fine, absolutely fine in the hospital.

Link to video

http://www.healthtalkonline.org/myflv.swf?myFlv=vid_bca23_TMA.flv

Women 12 (Health talk online Breast Cancer Interview 45)

Age at Interview: 70

Age at Diagnosis: 70

Brief outline: Diagnosed with breast cancer in 2001, had a bilateral mastectomy and was given Tamoxifen.

Explains why, aged 70 she saw her cancer diagnosis more as a nuisance than a disaster,

So when he said: "Yes, I'm sorry I'm afraid it is a cancer," I thought: "Ugh." It is a slight you know. Not because it was cancer. I will not join in this great myth that it's the most terrible diagnosis in the world, it is not, believe me there are some nastier illnesses than cancer. I wouldn't like to have Parkinson's. I don't want to have a stroke. I don't want to have multiple sclerosis. Cancer at 70, I'm 70 is like you know not such a terrible thing. It's a slow growing thing, it's easier to treat. At the moment of being told I had cancer I remember thinking frankly, I thought: "Oh bugger," because it was a nuisance, because it was tiresome. But I wasn't, it wasn't, I wasn't overwhelmed I knew enough about the disease to know that I was not a candidate for immediate death and I don't think a diagnosis of cancer is a death sentence anyway. I think this is one of the great myths. I've known too many people have done very, very well and are doing very, well.

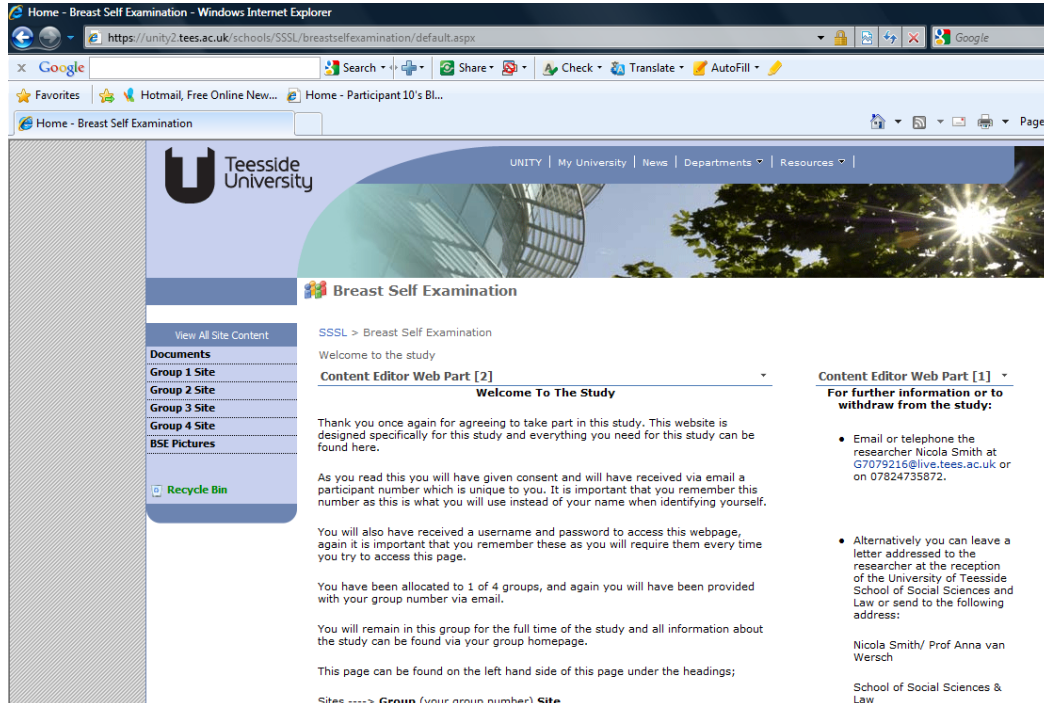
Link to video

http://www.healthtalkonline.org/myflv.swf?myFlv=vid_bca45_DIP.flv

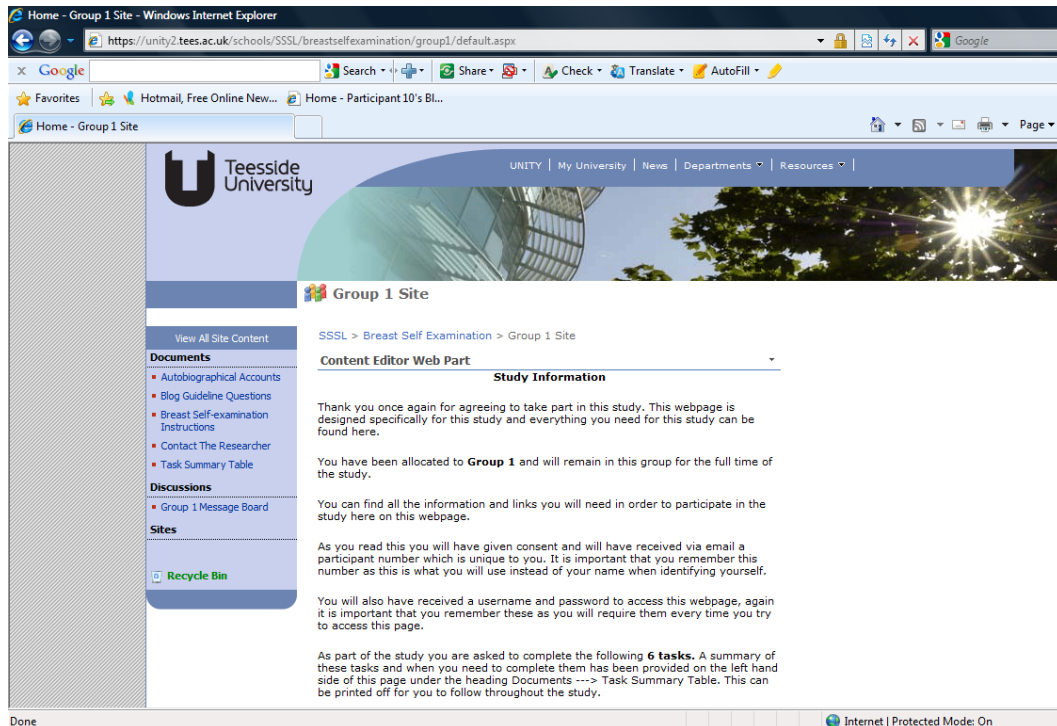
Appendix 9: Screen Shots of Study Website

Site Homepage

This page was hidden to participants following feedback from the pilot study. Instead they were directed immediately to their respective group homepage.



Group 1 Site Homepage



Appendix 9

Group 2 Site Homepage

The screenshot shows the Group 2 Site Homepage in Internet Explorer. The browser address bar displays the URL: <https://unity2.tees.ac.uk/schools/SSSL/breastselfexamination/group2/default.aspx>. The page features the Teesside University logo and navigation links for UNITY, My University, News, Departments, and Resources. The main content area is titled "Group 2 Site" and includes a "Content Editor Web Part" with "Study Information". The study information text reads: "Thank you once again for agreeing to take part in this study. This webpage is designed specifically for this study and everything you need for this study can be found here. You have been allocated to **Group 2** and will remain in this group for the full time of the study. You can find all the information and links you will need in order to participate in the study here on this webpage. As you read this you will have given consent and will have received via email a participant number which is unique to you. It is important that you remember this number as this is what you will use instead of your name when identifying yourself. You will also have received a username and password to access this webpage, again it is important that you remember these as you will require them every time you try to access this page."

Group 3 Site Homepage

The screenshot shows the Group 3 Site Homepage in Internet Explorer. The browser address bar displays the URL: <https://unity2.tees.ac.uk/schools/SSSL/breastselfexamination/group3/default.aspx>. The page features the Teesside University logo and navigation links for UNITY, My University, News, Departments, and Resources. The main content area is titled "Group 3 Site" and includes a "Content Editor Web Part" with "Study Information". The study information text reads: "Thank you once again for agreeing to take part in this study. This webpage is designed specifically for this study and everything you need for this study can be found here. You have been allocated to **Group 3** and will remain in this group for the full time of the study. You can find all the information and links you will need in order to participate in the study here on this webpage. As you read this you will have given consent and will have received via email a participant number which is unique to you. It is important that you remember this number as this is what you will use instead of your name when identifying yourself. You will also have received a username and password to access this webpage, again it is important that you remember these as you will require them every time you try to access this page."

Appendix 9

Group 4 Site Homepage

The screenshot shows a web browser window titled "Home - Group 4 Site - Windows Internet Explorer". The address bar displays the URL: <https://unity2.tees.ac.uk/schools/SSSL/breastselfexamination/group4/default.aspx>. The browser's search bar contains "Google".

The website header features the Teesside University logo on the left and navigation links for "UNITY", "My University", "News", "Departments", and "Resources" on the right. A search bar is also present with the text "This Site: Group 4 Site".

The main content area is titled "Group 4 Site" and includes a breadcrumb trail: "SSSL > Breast Self Examination > Group 4 Site". Below this is a "Content Editor Web Part" with the heading "Study Information".

The left sidebar contains several sections:

- View All Site Content**
- Documents**
 - Blog Guideline Questions
 - Breast Self-examination Video and Instructions
 - Contact The Researcher
 - Task Summary Table
- Discussions**
 - Group 4 Message Board
- Sites**
- Recycle Bin**

The main text area contains the following information:

Study Information

Thank you once again for agreeing to take part in this study. This webpage is designed specifically for this study and everything you need for this study can be found here.

You have been allocated to **Group 4** and will remain in this group for the full time of the study.

You can find all the information and links you will need in order to participate in the study here on this webpage.

As you read this you will have given consent and will have received via email a participant number which is unique to you. It is important that you remember this number as this is what you will use instead of your name when identifying yourself.

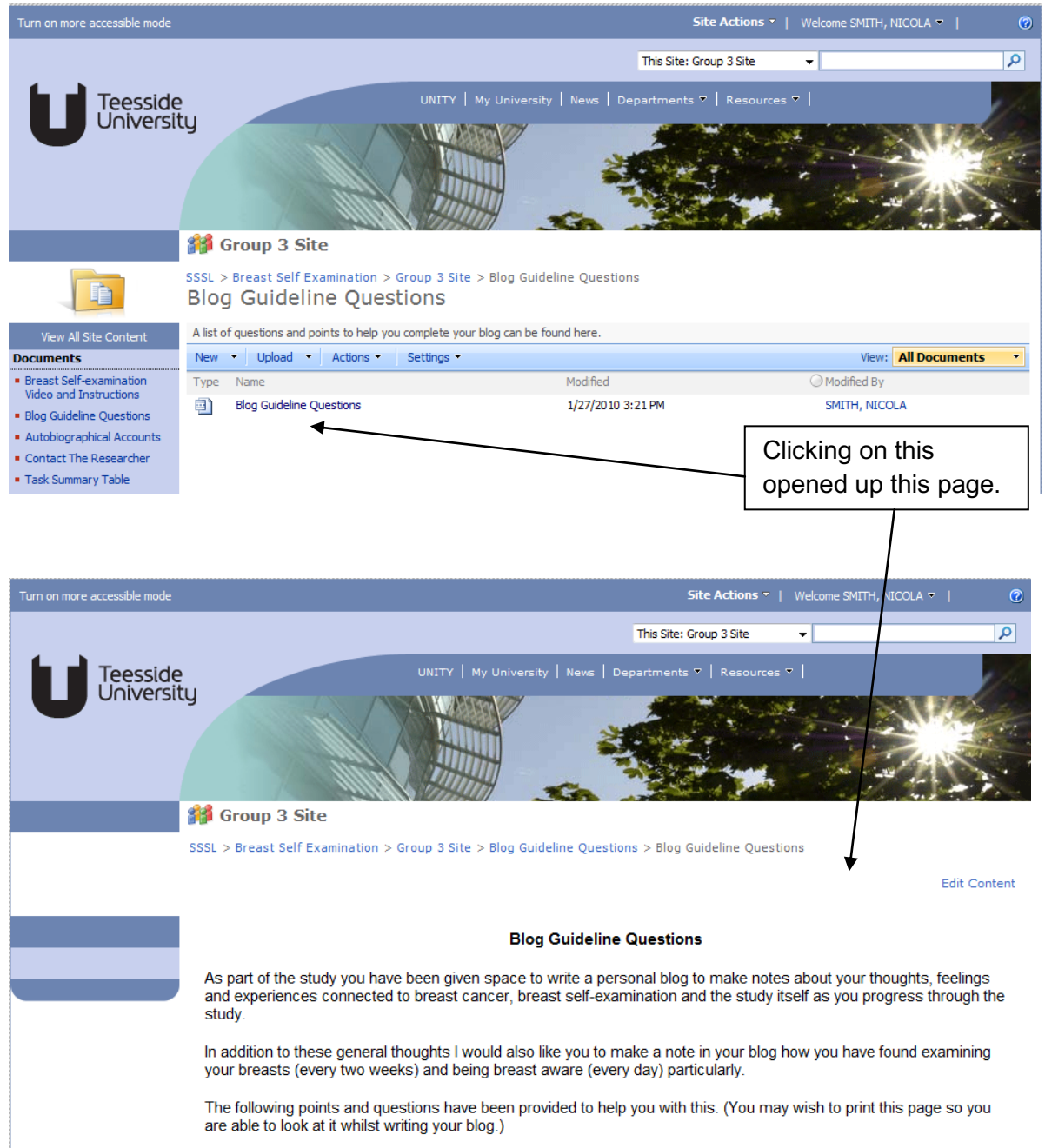
You will also have received a username and password to access this webpage, again it is important that you remember these as you will require them every time you try to access this page.

The browser status bar at the bottom shows "Done" and "Internet | Protected Mode: On".

Appendix 10: Blog Guideline Questions Webpage

Screenshot of Webpage

The format of the Blog Guideline Question page and the information displayed were the same for all four study group pages.



Information Contained Within the Page

As part of the study you have been given space to write a personal blog to make notes about your thoughts, feelings and experiences connected to breast cancer, breast self-examination and the study itself as you progress through the study.

In addition to these general thoughts I would also like you to make a note in your blog how you have found examining your breasts (every two weeks) and being breast aware (every day) particularly.

The following points and questions have been provided to help you with this. (You may wish to print this page so you are able to look at it whilst writing your blog.)

Breast Self-examination

After you have examined your breasts you need to write in your blog how you found the examination. You may use the following seven questions to help you do this.

1. Did you manage to carry out the breast self-examination technique?

If no, was there a particular reason why you did not?

2. How easy/difficult did you find examining your breasts?

3. Were you able to follow all aspects of the examination procedure with ease?

4. What parts (if any) did you have a problem following or doing?

5. Do you enjoy following the breast self-examination instructions?

6. Please discuss what you think about breast self-examination generally.

7. Please discuss what you think about the breast self-examination technique you have been doing.

Breast Awareness

You also need to write in your blog how you have found being aware of your breasts on a daily basis. You may use the following two questions to help you do this.

1. How often have you looked, felt or just been generally aware of your breasts over the past 14 days?

2. How did you find doing this?

Appendix 11: Researcher's Contact Details Webpage

Screenshot of Webpage

The format of the Contact The Researcher page and the information displayed was the same for all four study group pages.

Turn on more accessible mode Site Actions | Welcome SMITH, NICOLA | This Site: Group 3 Site

Teesside University UNITY | My University | News | Departments | Resources

Group 3 Site

SSSL > Breast Self Examination > Group 3 Site > Contact The Researcher

Contact The Researcher

Contact details for the researcher and information about withdrawing from the study can be found here.

View: All Documents

Type	Name	Modified	Modified By
	ContactTheResearcher	4/16/2010 3:03 PM	SMITH, NICOLA

Clicking on this opened up this page.

Group 3 Site

SSSL > Breast Self Examination > Group 3 Site > Contact The Researcher > ContactTheResearcher

Edit Content

For further information or to withdraw from the study:

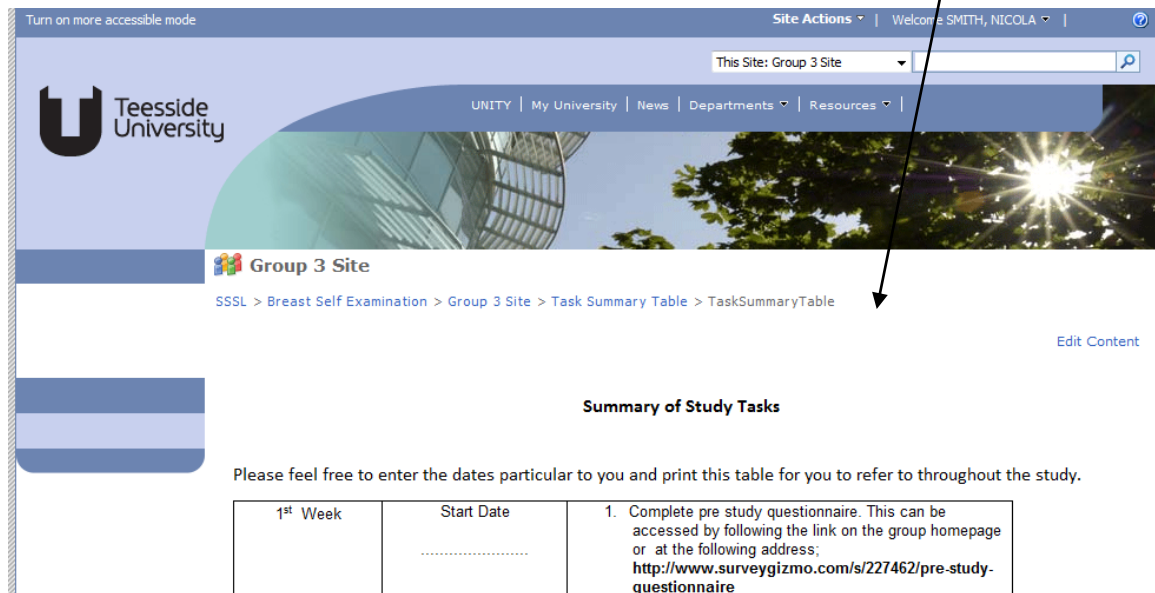
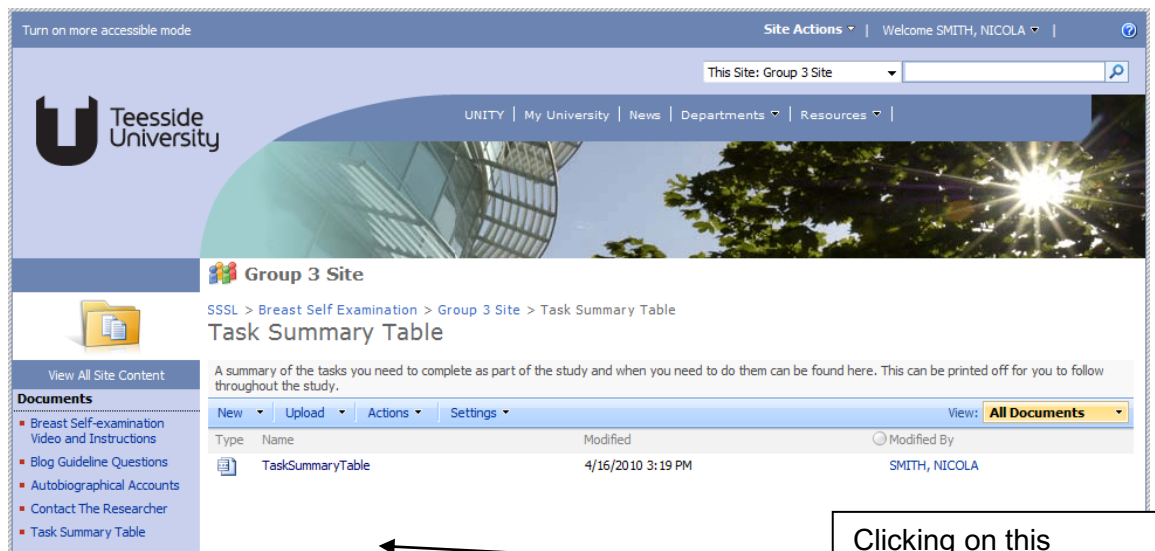
- Email or telephone the researcher Nicola Smith at G7079216@live.tees.ac.uk or on 07824735872.
- Alternatively you can leave a letter addressed to the researcher at the reception of the University of Teesside School of Social Sciences and Law or send to the following address:

Nicola Smith/ Prof Anna van Wersch
 School of Social Sciences & Law
 University of Teesside
 Borough Road
 Middlesbrough
 TS1 3BA
- To ensure the withdrawal process is kept strictly confidential you should include your username (given to you at the start of the study) instead of your name.

Appendix 12: Summary of Study Tasks Webpage

Screen Shot of Webpage

The format of the Task Summary Table page was the same for all four study group pages. The information was exactly the same for groups 1 and 3, and for groups 2 and 4 the information was the same apart from task 3 - view autobiographical accounts was omitted in their summary tables.



*Information Contained Within the Page***Summary of Study Tasks**

Please feel free to enter the dates particular to you and print this table for you to refer to throughout the study.

1 st Week	Start Date	<ol style="list-style-type: none"> 1. Complete pre-study questionnaire. This can be accessed by following the link on the group homepage or at the following address; http://www.surveygizmo.com/s/227462/pre-study-questionnaire 2. Be aware of how your breasts look and feel on a daily basis. You do not need to follow a structured technique to do this just simply look and feel for any changes. 3. Read autobiographical account set 1. 4. Examine your breasts using the steps provided on the group homepage. 5. Write about your experience examining your breasts – and any thoughts you have connected to the study in the blog provided.
2 nd Week	Date Week Beginning	<ol style="list-style-type: none"> 1. Be aware of how your breasts look and feel on a daily basis. 2. Write about any thoughts you have connected to the study in the blog provided.
3 rd Week	Date Week Beginning	<ol style="list-style-type: none"> 1. Be aware of how your breasts look and feel on a daily basis. You do not need to follow a structured technique to do this just simply look and feel for any changes. 2. Read autobiographical account set 2 3. Examine your breasts using the steps provided on the group homepage. 4. Write about your experience examining your breasts – and any thoughts you have connected to the study in the blog provided.
4 th Week	Date Week Beginning	<ol style="list-style-type: none"> 1. Be aware of how your breasts look and feel on a daily basis. 2. Write about any thoughts you have connected to the study in the blog provided.
5 th Week	Date Week Beginning	<ol style="list-style-type: none"> 1. Be aware of how your breasts look and feel on a daily basis. You do not need to follow a structured technique to do this just simply look and feel for any changes. 2. Read autobiographical account set 3 3. Examine your breasts using the steps provided on the group homepage. 4. Write about your experience examining your breasts – and any thoughts you have connected to the study in the blog provided.

6 th Week	Date Week Beginning	<ol style="list-style-type: none"> 1. Be aware of how your breasts look and feel on a daily basis. 2. Write about any thoughts you have connected to the study in the blog provided.
7 th Week	Date Week Beginning	<ol style="list-style-type: none"> 1. Be aware of how your breasts look and feel on a daily basis. You do not need to follow a structured technique to do this just simply look and feel for any changes. 2. Read autobiographical account set 4 3. Examine your breasts using the steps provided on the group homepage. 4. Write about your experience examining your breasts – and any thoughts you have connected to the study in the blog provided.
8 th Week	Date Week Beginning	<ol style="list-style-type: none"> 1. Be aware of how your breasts look and feel on a daily basis. 2. Write about any thoughts you have connected to the study in the blog provided.
9 th Week	Date Week Beginning	<ol style="list-style-type: none"> 1. Be aware of how your breasts look and feel on a daily basis. You do not need to follow a structured technique to do this just simply look and feel for any changes. 2. Read autobiographical account set 5 3. Examine your breasts using the steps provided on the group homepage. 4. Write about your experience examining your breasts – and any thoughts you have connected to the study in the blog provided.
10 th Week	Date Week Beginning	<ol style="list-style-type: none"> 1. Be aware of how your breasts look and feel on a daily basis. 2. Write about any thoughts you have connected to the study in the blog provided.
12 th Week	Date Week Beginning	<ol style="list-style-type: none"> 1. Be aware of how your breasts look and feel on a daily basis. You do not need to follow a structured technique to do this just simply look and feel for any changes. 2. Read autobiographical account set 6 3. Examine your breasts using the steps provided on the group homepage. 4. Write about your experience examining your breasts – and any thoughts you have connected to the study in the blog provided.
13 th Week	Date Week Beginning	<ol style="list-style-type: none"> 1. Be aware of how your breasts look and feel on a daily basis. 2. Write about any thoughts you have connected to the study in the blog provided.

		<p>3. At the end of this week complete the post-study questionnaire. This can be accessed by following the link on the group homepage or at the following address; http://www.surveymzmo.com/s/252038/post-study-questionnaire</p>
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Appendix 13: Static BSE Instructions Webpage

Screenshot of Webpage

The format of the static BSE Instructions page and the information displayed was the same for both Groups 1 and 2.



Breast Self-exam Instructions

Please follow the five steps detailed below to examine your breasts. You can choose to have the instructions displayed on the computer screen or print them off to use elsewhere, whichever you prefer.

Looking

Step 1

The first part in performing a breast self-exam involves looking at your breasts in a mirror. Looking allows you to notice any changes in your breast.

A regular breast examination will help you become familiar with what is normal for you and make it easier to spot when there is a change.



With your arms relaxed at your sides, look at the texture and colour of your skin, including the size and shape of your breasts and nipples.

Look for any sores, dimpling, scaling, skin irritation or discharge. Remember it is not unusual for one breast to be slightly larger than the other.

Step 2

Now place your hands on your hips. Turn side to side and check the side angle of your breasts. Look for any unusual moles, rashes, skin irritations, dimples and flattening of your breasts.



Step 3

Finally, bend slightly forward with your hands on your hips. In this position, inspect both breasts for any dimpling – which can be caused by a growing tumour tugging on the breast tissue or nipple.



Feeling

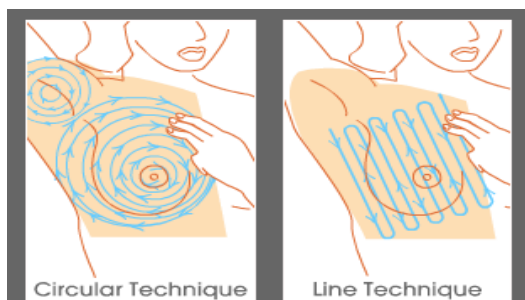
The second part in performing a breast self-exam involves feeling your breasts.

Examining the breasts can be tricky for some women, particularly those with dense or firm breast tissue. The breast is constructed like an orange; you'll feel segments, and that can be scary but it is important to remember that is normal. You need to examine your breasts regularly to become familiar enough with your own body to know what is normal for you. Feeling your breasts regularly will allow you to do this.

It is also important to examine your breasts both standing up and laying down. Masses in the lower part of the breast may be more easily felt when lying down and masses in the upper part of the breast may be easier to detect whilst standing up and by examining your breasts in both positions you are giving yourself the best chance to find any possible problems. If you have large breasts you may need to spend longer examining your breasts than those women with smaller breasts. It is important that you cover the whole breast area including the breast itself, the surrounding area and the area between your breast and underarm including the underarm itself.

To ensure you cover the whole area take your time and follow a definite pattern.

The “circular” and “line” techniques are two ways (or patterns) you can use to examine your breasts. Choose the one that is most comfortable for you.



Step 4

Feeling - laying down

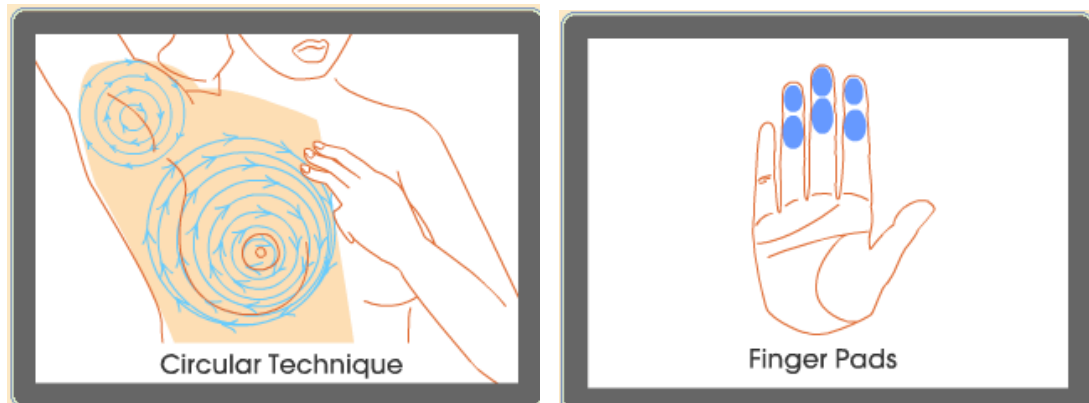
To begin lay on your bed. Place a pillow or folded towel under your right shoulder. This will elevate your right side.



Rest your right hand behind your head. This spreads your breast evenly to allow for a more thorough examination.

Circular Technique

To perform the circular exam, use the pads of your fingers to press in a circular motion on and around your breast.



Follow this motion in a clockwise pattern.

Begin pressing around the entire rim of your breast moving slowly until you reach the 12 o' clock position. Always keep your fingers on your skin as move along.

Vary the amount of pressure you exert to feel different levels of the skin – first lightly, then medium pressure and finally deeper. This will help you to feel the entire thickness of your breast. You are feeling for a lump or changes in breast tissue.



Then move inward about an inch and repeat the same pattern. Continue until you have felt the entire breast including your nipple.

Check for a discharge by gently squeezing your nipple.

Use the same technique to examine your arm pit. You are feeling for changes in both breast tissue and swollen lymph nodes.

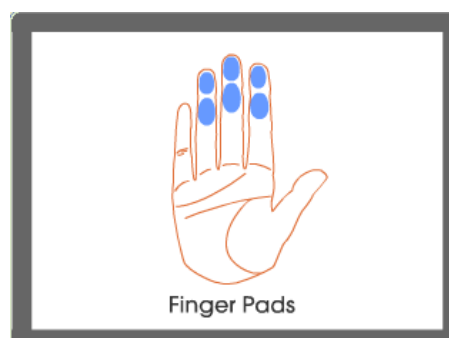
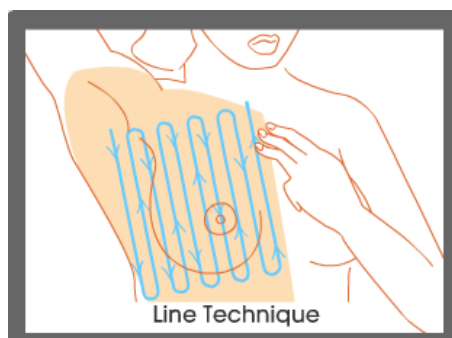


Lymph nodes are small rounded structures that are present at various points in the body including the armpit. Their function is to produce disease-fighting white blood cells and filter out harmful microorganisms and toxins. Breast cancer can cause the lymph nodes in the armpit to become enlarged when the breast itself seems perfectly normal so it is important to ensure you always include the armpit when examining your breasts. Most lymph nodes cannot be felt until they become swollen.

Now switch sides and repeat.

If you are not sure that what you feel is normal, visit your doctor.

Line Technique



To perform the line technique start in the underarm area, moving the pads of your fingers downward little by little until they are below the breast.



Then move your fingers slightly toward the middle, and slowly move back up. Go up and down until you cover the whole area from your neckline to your bra-line.

Be sure to vary the amount of pressure to feel different levels of the skin- first apply light pressure then medium pressure and finally deeply. This will help you feel the entire thickness of your breast.

You are feeling for a lump or changes in your breast tissue. Continue until you have felt the entire breast including your nipple. Check for a discharge by gently squeezing your nipple.

Use the same technique to examine your arm pit. You are feeling for changes in both breast tissue and swollen lymph nodes.

Lymph nodes are small rounded structures that are present at various points in the body including the armpit. Their function is to produce disease-fighting white blood cells and filter out harmful microorganisms and toxins. Breast cancer can cause the lymph nodes in the armpit to become enlarged when the breast itself seems perfectly normal so it is important to ensure you always include the armpit when examining your breasts. Most lymph nodes cannot be felt until they become swollen.

Now switch sides and repeat.

If you are not sure what you feel is normal, visit your doctor.

Step 5

Feeling - standing up

Again you can choose to use either the circular or line technique to examine your breasts but this time standing up.

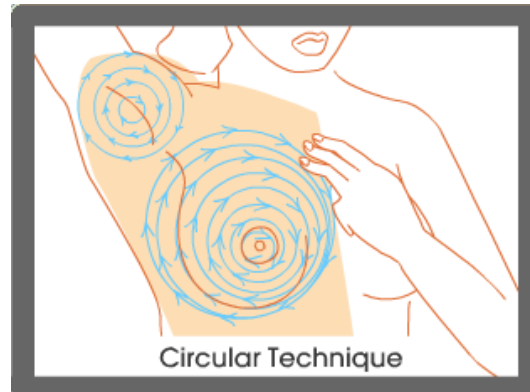
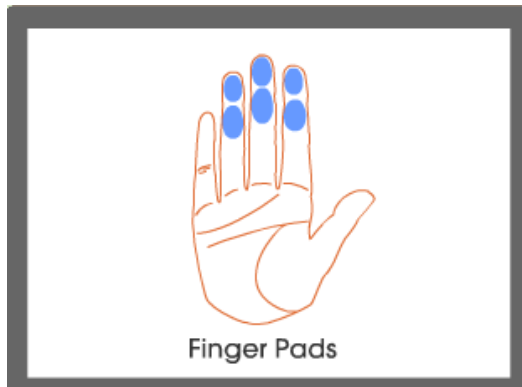
Circular Technique

To perform the circular exam raise your right arm above your head.

Appendix 13



Use the pads of your fingers to press in a circular motion on and around your breast. Follow this motion in a clockwise pattern.



Begin pressing around the entire rim of your breast moving slowly until you reach the 12 o' clock position.



Always keep your fingers on your skin as you move along.

Vary the amount of pressure to feel different levels of the skin- first apply light, then medium pressure and finally deep.

This will help you to feel the entire thickness of your breast. You are feeling for a lump or changes in your breast tissue.

Then move inward about an inch and repeat the same pattern. Continue until you have felt the entire breast including your nipple.

Check for a discharge by gently squeezing your nipple.

Use the same technique to examine your armpit. You are feeling for both breast tissue and swollen lymph nodes.



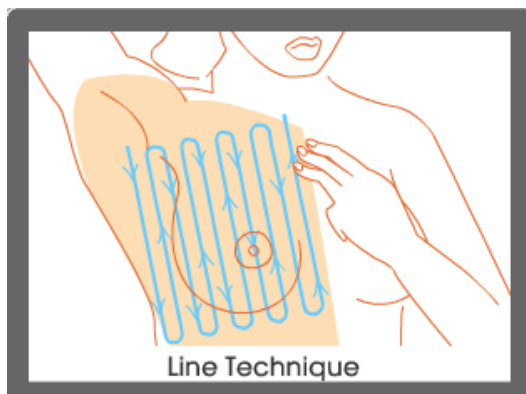
Lymph nodes are small rounded structures that are present at various points in the body including the armpit. Their function is to produce disease-fighting white blood cells and filter out harmful microorganisms and toxins. Breast cancer can cause the lymph nodes in the armpit to become enlarged when the breast itself seems perfectly normal so it is important to ensure you always include the armpit when examining your breasts. Most lymph nodes cannot be felt until they become swollen.

Now switch sides and repeat.

If you are unsure what you feel is normal, visit your doctor.

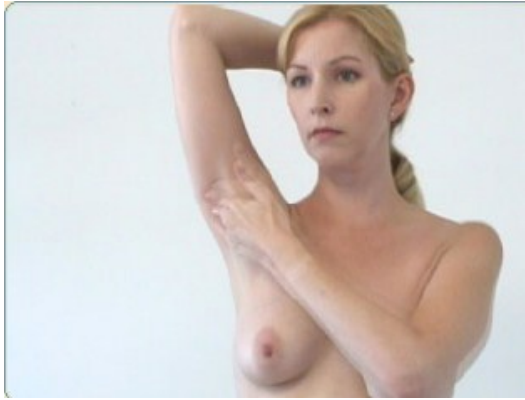
Line Technique

To perform the line technique start in the underarm area, moving the pads of your fingers downward little by little until they are below the breast.



Then move your fingers slightly toward the middle, and slowly move back up.

Go up and down until you cover the whole area from your neckline to your bra-line.



Be sure to vary the amount of pressure to feel different levels of the skin - first lightly then medium pressure and finally deeply. This will help you to feel the entire thickness of your breast.

You are feeling for a lump or changes in your breast tissue. Continue until you have felt the entire breast including your nipple.

Check for a discharge by gently squeezing your nipple.

Use the same technique to examine your armpit. You are feeling for changes in both breast tissue and swollen lymph nodes.

Lymph nodes are small rounded structures that are present at various points in the body including the armpit. Their function is to produce disease-fighting white blood cells and filter out harmful microorganisms and toxins. Breast cancer can cause the lymph nodes in the armpit to become enlarged when the breast itself seems perfectly normal so it is important to ensure you always include the armpit when examining your breasts. Most lymph nodes cannot be felt until they become swollen.

Now switch sides and repeat.

If you are not sure what you feel is normal, visit your doctor.

Appendix 14: Video-Enhanced BSE Instructions Webpage

The format of the video-enhanced BSE Instructions page and the information displayed was the same for both Groups 3 and 4.

Screenshot of Webpage

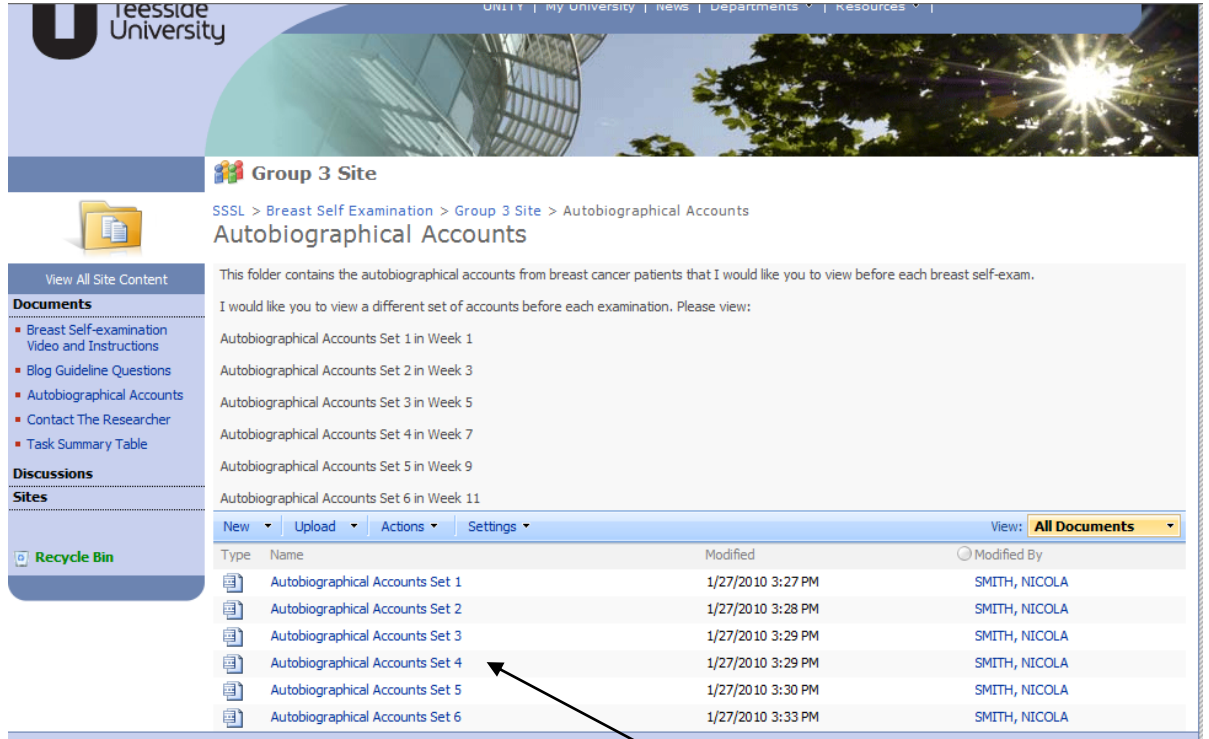


The information contained within the page was the same as the static BSE instructions; but the static pictures were replaced with videos. For the video footage displayed on this page see enclosed DVD.

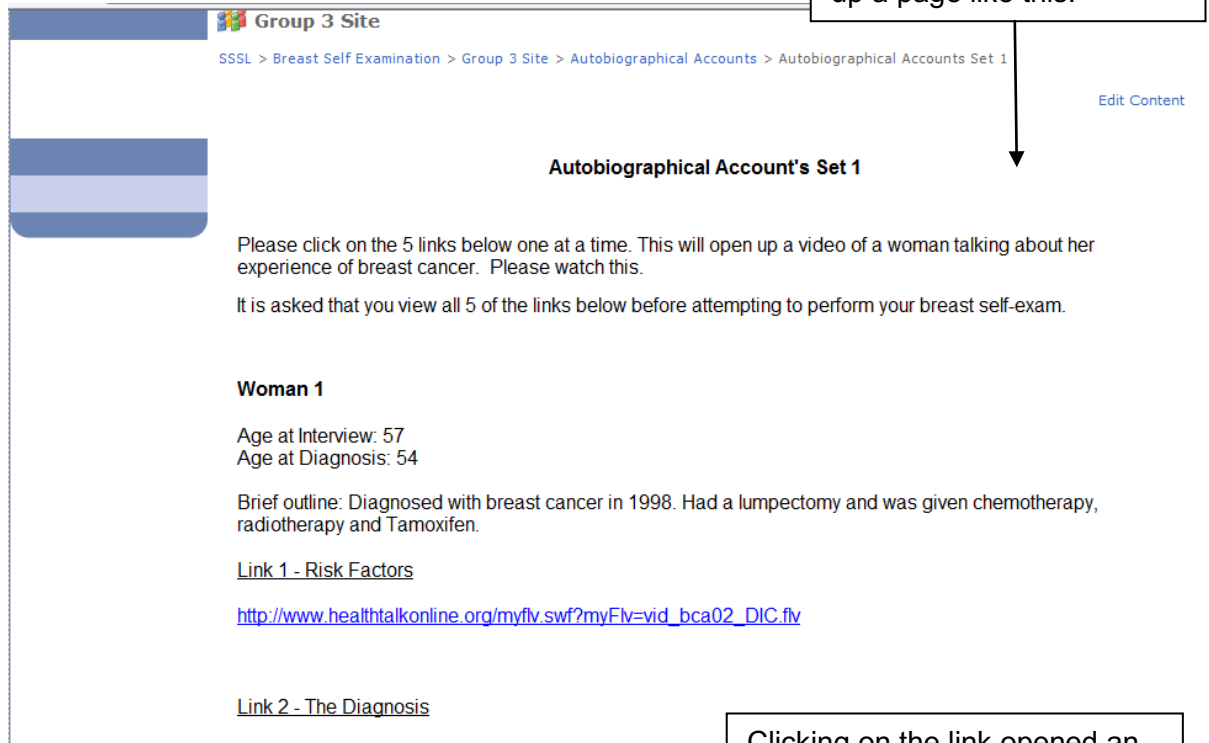
Appendix 15: Autobiographical Accounts Webpage

Screenshot of Webpage

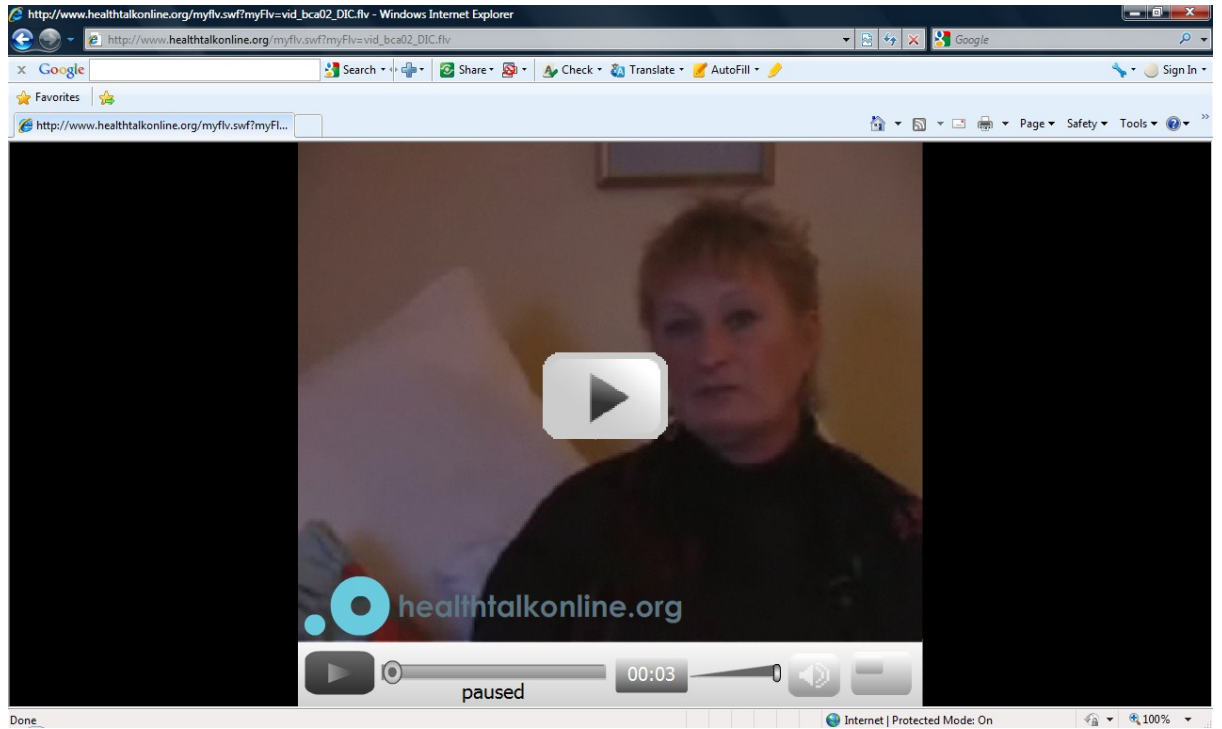
The format of the Autobiographical Accounts page and the information displayed was the same for both groups 1 and 3.



Clicking on these opened up a page like this.



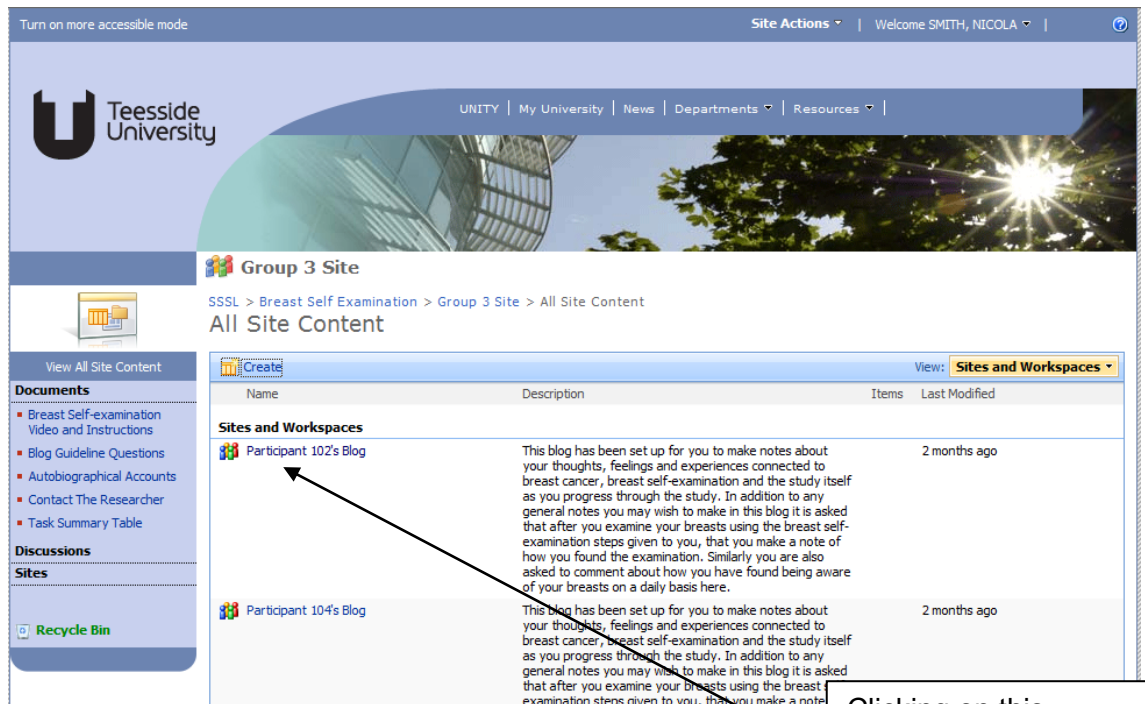
Clicking on the link opened an autobiographical account video.



Appendix 16: Blog Webpage

Screenshot of Webpage

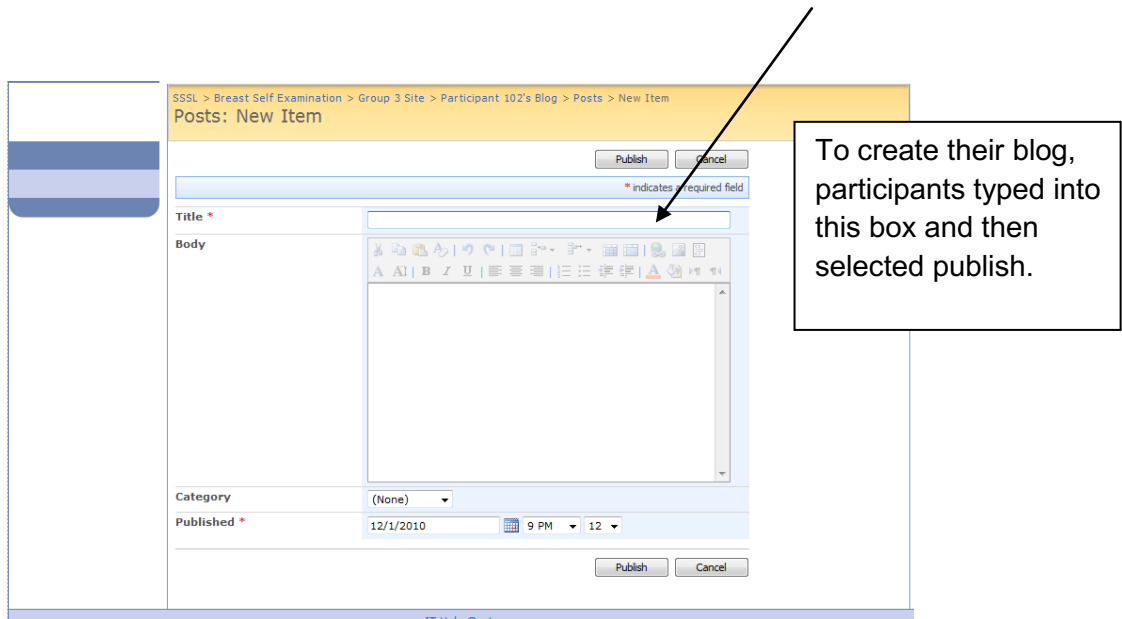
The format of the Blog page and the information displayed was the same for all four study group pages. The only difference was the name used as each participant was addressed by their own name.



Clicking on this opened up this page.



Clicking on this opened up this page.



The screenshot shows a web application interface for creating a new blog post. The breadcrumb trail at the top reads: "SSSL > Breast Self Examination > Group 3 Site > Participant 102's Blog > Posts > New Item". The page title is "Posts: New Item". There are "Publish" and "Cancel" buttons at the top right. A red asterisk indicates a required field. The form includes a "Title" field, a "Body" field with a rich text editor toolbar, a "Category" dropdown menu set to "(None)", and a "Published" field with a date picker set to "12/1/2010", a time dropdown set to "9 PM", and a month dropdown set to "12". There are "Publish" and "Cancel" buttons at the bottom right. A callout box on the right contains the text: "To create their blog, participants typed into this box and then selected publish." An arrow points from the callout box to the "Body" text area.

Appendix 17: Participant Demographics for Website Pilot

Table 17.1

Demographic Data for Participants of Website Pilot

Participant No	Age	Marital Status	Ethnic Origin
5	20	Single	White
9	51	Married	White British
8	25	Single	White British
12	24	Single	White
6	19	Single	White British
17	24	Single	White British
7	25	Co-habiting	White
14	28	Married	White British
10	24	Single	White British
16	33	Single	White
13	26	Single	White British
27	19	Single	White British
3	41	Single	Latin American
22	26	Single	White British
20	26	Single	White British
11	24	Co-habiting	White British

Appendix 18: Website Pilot Quantitative Raw Data

Table A18.1

Responses Relating to Website Welcome Page

P No	Q1: How did you find accessing the study website?	Q2: How did you find reading the information on the website?	Q3: Was the study information displayed on this page sufficient?	Q4: Using the website was easy
5	5	5	Yes	5
9	3	3	Yes	3
8	3	4	Yes	3
12	5	5	Yes	5
6	4	4	Yes	4
17	4	4	Yes	4
7	3	3	Yes	4
14	5	5	Yes	5
10	4	4	Yes	5
16	4	3	Yes	4
13	4	4	Yes	4
27	4	4	Yes	4
3	4	3	Yes	4
22	4	4	Yes	4
20	5	4	Yes	4
11	4	4	Yes	4

P No	Q5. Becoming skilful at using the website was easy	Q6: The website was easy to navigate	Q7: I found using the website enjoyable	Q8: The actual process of using the website was pleasant	Q9 I had fun using the website
5	5	5	5	5	5
9	4	4	3	3	3
8	3	2	3	4	4
12	4	5	5	5	4
6	4	4	3	3	3
17	4	4	3	3	3
7	3	4	3	3	3
14	5	4	4	4	2
10	5	5	5	4	5
16	4	4	3	3	3
13	4	4	3	4	3
27	4	4	4	4	3
3	4	4	4	3	3
22	4	4	3	4	3
20	3	4	3	4	4
11	4	4	4	4	4

Table A18.2

Responses Relating to Website Group Page

P No	Q1: How did you find accessing the study website group page?	Q2: How did you find reading the information on this page?	Q3: Was the study information displayed on this page sufficient?	Q4: Was it clear from reading this page when and what tasks you would be required to do as a participant?	Q5: Did the link to the pre and post study questionnaire work for you?
5	5	5	Yes	Yes	Yes
9	4	4	Yes	Yes	Yes
8	5	3	Yes	Yes	Yes
12	4	5	Yes	Yes	Yes
6	4	4	Yes	Yes	Yes
17	4	4	Yes	Yes	Yes
7	4	4	Yes	Yes	Yes
14	5	5	Yes	Yes	Yes
10	4	4	Yes	Yes	Yes
16	2	1	Yes	No	Yes
13	4	4	Yes	Yes	Yes
27	3	4	Yes	Yes	Yes
3	4	4	Yes	Yes	Yes
22	4	4	Yes	Yes	Yes
20	4	4	Yes	Yes	Yes
11	4	4	Yes	Yes	Yes

P No	Q6: Were you able to access and read the autobiographical accounts? (Only those in group 1 & 3).	Q7: Were you able to access and read/view the breast self-examination instructions ok?	Q8: Using the website was easy	Q9: Becoming skilful at using the website was easy	Q10: The website was easy to navigate
5	Yes	Yes	5	5	5
9	Yes	Yes	3	4	4
8	-	No	3	3	2
12	-	Yes	5	4	5
6	-	Yes	4	4	4
17	Yes	Yes	4	4	4
7	Yes	Yes	4	3	4
14	-	Yes	5	5	4
10	-	Yes	5	5	5
16	-	Yes	2	2	1
13	Yes	Yes	4	4	4
27	Yes	Yes	4	4	4
3	Yes	Yes	4	4	4
22	-	Yes	4	4	4
20	-	Yes	5	4	5
11	Yes	Yes	4	4	4

P No	Q11: I found using the website enjoyable	Q12: The actual process of using the website was pleasant	Q13: I had fun using the website
5	5	5	5
9	3	3	3
8	3	3	3
12	4	4	4
6	3	4	3
17	4	4	4
7	3	3	3
14	3	3	3
10	5	4	5
16	3	3	2
13	4	3	3
27	4	4	3
3	2	3	2
22	4	3	3
20	4	4	4
11	4	4	4

Table A18.3

Response Relating to Breast Self-Examination Technique

P No	Written Was the procedure described clear and easy to understand?	Instructions Do you think it would be possible for you to complete the steps using those written instructions supplied?	Video & Was the procedure shown in the video and accompanying text clear and easy to understand?	Accompanying Text Do you think it would be possible for you to complete the steps using those instructions supplied in the video and accompanying text?
5	Yes	Yes		
9	Yes	Yes		
8			No	No
12			Yes	Yes
6	Yes	Yes		
17	Yes	Yes		
7			Yes	Yes
14	Yes	Yes		
10	Yes	Yes		
16			Yes	Yes
13	Yes	Yes		
27			Yes	Yes
3			Yes	Yes
22	Yes	Yes		
20			Yes	Yes
11			Yes	Yes

Table A18.4

Response Relating to Group Page Personal Blog

P No	Q1: How did you find accessing the blog?	Q2: How did you find reading the blog?	Q3: How did you find writing in the blog?	Q4: Do you think the blog instructions are sufficient to read and write within the blog?	Q5: Do you think the 'questions to help you write your blog' are sufficient to do this?	Q6: Writing a blog was easy
5	5	5	5	Yes	Yes	5
9	4	4	4	Yes	Yes	4
8	4	4	4	Yes	Yes	4
12	4	4	3	Yes	Yes	3
6	4	4	4	Yes	Yes	4
17	4	4	4	Yes	Yes	4
7	4	4	3	Yes	Yes	3
14	5	5	5	Yes	Yes	5
10	5	5	5	Yes	Yes	5
16	4	4	4	Yes	Yes	4
13	4	4	4	Yes	Yes	4
27	3	3	3	Yes	Yes	3
3	3	3	4	Yes	Yes	4
22	4	4	4	Yes	Yes	4
20	4	3	4	Yes	Yes	5
11	4	4	4	Yes	Yes	4

P No	Q7: Becoming skilful at writing a blog was easy	Q8: The blog was easy to navigate	Q9: I found writing a blog enjoyable	Q10: The actual process of writing a blog was pleasant	Q11: I had fun writing a blog
5	4	5	4	4	4
9	3	4	3	4	3
8	4	4	4	4	4
12	3	5	3	3	3
6	4	4	4	4	3
17	4	4	4	4	4
7	3	3	3	3	3
14	3	4	5	3	2
10	5	5	4	4	4
16	4	4	4	4	4
13	4	4	4	4	4
27	3	4	4	4	3
3	4	4	3	3	3
22	4	4	4	4	4
20	5	5	4	4	4
11	4	4	4	4	4

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Table A18.5

Responses Relating to Entire Website

P No	Q1: Using the website was easy	Q2: Becoming skilful at using the website was easy	Q3: The website was easy to navigate	Q4: I found using the website enjoyable	Q5: The actual process of using the website was pleasant	Q6: I had fun using the website
5	5	5	5	5	5	5
9	3	4	4	3	3	3
8	3	3	3	3	3	3
12	5	5	5	5	4	4
6	4	4	4	4	4	4
17	4	4	4	4	4	4
7	3	3	3	3	3	3
14	5	4	4	3	3	3
10	5	5	5	5	4	5
16	3	4	3	3	3	3
13	4	4	4	4	4	3
27	4	4	4	4	4	4
3	4	4	4	3	3	3
22	4	4	4	4	4	3
20	4	4	4	4	4	4
11	4	4	4	4	4	4

Appendix 19: Website Pilot Qualitative Responses

Table A19.1

Responses for Website Welcome Page

P No	Open Questions and Participants Responses – Website Welcome Page
	Q: Further comments or suggestions for improvements of the website welcome page.
9	I was concerned at first about using the site but once I got into it and realised what I was doing I found it easy.
16	Would have preferred to have accessed my group homepage straightaway, and to have found the welcome information incorporated there, perhaps as a link. The information displayed is sufficient, however I have found that the text is too lengthy and a bit off putting, regarding keeping on with the study, as it feels there are many different stages involved and a great amount of my time will be required.
13	Maybe larger links to different pages?

Table A19.2

Responses for Website Group Page

P No	Open Questions and Participants Responses – Website Welcome Page
	Q: If you found accessing or reading the information on the study website group page difficult or very difficult please try to explain.
16	Some of the welcome page information is repeated, which is a bit tiring and repetitive, also the links on the right hand side displaying all the different weeks are overwhelming, I felt that I would have to put too much energy into this.
	Q: If it wasn't clear what tasks you would be required to do as a participant please describe why.
16	Felt confused with regard to the order of tasks and what exactly I would have to do. Would have preferred a personalised table (where I could write my name for example and receive a welcome note with my name), where the timeline of tasks to be taken would be stated more clearly and all the text could be accessed by clicking on the title of the task (having it displayed is again too much). Also, it's unclear how tasks and weeks connect together, if I understood this right then I would have liked for example end of week 2 now go to task 3 and so on and so forth.
	Q: Further comments or suggestions for improvements of the website group page.
16	Merge welcome page information with each group's homepage information, and create a visually accessible line of tasks to be taken, without displaying all that text, just to get an overall idea of where things begin, what's involved, where everything ends, and then click on each one of them to access the task information/instructions. Also, merge tasks and weeks together as appropriate.
13	More detailed links to the different sections of the video autobiographies perhaps. It is unclear why the footage is divided at first, could maybe be made clearer by headings such as "Diagnosis" "Initial reaction" etc for each individual. Just being picky though, I really liked this section.

Table A19.3

Responses for Personal Blog

P No	Open Questions and Participants Responses – Personal Blog
	Q: If you do not think the blog instructions are sufficient please describe why.
16	Would have liked information to have been organised/presented differently and not just as a list of questions (perhaps have a pic of a girl in the middle where I could type my name in and have bubbles with different colours all around me, where I would be asking myself those same questions instead of having someone else asking me). I quite enjoyed accessing that as there is minimal information included which gave me more confidence as a user.

Table A19.4

Responses for Breast Self-Examination Technique

P No	Open Questions and Participants Responses – Breast Self-Examination Technique
	Q: If you were not able to view the breast self-examination instructions please describe what happened.
8	I was able to access and read the instructions ok but the videos would not play at first. However once I'd messed around with my virus protection, I was able to play the videos.
	Q: If the procedure described in the text is not clear or you feel you would be unable to complete the BSE steps please try and explain why.
13	Just a really minor wording issue, I thought the description of the breast tissue to be like orange segments a very good and useful description, but it was suggested afterwards this might seem "scary", I would maybe use a different word, maybe "unusual" as suggesting something might be scary can often make a person wary of something before doing it and might seem a bit intimidating, "pink elephant" syndrome kind of thing so I'd maybe avoid the word scary.
	Q: If the procedure described in the video and accompanying text is not clear or you feel you would be unable to complete the BSE steps please try and explain why.
16	Found videos more useful, instructions are too lengthy and would not go on to read them, perhaps have accompanying text but not show it, maybe as a link, as the lengthy text would put me off watching the videos, would feel it would take me ages to do the self-examination.

Appendix 20: Demographic Characteristics of Main Sample

Table A20.1

Age, Ethnicity, Marital Status, No of Children and Region.

P No	Group	Age	Ethnicity	Marital Status	No of Children	Region
11	1	64	White British	Divorced	2	West Midlands
66	1	40	White British	Single	1	North East
23	3	66	White British	Married	3	North East
38	4	28	White	Single	0	North East
60	2	59	White British	Married	2	North East
65	1	25	White British	Cohabiting	0	Yorkshire and Humberside
14	3	25	White British	Cohabiting	0	North East
74	1	49	White British	Married	2	North East
64	4	55	White	Married	2	North East
9	1	51	White British	Married	2	North East
51	3	20	White British	Single	0	North East
42	4	37	White British	Married	2	Yorkshire and Humberside
59	2	28	White British	Married	0	North East
82	1	35	White British	Divorced	0	North East
30	2	39	White British	Divorced	2	North East
88	4	38	White British	Divorced	0	North East
24	3	67	White British	Married	1	North East
57	1	41	White British	Married	0	North East
12	1	66	White British	Cohabiting	0	North East
71	4	25	White British	Single	0	North East
105	3	25	White British	Cohabiting	0	North East
68	2	48	White British	Married	2	North East
56	4	53	White	Married	0	North East
17	3	32	White British	Married	0	North East
69	3	26	White British	Single	1	North East
34	2	43	White British	Cohabiting	1	North East
62	3	49	White British	Married	1	North East
75	2	41	White British	Married	2	North East

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29	2	32	White	Married	2	South East
36	2	24	White British	Cohabiting	0	North East
77	3	27	White	Single	0	North East
53	2	52	White British	Married	3	North East
79	4	41	White British	Married	1	North East
13	3	25	White British	Single	0	North East
18	3	39	White British	Cohabiting	0	North East
76	2	60	White	Widowed	2	North East
54	2	48	White British	Married	2	North East
81	1	19	White British	Single	0	North East
89	1	25	White	Single	0	North East
83	2	27	White British	Married	1	North East
84	2	38	White British	Married	1	North East
91	3	25	White British	Single	0	North East
58	1	45	White British	Married	2	North East
47	4	52	White British	Married	2	North East
50	1	19	White British	Single	0	North East
8	1	25	White British	Single	0	North East
63	4	19	White British	Single	0	North East
100	4	26	White British	Cohabiting	2	North East
37	4	21	White	Single	0	North East
86	3	25	White British	Cohabiting	0	North East
39	4	31	White British	Single	0	North East
80	4	46	White British	Married	3	North East
45	4	47	White	Separated	2	North East
70	3	39	White British	Married	1	North East
44	4	43	White	Married	1	North East
20	3	51	White British	Single	2	North East
96	2	24	White British	Cohabiting	0	North East
67	2	21	White British	Single	0	North West
93	1	50	White British	Married	3	North East
97	1	22	White British	Single	0	North West

Table A20.2

Education, Employment Status, Length of Unemployment and Employment Area.

P No	Group	Education	Employment Status	Length of Un-employment	Employment Area
11	1	Postgraduate Award/ Masters/ PHD	Retired	0	-
66	1	Degree	Employed	0	Health, Nursing
23	3	Primary	Retired	0	-
38	4	College certificate/ A level	In Full Time Education	0	-
60	2	College certificate/ A level	Employed	0	Sales
65	1	Postgraduate Award/ Masters/ PHD	Employed	0	Health, Nursing
14	3	Degree	Employed	0	Health, Nursing
74	1	College certificate/ A level	Employed	0	Management Consultancy
64	4	Degree	In Full Time Education	0	-
9	1	Degree	Employed	0	Retail, Wholesale
51	3	College certificate/ A level	In Full Time Education	0	-
42	4	Degree	Employed	0	Marketing, Advertising, PR
59	2	Degree	Employed	0	Engineering, Manufacturing, Utilities
82	1	College certificate/ A level	Employed	0	Public Sector Services
30	2	College certificate/ A level	In Full Time Education	0	-
88	4	Postgraduate Award/ Masters/ PHD	Employed	0	Health, Nursing
24	3	Postgraduate Award/ Masters/ PHD	Retired	0	-
57	1	College certificate/ A level	Employed	0	Engineering, Manufacturing, Utilities

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12	1	Postgraduate Award/ Masters/ PHD	Employed	0	Not for profit, Charities
71	4	Postgraduate Award/ Masters/ PHD	Employed	0	Education
105	3	Degree	Employed	0	Retail, Wholesale
68	2	College certificate/ A level	Self Employed	0	Social Services
56	4	GCSE	Retired	0	-
17	3	Postgraduate Award/ Masters/ PHD	Employed	0	Education
69	3	Degree	Employed	0	Public Sector Services
34	2	Postgraduate Award/ Masters/ PHD	Employed	0	Education
62	3	College certificate/ A level	Employed	0	Education
75	2	Postgraduate Award/ Masters/ PHD	Employed	0	Secretarial, PAs, Administration
29	2	Postgraduate Award/ Masters/ PHD	Employed	0	Public Sector Services
36	2	College certificate/ A level	Employed	0	Public Sector Services
77	3	Degree	Unemployed	23	-
53	2	GCSE	Self Employed	0	Retail, Wholesale
79	4	Postgraduate Award/ Masters/ PHD	Employed	0	Education
13	3	College certificate/ A level	In Full Time Education	0	-
18	3	Postgraduate Award/ Masters/ PHD	Employed	112	Education
76	2	Postgraduate Award/ Masters/ PHD	Self Employed	0	Media, New media, Creative
54	2	GCSE	Unemployed	3	-
81	1	GCSE	Employed	0	Secretarial, PAs, Administration
89	1	Degree	Employed	0	Public Sector Services

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83	2	Degree	Employed	0	Engineering, Manufacturing, Utilities
84	2	Degree	In Full Time Education	0	-
91	3	College certificate/ A level	Employed	0	Retail, Wholesale
58	1	Degree	Employed	0	Not for profit, Charities
47	4	College certificate/ A level	Employed	0	Public Sector Services
50	1	College certificate/ A level	In Full Time Education	0	-
8	1	Degree	Employed	0	Education
63	4	GCSE	Employed	0	Education
100	4	College certificate/ A level	In Full Time Education	0	-
37	4	College certificate/ A level	Employed	0	Health, Nursing
86	3	Postgraduate Award/ Masters/ PHD	Employed	0	Graduate
39	4	Degree	Employed	0	Education
80	4	GCSE	Employed	0	-
45	4	College certificate/ A level	In Full Time Education	0	Secretarial, PAs, Administration
70	3	Degree	Employed	0	Not for profit, Charities
44	4	College certificate/ A level	Employed	0	Health, Nursing
20	3	Degree	Employed	0	Health, Nursing
96	2	College certificate/ A level	Employed	0	Health, Nursing
67	2	Degree	Employed	0	Retail, Wholesale
93	1	GCSE	Employed	0	Public Sector Services
97	1	College certificate/ A level	In Full Time Education	0	-

Table A20.3

Religion, Contraceptive Pill Use and Length of Time Taken, Menstrual State, Age Started the Menopause and Age Started Menstrual Cycle.

P No	Group	Religion	Pill Use	Length of Pill Use (month)	Menstrual State	Age Menopause	Age Menstrual Cycle
11	1	None	Have taken in past	0	Menopausal	45	13
66	1	Christian	Have taken in past	0	Non-Menopausal		13
23	3	Christian	Have taken in past	0	Non-Menopausal		12
38	4	None	Take at present	120	Non-Menopausal		15
60	2	Christian	Have taken in past	0	Menopausal	56	17
65	1	Christian	Take at present	96	Non-Menopausal		13
14	3	Christian	Have taken in past	0	Non-Menopausal		13
74	1	Christian	Take at present	408	Non-Menopausal		13
64	4	None	Have taken in past	0	Menopausal	53	13
9	1	Christian	Have taken in past	0	Non-Menopausal		12
51	3	Christian	Have taken in past	0	Non-Menopausal		13
42	4	None	Have taken in past	0	Non-Menopausal		17
59	2	Christian	Have taken in past	0	Non-Menopausal		12
82	1	None	Have taken in past	0	Non-Menopausal		15
30	2	Christian	Have taken in	0	Non-Menopausal		10

			past				
88	4	None	Have taken in past	0	Non-Menopausal		12
24	3	None	Have taken in past	0	Menopausal	56	11
57	1	Christian	Do not/ or have never taken	0	Non-Menopausal		15
12	1	Christian	Have taken in past	0	Non-Menopausal		17
71	4	Christian	Take at present	1	Non-Menopausal		12
105	3	Christian	Do not/ or have never taken	0	Non-Menopausal		14
68	2	Christian	Have taken in past	0	Menopausal	43	14
56	4	Christian	Do not/ or have never taken	0	Menopausal	40	10
17	3	None	Have taken in past	0	Non-Menopausal		12
69	3	Christian	Have taken in past	0	Non-Menopausal		13
34	2	Christian	Have taken in past	0	Non-Menopausal		14
62	3	Christian	Have taken in past	0	Menopausal	44	13
75	2	Christian	Have taken in past	0	Non-Menopausal		14
29	2	Christian	Have taken in past	0	Non-Menopausal		11
36	2	Christian	Have taken in past	0	Non-Menopausal		12
77	3	Pagan	Have taken in past	0	Non-Menopausal		16

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53	2	None	Do not/ or have never Taken	0	Non- Menopausal		14
79	4	Christian	Have taken in past	0	Non- Menopausal		12
13	3	None	Have taken in past	0	Non- Menopausal		12
18	3	Christian	Have taken in past	0	Non- Menopausal		13
76	2	None	Have taken in past	0	Menopausal	53	14
54	2	Christian	Have taken in past	0	Non- Menopausal		13
81	1	Christian	Have taken in past	0	Non- Menopausal		11
89	1	None	Have taken in past	0	Non- Menopausal		12
83	2	Christian	Take at present	47	Non- Menopausal		12
84	2	None	Have taken in past	0	Non- Menopausal		15
91	3	Christian	Take at present	72	Non- Menopausal		14
58	1	None	Have taken in past	0	Non- Menopausal		14
47	4	Christian	Have taken in past	0	Menopausal	49	13
50	1	Christian	Do not/ or have never taken	0	Non- Menopausal		13
8	1	Christian	Have taken in past	0	Non- Menopausal		12
63	4	Christian	Take at present	16	Non- Menopausal		13
100	4	Christian	Do not/ or have never taken	0	Non- Menopausal		13
37	4	None	Have taken in	0	Non- Menopausal		14

86	3	Christian	past Have taken in	0	Non- Menopausal		11
39	4	Christian	past Take at present	168	Non- Menopausal		12
80	4	Christian	Have taken in past	0	Non- Menopausal		13
45	4	Christian	Have taken in past	0	Non- Menopausal		15
70	3	Christian	past Have taken in	0	Non- Menopausal		13
44	4	None	past Have taken in	0	Non- Menopausal		10
20	3	Christian	past Have taken in	0	Menopausal	39	13
96	2	None	past Have taken in	0	Non- Menopausal		11
67	2	None	past Take at present	8	Non- Menopausal		13
93	1	Christian	Have taken in past	0	Menopausal	48	12
97	1	None	past Take at present	6	Non- Menopausal		13

Table A20.4

Family History, History of Non Blood Relatives and Friends, Breast Cup Size and Breast Tissue Density.

P No	Group	Family History	Other History	Breast Cup Size	Breast Tissue Density
11	1	Aunt, Cousin	Colleague, Friend	C	Loose
66	1	Mother	No	D	Dense (firm)
23	3	Grandmother, Mother	Sister in law	G	Loose
38	4	Great aunt	Colleague, Friend	E	Loose
60	2	No	Friend	D	Loose
65	1	Aunt	No	C	Dense (firm)
14	3	No	Mother in law	G	Dense

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74	1	No	No	B	(firm) Loose
64	4	Nephew	Friend	DD	Loose
9	1	No	Friend, Sister in law	C	Loose
51	3	No	No	F	Dense (firm)
42	4	No	No	A	Loose
59	2	No	Friend	E	Loose
82	1	Mother, Great aunt	Colleague	E	Loose
30	2	Mother	Friend	D	Dense (firm)
88	4	Grandmother, Great aunt	Friend	A	Dense (firm)
24	3	Sister, Aunt, Cousin	Colleague, Friend	C	Dense (firm)
57	1	Grandmother, Mother, Aunt	Mother in law	G	Loose
12	1	Grandmother, Mother, Sister	Friend	B	Dense (firm)
71	4	No	No	DD	Dense (firm)
105	3	Grandmother	No	FF	Loose
68	2	No	No	B	Dense (firm)
56	4	No	Friend	E	Loose
17	3	Grandmother, Great grandmother	No	GG	Loose
69	3	No	No	A	Loose
34	2	No	Friend	C	Loose
62	3	No	Aunt	C	Loose
75	2	No	Friend	A	Dense (firm)
29	2	No	Mother in law	B	Dense (firm)
36	2	No	Friend	B	Loose
77	3	No	No	AA	Dense (firm)
53	2	Great aunt	Sister in law	C	Loose
79	4	Mother	No	C	Dense (firm)
13	3	No	Friend	DD	Loose
18	3	Family History Not Available	No	D	Dense (firm)
76	2	No	Friend	DD	Dense (firm)
54	2	No	Friend	DD	Loose

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81	1	No	No	C	Dense (firm)
89	1	No	No	C	Dense (firm)
83	2	Family History Not Available	No	D	Loose
84	2	Aunt	Friend	C	Loose
91	3	No	No	B	Dense (firm)
58	1	No	No	B	Loose
47	4	Mother, Great grandmother	No	C	Loose
50	1	Grandmother	No	D	Dense (firm)
8	1	No	No	DD	Dense (firm)
63	4	Grandmother	No	D	Dense (firm)
100	4	No	Friend, Aunt	B	Dense (firm)
37	4	No	Godmother	D	Dense (firm)
86	3	No	No	A	Dense (firm)
39	4	Aunt	No	DD	Dense (firm)
80	4	Grandmother	No	C	Dense (firm)
45	4	No	No	DD	Loose
70	3	No	Sister in law, Friend	D	Loose
44	4	No	No	E	Loose
20	3	No	Friend	DD	Loose
96	2	Grandmother	No	C	Dense (firm)
67	2	Grandmother	No	DD	Dense (firm)
93	1	No	No	DD	Dense (firm)
97	1	No	No	DD	Dense (firm)

Appendix 21: Power Analysis

Calculated using Sample Power

2 × 2 Independent Measures Design Power analysis

The study adopted a 2 × 2 independent measures design. The first independent variable was autobiographical accounts: autobiographical accounts viewed or not viewed and the second independent variable was BSE support: BSE with the static support or BSE with the multimedia enhanced support.

Prospective power analyses using the statistical software program Sample Power were conducted to determine the required sample size needed to detect a small, medium and large effect of autobiographical accounts and/or BSE support on BSE for a significance level of 0.05. Following the study design it was decided a 2 × 2 analysis of variance would examine the effect of autobiographical accounts and BSE support and power analyses were made based on this.

Cohen (1992) suggests that one should aim to have a 0.2 probability of failing to detect a genuine effect, and so the corresponding level of power that he recommends is 0.80 (1-0.2). Following this the desired power for the current study was 0.80. Moreover, Cohen further suggests effect sizes for various indexes. The current study utilised his suggested effect sizes for f where 0.1 is a small effect, 0.25 a medium effect and 0.4 a large effect.

Significance level = 0.05 = p (rejecting $H_0|H_0$ true)

Desired Power = 0.80 = p (rejecting $H_0|H_0$ false).

Small Effect Size

Effect size $f = 0.10$ (small)

Required $n = 198$

Study has four experimental groups thus required $N = 4 \times n$

$$= 4 \times 198 = 792$$

Appendix 21

To achieve power of 0.8 and a small effect size ($f = 0.10$), a sample size of 792 is required to detect a significant effect of autobiographical accounts and/or BSE support.

Medium Effect Size

Effect size $f = 0.25$ (medium)

Required $n = 33$

Study has four experimental groups thus required $N = 4 \times n$

$$= 4 \times 33 = 132$$

To achieve power of 0.8 and a medium effect size ($f = 0.25$), a sample size of 132 is required to detect a significant effect of autobiographical accounts and/or BSE support.

Large Effect Size

Effect size $f = 0.40$ (large)

Required $n = 14$

Study has four experimental groups thus required $N = 4 \times n$

$$= 4 \times 14 = 56$$

To achieve power of 0.8 and a small effect size ($f = 0.40$), a sample size of 56 is required to detect a significant effect of autobiographical accounts and/or BSE support.

Health Belief Model (HBM) Multiple Regression Power Analysis

In addition to the effect of autobiographical accounts and BSE support the study further considered the predictive utility of the Health Belief Model in relation to BSE frequency and proficiency. In contrast to what could be expected given past research all six components of the HBM were not found to be statistically associated with BSE in the current study. Instead only the component confidence was found to be significant. It was hypothesised that one reason for the failure of the other components of the HBM to predict BSE may have been as a result of the small sample size employed within the

current study. The effect sizes reported for the HBM components with the exception of confidence were very small, ranging from 0.0001 to 0.04 and as such it was proposed that a sample size of 60 (as in the current study) may not have been sufficient to detect a significant effect of these components. In order to explore this further, retrospective power analyses using the statistical software program Sample Power were conducted to determine the required sample size needed for a significant result with these reported effect sizes.

Following Cohen (1992), the desired power was again set at 0.80 and a significance level of 0.05 used. The results of the power analyses are presented in Table A21 and suggest that a larger sample size than 60 may have been needed for all components of the HBM but confidence. This may be why the current study found confidence to be the only significant predictor of both BSE frequency and proficiency.

Table A21.

Results of Power Analysis: Sample Size Needed Based on Reported Effect Sizes in Multiple Regression.

HBM Component	BSE Frequency		BSE Proficiency	
	sr^2	N Required for Power 0.80	sr^2	N Required for Power 0.80
Confidence	0.28	23	0.24	27
Health Motivation	0.0005	15692	0.0004	19617
Susceptibility	0.03	256	0.02	387
Seriousness	0.001	7843	0.04	191
Benefits	0.04	191	0.0002	39239
Barriers	0.0005	15692	0.01	779

Significance level = 0.05 Desired Power 0.80

Note. N for the current study was 60.

Appendix 22

Appendix 22: Reflective Journal

See enclosed DVD.

Appendix 23: Ethical Clearance Confirmation

Providing **Opportunities** - Pursuing **Excellence**



29 January 2009

Professor Anna van Wersch

Dear Anna

School Research Ethics Committee

Project title: The effects of autobiographical accounts of breast cancer patients and an electronically designed breast self examination (BSX) skills program on women's knowledge, beliefs and behaviours towards breast self examination (BSE)

Student(s) Names: Nicola Smith

The above proposal has received ethical clearance and the project may proceed.

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

A handwritten signature in blue ink that reads 'Barbara Cox'.

Dr Dr Andrea Abbas
Co-Chair
Research Ethics Committee
School of Social Sciences and Law



INVESTOR IN PEOPLE
VAT REG NO. GB 686 4809 81



Mrs Liz Barnes
Dean

SCHOOL OF SOCIAL SCIENCES & LAW

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www.tees.ac.uk

Appendix 24: Study Recruitment Webpage Including Information for Participants

www.breast-aware.co.uk

Breast Self-examination Study

INFORMATION ABOUT THE STUDY

Background

Breast cancer is now the most common cancer in the UK. Each year more than 44,000 women are diagnosed with breast cancer and of these more than 12,000 die each year (Cancer Research UK, 2008). More women die in the UK compared to the rest of Europe (Mayor, 2003), partly because of the advanced stage of the disease when women consult a GP (McCready et al., 2005). Regular breast self-examination aids the care and understanding of one's breasts so that abnormalities are detected early to speed up consultations with doctors (Cancer Research UK, 2008), but unfortunately regular breast self-examination is not widespread. A public health initiative is needed which promotes breast self-examination (BSE) and breast awareness in all women from adolescence onwards such that looking after their breasts becomes part of their daily lives as cleaning their teeth or putting on their make-up. The success of such an initiative however depends on a clear understanding of a women's breast awareness and their decision to engage in breast self-examination.

What is the purpose of the study?

- The aim of the study is to investigate women's knowledge, beliefs and behaviours towards breast self-examination (BSE), by exploring different methods of BSE.
- It is hoped that these findings will help us understand why some women choose to engage in breast self-examination and others do not.
- This understanding is key to the success of future interventions encouraging breast self-examination and will help decide whether existing methods of breast self-examination can be improved.

What will happen to me if I take part?

- You will first be allocated to 1 of 4 groups and asked to provide an email address that I (Nicola Smith) can use to contact you throughout the study.
- You will then be provided with a participant number, username and password to gain access to a personal blog (online diary) and a message board on this website.
- In your personal blog you will be asked to make notes about your thoughts, feelings and experiences connected to breast cancer, self examination and the study itself as you progress through it. This blog will be kept strictly confidential and will be only accessible to you and me.
- A message board will also be made available to you and this will give you the opportunity to discuss your thoughts, feelings and experiences connected to breast cancer, self-examination and the study itself with other participants in the study.

- Data from the message boards and private blogs will use your participant number rather than your name.
- Before the start of the study you will be asked to complete a pre-assessment questionnaire asking you for personal details (age, occupation etc.) and your general thoughts and feelings regarding breast cancer and breast self-examination.
- Once you have completed this questionnaire you will be given instructions on how to carry out a breast self-examination procedure and you will be asked to implement this fortnightly for 3 months. Some of you will also be asked to read some additional information to see whether that makes any difference. In addition to this you will be asked to give feedback fortnightly on both the frequency and usability of the breast self examination procedure in your personal blog.
- After three months you will be asked to complete a post assessment questionnaire in which you can reveal your thoughts and feelings about breast cancer and breast self-examination, the breast self-examination procedure you followed and your experience of the study generally.

Are there any disadvantages in or possible risks of taking part in this study?

- A change in one of your breasts might be found as a result of you examining your breasts during the study. Should this occur you are advised to have these changes checked by your doctor at your local health centre.

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 cancer prevention 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 April 2011.
- If you do choose to withdraw from the study you can email the researcher Nicola Smith at G7079216@live.tees.ac.uk or telephone her on 07824735872.
- Alternatively you can leave a letter addressed to the researcher at the reception of the school of social sciences and law or send to the following address.

Nicola Smith/Professor Anna Van Wersch
School of Social Sciences & Law
Teesside University
Borough Road
Middlesbrough
TS13BA

- 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 you can contact the researcher

- Nicola Smith (PHD student at Teesside University)
- via telephone on 07824735872 or email at G7079216@live.tees.ac.uk
- If you would like any further information about breast cancer and breast self-examination the following Websites may be useful;
- www.breakthrough.org.uk/breast-cancer
- www.cancerresearchuk.org
- www.breastcancer.org
- www.nhs.uk
- Furthermore should you find any lumps or notice any changes in your breasts we advise you to contact your doctor 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 consent page.

Best wishes,
Nicola

INTERESTED?

(Please click the blue link.)

Clicking the blue link directed the women to the study consent form.

Appendix 25: Consent Form

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Breast Self-examination Study Consent
=====

CONSENT FORM & BRIEF QUESTIONNAIRE

Breast Self-examination Project

Researcher: Nicola Smith (PhD Student)

(A) CONSENT FORM

Thank you for agreeing to take part in this research. In agreeing to participate you have the following rights and protections as laid down in the British Psychological Society's ethical guidelines.

Your participation is entirely voluntary.

Under no circumstances will your real name or identifying information be included in the reporting of this research.

You may withdraw the information you provide through the study at any point up until 1st January 2011.

Nobody, except the researcher and the supervisory team will have access to this anonymised material in its entirety.

In agreeing to the terms of this consent form you should be aware that any anonymised material is only for use in the current research project.

1. Please read the following seven statements and if you agree to these terms and wish to participate in this study select the check box next to each statement.

I confirm that I have read and understood the page with information about taking part in the above study and have had the opportunity to ask questions.

I understand that my participation is voluntary and that I am free to withdraw at any time (up until 1st January 2011) without giving any reason.

I give permission for the researcher to use all the information I provide through the study

I give permission for the researcher to create a computer account on my behalf. I will use this computer account to take part in the research.

I agree to take part in the above study.

2.

Name _____

Date _____

Thank you for agreeing to take part in the study.

(B) BRIEF QUESTIONNAIRE

I would appreciate it if you could spare one more minute to answer a few questions which will help form groups for the study.

3. Gender
4. Age (in years)
5. Ethnic origin?
6. Other (please state)
7. Highest educational qualification you have obtained?
8. Is English your first language?
9. If no; Can you read and write in English comfortably?
10. Do you currently have breast cancer?
11. Are you suffering from mentally ill health?

Please provide your email address in the box below so you can be contacted with further study instructions. If you feel comfortable doing so it would also be useful for you to provide a contact number which the researcher could use should any problems be experienced contacting you via email.

Both your email address and telephone number (if provided) will be kept strictly confidential and will not be shared with anyone else. Once the study is finished all communication between you and the researcher will be stopped and the email address and contact numbers (if provided) deleted.

12. Email

13. Contact Number (Optional)

Home _____

Mobile _____

=====

Thank You!

=====

Thank you once again for taking the time to complete these questions and I will be in touch with further study instructions soon.

Best Wishes, Nicola

Appendix 26

Appendix 26: SPSS Outputs and Data File

See enclosed DVD.

Appendix 27: Additional Result Summary Tables and Figures**Hierarchical and Multiple Regression Summary Tables for Demographic Characteristics and E-HBM Analyses.**

Table A27.1

Hierarchical Multiple Regression of Age and Family History of Breast Cancer on Anxiety.

Variables	Anxiety (DV)	Age	Family History Dummy 1	Family History Dummy 2	<i>b</i>	β	sr^2
Age	- 0.30				- 0.21	- 0.25	0.08 *
Family History Dummy 1	- 0.41	0.15			- 9.16	- 0.40	0.15 **
Family History Dummy 2	- 0.14	- 0.06	- 0.15		- 13.26	- 0.21	0.04
					Constant <i>a</i> = 52.53		
Means	40.68	37.72					$R^2 = 0.27$
Standard Deviations	11.29	13.73					Adjusted $R^2 = 0.23$
							** $R = 0.52$

* $p < 0.05$. ** $p < 0.01$.

Table A27.2

Standard Multiple Regression of Number of Children, Age Started the Menopause and Non-blood Relatives Breast Cancer History on Powerful Others HLC.

Variables	Powerful Others HLC (DV)	Number of Children	Age Started The Menopause	Non-Blood Relatives Breast Cancer History	<i>b</i>	β	sr^2
Number of Children	- 0.44				- 4.36	- 0.72	- 0.34 *
Age Started the Menopause	0.64	0.24			0.65	0.83	0.60 **
Non-Blood Relatives Breast cancer History	0.29	-0.50	0.12		- 1.67	-0.16	0.02
					Constant <i>a</i> = - 6.31		
Means	16.18	1.73	47.82				$R^2 = 0.80$
Standard Deviations	4.79	0.79	6.11				Adjusted $R^2 = 0.72$
							** $R = 0.90$

* $p < 0.05$. ** $p < 0.01$.

Appendix 27

Table A27.3

Hierarchical Multiple Regression of Age Started the Menstrual Cycle and Family History of Breast Cancer on the Illness Representation Component Identity.

Variables	Identity (DV)	Age Started Menstrual Cycle	Family History Dummy 1	Family History Dummy 2	<i>b</i>	β	<i>sr</i> ²
Age	0.26				0.21	0.27	0.07 *
Started Menstrual Cycle							
Family History Dummy 1	- 0.32	0.04			- 0.77	- 0.31	0.10 *
Family History Dummy 2	0.11	- 0.06	- 0.15		0.52	0.08	0.01
					Constant <i>a</i> = 2.35		
Means	0.48	13.02					<i>R</i> ² = 0.18
Standard deviations	1.22	1.58					Adjusted <i>R</i> ² = 0.13
							** <i>R</i> = 0.42

* *p* < 0.05. ** *p* < 0.01.

Table A27.4

Standard Multiple Regression of Education and Employment Status (Employ Status) on the Illness Representation Component Risk Factors

Variables	Risk Factors (DV)	Education 1	Education 2	Education 3	Education 4	Employ Status 1	Employ Status 2	Employ Status 3	Employ Status 4	b	β	sr^2
Education Dummy 1	0.15									-0.12	-0.01	0.00
Education Dummy 2	0.17	-0.34								0.15	0.12	0.01
Education Dummy 3	0.08	-0.24	-0.19							0.08	0.05	0.00
Education Dummy 4	0.10	-0.09	-0.07	-0.05						0.33	0.09	0.00
Employ Status Dummy 1	-0.15	0.08	-0.10	0.22	-0.02					-0.37	-0.13	0.02
Employ Status Dummy 2	0.46	-0.15	-0.15	0.07	0.16	-0.04				0.10	0.44	0.18**
Employ Status Dummy 3	-0.12	-0.10	-0.24	-0.16	-0.06	-0.08	-0.10			-0.06	-0.04	0.00
Employ Status Dummy 4	0.11	-0.15	-0.07	-0.16	0.57	-0.04	-0.05	-0.10		0.12	0.05	0.00
Mean	3.05									Constant a = 3.63		
Standard Deviation	0.50									$R^2 = 0.27$		
										Adjusted $R^2 = 0.15$		
										** $R = 0.52$		

* p < 0.05. ** p < 0.01.

Table A27.5

Standard Multiple Regression of Cup Size on the Illness Representation Component Consequences (Cons)

Variables	Cons (DV)	Cup Dummy 1	Cup Dummy 2	Cup Dummy 3	Cup Dummy 4	Cup Dummy 5	Cup Dummy 6	Cup Dummy 7	Cup Dummy 8	Cup Dummy 9	Cup Dummy 10	b	β	s_r^2
Cup Dummy 1	-0.13											-0.59	-0.16	0.02
Cup Dummy 2	0.14	-0.04										0.11	0.06	0.00
Cup Dummy 3	-0.13	-0.04	-0.10									-0.30	-0.19	0.03
Cup Dummy 4	0.12	-0.06	-0.14	-0.16								0.00	0.00	0.00
Cup Dummy 5	-0.28	-0.07	-0.15	-0.17	-0.24							-0.38	-0.32	0.07*
Cup Dummy 6	0.30	-0.04	-0.09	-0.10	-0.14	-0.15						0.36	0.21	0.04
Cup Dummy 7	-0.27	-0.02	-0.04	-0.04	-0.06	-0.07	-0.04					-1.09	-0.29	0.08*
Cup Dummy 8	-0.06	-0.02	-0.04	-0.04	-0.06	-0.07	-0.04	-0.02				-0.34	-0.09	0.01
Cup Dummy 9	-0.03	-0.03	-0.07	-0.08	-0.11	-0.12	-0.07	-0.03	-0.03			-0.17	-0.08	0.01
Cup Dummy 10	-0.06	-0.02	-0.04	-0.04	-0.06	-0.07	-0.04	-0.02	-0.02	-0.03		-0.34	-0.09	0.01
Mean	3.98											Constant a = 4.09		
Standard Deviation	0.48											$R^2 = 0.30$		
												Adjusted $R^2 = 0.16$		
												** $R = 0.55$		

* $p < 0.05$. ** $p < 0.01$.

Table A27.6

Hierarchical Multiple Regression of Family History and Cup Size on Susceptibility (Susc)

Variables	Susc (DV)	Family 1	Family 2	Cup 1	Cup 2	Cup 3	Cup 4	Cup 5	Cup 6	Cup 7	Cup 8	Cup 9	Cup 10	b	β	sr^2
Family Dummy 1	0.33													0.58	0.09	0.10**
Family Dummy 2	-0.07	-0.15												0.74	0.25	0.01
Cup Dummy 1	0.00	-0.11	-0.02											0.31	0.12	0.01
Cup Dummy 2	0.11	-0.12	-0.06	-0.04										-0.22	-0.10	0.05
Cup Dummy 3	-0.06	-0.16	-0.06	-0.04	-0.10									0.33	0.16	0.01
Cup Dummy 4	0.35	-0.04	0.39	-0.06	-0.14	-0.16								1.26	0.43	0.01
Cup Dummy 5	-0.06	-0.15	-0.09	-0.07	-0.15	-0.17	-0.24							0.18	0.03	0.02
Cup Dummy 6	0.07	0.00	-0.06	-0.04	-0.91	-0.10	-0.14	-0.15						0.39	0.06	0.15**
Cup Dummy 7	0.30	-0.11	-0.02	-0.02	-0.04	-0.04	-0.06	-0.07	-0.04					1.25	0.34	0.00
Cup Dummy 8	0.16	0.16	-0.02	-0.02	-0.04	-0.04	-0.06	-0.07	-0.04	-0.02				0.99	0.16	0.00
Cup Dummy 9	0.33	0.13	-0.43	-0.03	-0.07	-0.08	-0.11	-0.12	-0.07	-0.03	-0.03			0.59	0.36	0.10
Cup Dummy 10	-0.07	0.16	-0.24	-0.02	-0.04	-0.04	-0.06	-0.07	-0.04	-0.02	-0.02	-0.03		0.49	0.11	0.02
Mean														Constant a = 2.02		
Standard Deviation	2.60													$R^2 = 0.43$		
	0.81													Adjusted $R^2 = 0.28$		
														** $R = 0.65$		

* p < 0.05. ** p < 0.01.

Appendix 27

Table A27.7

Standard Multiple Regression of Education (Edu) on Health Motivation

Variables	Health Motivation (DV)	Edu Dummy 1	Edu Dummy 2	Edu Dummy 3	Edu Dummy 4	B	β	sr^2
Education Dummy 1	- 0.04					0.09	0.09	0.01
Education Dummy 2	0.37	- 0.34				0.45	0.39	0.12**
Education Dummy 3	- 0.07	- 0.24	- 0.19			0.03	0.02	0
Education Dummy 4	- 0.21	- 0.09	- 0.07	- 0.05		-0.63	-0.17	0.03
						Constant $a = 3.63$		
Means	3.74							$R^2 = 0.18$
Standard deviations	0.48							Adjusted $R^2 = 0.12$
								** $R = 0.42$

* $p < 0.05$. ** $p < 0.01$.

Table A27.8

Standard Multiple Regression of Type of Employment (Emp) on Barriers

Variables	Barrier (DV)	Emp 1	Emp 2	Emp 3	Emp 4	Emp 5	Emp 6	Emp 7	Emp 8	Emp 9	Emp 10	Emp 11	Emp 12	b	β	sr^2
Emp Dummy 1	0.43													1.49	0.41	0.15**
Emp Dummy 2	-0.17	-0.04												-0.37	-0.17	0.02
Emp Dummy 3	-0.30	-0.07	-0.13											-0.37	-0.26	0.04
Emp Dummy 4	0.06	-0.02	-0.04	-0.07										0.20	0.06	0.00
Emp Dummy 5	-0.06	-0.02	-0.04	-0.07	-0.02									-0.23	-0.06	0.00
Emp Dummy 6	0.03	-0.02	-0.04	-0.07	-0.02	-0.02								0.06	0.02	0.00
Emp Dummy 7	0.45	-0.04	-0.07	-0.13	-0.04	-0.04	-0.04							0.87	0.40	0.13**
Emp Dummy 8	0.02	-0.06	-0.12	0.21	-0.07	-0.07	-0.07	-0.12						0.00	0.00	0.00
Emp Dummy 9	-0.04	-0.06	-0.10	-0.17	-0.06	-0.06	-0.06	-0.10	-0.16					-0.08	-0.05	0.00
Emp Dummy 10	-0.01	-0.02	-0.04	-0.07	-0.02	-0.02	-0.02	-0.04	-0.07	-0.06				-0.08	-0.02	0.00
Emp Dummy 11	-0.05	-0.04	-0.07	-0.13	-0.04	-0.04	-0.04	-0.07	-0.12	-0.10	-0.04			-0.13	-0.06	0.00
Emp Dummy 12	-0.10	-0.02	-0.04	-0.07	-0.02	-0.02	-0.02	-0.04	-0.07	-0.06	-0.02	-0.04		-0.37	-0.10	0.01
Mean	2.34													Constant a = 2.37		
Standard Deviation	0.55													$R^2 = 0.48$		
														Adjusted $R^2 = 0.28$		
														** $R = 0.69$		

* p < 0.05. ** p < 0.01.

Appendix 27

Table A27.9

Standard Multiple Regression of Age and Age Started the Menstrual Cycle on BSE Frequency

Variables	BSE Frequency (DV)	Age	Age Started the Menstrual Cycle	<i>b</i>	β	sr^2
Age	0.46			0.15	0.43	0.18 **
Age Started the Menstrual Cycle	0.26	0.16		0.58	0.20	0.04
Means	4.67	37.72	13.02	Constant $a = - 8.34$		
Standard deviations	4.66	13.73	1.58	$R^2 = 0.25$		
				Adjusted $R^2 = 0.22$		
				$**R = 0.50$		

* $p < 0.05$. ** $p < 0.01$.

Tables and Scatter Plots Depicting the Direction of the Predictive Relationship between Demographic Characteristics and Components of the E-HBM.

Figure A27.1. Scatter Plot Depicting Pre-Intervention Anxiety Scores by Age

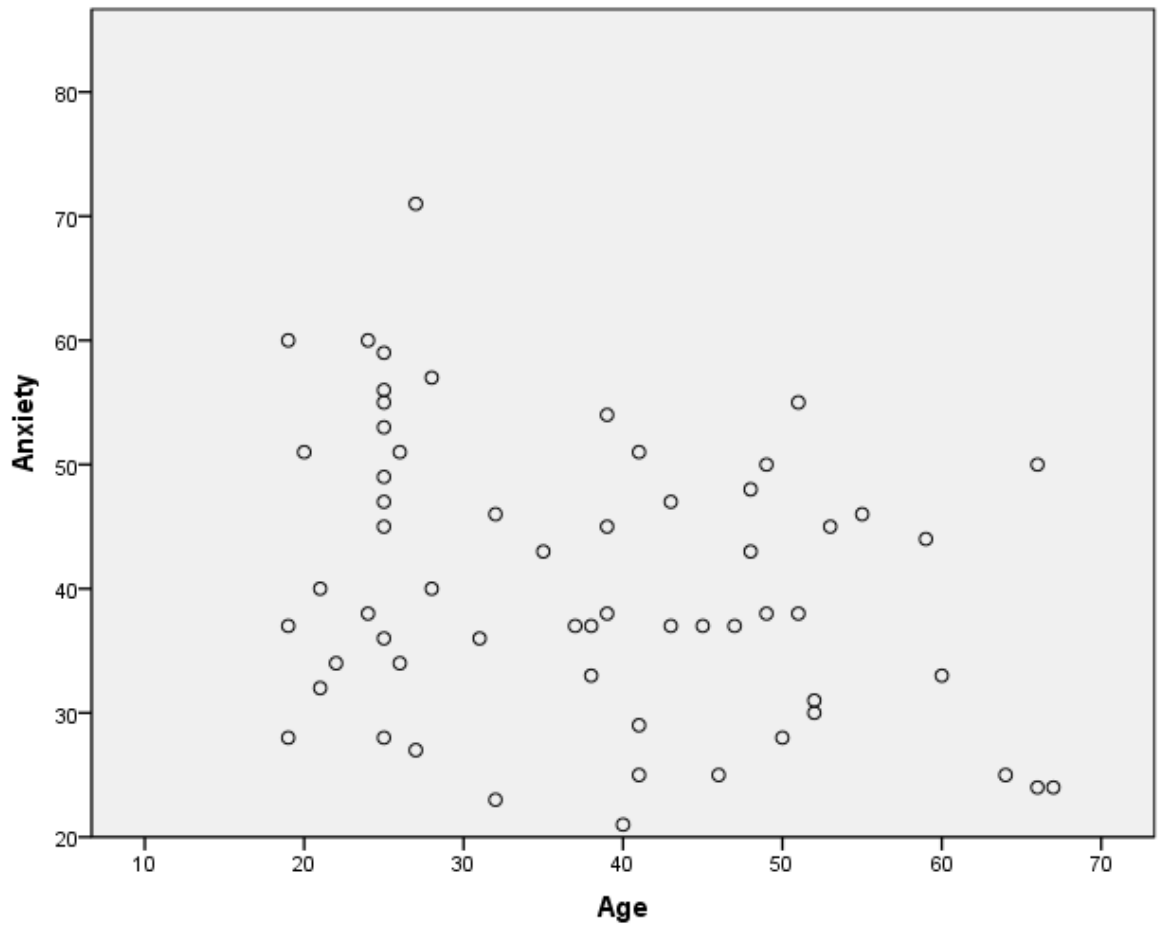


Table A27.10

Descriptive Statistics for Pre-Intervention Anxiety by Family History of Breast Cancer

Family History of Breast Cancer	Mean	SD	N
Family History	35.12	9.72	24
No Family History	45.09	10.66	34
Family History Not Available	32.50	7.78	2

Figure A27.2. Scatter Plot Depicting Pre-Intervention Powerful Others HLC Scores by Age Started the Menopause.

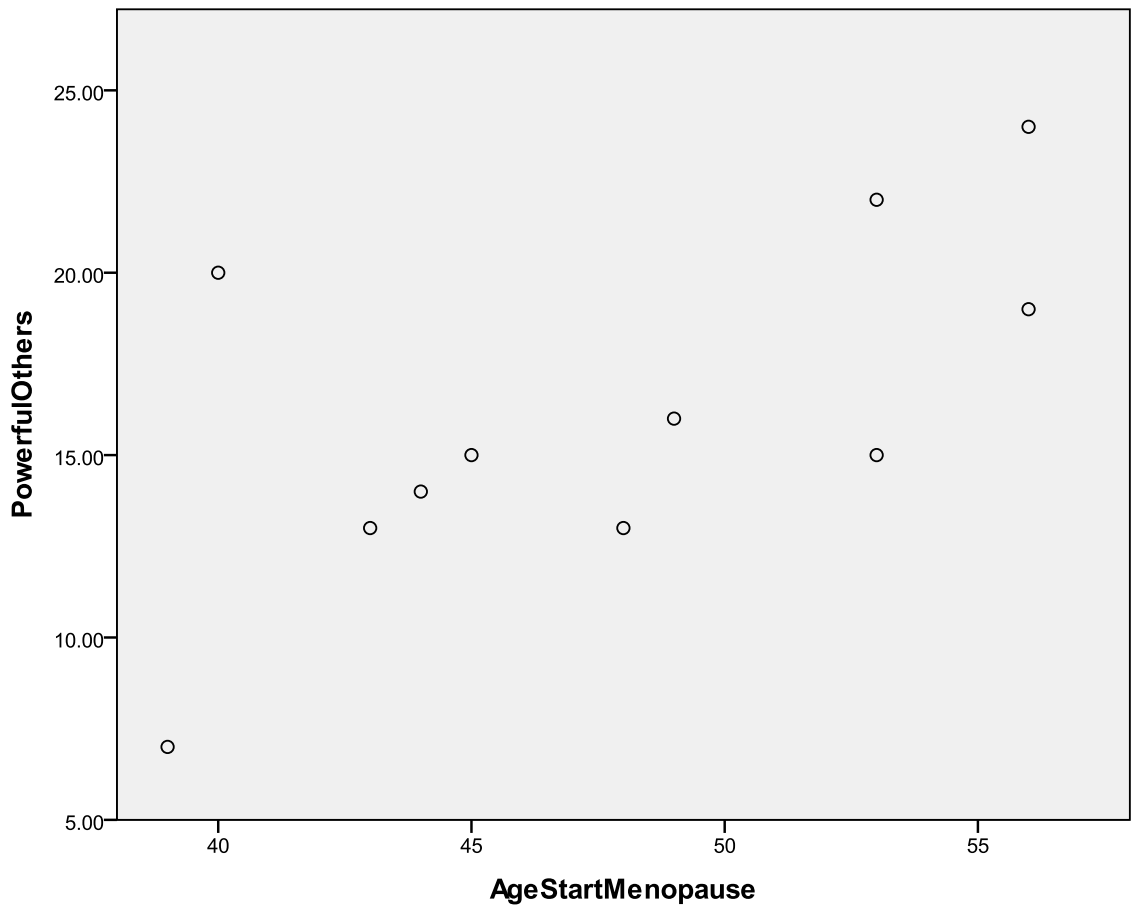


Figure A27.3. Scatter Plot Depicting Pre-Intervention Powerful Others HLC Scores by Number of Children.

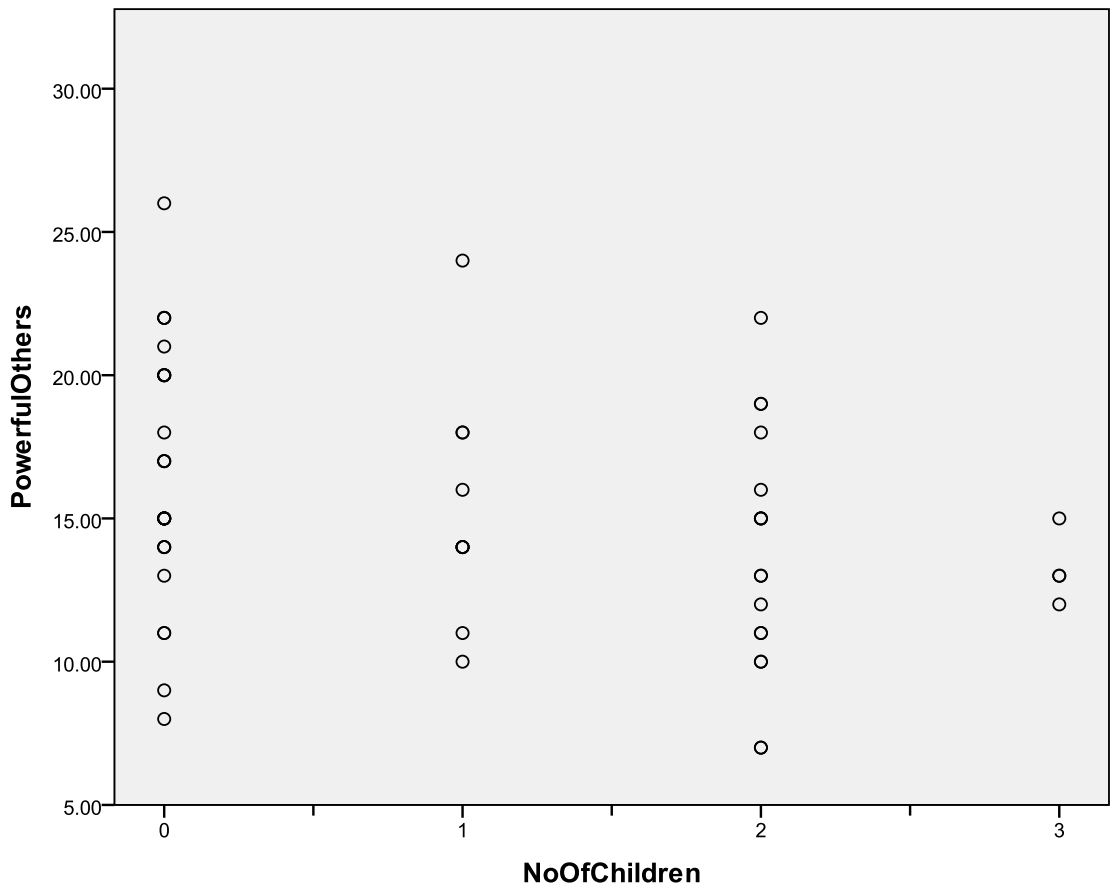


Figure A27.4. Scatter Plot Depicting Pre-Intervention Internal HLC Scores by Age Started the Menstrual Cycle.

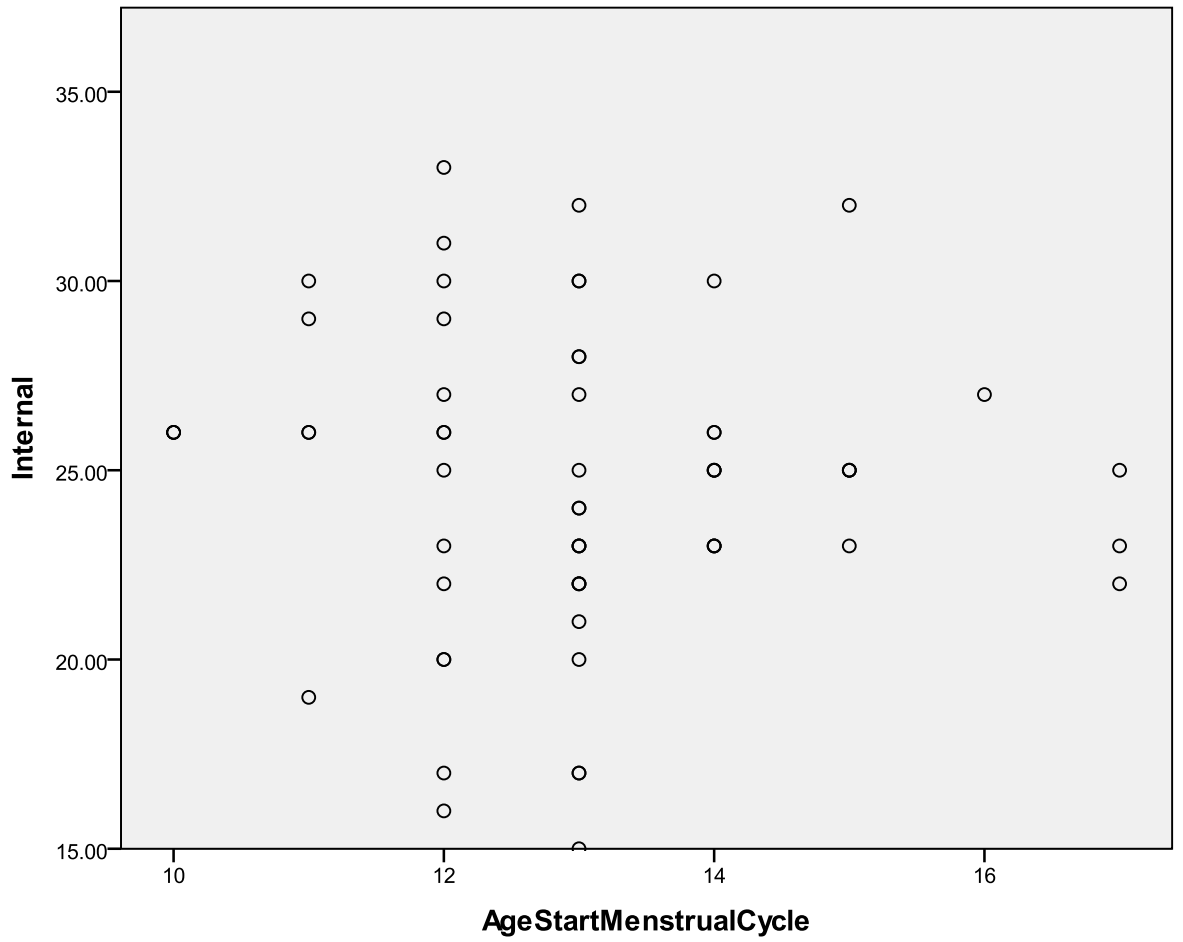


Figure A27.5. Scatter Plot Depicting Pre-Intervention Internal HLC Scores by Family History of Breast Cancer.

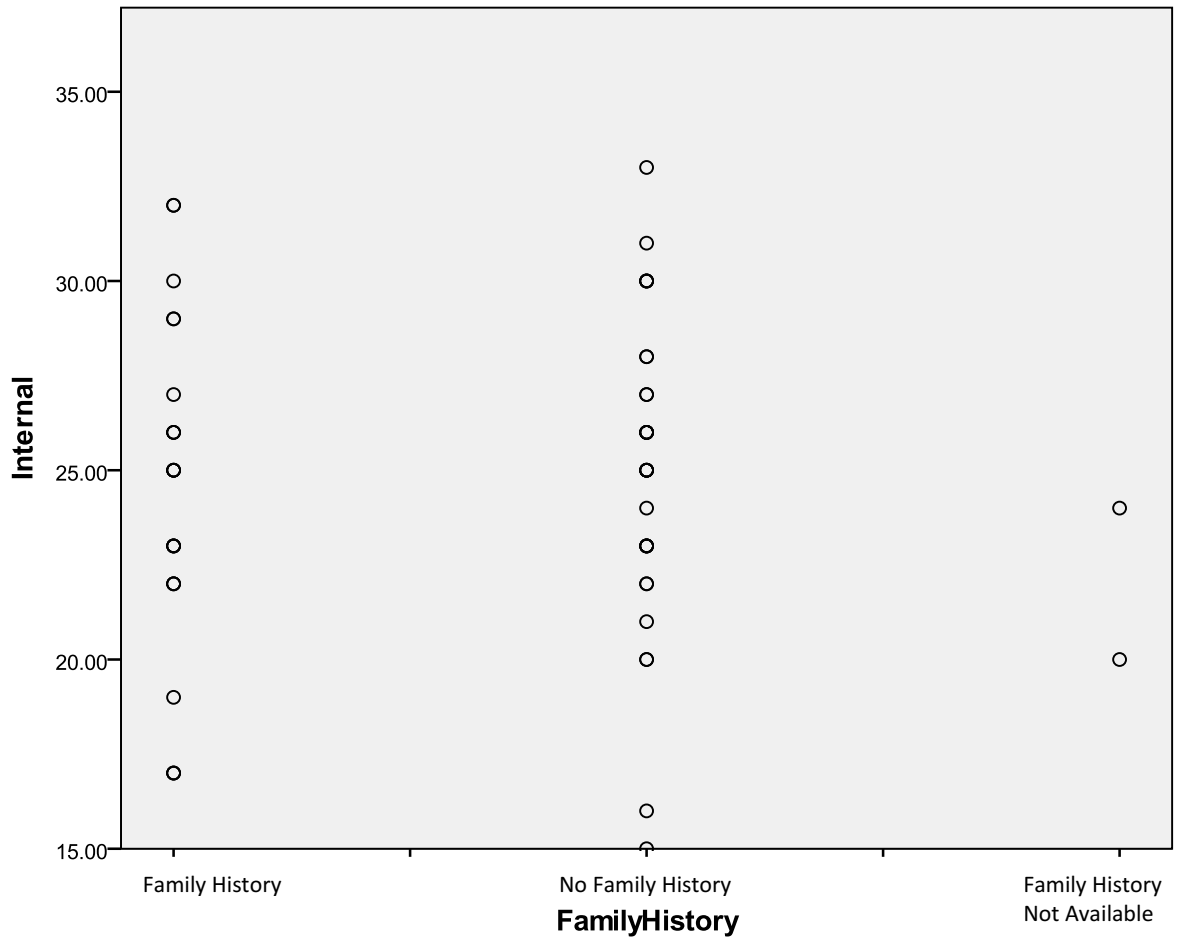


Table A27.11

Descriptive Statistics for Pre-Intervention Consequences by Cup Size

Cup Size	Mean	SD	n
AA	3.50	-	1
A	4.20	0.33	5
B	3.88	0.64	8
C	4.09	0.40	14
D	4.08	0.47	9
DD	3.71	0.28	12
E	4.45	0.41	5
F	3	-	1
FF	3.75	-	1
G	3.92	0.72	3
GG	3.75	-	1

Appendix 27

Table A27.12

Descriptive Statistics for Pre-Intervention Risk Factors by Employment Status

Employment Status	Mean	SD	N
Employed	3.01	0.46	41
Unemployed	2.64	0.71	2
Self Employed	4.05	0.66	3
In Full Time Education	2.92	0.31	10
Retired	3.32	0.21	4

Table A27.13

Descriptive Statistics for Pre-Intervention Susceptibility by Family History and Cup Size

Cup Size	Mean	SD	n	Family History	Mean	SD	n
AA	2.60	-	1	Family History	2.93	0.78	24
A	2.88	0.52	5	No Family History	2.38	0.79	34
B	2.23	0.65	8	Family History	2.30	0.42	2
C	2.40	0.92	14	Not Available			
D	2.22	0.65	9				
DD	2.50	0.79	12				
E	3.52	0.50	5				
F	2.20	-	1				
FF	3	-	1				
G	3.67	0.42	3				
GG	3.60	-	1				

Table A27.14

Descriptive Statistics for Pre-Intervention Health Motivation by Education

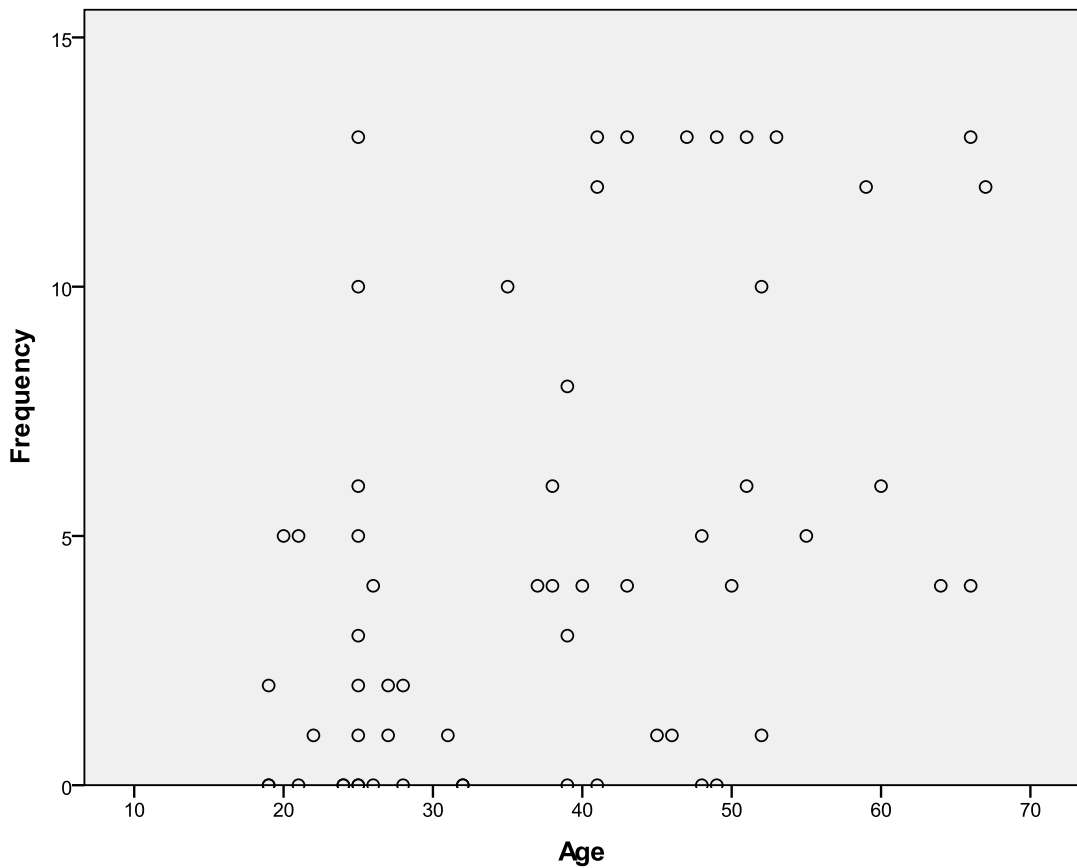
Education	Mean	SD	N
Primary	3	-	1
GCSE	3.65	0.60	7
College certificate/ A level	3.61	0.41	20
Degree	3.71	0.52	18
Postgraduate Award/Masters/PhD	4.06	0.28	14

Table A27.15

Descriptive Statistics for Pre-Intervention Barriers by Employment Area

Employment Area	Mean	SD	N
Graduate	3.86	0.37	1
Education	2.37	-	9
Engineering, Manufacturing, Utilities	2	0.37	3
Health, Nursing	2	0.38	8
Management Consultancy	2.57	0.30	1
Marketing, Advertising, PR	2.14	-	1
Media, New media, Creative	2.43	-	1
Not for profit, Charities	3.24	-	3
Public Sector Services	2.37	0.70	7
Retail, Wholesale	2.29	0.62	5
Sales	2.29	0.42	1
Secretarial, PAs, Administration	2.24	-	3
Social Services	2	0.65	1

Figure A27.6. Scatter Plot Depicting Pre-Intervention BSE Frequency by Age.



Appendix 27

Table A27.16

Standard Multiple Regression of God HLC, Chance HLC, Risk Factors and Anxiety on Powerful Others HLC.

Variables	Powerful Others HLC (DV)	God HLC	Chance HLC	Risk Factors	Anxiety	<i>b</i>	β	sr^2
God HLC	0.47					0.21	0.28	0.06*
Chance HLC	0.51	0.48				0.32	0.30	0.07*
Risk Factors	0.31	0.12	0.14			1.56	0.24	0.05*
Anxiety	0.26	0.21	0.31	-0.05		0.05	0.12	0.01
					Constant <i>a</i> = 1.76			
Means	16.2	8.73	18.27	2.97	39.27			$R^2 = 0.39$
Standard Deviations	4.41	5.76	4.19	0.67	10.05			Adjusted $R^2 = 0.34$
								** $R = 0.62$

Appendix 28

Appendix 28: Main Study Qualitative Responses

See enclosed DVD.

Appendix 29: Dissemination of Study

The results of this thesis were disseminated at the following conferences. Abstracts from these presentations are presented overleaf.

Annual European Health Psychology Conference 2010

Attended and presented a poster at the European Health Psychology Conference 2010, in Cluj-Napoca, Romania.

Annual British Psychological Society Health Psychology Conference 2010

Attended and presented a poster at the British Psychological Society Health Psychology Conference 2010, in Belfast.

Teesside University SoFI Seminar Series 2011

The Social Futures Institute (SoFI) organise a weekly SoFI seminar series in which researchers are invited to present their work to colleagues within the university and the general public. This research project was presented as part of this series.

Teesside University Annual Post Graduate Research Student Conference 2011

Attended and presented a Pechua Kucha style presentation at Teesside University's Postgraduate Annual Research Conference 2011.

In addition to these conferences the research was further presented less formally at the following two events. No abstract was submitted for these events, instead a poster was displayed and informal discussions were led with interested attendees.

Subject Enrichment Conference 2010

Teachers from across the region were invited to attend a Subject Enrichment Conference organised by the University and researchers within the university were invited to informally

discuss their research with attendees. A poster discussing the research study was displayed and informal discussions were led with interested attendees.

Vitae Yorkshire and North East Hub Public Engagement Event 2010

The Vitae Yorkshire and North East Hub annually hold a public engagement event in which researchers are invited to present their research to the general public and other researchers from a range of disciplines. A poster discussing the research study was presented at this event and informal discussions were led with interested attendees.

Finally, the research was discussed and presented as part of the MSc Health Psychology Current Topics Module.

MSc Health Psychology Guest Lecture 2011

A guest lecture was led for MSc Health Psychology students, in which the research was presented and discussed with attending students.

For the posters and slides presented as part of this dissemination process please see enclosed DVD.

**Abstract for the Research Presented at the European Health Psychology
Conference 2010**

Women's knowledge, beliefs and behaviours towards breast cancer, breast self examination and the conventional 5 step technique: an exploratory study

Objectives

Despite its potential for cancer detection regular breast self-examination (BSE) is not widespread. This study aimed to explore Women's knowledge, beliefs and behaviours towards breast cancer, BSE and the conventional 5-step BSE technique.

Method

Eight women aged 18-51 years participated in the research using a semi-structured-interview-guide.

Results

Thematic analysis elicited three themes regarding breast cancer and BSE generally and three regarding the 5-step BSE technique. Results showed that breast cancer and BSE are seen as frightening concepts dealt with through adopting an avoidance strategy. A lack of knowledge and education appeared to be associated with women avoiding regular BSE. When provided with a set of detailed examination guidelines women became more positive towards and willing to consider examining their breasts. Women indicated to find the 5-step-technique a useful teaching tool. Those women not engaging in any form of BSE highlighted that the steps provided them with the necessary knowledge to enable and encourage them to start performing BSE.

Conclusions

A major obstacle preventing women conducting BSE is their lack of knowledge of accurate performance, providing women with a teaching tool was evaluated positively and gives further scope for exploration in relation to the reduction of fear and avoidance.

Abstract for the Research Presented at the BPS Health Psychology Conference 2010

Women's knowledge, beliefs and behaviours towards breast cancer, breast self examination and the conventional 5 step breast self examination technique: an exploratory study

Background

Breast cancer is the most common cancer in women in the UK. Each year more than 44,000 women are diagnosed and more than 12,000 of these die from the disease. Regular breast self-examination (BSE) can ensure that breast cancer is detected early. A 5-step BSE technique has been recommended as the most comprehensive way to examine the breasts.

Method

This study used a semi-structured interview-guide to investigate knowledge, beliefs and behaviours towards breast cancer generally, and BSE and the 5-step BSE technique more specifically in eight women aged 18-51 years.

Findings

Thematic analysis elicited three themes regarding breast cancer and BSE generally and a further three regarding the 5 step BSE technique. The results showed that breast cancer and BSE are seen as frightening concepts dealt with through adopting an avoidance strategy. A lack of knowledge and education appeared to be associated with women

avoiding regular BSE. When provided with a set of detailed examination guidelines women became more positive towards and willing to consider examining their breasts. Women indicated to find the 5-step technique a useful teaching tool. Those women not engaging in any form of BSE highlighted that the steps provided them with the necessary knowledge which would enable and encourage them to start performing BSE.

Discussion

A major obstacle preventing women conducting BSE is their lack of knowledge of accurate performance, providing women with a teaching tool was evaluated positively and gives further scope for exploration in relation to the reduction of fear and avoidance.

Abstract for the Research Presented at the SoFI Seminar Series and the Annual Post Graduate Research Student Conference

The Effect of Autobiographical Accounts of Breast Cancer Patients and a Multimedia Programme on Women's Knowledge, Beliefs and Behaviour Towards Breast Self-Examination

Each year more than 44,000 women are diagnosed with breast cancer and more than 12,000 of these die from the disease. These mortality rates are relatively high compared to the rest of Europe (Berrino et al., 2007; Mayor, 2003), which in part is due to the advanced stage of the disease at first presentation (McCready et al., 2005; Sant et al., 2003). Regular breast self-examination (BSE) can facilitate early detection (Cancer Research UK, 2008), yet it is not widespread. Identifying the motivational and contextual factors is likely to lead to the development of effective interventions as part of being 'breast-aware'. This is particularly important given that mammography screening may not be effective (Crossing & Mansezewicz, 2003) or recommended for younger women (Cancer Research UK, 2009) and that BSE may be beneficial in offering women the opportunity to create a positive relationship with their body. This study sought to develop a

new way to provide guidance and to encourage BSE by investigating the effect of autobiographical accounts of breast-cancer patients and a multimedia BSE support programme comparing video-enhanced or static guided instructions on women's knowledge, beliefs & behaviour towards breast self-examination. The study adopted a 2x2 mixed methods design and 60 white British women aged between 19 and 67 participated. Analysis of Covariance revealed an interaction effect of autobiographical accounts and BSE support on BSE frequency and proficiency and thematic analysis elicited five themes; Previous Experience, BSE Irregularity, Perceived Susceptibility, Coping Style and The Usability of the 5 Step Model of BSE. The study concludes that the 5-step technique encourages BSE through creating a more pleasant experience, as women form an improved relationship with their breasts. Both the video-enhanced and static BSE supports are effective in terms of encouraging BSE and the effect of autobiographical accounts appears to be dependent on the type support. The practical implications and direction for future BSE interventions are discussed.