CORA Cork Open Research Archive
Cartlann Taighde Oscailte Chorcaí

Title	Women's help seeking behaviour and the associated influencing factors on self discovery of a breast symptom
Authors	Ní Mháthuna, Máirín
Publication date	2011-11
Original Citation	Ní Mhathúna, M. 2011. Women's help seeking behaviour and the associated influencing factors on self discovery of a breast symptom. PhD Thesis, University College Cork.
Type of publication	Doctoral thesis
Link to publisher's version	http://library.ucc.ie/record=b2031138~S0
Rights	© 2011, Máirín Ní Mháthuna - http://creativecommons.org/licenses/by-nc-nd/3.0/
Download date	2026-11-15 17:58:31
Item downloaded from	https://hdl.handle.net/10468/892

UCC
University College Cork, Ireland
Coláiste na hOllscoile Corcaigh

WOMEN'S HELP SEEKING BEHAVIOUR AND THE ASSOCIATED INFLUENCING FACTORS ON SELF DISCOVERY OF A BREAST SYMPTOM.

BY

Máirín Ní Mháthuna (O'Mahony) **MSc, BNS, RNT, RM, RGN,**

A Thesis Submitted to the School of Nursing and Midwifery in Fulfilment for the Award of PhD Degree.

National University of Ireland, Cork.
Catherine McAuley School of Nursing and Midwifery

November 2011

Head of School
Professor Geraldine McCarthy, PhD, MSN, MEd, DIPN, RNT, RGN.

Supervisor

Professor Josephine Hegarty, PhD, MSc, BSc, RNT, RGN.

Table of Contents

Declaration vii

Acknowledgements viii

Abstract ix

Introduction and Background 10
Breast cancer and early diagnosis 10
Delay in symptom presentation 12

Chapter 1 Help Seeking for Cancer Symptoms 19
Introduction 19
1.1 Cancer, help seeking and early detection 19
1.2 Defining help seeking 20
1.3 Help seeking for cancer symptoms 21
1.4 Theoretical perspectives on HSB for breast cancer symptoms 25
Summary 36

Chapter 2 Knowledge and Beliefs and their Influence on Help Seeking Behaviour (HSB) for Cancer Symptoms 38
Introduction 38
2.1 Knowledge and beliefs and HSB for cancer symptoms 38
2.2 Knowledge and beliefs and HSB for specific cancer symptoms 43
2.3 Knowledge and beliefs and HSB for breast cancer symptoms 47
2.3.2. A European Perspective 55
Summary 67

Chapter 3 Emotional Responses to Symptom discovery and their Influence on Help Seeking Behaviour (HSB) for Cancer Symptoms 70
Introduction 70
3.1 Emotional responses to non breast cancer symptoms and HSB 70
3.2 Emotional responses to symptom discovery and HSB for women with a breast cancer diagnosis 72
3.3 Emotional responses to symptom discovery and HSB for women with mixed or unknown diagnoses 76
Summary 80

Chapter 4 Socio-demographic Factors, Social Factors, Health Seeking Habits, Health Service System Factors and their Influence on HSB for cancer symptoms 83
Introduction 83
4.1 Socio-demographic factors and HSB 83
4.2 Social factors and HSB 84
4.3 Health Seeking Habits and HSB 86
4.4 Health Services System Utilisation Factors and HSB 90
Summary 95
Conclusion 97

Chapter 5 Methodology 103
Introduction 103
5.1. Conceptual Framework 103
5.2 Research Aim 105
5.3 Research Objectives 106
5.4. Operational definitions 106
5.5 Research Hypotheses 108
5.6. Research Design 110
5.7 Research Methods 111
5.7.1. Instrument Design and Development 111
5.8 Validity and Reliability 126
5.9. Pilot Study 131
5.10. Population and Sample 133
5.11. Data Collection 134
5.12. Ethical Considerations 135
5.13. Preparing the Data File 137
5.14. Data Analysis 138
Summary 144

Chapter 6 145
Findings 145
Introduction 145
6.1 Socio-Demographic Factors 145
6.2 Symptom Discovery and Responses 147
6.2.1 Breast Symptom Identity (Knowledge) 147
6.2.2. Alternative Help Seeking Behaviour (Beliefs) 148
6.2.3 Emotional Response(s) to Symptom Discovery 148
6.2.4 Symptom Disclosure (Social Factor) 149
6.2.5. Help Seeking Behaviour 150
Summary 151
6.3 Health Seeking Habits 152
6.4 Health Service System Utilisation, Personal Experience of Prejudice and Social Factors 153
6.4.1 Health Service System Utilisation 153
6.4.2. Personal Experience of Prejudice 154
6.5 Social Factors 155
Summary 156
6.6 Knowledge and Beliefs 157
6.6.1 Family History 157
6.6.2 Beliefs Relating to the Breast Symptom 157
6.6.2.1 Beliefs Relating to Symptom Cause 158
6.6.2.2 Beliefs Relating to Symptom Duration 159
6.6.2.3 Beliefs Relating to Symptom Consequence 160
6.6.2.4 Beliefs Relating to Symptom Cure/Control 161
6.6.2.5. Beliefs Relating To Symptom Outcome 163
Summary 163
6.6.3. Breast Cancer Knowledge 164
Summary 167
6.7. Help seeking behaviour and associated relationships 169

6.7.1 Declarative Statement on Help Seeking Behaviour (HSB). 169
6.7.2 Hypotheses # 1: Socio-demographics and HSB 170
Summary 171
6.7.3 Hypothesis # 2 There is a relationship between women's knowledge and beliefs concerning their breast symptom. 172
6.7.4. Hypothesis # 3 Emotional Response to Symptom Discovery 179
6.7.5. Hypothesis # 4 There is a relationship between social factors and HSB. 181
6.7.6. Hypothesis # 5 There is a relationship between Health Seeking Habits and HSB 182
6.7.7. Hypothesis # 6 There is a relationship between Health Service System Utilisation (HSSU) and HSB. 184
Summary 185
6.8. Univariate Logistic Regression 186
6.8.1 Univariate logistic regression results for categorical variables and delayed HSB 187
6.8.2. Univariate Logistic Regression for Continuous (ordinal) Variables and Delayed HSB 189
6.8.2.1 Beliefs Relating to the Breast Symptom 189
6.8.2.3. Symptom Emotional Distress 189
6.8.2.4.. Health Service System Utilisation 189
6.8.3. Multiple Logistic Regression 190
6.8.3.1 Simultaneous entry approach 190
6.8.3.2. Forward stepwise approach 192
6.8.4. Performance of the Multiple Regression Model 193
Summary 193

Chapter 7 Discussion of Findings 196
Introduction 196
7.1 Profile of Participants 196
7.2 Help Seeking Behaviour (HSB) and Influencing factors 196
7.3 Socio-Demographic Factors and HSB 198
7.4 Knowledge and Beliefs 200
7.5. Emotional Response(s) 208
7.6. Social Factors 211
7.7. Health Seeking Habits 213
7.8. Health Service System Utilisation 215
7.9. Evaluation of the conceptual framework guiding the study 218
Summary 221

Conclusion 223
Limitations 233
Recommendations 234
Nursing Practice 235
Nurse Education 237
Nursing Research 238

References 240

List of Figures

Figure 1.1. Judgement to Delay Model 27
Figure 1.2. Common Sense Model of Self Regulation 31
Figure 1.3. Model for understanding delayed presentation with breast cancer ... 32
Figure 1.4. Framework to promote early help seeking 33

List of Tables

Table 1.1 Delay in Help Seeking Behaviour 13
Table 5.1. Instrument Development, Scoring and Reliability Details 114
Table 6.1 Socio-demographic profile of sample 146
Table 6.2 a Breast symptom and symptom discovery details 147
Table 6.2 b Alternative Help Seeking Behaviour 148
Table 6.2c Symptom Emotional Distress 149
Table 6.2d Symptom Disclosure 150
Table 6.2 e Women's Help Seeking Behaviour 150
Table 6.2 f Delay ≥ 3 months 151
Table 6.3 Health Seeking Habits 152
Table 6.4 a Health Service System Utilisation 154
Table 6.4 b Perceptions of Experienced Prejudice 155
Table 6.5 Social factors 156
Table 6.6a Family history of Breast Cancer 157
Table 6.6 b Beliefs relating to internal cause of symptom 159
Table 6.6 c Beliefs relating to external cause of symptom 159
Table 6.6 d Beliefs relating to duration of symptom 160
Table 6.6 e Beliefs relating to symptom consequences 161
Table 6.6 f Beliefs relating to symptom cure /control 162
Table 6.6g Beliefs relating to symptom outcome 163
Table 6.6 h Breast Cancer Knowledge: Changes Associated with Breast Cancer 166
Table 6.6 i Breast Cancer Knowledge: Overall Scores 167
Table 6.7 Socio-demographic data cross tabulated with HSB. 171
Table 6.8 Symptom identities cross tabulated with HSB 173
Table 6.9a Breast Cancer Knowledge cross tabulated with HSB 174
Table 6.11 Group statistics and independent sample T-Test for symptom beliefs sub scales 172
Table 6.13 Alternative HSB cross tabulated with HSB 178
Table 6.14. Symptom Emotional Distress cross tabulated with HSB 180
Table 6.15 a Symptom disclosure cross tabulated with Delayed HSB 181 176
Table 6.16 Health Seeking Habits cross tabulated with HSB 183
Table 6.17 Logistic Regression for categorical variables and delayed HSB 188
Table 6.19 Multiple Regression model using forward stepwise approach predicting the likelihood of delayed HSB 193
Table 6.18 Multiple Regression model using simultaneous entry approach predicting the likelihood of delayed HSB 191

List of Appendices

Appendix 1a Questionnaire Package 251
Appendix 1b Questionnaire Package 251
Appendix 2 Letters of permission to reprint models and utilise research scales 263
Appendix 2a. Permission to adapt Illness Perception Questionnaire 263
Appendix 2b. Permission to reprint the Judgment to delay model and adapt questionnaire scales from Professor Facione .....
Appendix 3a Content validity of questionnaire items and scales 271
Appendix 3b Document sent to reviewers regarding face validity of questionnaire 272
Appendix 4 Letter of Approval from Ethical Committee 275
Appendix 5 Letters of Approval from Consultants 276
Appendix 6a Letters of Approval from Director of Nursing 277
Appendix 6b Letter of approval from Board of Directors 278
Appendix 7a Letters to Breast Care Nurse Specialists 279
Appendix 7b Letter to Cancer Care Co-ordinator 280
Appendix 8 Information leaflet for women attending the breast clinic 281
Appendix 9 Consent Form 282
Appendix 10 Code book for data Interpretation 283
Appendix 11 Hypotheses, data measurement and statistical tests 286
Appendix 12 Additional Tables 290
Appendix 13 Logistic Regression Procedure: Selection of Variables .....

Declaration

This is to declare that the content of this thesis is my own work and has not been submitted for another degree, either at University College Cork or elsewhere.

Signed:_____ **Date:**_____

Acknowledgements

The author wishes to acknowledge the support of the following people without whom the completion of this thesis would never have been possible:

To my supervisor Professor Josephine Hegarty for her constant advice, support, guidance and patience.

To my co-supervisor Professor Geraldine McCarthy, for her advice and support throughout the course of the thesis.

To Professor Joyce Fitzpatrick for her guidance and encouragement.

To Dr. Paul Corcoran whose expertise, knowledge and guidance on statistical matters was invaluable.

To the Directors of Nursing, Breast Care Nurse Specialists, Nurses, Hospital Administrative Staff and Consultants who facilitated this study.

To the women in the breast clinics who were so willing to give their time to participate in the study, particularly at a time when they were worried about the outcome of their breast symptom.

To my parents Donal and Kathleen, for always being there no matter what.

To my brothers and sisters, brothers and sisters in-law, nieces and nephews who were always there when needed and helped me to keep a perspective on the important things in life.

To my colleagues, particularly those on the 'third floor' Margaret, Alice and Patricia and Bridie who gave so much of their time to listen, support and advise whenever needed.

To Rhona, whose knowledge and expertise on 'formatting' was greatly appreciated.

To my many friends who were there to listen and support but in particular to Helen and 'Sav' who were always willing to meet for coffee on Saturday mornings (no matter how early!) over the past months.

To Edel and David whose courage and optimism following David's cancer diagnosis in February 2009, gave me the determination to persevere when the going got tough.

Finally, to my dear friend Gina who passed away in March 2010 and whose spontaneity and fun I miss so much. Ar Deis Dé go Raibh a hAnam.

Abstract

Aim: To investigate women's help seeking behaviour (HSB) following self discovery of a breast symptom and determine the associated influencing factors.

Design: A descriptive correlational design was used to ascertain the help seeking behaviour (HSB) and the associated influencing factors of a sample of women (n = 449) with self discovered breast symptoms. The study was guided by the 'Help Seeking Behaviour and Influencing Factors" conceptual framework (Facione et al., 2002; Meechan et al.,2003, 2002; Leventhal, Brissette and Leventhal, 2003 and O'Mahony and Hegarty, 2009b).

Instrument: Data were collected using a researcher developed multi-scale questionnaire package to ascertain women's help seeking behaviour on self discovery of a breast symptom and determine the factors most associated with HSB. Factors examined include: socio-demographics, knowledge and beliefs (regarding breast symptom; breast changes associated with breast cancer; use of alternative help seeking behaviours and presence or absence of a family history of breast cancer), emotional responses, social factors, health seeking habits and health service system utilisation and help seeking behaviour.

Sample: A convenience sample (n = 449) was obtained by the researcher from amongst women attending the breast clinics of two large urban hospitals within the Republic of Ireland. All participants had self- discovered breast symptoms and no previous history of breast cancer.

Findings: The study identified that while the majority of women (69.9%; n=314) sought help within one month, 30.1% (n=135) delayed help seeking for more than one month following self discovery of their breast symptom. The factors most significantly associated with HSB were the presenting symptom of 'nipple indrawn /changes' (p = 0.005), 'ignoring the symptom and hoping it would go away' (p < 0.001), the emotional response of being 'afraid' on symptom discovery (p = 0.005) and the perception/ belief in longer symptom duration (p = 0.023). It was found that women who presented with an indrawn/changed nipple were more likely to delay (OR = 4.81) as were women who 'ignored the symptom and hoped it would go away' (OR = 10.717). Additionally, the longer women perceived that their symptom would last, the more likely they were to delay (OR = 1.18). Conversely, being afraid following symptom discovery was associated with less delay (OR = 0.37; p = 0.005).

Conclusion This study provides further insight into the HSB of women who self discovered breast symptoms. It highlights the complexity of the help seeking process, indicating that is not a linear event but is influenced by multiple factors which can have a significant impact on the outcomes in terms of whether women delay or seek help promptly. The study further demonstrates that delayed HSB persists amongst women with self discovered breast symptoms. This has important implications for continued emphasis on the promotion of breast awareness, prompt help seeking for self discovered breast symptoms and early detection and treatment of breast cancer, amongst women of all ages.

Introduction and Background

The impetus for this study stems from the researcher's perioperative experience in caring for women undergoing surgical breast biopsy. Oftentimes, the surgery was referred to as "just a biopsy". However, it was noted that women were very anxious and worried around this time as the diagnosis could either be benign or malignant. This instigated a literature review on women and breast biopsy resulting in a phenomenological study on women's lived experience of breast biopsy, as part fulfilment of the degree of Master of Science in Nursing. Findings from the study highlighted, among other issues, that some women delayed help seeking for self discovered breast symptoms (O'Mahony, 2001). This prompted further review of the literature on delay for self discovered breast cancer symptoms. The background to the present research is presented in the context of breast cancer and early diagnosis and delay in presentation of symptoms to a health care professional (HCP).

Breast Cancer and Early Diagnosis

The global burden of cancer is continuously increasing, with cancer being the leading cause of death in developed countries (Jemal, Bray et al., 2011). Breast cancer is the most frequently diagnosed cancer and the leading cause of death amongst females worldwide (Jemal, et al., 2011). In Ireland, breast cancer was the most common female cancer diagnosed during 2000-2004 with an average of 3,095 cases reported annually and an average of 947 deaths (Donnell, Gavin, and Comber, 2009). Ireland's breast cancer mortality rate remains above that of the European Union (Verdecchia, Francisci, Brenner, et al., 2007; Department of Health and Children (DOH&C) 2010). Thus, breast cancer is a major public health issue. In England, Richards, (2009a) highlighted that breast cancer is one of the cancers for which one year survival is

below the European average and considerably lower than some other European countries. It is suggested that these poor survival rates translate into “avoidable deaths” (Abdel-Rahman, Stockton, Hakulinen et al., 2009). Furthermore, it was suggested that Ireland’s significantly lower survival rates could also be due to more women being diagnosed with late stage disease, when treatments are less effective. (Campo, Comber and Gavin, 2004). Up to recently, this could have been due to the lack of nationwide screening for breast cancer (Campo et al., 2004). However, screening is now available nationwide to all women who are over fifty years of age. In a publication on women and cancer in Ireland (The National Cancer Registry and Women’s Health Council, 2006) it was questioned whether late diagnosis of some cancers (including breast cancer) could be due to access to health services (including screening), lack of information and “other factors”, which suggests that more research is needed to clarify and identify these factors.

Currently, in the United States, the National Breast Cancer Coalition (NBCC) is promoting an end to breast cancer by January 1 2020, challenging all policymakers, researchers and scientists worldwide to work towards this target (Breast Cancer Network (BCN) News, 2010). Furthermore, the vision of the Irish National Cancer Strategy asserts that by 2015 Ireland will have a system of cancer control in place, resulting in reduced incidence, morbidity and mortality rates relative to other EU15 countries (DOH&C, 2006). Thus, in relation to breast cancer, it is crucial that this agenda is informed by up to date research on the factors influencing late diagnosis.

On-going evidence suggests that the earlier the diagnosis of breast cancer is made the more likely it is that women will have a favourable outcome (Richards, Smith, Ramirez et al, 1999a; Richards, Westcombe, Love et al, 1999b). A systematic review of 87 studies (101,954 women) highlighted that a longer delay in presenting with breast symptoms is associated with a lower survival rate from breast cancer (Richards et al, 1999b). In addition, Hardin, Pommier and Pommier (2006) found that a more advanced stage of disease at diagnosis, correlated with decreased survival. This is further reiterated by Richards (2009a) who asserts that delays leading to more advanced disease at diagnosis, amongst women with breast symptoms contributes to the lower than average survival rates in England. The concept of delay in the context of symptom presentation to a health care professional (HCP) will now be addressed.

Delay in symptom presentation

It has been documented that women themselves detect most breast tumours (Arndt, Sturmer, Stegmaier et al., 2002; Facione, Miaskowski, Dodd, et al., 2002). Despite the association between delay and survival, a considerable number of women wait for three months or longer before presenting to a HCP with a breast symptom (Burgess, Ramirez, Richards et al., 1998; Nosarti Crayford, Roberts et al., 2000; O'Mahony, 2001; Burgess, Hunter and Ramirez, 2001; Arndt, Strumer, Steigmaier et al., 2002; Meechan, Collins and Petrie, 2002; O'Mahony and Hegarty, 2009b) (Table 1.1).

Table 1.1 Delay in Help Seeking Behaviour

Authors	Sample Size Total	Time from symptom discovery to visit to General Practitioner	n (%)
Burgess et al., 1998	185	≥ 3 months	36 (19.0)
Burgess et al., 2001	46	≥ 3 months	31 (67.4)
Nosarti et al., 2000	692	≥ 1 month > 3 months	242 (35) 117 (17)
O'Mahony, 2001	10	> 3 months	2 (20.0)
Arndt et al., 2002	287	< 1month 1-3 months > 3 months	183 (64.1) 53 (18.5) 50 (17.4)
Meechan et al., 2002	85	≤ 7 days ≤ 14 days ≤ I month ≥ 3 months	34 (40.0) 44 (52.0) 59 (69.0) 11 (14.0) (cumulative rates)
O'Mahony and Hegarty, 2009b	99	≤ I month 1-3 months > 3months	73 (72.3) 14 (14.1) 12 (12.1)

In general, delay in diagnosis and treatment of breast cancer is categorized into patient delay and provider delay (Facione, 1993; Burgess et al, 1998). Patient delay is defined as "the interval between first detection of a symptom and first presentation to a health professional, usually a general practitioner (GP)" (Burgess et al, 1998, p. 1343). Provider delay refers to "the period from the first consultation to definite diagnosis and treatment" (Arndt et al, 2002. p. 1034). There is a lack of consensus in the literature as to what constitutes delay, however many authors consider three months as the definition of prolonged delay. This definition is based on the early study by Pack and Gallo (1938) who defined delay as being "reasonable" when the time lapse from symptom discovery to presentation is "under three months" and an interval of "three months or over" as "undue delay" (p. 443). Conversely, delay has also been categorised in time periods of less than one month, one to three months and more than three months (Arndt et al., 2002). Nosarti, Crayford, Roberts et al., (2000) used a cut

off point of 27 days in a study of delay amongst women (n=692) presenting with breast symptoms to a London clinic. A time span of less than 27 days from symptom discovery to symptom presentation was considered “short delay” and over 27 days a “long delay”. In order to address this issue of ambiguity surrounding delay, it was suggested by some authors that delay time be treated as a “continuous variable” (Mason and Strauss, 2004b: Scott, Grunfeld, Main, et al., 2006). Richards et al., (1999b) categorised delay using the cut off points of “around” three months (2-4 months) and “around” six months (5-7 months) and as “twelve weeks or more” (Richards et al., 1999b). Prolonged delay has also been defined as “an interval greater than twelve weeks” (Burgess et al, 1998) and delay as a period of “more than three months” (Burgess et al., 2001). Scott, McGurk and Grunfeld, (2008b.p.143) considered a “cut off” of 31 days to be a more appropriate measure of delay as opposed to the more widely but “arbitrary” use of “three months or more”.

Despite such confusion in the literature as to what actually constituted delay, most studies support the urgency of early detection of cancer which necessitates prompt presentation of symptoms to a Health Care Professional (HCP). In addition, current strategies and policies advocate prompt diagnosis and treatment for all cancers (DOH&C, 2006; Health Information and Quality Authority, 2006; Irish Cancer Society, 2011). Furthermore, the factors relating to delay of four weeks or more are similar to those relating to delay of three months (Nosarti et al., 2000). Thus, in the current study, time from symptom discovery to presentation to a HCP (Health Care Professional) is categorised in time intervals of up to one month ($\leq$ 4 weeks) i.e. prompt help seeking and more than one month (> 4 weeks) i.e. delayed help seeking.

In addition, delay has been studied at different points of the symptom experience including prior to the occurrence of a symptom (Hunter et al, 2003, Facione et al, 2000; Facione et al, 2002,); following symptom occurrence but prior to seeing the consultant in the breast clinic (DeNooijer., Lechner, De Vries, , 2001a; Nosarti et al, 2000; Meechan et al, 2002, 2003; O'Mahony and Hegarty, 2009b) following symptom evaluation prior to diagnosis (Lauver, Coyle, and Panchmatia, 1995; Unger-Saldana and Infante-Castaneda, 2011) and following diagnosis of breast cancer or benign breast disease (Burgess et al, 1998; Richards at al, 1999b Burgess et al, 2001; O'Mahony, 2001; Arndt et al, 2002).

In an effort to address the problem of delayed presentation to a HCP in the event of symptom discovery, it is emphasised that efforts need to be directed at promoting awareness and early diagnosis amongst the 90% of cancer patients who will present symptomatically as opposed to being diagnosed through screening (Richards, 2009a). To this end, the National Awareness and Early Diagnosis Initiative (NAEDI) was established in England to meet one of the key commitments of the Cancer Reform Strategy as part of the Government's commitment to improve cancer outcomes (Department of Health, 2007). The steering group for this initiative developed a provisional NAEDI pathway (Richards 2009b) to assist in the testing of hypotheses relating to late diagnosis of cancer and its impact. Late presentation of symptoms to a general practitioner (GP) is the first point of delay outlined on the NAEDI pathway. In addition, Richards (2009b) highlights the value of performing more research, measuring the extent of delay and the contributing factors, in different countries. Furthermore, it is suggested that early detection and treatment of cancer would help to address the current global burden of cancer (Jemal et al., 2011). Thus, a study on

women's help seeking behaviour (HSB) for self discovered breast symptoms in an Irish context is timely.

A literature search of CINAHL, PubMed, PsychInfo data bases was carried out. In order to focus the review and retrieve the most up-to-date literature, (apart from seminal studies by Facione and colleagues and others).The search was limited to papers published in English between 1998-2011. The reference lists of articles identified were searched and additional articles and book chapters were included based on their relevance to the discussion. Initially, the MeSH terms and key words used were "help-seeking"; 'help-seeking'; 'help seeking'; 'help seeking behaviour'; 'care seeking', 'cancer' and 'oncology'. Inclusion criteria were papers with 'cancer' or 'oncology' and one of the aforementioned key words in the titles and/or abstract. Where pertinent, research on help seeking relating to other diseases or conditions was reviewed to further clarify the term help seeking. A search for HSB and influencing factors included the key words and mesh terms 'cancer', 'breast', 'breast cancer', 'help seeking', 'help seeking behaviour', 'delay' and 'influencing factors'. Combined and isolated forms of the key words: 'cancer', 'cancer symptoms', 'knowledge', 'beliefs', 'perceptions', 'symptom knowledge' and 'symptom beliefs' were utilised in the search regarding knowledge and beliefs and HSB. In relation to psychological factors and HSB, separate and combined forms of the search terms: 'breast symptom', 'breast cancer', 'breast cancer symptom', 'help seeking', 'psychological factors'; 'psycho-social factors' was performed. In addition, each of the variables 'fear', 'anxiety', 'worry', 'distress', 'scared', 'depression' and 'uncertainty' were combined with the original search terms. Finally, literature already retrieved was reviewed specifically regarding socio-demographic factors, social factors, health seeking habits, health service system utilisation factors and HSB.

In Chapter One a review of the literature on help seeking from an empirical and theoretical perspective, is presented. The concept of help seeking is defined together with an exploration of the literature on HSB for cancer symptoms. As will be seen, The Judgement to Delay Model (Facione et al., 2002) is identified as an appropriate framework together with the Common-Sense Model of Self-Regulation (Leventhal, Brissette and Cameron, 2003) to guide the study of women's HSB on self discovery of a breast symptom.

Chapter Two focuses on a review of research relating to knowledge and beliefs and HSB for cancer symptoms both generally and specifically, including breast cancer. It highlights that symptom discovery stimulates the process of symptom appraisal. Symptom appraisal is dependent on an individual's knowledge and beliefs about the symptom identity together with beliefs surrounding the symptom. The theoretical underpinnings of The Common-Sense Model of Self-Regulation (Leventhal et al., 2003) which focuses on "illness and treatment representations" is reaffirmed as a suitable framework to determine women's beliefs about their breast symptom. The key dimensions of knowledge and beliefs relevant to the current study are identified.

In Chapter Three studies on people's emotional response to symptom discovery are reviewed. It is highlighted that individuals' emotional responses to threatening situations such as potential cancer symptom discovery, are complex. In addition, the use of avoidance and denial as coping strategies are seen to impact on emotional responses and subsequent HSB. The need to further explore women's emotional response to breast symptoms, particularly in the context of actual HSB, is emphasised.

Chapter Four focuses on socio-demographics, social factors, help seeking habits and health service utilisation factors and HSB. The key dimensions of these variables

pertinent to the study of women's actual help seeking behaviour for self discovered breast cancer symptoms are identified. This is followed by a conclusion to the literature review which highlights the key issues emanating from the review, identifies the gaps in the literature and justifies the need for the present study.

Chapter Five outlines the research methodology. Initially an overview of the conceptual framework is presented. This is followed by an outline of the research design including the aim, objectives, operational definitions and hypotheses. Details concerning the population, sample, access to the sample and ethical considerations are addressed. The study instrument, validity and reliability and the pilot study are then discussed followed by a detailed account of the data collection, management and analysis procedures..

Chapter Six describes the research on women's HSB following self discovery of a breast symptom. Findings are presented as sequenced in the data collection questionnaire. Initially, a descriptive account of the findings relating to the independent variables and dependent variable are presented. This is followed by presentation and description of inferential statistical testing of relationships between the independent variables and the dependent variable of HSB. Finally, results of logistic regression analysis which sought to identify the variables having the most significant impact on women's HSB are presented.

Chapter Seven presents a discussion of the findings in relation to the literature reviewed. The strengths and limitations of the study are addressed followed by recommendations for nursing practice, education and research.

Chapter 1 Help Seeking for Cancer Symptoms

Introduction

In this chapter a review of the literature on help seeking is presented in order to determine how authors conceptually, operationally and theoretically define 'help seeking'. The issue of cancer and early detection is addressed. In order to further understand the concept of 'help seeking', definitions of 'help seeking' are reviewed and an operational definition is presented. This is followed by a review of literature on 'help seeking' for cancer symptoms. Theoretical perspectives on 'help seeking' behaviour for breast cancer symptoms are then reviewed concluding with a preliminary conceptual framework to guide the current study.

1.1 Cancer, help seeking and early detection

Cancer is a major public health problem world wide with approximately 12.7 million cancer cases and 7.6 million cancer deaths reported in 2008 (Jemal et al., 2011). Although much progress has been made in reducing mortality rates and improving survival, it has been highlighted that a substantial proportion of cancer deaths could be prevented through early detection and treatment (Campo et al., 2004, DOH&C, 2006; Richards, 2009a; Jemal et al., 2011). In the case of self discovered cancer symptoms, early detection is dependent on prompt help seeking from a health care professional (HCP). However, there is evidence that many people delay seeking help for self discovered cancer symptoms (Facione and Giancarlo, 1998; Meechan et al., 2002; Cockburn, Paul, Tzelepis, McElduff, and Byles, 2003; Koldjeski, Kirkpatrick, Everett et al., 2004; Mason and Strauss, 2004b; Bish, Ramirez, Burgess and Hunter,

2005; Ristvedt and Trinkhaus, 2005; Corner, Hopkinson and Roffe, 2006; Scott, et al., 2006; Howell, Smith, and Roman, 2007; Neal, 2009; O'Mahony and Hegarty, 2009b).

Help seeking is a ubiquitous term that is used in many different contexts. The terms help seeking, help-seeking, seeking help and care seeking are utilized interchangeably throughout the literature and are often discussed in the context of health seeking behaviour. The aim of this chapter is to delineate how the concept 'help seeking' and related concepts are used within the literature in order to identify an operational definition of the term 'help seeking' in the context of cancer symptom discovery. In addition, theoretical literature which assists in understanding the concept of help seeking will be reviewed.

1.2 Defining help seeking

Help seeking is described in many different contexts throughout the literature and is generally expressed as a behaviour dependent on the recognition and interpretation of a symptom. In a concept analysis of 'help seeking behaviour' (HSB) for a general health problem, Cornally and McCarthy (2011) define help seeking behaviour as a "problem focused, planned behaviour, involving interpersonal interaction with a selected helper" (p. 286). Scott and Walter (2010) maintain that help seeking behaviour for symptoms involves "a process of symptom perception, interpretation, appraisal and decision making" together with "the ability and motivation to enforce the decision by visiting a HCP" (p. 531).

In relation to rectal cancer symptoms, Ristvedt and Trinkaus, (2005) maintain that delayed help seeking is indicative of a person's general pattern of health related behaviour, suggesting that help seeking behaviour is part of the broader concept of health related behaviour. Tromp, Brouha, Hordijk et al., (2005) in their study on

medical “care seeking” and health-risk behaviour in patients with head and neck cancer, suggest that both care seeking and help seeking are components of health seeking behaviour. They assert that “health behaviour plays an important role in the development, detection and course of cancer of the head and neck” (p.666) and that relevant “health behaviour” includes prompt “medical care–seeking” (p.665). Howell et al., (2007) describe help seeking in patients with lymphoma as “the first step on the pathway to diagnosis” (p.9). Reifenstein (2007) defined care seeking as “the number of days that elapsed between finding a breast symptom and first contact with a health care professional (HCP)” (p.424).

These definitions suggest that care seeking behaviour and help seeking behaviour are similar concepts and that help seeking “involves contact with a HCP” and “is a response to health changes and part of the broader process of health seeking behaviour” (O’Mahony and Hegarty, 2009b, E182). In the current study, HSB was operationalised as ‘the time from symptom discovery to presentation of the symptom to a general practitioner (GP)’. Help seeking within one month (≤ 4 weeks) of symptom discovery was considered ‘prompt’ and more than one month (> 4 weeks) was considered as ‘delay’.

1.3 Help seeking for cancer symptoms

The presentation of cancer symptoms varies according to the site and extent of the disease. This situation is further complicated by the fact that cancer is a life–threatening condition which may foster distress and potential delay in HSB. Studies on help seeking and cancer from a general perspective provide insights into the “broad spectrum of help seeking behaviour” from the perspective of those with no symptoms who seek help (de Nooijer, Lechner, and De Vries, 2001a), those with symptoms who

seek help (deNooijer at al., 2001a, 2001b), those with symptoms who delay (deNooijer et al., 2001ab; Smith, Pope and Botha, 2005) and the intentions of those who are symptom free (Sheikh and Ogden,1998; deNooijer at al., 2002a, 2002b; deNooijer at al., 2003;). It is asserted that "intention is generally one of the most significant predictors of behaviour" (de Nooijer at al., 2002a p.368). However, it is emphasised that while actual help seeking may be expected in certain situations, it is not certain that it will occur in reality (de Nooijer at al., 2002a).

Studies on help seeking for self discovered cancer symptoms highlight that delayed help seeking is a cause for concern, given the benefits of early detection of cancer. Studies reviewed were both quantitative and qualitative in nature and the majority were of European origin apart from those undertaken by Facione and colleagues in the United States and one New Zealand study (Meechan et al., 2002). Lack of knowledge leading to uncertainty and minimisation of symptoms were associated with delayed help seeking for symptoms of bowel cancer (Cockburn et al., 2003); rectal cancer (Ristevdt and Trinkhaus, 2005); breast cancer (Facione and Giancarlo, 1998; Meechan et al., 2002; Bish et al., 2005); testicular cancer (Mason and Strauss, 2004 a, b); ovarian cancer (Koldjeski et al., 2004); lung cancer (Corner at al., 2006); oral cancer (Scott et al., 2006) and lymphoma (Howell et al., 2007). In addition, the ageing process was mistakenly linked to the occurrence of symptoms for testicular cancer (Mason and Strauss, 2004a); lymphoma (Howell et al., 2007) and lung cancer (Corner at al., 2006), leading to the assumption that symptoms are harmless. It is suggested that in some instances, relaxed health behaviours might include a general tendency not to worry, thus leading to delayed help seeking (Ristevdt and Trinkaus, 2005). In addition, the media's bias towards breast cancer and lack of recognition of lung cancer as a disease entity was highlighted (Corner at al., 2006). This was reiterated in

a study on testicular cancer where men perceived breast cancer as "socially acceptable" as opposed to the "taboos" surrounding genital health and help seeking (Mason and Strauss, 2004a). The effects of delayed help seeking were reiterated as were the issues of stigma and embarrassment in the context of help seeking for genital health issues (Mason and Strauss, 2004a). In addition, the inappropriateness of the term "delay" was highlighted (DeNooijer at al. 2003; Mason and Strauss, 2004b; Corner et al., 2006). The need for future researchers to be sensitive to the "pejorative" implications of "delayed" help seeking and resort to use of another term such as "lag time" (Mason and Strauss, 2004b, p. 123) was suggested.

In the United States, help seeking for self discovered breast cancer symptoms has been studied by Professor Noreen Facione and colleagues since 1993 with research focusing on help seeking, delayed help seeking and intentions to seek help. The role of knowledge, interpretation of symptoms and fear are emphasised in the literature (Sheikh and Ogden, 1998; de Nooijer at al., 2001a) as are the issues of gender, "sanctioning" (by media, family and friends) and "legitimising" help seeking by "raising issues when consulting (a HCP) for another symptom" (Smith, et al., 2005, p.829). In addition, deNooijer et al., (2001b) identified knowledge, social support and being ashamed and embarrassed as issues for delay among patients with cancer symptoms. These studies provide important insights into the complexity of HSB in terms of symptom recognition, appraisal, interpretation and subsequent decision to seek help for both men and women with cancer symptoms. In addition, the impact of knowledge, together with beliefs and emotions on intentions to seek help were highlighted (Sheikh and Ogden, 1998; deNooijer at al., 2002a; 2002b).

In relation to help seeking intention among asymptomatic Dutch women (n=618), De Nooijer at al., (2003) studied the social psychological correlates of the two main aspects of the process of cancer detection i.e. passive detection (paying attention to cancer symptoms) and intentions to seek help. The aim of the study was to identify factors that explained 'paying attention' to cancer symptoms and the intentions to seek help for possible cancer symptoms within an appropriate time frame. The study used a social cognition model based on the Theory of Planned Behaviour (TPB) (Ajzen and Madden, 1986) and Bandura's (1977) self-efficacy construct. It was found that knowledge, advantages of help seeking, moral obligation, anticipated regret, social norm (what is thought to be socially accepted) and self-efficacy correlated with the intention to seek help. The authors concluded that intentions to seek help can be encouraged by providing knowledge about cancer symptoms and addressing the importance and moral obligation of seeking help. In addition, the anticipated regret that may occur in the absence of help seeking and the importance of discussing the barriers to help seeking were noted (De Nooijer at al., 2003). This highlights the need for researchers to be sensitive to the issues surrounding delay, when studying help seeking behaviour.

Regarding help seeking for self discovered breast cancer symptoms, throughout the literature, it is highlighted that a complex array of factors (facilitators and barriers), influence women in seeking help. Such factors range from socio-demographics (in particular age), to women's knowledge and beliefs, social and psychological factors, health service issues, health seeking habits, to symptom discovery matters (Facione and Dodd, 1995; Facione and Giancarlo, 1998; Burgess et al., 1998; Ramirez et al., 1999; Nosarti et al., 2000; Burgess et al., 2001; O'Mahony, 2001; Arndt et al., 2002; Meechan et al., 2002, 2003; Bish 2005; O'Mahony and Hegarty, 2009b). However, as

highlighted by Scott and Walter (2010) an enhanced understanding of the factors influencing help seeking behaviour from a theoretical perspective is warranted in order to gain an holistic view of the process and the key issues that impact on HSB in the event of actual symptom discovery. Theoretical perspectives on HSB for breast cancer symptoms will now be reviewed.

1.4 Theoretical perspectives on HSB for breast cancer symptoms

In an effort to further understand delayed HSB for self discovered breast cancer symptoms, predicting delay and women's intentions to seek help for potential breast cancer symptoms were the focus of many studies (Facione et al., 2000; Facione, et al.,2002; Grunfeld, Hunter, Ramirez and Richards, 2003; Hunter, Grunfeld and Ramirez, 2003). These studies highlight the possibility of preventing delay by identifying women who are likely to delay through the use of models such as the Judgement to Delay Model (J-Delay Model) (Facione et al., 2002) (Figure 1.1), the Self-Regulation Model (Leventhal, Nerenz and Steele 1984) and Theory of Planned Behaviour (Ajzen and Madden 1986) (Hunter at al., 2003). The J-Delay Model will now be described.

The Judgement to Delay Model

Initially, Facione (1993) used social behavioural theory (Rosenstock 1966; Fishbein, 1979; Triandis, 1979) as a framework for her meta analysis of studies (n=12) on delay versus help seeking for breast cancer symptoms. Subsequently, the key concepts within the social psychological models of (Triandis 1979; Ajzen and Fishbein, 1980) together with findings from previous qualitative studies (Facione and Dodd, 1995; Facione and Giancarlo, 1998) informed the development of the J-Delay Model (Facione et al., 2002, p. 398) (Figure 1.1). This model theoretically integrates factors

associated with delay behaviour i.e. demographics, symptom appraisal, knowledge and beliefs, health related habits, health service system issues, affective responses, relationship constraints and personality attributes all of which lead to problem resolution which is depicted as seeking evaluation (help seeking) or patient delay (Facione et al, 2002).

In the paper reporting on the development and testing of the J-Delay model, Facione et al., (2002) relate how the model began with the "assumption that symptom appraisal is a cognitive decision-making process dependent on the estimation of potential risk posed by the symptom" (p 398). They also suggested that "the decision to seek help or delay involves an intention formation" (p 398). Using the J-Delay model as a framework, it was proposed that women who were likely to delay could be identified and encouraged to seek help early through breast health promotion programmes targeting those who are likely to delay (Facione et al., 2002).

The study sought to examine whether these variables believed to predict delay can identify women's predisposition to delay even before symptoms occur. Findings highlighted that, amongst a convenience sample (n=699) of asymptomatic women recruited from community settings in the San Francisco bay area, 24% (n=166) of women reported likelihood to delay (Facione et al., 2002).

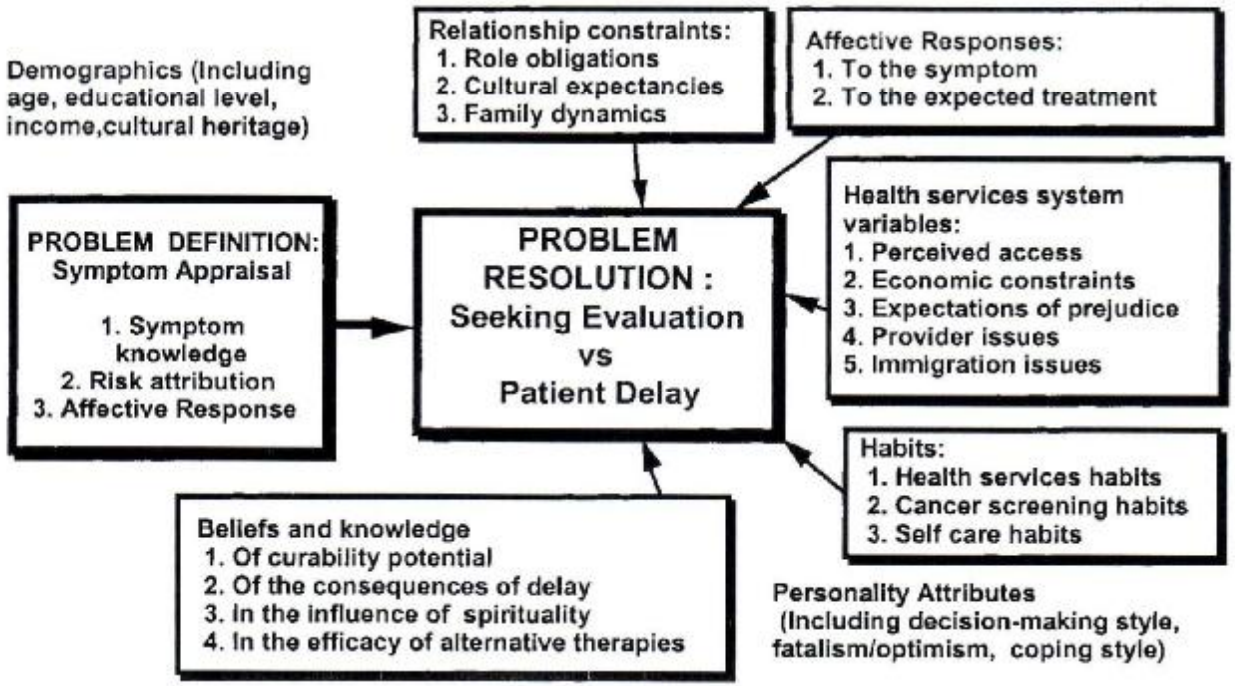


Figure 1.1 Judgement to Delay Model (Facione et al., 2002 Page 398), Reproduced with permission (Appendix 2)

Likelihood to delay help seeking was associated with lower income, lower educational level, identification as Latino or black, having experienced prejudice in care delivery, perceived lack of access to health care, fatalistic beliefs about breast cancer, poor health care utilization habits, use of self-care behaviour, perceived constraints from spouse/partner and employer, problem solving style and lack of knowledge of breast cancer's presenting symptoms (Facione et al., 2002). The researchers concluded that self reported likelihood of patient delay is measurable in advance of symptom occurrence. Hence, they deduced that successful targeting of women who are likely to delay could offer new potential to decrease advanced cancer at diagnosis. It was suggested that if women perceive themselves as likely to delay this perception could be targeted by interventions aimed at early detection.

More recently, Facione and colleagues have focused on the use of heuristic reasoning and argumentative analysis in relation to perceived breast cancer risk (Facione 2002; Katapodi et al., 2005) and how women sustain confidence in a decision to delay diagnosis of self-discovered breast symptoms (Facione and Facione, 2006). The researchers conclude that this methodology provides a useful approach towards examining health related decision making and understanding the arguments that women use when deciding whether to delay or seek help. However, it employs a very rationalistic and logical approach to decisions made at a very distressing (and perhaps irrational) time for women. Therefore, this approach while useful, may not reflect the reality of symptom discovery and HSB among women with breast symptoms.

A recent study by Unger-Saldana and Infante-Castaneda (2011) on breast cancer delay amongst women (n=17) (attending a specialised cancer care hospital for uninsured patients in Mexico City) with "highly suspicious" breast cancer symptoms, provides a

model of HSB based on Illness Behaviour Theory (Mechanic, 1986). The multi-dimensional model depicts the complexity of HSB. The four key dimensions within the model are "context", "symptom interpretation and decision making processes", "social networks" and "health services utilisation". While this model is helpful in advancing understanding of HSB and why women delay, it is grounded in a very different socio-cultural context where public health insurance is absent and health care utilisation is based on "ability to pay" for private services. However, the model needs further refinement and testing prior to use in a western health services context.

In tandem with Facione's research, in the United Kingdom, Bish et al., (2005), proposed a theoretical model to explain delayed help seeking for breast cancer symptoms. This model expanded on the existing model of patient delay (Andersen, Cacioppo and Roberts, 1995) utilising elements of self-regulation theory, (Leventhal, Nerenz and Steele, 1984) together with the theories of Planned Behaviour (TPB) (Azjen, 1991) and Implementation Intentions (Gollwitzer, 1993). The key concepts of the self-regulation model, which has relevance to the study of HSB for self discovered breast cancer symptoms, will now be reviewed.

Self Regulation Model

The self regulation model was originally developed by Leventhal, Meyer and Nerenz (1980) and Leventhal, Nerenz and Steele (1984) proposing that people construct cognitive representations of an illness/ disease in order to understand and cope with a health problem. Initially, the model was labelled the "Parellel Model" to illustrate the interdependence between fear and danger control. According to Leventhal et al., (1980) cognitive representations include "beliefs about cause, cure, underlying mechanisms, and the effects of disease on coping behaviour" (p.17). In addition,

peoples' beliefs about illness duration (acute/ chronic or cyclic) and past experience with illness and injury impact on their symptom attribution. These representations of illness, coping responses and methods used for evaluating coping outcomes comprise "the complete self regulation system for control of danger/threat (p.23). Leventhal et al., (1980) proposed that peoples' beliefs about illness are an integration of "common sense" perceptions of illness experiences together with the views of the HCP's, hence the title "Common-Sense Model of Self-Regulation".

Later, in their description of the Common-Sense Model (CSM) of Self-Regulation, Leventhal, Brissette and Leventhal (2003), assert that inherent in the model is that people act as "common sense scientists" (p. 49) when creating representations of illness threats. These representations help to develop goals for self management. The cognitive process involves the formation of five illness representations regarding the symptom/ threat. These include labelling (identity); perceived duration (time-line); perceived outcomes (consequences); internal and external agents (causes) and whether the disease/illness is perceived as preventable, curable or controllable (controllability) (Leventhal, et al., 2003, p.50) (Figure 1.2). These representations then guide the selection and implementation of coping mechanisms (such as symptom monitoring, self medication, help seeking). Once the representations and coping strategies are linked to an action plan, the self regulation is complete (Leventhal, et al., 2003). Thus, the Common-Sense Model of Self-Regulation (Leventhal, et al, 2003), with its focus on the five illness representations (i.e. identity, time-line, consequences, causes, curability/controllability) could be utilised as a framework to explore women's beliefs concerning their breast symptom.

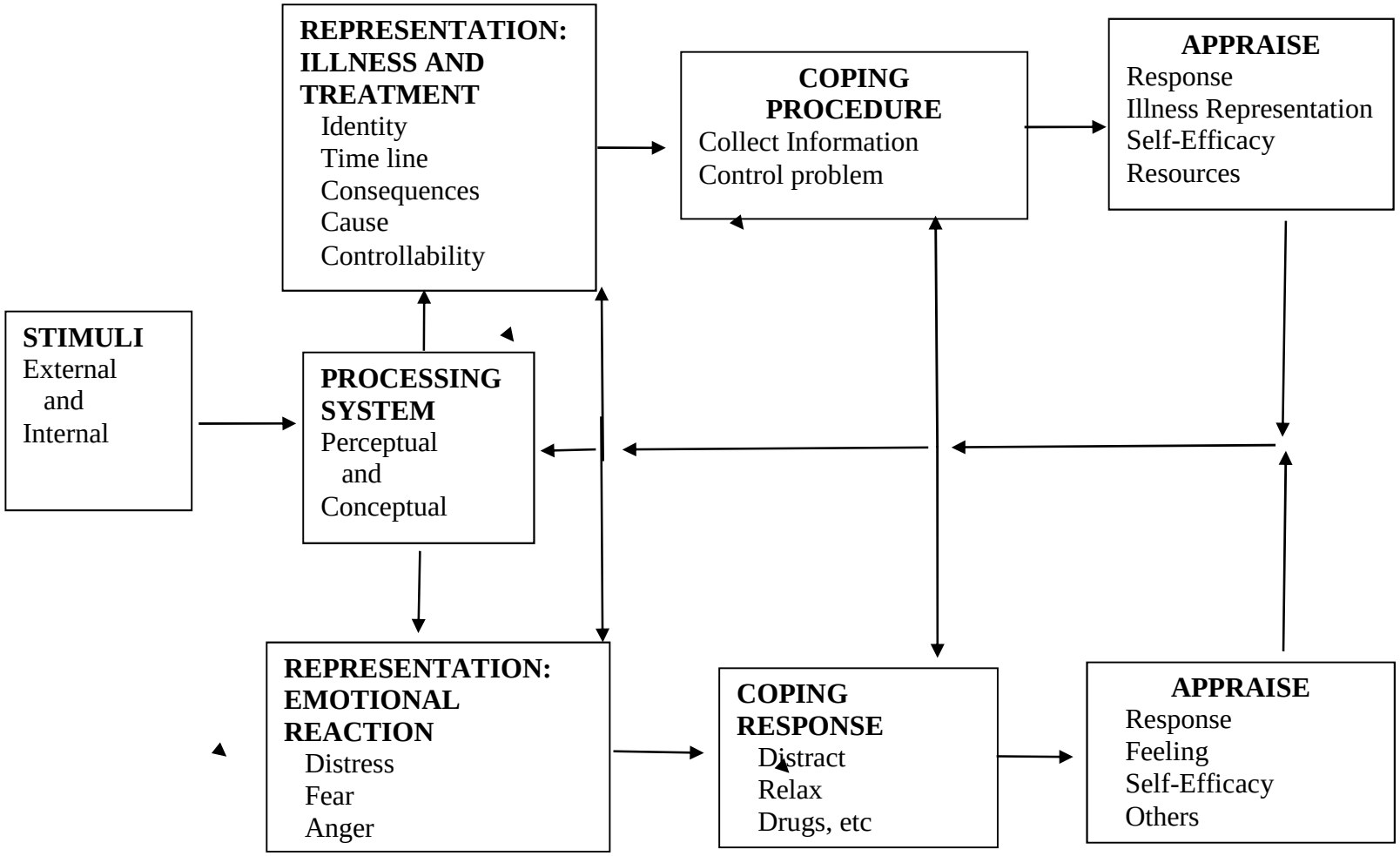


Figure 1.2 Common Sense Model of Self Regulation (Leventhal, Leventhal and Schaefer, 1991 in Leventhal, Leventhal and Cameron, 2001, p. 19. Reproduced with permission (Appendix 2)

Subsequently, Bish et al.'s (2005) explanatory model (Figure 1.3) (further discussed in Chapter Two) of delayed help seeking informed the theoretical framework (Figure 1.4) for the development of a psycho-educational intervention promoting early detection of breast cancer in older women (Burgess, Bish, Hunter et al., 2008).

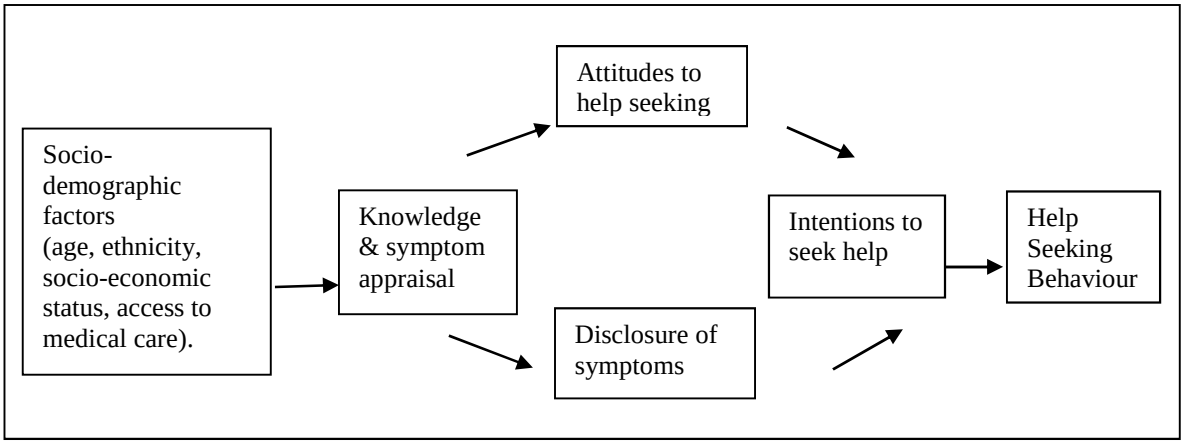


Figure 1.3 Model for understanding delayed presentation with breast cancer (Bish et al., 2005) (Reproduced with permission, Appendix 2)

While the purpose of Bish et al.'s (2005) model is to increase understanding of why women delay in seeking help for breast cancer symptoms, it does not clearly depict delay as an option and is limited to four key areas i.e. socio-demographics, knowledge and symptom appraisal, attitudes to seeking help and disclosure of symptoms. Although attitudes to help seeking are included, a notable limitation of the model is the absence of emotional responses which have been shown to impact on HSB and will be discussed further in Chapter Three.

The theoretical framework developed by Burgess et al., (2008) (Figure 1.4) draws on the above model (Bish et al., 2005 Figure 1.3) and social cognitive theory (self-efficacy) (Bandura, 1977). The framework outlines how, in the event of breast symptom discovery, socio-demographic factors (including age, socio-economic status and ethnicity) influence the woman's knowledge of symptoms, knowledge of personal

risk and confidence in detecting a breast change and thus, bring about the decision to seek help (Burgess et al., 2008). Additional factors that may affect the woman's likelihood to delay help seeking include her attitude towards seeking medical help in general, whether she reveals the symptom to somebody close and her beliefs about cancer and its management (Burgess at al., 2008). A recent randomised control trial confirmed the effectiveness of the resultant intervention in increasing breast cancer awareness amongst a sample of older women (Linsell, Forbes, Kapari et al., 2009).

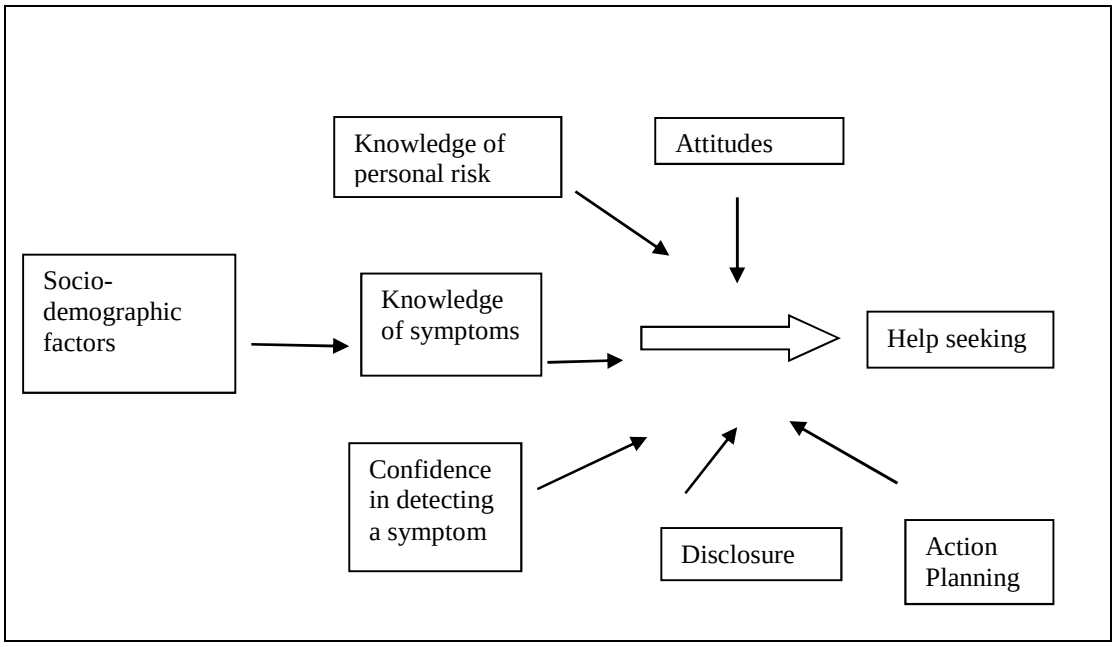


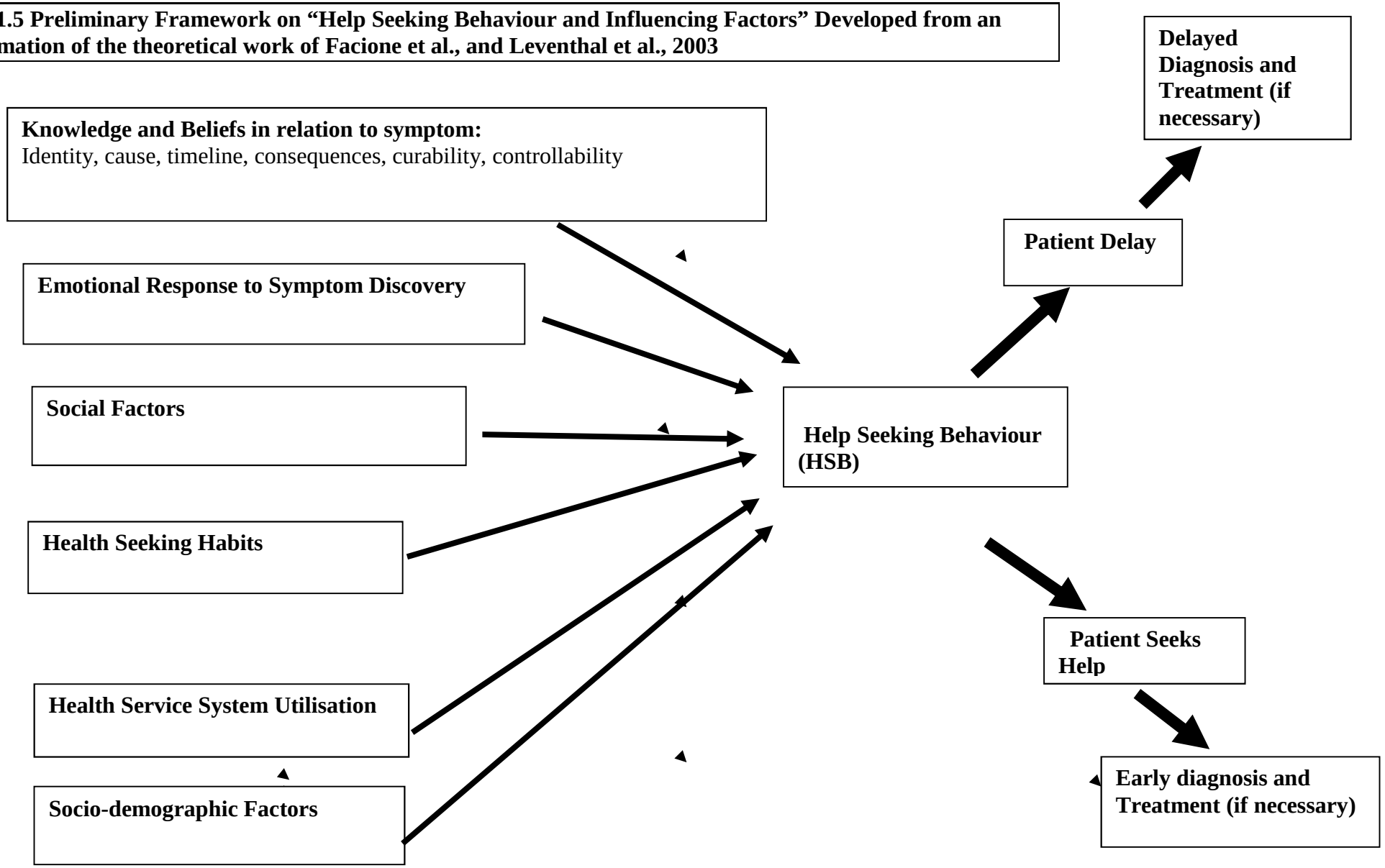
Figure 1.4 Framework to promote early help seeking (Burgess et al., 2008) (Reproduced with permission Appendix 2)

While these frameworks are valuable to understanding the process of help seeking, they are limited in that they do not address broader components of HSB such as women's emotional responses to symptom discovery and health service utilisation issues.

It is apparent therefore, that the J-delay Model (Figure 1.1) provides an holistic and culturally sensitive framework depicting the key variables that impact on women's help seeking behaviour for self discovered breast symptoms since it has been

developed from research with a culturally diverse population in the San Francisco bay area. Although the model focuses on women's intentions to seek help for potential breast cancer symptoms, it depicts key variables that were identified by previous studies of women with breast symptoms. The model provides an all encompassing framework that could be adapted, with the aid of further qualitative research, to study help seeking for actual symptom discovery in a different health care context. In addition, the key elements of Leventhal et al's (2003) Common-Sense Model of Self-Regulation and its focus on the five illness representations i.e. identity, time-line, consequences, causes and curability/controllability is pertinent to the study of women's beliefs concerning self discovered breast cancer symptoms. A preliminary conceptual framework incorporating the key concepts of the J-Delay Model (Facione et al., 2002) and the illness representations of the Common Sense Model of Self Regulation (Leventhal et al., 2003) which will be used to guide the current study, is presented in Figure 1.5.

Figure 1.5 Preliminary Framework on "Help Seeking Behaviour and Influencing Factors" Developed from an amalgamation of the theoretical work of Facione et al., and Leventhal et al., 2003



Summary

This chapter offers an overview of current literature on help seeking in order to delineate how the concept "help seeking" and related concepts are used and to identify an operational definition for the term help seeking. The issue of early detection through prompt help seeking for potential cancer symptoms was highlighted. Help seeking was seen to involve contact with a HCP and defined as "a response to health changes and part of the broader process of health seeking behaviour". Research on help seeking for cancer symptoms highlighted that delay is a common phenomenon across all cancers, with many influencing factors. In particular, the process of symptom appraisal was emphasised. Theoretical literature was reviewed in order to identify a theoretical framework to explain the process of help seeking for self discovered breast cancer symptoms. The Judgment to Delay Model (Facione et al., 2002), together with frameworks to understand delayed presentation of breast symptoms (Bish et al., 2005) and to guide the development of an intervention to promote help seeking (Burgess et al., 2008) were then reviewed. The Self-Regulation Model (Leventhal et al., 1980; Leventhal et al., 1984; Leventhal et al., 2003) which guided the development of these frameworks was included due to its focus on illness representations for actual health threats such as breast symptoms. The use of heuristic reasoning and argumentative analysis in the study of women's decision making around HSB (Facione 2002; Katapodi et al., 2005; Facione and Facione, 2006) was recognised as a useful approach but its emphasis on logic and precision may detract from its usefulness in the event of actual symptom discovery. A model of HSB developed by Unger-Saldana and Infante-Castaneda (2011) was seen to offer insight into the factors influencing HSB for breast cancer symptoms from the perspective of uninsured women in Mexico City. Again, this model is helpful but is representative of

a very different health care context to the models used in the Western world. Therefore, no all encompassing framework explaining the process of actual help seeking behaviour for self discovered breast symptoms, in its entirety was identified.

It is apparent that Facione et al's (2002) J-Delay Model while focusing on help seeking intentions and the likelihood to delay HSB, provides an holistic and detailed framework outlining the key issues associated with delayed HSB. This model could be adapted to explore HSB in the event of actual breast symptom discovery. In addition, Leventhal et al's (2003) Common-Sense Model of Self-Regulation was deemed relevant due to its focus on illness representations inherent in the occurrence of symptoms/ threats.

To conclude, this chapter highlights that help seeking for self discovered breast cancer symptoms is an area in need of further research as much of the empirical and theoretical literature focuses on help seeking intentions in asymptomatic situations as opposed to help seeking following self discovery of breast symptoms. While much research has been done, further knowledge development around actual help seeking behaviour is warranted in order to address the problem of late diagnosis following self discovered breast cancer symptoms. A preliminary framework to guide this study is presented in Figure 1.5. The following chapters will review the literature on the key issues identified in this framework, commencing with knowledge and beliefs and HSB.

Chapter 2 Knowledge and Beliefs and their Influence on Help Seeking Behaviour (HSB) for Cancer Symptoms

Introduction

In the previous chapter, Facione et al's (2002) Judgement to Delay Model which outlines the key issues associated with intentions to delay HSB was identified as an holistic framework suitable for the current study of HSB in the event of actual symptom discovery. In addition, Leventhal et al's (2003) Common-Sense Model of Self-Regulation was considered to be appropriate due to its focus on illness representations inherent in the occurrence of symptoms/threats. Thus, a preliminary framework to guide the study of HSB for self discovered breast symptoms was outlined (Figure 1.5).

It is apparent from the literature that knowledge, beliefs and perceptions are not mutually exclusive. The concepts however, have been studied both separately and simultaneously. This chapter reviews the literature on knowledge and beliefs and HSB in an attempt to ascertain the specific dimensions of these variables and whether or not they are interrelated. The influence of knowledge and beliefs on women's HSB will also be discussed. The review is presented from an International perspective in order to provide a global overview of current research. Studies reviewed are presented in relation to cancer in general, specific cancers and breast cancer.

2.1 Knowledge and beliefs and HSB for cancer symptoms

Knowledge and beliefs relating to cancer symptoms and their impact on HSB have been the focus of studies from a general cancer perspective. In this section, six studies of mixed cancer populations are reviewed. Initially, four studies focus on knowledge

and HSB for hypothetical cancer symptoms (although some participants in one study had experienced a cancer symptom they were worried about in the three months prior to the study). The remaining two are concerned with knowledge and beliefs for actual cancer symptoms.

In an effort to determine whether or not people are likely to seek help, Sheikh and Ogden (1998) report a mixed method study on the role of knowledge and beliefs in HSB for hypothetical cancer related symptoms. The quantitative element of the study explored knowledge of cancer symptoms amongst a random sample of patients (n=288), aged between 17 and 70 years, chosen from an urban four doctor practice within the UK. Follow up qualitative interviews were carried out (n=20) to further explore participants' understanding of cancer and their reasons for seeking help.

Findings demonstrated that overall, patients knowledge about cancer symptoms was fair and generally help seeking intentions for these symptoms were appropriate. However, the complex nature of the relationship between knowledge, beliefs and HSB was apparent within the qualitative data. Here, patients provided various explanations for the causes of cancer ranging from internal, external, behavioural and fatalistic causes. This study identified the importance of knowledge to HSB for cancer symptoms but also highlights that peoples' beliefs and emotions have a crucial role to play in the help seeking process. It is suggested by the authors that exploration of beliefs has potential to provide insights into the gap that exists between knowledge and behaviour.

More recently, Robb, Stubbings, Ramirez et al., (2009) completed a population based (n=2216) survey to assess public awareness of cancer in Britain using the 'Cancer Awareness Measure (CAM) (Stubbings et al., 2009). Overall, awareness was good

however, it was found to be lower in males, younger age groups and those from lower socio-economic groups or ethnic minorities. Simon, Waller Robb et al., (2010) utilized face to face interviews to study patient delay for possible cancer symptoms amongst 2071 individuals from the same sample (Robb et al., 2009). They also used CAM to assess knowledge of cancer symptoms and barriers to help seeking generally. Over one in ten respondents (11.4%; n=236) had experienced a symptom that they were worried about in the previous three months. Amongst those who experienced a symptom, 75% (n = 177) visited a doctor to discuss it. The most common reason for delaying was related to symptom interpretation. Some respondents mentioned using 'alternative sources of information', 'self medicating' and 're-appraising the symptom' as being less serious because it was "mild" (n=6) or "went away" (n=9). As highlighted by the authors, and as in the current study, one of the strengths of the study was that it also focused on help seeking for actual symptoms as opposed to the hypothetical situation only. The study demonstrated that raising awareness of early signs and symptoms empowers the public to identify cancer symptoms at an early stage. However, it also emphasised that the barriers to help seeking need to be addressed as knowledge alone does not always guarantee that appropriate help seeking will take place. Thus, assessment of women's beliefs in the use of 'alternative help seeking behaviours' in the context of actual symptom discovery, is important. Additionally, the need to use a more holistic framework to study help seeking behaviour at the symptom level i.e. as close to the time of symptom discovery as possible, is highlighted.

In, an earlier European study (De Nooijer, et al., 2001a), delay ranging from a few hours to several years was found amongst a sample (n=23) of patients with various

cancer diagnoses. Additionally, associating symptoms with cancer in some cases and attributing symptoms to common ailments in others, contributed to delayed HSB.

Wong-Kim, Sun and De Mattos (2003) completed a two phased study on the general cancer beliefs of a Chinese immigrant group of men and women (n = 798) living in San Francisco to test the relationship between the level of "acculturation" and beliefs towards cancer. "Acculturation" was not defined by the researchers but its meaning is implied in their assumption that participants' beliefs towards cancer would be affected by their length of stay in the United States and their fluency with the English language. Initial focus group interviews (cancer patients: n = 5; non-cancer patients: n=9) identified that participants in both groups considered cancer a taboo subject. Some perceived cancer as being a "time bomb" or a "death sentence" and a few participants in both groups believed cancer to be contagious. In addition, participants in the cancer group described how they had experienced discrimination in the community when people found out that they had cancer. One patient disclosed how she did not tell her Tai Chi group about her diagnosis because the group had at one time discussed that cancer was incurable and that people diagnosed with cancer "should just die quickly". In relation to causes of cancer, members of the cancer group tended to believe in fate and that cancer was not preventable. Some mentioned how a stressful life could have contributed to their diagnosis. Those in the non cancer group believed that cancer could have been caused by risky behaviours and bad health habits and one person jokingly said that cancer might be due "to a crime committed in their last life" (p.24).

Phase two of the study utilised a telephone administered questionnaire to ascertain beliefs concerning the contagiousness and preventability of cancer, amongst a random

sample of Chinese immigrants (n=789) (41% male, n=327; 59% female, n= 471). A belief in the contagiousness of cancer was repeated amongst 25.7% (n= 205) of participants. In addition, polluted environment, diet and genetics were more likely to be considered as causes of cancer than immoral behaviour or punishment due to ancestor's conduct (a common belief amongst Chinese people). Surprisingly, logistic regression indicated that women in low income groups living in the United States for an extended period of time were more likely to believe that cancer is contagious. The authors concluded that education and the process of socialisation may be interrelated. This study highlights the impact of cultural beliefs on individuals' beliefs about cancer.

A more recent study focused on the beliefs, perceptions and myths surrounding cancer and its treatment (type not specified) amongst patients (n=95) attending an Oncology and Radiotherapy Outpatient Department (OPD) in a Delhi teaching hospital (Kishore, Ahmad, Kaur and Mohanta, 2007). Findings demonstrated that myths and misconceptions about cancer were prevalent among these patients. Most patients believed cancer to be caused by "God's curse", the presence of an "evil eye" and individuals' "past or present sins". Similar to the above study, 27.4 % (n=26) of patients believed cancer to be contagious, the majority of whom were illiterate and in semiskilled/ unskilled occupations. It was reported that 48% (n=45) of patients sought help promptly following symptom discovery whereas the average time taken by the remaining 52% (n=49) of patients to seek help was two years. This delay could be due to the fact that almost half (51.6%; n=49) of these patients went to faith healers and alternative medicine practitioners for approximately six months. Most patients believed that people with cancer could not lead productive lives and nearly half (48%; n=45) had fatalistic views about the outcomes of cancer. The majority of patients

were discriminated against in some way following their cancer diagnosis and 60% reported feeling “completely isolated. This study reiterates that while knowledge influences HSB as highlighted by the authors, personal and cultural beliefs also act as mediators between knowledge and HSB.

In summary, these studies highlight that knowledge and beliefs play a significant role in HSB for general cancer symptoms, both from an hypothetical and actual perspective. In particular, the nature of the symptom and the associated knowledge determine initial interpretation of the symptom. In turn, individuals’ beliefs (both personal and cultural) further impact on symptom interpretation and help to understand the gaps between knowledge and HSB. This emphasises the importance of applying an holistic perspective to the study of HSB for cancer symptoms particularly at the ‘actual symptom’ level. Research (n=4) focusing on knowledge and beliefs and HSB following the occurrence of specific cancer symptoms will now be reviewed.

2.2 Knowledge and beliefs and HSB for specific cancer symptoms

Pullyblank, Cawthorn and Dixon (2002) examined the symptom knowledge of both colorectal and breast cancer in patients attending breast (n=75, mean age 46 years) and coloproctology (n=78, mean age 59 years) clinics in a hospital in Bristol. The study found that participants’ breast cancer knowledge was significantly greater than that relating to colorectal cancer in both patient groups ($p < 0.0001$). Seventy five percent of women (n=56) attending a breast clinic could name a breast symptom whereas only 37% (n=29) of patients attending a colorectal clinic could name a bowel symptom. A positive association was found between cancer knowledge, family history and female gender. It was suggested by the authors that the difference in knowledge between both cancer groups could be due to the vague nature of colorectal

cancer symptoms and the difficulty in distinguishing them from normal changes in bowel habit. In addition, more knowledge sources were identified for breast cancer than for colorectal cancer within both clinic groups possibly accounting for the lack of knowledge about colorectal cancer. The study highlights the need for more health promotion and media attention in relation to colorectal cancer so that people can recognise potential symptoms. The importance of symptom knowledge in the promotion of early help seeking for all cancer symptoms is further acknowledged.

In relation to oral cancer symptoms, Scott, Grunfeld, Main and McGurk (2006), using a qualitative approach, concluded that lack of knowledge and failure to attribute symptoms to cancer impacted on delayed HSB in patients (n=17) with a confirmed cancer diagnosis. Scott, McGurk and Grunfeld (2007), utilised semi structured telephone interviews to explore the cognitive and emotional responses to symptom discovery of participants with oral cancer symptoms (n=57). The domains of illness representations from the Common-Sense Model of Self-Regulation (Leventhal et al., 1980 and Leventhal et al., 2003) were used as a framework to explore beliefs about the symptom in terms of its "identity, timeline, cause, consequences, and control". Participants were asked if and when these beliefs had changed and the reasons for such changes. In addition, questions focused on participants' emotional reactions to the symptom and whether these had changed since symptom discovery.

Using 'framework" analysis, it was highlighted that participants often saw the symptoms as being minor ailments and thus, symptoms did not cause emotional distress. Few participants linked the symptoms to oral cancer, emphasizing a general lack of knowledge and awareness of the disease as indicated in other studies cited by the authors. Reappraisal and reinterpretation of symptoms was usually due to their

persistence, failure of coping mechanisms, receipt of new information, and change or progression of symptoms. The study provides insights into the process of symptom appraisal and interpretation of self discovered oral cancer symptoms and validates the relevance of the Self Regulation Model to the study of HSB for self discovered cancer symptoms.

Another phase of the above study reported on the barriers and triggers to help seeking. This data was collected in the original telephone interviews with patients (n=57), 10% of whom were diagnosed with oral cancer (Scott, Grunfeld, Auyeung, McGurk, 2008a). This report focused in particular on participants' help seeking decisions and the associated influencing factors, It was found that 53% (n=30) waited for 31 days before visiting a HCP and 37% (n=21) waited for three months or more. Beliefs regarding oral symptoms were among the main barriers to help seeking. Conversely, change in symptoms, persistence and pain were amongst the most important triggers to help seeking. The need for an early diagnosis and to resolve uncertainty were highlighted. This study further reiterates the complexity of the help seeking process and the important role of knowledge and beliefs in the decision to seek help for self discovered oral cancer symptoms.

In a larger quantitative study Scott, McGurk, Grunfeld (2008b) sought to provide a theoretically based insight into patient delay for potentially malignant oral symptoms. Participants (n=80) completed a questionnaire after receiving a potentially malignant diagnosis. The questionnaire utilized components of the Self Regulation Model (Leventhal et al., 1980; Leventhal et al., 2003) as an overall framework. Participants were asked about the identity of their presenting symptom and their initial and subsequent symptom interpretation, knowledge and beliefs about oral cancer and

perceived behavioural control and HSB. Using a “cut off of 31 days” to measure delay, it was found that 54% (n=42) experienced “prolonged” delay and 46% (n=38) sought help promptly. The majority of patients had confirmation of benign diagnosis (n=84%) and 16% had malignant disease. Univariate logisitic regression determined that the factors significantly associated with delayed HSB included the gravity of patients’ initial interpretation, knowledge of oral cancer and perceived ability to seek help. Multiple logistic regression confirmed that knowledge of oral cancer and perceived behavioural control were independent predictors of delay. This study confirms the usefulness of the Common-Sense Model of Self-Regulation in understanding patient delay and highlights the need to increase people’s knowledge of oral cancer symptoms and promote early detection amongst at risk individuals such as those living in deprived areas.

The difficulty in recognising ovarian cancer symptoms (Koldjeski et al., 2004) and lung cancer symptoms (Corner et al., 2006) has already been alluded to in Chapter One. More recently, the impact of knowledge and beliefs on HSB was further reiterated in a cross sectional quantitative survey on the HSB of patients (n=360) aged 37-87 years, who were diagnosed with primary lung cancer in Britain (Smith, Campbell, MacLeod et al., 2011). It was found that 50% (n=179) of participants waited for 14 weeks or more before visiting a HCP. Overall, 75% (n=270) of the sample reported having no knowledge of lung cancer symptoms and 48% (n=171) did not believe that their first symptom was serious. Interestingly, an almost “unrealistic optimism” was demonstrated amongst participants in that they did not see themselves to be at risk of getting lung cancer. Such optimistic beliefs had potential to have a negative impact on HSB.

To summarise, the impact of knowledge and beliefs on HSB for actual cancer symptoms is apparent. The difficulty surrounding the interpretation of various symptoms was highlighted including colo-rectal cancer symptoms (Pullyblank et al., 2002); oral cancer symptoms (Scott et al 2006; Scott et al., 2007; Scott et al., 2008a; Scott et al., 2008b); ovarian (Koldjeski et al., 2006) and lung cancer symptoms (Corner et al., 2006; Smith et al., 2011). The relevance of the Common-Sense Model of Self-Regulation (Leventhal et al., 1980; Leventhal, et al., 2003) and its focus on the five illness representations i.e. identity, time-line, consequences, causes and curability/controllability to guide further study on HSB for self discovered cancer symptoms, was further reiterated (Scott et al., 2007; Scott et al., 2008a; Scott et al., 2008b). These studies highlight that inadequate knowledge of presenting symptoms in relation to specific cancers has potential to impact on HSB in the event of symptom discovery. Additionally, the complex nature of the help seeking process is acknowledged. Studies on knowledge and beliefs and HSB for breast cancer symptoms will now be reviewed.

2.3 Knowledge and beliefs and HSB for breast cancer symptoms

The impact of knowledge and beliefs is reiterated in much of the literature on HSB for self discovered breast cancer symptoms. Studies are reviewed according to their country of origin in order to demonstrate the evolution of knowledge in the area. Initially, the seminal research of Facione and colleagues in the United States (n=4) is reviewed followed by Canadian (n=1) and American (n=3) studies which focus more specifically on beliefs in the context of breast screening practices (n=3) and HSB in the event of symptom discovery (n=1) for ethnic minority groups. A review of European studies including those in the United Kingdom by Burgess and colleagues

and Grunfeld and colleagues and two Irish studies, preceded by New Zealand (n=1), Iranian (n=1), Australian(n=2) and Mexican (n=1) studies, is then presented.

2.3.1 An American Perspective

In 1995, Facione and Dodd reported that help seeking is determined by how women interpret breast symptoms. Narratives of women (n=39), with a breast cancer diagnosis who were undergoing chemotherapy were analysed. The 'cognitive burden of interpreting breast symptoms' (Facione and Dodd, 1995, p.220) was noted. Interpretations of symptoms were discussed in terms of what women 'knew about their breasts and their bodies in general' (p. 221). It was found that many women in the sample were unaware that their breast pain or nipple symptoms could be a breast cancer symptom which could explain why 41% (n=16) delayed seeking evaluation. In addition, women in the sample had more advanced disease (72% had regional or distant metastases) than generally present in the overall population of women with breast cancer. This factor is attributable in part to the selection criterion that women would be receiving chemotherapy. However, it is reasonable to suggest that lack of knowledge about non-lump breast cancer symptoms could have impacted on women's delayed HSB which has potential for late stage tumour at diagnosis.

A later study focusing on African-American women's (n=352) intentions to seek help, measured (among other variables) women's perceptions of the positive and negative consequences of prompt help seeking versus delayed help seeking using the Perceived Consequences (PCONSEQ), researcher developed scale (Facione et al., 1997). It was found that women in the sample generally did not associate delayed help seeking with negative consequences such as more serious disease, potential for more extensive surgery and possible increased risk of death. Interpreting the potential threat of breast

symptoms was also a theme that emerged from Facione and Giancarlo's (1998) research on narratives of women (n=80) around breast symptom discovery and cancer diagnosis. Based on these findings and the key concepts of Social Behavioural Theories (Triandis 1979 and Ajzen and Fishbein, 1980) the J-Delay Model was developed (previously discussed). In this model, problem definition is depicted as being synonymous with "symptom appraisal", the dimensions of which are "symptom knowledge, risk attribution and affective response". It was suggested that, women's knowledge around breast cancer symptoms and the risks attributed to the symptom, are important dimensions of symptom appraisal and have a direct influence on women's subsequent HSB, in terms of "seeking evaluation versus patient delay" (Facione et al., 2002). Therefore, it appears that symptom appraisal and interpretation of the symptom are closely linked and are influenced by women's knowledge of breast symptoms and the risks they associate with these symptoms which ultimately influence women's intended HSB.

In the testing of the J-Delay Model, women's knowledge of the presenting symptoms of breast cancer was measured using The Breast Cancer Symptom Knowledge (BCSK) scale (Facione et al., 2002) developed from previous studies (Mor, Masterson-Allen, Goldberg et al., 1990 and Nagadowska and Kulakowski, 1991). This measure consisted of fifteen items each describing potential breast cancer symptoms. Women were asked to indicate whether they judged these possible changes to signal breast cancer using a "yes/no/ I don't know" scale. The number of symptoms correctly associated with breast cancer was then used to compute an index of breast symptom knowledge. This scale was later critiqued by Facione (2008), in that it suggests responses that may not otherwise be given by women (Personal

Communication with Facione, December, 2008). However, it provides a comprehensive tool for assessing women's general knowledge of breast cancer.

Facione et al., 2002 reported that breast cancer knowledge ranged from "extremely poor" (amongst 14% of the sample who identified "lump" only) to well informed (10% correctly identifying all or all but one symptom with breast cancer). Women with some college education associated significantly more symptoms with breast cancer than women who were educated to high school level or less ($p<0.001$). In addition, women who were likely to delay scored significantly lower on the BCSK scale than those who were not likely to delay ($p<0.001$). Thus knowledge and education impacted on women's help seeking intentions.

As previously discussed, women's beliefs also affect their HSB. Facione et al., (1997) measured the effects of beliefs such as 'religiousness' and 'fatalism' using the RELIG scale (Strayhorn, Weideman and Larson, 1990) and the FATE scale (researcher developed from previous focus group interviews), on women's helpseeking intentions. It was found that religiousness explained little variance in intentions to seek help. However, fatalistic beliefs about breast cancer were strongly related to help seeking intentions. Continuing with beliefs, an earlier study on women's narratives of breast symptom discovery and cancer diagnosis (Facione and Giancarlo, 1998) reported that women generally endorsed the use of spiritual or nutritional therapy for breast cancer symptoms, particularly when used in conjunction with medical therapy. Narratives from focus group discussions with ethnic groups (total n=57), referred to the use of herbs, diet, meditation, massage or manipulation to treat breast cancer symptoms. In their narratives about women with breast cancer, several white participants (total n=23), mentioned their admiration for women's "exhaustive use of alternative

complimentary therapies" (p.435). In addition, some African-American women in the sample mentioned religious beliefs, prayer and other complimentary self care activities.

Beliefs and knowledge relating to 'curability potential', 'consequences of delay', 'influences of spirituality' and 'the efficacy of complimentary therapies' were outlined in the J-Delay Model (Facione et al., 2002, Figure1.1). In testing the J-Delay Model (Facione et al., 2002), self-care behaviour relating to breast symptoms was measured by a 9-item scale which calculated the number of positive responses to specific behaviours (i.e. 'self diagnosis of breast problems, use of meditation, symptom monitoring, use of over the counter medication, alternative healing, home remedies and prayer'). Women who were likely to delay indicated that they would use significantly more 'self care practices' to manage self discovered breast symptoms than those not likely to delay ($p<0.001$). In addition, the breast cancer fatalism scale was used to measure fatalistic beliefs and demonstrated that women who were likely to delay had higher fatalism scores than women who were not likely to delay ($p<0.001$). Fatalistic beliefs were associated with race/ethnicity ($p<0.001$). Latino women had higher fatalism scores than black or white women (Facione et al., 2002).

It is apparent from the above, that symptom knowledge determines how women interpret breast symptoms and the associated risks and thereby appraise the symptom which in turn determines their intended and actual HSB. However, women's beliefs about the consequences of HSB, curability of breast cancer, efficacy of alternative help seeking behaviours together with spiritual and fatalistic beliefs, also impact on their HSB. Finally, a woman's previous experience or that of other women is likely to impact on her knowledge and beliefs about breast symptoms, breast cancer and HSB.

Therefore, both knowledge and beliefs play a major role in women's intended help seeking behaviour, as depicted in the J-Delay Model (Facione et al., 2002, Figure 1.1). Due to their possible impact on actual HSB, studies focusing more specifically on women's beliefs in the context of breast cancer screening practices amongst ethnic minority groups in Canada (n=1) and the United States (n = 2) are reviewed followed by one study on beliefs and actual HSB.

Botoroff, Johnson, Bhagat et al., (1998) used unstructured interviews to explore the breast health practices of South Asian women (n=50) living in Canada. The ethnoscience method was used to explore women's experiences and to obtain knowledge of their implicit and explicit cultural beliefs. Data analysis found that the major cultural issues affecting women's breast health practices concerned their beliefs regarding "a woman's calling", "cancer generally", "breast care", and "accessing services". Beliefs about a "woman's calling" centred on "keeping family honour", "being modest" and "putting others first". Women believed cancer to be "scary" or "a hidden killer". Taking care of breasts was not a priority. Some women did not see themselves as being at risk of breast cancer; however they would pay attention to symptoms, though the notion of asymptomatic screening was alien to them. This study provides valuable insights into the cultural beliefs of South Asian women and how they influence their breast health practices.

Narrative enquiry was used by Thomas (2004) to gain insight into the possible influence of memories and feelings about past experiences on current breast cancer screening behaviours, among twelve professional African American women aged 42 to 64 years. This group was chosen because of the consistently higher breast cancer mortality rates noted among African American women and the lack of research on

cancer and cancer screening behaviours of this diverse cultural group. Data were generated from women's journals, audio-taped interviews (n=12) and researcher's field notes. One of the categories highlighted was titled 'Breast Cancer and Cancer Beliefs'. Within this category, an issue of particular relevance to this review, was that some women's fatalistic views of cancer were a reason for not participating in breast cancer screening. Many women were of the view that screening was unnecessary since there was no history of breast cancer in their families. Findings reiterate that while women in the sample were knowledgeable about breast health issues, oftentimes their beliefs and perceptions created barriers to recommended help seeking behaviour.

Utilizing Powe's (1995) model of fatalism as a framework, Spurlock and Cullins (2006) carried out a cross sectional, descriptive correlational study to examine the relationships between perceptions of cancer fatalism and breast cancer screening in a convenience sample of African American women (n= 71) aged 20-73 years. Powe's Model proposed that fatalism is a factor which impacts on participation in cancer screening and that a relationship exists between demographic factors, cancer fatalism, knowledge of cancer and participation in screening (Powe, 1995). Participants completed a 15 item, adapted version of the Powe Fatalism Inventory (PFI), requesting a 'yes'/ 'no' response for each statement provided. Scores of 0-8 indicated low perception of cancer fatalism and 9-15 revealed a high perception of cancer fatalism.

The majority of women, who were unemployed and without insurance, expressed perceptions indicating fatalistic thinking, across all items of the PFI. Regardless of age, most women expressed a perception that "persons with breast cancer are meant to

have the disease" (p.40). Women who were more fatalistic were less likely to engage in breast screening. The most significant finding was that age was negatively or inversely associated with cancer fatalism i.e. breast cancer fatalism scores were higher in younger women than older women. These findings need to be considered regarding women who self discover breast symptoms as fatalistic beliefs have potential to impact on HSB for actual symptoms also.

In a metropolitan area of the south east United States, Gulatte, Brawley, Kinney et al., (2010) studied the relationships between religiosity, spirituality, breast cancer fatalism, and both time to seek medical care and breast cancer stage. A convenience sample (n=129) of African American women (30-84 years), who had been diagnosed with breast cancer following self discovered breast changes within the previous twelve month period, completed a self report questionnaire during a clinical visit to the oncologist. Regretfully, 59% (n = 76) of women reported waiting more than three months from symptom discovery to seeking help. The median time from symptom discovery to seeking help was four months. The most common symptom reported by women was a breast lump or "knot" (53%; n = 68) and 43% (n=55) reported more than one symptom (pain, "knot" or lump, nipple discharge, itching or change in skin colour). Using chi-square analysis, a significant association was found between time to seek help and breast cancer diagnosis ($p = 0.01$). Logistic regression demonstrated a significant positive association between delayed help seeking and stage of breast cancer ($p = 0.01$). Women who delayed for more than three months were significantly more likely (OR = 6.37) to present with a later stage cancer than those who sought help within three months of symptom discovery. Contrary to the previous studies, women's fatalistic beliefs were found to be low and cancer fatalism was unrelated to religiosity or spirituality. However, a positive relationship was found between

religiosity and spirituality (r = 0.53; p = 0. 01). Overall, women in the sample had high levels of religiousness and spirituality, although neither religiousness, spirituality or fatalistic beliefs about cancer were significant predictors of help seeking.

As suggested by the authors, fatalistic beliefs present at the time of symptom discovery could have been dispelled by the information women received about breast cancer and its treatability, following their diagnosis. The study demonstrated that delay is prevalent among African American women. This is one of the few studies to demonstrate that delayed help seeking is associated with more advanced stage of cancer at diagnosis. While there is a decrease in breast cancer mortality overall, the study reveals that presentation with advanced disease at diagnosis continues to be a problem amongst African American women.

In summary, this section of the review highlights that fatalistic beliefs impact on breast screening practices, suggesting that they have potential to affect HSB in the event of actual breast symptom discovery also. However, while delayed help seeking was found to be associated with more advanced stage of disease, fatalistic beliefs were found to be low amongst a sample of African American women following breast cancer diagnosis. Studies from a European perspective will now be reviewed.

2.3.2 A European Perspective

United Kingdom

Breast cancer and HSB were the focus of various groups of researchers in the UK. Burgess et al., (1998) studied the factors influencing delay in presenting with breast cancer (n= 185). Women with a diagnosis of breast cancer were interviewed while attending for treatment, eight weeks after diagnosis. One of the questions focused on

whether they recognized the symptom to be a particular cancer/ something serious versus a benign breast problem. The independent effect of the variables 'symptom type' and 'symptom attribution' on patient delay was assessed using logistic regression. It was found that women who did not experience a breast lump were over four times more likely to delay than those whose first symptom included a lump (OR 4.5, 95% CI 1.7-2.10, $p<0.003$). In addition, women whose symptom included a breast lump were more likely to attribute it to a particular cause ($p=0.0001$). The authors concluded that, of all the factors studied (fear, time spent thinking about the symptom, disclosing to another, source of motivation and reason for attending the GP, which are not discussed in this section), discovery of a breast symptom other than a breast lump was the most significant determinant of patient delay, suggesting that women's knowledge about breast cancer symptoms is crucial to their decisions around HSB.

A further qualitative study of delay among women diagnosed with breast cancer (n=46) (from within the original sample (n=185) above (Burgess et al., 1998) suggested that the help seeking process is influenced by a combination of knowledge, perceptions, beliefs and attitudes (Burgess, Hunter and Ramirez, 2001). These included interpretation of symptoms and beliefs and fears about the consequences of help seeking. Interpretation of symptoms depended on the nature of the symptom and women's previous experience of breast symptoms. Findings revealed that non delayers (n=15) experienced less ambiguity and sought help as they were concerned that the breast changes could be a threat to their health. Some women (n=31) delayed help seeking because of their beliefs about the consequences of cancer. Oftentimes, these beliefs were influenced by their past experience of cancer where a loved one died having experienced a long or painful death. Negative beliefs were also due to the

fact that some women were unaware of advances in treatment such as the availability of conservative surgery or treatments to counteract the side effects of chemotherapy. Thus, women's knowledge and beliefs both impacted on their HSB.

In a study on women with breast symptoms attending a London clinic (n=692), Nosarti et al., (2000) found that delay (> 27 days) was most common amongst women with non breast lump symptoms. In cross tabulating symptom attribution (benign/ malignant) with diagnosis, it was found that the majority of women suspecting benign diagnosis were correct. Conversely, of those who suspected that they had cancer the majority were incorrect. Logistic regression indicated that women who were diagnosed with breast cancer were more likely to have delayed because they thought their symptom was due to cancer. Although, not significant a family history of breast cancer was present amongst 18.7% (n=98) of the sample. The authors concluded that women's beliefs about breast symptoms and their attribution were the most important factors determining when women present to a HCP with symptoms.

Grunfeld, Ramirez, Hunter and Richards (2002) examined the breast cancer knowledge and beliefs of a randomly chosen sample of women from the general population (n=996). The specific aims of the study were to examine women's interpretations of potential symptoms of breast cancer, their beliefs about the risks and consequences of breast cancer and to examine these variables in relation to age and socio-economic status (SES). Data were collected through a series of questions focusing on knowledge of a woman's lifetime risk of developing breast cancer, knowledge of risk factors associated with breast cancer, knowledge of breast cancer symptoms and perceptions of breast cancer management and outcomes.

Findings highlighted that while women had good knowledge about some aspects of breast cancer, their knowledge about other important issues such as non lump symptoms and life time risk of developing the disease was limited. Variations were apparent in women's knowledge of potential symptoms and risk, according to age and SES. Older women demonstrated poorer knowledge of risk factors (including advancing age) for breast cancer. This lower level of knowledge was also present in SES Groups 3 and 4. In addition, professional women perceived themselves to be at less risk of breast cancer than other women in the sample. The most frequently cited risk factors were family history and personal history of breast cancer. It is highlighted by the authors that this emphasis on family history, while correct, could lead to a situation of complacency among women with no family history. Overall, the authors reported that women conveyed positive beliefs about breast cancer treatment and outcomes although older women (over 75 years) reported the belief that breast cancer always resulted in "some disfigurement" which the authors suggest, could reflect the experience of their peers who may have been treated at a time when treatments were less effective and possibly more radical in nature.

A second phase of the above study was carried out by Grunfeld et al., (2003) in a sample of women (n=546) recruited from within the original sample (n=996). The purpose of this phase was to apply the cognitive component of the self–regulation model (Figure 1.2) (i.e. illness representations: identity, timeline, consequences, causes, cure/control) (Leventhal, Nerenz and Steele, 1984) and the theory of planned behaviour (TPB) (Ajzen and Madden, 1986) to examine the differences in perceptions of potential breast cancer symptoms and help seeking intentions across the life span.

The hypothesis was that a woman would primarily draw on her knowledge and beliefs of breast cancer (Self Regulation Model) before drawing on her beliefs about help seeking behaviour (Theory of Planned Behaviour, TPB). Data were collected by a two sectioned questionnaire. Section one was based on an adaptation of the Illness Perceptions Questionnaire (Weinmann, Petrie, Moss-Morris et al., 1996) where questions were adapted to be of relevance to both breast cancer patients and a general healthy population. The second section of the questionnaire focused on the constructs of TPB (attitude towards help seeking, perceived behavioural control and subjective norms) (Ajzen and Madden, 1986). In addition, intentions to seek help were based on responses to twelve breast cancer symptoms, where women were asked to rate on a seven point scale from 'definitely' to 'definitely not' how likely they would be to seek help for each symptom.

Women's age groups were categorized as 16-34 years, 35-54 years, 55-64 years and 65 and over. Hierarchical multiple regression was performed within each age group to identify the subscales from the two theoretical models that contributed to intentions to seek help. Identification of potential symptoms was an important factor in predicting help seeking intentions across all age groups of women and was the only significant factor amongst the younger (16-35 years) and older (55-64) age groups. In the 35-54 age group, positive attitude towards help seeking and positive beliefs regarding the ability to seek help (perceived behavioural control) were found to be significant predictors of intentions to seek help. Belief that it was 'easy to talk to a doctor' was also a strong indicator of intention to seek help. Having positive beliefs about the consequences of help seeking was found to be a significant predictor of intention to seek help, amongst the oldest age group. In this group, specific items that best predicted intentions not to seek help were beliefs that breast cancer would be

'disabling', 'disfiguring', or would have negative economic implications. This study reiterates the impact of both knowledge and beliefs on intentions to seek help across the life span and highlights that negative beliefs can cause delayed help seeking amongst older women.

Hunter, Grunfeld and Ramirez (2003) reporteded another aspect of the above study to determine which aspects of The Self Regulation Model (Leventhal, Nerenz and Steele, 1984) and Theory of Planned Behaviour (TPB) (Ajzen and Madden, 1986) would best predict women's intention to seek help. The identification of symptoms as potential signs of breast cancer (identity) was found to be the variable within the self regulation model that most strongly predicted the intention to seek help. According to the authors, findings support one of the key components of the self regulation model that "symptoms are key in cognitive representations of health threats and in the initiation of the self regulation process" (page 329) as asserted by Cameron, Leventhal and Leventhal (1993). In addition, the study affirmed that having a positive attitude towards help seeking was a strong predictor of intention to seek help. Intentions to seek help were also influenced by women's beliefs regarding their confidence to seek help. Thus, the authors concluded that intentions to seek help incorporate a "two-component process where a woman appraises breast changes and having interpreted the change as a possible breast cancer symptom, cognitively processes the advantages and disadvantages of seeking help, drawing upon her beliefs and self efficacy beliefs."(p.331). This reiterates the role that women's knowledge and beliefs are likely to play in their HSB in the event of symptom discovery.

Later, a systematic review carried out by Bish et al., (2005) on understanding why women delay help seeking for breast cancer symptoms concluded that delay in help

seeking is influenced by a complex array of issues including cognitive factors. Utilising and expanding upon existing models of patient delay and social cognition, a model for understanding delayed presentation of breast symptoms was presented. This model (Figure 1.3) already referred to in Chapter One, draws on Self-Regulation Theory (Leventhal et al., 1984); Theory of Planned Behaviour (TPB) (Ajzen and Fishbein, 1986); Implementing Intentions Theory (Gollwitzer, 1993) and the model of delayed help seeking (Andersen, Cacioppo and Roberts, 1995.) According to this model, socio-demographic factors (age, ethnicity, socio-economic status, access to medical care) influence help seeking and this influence is mediated through the cognitive and behavioural factors depicted in the model (Bish et al., 2001). Two of the concepts within the model are 'knowledge and symptom appraisal' and the authors assert that "the identification and attribution of a symptom to cancer is the first step of the help-seeking process" (p.324). According to the authors, both Leventhal's Self Regulation Theory and Andersen et al's (1995) Model of Delayed Help Seeking focus partly on symptom appraisal, suggest that knowledge, beliefs and risk perceptions influence how an illness is viewed, thereby, affecting behaviour. The authors concluded that the proposed model could be used to develop an effective intervention to reduce delay.

Linsell, Burgess and Ramirez (2008), utilising a researcher developed questionnaire, completed a national survey on breast cancer awareness among older women (n = 712) aged between 67 and 73 years, The aims of the study were to ascertain women's knowledge of breast cancer symptoms and the risks of developing breast cancer and to assess their confidence in detecting a breast change. In addition, the study sought to examine women's knowledge and beliefs in relation to their socio-demographic

characteristics in order to ascertain which group of older women were most at risk of delayed presentation of symptoms.

Findings demonstrated that although older women had knowledge of breast symptoms and the risks associated with breast cancer, lack of awareness about some issues were prevalent in the less educated group. The main knowledge deficit was lack of recognition of non-lump symptoms as possible breast cancer symptoms and a poor understanding of risk. This reiterates the need for more concentrated efforts from HCPs to develop specific educational programmes targeting older women (who are more at risk of developing breast cancer) regarding breast cancer symptoms, risk and early detection.

To this end, Burgess et al., (2008) developed a psycho educational intervention (already mentioned in Chapter 1). Following an initial exploratory trial (Burgess, Linsell, Kapari et al., 2009), this intervention has subsequently been tested in a randomized control trial (Linsell et al., 2009) which demonstrated its effectiveness in increasing breast cancer awareness amongst older women. The theoretical framework (Figure 1.4) underpinning the intervention draws on self regulation theory, the theory of planned behaviour, implementation of intentions and social cognitive theory (Bandura, 1977). Included in the framework are "knowledge of personal risk, knowledge of symptoms and confidence in detecting a symptom" which are identified as risk factors for delayed presentation (Burgess et al., (2008).While the results of the trial are positive, their effects on women's long term HSB remain to be seen. However, this research emphasises the role of knowledge in raising awareness of breast cancer symptoms amongst older women. It is anticipated that this knowledge will have a positive effect on women's HSB in the event of breast symptom

discovery. Overall, these studies reiterate the importance of assessing women's knowledge and beliefs in relation to HSB for actual breast symptoms. Studies from an Irish perspective are now reviewed.

Irish Perspective

In an Irish context, McMenamin at al (2005) carried out a National survey to determine breast cancer awareness (knowledge relating to: risk factors, screening, symptoms, treatments and outcomes) amongst the general population. Purposive sampling identified potential participants from the general well and active population who were asked to complete a researcher developed questionnaire (n=2355; 1250 female and 1105 male). Most participants had heard about breast cancer and overall, their knowledge was good. The majority of participants knew that a positive family history was associated with breast cancer but knowledge of other risk factors was poor. Knowledge of symptoms, treatments and screening was better amongst women than men. Women were less optimistic and knowledgeable about age of onset of breast cancer and long term survival. Sixty six per cent of females (n=825) overestimated their risk of developing breast cancer while 88% (1100) underestimated the age at which it is most likely to develop breast cancer with 56% (n = 700) underestimating five year survival following diagnosis. Knowledge of incidence and survival was higher in male participants with higher education and those who received information from media sources, particularly television. Lack of knowledge concerning risk factors, incidence and outcome, led the researchers to conclude that in Ireland, the general population and at risk females were unlikely to make informed decisions regarding various breast cancer issues, including screening, treatment options or modifying risks through life style changes. Thus, further investigation of

the impact of women's knowledge and beliefs on their HSB would be helpful to inform the development of appropriate interventions.

To this end, following an in depth literature review and using the J-Delay Model as a conceptual framework, O'Mahony and Hegarty, (2009b) adapted a researcher developed questionnaire (Meechan et al., 2002) to study women's HSB in an Irish context (n=99). In addition to the issues included in the original questionnaire, the adapted version included a section on symptom discovery focusing, among other issues, on the identification of the symptom discovered. Women were also asked to indicate which factors facilitated (21 items, 11 relating to knowledge and beliefs) help seeking on a five item Likert type scale from 'strongly disagree' (1) to 'strongly agree' (5). This was repeated for a list of factors which may have acted as barriers (29 items, 8 of which related to knowledge and beliefs) to help seeking. In relation to HSB, 72.7% (n=73) of women visited their GP within one month, 14.1% (n=14) within one to three months and 10% (n=12) after three months. The issues regarding knowledge and beliefs that correlated significantly with prompt help-seeking were 'considering the symptom as harmless'; thinking 'the earlier it was seen to the better' and the 'nature of the symptom'. The item 'considering the symptom as harmless' also impacted significantly on delayed HSB as did 'considering the symptom as temporary'. Thus, women's knowledge and beliefs about their breast symptom significantly impacted on their HSB. While valuable information about women's HSB was gleaned by the 'Women's help seeking for breast symptoms' questionnaire, further development was considered necessary to establish its validity and reliability. Thus, additional study of women's HSB is necessary amongst a larger sample of women to ascertain the extent of delay and the associated influencing factors. Finally,

studies from New Zealand, Iranian, Australian and Mexican perspectives are reviewed.

2.3.3 New Zealand, Iranian, Australian and Mexican perspectives

Further studies on HSB for cancer symptoms reiterated knowledge and beliefs to be key influencing factors. In a study of delayed help seeking for self-detected breast symptoms amongst New Zealand women (n=85) (Meechan et al., 2002), delayed help seeking was associated more with non lump breast symptoms such as breast pain, suggesting that women's symptom related knowledge impacted on their HSB.

An Iranian study (Montazeri, Ebrahimi, Mehrdad et al., 2003) on delayed presentation of symptoms amongst women newly diagnosed with breast cancer identified that women with a positive family history of breast cancer were more likely to delay. Thus, the absence or presence of a family history is important to note.

A more recent population–based telephone survey of Australian women (n=3,000) aged between 30-69 years (Jones, Gregory, Nehill et al., 2010), explored women's perceptions of breast cancer and their responses to potential symptoms experienced. The results were compared to a previous survey undertaken in 2003 (Villanueva, Jones et al., 2008). It was reported that 86% of women cited a breast lump as the most common presenting symptom of breast cancer. While the proportion of women unable to name any potential symptom decreased from one in ten (in 2003) to approximately 1 in 20, women aged 30-39 reported less likelihood of seeking help for a self discovered breast symptom than older women. Women were most likely to seek help for a breast lump, thickening of the breast or swelling in the armpit. Reasons for not seeking help included confidence that it was not breast cancer/ thinking that the

symptom was hormonal, menstrual or menopause related and linking it to pregnancy or breast feeding. Women with most education were the least likely to seek help, which according to the authors could be due to the disappearance of the symptom and women being confident in making a decision not to seek help. Findings are encouraging overall in that women reported increased awareness of the significance of a breast lump. However, the key finding that women who experience symptoms other than a lump are less likely to seek medical advice and when they do, it takes longer than one month to do so, is a cause for concern.

In their model of HSB for breast cancer symptoms Unger-Saldana and Infante-Castaneda, (2011) demonstrate the interplay between women's symptom related knowledge and beliefs and the internal dialogue (concerning symptoms and emotions), in relation to symptom interpretation and decision making following symptom discovery. Symptoms were frequently interpreted as "normal changes" and oftentimes participants tried to find logical explanations for their symptoms such as trauma to the breast. Unique to this sample was that the most common symptom to trigger help seeking was pain. Other triggers included symptom visibility and persistence.

This review of studies from an international perspective demonstrates that overall, women's knowledge and beliefs about breast cancer symptoms are paramount to their initial appraisal of a breast symptom and subsequent HSB both from an intended and actual perspective. Thus, highlighting the need to include knowledge and beliefs as key variables in the study of women's HSB for self discovered breast cancer symptoms.

Summary

In summary, literature pertaining to knowledge and beliefs and HSB (both intended and actual) in the context of general cancer symptoms, specific cancer symptoms and breast cancer symptoms, from an International perspective, was reviewed. Overall, the review highlighted the complex nature of the relationship between knowledge and beliefs and their impact on HSB.

In relation to cancer symptoms generally, the six studies reviewed highlighted that knowledge about symptoms (Sheikh and Ogden 1998, Nooijer et al., 2001a; Robb et al., 2009; Simon et al., 2010) impact on HSB. Beliefs in the contagiousness and fatalism of cancer were also apparent (Wong-Kim, et al., 2003; Kishore et al., 2007) as were beliefs in 'alternative help seeking behaviours' (Simon et al., 2010). Studies on knowledge and beliefs and HSB for specific cancer symptoms, emphasised the lack of knowledge and the vague nature of colo-rectal cancer symptoms (Pullyblank et al., 2002); oral cancer symptoms (Scott et al., 2006; Scott et al., 2007; Scott et al., 2008a; Scott et al., 2008b); ovarian cancer symptoms (Koldjeski et al., 2004) and lung cancer symptoms (Corner, 2006; Smith et al., 2011) was associated with delayed HSB.

Studies on potential and actual breast cancer symptoms, highlighted that symptom appraisal and interpretation of the symptom are closely linked and are influenced by women's knowledge of breast symptoms and the risks they associate with these symptoms which ultimately influence women's actual (Facione and Dodd 1995; Facione and Giancarlo, 1998) and intended HSB (Facione et al., 1997; Facione et al., 2002). In addition beliefs in the use of 'alternative help seeking behaviours', religiousness and fatalism were emphasised as being key to women's intended help

seeking behaviour (Facione et al., 1997; Facione et al., 2002). Cultural beliefs (Botoroff et al., 1998) and fatalistic beliefs (Thomas, 2004; Spurlock and Cullins, 2006) were highlighted to impact negatively on screening for breast symptoms. Conversely, although delay of three months or more was associated with more advanced stage of breast cancer, fatalistic beliefs did not impact on HSB amongst African American women with breast symptoms.

In both the United Kingdom and Ireland, the impact of knowledge and beliefs for actual (Burgess et al., 1998; Burgess et al., 2001; Nosarti et al., 2001; O'Mahony and Hegarty, 2009b) and potential (Bish at al., 2005; McMenamin et al., 2005; Burgess et al., 2008; Burgess et al., 2009; Linsell et al., 2009) breast cancer symptoms was reiterated. Similarly, knowledge surrounding actual (Meechan et al., 2002; Montazeri et al., 2003; Unger-Saldana and Infante-Castaneda, 2011) and potential breast symptoms (Jones et al., 2010) impacted on HSB, in a New Zealand, Iranian, Mexican and Australian context. The relevance of The Common-Sense Model of Self - Regulation (Leventhal et al., 1980; Leventhal et al., 1984; Leventhal et al., 2003) to the study of HSB for self discovered cancer symptoms was further reiterated (Grunfeld et al., 2003; Hunter et al., 2003; Bish at al., 2005; Scott et al., 2007; Burgess et al., 2008; Scott et al., 2008a; 2008b; Linsell et al., 2009).

To conclude, this chapter highlighted that cancer symptom discovery stimulates the cognitive process of symptom appraisal. Symptom appraisal involves symptom identification, interpretation and attribution. In the case of breast symptom discovery, identification and labelling of a symptom enables a woman to articulate the symptom identity. Therefore, for the purpose of the present study, knowledge of breast cancer presenting symptoms will be determined by questioning women on their symptom

identity and the breast changes they associate with breast cancer. In addition their knowledge of the presence or absence of a family history of breast cancer will be ascertained.

In tandem with symptom knowledge, are the woman's beliefs relating to the cause, time-line (duration), consequences, curability and attribution (outcome) of the symptom. In addition, cultural and fatalistic beliefs and beliefs in the use of 'alternative help seeking behaviours' influence women's cognitive representations of the symptom. It is apparent from the review that such beliefs act as mediators between knowledge and behaviour and oftentimes take precedence over symptom knowledge, thus, determining the final outcome of the appraisal process as in prompt or delayed HSB.

The theoretical underpinnings of the Common-Sense Model of Self-Regulation of Health and Illness (Leventhal et al., 2003) and its focus on the threats inherent in the illness representations was confirmed as a suitable framework to determine women's beliefs about their actual breast symptom. Questions focusing on the key dimensions of symptom cause, time-line, consequences, control/ curability and attribution will ascertain women's beliefs about their self discovered breast symptom and establish how these impacted on their actual HSB. In addition women will be asked to identify their use of 'alternative help seeking behaviours' following symptom discovery. The literature on emotional responses to symptom discovery and their influence on HSB will be reviewed in Chapter Three.

Chapter 3 Emotional Responses to Symptom discovery and their Influence on Help Seeking Behaviour (HSB) for Cancer Symptoms

Introduction

Emotional responses to the discovery of breast cancer symptoms have been the subject of many studies. Terminology differs within the literature to include such terms as ‘psychological factors’; ‘pycho-social factors’; ‘psychological distress’; ‘affective responses’; ‘emotional barriers’ and ‘psychological barriers’. In addition, researchers have operationalised these factors in a variety of different ways. It is apparent that discovery of a potential cancer related symptom generally provokes an emotional (affective) response. Studies on the emotional responses influencing HSB for self discovered cancer symptoms are reviewed in order to identify the various dimensions of this variable and their impact on HSB. Initially studies relating to the emotional responses following discovery of non breast cancer symptoms are reviewed. Studies of women with breast cancer symptoms are then reviewed commencing with studies of women with breast cancer diagnosis followed by a review of studies involving women with predominantly benign or unknown diagnoses at the time of data collection.

3.1 Emotional responses to non breast cancer symptoms and HSB

This section reviews studies on the emotional responses to non breast cancer symptoms and their influence on HSB. Sheikh and Ogden (1998) in the qualitative element of their mixed method study on the likelihood of seeking help for cancer symptoms, reported that participants (n=20) described cancer in terms of “fear, death and a challenge” and described reasons for not attending cancer screening

programmes such as “avoidance, fear and denial”. De Nooijer at al., (2003), studied the factors that motivate paying attention to cancer symptoms and help seeking for symptom discovery amongst a convenience sample (n=618) of asymptomatic Dutch adults. Findings highlighted the need to acknowledge and discuss the “psychological barriers” to help seeking, such as uncertainty about the seriousness of a symptom and worry about the impending diagnosis. Uncertainty surrounding the vague nature of symptoms was also highlighted in qualitative studies on delayed help seeking for lung cancer (Corner et al., 2006) and oral cancer (Scott et al., 2006) symptoms and a mixed method study on early symptom patterns for ovarian cancer (Koldjeski et al., 2003).

In Scott et al.’s (2007) qualitative study (n=57) (reviewed in Chapter Two) on the cognitive and emotional responses to the detection of potentially malignant oral symptoms, a minority of patients reported distress concerning symptoms. Generally, patients were unconcerned about their symptoms at the time of initial discovery and when present, concern was linked more to symptom interpretations rather than to treatments. However, the emotional response of some patients changed from initial unconcern to more concern and anxiety as symptoms persisted and they attributed the symptom to something more ‘serious’ prior to seeking help. Utilizing the same sample (n=57), Scott et al., (2008a) reported that the emotional responses of uncertainty and worry facilitated HSB for self discovered oral cancer symptoms. The quantitative aspect of this study (n=80) firstly investigated the level of emotional distress experienced on symptom discovery (utilizing the 5 itemed / 5 point emotional distress scale, Meechan et al., 2003) and secondly, the presence of competing life events (measured by the Social Readjustment Rating Scale i.e. a list of forty life events each with a weighted score from 11 to 100 Holmes et al., 1967) (Scott et al., 2008b). Overall, levels of symptom related emotional distress were found to be low (M =10.6;

SD = 4.60). The severity of life events in the delay period was found to be amongst the factors significantly associated with delayed HSB. These studies highlight the close relationship that exists between peoples' cognitive and emotional responses to potential oral cancer symptoms.

A recent population based survey assessing public awareness (n=2216) of cancer in Britain (Robb et al., 2009), reported that "worry about the outcome" was one of the barriers to help seeking mentioned by those in the sample (n=177) who had actually experienced a symptom in the three months prior to the study. This was reiterated in another British study on cancer awareness amongst ethnic minority groups (n=1500 men and women) where one of the barriers to help seeking most frequently endorsed was 'worry about what the doctor might find' and women endorsed more 'emotional barriers' (i.e. worry about the outcome; embarrassment; scared and the lack of confidence in talking about the symptom) to HSB than men (Waller, Robb, Stubbings et al., 2009). These studies demonstrate the impact of emotional responses following symptom discovery on subsequent help seeking. Studies relating to emotional responses to HSB and breast cancer symptoms will now be reviewed, commencing with women with a breast cancer diagnosis.

3.2 Emotional responses to symptom discovery and HSB for women with a breast cancer diagnosis

In the United Kingdom, the study by Burgess et al., (1998) (discussed in Chapter Two), was undertaken to determine who and what influences delayed presentation of breast cancer amongst women (n=185) already diagnosed with breast cancer. In relation to emotional response, women were asked whether the fear they felt on symptom discovery was 'marked to moderate' or 'mild to none'. It was found that

women's responses to the discovery of a breast symptom were related to the extent of delay and 13% (n=25) of women who attributed their symptom to cancer delayed for 12 weeks or more. Overall, those who delayed reported less fear on discovering the symptom (p= 0.05). In addition some of the emotional responses were related to the nature of the presenting symptom. Women whose symptom included a breast lump were significantly more likely to attribute it to a specific cause (p = 0.0001), significantly more likely to experience fear (p = 0.02) and to think about the symptom for a marked/moderate amount of time (p = 0.01) (Burgess et al., 1998). Thus, women's initial emotional response depended on the nature of the presenting symptom, highlighting the need for further education of women concerning non breast lump symptoms.

Burgess, Ramirez, Smith, and Richards (2000) sought to determine if adverse life events and mood disorders influenced delayed presentation of breast cancer. Women (n=158) were interviewed five months after receiving a diagnosis of invasive breast cancer (having presented with self discovered symptoms). The prevalence of adverse life events and difficulties were assessed using the Bedford College Life Events and Difficulties Schedule (LEDS) and psychiatric morbidity was assessed using the Structured Clinical Interview (SCID) and DSM-111-R diagnostic criteria. Findings showed no association between experiencing a life event or difficulty in the year preceding breast symptom discovery, and patient delay. Neither was patient delay related to prevalence of depression or anxiety during that time. The authors concluded that a better understanding of the risk factors for women's delayed presentation with breast cancer symptoms would inform effective interventions to reduce delay and improve survival for women diagnosed with breast cancer.

A Norwegian study (Tjemsland and Soreide, 2004) on a convenience sample (n=96) of women with stage one or two breast cancer sought to identify the oncological and emotional characteristics associated with patient delay. Emotional characteristics were determined using questions on psychological distress, coping style and emotional control (Beck et al., 1993). Psychological distress was assessed by the Montgomery Aasberg Depression rating Scale (MADRS) and Impact of Event Scale (IES). The extent to which patients suppress negative emotions was recorded using the Courtauld Emotional Control Scale (CEC) (Watson and Greer, 1983). Women who delayed for one month or more (n=29) were found to have a significantly higher emotional control score in comparison to non delayers (mean score on CEC = 54.5 vs 46.4; p = 0.003). In addition, delayers reported use of avoiding behaviours more so than non–delayers, although this did not reach statistical significance (p = 0.073).

Findings suggest that it is more the degree of control of symptom related anxiety, rather than the level of anxiety experienced that predicts hesitation before seeking help. Furthermore, it was also found that delay did not appear to have a negative impact on diagnosis. Therefore, the authors speculated that the increased emotional control demonstrated by some women (referred to as “wisdom of the body” as in “wait and see”, “don’t be anxious”, “calm down” p232) could have been the most suitable response, in this instance. However, these findings need to be interpreted with caution as delay in presentation of breast symptoms is not a response to be advocated generally. Nonetheless, this study offers some understanding of the mechanisms influencing women’s decisions to seek medical help when they experience breast symptoms and provides further insight into the emotional responses influencing women’s HSB.

Bradley (2005) undertook a study to ascertain the extent of delayed help seeking and worry relating to breast cancer symptoms, amongst a purposive sample of African American women (n=60; aged 24-75 years) who were diagnosed with breast cancer, in the Urban North Eastern part of the Unites States. The sample included women who were receiving or had completed breast cancer treatments, including radiation, chemotherapy and surgery. General health worry was measured by the Ware Health Perceptions Questionnaire (HPQ) subscale of health; worry/concern (Ware, 1976). Symptom related worry was measured by asking participants to rate their worry on first noticing the symptom and their worry on initial diagnosis from (1) 'not at all' to (10) 'a lot'.

It was found that the majority of women (n=52) sought help within four weeks. Amongst those who delayed, delay ranged from 4-15 weeks (n=5); 16-36 weeks (n=1) to more than 48 weeks (n=2). Regarding worry about health, 50% (n=30) of the group tended to worry somewhat about their health, 28% (n=17) worried a little and 22% (n=13) had moderately high levels of worry. Almost one third of the sample reported worry levels concerning their breast symptoms to be high and to be a motivator for help seeking. Another one third perceived worry as not helpful and the middle third had neutral views. This reiterates that moderate levels of worry are beneficial because they motivate women to seek information and engage in risk reducing behavious such as HSB. Further study to determine the worry levels of women who delay could be helpful to guide HCP's in addressing the issue. The emotional responses impacting on HSB for women with mixed or unknown diagnoses will now be reviewed.

3.3 Emotional responses to symptom discovery and HSB for women with mixed or unknown diagnoses

As far back as 1977, Magarey, Todd and Blizard carried out a study in New South Wales, Australia on the psycho-social factors influencing delay (and breast self examination) in women (n=90) with breast cancer symptoms. Women participated in video recorded interviews (at least one day prior to their breast biopsy) utilising open-ended questions to explore their fears and concerns about their breast symptoms and the forthcoming surgery. Women were also asked to complete the Speilberger (1968) Anxiety Inventory, Millimet's (1970) Manifest Anxiety-Defensiveness Scale and the Depression Scale of the Minnesota Multiphasic Personality Inventory (Dahlstrom et al., 1972). Thirteen women in the sample delayed for more than four months. Factors significantly related to delay were ego-defences (denial and suppression) anxiety and depression. This early study highlighted the need for HCPs to be attentive to the presence of such "unconscious" psychological factors amongst women with self discovered breast symptoms.

In the United States, an initial literature review and two subsequent qualitative studies highlighted that fear and anxiety were issues for women around help seeking for self discovered breast cancer symptoms in samples with both benign and cancer diagnoses (Facione 1993, Facione and Dodd, 1995, Facione and Giancarlo 1998). Facione et al., (1997) concluded that fear was a stimulus to intended help seeking and lack of concern and anger were related to intentions to delay. While the concept of 'affective responses' to both the symptom and the expected outcome is depicted in the Judgement to Delay Model (J-Delay), its impact on intentions to seek help was not tested and was highlighted as an area in need of further study (Facione et al., 2002). However, the difficulty of accurately measuring affective responses in a hypothetical

situation is emphasised, thus exploration of the emotional responses of women who have been through the experience of finding a breast symptom is necessary.

Nosarti et al., (2000) sought to identify factors associated with delay in presentation amongst women (n= 692) attending a breast clinic for evaluation of breast symptoms (already reviewed in Chapters Two and Three). The aim of the study was to isolate the risk factors for women who tend to have long delays (> 27days) and who may be targeted for future interventions. Data were collected by semi structured interview, general health questionnaire (GHQ-12) (Goldberg and Williams, 1988) (used to measure psychiatric morbidity) and the General Health Awareness questionnaire (designed and piloted for this study). The median delay was 13 days, 35% (n=242) of women delayed for four weeks or more, 17% (n=117) delayed for over three months. Women who turned out to have cancer (12.6%; n=87) delayed less but not significantly so. Psychological distress (indexed as an expression of fear of cancer and by GHQ scores) was linked with longer delays. In addition, those who were least anxious about symptoms also delayed. Logistic regression indicated that women who were diagnosed with breast cancer were more likely to delay due to fear compared to those with benign diagnosis. Similar to previous findings (Burgess et al., 1998), women with a breast lump had less patient and system delay. The authors concluded that women be encouraged to view breast symptoms as urgent but not necessarily serious and should be prompted to present to their doctor as soon as possible. It was highlighted that HCPs need to be alert to those who are hesitant to present and should act promptly in such circumstances.

The emotional response to symptom discovery and its relationship to delayed help seeking, was one of the variables examined in an Australian study (Meechan et al.,

2003) of women (n = 85) referred to a specialist breast clinic, for evaluation of breast symptoms. Using the symptom emotional distress scale, women were asked to rate their emotional response to symptom discovery as in the extent that they felt "afraid, anxious, distressed and scared", on a Likert scale from 'very slightly' (1) to 'very much' (5). It was found that 14% (n=11) of women waited for three months or more before seeking help and women with higher levels of emotional response delayed less ($r = -0.29$, $p = 0.01$). Lower initial symptom distress was found to be one of the factors most predictive of delay ($p = 0.001$).

A Japanese study (Iwamitsu, Shimoda, Abe et al., 2005) examined the influence of anxiety and emotional suppression on psychological distress in a sample of 21 patients with breast cancer and 72 patients with benign breast tumour, after they were told the diagnosis. It was found that patients diagnosed with breast cancer who suppressed emotions and had chronically high levels of anxiety, reported more emotional distress both before and after the diagnosis. In addition, (and of particular relevance to the current review) highly anxious patients with benign tumours felt more psychological distress at their first visit in comparison to their second visit, (when they were told the diagnosis). This suggests that women with breast symptoms are prone to psychological distress up to the time of symptom diagnosis.

Using the Health Belef Model (HBM) (Becker 1974 and Rosenstock, 1990) Friedman, Kalidas, Elledge et al., (2006) carried out a cross sectional survey of women (n=99) with breast symptoms who were attending a breast clinic in a county general hospital in Houston, Texas. The purpose of the study was to examine the relationships between delay in help seeking and selected variables from the HBM and additional variables one of which included psychosocial factors. Data were collected

by a self completed researcher developed questionnaire prior to women being seen by the consultant. A “symptom distress” score was computed from women’s responses to questions on an adaptation of the symptom emotional distress scale (Meechan et al., 2003).

The majority of participants were Hispanic (55%; n= 57) ranging in age from 18-81 (Mean 44.3; SD 14.0). Mean delay time in seeking help was 9 months with 45% (n = 47) waiting for three months or more before seeking help. Women’s initial emotional response to finding a breast symptom was not significantly related to delay. However, ‘worry that it might be cancer’ (39%; n = 40), ‘fear of breast loss’ (15%; n =16), ‘worry about cancer treatment’ (13%; n = 13) and ‘not wanting to think about it’ (10%; n =10) were amongst the most frequently cited reasons for waiting to seek help. In addition, women who delayed were more likely to identify denial (i.e. ‘not wanting to think about the breast symptom(s)’) as a barrier to seeking help ($p = 0.022$).

This symptom emotional distress scale was subsequently adapted by O’Mahony and Hegarty (2009b) in their study on help seeking among a sample (n=99) of Irish women, with the addition of the items ‘uncertainty’, ‘depression’ and ‘anger’. Ten per cent of women (n=12) reported delayed help seeking of three months or more and an additional 14.1% (n=14) delayed for over one to three months, following symptom discovery. The strongest feelings reported by women in the sample were those of being ‘anxious’, ‘afraid’, ‘scared’ and ‘unsure’. Fifteen per cent of women (n=14) indicated feeling ‘distressed’ and feelings of ‘depression’ and ‘anger’ were reported by a minority of women. While no significant relationship was found between overall symptom distress and HSB, a strong negative correlation was observed between the item being anxious and delay ($r = -0.31$; $p = 0.003$). In addition, one of the most

significant barriers to prompt HSB was 'deciding to wait a while before making the appointment'. An earlier Irish study on the views and perceptions of women (n=199) who attended symptomatic breast clinics, (Kennedy, Quin and Murphy-Lawless, 2000) reported that the most important reason for waiting two weeks or longer before seeking help was avoidance due to fear. This was reiterated in a recent grounded theory study of Mexican women's (n=17) HSB on breast symptom discovery where both fear and denial caused some women to delay (Unger-Saldana and Infante-Castanda, 2011). However, as identified in other studies (Facione 1997; Bradley, 2005; Scott et al., 2008a) fear also accelerated help seeking. These findings reiterate that emotional response to breast symptom discovery can either stimulate or deter prompt help seeking.

Summary

Twenty seven studies were reviewed on the influence of the emotional responses to symptom discovery, on HSB for cancer symptoms. Emotional responses were referred to as 'psycho-social' factors in one study (Margery et al., 1977) and otherwise related to the variables "fear", "anxiety" "worry", "distress" and "uncertainty". Studies on non breast cancer symptoms (Sheikh and Ogden, 1998; deNooijer et al., 2003, Koldjeski et al., 2004; Corner et al., 2006; Scott et al., 2006; Scott et al., 2007; Scott et al., 2008a; Scott et al., 2008b; Robb et al., 2009; Waller et al., 2009); and breast cancer symptoms (Margery et al., 1977; Facione, 1993; Facione and Dodd, 1995; Facione et al., 1997; Burgess et al., 1998; Facione and Giancarlo, 1998; Burgess et al., 2000; Kennedy et al., 2000; Nosarti et al., 2000; Facione et al., 2002, Meechan et al., 2003; Tjemsland and Soreide, 2004; Bradley 2005; Iwamitsu et al., 2005; Friedman et al., 2006; O'Mahony and Hegarty, 2009b; Unger-Saldana and Infante-Castanda, 2011) were reviewed. Studies were predominantly quantitative in nature with the

exception of eight qualitative studies (Facione and Dodd, 1995; Burgess et al., 1998; Facione and Giancarlo, 1998; Corner et al., 2006; Scott et al., 2006; Scott et al., 2007; Scott et al 2008a; Unger-Saldana and Infante-Castanda, 2011), one mixed method study (Koldjeski et al., 2004) and one literature review (Facione, 1993). The review was structured around the influence of emotional responses on HSB for (i) non breast cancer symptoms (n=10) (ii) women with breast cancer diagnosis (n=4) and (iii) women with mixed or unknown diagnoses (n=10). The majority of studies focused on actual help seeking behaviour with the exception of two which were on women's help seeking intentions (Facione et al 1997; Facione et al., 2002).

Overall, the review highlights that individuals' emotional responses to threatening situations such as potential cancer symptom discovery, is complex. Regardless of the outcome, symptom discovery evokes an emotional response that can impact positively or negatively on HSB. Responses have been studied from a hypothetical and actual symptom discovery perspective and vary from initial unconcern to concern, uncertainty, fear/scared, worry, anxiety, distress/ psychological distress/ symptom distress to depression. Another complexity is the issue of coping, where defence mechanisms of avoidance and denial are utilized, oftentimes to the detriment of appropriate HSB. It is difficult to strike a balance between unnecessary worry and concern about self discovered cancer symptom. The review highlights the need to further explore women's emotional responses to actual breast symptom discovery and how they influence their HSB.

Various instruments have been used to measure emotional responses to cancer symptoms throughout the studies reviewed. It is apparent that women's emotional responses to cancer symptom are best captured through study of HSB after the event

has occurred. It is only then that women can reflect back and identify how they responded to their symptom discovery. This response can then be correlated by the researcher to their HSB. The Symptom Emotional Distress scale (Meechan et al.,2003) utilised in the study of oral cancer symptoms (Scott et al., 2008b) and breast cancer symptoms (Friedman et al.,2006 and O'Mahony and Hegarty, 2009b), provides a concise user friendly means of measuring the key dimensions of women's emotional responses to symptom discovery. These responses have been highlighted in the literature to include being afraid (fear), anxious (anxiety), distressed, scared, depressed, angry, unsure/uncertain. This scale also reflects the three dimensions of the emotional response to a health threat (distress, fear, anger) as depicted in the Common-Sense Model of Self-Regulation (Leventhal, Leventhal and Cameron (2003) which was identified as a suitable framework (Figure 1.2) to guide exploration of women's knowledge and beliefs regarding their breast symptom and how these impact on their HSB. Thus, reiterating the appropriateness of both the Common-Sense Model of Self-Regulation and the 'Emotional Distress Scale' for use in the current study.

Chapter 4 Socio-demographic Factors, Social Factors, Health Seeking Habits, Health Service System Factors and their Influence on HSB for cancer symptoms

Introduction

The 'help seeking behaviour and influencing factors' (Figure 1.5) framework (Facione et al., 2002; Leventhal et al., 2003) was identified in Chapter One as a preliminary framework to guide the present study on help seeking behaviour for self discovered breast symptoms. Outlined in this framework are the key variables proposed to influence women's HSB following self discovery of a breast symptom. These variables include 'socio-demographics', 'social factors', 'health seeking habits', and 'health service system utilisation' factors. This chapter presents the findings related to these key variables from within the literature reviewed in previous chapters and additional relevant studies (n=6).

4.1 Socio-demographic factors and HSB

Review of the literature on the influence of socio-demographic factors on HSB for self discovered breast symptoms, revealed that both older age (Burgess et al., 2000; Bish et al., 2005; Burgess et al., 2008; MacLeod, Mitchell, Burgess, et al., 2009) and younger age (Friedman et al., 2006); relationship status (single/divorced/widowed as opposed to married or partnered) (Facione and Dodd, 1997; Montazeri et al., 2003;); having less income (Facione and Dodd, 1997; Facione et al., 2002; Gulatte et al., 2010); general economic status (poverty)(Facione and Giancarlo, 1998; Scott et al., 2008a); lack of insurance benefits (Facione and Giancarlo, 1998; Facione et al., 2002) and lower education level (Facione et al., 2002; Montazeri et al., 2003; Friedman et al., 2006; MacLeod et al., 2009; Waller et al., 2009) were associated with delay. In

addition issues such as socio-economic status and ethnicity (Facione et al., 2002; Bish et al., 2005) have been associated with delayed HSB.

Conversely, O' Mahony and Hegarty (2009b) found that out of a sample of 99 women, education impacted on HSB in that a higher percentage of delayers (n=26) had higher educational qualification (i.e. had attended university (n=12; 46%) or attained a professional qualification (n= 4; 15%). Similarly, Jones et al., (2010) reported that in a population–based survey of Australian women's (n=3000; 30-69 years) perceptions of breast cancer and their responses to potential cancer symptoms already experienced (n=750), those with most education were the least likely to seek help. As suggested by the authors, this could be due to women being confident in making the decision to postpone having the symptom investigated. Therefore, age, nationality, relationship status, occupation, medical insurance and educational level, are important dimensions of socio-demographic factors for consideration in HSB for self discovered breast symptoms.

4.2 Social factors and HSB

Competing social roles (e.g. family commitments and work commitments) were identified as barriers to help seeking (Facione 1993; Lauver et al, 1995; Facione et al., 1997; Facione and Giancarlo, 1998; Burgess et al., 2001; Facione et al., 2002; Friedman et al., 2006; O'Mahony and Hegarty, 2009b). In addition, the J-Delay model (Facione et al., 2002) included the concept "Relationship Constraints" which incorporated the dimensions of 'role obligations, cultural expectancies and family dynamics' (measured by the nine item CONSTRAINT scale) (Facione et al., 1997; Facione and Giancarlo, 1998; Facione and Giancarlo and Chan, 2000). In testing the J-Delay model, Facione et al., (2002) found that perceived constraints related to role

obligations were rare. Constraints to help seeking concerning roles as spouse/partner, child or elder care provider or employee, were disregarded by 60% (n = 419) of women. However, these items were endorsed significantly more often by women who were likely to delay as opposed to those not likely to delay ($t = 6.83$, $P < 0.001$). This difference was more obvious for constraints related to the 'employee role' (22.2%; n=155) compared to those relating to 'spouse/partner' (14.7%; n=102) or 'being child/ elder care provider' (16.6%; n=116). Other studies identified practical issues ('being too busy'; 'having other things to worry about') as barriers to hypothetical (Robb et al., 2009; Waller at al., 2009) and actual help seeking (Simon et al., 2010) for cancer symptoms generally.

Disclosure of symptoms to another person or somebody close was seen to facilitate help seeking (Botoroff, 1998; Burgess et al., 1998; Burgess et al., 2000; De Nooijer et al., 2001a; Bish et al 2005; Burgess et al., 2008; MacLeod et al., 2009; Gulatte et al., 2010; O'Mahony and Hegarty, 2009b). Marital status has also been associated with delayed HSB. Burgess at al., (1998) reported that immediate disclosure of a symptom to another person depended on whether women lived with a partner as opposed to being single/ married or divorced. Similarly, risk of longer delay was found amongst widowed or divorced Iranian women (Montazeri et al., 2003). In some instances, the "sanctioning" of help seeking by family and friends was seen to justify help seeking (Smith et al., 2005). In addition, "moral obligation" as in the extent that one considers it an obligation to themselves and their family to seek help for cancer symptoms correlated with intentions to seek help (DeNooijer et al., 2003).

Scott et al., (2008a) identified advice from significant others as a facilitator for help seeking for self discovered oral cancer symptoms. Smith et al., (2011) found that

delayed HSB was associated with living alone (n=57) amongst a sample of patients with lung cancer symptoms (n=360), who waited for fourteen weeks or more (n=171) before visiting a HCP, suggesting that "co-habitees" noticed symptoms and encouraged HSB. The importance of social support was further reiterated by Mexican women in a recent grounded theory study on HSB (Unger-Saldana and Infante-Castanda, 2011). Thus, social factors are an important aspect of HSB. Key issues to be recorded in terms of actual HSB include women's living arrangements (i.e. alone or otherwise, recorded with socio-demographic data in the current study), social constraints (family/ work commitments) and disclosure of symptoms to another person.

4.3 Health Seeking Habits and HSB

The health seeking habits including breast self examination (BSE) and mammography screening and use of alternative/ complimentary/therapies and self care practices have been studied in relation to HSB. An early Australian study on the psycho-social factors influencing delay and breast self examination in women (n=90) with breast cancer symptoms (Magarey et al., 1977), found that women who did not practice BSE were more likely to have a malignant outcome. Facione (1993) highlighted that "habits and prior learning" impacted on women's HSB for self discovered breast symptoms. Later, Facione et al., (1997) utilized the researcher developed HABIT scale to assess the relationship between 'health care utilization habits' ('visiting a health care provider for general illness', 'cancer screening practises' and 'self care treatment with home remedies') and intentions to seek help amongst a sample (n=352) of African American women. A significant relationship was found between having stronger healthcare utilisation habits and intentions to seek help ($p = 0.001$). The variable "self care habits" was later included in the J Delay Model (Figure 1.1) as

a dimension of “Habits of Health Service Utilisation” (HHSU) (Facione et al., 2002) (discussed below). However, for the purpose of this study on HSB for actual symptoms “self-care habits” were operationalised as women’s beliefs in “alternative help seeking behaviours” (already addressed in Chapter 2).

“Habit hierarchies” including cancer screening, where women were asked about BSE and mammography to determine their adherence to these practices, were examined in a study by Facione (1999) relating to access to services (reported in more detail later). Subsequently, the Habits of Health Services Utilisation (HHSU) scale, was developed (from the HABIT scale). The scale measured habits in relation to visits to a HCP for health promotion (cancer screening i.e. mammography and Pap screening) and illness purposes and was utilised in the study to test the J-Delay Model (n=699)(Facione et al., 2002). It was found that women who were likely to delay (23.7% : n=166) scored significantly lower on the scale than women who were not likely to delay ($p < 0.001$). A study on patient delay amongst women attending a London clinic for actual breast symptoms (Nosarti et al., 2000) reported that women who delayed and were diagnosed with breast cancer, were less likely to have had a screening mammogram.

In their study on delayed HSB among New Zealand women (n=85), Meechan et al., (2002, 2003) reported no difference in delay between those who performed BSE and those who did not. However, regular BSE was performed by 62% (n=53) of participants and facilitated breast symptom discovery for 22% (n=18) of women. A trend ($p=0.07$) was noted for women whose presenting symptom was pain to have a longer delay time compared to women who discovered the symptom by chance or through BSE (Meechan et al., 2002, 2003).

Linsell et al., (2008) examined confidence in detecting breast changes amongst a sample (n=712) of older British women who were asked how often they examined their breasts, and how confident they were in noticing how their breasts normally look and feel. Responses ranged from weekly (n=193; 27.3%), monthly (n=273; 38.6%), six monthly (n= 104; 14.7%) to rarely or never (137; 19.4%). Almost one third of women (n=220; 31.1%) indicated that they were not confident in detecting a breast change with 15% (n=108) not confident about how their breasts normally felt. Apart from education, there was no association between confidence in detecting breast changes and socio-demographics. Interestingly, women who were more highly educated were less likely to check their breasts when compared to women with no education. However, this finding was significant only for the most highly educated group (p= 0.024).

Similarly, a population based study (Montazeri et al., 2008) investigated the self reported practice of breast self examination (BSE) (and breast cancer knowledge) amongst a sample (n= 1402) of Iranian women. Two questions focusing on BSE (from within a researcher developed fifteen item questionnaire) asked women to indicate how often they examined their breast and to identify reasons for not doing so. Findings reported that 37% (n=520) practiced BSE with only 17% doing so on a regular basis. The most common reason for 'not doing BSE' was 'not knowing how' which was indicated by 64% of women. Performance of BSE was significantly related to age, marital status, education, knowledge of breast cancer and knowledge about breast cancer screening programmes. Overall, the results suggested that the likelihood of BSE performance was associated with women's age (40-59), being married, having higher education and being more informed about breast cancer generally. The authors advocate performance of BSE as a preventive measure for early detection of breast

cancer in developing countries, thus highlighting its potential for prompt HSB in the event of symptom discovery

In a previous study, O'Mahony and Hegarty (2009b) included the concept "health seeking habits" in their adaptation of Meechan et al.'s (2002, 2003) questionnaire titled "Women's help seeking for breast symptoms." Dimensions of the concept assessed in the questionnaire were: frequency of visits to the GP over the past three years and frequency of BSE and mammography. No significant relationships were found between women's health seeking habits and HSB. However, findings revealed that the majority of women (71.7% n =71) indicated that they had attended their G.P at least once a year (in the past three years), 65.7% (n=65) of women regularly performed BSE, and 82.8% (n=82) reported never having had a mammogram. Low mammography rates could be explained by women's age which ranged from 18-75 years (mean age = 40; SD =11.84) and the fact that at the time of data collection the national breast screening programme, providing free breast screening to all women aged between 50-64 years, was not expanded to all of the Health Service Executive Regions within the Republic of Ireland.

While current breast health promotion strategies advocate breast awareness as opposed to BSE, it is argued that if women are to be breast aware they need to be encouraged to look at and touch their breasts (Linsell et al., 2008). Therefore, assessment of women's health seeking habits in relation to frequency of BSE and mammography is relevant in the study of HSB for self discovered breast symptoms.

4.4 Health Services System Utilisation Factors and HSB

Access to health care: cost, convenience, relationship with HCP

A significant lack of research directly addressing women's actual or perceived access to health care for self discovered breast cancer symptoms was identified by Facione (1993). Lack of knowledge on how to access the system and inability to get an appointment (Lauver et al., 1995), were later recognised as barriers to help seeking amongst a sample of women (n = 138) in Wisconsin, USA. Subsequently, Facione et al's (1997) study used a researcher developed fourteen item scale to measure women's perceived access to healthcare services (ACCESS). The scale addressed issues relating to health care facilities i.e. 'convenience of location', 'cost of health care', 'the nature of the patient/provider relationship', 'characteristics of the facility' and the 'availability of health care insurance'. Help seeking intention was found to be positively and significantly related to women's perceptions of health care access ($r = 0.49$, $p < 0.01$). Facione and Giancarlo's (1998) study on women's narratives surrounding breast symptom discovery and cancer diagnosis highlighted that poverty was an inhibiting factor for help seeking among all participants. One woman decided not to have a symptom evaluated "because her insurance benefits were not good". Another Latina woman from Guatemala, reported how she refused to take the phone call from the physician who was trying to report her breast cancer diagnosis to her, because she had no money for health care.

Already alluded to, within a subset (n=838) of a multicultural sample from a large cross sectional study (Facione and Dodd, 1995), Facione (1999) reported on the interconnections between 'facilitating conditions' and 'habit hierarchies'. Facilitating conditions referred to the constructs 'accessibility and acceptability' and included the dimensions of 'perceived access', 'economic constraints' and 'expectations of

prejudice' (discussed later). 'Habit hierarchies' focused on 'health service utilisation' and 'cancer screening habits' (i.e. mammography and BSE).

Instruments included 'The Perceived Access to Health Services' (PAHS) scale, a four-point Likert-style scale addressing cost, convenience and the existence of a relationship with a Health Care Provider (HCP). 'The Habits of Health Services Utilisation' (HHSU) (already described) measured the likelihood of using healthcare services. Women were also asked about the frequency of mammography and breast self examination. Finally, economic accessibility was determined by questioning women on annual family income, availability of money to spend on healthcare and availability of private health insurance.

Women generally perceived themselves to have good access to health care and those aged 40 years and older had significantly higher PAHS scores than younger women ($p<0.001$). Participation in screening for cancer depended on their previous experiences of health care delivery and economic access to services. Participation in mammography screening and perceived access was partly related to women's perception of prejudicial treatment (discussed later). It was suggested that decreased BSE behaviour could have been influenced by women's ability to pay for possible diagnosis and treatment of breast cancer. The study highlighted that facilitating conditions (i.e. perceived access to health care; economic constraints and expectations of prejudice) and habits of heath care use are important variables in predicting HSB. These issues were included in the evolving model predicting HSB for self discovered cancer symptoms (Facione et al., 1999, p. 690).

Subsequently, 'Health Service System Variables' detailed in the J-Delay Model (Facione et al., 2002) addressed (among others) the dimensions of 'perceived access

to health care' (convenience) ;'economic constraints' (cost); the 'existence of a provider relationship' and 'expectations of prejudice'. In the study testing the J delay Model (n=699) (Facione et al., 2002) it was reiterated that women generally reported high perceived access to health care services with less than 10% perceiving lack of access. However, women who were likely to delay had significantly lower PAHS scores than women who were not likely to delay ($p< 0.001$). Approximately 50% of the sample reported personal experiences of prejudice in health care which increased the likelihood of delay amongst both Latino ($p< 0.001$) and black women ($p< 0.001$).

Later, Friedman et al., (2006) found that cost was a significant barrier to help seeking for women (n = 99) in Houston, Texas who had self discovered breast cancer symptoms, despite the fact that the cost of their medical care was based on an assessment of their ability to pay for it. However, as suggested by the authors women could have perceived costs in terms of the indirect expenses associated with help seeking. More recently, Unger-Saldana and Infante-Castanda's (2011) identified that lack of accessibility to services impacted on delayed HSB amongst uninsured women (n = 17) in Mexico City. Therefore, costs associated with access to health care is a variable worthy of further study among women seeking help for self discovered breast symptoms.

In relation to the HCP visit, "feelings about the provider visit" was one of the narratives in Facione and Giancarlo's (1998) study. While some women reported having comfortable relationships with their HCP, others reported having had negative experiences where providers were "insensitive or rushed" (p. 436). Thus, women would be hesitant to report breast symptoms during a routine health visit due to lack of time. Dissatisfaction with the health care system in the United States was

highlighted (Facione, et al., 2000). Unger-Saldana and Infante-Castanda's (2011) also found that substandard quality health care was one of the issues most associated with delayed diagnosis amongst uninsured women in Mexico City.

Provider issues such as having a female HCP and preserving modesty impacted on help seeking intentions among some Chinese American women (Facione et al., 2000). Similarly, preference for a female consultant and having had a recent visit to the GP were associated with longer delays in HSB amongst a sample of women in the UK (Nosarti et al., 2000). Low mammography and BSE rates were associated with having a male practitioner and the breast being touched by a stranger, in a study on breast cancer screening amongst Asian American women (Wu, et al., 2006). Not knowing a gynaecologist for out-patient care and not attending health check ups for five years (Arndt et al., 2002) militated against help seeking in a German sample of women. Additionally, "difficulty in making an appointment" was one of most frequently cited reasons for delayed help seeking in a sample of women from Houston Texas (Friedman et al., 2006) and among participants in a recent British population based survey on general cancer awareness (Robb et al., 2009). In addition "not wanting to waste the doctor's time" was also mentioned as a barrier to help seeking, (Robb et al., 2009). The fear of being labelled as "time wasters" was also highlighted as being a reason for delay in a synthesis of qualitative studies (n=32) on patients' help seeking experiences and delay in cancer diagnosis (Smith et al., 2005). Utilisation of services have also been linked to HSB for oral cancer symptoms where the "presence of another reason to visit the GP" facilitated help seeking (Scott et al., 2008b). Thus, women's relationship with their HCP (GP) is an indication of their access to and overall utilisation of health services.

Perceived experiences of prejudice

As already mentioned, personal experiences of prejudice in health care were reported amongst almost 50% of women (n-699) in the study testing the J-Delay model (Facione et al., 2002). Using data (n=838) from a previous study (Facione, 1999) perceived prejudice in relation to healthcare and preventive health protective behaviours were reported by Facione and Facione (2007). These behaviours focused on adherence to recommended cancer screening practices (BSE, clinical breast examination (CBE), mammography and Papanicolaou smear screening (Pap).

Perceptions of having experienced prejudice were measured by a researcher developed (Facione, 1999) four point Likert scale addressing the acceptability of access in relation to age, income, sexual orientation and race. This scale consisted of two subscales one five item scale measuring general perceptions of prejudice (GPP) in health care delivery. The other five item scale measured women's perceived experience of prejudice (PEP) in delivery of health care (Facione, 1999).

It was found that general perceptions of prejudice (GPP) were highest amongst women who were white, English speaking, born in the USA and with higher income. In addition, education levels impacted on GPP. At each level of education (grade school, high school, college, graduate school), GPP scores were significantly higher. In addition, significantly higher scores of GPP were noted for women who were lesbian and bisexual as opposed to heterosexual women ($p<0.001$). In addition, PEP were higher in lesbian and bisexual women and those with graduate level education. Highest PEP score was amongst black women followed by Whites and Hispanics (Facione and Facione, 2007).

Women's personal experience of prejudice (PEP) in health care delivery was significantly related to perceived access to health care services, habits of health care utilisation and three of the four recommended cancer screening behaviours studied (i.e. clinical breast examination (CBE), mammography and cervical screening) all of which required access to a HCP. Based on these findings, the authors recommended that examination of perceived personal experience of prejudice in health care should be included in future studies on women's healthcare utilization habits and health protective behaviours. Furthermore, as already highlighted in Chapter Two, the experience of discrimination within the community was also reported by some women following cancer diagnosis (Wong-Kim et al., 2003; Kishore et al., 2007). These experiences cannot be helpful to women in the event of symptom discovery. Thus, the issue of prejudice and its effects on women's help seeking behaviours for self discovered breast symptoms was considered worthy of further exploration in the current study.

Summary

The literature regarding socio-demographics, social factors, health seeking habits and health service system utilisation factors in relation to HSB for self discovered breast symptoms, was reviewed. In total forty nine articles were included: three literature reviews (Facione 1993; Bish et al., 2005; Macleod et al., 2009); thirteen qualitative studies and thirty three quantitative studies. The key dimensions of the variables pertinent to the current study of actual help seeking behaviour for self discovered breast symptoms were identified as follows: socio-demographics (age, nationality, relationship status, occupation; health insurance/medical card and education level); social factors (living arrangements (recorded with socio-demographic factors), role obligations and disclosure of symptoms); health seeking habits (BSE and

mammography) and health service system utilisation (perceived access to health care i.e. cost, convenience, relationship with HCP and personal experience of prejudice). These variables and their dimensions are outlined in the 'Help Seeking Behaviour and Associated Factors' conceptual framework (Figure 4.1), used to guide the current study. The overall conclusion to the literature review will now be presented.

Conclusion

The introduction and background to the literature review highlighted that breast cancer is a major public health problem globally. In Ireland, an average of 3,095 cases is reported annually with approximately 947 deaths (Donnelly et al., 2009). Early diagnosis of breast cancer is linked to more favourable outcomes and longer survival for women (Richards et al 1999a, Richards 2009a; Gulatte et al., 2010; Jenner et al., 2011). However Ireland's breast cancer mortality rate remains above that of the European Union (Verdecchia et al., 2007; DOH&C, 2010).

It has been documented that women themselves detect most breast symptoms (Arndt et al, 2002; Facione et al, 2002; Richards 2009b). Yet, despite the association between delay and survival, a considerable number of women wait for three months or longer before presenting to a HCP with a breast symptom (Burgess et al., 1998; Nosarti et al., 2001; Burgess et al., 2001; O'Mahony, 2001; Arndt et al., 2002; Meechan et al, 2002; O'Mahony and Hegarty, 2009b). Moreover, delay has been studied in relation to both asymptomatic and symptomatic situations. Compounding the confusion is the lack of consensus on what constitutes delay within the literature, although "a wait of three months or more" (Pack and Gallo, 1938) is generally taken to be the definition of "undue delay". Regardless, current health promoting strategies and initiatives are advocating early diagnosis and treatment for all cancers. In relation to breast cancer, this is dependent on prompt presentation to a HCP by women who self discover breast symptoms. Since the majority of symptoms are detected by women themselves, and in view of Ireland's lower survival rates, a study to measure the extent of delay and the factors influencing women's help seeking behaviour in an Irish context is timely. Thus, an initial review of the literature on the concept of "help seeking" was presented.

Chapter One provided an overview of current literature on help seeking in order to delineate how the concept "help seeking" and related concepts are used and to identify an operational definition for the term help seeking. Help seeking was seen to involve contact with a HCP and defined as "a response to health changes and part of the broader process of health seeking behaviour" (O'Mahony and Hegarty, 2009b, E.182). A review of the theoretical literature on help seeking for breast symptoms included the Judgment to Delay Model (Facione et al., 2002); a framework on delayed presentation of breast symptoms (Bish et al., 2005) and a model to promote prompt help seeking (Burgess et al., 2008). In addition, the Common-Sense Model of Self-Regulation (Leventhal et al., 1980; Leventhal et al., 1984; Leventhal et al., 2003) (utilised in the development of these frameworks by Bish et al., 2005; Burgess et al., 2008) was reviewed due to its focus on illness representations for actual health threats such as breast symptoms. In view of the need for more theoretically driven research on HSB (Scott and Walter, 2010), the researcher concluded that the J-Delay Model (Facione et al's 2002) while focusing on help seeking intentions and the likelihood to delay HSB, provides an holistic and detailed framework outlining the key issues associated with delayed HSB that could be adapted to explore HSB in the event of actual symptom discovery. In addition, Leventhal et al's (2003) Common-Sense Model of Self-Regulation was deemed relevant due to its focus on illness representations inherent in the occurrence of symptoms/ threats. A preliminary model to guide the study on the HSB of women in an Irish Setting and the associated influencing factors was presented (Figure 1.1).

In Chapter Two, literature on knowledge and beliefs and their influence on HSB (both intended and actual) in the context of general cancer symptoms, specific cancer symptoms and breast cancer symptoms, was reviewed, from an international

perspective. The complex nature of the relationship between knowledge, beliefs and their impact on HSB for potential cancer symptoms was highlighted. It was apparent that symptom discovery stimulates the cognitive process of symptom appraisal involving symptom identification, interpretation and attribution. These are dependent on an individual's knowledge about the presenting symptoms of breast cancer and the associated breast changes. Knowledge of the presence or absence of a family history of breast cancer was also deemed to be important. In addition, beliefs regarding the "illness representations" (i.e. cause, time-line (duration), consequences and curability of the symptom) were seen to impact on symptom interpretation and attribution. Simultaneously, individuals' cultural beliefs, beliefs in fatalism and in the use of 'alternative help seeking behaviours' also impact on their symptom appraisal. It became apparent that beliefs act as mediators between knowledge and behaviour and oftentimes take precedence over symptom knowledge thus, determining the final outcome of the appraisal process for potential cancer symptoms i.e. prompt or delayed HSB. The suitability of the Common-Sense Model of Self-Regulation of Health and Illness (Leventhal et al., 2003) and its focus on the threats inherent in illness representations was reiterated as an appropriate framework to determine women's knowledge and beliefs about their actual breast symptom.

Individuals' emotional responses to threatening situations, such as potential cancer symptom discovery, were discussed in Chapter Three. Studies were reviewed from a general cancer and specific cancer (oral, lung and breast cancer perspective). It was highlighted that regardless of the final outcome, symptom discovery evokes an emotional response that can impact positively or negatively on HSB. Responses have been studied from a hypothetical and actual symptom discovery perspective and vary from initial unconcern to concern, uncertainty, fear/scared, worry, anxiety, distress/

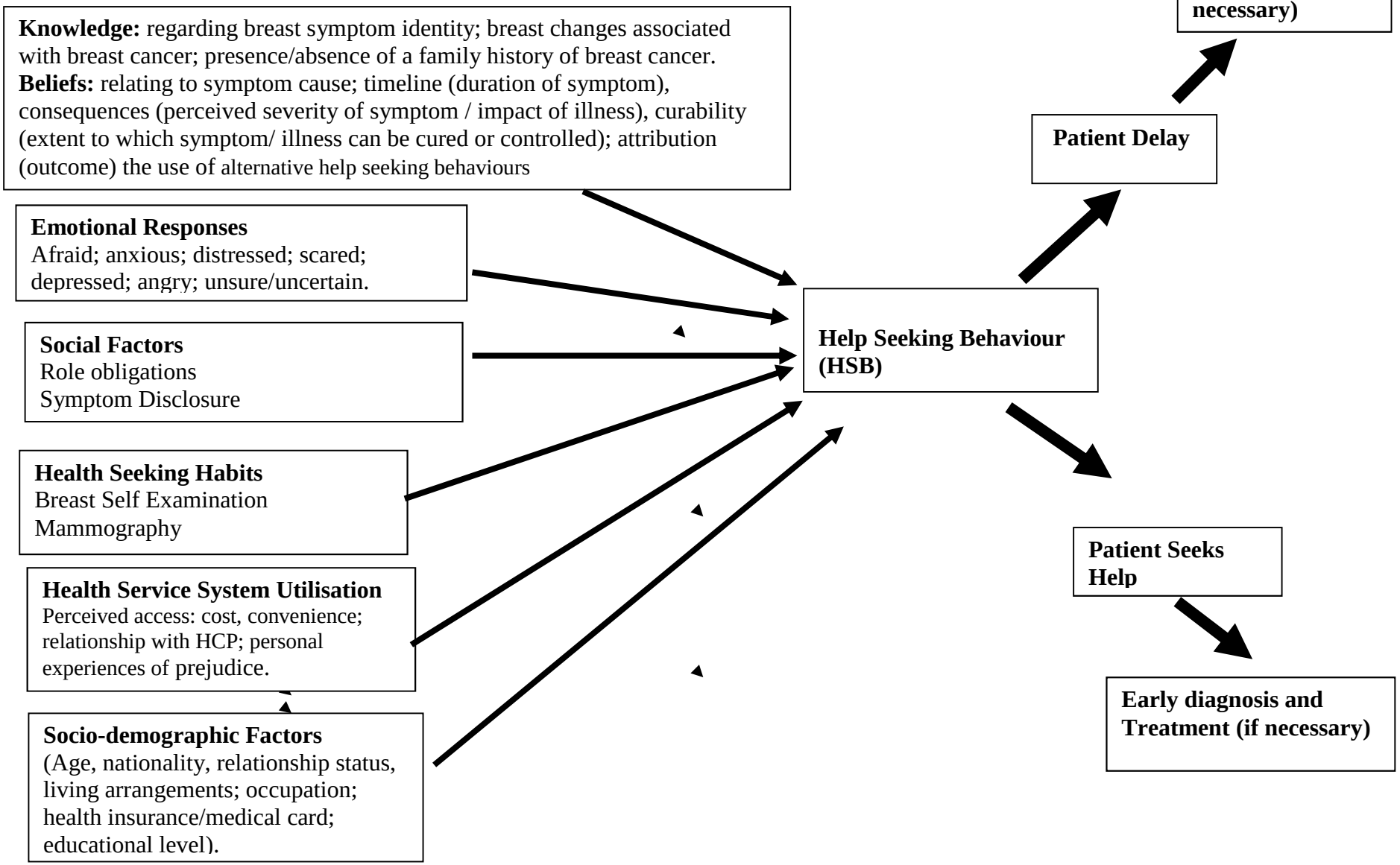
psychological distress/ symptom distress to depression. Compounding this response is the issue of coping, where defence mechanisms of avoidance and denial are utilized, oftentimes to the detriment of appropriate HSB. The difficulty in striking a balance between unnecessary worry and concern about self discovered cancer symptoms was emphasised. The review reaffirmed the need to explore women's emotional responses to breast symptom discovery, particularly in the context of their HSB. The emotional distress scale (Meechan et al., 2003) recently adapted and utilised (O'Mahony and Hegarty, 2009b) was confirmed to be a suitable tool to measure women's emotional responses to symptom discovery, in the current study.

Finally, in Chapter Four of the review the focus was on socio-demographics, social factors, health seeking habits, and health service system utilisation factors. The key dimensions of the variables pertinent to the study of actual help seeking behaviour for self discovered breast symptoms were identified. These include socio-demographics (age, nationality, relationship status, occupation, health insurance/medical card and education level); social factors (living arrangements which were recorded with socio-demographic factors; role obligations and disclosure of symptoms); health seeking habits (BSE and mammography) and health service system utilisation factors (perceived access to health care i.e. cost, convenience, relationship with HCP and personal experience of prejudice). These variables and their dimensions were outlined in the help seeking behaviour and associated factors conceptual framework (Figure 4.1) used to guide the current study.

To conclude, the review highlights that there is a large amount of empirical literature on help seeking behaviour from the perspective of cancer in general, specific cancers and breast cancer. However, the need for more theoretically based studies was

highlighted (Scott and Walter, 2010). In addition, there are limitations in previous studies that need to be addressed in that much research focuses on intentions to seek help and preventive health related practices and in many cases, data have been collected on a limited set of concepts and from specific cultural perspectives. Furthermore, data are often collected at a time remote from the discovery of the symptom and in many cases following diagnosis of breast cancer, which contaminates the sample in terms of recall bias and the effects of a breast cancer diagnosis. As far as the author could determine, no study has encompassed all of the factors affecting HSB in the event of actual symptom discovery. Therefore, the present study sought to investigate the help seeking behaviour of a sample of women with self discovered breast symptoms and determine the associated influencing factors utilising the 'Help Seeking Behaviour and Associated Factors' conceptual framework (Figure 4.1). This framework (detailed in Chapter Six) was developed from an amalgamation of the empirical (Facione et al., 2002; Meechan 2003, 2002; O'Mahony and Hegarty, 2009b) and theoretical literature (Facione et al., 2002; Leventhal et al., 2003) reviewed. The methodology for the study is presented in Chapter Six.

Figure 4.1 The Conceptual Framework 0f 'Help Seeking Behaviour and Influencing Factors'. Developed from an amalgamation of the empirical (Facione et al., 2002; Meechan 2003, 2002; O'Mahony and Hegarty, 2009b) and theoretical literature (Facione et al., 2002; Leventhal Brissette and Leventhal, 2003).



Chapter 5 Methodology

Introduction

This chapter describes the research methods used. Initially, the conceptual framework validated by a qualitative study (O'Mahony, Hegarty and McCarthy, 2011: Appendix 1a) is discussed. The research design is described followed by an outline of the aim, objectives, operational definitions and hypotheses. The study instrument, validity and reliability and the pilot study are then addressed. Details pertaining to the population, sample, access to the sample and ethical considerations are outlined. Finally, data collection, management and analysis procedures are described.

5.1 Conceptual Framework

Based on a comprehensive literature review and the aim of the study, a conceptual framework of the key issues to be addressed was developed by the researcher (Figure 4.1). This study framework outlines the factors influencing help seeking behaviour on self discovery of a breast symptom and was largely informed by the work of Facione et al., (2002); Meechan et al., (2002, 2003); Leventhal et al., (2003) and O'Mahony and Hegarty, (2009b).

Within the conceptual framework, knowledge relates to women's knowledge of symptom identity, the presence or absence of a family history of breast cancer and breast changes associated with breast cancer. Beliefs relate to what women believe about their breast symptom and the possible outcomes of the symptom. Beliefs about women's breast symptom are categorised according to the theoretical underpinnings of the Common-Sense Model of Self-Regulation Model (Leventhal et al., 2003) which suggests that perception of illness/threat is determined by an individual's

perceptions/beliefs regarding the identity, cause, time-line, risk factors and control/curability of the illness/ threat. In this study, these dimensions focused on women's beliefs regarding their breast symptom. Beliefs also related to the use of "alternative help seeking behaviours" (which addressed religiousness/prayer) on symptom discovery. Beliefs in the symptom being caused by chance and recovery being due to chance/fate were also addressed within the Illness Perception Questionnaire.

The remaining variables within the framework reflect the concepts within the Judgment to Delay Model (Facione et al., 2002) and the findings from the literature review. Emotional responses relate to the extent to which women felt 'afraid, anxious distressed, scared, depressed, angry, unsure/uncertain' on discovery of their breast symptom (Meechan et al., 2003; O'Mahony and Hegarty, 2009b). Social factors are concerned with women's roles, responsibilities and commitments and disclosure of the symptom to another person. In addition, relationship status and living arrangements are addressed with socio-demographics. Health service system utilisation factors concern women's perceived access to health care in terms of cost, convenience, relationship with a health care professional and their perceptions of experienced prejudice within the health system. Health seeking habits involve frequency of performance of breast self examination, and frequency of mammography screening. Socio-demographic factors include women's age, nationality, education level and employment status (Figure 4.1). Finally, HSB is determined by recording the time period (in weeks) from initial symptom discovery up to the time of visiting the GP, the outcome of which could be prompt or delayed HSB. Validation of this framework will now be addressed.

Validation of study framework

According to Polit and Beck (2008), the development and validation of a quantitative instrument is sometimes enhanced by the collection of qualitative data. They assert that researchers can be more confident about the validity of their results when a model is supported by "multiple and complimentary types of data" (Polit and Beck, 2008 p. 309). Thus, a qualitative descriptive study (n=10) was used in order to validate the "Help Seeking Behaviour and Influencing Factors" framework (Figure 4.1). This validation study expanded knowledge and understanding of women's HSB on self discovery of a breast symptom and illuminated the key variables linked to delayed help seeking i.e. emotional responses, social factors, knowledge and beliefs. In particular, the importance of questioning women on their denial was highlighted. Thus, item number seven (ignoring the symptom and hoping it would go away) was added to The Alternative Help Seeking Behaviour scale (question number 10) (Table 5.1). The study also reiterated the importance of questioning women on their knowledge and beliefs concerning their breast symptom, their fear surrounding symptom discovery and the impact of family and work commitments on their HSB. Findings demonstrated that the variables within the "Help Seeking Behaviour and Influencing Factors" framework act both as facilitators and barriers to women's HSB (O' Mahony et al., 2011). Thus, validating the appropriateness of this conceptual framework for the current quantitative study of symptomatic women.

5.2 Research Aim

To describe women's help seeking behaviour (HSB) and the associated influencing factors on self discovery of a breast symptom.

5.3 Research Objectives

Based on the aim of the study the following objectives were developed:

1. To ascertain the extent of delay in women's HSB on self discovery of a breast symptom **(Declarative statement # 1)**

2. To determine the relationships between HSB and the following variables: socio-demographic factors, knowledge and beliefs, emotional responses, social factors, health seeking habits, health service system utilisation factors and HSB **(Hypothesis #1-6).**

3. To compare women who delayed help seeking for more then one month (> 4 weeks) with women who sought help within one month (≤ 4 weeks) of finding their breast symptom(s).

4. To ascertain the final diagnosis of women who delayed for three months or more.

5.4 Operational definitions

Help Seeking Behaviour (HSB)

Help seeking has been described as "a response to health changes and part of the broader process of health seeking behaviour" (O'Mahony and Hegarty, 2009a, page E182). Throughout this study HSB was operationalised as the time (in weekly intervals) from symptom discovery to presentation of the symptom to a HCP. Help seeking within one month (≤ 4 weeks) of symptom discovery was considered 'prompt' and more than one month (> 4 weeks) was considered as 'delay'.

Health Care Professional (HCP)

Since first presentation to a HCP is usually the general practitioner (GP), for the purpose of presentation of the study findings, "HCP" denotes the "GP".

Self Discovered Breast Symptom

Denotes that the breast symptom has been discovered by the woman herself or her husband/partner, as opposed to by a nurse/doctor/ health practitioner or through screening mammography.

Breast Symptom

Refers to one or more of the following breast cancer symptoms:

- Change in size or shape of the breast
- Changes in the nipple: direction or shape, pulled in or flattened, or an unusual discharge
- Changes on or around the nipple: rash, flaky or crusted skin
- Changes in the skin: dimpling, puckering or redness
- 'Orange Peel' appearance of the skin caused by unusually enlarged pores
- Swelling of the armpit or around the collarbone
- A lump, any size, or thickening of the breast
- Constant pain in one part of the breast or armpit

(American Breast Cancer Society, 2009; Health Service Executive, 2009; Irish Cancer Society, 2011).

5.5 Research Hypotheses

Based on the conceptual framework (Figure 4.1) and the aim and objectives of the study, the following declarative statement and hypotheses were developed:

Declarative statement # 1 Help Seeking Behaviour (HSB)

20-30% of women delay HSB for one month or more on self discovery of a breast symptom.

Hypothesis # 1 Socio-demographics and HSB

There is a relationship between socio-demographic variables (age, nationality, relationship status, living arrangements, occupation; having a medical card / health insurance; educational level) and HSB.

Hypothesis # 2 Knowledge and Beliefs and HSB

There is a relationship between women's knowledge concerning their breast symptom and HSB.

Sub Hypothesis # 2.1

There is a relationship between knowledge regarding symptom identity and HSB.

Sub Hypothesis # 2.2.

There is a relationship between knowledge relating to breast changes associated with breast cancer and HSB.

Sub Hypothesis # 2.3

There is a relationship between knowledge concerning the presence or absence of a family history of breast cancer and HSB.

Sub Hypothesis # 2.4

There is a relationship between beliefs concerning symptom cause, and HSB.

Sub Hypothesis # 2.5

There is a relationship between beliefs concerning symptom duration and HSB.

Sub Hypothesis # 2.6

There is a relationship between beliefs concerning symptom consequences and HSB.

Sub Hypothesis # 2.7

There is a relationship between beliefs concerning symptom cure/control and HSB.

Sub Hypothesis # 2.8

There is a relationship between beliefs concerning symptom outcome and HSB.

Sub Hypothesis # 2.9

There is a relationship between women's beliefs in the use of alternative help seeking behaviour and HSB.

Hypothesis # 3 Emotional Responses and HSB

There is a relationship between women's emotional response to breast symptom discovery and HSB.

Hypothesis # 4 Social Factors and HSB

There is a relationship between social factors and HSB.

Sub Hypothesis # 4.1.

There is a relationship between disclosing the symptom to another person; and HSB.

Sub Hypothesis # 4.2

There is a relationship between role obligations (ie; caring for children and/or older relatives; work commitments; spouse/partner views) and HSB.

Hypothesis # 5 Health Seeking Habits

There is a relationship between frequency of health seeking habits and HSB.

Sub Hypothesis # 5.1

There is a relationship between frequency of breast self examination (BSE) and HSB.

Sub Hypothesis # 5.1

There is a relationship between frequency of mammography and HSB.

Hypothesis # 6 Health Service System Utilisation

There is a relationship between health service system utilisation and HSB

Sub Hypothesis # 6.1

There is a relationship between perceived access (i.e. cost, convenience, relationship with HCP) personal experiences of prejudice) and HSB.

Sub Hypothesis # 6.2

There is a relationship between personal experiences of prejudice and HSB.

5.6 Research Design

A descriptive, cross sectional, correlational design was used. The rationale for this design is that much of the work reviewed was based on women's intentions to seek help in the event of breast symptom discovery (Facione et al., 2002; Hunter et al., 2003; Burgess et al., 2009). Many of the studies focused on samples of asymptomatic women, from various cultural backgrounds and their intended help seeking behaviour in the event of symptom discovery. However, it has been emphasised that intentions to seek help are not always indicative of what happens in the real situation of breast symptom discovery (de Nooijer at al., 2002a). The Judgement to Delay Model (Facione et al., 2002) provided a holistic framework of the factors likely to influence

women's HSB should they discover a breast symptom. The model was developed from studies on both asymptomatic and symptomatic women, from within both American and ethnic minority groups, living in the San Francisco Bay area of the United States. However, to date, the model has not been utilised in its entirety to test HSB in a sample of women who have actually found a breast symptom and sought help from a HCP. A descriptive, cross sectional, correlational design enabled the researcher to collect data from a sample of symptomatic women at the time of their first visit to the breast clinic. Data were collected by means of the study instrument (Appendix 1b) which consisted of a researcher developed questionnaire package to investigate women's help seeking behaviour in terms of whether they sought help promptly (within one month) or whether they delayed (postponed help seeking for longer than one month) and the associated influencing factors as depicted in the conceptual framework already described (Figure 4.1).

5.7 Research Methods

The next section of the chapter focuses on the creation of the questionnaire package used to survey women's HSB. The design and development of the instrument used including its validity and reliability are described. This is followed by a description of the pilot study and subsequent changes made to both the research instrument and the process of accessing women.

5.7.1 Instrument Design and Development

The instrument design and development was further guided by devising a framework (Figure 5.1) described as a "ladder of abstraction which involves "moving from the broad to the specific and from the abstract to the concrete" (DeVaus, 2002 p.48). This operational framework depicted the dependent variable 'help seeking behaviour', the

factors / independent variables proposed to influence HSB as identified within the literature review, the specific dimensions of each factor, the scales used to measure these dimensions and the sample of women who participated in the study. The research instrument / questionnaire package will now be described in detail. While the guiding framework presented (Figure 4.1) outlines the factors as they are discussed in the literature review, the next section discusses the factors as they were presented in the questionnaire package (Appendix 1b). The key issues relating to the utilisation and adaptation of relevant scales addressed in the following sections are summarised in Table 5.1.

Figure 5.1: Questionnaire development framework for the study of 'Women's help seeking behaviours on self discovery of a breast symptom'

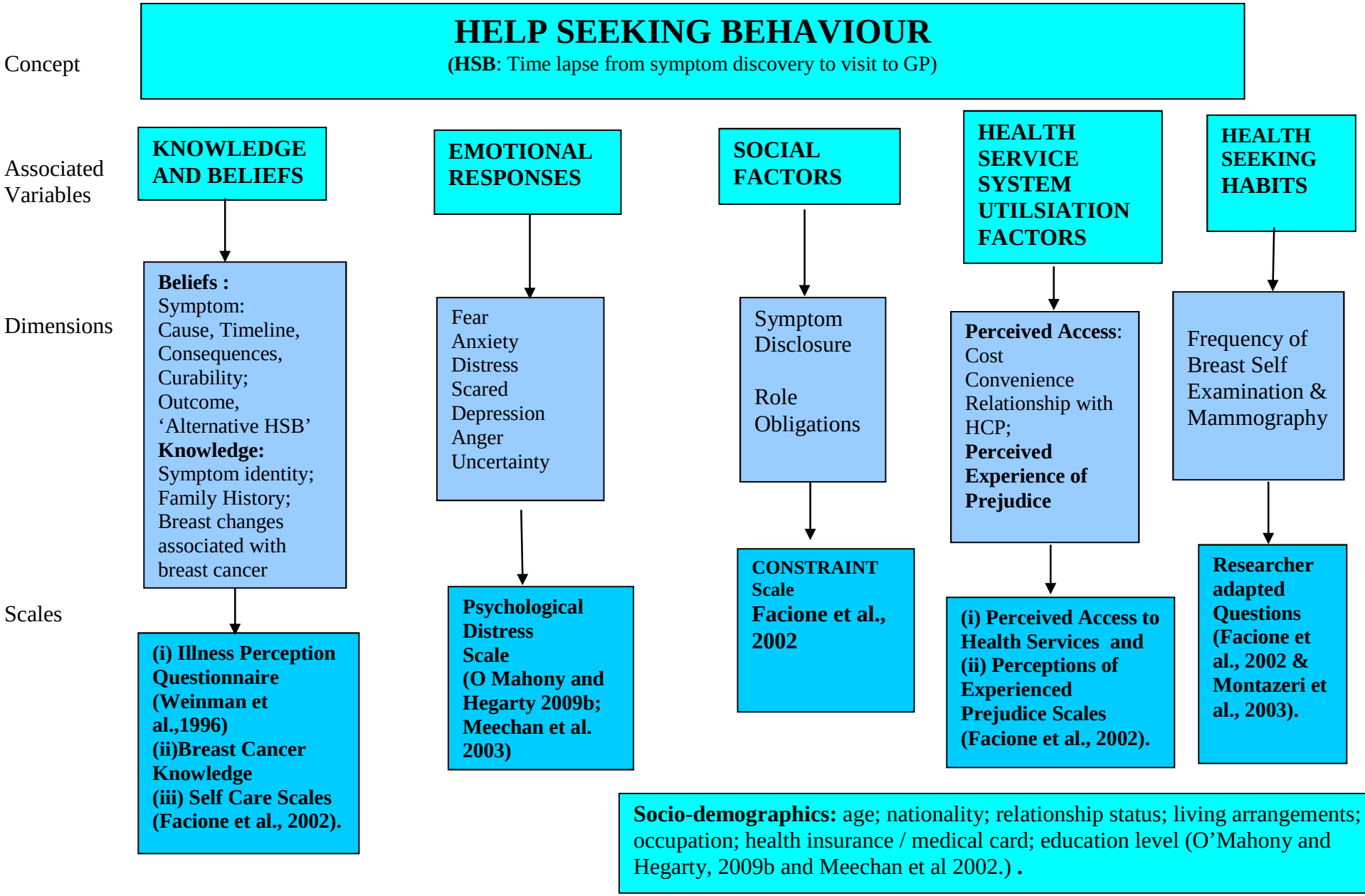


Table 5.1 Instrument Development, Scoring and Reliability Details

Dimension Measured	Original Questionnaire	Adjustment to Original Questionnaire	Scoring Details	Reliability of Scales
Question 1-7 Socio demographic factors Age Nationality Relationship status Living arrangements Occupation Health insurance/Medical card Education level	Meechan et al.,2002 McMenamin et al., 2005 O'Mahony and Hegarty 2009b	Format and structure of questions	Not relevant Nominal categorical data	Not relevant
Question 8 Knowledge: Symptom Identity	List of recognised breast symptoms: American Breast Cancer Society, 2009; Health Service Executive, 2009; Irish Cancer Society, 2011)		Not relevant Nominal categorical data	Not relevant
Question 9 Who discovered the symptom?	"Yourself" or "Partner"	Researcher developed	Not relevant Nominal categorical data	Not relevant

Dimension Measured	Original Questionnaire	Adjustment to Original Questionnaire	Scoring Details	Reliability of Scales Where relevant
Question 10 Beliefs: Alternative help seeking behaviour.	Self Care Scale (8 items) (Facione et al., 2002)	Items extracted from original 'Judgment to delay' scale and labelled 'Alternative help seeking behaviour' Items 1and 6 were addressed as one item together on original scale Items 7 ('I ignored it and hoped it would go away') and 8 (I meditated/reflected about the breast problem to try and heal it) were added to the scale. Scale re-titled "alternative help seeking behaviour" scale Total number of items:8	Responses Yes/ No Yes=1 No=0 No summative score Reported frequency and percentage of women who responded positively and negatively to each item.	Not relevant as scores not summed
Question 11 Psychological factors: women's emotional responses to symptom discovery	"Symptom Emotional Distress Scale" measuring women's emotional response to symptom discovery (4 items) (Meechan et al., 2003)	Added three dimensions to original (Meechan et al., 2003 scale) "depression" " angry" "unsure/uncertain" to measure women's emotional response to symptom discovery Total number of items:7	5 point Likert scale. 1('not at all') to 5 ('very much') Score range: 7-35. High scores indicate high levels of emotional distress on symptom discovery; low scores indicate low levels of psychological distress	Cronbach's alpha for 4 item scale : 0.89 (Meechan et al., 2003; Friedman et al., 2006) Cronbach's alpha for 7 item scale : 0.89 (O'Mahony and Hegarty, 2009b). Cronbach's alpha in current study: 0.89

Dimension Measured	Original Questionnaire	Adjustment to Original Questionnaire	Scoring Details	Reliability of Scales
Question 12 Social Factors (a) Symptom Disclosure	Meechan et al.,2002 O'Mahony and Hegarty 2009b	Added 'Husband/ partner' 'General Practitioner' and 'Action Breast Cancer Help Line'	Not relevant Nominal categorical data	Not relevant
Question 13 Help Seeking Behaviour: Time from symptom discovery to visit to GP	Meechan et al.,2002 O'Mahony and Hegarty 2009b	Categorised initially in weekly intervals as: < 1week;1-2 weeks; 3-4 weeks: **(≤ one month i.e. prompt help seeking)** 5-6 weeks; 7-8 weeks; 9-12 weeks; > 3 months: **(> one month i.e. delayed help seeking)**	Not relevant Nominal categorical data	Not relevant
Question 14 Help seeking Habits Breast Self Examination	Facione 1999 and Montazeri et al., 2008	Altered time intervals for BSE Edited 'it takes time' Montazeri et al., 2008 to 'I do not have time'	Not relevant Nominal categorical data	Not relevant
Question 15 Help seeking Habits Frequency of mammography	Facione 1999;	Time intervals edited to include: 'every 2-3 years' and 'every 4-6 years'	Not relevant Nominal categorical data	Not relevant

Dimension being measured	Original Questionnaire	Adjustment to questionnaire	Scoring details	Reliability of scales where relevant
Question 16 **Health Service System Utilisation** (Contains two scales) Cont.	**1).** Perceived access to health services scale (PAHS) Addresses -convenience -cost -existence of health care provider (HCP) relationship (13 items: Facione et al., 1997).	'Health care provider' and 'doctor nurse' changed to 'GP'. Deleted 4 items re access, cost, worry due to overlap; added two items (6 and 11). Changed question on accessing GP from three to two years. New scale 11 items -convenience: 4 items (2,3,5,8) -cost: 2 items (1,11) - relationship with GP 5 items (4,6,7,9,10). Original 4 point Likert scale ranged from 'strongly agree' to 'strongly disagree' changed to read from 'strongly disagree' to 'strongly agree' in order to maintain consistency with response range in question 19 thus making it easier for women to complete. **Total number of items :11**	4 point Likert scale 1("strongly disagree") to 4 ("strongly agree") Score range: 11-44 Reverse coding for items (1,2,4,7,8,9,11) High scores indicate good perceptions of access to services, low scores indicate perceptions of limited access to health services.	Cronbach's alpha for 13 items : **0.78** (Facione et al., 1997). Cronbach's alpha in current study: **0.64**

Dimension being measured	Original Questionnaire	Adjustment to questionnaire	Scoring details	Reliability in previous studies
Question 16 cont. **Subscale** Personal experience of prejudice scale	**2).** 'Personal experience of prejudice' **(PEP)** (Facione et al., 2007) 4 items	Incorporated into end of HHSU scale Substituted 'GP' office for 'health care provider office' for each item (12,13,14,15) Original 4 point Likert scale ranged from 'strongly agree' to 'strongly disagree' changed to read from ' strongly disagree' (-2) to strongly agree (+2) to maintain consistency with scoring for the HHSU scale above. Total number of items:4	4 point Likert scale Reverse coding item 15 Total scores: -8 to +8 Positive scores affirm and negative scores deny personal experience of prejudice	Cronbach's alpha: 0.71 (Facione et al., 2002) 0.73 (Facione and Facione 2007). Cronbach's alpha in current study: 0.42 Mean inter-item correlation in current study: 0.24
Question 17. **Social factors (b):** Constraints to HSB	**CONSTRAINT** scale: Nine items in (Facione et al., 2002) Reduced to four items to address the (work/family/ someone to talk to/ views of spouse) identified in the literature	Three items adapted from CONSTRAINT scale ie questions on family and work commitments and influence of spouse/partner Question on 'nobody to talk to' was added following review of literature Total number of items:4	Responses: Yes (1), No (2) and Not applicable (3) Not appropriate to sum items, as each represents a specific variable therefore, responses were analysed and reported individually. Results further collapsed into Yes/ No and reported accordingly.	Cronbach's alpha: 0.76 (Facione et al., 2002) Not relevant in current study as scores were not summed.

Dimension being measured	Original Questionnaire	Adjustments to questionnaire	Scoring details	Reliability in previous studies
Question 18 **Knowledge**: regarding the absence or presence of a family history	Meechan et al., 2002 O Mahony & Hegarty 2009b	Edited presentation of questions and possible responses	Not relevant Nominal categorical data	Not relevant
Question 19. **Beliefs about breast symptom relating to** Cause Time-line/ Duration Consequences Cure/ Control	Illness perception Questionnaire (**IPQ**) Weinman et al., 1996 24 items in total	1) Re titled to 'Symptom Perception Questionnaire' 2) Symptom identity subscale was excluded ; 3) 'Illness' was replaced with 'symptom'; 4) Two items deleted and replaced by items on 'symptom outcome' (25, 26) (Burgess et al., 1998) **Total number of items :26**	5 point scale Likert scale scored 1('strongly disagree') to 5 ('strongly agree') throughout questionnaire. After reverse scoring items (10,15,16,22,23) scores for time-line, consequences and cure/ control scales were obtained by adding all the scale items and dividing by the number of items in that scale (Weinman et al., 1996).	
Symptom Cause	Subscale of IPQ (Weinman et al., 1996) 9 items (1-9)	'Illness' was replaced with 'symptom' Excluded item 'my illness was caused by poor medical care in the past'	Not appropriate to sum items as each represents a specific causal belief. Items were grouped into 'external' (2.3.5.6.8) and 'internal' (1,4,7,9) and results analysed and reported for individual items.	Not relevant as scores were not summed
Symptom Duration	Subscale of IPQ Weinman et al., 1996 3 items (10-12)	'Illness' was replaced with 'symptom'	High time-line score indicates perception/belief that the symptom will last for a long time and vice versa.	Cronbach's alpha: **0.73** (Weinman et al., 1996). Cronbach's alpha in current study: **0.75**
Symptom Consequences	Subscale of IPQ Weinman et al., 1996 7 items (13-19)	'Illness' was replaced with 'symptom'	Higher the score the more serious the participant perceived/ believed the symptom to be.	Cronbach's alpha: **0.82** (Weinman et al., 1996). Cronbach's alpha in current study: **0.79**.

Dimension being measured	Original Questionnaire	Adjustment to questionnaire	Scoring details	Reliability in previous studies
Symptom Cure/Control	Subscale of IPQ Weinman et al., 1996 5 items(20-24)	Illness" was replaced with "symptom" Excluded item 'my treatment will be effective in curing my illness	Higher the score the more control the participant perceives to have over the symptom	Cronbach's alpha: **0.73** (Weinman et al., 1996). Cronbach's alpha in current study: **0.50** Mean inter-item correlation in current study: **0.17**
Symptom outcome	Researcher added- 2 items (25-26)	Questions adapted from classification of responses in Burgess et al., 1998 Qualitative study p.1344.	It is not appropriate to sum items for these questions as each represents a specific belief about the outcome of the symptom. Responses were analysed and reported for each item individually.	Not relevant as scores were not summed
Question 20 Knowledge relating to breast changes associated with breast cancer	Breast Cancer Knowledge Scale (Facione et al., 2002) 15 items	Deleted one question relating to "occasional pain at time of period" (not listed as a potential breast cancer symptom American Cancer Society, 2009; HSE Guidelines, 2009; Irish Cancer Society, 2011). Deleted item on menstruation Added item 3 relating to the presence of 'a lump under the arm'. Edited item 8 to read a thickened 'area' instead of thickened 'spot'. **Total number of items :15**	Scored as 'Yes' (1); 'No' (2)'; Don't know' (3) Responses further collapsed into two categories "Yes" and "No/Don't know". Knowledge of breast changes associated with breast cancer calculated as the number of responses (1-15) endorsing "yes" to each item on the scale ranging from 'low'(0-4); 'medium'(5-9) to 'high'(10-15).	Validity reported previously and cited in Facione et al., 2002. Content validity further reaffirmed by: (1) Ensuring that listed breast changes reflect those in literature (American Cancer Society, 2009 and HSE Guidelines, 2009; Irish Cancer Society, 2011). 2) Average Content validity index for scale: 0.85
Total Items		**75 items**		
Total No of Questions (including individual items)		**89**		

Section 1: Socio-demographic factors

The first part of the instrument allowed the researcher to collect data on socio-demographic factors including women's age, nationality, relationship status, living arrangements, occupation and education level (Questions 1-7), adapted from Meechan et al., 2002 and Mc Menamin et al., 2005. These questions were considered important as the literature review highlighted that older age acted as a barrier to women's HSB (Bish et al., 2005; Burgess et al., 2006). Recording of women's nationality enabled the researcher to describe the sample and gave insight into the number of women from ethnic minority groups. This could have been an influencing factor on HSB in terms of access to services, and was included in most studies reviewed as was the possession of 'health insurance' or a 'medical card'. Relationship status and living arrangements provided information on women's social history and whether or not they had access to potential social support from significant others. Finally, information pertaining to education level and occupation was ascertained to determine their impact on women's help seeking behaviour.

Section 2: Symptom discovery and responses

This section of the instrument was researcher developed and focused on the symptom discovery period in terms of symptom identity (knowledge) who found the breast symptom (women or partner), alternative help seeking behaviour (beliefs) women's emotional response to symptom discovery, disclosure of symptoms to another person and help seeking behaviour i.e. time from symptom discovery to visit to a general practitioner. Women were asked to identify their breast symptom(s) from a list of recognised breast symptoms (Question 8) (American Breast Cancer Society, 2009; Health Service Executive, 2009; Irish Cancer Society, 2011).

This was followed by a question to confirm that women (or their partner) discovered the symptom (Question 9). An eight itemed question (Question 10) on women's 'alternative' help seeking behaviour was utilised to determine whether or not women engaged in /believed in a range of other behaviours such as 'meditating about the problem', 'praying to God' or 'visiting an alternative therapist' on finding their breast symptom. This scale is an adaptation of Facione et al.'s (2002) eight item 'SELF CARE' scale which measured women's intended self care practices relating to possible breast symptoms.

Emotional responses to symptom discovery were ascertained using the 'symptom emotional distress scale' (Question 11) which was developed and utilised in a study on the relationship of breast symptoms and psychological factors to delayed help seeking amongst women having self discovered breast symptoms (Meechan et al., 2003). The scale was subsequently utilised by Friedman et al (2006) and following adaptation by O'Mahony and Hegarty (2009b), in the study of the help seeking behaviour of women with breast symptoms. The scale provides a concise user friendly means of measuring the key dimensions of women's emotional response to breast symptom discovery (fear, anxiety, distress, scared, depression, anger, uncertainty).

Women's disclosure of the symptom to another person was then recorded (Question 12). Help seeking behaviour was determined by estimating the time period between symptom discovery and help seeking (visit to GP) which was recorded in weekly time intervals (1-12 weeks). If over three months, a space was provided for women to specify the time period themselves (Question 13). These time periods were chosen to ensure accuracy and to reflect in as far as possible, help seeking time frames as categorised in the literature i.e. of up to one month (4 weeks); within one to three

months (5-11 weeks) and three months (12 weeks) or over. A calendar was included at the end of the questionnaire, to help women be as accurate as possible about these timeframes.

Section 3: Health Seeking Habits

This section addressed women's help seeking habits relating to breast self examination (BSE) (question 14) and mammography (question 15). Women were asked to indicate how often they performed BSE and if never or rarely to indicate or specify why not. Similarly, women were asked about the frequency of attending for mammography. Responses to questions on BSE (question 14) were adapted from Facione, (1999) and Montazeri et al., (2008).

Section 4: Health Service System Utilisation

Section four of the questionnaire package concerned health service system utilisation factors (Question 16) which were measured by an adaptation of the Perceived Access to Health Services scale (PAHS) (Facione et al., 2002). In addition, women's personal experience of prejudice (PEP) in health care delivery and its impact on HSB was measured by a subscale titled 'Perceived Prejudice in Health Care'(Facione and Facione, 2007). This four itemed scales was incorporated into the end of the PAHS scale (items 12-15).

Constraints on women's HSB (inherent in social factors) were measured by an adaptation of the CONSTRAINT scale (Question 17), (Facione et al., 2002). The original version of this eighteen itemed scale measured women's perceptions of constraints to their visiting the General Practitioner (GP) with response choices of 'true' or 'false' (Facione et al., 2002). Seven items measured women's perceived role

related constraints due to child care or elder relative care responsibilities, five items focused on work commitments and the remaining six items related to spouse/partner issues (Facione et al., 2002). In the current study this scale was reduced to a four item scale questioning women on the constraints such as 'caring commitments (child older relative)', 'work commitments', 'having someone to talk to about the symptom' and the influence of a 'spouse/partner' on the woman having her breast examined by a HCP. These dimensions (together with 'symptom disclosure') were highlighted as being the key issues likely to inhibit women's help seeking behaviour, in the literature reviewed and thus were deemed necessary to include in the current study.

Section 5: Knowledge and Beliefs

This section of the questionnaire related to women's beliefs concerning their breast symptom and their knowledge of the breast changes associated with breast cancer. Knowledge of the presence or absence of a family history of breast cancer which could have implications for women's HSB (Meechan et al., 2002; Montazeri et al., 2008; O'Mahony and Hegarty, 2009b), was also ascertained (Question 18).

Beliefs

Chapter Two of the literature review highlighted that following symptom discovery, symptom appraisal is dependent on an individual's knowledge and beliefs about their symptom. In addition, it was apparent that perceptions and beliefs act as mediators between knowledge and behaviour. While various tools have been used to measure knowledge and beliefs around cancer symptoms, no all encompassing tool was identified to measure knowledge and beliefs around breast cancer symptoms. Therefore, Leventhal's Common -Sense Model of Self-Regulation (Leventhal et al., 2003) was deemed a suitable framework to capture the core dimensions of women's

beliefs surrounding their breast symptom in relation to the associated "cause, time-line, consequences and curability." According to Weinman et al., (1996) the Illness Perceptions Questionnaire (IPQ) has been adapted and utilised by many researchers to ascertain patients' representations of illness. Furthermore, it has been adapted and utilised in relation to help seeking for potential breast cancer symptoms. (Hunter et al., 2003) and oral cancer symptom (Scott et al., 2007; Scott et al., 2008). Therefore, the IPQ was deemed appropriate to determine women's beliefs (inherent in their perceptions) about their breast symptom and was adapted with permission from Weinman (Appendix 2). This involved replacing the word 'illness' on the IPQ with the word 'symptom' and excluding the 'Identity' section of the questionnaire, as women were already asked to identify their symptoms in question number seven. Additionally, two items were excluded from the causes and cure/control subscales as they were considered inappropriate due to their specific focus on illness. Two questions relating to women's beliefs on the outcome of the symptom (i.e. breast cancer or a benign problem) were adapted (Burgess et al., 1998) and added to the end of the questionnaire.

In summary, the adapted version of the Illness Perception Questionnaire asked women to indicate how much they agreed or disagreed with statements pertaining to their beliefs on the cause (items 1-9), duration/time-line (items 10-12), consequences (items 13-19), cure/control (items 20-24) of their breast symptom. on a five point Likert scale ranging from "strongly disagree" to "strongly agree" which was scored from 1 to 5 with reverse scoring where appropriate. In addition, their beliefs concerning symptom attribution / outcome (2 researcher added items, 25-26) were ascertained. Two questions (item 22 and 23) regarding controllability also addressed

beliefs concerning fatalism which were highlighted to impact on HSB in Chapter Two.

Knowledge

Knowledge relating to breast changes and their association with breast cancer (question 20) was ascertained using The Breast Cancer Knowledge (BCSK) checklist (Facione et al., 2002). Having reviewed many scales on breast cancer knowledge this scale was deemed the most appropriate to meet the needs of the current study. This measure includes a total of 15 items each describing a potential presenting symptom of breast cancer. Two questions from the original scale were deleted as they were not listed as potential breast cancer symptoms (American Breast Cancer Society, 2009; HSE 2009, Irish Cancer Society, 2011) and a further two items were added to reflect the breast changes associated with breast cancer as outlined in the literature (Table 5.1). Women were asked to indicate whether any of the list of breast changes might be signs of breast cancer using response choices of 'yes', 'no' or 'I don't know' and an overall score of correct responses ranging from one to fifteen was computed. Finally, an open ended question (number 22) invited women to comment on any aspect of their symptom discovery and the factors that influenced their help seeking behaviour. Scoring for all of the scales used is discussed further in section 5.13 (Data Analysis) and is summarised in Table 5.1. Validity and reliability of the research instrument will now be addressed.

5.8 Validity and Reliability

Validity of an instrument determines the extent to which it actually reflects the construct under study (Burns and Grove, 2005) or the extent to which it "measures what it intended to measure" (Carmines and Zeller, 1979, p. 17). Three primary types

of validity generally discussed are content validity, predictive validity and construct validity. In relation to this study content validity and face validity of the research instrument were established. These processes will now be described.

Content Validity

According to Burns and Grove (2005) content validity is ascertained by the literature review together with the "representativeness" of the study population and validation by a panel of research experts. The content validity of the questionnaire package for the current study was determined by the literature review which identified the meaning of the concept "help seeking behaviour", the influencing variables, their key dimensions and how they are measured (Figure 5.1). In addition, content validity of the questionnaire package was established through its review by a panel of experts (n=8) including three breast care nurse specialists, a specialist breast care physician, one general practitioner, two experienced nurse researchers and one woman who had previously experienced a self discovered breast symptoms. This panel was based on the recommendation of a minimum of five experts (Burns and Grove, 2005; Polit and Beck, 2008).

Content Validity Index

A content validity index (CVI) instrument was developed by the researcher to provide a numerical value to determine the content validity of the questionnaire package (Burns and Grove, 2005; Polit and Beck 2008). This instrument enabled the experts to rate the content relevance of each item using a four point rating scale reading: 1('not relevant'); 2 ('unable to assess relevance/item in need of revision') 3 ('relevant but needs minor alteration') and 4 ('very relevant and succinct'), as suggested by Lynn 1986 cited in Burns and Grove, 2005 (p. 378). The standard method for calculating a

CVI at the item level (I-CVI) is based on the number of raters giving a rating of either 3 or 4 on the 4 point 'relevant' scale, divided by the total number of raters on the panel, with a recommended I-CVI of 0.78 or higher (Polit, Beck and Owen, 2007). A content validity index was also determined for each scale termed 'S-CVI/Average' (S-CVI/Ave). This involved calculating an average score across I-CVI's for each individual scale (Polit and Beck, 2008). 'Excellent' content validity is indicated by 'I-CVI' of 0.78 or higher and 'S-CVI' of 0.90 or higher (Polit and Beck, 2006; Polit, Beck and Owen 2007). Content validity of the items and scales used in the questionnaire package are outlined below and detailed in Appendix 3a.

Results of I-CV1's in the questionnaire package ranged from 0.63-1.00. The item concerning nationality scored 0.63 as three of the experts did not consider this issue to be relevant to the study. However, the researcher was confident that following review of the literature, piloting of the questionnaire package and in view of the current multicultural nature of Irish society, this question warranted inclusion in the questionnaire package.

Average S-CVI results ranged from 0.78-1.00. A score of 0.78 was computed for the 'Alternative HSB' 8 itemed scale (question 11) and a score of 0.85 for the 15 itemed 'Breast Cancer Knowledge' (question 20) scale. These consisted of both a series of questions with dichotomous ('Yes/ NO') responses. The 'Health Service System Utilisation' scale had an S/CVI-Ave of 0.87 which could have resulted from low I-CVI for two items (12 and 15), addressing issues of perceived prejudice, oftentimes not seen as a problem in Ireland. However, they were considered worthy of further study by the researcher, in relation to women's HSB for self discovered breast symptoms. Finally the S-CVI's for the three itemed duration subscale of the

‘Symptom Perception Questionnaire’(question 19) was computed at 0.80. The remaining of scales had S-CVI averages of 0.9-1.00, indicating good content validity overall (Appendix 3a).

Face Validity

Polit and Beck (2008) also refer to “face validity” being achieved when an instrument “looks as though it is measuring the appropriate construct” (p. 458). Face validity of the questionnaire package was determined by also asking the group of experts to comment on the overall relevance (Appendix 3b) of the questionnaire package to the aim and objectives of the study (Parahoo, 1997). Overall, responses indicated that the questionnaire package addressed the aim and objectives of the study. However, some minor changes were made to the questionnaire as suggested by members of the expert group in the open commentary included in the validity documentation given to them.

These included addition of a specific question (number 6) relating to having ‘health insurance’ or a ‘medical card’. The options of ‘husband’ or ‘partner’ and “general practitioner” were included in question number 12 concerning disclosure of the symptom to another person. Item number 11 (question 16) was edited to focus on possession of a medical card (as opposed to heatlh insurance), as it was suggested that this would impact more on access to health services. In addition, item number 26 (question 19) was edited from ‘benign’ breast problem to ‘a non-threatening/ less serious/ benign’ breast problem, in order to clarify the meaning of the medical term ‘benign’. These changes further enhanced the validity of the final questionnaire package (Appendix 1b).

Reliability of the Research Instrument

Reliability of an instrument denotes the consistency of measures obtained and indicates the extent of "random error" in a measurement (Burns and Grove, 2005). The power of a study in detecting significant differences and relationships that actually occur in the population under study is enhanced by the use of reliable instruments (Burns and Grove, 2005). Reliability is usually expressed as a "correlation coefficient" (Burns and Grove, 2005, p. 374), measured by the 'coefficient alpha' (Cronbach's alpha) (Polit and Beck, 2008). A result of 1.00 indicates perfect reliability and 0.00 indicates no reliability. The lowest acceptable reliability coefficient for a well established psychosocial measurement is taken to be 0.80 while a coefficient of 0.70 is considered acceptable for a newly developed instrument (Burns and Grove, 2005). The reliability of the ordinal scales used in the study questionnaire will now be addressed in order of sequencing in the questionnaire package (Appendix 1b). These are further detailed in Table 5.1.

In the current study, low internal consistency results were obtained for some of the scales. However, according to Pallant (2007), Cronbach alpha values are sensitive to the number of items and with short scales (of less than ten items) it is not uncommon to find low Cronbach values e.g. 0.5. In such cases it is suggested that reporting the "mean inter-item correlation" for the items may be more appropriate with optimal scores ranging from 0.2-0.4 (Pallant, 2007). The number of items in most of the scales used in the current study ranged from three to seven and only one of the scales used had more than ten items (PAHS, eleven itemed scale) which may account for the low Cronbach results for some of the scales (Pallant, 2007). The mean inter-item

correlation (0.24 for the PEP scale and 0.17 for the cure/control scale) were within and close to the recommended 0.2-0.4 range.). However, since all of the scales used had previously reported coefficient values of 0.70 or over (Table 5.1), they were deemed acceptable for use in the current study. In addition, the adapted "Symptom Emotional Distress Scale" (Meechan et al., 2003) had a Cronbach's alpha of 0.89. The adapted symptom duration and symptom consequences sub scales yielded Cronbach's alpha results of 0.75 and 0.79 respectively, both of which are within the acceptable range for scales with less than ten items (Pallant, 2007) (Table 5.1).

5.9 Pilot Study

Once ethical approval was obtained, a pilot study was carried out to test the feasibility of the main study (Polit and Beck, 2008). This involved a small scale version of the proposed study (n=10) to test the research methods and minimise the occurrence of any problems in conducting the main study (Polit and Beck, 2008). The pilot study highlighted problems in accessing women in the breast clinic. Initially, on arrival to the breast clinic the researcher was given a list of the names of women attending on that day from which it was possible to select those women attending for the first time. The researcher found it difficult to identify these women due to geographical lay out of the clinic. The only way of identifying women other than calling their names loudly (which the researcher was reluctant to do) was to ask each woman if this was her first visit and then clarify whether or not she found the symptom herself and then invite her to take part. Having reviewed this situation and discussed it with the nursing staff in the clinic, it was decided to give the study information leaflet (Appendix 8) to all women coming to the clinic for the first time. This facilitated the researcher in identifying women as they awaited their visit to the consultant. This leaflet was edited to a one page question and answer format outlining the nature of the study,

highlighting the participatory criterion of self discovery of the breast symptom and assuring women that the principles of beneficence, respect for human dignity and justice would be upheld throughout the study. In addition, the information leaflet was printed on coloured paper to further facilitate the researcher in identifying women. At this point the researcher was able to approach women who had information leaflet and further inform them about the study and answer any additional questions. Subsequently, women who were willing to participate were asked to sign the consent form (Appendix 9). This form was also edited from a two page detailed document to a one page more concise document reiterating that women were fully informed about the nature of the study and were willing to participate as outlined.

The pilot study also highlighted one area on the questionnaire for review. Question 19 (Appendix 1b) on women's views about their breast symptom posed a problem for some women who commented that they would be better able to answer items in this question following their consultation with the breast physician. Conversely, other women answered all of the items thus, indicating their relevance to them. However, in order to enhance the relevance of this question for women, the instructions were edited to highlight that the focus was on their breast symptom and women's 'own views (beliefs)' and what their breast symptom means to them (which was underlined in bold). In addition, guidelines for question number 20 were edited highlighting that the focus of the question was on 'changes that might be signs of breast cancer, in general' as opposed to relating specifically to each woman's individual situation. Thus, the pilot study enabled the researcher to identify and rectify problems with both the research process and the data collection instrument which enhances the validity and quality of the study overall. The next section describes the population, sample,

access to the sample and ethical considerations followed by an account of the data collection and analysis procedures.

5.10 Population and Sample

The complete population for the study was women attending the breast clinics in two urban hospitals within the Republic of Ireland. The target population (n = approximately 100 per week) was women attending the clinics for the first time and the accessible population was women who were waiting in the clinic prior to their appointment with their consultant. The study sample (a subset of the accessible sample) consisted of all the women visiting either of the breast clinics involved in the study, with a self discovered breast symptom (Polit and Beck, 2008).

Non probability, convenience sampling was used to select women who met the inclusion criteria of being over 18 years of age, with a self discovered breast symptom and no previous history of breast cancer. This method of sampling was chosen as it limited volunteerism by enabling the consecutive selection of every accessible woman meeting the inclusion criteria of the study. Following consultation with a statistician a sample size of 430 women was recommended. This number was based on 80% statistical power to identify a characteristic significantly associated with delayed help-seeking at the 5% level of statistical significance. It was estimated that overall, approximately one hundred women attend the breast clinics on a weekly basis in both research sites (Personal Communication with the Breast Care Nurse Specialists, April 2009.) Allowing for an average participation rate of 30 women per week (based on previous experience) data collection took place as anticipated, over a period of four months from August 11th 2009 up to December 9th 2009.

5.11 Data Collection

Access to the Sample and data collection procedure

Data collection took place in the breast care clinics of the two research sites. Initially, letters were sent to The Clinical Research Ethics Committee of the Local Teaching Hospitals, Consultants and Directors of Nursing of the relevant research sites. Having gained ethical approval (Appendix 4) and permission to proceed with the study from Consultants (Appendix 5), Directors of Nursing (Appendix 6a) and the Board of Directors (Appendix 6b), a letter was sent to the Breast Care Nurse Specialists (Appendix 7a) and the Cancer Care Co-ordinator (Appendix 7b) formally outlining the purpose of the study and requesting their assistance in accessing the sample. In addition, the study was registered in the Quality Unit of one of the sites as required (Appendix 6a). Women attending the clinics for the first time were given the study information leaflet (Appendix 8) by the nurse or receptionist, on admission to the clinic. The researcher, who was present at the clinic, then met with these women and further explained the study details to them. This ensured that women met the study criterion of self discovery of a breast symptom and that the researcher was available to answer any further questions about the study. Women who were willing to participate were then asked to sign a consent form (Appendix 9).

Following completion of the consent form (Appendix 9) the research questionnaire (Appendix 1b) was distributed to women. Participants were advised that the completed questionnaire would be collected by the researcher, who was present in the clinic throughout the data collection period. In the event of any woman being called to

see the consultant prior to completion, she was facilitated in completing the questionnaire in the clinic following her consultation, if she so wished. Finally, outcomes for women who delayed help seeking for three months or more (prolonged delay) and whether or not these women were diagnosed with a more advanced stage of breast cancer, were ascertained. This involved the researcher returning to the research sites to review the relevant patients' files. Permission to do so had previously been sought and consent granted from women, consultants, ethical committee, hospital management of one hospital and quality unit of the other as outlined in the previous section. Overall, 95% of women who met the study criterion agreed to participate. In as far as possible, questionnaires were completed prior to women being seen by the consultant.

5.12 Ethical Considerations

The three primary ethical principles applied to research are beneficence, respect for human dignity and justice (Burns and Grove, 2005; Dooley and McCarthy, 2005 and Polit and Beck, 2008). These principles are now discussed in the context of the current study. According to Burns and Grove (2005) the principle of beneficence requires the researcher "to do good "and above all "to do no harm" (p.180). Regarding beneficence, this study sought to explore women's help seeking behaviours and did not in any way affect women's care or restrict their access to health care services. Respect for persons maintains that "people have the right to self determination and freedom to participate or not to participate in research" (Burns and Grove, p. 180). Protection of human rights is discussed in the context of rights to self determination, right to privacy, right to autonomy and confidentiality, right to fair treatment and rights to protection from human harm (Burns and Grove, 2005).

Respect for human dignity was assured to women participating in this study through their voluntary participation. Women were given an information leaflet outlining the nature of the study and inviting them to participate (Appendix 8). Women were free to clarify any issues at any time, with the researcher who was present at the breast clinic. Having gained full explanation of the study details, women who agreed to participate were asked to sign consent accordingly (Appendix 9). The consent form highlighted that all procedures were explained to participants, that their participation was voluntary and that they were free to withdraw from the study at any time. It was reiterated that women's decision to withdraw would not restrict their access to the health care services in any way. Women were assured of confidentiality and anonymity relating to all records concerning their involvement in the study. In addition, it was emphasised that anonymity of persons and places would be upheld in any future presentations and publications emanating from the study thus, assuring women's right to privacy.

Burns and Grove (2005) discuss the necessity of balancing the benefits and risks for the study. While there are no physical risks involved in participating in the study, the researcher was mindful throughout the study of the fact that this was likely to be a stressful time for women and that both interviews and questionnaires could unearth distressing emotions for women. Therefore, access to women was sought with sensitivity and a quiet area was available to the researcher in the event of women becoming upset. Additionally, referral pathways to the breast care nurse specialist and onwards to a psycho-oncologist were available should the need have arisen. Notably, on two occasions women became upset, at which point they were guided by the researcher to a room adjacent to the clinic. Here the researcher listened to women's fears and worries and assured them that their participation was voluntary and they

were absolutely free to refuse to take part if they so wished. While the researcher found this to be challenging at times, it also provided the opportunity to talk to women and support them at a time when they were at their most vulnerable. Thus, it was a case of putting the study to one side and taking time to listen to women to allay their worries and fears and address their information needs.

Furthermore, the researcher was present in the breast clinic while women completed the questionnaire, and was available to respond to any additional questions or concerns that emerged for women during or after completion of the questionnaire. All women were given copies of the study information leaflet (Appendix 8) containing the researcher's contact details, should they need to make contact for clarification purposes. Thus, the researcher is confident that the principles of beneficence, respect for human dignity and justice were upheld throughout the course of the study. Preparation of the data file, data management and analysis are discussed in the next section.

5.13 Preparing the Data File

The Statistical Package for Social Sciences (SPSS Version 17.0 for Windows) was utilised for data storage, analysis and presentation. Prior to the commencement of data collection, a code book (Appendix 10) detailing instructions to transform the information obtained from the questionnaire into a format that SPSS can interpret, was prepared (Pallant, 2007). This involved defining and labelling of each variable with a code and assigning numbers to all potential responses to specific questions (Pallant, 2007). Scoring of each scale used in the questionnaire was also recorded in the codebook. Scoring of the scales utilised in the questionnaire package (Appendix

1b) are detailed in Table 5.1. Following data collection each questionnaire was double entered into the SPSS file.

5.14 Data Analysis

Descriptive Analysis

Data analysis depends on the measurement of the variables under study. Levels of measurement are categorised as nominal, ordinal, interval and ratio (Polit and Beck, 2008). However, there is much confusion amongst researchers on the definition of these terms. According to Maltby, Williams, McGarry and Day (2010) it is easier to consider variables as being either 'categorical' (variables that form separate categories) or continuous ('numerically ordered and can be ordinal, interval or ratio') (p.181). In addition, variables assigned a small range of discrete non-quantitative values are termed 'categorical variables' which, when they have only two values such as 'Yes/No' are called 'dichotomous variables'.

In the current study, the dependent variable of women's help seeking behaviour (whether prompt or delayed) was classified as categorical and dichotomous (i.e. yes: prompt help seeking (within one month) no: delayed help seeking (more than one month) (Appendix 1b).

Nominal measurement involves the use of numbers to group characteristics into categories also referred to as categorical data (Maltby et al., 2010). In the current questionnaire (Appendix 1b) the variables age, nationality, relationship status, living arrangements, occupation, having health insurance/medical card, educational level, symptom type, who discovered the symptom, practice of BSE, frequency of

mammography and family history were considered as nominal categorical data and coded accordingly.

The next level of measurement is ordinal or ranking where numbers indicate measurements about objects according to their relative ranking on an attribute (Polit and Beck, 2008). Ordinal (continuous) data were obtained in questions 11 regarding emotional distress, question 16 in relation to health service system utilisation and women's perceived experience of prejudice and question 19 on women's beliefs about their breast symptom (Appendix 11).

Following screening and 'cleaning' (finding and correcting of any errors) of the data file (Pallant, 2007), descriptive statistics were used to compute frequencies within the data. Summary statistics (mean/ median/ standard deviation) were used for continuous variables (e.g. age) and ordinal scale measurements (e.g. symptom emotional distress, health service system utilisation, perceptions of perceived prejudice, symptom beliefs). The characteristics and profile of the sample including the number of women who participated, their age range, nationality, relationship status, occupation, and education level were described. This was followed by presentation of the frequency and range of breast symptoms women presented with and verification that women found the breast symptom themselves (as opposed to their partner or significant other, which is oftentimes the case). Women's help seeking behaviour was re categorised and frequencies were presented in time frames of up to one month (1-4 weeks); up to two months (5-8 weeks) and three months (12 weeks) or more. Time intervals for prolonged delay (three months or more) were computed and presented. This was followed by a summary of the people to whom women disclosed the symptom. Responses to the question on alternative behaviours were calculated to reflect whether

or not women engaged in alternative help seeking behaviours on symptom discovery and if so, which behaviours were identified more than others.

Women's emotional response to symptom discovery were analysed to compute an overall score range including the mean and standard deviation. Frequencies of responses to each item on the scale were computed and presented also. Frequency of engaging in health seeking habits (BSE and mammography) was then calculated and presented. Health service system ultilisation was determined by computing an overall score range and the mean and standard deviation for the PAHS and PEP scales (Q 16). Results described women's health service utilisation in terms of their perceived access (cost, convenience, relationship with HCP) and perceptions of experienced prejudice and whether or not they impacted on their HSB.

Data on constraining factors (Q 17) was calculated to reflect the frequencies of both positive and negative responses to the items concerning the impact of social factors (family commitments; work commitments; having someone to talk and reluctance of spouse/partner to the woman having her breasts examined by the GP) on HSB.

Knowledge and beliefs about family history of breast cancer were computed and are presented as the percentage of women with a family history and an indication of the nature of that history i.e. whether first degree relative or otherwise. Women's beliefs concerning their breast symptom were analysed to compute an overall score range including the mean and standard deviation within each of the subscales (i.e. duration, consequences, cure/ control and outcome of their breast symptom). Since it was not possible to sum the 'causes' subscales as each item represents a "specific causal belief" causes were combined as 'internal' and 'external' and results were analysed and reported individually. In addition, frequencies of responses to each dimension

within the remaining subscales were computed and are presented in separate tables. Women's knowledge about breast symptoms and their association with breast cancer was calculated and initially presented in table format as the number and percentage of women who indicated responses of ' yes'/ 'no'/'don't know' to a list of fifteen breast changes associated with breast cancer. This data were further categorised into 'yes' and 'no/don't know' and computed to produce a score of breast cancer knowledge ranging from low (0-4), medium (5-9) to high (10-15) (Appendix 11).

Inferential Analysis

Inferential statistics were utilised to measure the magnitude and direction of the relationships between help seeking behaviour and the associated variables. Chi-square tests were used to assess/examine the associations between pairs of categorical variables (e.g. HSB: prompt: yes/delay: no) and nominal and continuous (age) variables. In order to demonstrate differences between women who sought help promptly (within one month) and women who delayed help seeking (for more than one month), data were presented in table format for both groups.

In addition, Independent sample t-tests were used to assess the differences between two groups (women who sought help promptly (within one month) and those who delayed (for more than one month) in relation to continuous (ordinal) variables, if the variable had a normal distribution. This was done for the symptom emotional distress scale, the health service utilisation scale, the perceived experience of prejudice scale and the duration, consequences, cure/control subscales of the symptom perception questionnaire. Results for the symptom emotional distress scale, the health service utilisation scale and the perceived experience of prejudice scale were further collapsed into "Yes/ No" categories and relationships between individual items on each scale

and HSB were further tested using Chi-square tests. This was also done for items on the symptom perception subscales to ascertain any relationships between individual items and HSB (Appendix 11). A significance level of $p < 0.05$ was used throughout the study.

Logistic Regression

Logistic regression was used to determine the effects of the independent variables on HSB (Polit and Beck, 2008). It is recommended that the selection process for including a variable in a regression model should begin with univariate analysis of each variable (Hosmer and Lemeshow, 2000). In relation to deciding which variables to include, there appears to be lack of consensus in the literature and few research studies report the procedure in detail. According to Hosmer and Lemeshow, (2000) epidemiological methodologists suggest including all "clinically and intuitively relevant variables in the model regardless of statistical significance (p.92). Regarding univariate analysis, selection of variables with "at least a moderate level of association" is recommended (Hosmer and Lemeshow, 2000, p.93). In the current study, in order to ensure that all variables of statistical and clinical importance were included (Hosmer and Lemeshow, 2000) and to avoid disregarding any individual variables that were of borderline significance, it was decided to conduct univariate analysis on all variables with a p value of < 0.1 (on inferential statistical testing). Results of this analysis are presented in table format highlighting results that reached a significance level of $p < 0.05$.

Multiple regression analysis was then carried out to further ascertain which variables had most impact on delayed HSB and therefore, were most important in predicting delay. Selection of variables for the multivariable model was based on the

recommendation that variables whose "univariate test have a p-value < 0.25" together with variables of "clinical importance" (Hosmer and Lemeshow, 2000, p. 95) would be suitable for entry. Therefore, as above all variables reaching $p < 0.1$ on univariate analysis were entered. Initially, these variables were entered simultaneously into a multiple logistic regression model, followed by a forward stepwise approach. Results of multiple regression analysis were presented in table format highlighting those reaching a significance level of $p < 0.05$.

The Omnibus Test of Model Coefficients and the Hosmer-Lemeshow Test were used to assess the overall performance of the multiple regression model. The Omnibus Test of Model Coefficients provides an overall indication of how well the model performs (Pallant, 2007). A highly significant value ($p< 0.05$) is recommended for this test. The Hosmer-Lemeshow Test determines the model fit where poor fit is indicated by a significance value greater than 0.05 (Pallant, 2007). The chi square values and significance levels for both tests are reported and tabled in Chapter Six.

Review of Patient Files

The case notes of women who delayed help seeking for three months or more were reviewed. The number of women who were diagnosed with breast cancer and the stage of diagnosis are also presented in Chapter 6.

Qualitative Comments

Content analysis, of women's qualitative comments using the conceptual framework (Figure 5.2) as a guide, will be reported in a future paper.

Summary

This chapter has presented the methodology used for the study of women's help seeking behaviour and the associated influencing factors on self discovery of a breast symptom. Initially, the conceptual framework validated by a qualitative descriptive study (O'Mahony et al., 2011: Appendix 1a) was described. The research design was detailed followed by an outline of the aim, objectives, operational definitions and hypotheses. The study instrument, validity and reliability and the pilot study were then discussed. Details pertaining to the population, sample, data collection procedure and ethical considerations were addressed. Finally, procedures for data management and analysis were described. The findings of the study are presented in Chapter 6.

Chapter 6

Findings

Introduction

In this chapter findings on women's help seeking behaviour (HSB) and the associated influencing factors on self discovery of a breast symptom are presented. Initially, the findings in relation to the aim of the study are described. This is followed by a description of the findings relating to the objectives and hypotheses of the study as outlined in Chapter 5. Descriptive findings are presented as sequenced in the study questionnaire (Appendix 1b). Findings on proposed relationships are then presented according to their associated hypotheses. It is important to note that variance occurred in women's response rates, thus the denominator varies for the percentages calculated on some of the variables. This needs to be considered when interpreting the data.

6.1 Socio-Demographic Factors

This section of the questionnaire ascertained women's age, nationality, relationship status, whether or not they lived alone, their occupation, medical cover (i.e. medical insurance/medical card) and educational qualifications. Four hundred and fifty women took part in the study; one respondent was excluded from the analysis as she did not answer the key question on HSB. The remaining four hundred and forty nine women ranged in age from 18 to over 80 years. The most common age group was 31 to 40 years (32.7%) and the majority of women (84.7%) were under 50 years and of Irish nationality (86.6%). Most women (56.7%) were married and living with another person (86.6%). Regarding occupation, just over half of the sample (54.3%), were professionals and 24.7% of women rated themselves as homemakers. Half of the sample (51.6%) had private health insurance, 28.3% had a medical card and 20.1%

had neither. Educational levels attained ranged from university/ third level degree (52.3%); secondary school (42.4%) to 5.2% of women exiting at the end of primary school (Table 6.1).

Table 6.1 Socio-demographic profile of sample

Variable	N	%
Age		
18-30	116	26.0
31-40	146	32.6
41-50	117	26.1
51+	69	15.3
Nationality		
Irish	388	86.6
English	19	4.2
Other	41	9.2
Relationship Status		
Single	96	21.3
Married	254	56.7
Separated	19	4.2
Widowed	8	1.8
Divorced	12	2.7
Partner	60	13.3
Living alone		
Yes	60	13.4
No	388	86.6
Occupation		
Homemaker	110	24.7
Professional	242	54.3
Non-professional	42	9.4
Student	26	5.8
Unemployed	16	3.6
Retired	7	1.6
Self-employed	3	0.7
Medical Cover		
Medical card	127	28.3
Health insurance	231	51.6
No medical insurance	90	20.1
Education Level		
Primary school	23	5.1
Secondary school	190	42.4
University/ Third level	235	52.5

Missing data: age=2; nationality =1; living alone =1; occupation = 3; medical insurance =1; Education level = 1

6.2 Symptom Discovery and Responses

This section presents the findings on women' symptom discovery including identity of the symptom (knowledge), who discovered the symptom, alternative help seeking behaviour (beliefs), emotional responses to symptom discovery, symptom disclosure (social factor) and help seeking behaviour.

6.2.1 Breast Symptom Identity (Knowledge)

Women were asked to identify their presenting breast symptom(s) from a list of breast symptoms associated with breast cancer. The most common presenting symptoms were a breast lump (54.6%) and breast pain (49.0%). Additional presenting symptoms varied from nipple discharge to change in shape of breast, skin changes, mastitis, axillary swelling and "other". In some cases, women presented with more than one symptom. Symptom discovery was by women themselves for 97.8% of the sample and by their partners in 1.6% of cases (Table 6.2a).

Table 6.2a Breast symptom and symptom discovery details

Breast Symptom	**n**	**%**
Breast Lump	245	54.6
Breast Pain	220	49.0
Nipple Discharge	36	8.0
Nipple indrawn or changed	22	4.9
Skin changes	10	2.2
Change in shape of breast	27	6.0
Mastitis	2	0.4
Axillary swelling	1	0.2
Other	70	15.6
Who discovered the symptom	**n**	**%**
Self	439	97.8
Partner	7	1.6
Other	2	0.4

Missing Data: who discovered = 1

6.2.2 Alternative Help Seeking Behaviour (Beliefs)

Women were then asked to respond "yes" or "no" to eight questions relating to alternative HSB. The most frequently endorsed items were "I checked it periodically myself to make sure it did not change" (79.1%), "I listened to the advice of others about whether to go to the GP" (42.6%) and "I prayed to God about the breast symptom" (42.9%). Other less frequently endorsed items were "I consulted a wide variety of people to see what I should do" (19.8%), "I ignored it and hoped that it would go away" (17.3%; n= 64), "I took medicine to make it better" (11.1%), "I meditated/ reflected about the breast problem to try and heal it" (5.0%) and "I used alternative therapies/ home remedies to make it better" (1.9%) (Table 6.2b).

Table 6.2b Alternative Help Seeking Behaviour

Alternative Help Seeking Behaviour **Please tick yes/no as appropriate to what you did when you found your breast symptom**.	**YES**	**%**	**NO**	**%**
1. I prayed to God about the breast symptom (n=383)	**164**	42.9	**218**	57.1
2. I consulted a wide variety of people to see what I should do (n=374)	**74**	19.8	**300**	80.2
3. I checked it periodically myself to make sure it did not change (n=402)	**318**	79.1	**84**	20.9
4. I took medicine to make it better (n=361)	**40**	11.1	**321**	88.9
5. I listened to the advice of others about whether to go to the GP (n=391)	**166**	42.6	**224**	57.4
6. I used alternative therapies/ home remedies to make it better (n=364)	**7**	1.9	**357**	98.1
7. I ignored it and hoped that it would go away (n=371)	**64**	17.3	**307**	82.7
8. I meditated/ reflected about the breast problem to try and heal it (n=359)	**18**	5.0	**341**	95.0

6.2.3 Emotional Response(s) to Symptom Discovery

Women's emotional responses to symptom discovery were measured by the seven itemed "Symptom Emotional Distress Scale" which asked women to indicate the extent that they felt "afraid, anxious, distressed, scared, depressed, angry, and

unsure/uncertain" when they found their breast symptom. Items were rated on a Likert scale from "not at all" (1) to "very much" (5) with possible scores ranging from 7-35. In the current study women's emotional response ranged from 7-35 (M = 16.34; SD = 6.5), indicating a moderate level of emotional distress, overall. With the exception of feeling "depressed" and "angry", the majority of women indicated feeling "a little bit" to "vey much" "afraid", "anxious", "scared" and "uncertain" following symptom discovery (Table 6.2c).

Table 6.2c Symptom Emotional Distress

When I first noticed my symptom(s), I felt	Not at all n (%)	A little bit n (%)	Moderately n (%)	Quite a bit n (%)	Very much n (%)
1. Afraid (n=419)	63 (15.0)	146 (34.8)	79 (18.9)	68 (16.2)	63 (15.0)
2. Anxious (n= 414)	24 (5.8)	159 (38.2)	90 (21.7)	85 (20.5)	57 (13.8)
3. Distressed (n=392)	130 (33.2)	118 (30.1)	58 (14.8)	43 (11.0)	43 (11.0)
4. Scared (n=406)	79 (19.5)	144 (35.5)	58 (14.3)	61 (15.0)	64 (15.8)
5. Depressed (n=378)	257 (68.0)	62 (16.4)	32 (8.5)	14 (3.7)	13 (3.4)
6. Angry (n= 383)	307 (80.2)	44 (11.5)	11(2.9)	10 (2.6)	11 (2.9)
7. Unsure/ Uncertain (n=389)	70 (18.0)	127 (32.6)	65 (16.7)	70 (18.0)	57 (14.7)

6.2.4 Symptom Disclosure (Social Factor)

In relation to symptom disclosure following symptom discovery, the majority of women (56.3%) told their husband or partner. Other confidantes included family members (15.8%); GP (13.1%); friend (7.1%) and 5.3% did not confide in anybody. The remainder of women disclosed to colleagues, Voluntary Health Insurance (VHI) helpline, Action Breast Cancer and their Gynaecologist (Table 6.2d).

Table 6.2d Symptom Disclosure

Symptom Disclosure	n (%)
No one	24 (5.3)
Husband/partner	253 (56.3)
Family member	71 (15.8)
Friend	32 (7.1)
Colleague	4 (0.9)
General Practitioner	59 (13.1)
Action breast cancer help line	1 (0.2)
Gynaecologist	1 (0.2)
VHI helpline	2 (0.4)
Other	2 (0.4)

6.2.5 Help Seeking Behaviour

Help seeking behaviour was initially categorised in time intervals of weeks which were then re-categorised into intervals of up to one month (4 weeks); within one to two months (between 5-8 weeks) and three months (12 weeks) or over. The majority of women (69.9%) sought help within one month, 13.4% delayed for one to two months and 16.7% delayed for three months or more (Table 6.2e). Overall, 30.1% (n = 135) of women in the study delayed help seeking for more than one month (four weeks).

Table 6.2e Women's Help Seeking Behaviour

Time interval	n	%
≤ One Month (1-4 weeks)	314	69.9%
>1 month ≤ 2 months (5-8 weeks)	60	13.4%
≥ 3 months (≥ 12 weeks)	75	16.7%
Total	449	100%

Delay of three months or more (prolonged delay) was further categorised into time spans ranging from three months through to 120 months. Delay of three months was the most common (8.7%; n =39) time span (Table 6.2f).

Table 6.2f Delay ≥ 3 months

Delay ≥ 3 months	**n**	**%**
Three Months	39	8.7 %
Four Months	5	1.1 %
Five Months	5	1.1%
Six Months	17	3.8%
Nine Months	1	0.2%
Twelve Months	3	0.7%
Eighteen Months	2	0.4%
Twenty Four Months	1	0.2%
Thirty Six months	1	0.2%
120 months	1	0.2%
Total	75	16.7 %

Summary

This section presented the findings relating to socio-demographics factors and symptom discovery details of a sample of women (n=449) with self discovered breast symptoms. The majority (86.6%) of women were of Irish nationality and living with another person (86.6%). The majority of women (84.7%) were under 50 years with most in the 31-40 year age group and 56.7% of women were married. The most frequently endorsed occupations were “professional” (54.3%) and “homemaker” (24.7%). More than half of the sample had private health insurance (51.6%) and 52.5% of women were educated to third level. The most common presenting breast symptoms were breast lump (54.6%) and breast pain (49%). Following symptom discovery, the majority of women (79.1%) ‘checked the symptom periodically to make sure that it had not changed’ and overall, women experienced moderate levels of emotional distress. The majority of women disclosed the symptom to another

person who in most cases (56.3%) was reported as being their husband or partner. Regarding HSB, the majority (69.9%) sought help promptly, whereas, 30.1% delayed for one month or more. Findings regarding health seeking habits, health service system utilisation and social factors will now be presented.

6.3 Health Seeking Habits

Women were then asked about their frequency of breast self examination performance and mammography screening. Frequency of BSE was rated as rarely (37.2%); monthly (36.0%); two monthly (18.0%) and never (8.8%). The main reasons indicated for not performing BSE were 'forgetting' (40.3%); 'not knowing how' (22.8%) and 'fear' (21.4%). In relation to mammography, the majority of women (74.9%) reported never having had a mammogram and other responses ranged from once ever (12.0%) to every four to six years (3.2%) (Table 6.3).

Table 6.3 Health Seeking Habits

Breast Self Examination	**n (%)**
Monthly	160(36.0)
Every Two Months	80(18.0)
Rarely	165(37.2)
Never	39(8.8)
Reasons for rarely/ never doing BSE	
I do not know how	47(22.8)
I forget	83(40.3)
Fear of finding a lump	44(21.4)
I do not have time	8(3.9)
Other	13(6.3)
Mammography	**n (%)**
Never	331(74.9)
Once ever	53(12.0)
Once every 3 years	9(2.0)
Every 2-3 years	35(7.9)
Every 4-6 years	14(3.2)

Missing Data: BSE =5; Mammography = 7

6.4 Health Service System Utilisation, Personal Experience of Prejudice and Social Factors

6.4.1 Health Service System Utilisation

Health care services utilisation factors were measured by an adaptation of the Perceived Access to Health Care Services Scale (PAHS) (Facione et al., 2002). This eleven itemed, four point Likert scale recorded women's responses to how much they disagreed or agreed with statements addressing their access to a HCP (generally their GP) in terms of costs, convenience and existence of a HCP relationship. Responses ranged from 'strongly disagree' (1) to 'strongly agree' (4) with a total possible score ranging from 11 to 44. In the current study, results ranged from 22 to 44 (M=34.0; SD 4.0) indicating that women's perceptions of access to health care were generally positive (Table 6.4a). Disagreement with the statement 'Prior to the occurrence of this breast symptom, I have not been to see my GP for at least two years' (86.9%) indicates that women visited their GP more regularly than every two years. Notably, a considerable number of women (33.4%) indicated agreement with the statements "Sometimes I go without the medical care I need because it is too expensive" and "the GP office should be open for more hours than it is" (43%), suggesting that expense and access were problematic for these women.

Table 6.4a Health Service System Utilisation

Please indicate how much you agree or disagree with the following statements in relation to your own experience:	**Strongly disagree**	**Disagree**	**Agree**	**Strongly agree**
	n (%)	**n (%)**	**n (%)**	**n (%)**
1) Sometimes I go without the medical care I need because it is too expensive. **(n=434)**	151 (34.8)	138 (31.8)	101(23.3)	44 (10.1)
2) The GP office should be open for more hours than it is **(n=432)**	42 (9.7)	205(47.2)	137 (31.7)	49 (11.3)
3) The GP office is conveniently located. **(n=434)**	11(2.5)	27(6.2)	274 (63.1)	122 (28.1)
4) GP's often do not listen to people **(n=433)**	119 (27.5)	217 (50.1)	76 (17.6)	21 (4.8)
5) I have easy access to my GP **(n=436)**	7 (1.6)	31 (7.1)	273(62.6)	125 (28.7)
6) I have a female GP which makes it easier for me to attend **(n=427)**	40(9.4)	97 (22.7)	167 (39.1)	123 (28.8)
7) Prior to the occurrence of this breast symptom, I have not been to see my GP for at least two years **(n= 439)**	182(41.5)	208 (47.4)	26 (5.9)	23(5.2)
8) When it comes to health care visits, transportation is a big problem for me **(n=440)**	218 (49.5)	192(43.6)	16 (3.6)	14 (3.2)
9) I see a different GP almost every time I get an appointment. **(n=439)**	183(41.7)	202 (46.0)	38 (8.7)	16 (3.6)
10) I have a GP with whom I feel comfortable talking to when I need medical care **(n=444)**	11 (2.5)	26 (5.9)	214 (48.2)	193 (43.5)
11) It is difficult for me to go to the GP as I do not have a medical card **(n=437)**	148 (33.9)	195 (44.4)	77(17.6)	18(4.1)

6.4.2 Personal Experience of Prejudice

In addition, women's personal experience of prejudice (PEP) in health care delivery was measured by a subscale of the Perceived Prejudice in Health Care Scale, detailed by Facione and Facione (2007). This four itemed scale assessed the extent to which

women disagreed (-2) or agreed (+2) with statements relating to perceived prejudice, with positive scores affirming and negative scores denying women's personal experience of prejudice (Facione and Facione, 2007). Results ranged from -8 to 5, (M = -4.7, SD = 2.7) indicating an absence of prejudice generally amongst the current sample (Table 6.4b). However, a review of women's responses to individual items highlighted that of the women who responded to the item 'my own health has never been affected by discrimination', 32.1% (141) disagreed with the statement indicating that they perceived their health to have been affected by discrimination, at some point. In addition, 19.5% (n=86) of women who responded (n=442) to the item 'I have not always been treated respectfully by doctors and nurses' indicated that they agreed with this statement.

Table 6.4b Perceptions of Experienced Prejudice

Please indicate how much you agree or disagree with the following statements in relation to your own experience:	**Strongly disagree n (%)**	**Disagree n (%)**	**Agree n (%)**	**Strongly agree n (%)**
12) Sometimes I have been ignored by a GP because I am a woman. **(n=437)**	279 (63.8)	143 (32.5)	9 (2.1)	7 (1.6)
13) I have not always been treated respectfully by doctors and nurses **(n=442)**	201(45.5)	155 (35.1)	54 (12.2)	32 (7.2)
14) I have experienced discrimination in a GP's office **(n=437)**	269 (61.6)	155 (35.5)	4 (0.9)	9 (2.1)
15) My own health has never been affected by discrimination. **(n=439)**	83 (18.9)	58 (13.2)	136 (31.0)	162 (36.9)

6.5 Social Factors

Social factors were then explored in terms of their constraints to women's HSB. Women were asked to indicate whether or not social issues such as: family or work

commitments, having nobody to talk to and the reluctance of their spouse/ partner to having their breasts examined by the GP, impacted on their HSB. The majority of women indicated that none of the items listed, impacted negatively on their HSB. However, family commitments (10.1%); work commitments (14.3%) and having nobody to talk to (3.8%) prevented some women from visiting their GP (Table 6.5).

Table 6.5 Social factors

Social Factors **Please tick yes/no as appropriate to what you did when you found your breast symptom.**	**Yes** **n (%)**	**No** **n (%)**	**Not Applicable** **n (%)**
1) Taking care of my family (children / older relative) prevented me from going to the GP **(n=446)**	45 (10.1)	272 (61.0)	129 (28.9)
2) Work commitments prevented me from going to the GP **(n=446)**	64 (14.3)	311 (69.7)	71(15.9)
3) I had nobody to talk to about the symptom **(n=446)**	17 (3.8)	351 (78.7)	78 (17.5)
4) My spouse/ partner did not like me having my breasts examined by the GP **(n=445)**	0	335 (75.3)	110 (24.7)

Summary

Health seeking habits, health service utilisation and social factors were presented. BSE was performed monthly by 36% of women and the most common reason for rarely or never performing BSE (46%; n=204) was forgetting to do so (40.3% n=80). The majority of women (74.9%) reported not having had a mammogram previously. Health service system utilisation, determined through women's perceived access to health services, was generally positive. However, review of individual responses highlighted that 33.4% of women sometimes went without medical care due to expense. While results revealed low perceived experiences of prejudice, 32.1% of women indicated that they had experienced discrimination at some point and 19.5% (n=86) indicated that they were not always treated respectfully by HCP's. Social

factors did not appear to impact on HSB for the majority of women although, family commitments (10.1%), work commitments (14.3%) and having nobody to talk to about their symptom (3.8%), were highlighted by some, as impacting on HSB.

6.6 Knowledge and Beliefs

This section of the questionnaire examined women's knowledge regarding the presence or absence of a family history of breast cancer and their beliefs relating to their breast symptom. In addition, their knowledge of breast changes associated with breast cancer was explored.

6.6.1 Family History

The majority of women (66.4%) indicated that they did not have a family history of breast cancer and 33.6% affirmed the presence of a family history (Table 6.6a).

Table 6.6a Family history of Breast Cancer

Family History	**n (%)**
Yes	149 (33.6)
No	295 (66.4)
Missing	5
Nature of relationship	
Mother	38 (24.7)
Sister	13 (8.4)
Grandmother	38 (24.7)
Aunt	40 (26.0)
Others	25 (16.2)
Total	**154**

6.6.2 Beliefs Relating to the Breast Symptom

Women's beliefs (perceptions) concerning their breast symptom were ascertained using an adaptation of the Illness Perception Questionnaire (Weinman et al., 1996) which focused on their beliefs regarding the cause, duration, consequences,

cure/control of their breast symptom. In addition, women's beliefs on the outcome of their symptom i.e. whether benign or cancerous were ascertained using two questions adapted from Burgess et al., 1998. The adapted 26 itemed, five point, Likert scale rated women's level of agreement with a number of statements concerning these dimensions of their symptom from 'strongly disagree'(1) to 'strongly agree'(5). Scores for each subscale will be reported individually.

6.6.2.1 Beliefs Relating to Symptom Cause

It was not appropriate to sum all of the nine items on the 'causes' sub-scale as each represents a specific causal belief. Items were therefore, grouped as 'internal' (5 items with possible score range of 5-25) and 'external' (4 items with possible score range of 4-20) (Weinman et al., 1996). Results indicated that the majority of women disagreed that internal causes (such as a germ, virus, diet, genetics, own behaviour, state of mind) were to blame for the occurrence of their breast symptom (Table 6.6b). Notably, 23.1% (n=102) of women were in agreement with the statement 'the symptom is hereditary, it runs in my family', indicating that these women had some family history of breast cancer and were aware of its heritable nature. In relation to 'external causes', while 'pollution' and 'other people' were not perceived to be the causative factors by the majority of women in the sample, 53.8% (n = 235) of women agreed that the symptom 'occurred by chance' and 24.7% (n=109) agreed that 'stress was a major factor' in causing their breast symptom (Table 6.6b and c).

Table 6.6b Beliefs relating to internal cause of symptom

My views/beliefs about my breast symptom are that	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
Cause: Internal	**n (%)**	**n (%)**	**n (%)**	**n (%)**	**n (%)**
1) The symptom was caused by a germ or virus **(n=446)**	228 (51.1)	118 (26.5)	91 (20.4)	6 (1.3)	3 (0.7)
2) Diet played a major role in causing the symptom **(n=445)**	136 (30.6)	163 (36.6)	114 (25.6)	31(7.0)	1 (0.2)
4) The symptom is hereditary- it runs in my family **(n=442)**	105 (23.8)	144(32.6)	91 (20.6)	83 (18.8)	19 (4.3)
7) My breast symptom was caused by my own behaviour **(n=444)**	152 (34.2)	187 (42.1)	88 (19.8)	15 (3.4)	2 (0.5)
9) My state of mind played a major role in causing my breast symptom **(n=435)**	180 (41.4)	163 (37.5)	55 (12.6)	32 (7.4)	5 (1.1)

Table 6.6c Beliefs relating to external cause of symptom

Cause: External	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
3) Pollution in the environment caused the symptom **(n=441)**	133 (30.2)	155 (35.1)	125 (28.3)	23 (5.2)	5 (1.1)
5) The symptom occurred just by chance **(n=437)**	25 (5.7)	52 (11.9)	125 (28.6)	208 (47.6)	27 (6.2)
6) Stress was a major factor in causing my breast symptom **(n=441)**	53 (12.0)	151(34.2)	128 (29.0)	89 (20.2)	20 (4.5)
8) Other people played a major role in causing my breast symptom to occur **(n=446)**	221 (49.6)	170 (38.1)	43 (9.6)	10(2.2)	2 (0.4)

6.6.2.2 Beliefs Relating to Symptom Duration

Women's beliefs on the duration of their symptom were ascertained using the three itemed timeline scale with possible scores ranging from 3-15. As above, it was predicted that high scores would indicate that women believed that the symptom would last for a long time (possibly cancerous) with low scores indicating the belief that the symptom was of short duration (possibly due to a benign breast problem).

Results ranged from 3 to 15 (M = 7.9; SD = 2.1). Overall, 32.4% (n = 143) of women agreed with the statement that their breast symptom 'will last for a short time' and 43.7% (n =190) disagreed that the symptom 'is likely to be permanent rather than temporary'. Similarly, 42.3% (n =182) disagreed that the symptom 'will last for a long time'. Notably, almost 50% of women selected the neutral response to the three questions on the duration subscale (Table 6.6d). This is understandable as some women commented afterwards that they were unable to ascertain the response to this question prior to seeing the consultant.

Table 6.6d Beliefs relating to duration of symptom

My views/beliefs about my breast symptom are that	**Strongly disagree**	**Disagree**	**Neither agree nor disagree**	**Agree**	**Strongly agree**
Duration	**n (%)**	**n (%)**	**n (%)**	**n (%)**	**n (%)**
10) My breast symptom will last for a short time(**n=441)**	20 (4.5)	50 (11.3)	228 (51.7)	123 (27.9)	20 (4.5)
11) My breast symptom is likely to be permanent rather than temporary **(n=435)**	57 (13.1)	133 (30.6)	203 (46.7)	40 (9.2)	2 (0.5)
12) My breast symptom will last for a long time **(n=430)**	59 (13.7)	123 (28.6)	206 (47.9)	40 (9.3)	2 (0.5)

6.6.2.3 Beliefs Relating to Symptom Consequence

The seven itemed consequences scale, with possible scores ranging from 7-35, indicates how serious women perceived the symptom to be. Higher scores indicate beliefs that the symptom is serious and low scores indicate beliefs that the symptom is less serious. Results ranged from 7 to 33 (M = 17.6; SD = 4.5), suggesting that almost 50% of women were unsure about the consequences of the symptom, In addition, review of actual responses (Table 6.6e) indicates that a considerable number of women responded neutrally to items on this scale. However, 36.9% (n =159) of women disagreed that the symptom 'is easy to live with'. Furthermore, 22.1% (n=97)

were in agreement that the symptom is a 'serious condition' and 21.9% (n=96) agreed that the symptom 'has a major effect' on their lives suggesting that the symptom was problematic for these women, as would be expected.

Table 6.6e Beliefs relating to symptom consequences

My views/beliefs about my breast symptom are that	**Strongly disagree**	**Disagree**	**Neither agree nor disagree**	**Agree**	**Strongly agree**
Consequences	**n (%)**	**n (%)**	**n (%)**	**n (%)**	**n (%)**
13) My breast symptom is a serious condition **(n=438)**	35 (8.0)	111 (25.3)	195 (44.5)	82 (18.7)	15 (3.4)
14) My breast symptom has a major effect on my life **(n=439)**	60 (13.7)	180 (41.0)	103 (23.5)	78 (17.8)	18 (4.1)
15) My breast symptom is easy to live with **(n=433)**	28 (6.5)	131 (30.3)	137 (31.6)	126 (29.1)	11 (2.5)
16) My breast symptom has not had much effect on my life **(n=441)**	35 (7.9)	140 (31.7)	89 (20.2)	164 (37.0)	14 (3.2)
17) My breast symptom has strongly affected the way others see me **(n=437)**	159 (36.4)	172 (39.4)	100 (22.9)	6 (1.4)	0
18) My breast symptom has had serious economic and financial consequences for me **(n=441)**	152 (34.5)	177 (40.1)	94 (21.3)	12 (2.7)	6 (1.4)
19) My breast symptom has strongly affected the way I see myself as a person **(n=443)**	145 (32.7)	173 (38.8)	74 (16.7)	45 (10.2)	7 (1.6)

6.6.2.4 Beliefs Relating to Symptom Cure/Control

Women's beliefs relating to the cure/control of their symptoms were ascertained by the five itemed cure scale, with possible scores ranging from 5 to 25. High scores indicate that women perceived/believed the symptom to be curable/ controllable and low scores suggest perceptions/beliefs of less control / curability of the symptom. Overall, results ranged from 8 to 25 (M =16.9; SD = 2.7), indicating that the majority of women were positive regarding the curability and controllability of their breast symptom. Item by item review of responses further support this positive view as

59.3% (n=262) of women were in agreement that the symptom "will improve in time". Moreover, 49.5% (n=216) disagreed with the statement that "little can be done to control" their breast symptom. "Chance" or "fate" were perceived not to influence recovery from the breast symptom for 52.2% (n=229) of women who disagreed with the statement that "recovery from my breast symptom is dependent on chance or fate". Conversely, 20.1% (n=88) agreed with this statement. Finally, a considerable number of women perceived themselves to be in control of the symptom as 45.5% (n=195) agreed with the statement "what I do can determine whether the symptom gets better or worse", which is very much the case, in the context of HSB. Notably 32.4% (n=139) of women endorsed the neutral response to this item, suggesting that some women were uncertain about this issue (Table 6.6f).

Table 6.6f Beliefs relating to symptom cure /control

My views/beliefs about my breast symptom are that	**Strongly disagree**	**Disagree**	**Neither agree nor disagree**	**Agree**	**Strongly agree**
Cure/control	**n (%)**	**n (%)**	**n (%)**	**n (%)**	**n (%)**
20) My breast symptom will improve in time **(n=442)**	6 (1.4)	12 (2.7)	162 (36.7)	220 (49.8)	42 (9.5)
21) There is a lot I can do to control my breast symptom **(n=443)**	23 (5.2)	94 (21.2)	189 (42.7)	121 (27.3)	16 (3.6)
22) There is very little that can be done to control my breast symptom **(n=436)**	49 (11.2)	167 (38.3)	160 (36.7)	53 (12.2)	7 (1.6)
23) Recovery from my breast symptom is largely dependent on chance or fate **(n=439)**	72 (16.4)	157 (35.8)	122 (27.8)	78 (17.8)	10 (2.3)
24) What I do can determine whether the symptom gets better or worse **(n=429)**	19 (4.4)	76 (17.7)	139 (32.4)	160 (37.3)	35 (8.2)

6.6.2.5 Beliefs Relating To Symptom Outcome

Women's responses to the researcher adapted questions (25 and 26) on symptom outcome were scored from 1-5 indicating specifically whether women believed that the symptom could be attributable to breast cancer or to a benign breast problem. Regarding attribution to breast cancer, 38.9% (n = 169) were in agreement with this possibility. Conversely, a larger proportion of women agreed (68.9%; n = 274) that the symptom could be due to a "non-threatening /less serious/ benign" breast problem (Table 6.6g). Therefore, women's beliefs on the outcome of the symptom were positive, overall.

Table 6.6g Beliefs relating to symptom outcome

My views/beliefs about my breast symptom are that:	**Strongly disagree**	**Disagree**	**Neither agree nor disagree**	**Agree**	**Strongly agree**
Outcome of Symptom	**n (%)**	**n (%)**	**n (%)**	**n (%)**	**n (%)**
25) My breast symptom could be due to breast cancer **(n=434)**	16 (3.7)	61 (14.1)	188 (43.3)	155 (35.7)	14 (3.2)
26) My breast symptom could be due to a non-threatening/less serious/benign breast problem **(n=441)**	4 (0.9)	14 (3.2)	119 (27.0)	255 (57.8)	49 (11.1)

Summary

This section presented findings on women's beliefs concerning their breast symptom. Results were calculated from the total number of women who responded to each item. More than half of the women (53.8%; n=235) believed that the symptom occurred just by chance. Stress (24.7%; n=109) and hereditary factors (23.1%; n=102) were the next most common causes to be endorsed. In relation to symptom duration, while a considerable number of women endorsed neutral response to items on this subscale, the remainder were optimistic that their symptom was temporary and would last for a

short time. Similarly, responses to the consequences subscale suggested that some women were unsure about the consequences of the symptom. However, the symptom was problematic for 36.9% (n=159) who disagreed that the symptom 'is easy to live with' and 22% of women who agreed that the symptom 'is a serious condition' and has 'had a major effect' on their lives. Overall, women were positive regarding the curability and controllability of their breast symptom as 59.3% (n=262) agreed that the symptom 'will improve in time' and 49.5% (n=216) disagreed that 'little can be done to control' their breast symptom. In addition, 52.2% (n=229) of women indicated disbelief in the statement 'recovery from my breast symptom is dependent on chance or fate'. Almost half of the sample perceived themselves to be in control of their symptom as 45.5% (n=195) agreed with the statement 'what I do can determine whether the symptom gets better or worse'. Finally, regarding the outcome of the symptom the majority of women (68.9%; n = 274) were of the view that the symptom could be due to a 'non-threatening /less serious/ benign' breast problem while 38.9% (n = 169) believed that the symptom was due to 'breast cancer'. Notably, a substantial number of women endorsed the neutral responses to items on all subscales suggesting that some women were uncertain about these aspects of their breast symptom (Tables 6.6 b-g).

6.6.3 Breast Cancer Knowledge

Finally, women's breast cancer knowledge was ascertained by calculating the total number of symptoms considered by women to be changes that "might" be signs of breast cancer, from the Breast Cancer Knowledge scale (BCKS). This scale consists of a list of fifteen verified symptoms (Facione et al., 2002 American Breast Cancer Society, 2009; Irish Breast Cancer Society, 2009; Irish Cancer Society, 2011) which

women were asked to indicate, whether or not, they considered to be changes that "might be signs of breast cancer" generally. The total score was attained by summing correct responses (Facione et al., 2002) and computing an index of breast cancer symptom knowledge ranging from extremely poor (where participants rated none of the changes as being associated with breast cancer) to well informed (where all of the changes were endorsed as being possible signs of breast cancer).

Initially, response options to the questions were 'Yes', 'No', 'Don't Know'. Results demonstrated that the majority of women (84.8%; n=369) considered 'a breast lump' they had 'never noticed before'; 'a lump under their arm' (73.5%; n=316) or 'a lump becoming bigger' (73.9%; n=230) to be signs of breast cancer. The item 'constant pain in one area of the breast' was the next most common breast change considered by women (65.7%; n=286) to be associated with breast cancer. Endorsement of the eleven remaining items ranged from 36.7% (n=155) ('a hot reddened painful area') to 59.2% (n=254) ('a thickened area in one breast') as being changes associated with breast cancer. Notably, the item 'persistent itching of the skin' was considered by only 21.6% (n=90) of women to be a possible sign of breast cancer. A considerable number of women chose either a 'no' or 'don't know' response to the breast symptoms listed. In particular, 'a hot reddened area' was a change that 35.8% (n= 151) of women did not associate with breast cancer. Similarly, 40.3% (n=172) of women did not connect 'a sore or scab on one nipple' with breast cancer. 'A clear drainage from one nipple' was also deemed to be a change unrelated to breast cancer by 34.3% (n=146) of women and 27.9% (n=119) indicated that they 'did not know' for this item (Table 6.6h).

Table 6.6h Breast Cancer Knowledge: Changes Associated with Breast Cancer

BREAST CHANGES ASSOCIATED WITH BREAST CANCER	**YES**	**NO**	**Don't Know**
	n (%)	**n (%)**	**n (%)**
1) Persistent itching of the skin **(n=417)**	90 (21.6)	197 (47.2)	130 (31.2)
2) A breast lump I never noticed before **(n=434)**	369 (84.8)	54 (12.4)	12 (2.8)
3) A lump under my arm …..**(n=430)**	316 (73.5)	99 (23.0)	15 (3.5)
4) A hot reddened painful area **(n=422)**	155 (36.7)	151 (35.8)	116 (27.5)
5) Constant pain in one area of the breast **(n=435)**	286 (65.7)	85 (19.5)	64 (14.7)
6) A darkening of the skin **(n=426)**	179 (42.0)	136 (31.9)	111(26.1)
7) A little blood coming from one nipple **(n=425)**	230 (54.1)	124 (29.2)	71 (16.7)
8) A thickened area in one breast **(n=429)**	254 (59.2)	106 (24.5)	70 (16.3)
9) One nipple beginning to sink inwards **(n=431)**	215 (49.9)	139 (32.0)	78 (18.1)
10) A sore or scab on one nipple **(n=424)**	133 (31.4)	172 (40.3)	120 (28.3)
11) A clear drainage from one nipple **(n=426)**	161 (37.8)	146 (34.3)	119 (27.9)
12) A change in the shape of one breast **(n=431)**	254 (58.9)	113 (26.2)	64 (14.8)
13) A lump becoming larger **(n=433)**	320 (73.9)	89 (20.6)	24 (5.5)
14) A dimpling in the skin of one breast **(n=426)**	192 (45.1)	135 (31.7)	99 (23.2)
15) One breast getting larger **(n=427)**	182 (42.6)	124 (29)	121 (28.3)

In order to compute an overall score of breast cancer knowledge, responses were collapsed into two categories 'yes' and 'no'('no/don't know' combined). Total scores (ranging from 0-15) for the BCKS indicate that women's breast cancer knowledge ranged from low i.e. score 0-4 (31.5%; n=140), medium i.e. score 5-9 (31.5%; n=141) to high i.e. score 10-15 (37.1%; n=166) (Table 6.6i) (M = 7.5; SD = 4.4). Notably,

1.6% (n=7) of women perceived none of the listed changes to be associated with breast cancer.

Table 6.6i Breast Cancer Knowledge: Overall Scores

Knowledge score	Knowledge category	Frequency n (%)
0-4	Low Knowledge Level	140 (31.5)
5-9	Medium Knowledge Level	141 (31.5)
10-15	High Knowledge level	166 (37.1)
	Missing Data	2
	Total	**449**

6.7 Breast Cancer Diagnosis and HSB

It was verified that out of the women who delayed help seeking for three months or more (n=75), two women were diagnosed with breast cancer. One woman whose symptom was present for four months prior to visiting the GP was diagnosed with a Grade 3 intra-ductal breast carcinoma. The other woman who visited the GP five months following symptom discovery was diagnosed with Grade 2 invasive ductal carcinoma.

Summary

This section presented the descriptive findings of the HSB of a sample of women (n=449) ranging in age from 18-80+, following self discovery of a breast symptom. Results demonstrated that the majority of women were of Irish nationality and educated to third level. Regarding symptom discovery and associated responses, the most common presenting symptoms were a breast lump (54.6%) and breast pain (49.0%). Following symptom discovery, alternative help seeking behaviours included ‘checking the symptom periodically to make sure it did not change’ (79.1%);

‘listening to the advice of others about visiting the GP’ (42.6%) and ‘praying to God about the breast symptom’ (42.9%). Women reported moderate levels of emotional distress and the majority of women (94.7%) disclosed the symptom to another person. In relation to ‘help seeking behaviour’, the majority of women (69.9%) sought help within one month, 13.4% delayed for one to two months and 16.7% delayed for three months or more.

Health seeking habits in relation to frequency of BSE performance ranged from rarely (37.2%) to monthly (36.0%), two monthly (18.0%) and never (8.8%) and the majority of women (74.9%) reported never having had a mammogram. Health service system utilisation was positive in that overall, perceived access to health care was good and the majority of women (86.9%) reported visiting their GP within the past two year period. Notably, 33.45% of women indicated that they would sometimes go without medical care due to expenses and 43.1% believed that the GP office should have longer opening times. Personal experiences of prejudice were minimal, however 32.1% (n=141) of women perceived that their health had been affected by discrimination at some point and 19.5% (n=86) of women indicated that they had not always been treated respectfully by doctors and nurses. Social factors as in family commitments (10.1%), work commitments (14.3%) and having nobody to talk to (3.8%) were problematic for some women in relation to their HSB.

Exploration of knowledge and beliefs established that women were knowledgeable about the presence of a family history of breast cancer and the majority (66.4%) indicated an absence of a family history. As already highlighted women’s beliefs relating to breast symptom cause, duration, consequences, cure/ control and outcome varied. More than half of the sample believed the symptom occurred by chance and

beliefs regarding the duration, consequences, cure/ control and outcome were generally positive. However, a considerable number of women endorsed the neutral response, suggesting that they were uncertain about these issues. Knowledge of breast changes associated with breast cancer ranged from low 31.5% (n=140), medium 31.5% (n=141) to high 37.1% (n=166). The majority of women were aware that lump related symptoms were associated with breast cancer. However, more than 50% of women were unaware or unsure of the association between the non lump symptoms of 'persistent itching of the skin'; 'a hot reddened area'; 'a sore or scab on one nipple' and 'a clear drainage from one nipple' with breast cancer. Finally, review of the case notes of women who delayed for three months or more (n=75) revealed that of the two women diagnosed with breast cancer, one had Grade 2 'Invasive Ductal Carcinoma' and the other Grade 3 'Intra-Ductal Carcinoma'. The results of inferential statistical testing of the proposed hypotheses will now be presented.

6.8 Help seeking behaviour and associated relationships

Findings relating to the objectives of the study and the statistical testing of the hypotheses (as developed from the aim and objectives) will now be presented. The declarative statement relating to the dependent variable (HSB) will be addressed initially. Thereafter, findings on significant relationships between independent variables and the dependent variable (HSB) will be presented.

6.8.1 Declarative Statement on Help Seeking Behaviour (HSB).

It was asserted that 20-30% of women would delay HSB for more than one month (> 4 weeks) on self discovery of a breast symptom.

This assertion was supported, albeit that (30.1%; n=135) of women delayed HSB for more than one month and slightly more than two thirds (69.9%; n = 314) of the sample sought help within one month.

6.8.2 Hypotheses # 1: Socio-demographics and HSB

There is a relationship between socio-demographic variables (age; nationality; relationship status; living arrangements; occupation; medical cover i.e. health insurance/ medical card and educational level) and help seeking behaviour (HSB).

On testing relationships between socio demographic variables (outlined above) and HSB, no significant relationships were found (Table 6.7). In addition, on re-categorising the item health insurance/ medical card into two categories (health insurance or medical card combined (yes/no), no significant relationship was detected with HSB.

Table 6.7 Socio-demographic data cross tabulated with HSB.

Variable	Prompt HSB n (%) 314 (69.9%)	Delayed HSB n (%) 135 (30.1%)	Total n	Pearson Chi-Square	Degrees of freedom	p value
Age group				0.96	3	0.811
18-30	82 (70.7%)	34 (29.3%)	116			
31-40	103 (70.5%)	43 (29.5%)	146			
41-50	77 (66.4%)	39 (33.6%)	116			
51+	50 (72.5%0	19 (27.5%)	69			
Total	312 (69.5%)	135 (30.0%)	447			
Nationality				1.40	1	0.236
Irish:Yes	275(70.9%)	113 (29.1%)	388			
No	38 (63.3%)	22 (36.7%)	60			
Total						
Relationship status				1.47	1	0.225
Yes	225 (71.7%)	89 (28.3%)				
No	89(65.9%)	46(34.1%)				
Total	314(69.9%)	135 (30.0%)				
Living Alone				1.40	1	0.236
Yes	38 (63.3%)	22 (36.7%)	60			
No	275(70.9%)	113 (29.1%)	388			
Total	313 (69.7%)	135 (30.0%)	448			
Occupation				0.34	2	0.845
Homemaker	76(69.1%)	34(30.9%)	110			
Employed	200 (69.75%)	87(30.3%)	287			
Other	36(73.5%)	13 (26.5%)	49			
Total	312 (70.0%)	134 (30.0%)	446			
Medical Cover						
Medical card	80 (63.0%)	47 (37.0%)	127	4.18	2	0.123
Health Insurance	166 (71.9%	65 (28.1%)	231			
No cover	67 (74.4%)	23 (25.6%)	90			
Total	313 (69.7%)	135 (30.0%)0	448			
Education Level				2.23	2	0 .892
Primary School	16(69.6%)	7 (30.4%)	23			
Secondary School	131(68.9%)	59(31.1%)	190			
University/ 3rd Level	167 (71.1%)	68(28.9%)	235			
Total	314 (69.8%)	134 (30.0%%)	448			

***P< 0.05**

Summary

In summary, declarative statement # 1 was supported albeit that 30.1% of women delayed HSB for more than one month. Hypothesis # 1 was unsupported.

6.8.3 Hypothesis # 2 There is a relationship between women's knowledge and beliefs concerning their breast symptom.

Sub Hypothesis # 2.1

There is a relationship between knowledge regarding breast symptom identity and HSB.

Amongst women who delayed (n=135), the most common presenting symptoms were breast pain (56.3%; n=76), breast lump (41.5%; n=56) nipple discharge (10.4%; n=14) and "nipple indrawn/ changes" (9.6%; n=13). Significant relationships were found between HSB and breast lump (Chi-square=13.33; d.f. = 1; $p < 0.001$); nipple indrawn/changes (Chi-square= 9.29; d.f. = 1; $p = 0.002$) and breast pain (Chi-square = 4.12, d.f. = 1, $p = 0.043$) (Table 6.8). Responding "yes" to 'breast lump' facilitated prompt HSB whereas in the delay group, a proportionally higher number of women with 'breast pain' delayed (34.5%; n= 76) as was the case for women who responded 'yes' to 'nipple indrawn/ changed' (59.1%; n= 13).

Table 6.8 Symptom identities cross tabulated with HSB

Symptom	Prompt HSB 314 (69.9%) n (%)	Delayed HSB 135 (30.1%) n (%)	Pearson Chi-Square	*p value*
Breast Lump			13.33	**<0.001***
Yes	189 (77.1%)	56 (22.9%)		
No	125 (61.3%)	79 (38.7%)		
Nipple discharge			1.45	0.229
Yes	22 (61.1%)	14 (38.9%)		
No	292 (70.7%)	121(29.3%)		
Breast pain			4.12	0.043*
Yes	144 (65.5%)	76 (34.5%)		
No	170 (74.2%)	59 (25.8%)		
Nipple indrawn/ Changes			9.27	0.002*
Yes	9 (40.9%)	13 (59.1%)		
No	305 (71.4%)	122(28.6%)		
Skin changes			1.93	0.164
Yes	5 (50%)	5 (50.0%)		
No	309 (70.4%)	130 (29.6%)		
Change breast shape			2.82	0.093
Yes	15(55.6%)	12(44.4%)		
No	299(70.9%)	123(29.1%)		
Mastitis			.86	0.353
Yes	2 (100.0%)	0 (.0%)		
No	312 (69.8%)	135(30.2%)		
Axillary swelling			.43	0.512
Yes	1(100.0%)	0 (.0%)		
No	313 (69.9%)	135 (30.1%)		
Other			.07	0.787
Yes	48 (68.6%)	22(31.4%)		
No	266 (70.2%)	113(29.8%)		

Note: All chi-square tests had one Degree of freedom; *P < 0.05

Sub Hypothesis # 2.2

There is a relationship between knowledge relating to breast changes associated with breast cancer and HSB.

The levels of knowledge concerning breast changes associated with breast cancer, of women who delayed help seeking ranged from low (28.6%; n = 40), medium (35.5%; n = 50), to high (27.1%; n = 45) (Table 6.9a). No significant relationship was found between overall knowledge relating to breast changes associated with breast cancer and HSB (Chi-square = 2.78 d.f. = 2; p = 0.249).

Table 6.9a Breast Cancer Knowledge cross tabulated with HSB

Knowledge score	Knowledge category	Prompt HSB n (%)	Delayed HSB n (%)
Low 0-4	Low Knowledge Level	100 (71.4%)	40 (28.6%
Medium 5-9	Medium Knowledge Level	91 (64.5%)	50 (35.5%)
High 10-15	High Knowledge level	121(72.9%)	45 (27.1%)

Results for the breast cancer knowledge scale were further computed into two categories (‘yes’ and ‘no’) following amalgamation of the ‘No’ and ‘Don’t know’ responses (Appendix 12). Apart from the two lump related items (2 and 13), the frequency at which all other items were endorsed in the ‘no/ don’t know’ category is of particular concern. Within the ‘no/ don’t know category’, a significant relationship was evident between the item ‘a clear drainage from one nipple’ (Chi-square = 4.27; d.f. = 1; p = 0.039) and HSB. The majority of women (75.8%) who responded ‘ yes’ to this item (n=161) sought help promptly. In addition, the relationship between the item ‘a breast lump I never noticed before’ approached statistical significance (Chi-square = 3.72 d.f. = 1; p = 0.054) with HSB. Prompt help seeking also occurred amongst the majority of women (71.7%; n=264) who responded positively to this item (n=368) (Table 6.9b: Appendix 12).

Sub Hypothesis #2.3

There is a relationship between knowledge concerning the absence or presence of a family history of breast cancer and HSB.

This sub hypothesis was unsupported (Table 6.10: Appendix 12).

Hypothesis # 2-4-2.8 There is a relationship between women's beliefs concerning their breast symptom and HSB.

Independent samples t-tests were performed to explore differences between women who sought help promptly and women who delayed HSB regarding their beliefs on the cause, duration, consequences, cure/control and outcome of their symptom (Table 6.11). Additionally, relationships between individual subscale items and HSB were further determined using chi-square tests, results of which are detailed in Appendix 12.

Sub Hypothesis # 2.4

There is a relationship between beliefs concerning symptom cause and HSB.

Sub Hypothesis # 2.7

There is a relationship between beliefs concerning symptom cure/control and HSB.

Sub Hypothesis # 2.8

There is a relationship between beliefs concerning symptom outcome and HSB.

These sub hypotheses were not supported (Tables 6.12 a,b,e,f : Appendix 12).

Sub Hypothesis # 2.5

There is a relationship between beliefs concerning symptom duration and HSB.

A statistically significant difference was evident between women who sought help promptly and women who delayed HSB regarding beliefs about symptom duration (t = 2.75; d.f. = 289, p = 0.006) (Table 6.11). Women who delayed had higher scores on the duration subscale, indicating that they perceived their symptom to be of longer duration.

Table 6.11 Group statistics and independent sample T-Test for symptom beliefs sub scales

Variable	HSB	N	Mean	Standard deviation	t	d.f.	p value
Duration	Prompt Delay	297 126	7.74 8.29	2.18 1.76	2.75	289	0.006*
Consequences	Prompt Delay	304 133	17.67 17.04	4.59 4.27	1.36	435	0.174
Cure/ Control	Prompt Delay	293 127	16.88 16.76	2.61 2.81	0.45	418	0.65

***P < 0.05**

In addition, chi-square testing of relationships between individual subscale items and HSB, detected significant relationships between the item "my breast symptom is likely to be permanent rather than temporary" (Chi-square = 11.43; d.f. = 4; p = 0.022) and the item "my breast symptom will last for a long time" (Chi-square = 13.71 d.f. = 4; p = 0.008). A higher proportion (89.8%) of women who "strongly disagreed" (n= 59) that "the symptom will last for a long time", sought help promptly. In addition, strongly disagreeing that the "breast symptom is likely to be permanent rather than temporary" (n=57) instigated prompt help seeking amongst 87.7% (n=50) of women (Table 6.12 c : Appendix 12).

Sub Hypothesis # 2.6

There is a relationship between beliefs concerning symptom consequences and HSB.

No significant difference was found between women who sought help promptly and women who delayed regarding beliefs about the consequences of their breast symptom (Table 6.11). However, on Chi-square tests between individual items on the consequences subscale and HSB, a trend was noted between the item "My breast symptom has strongly affected the way others see me" and HSB (linear- by- linear association = 3.73; d.f. = 1; p = 0.053). Although the number was small (n=6), all women who agreed with this statement, sought help promptly (Table 6.12d: Appendix 12).

Sub Hypothesis # 2.9

There is a relationship between women's beliefs in the use of alternative help seeking behaviour and HSB.

The most common alternative help seeking behaviours practiced by women in the delay group were 'I checked it periodically myself to make sure it did not change' (77%; n = 104); 'I prayed to God about the breast symptom' (34%; n = 46); 'I ignored it and hoped it would go away' (34%; n = 46) and 'I listened to the advice of others about whether to go to the GP' (32.5%; n = 44) (Table 6.13). Significant relationships were found between the items 'I ignored it and hoped it would go away' (Chi-square = 61.52; d.f. =1; p < 0.001); 'I used alternative therapies/ home remedies to make it better'(Chi-square= 5.75; d.f. = 1; p = 0.017) and HSB. A higher proportion (71.9%; n=46) of delay occurred amongst women who 'ignored it and hoped that it would go

away' (n=64). Delay was also proportionally higher (71.4%; n =5) for women who 'used alternative therapies/ home remedies' (n=7) (Table 6.13).

Table 6.13 Alternative HSB cross tabulated with HSB

Alternative help seeking behaviour on symptom discovery	Yes / No	Prompt HSB 314 (69.9%) n (%)	Delayed HSB 135 (30.1%) n (%)	Pearson Chi-Square	P value
1. I prayed to God about the breast symptom				0.58	0.447
	Yes	118(72.0%)	46(28.0%)		
	No	149(68.3%)	69(31.7%)		
2. I consulted a wide variety of people to see what should do				0.01	0.919
	Yes	52 (70.3%)	22(29.7%)		
	No	209(69.7%)	91(30.3%)		
3. I checked it periodically myself to make sure it did not change				3.18	0.074
	Yes	214(67.3%)	104(32.7%)		
	No	65(77.4%)	19(22.6%)		
4.I took medicine to make it better				0.00	0.977
	Yes	28(70.0%)	12 (30.0%)		
	No	224(69.8%)	97(30.2%)		
5. I listened to the advice of others about whether to go to the GP				1.68	0.195
	Yes	122(73.5%)	44(26.5%)		
	No	151(67.4%)	73(32.6%)		
6. I used alternative therapies/ home remedies to make it better				5.75	0.017*
	Yes	2(28.6%)	5(71.4%)		
	No	252(70.6%)	105(29.4%)		
7. I ignored it and hoped that it would go away				61.52	<0.001*
	Yes	18(28.1%)	46(71.9%)		
	No	239(77.9%)	68 (22.1%)		
8. I meditated/ reflected about the breast problem to try and heal it				1.78	0.182
	Yes	10(55.6%)	8(44.4%)		
	No	240(70.4%)	101(29.6%)		

Note: All chi-square tests had one degree of freedom; *p < 0.05

Summary

In this section the testing of the relationship between women's knowledge and beliefs concerning their breast symptom and HSB is presented. Regarding symptom identity, significant relationships were found between the presenting symptoms of breast lump ($p < 0.001$); breast pain ($p = 0.002$); nipple indrawn/ changes ($p = 0.043$) and HSB. In relation to knowledge concerning breast changes associated with breast cancer, a significant relationship was evident between the 'no/don't know response' to the item 'a clear drainage from one nipple' and HSB. The item 'a breast lump I never noticed before' approached statistical significance ($p = 0.054$) with HSB.

Regarding beliefs, a significant difference was detected between women who sought help promptly and women who delayed concerning beliefs about duration of the symptom ($p = 0.006$). In addition, a trend was noted between the item 'my breast symptom has strongly affected the way others see me' (from the consequence subscale) and HSB ($p = 0.053$). Finally, a belief in the use of the alternative help seeking behaviour of 'ignoring the symptom and hoping that it would go away' ($p < 0.001$) and the use of 'alternative therapies/ home remedies' ($p = 0.017$) were significantly associated with HSB.

6.8.4 Hypothesis # 3 Emotional Response to Symptom Discovery

There is a relationship between women's emotional response to breast symptom discovery and HSB.

The initial responses on the Symptom Emotional Distress (SED) scale ranged across a five point Likert scale from 'not at all' to 'very much' (Table 6.2c) with total scores ranging from 7-35. Total results for SED were computed for women who delayed (n=117) (M= 15.86; SD = 5.76) and those who sought help promptly (n= 262) (M=

16.60; SD = 6.85). Results demonstrated that women who sought help promptly had higher emotional distress scores than those who delayed. Independent samples t-tests established that this difference (between prompt and delayed help seekers) was not statistically significant (t = 1.08; d.f. = 262; p = 0.283). The scale categories were collapsed into two categories 'Yes' ('a little bit/moderately/ quite a bit/ very much') and 'No'('not at all') and results were cross tabulated with HSB (Table 6.14). No significant relationships were found between individual items on the scale and HSB.

Table 6.14 Symptom Emotional Distress cross tabulated with HSB

WHEN I FIRST NOTICED MY SYMPTOM(S) I FELT	Yes/N0 n	Prompt HSB 314 69.9%) n (%)	Delay HSB 135 (30.1%) n (%)	Chi-square & p value
1.Afraid	Yes= 356	254 (71.3%)	102 (28.7%)	3.08 0.079
	No= 63	38(60.3%)	25 (39.7%)	
2. Anxious	Yes=391	269 (69%)	121(31.0%)	1.11 0.292
	No=24	19(79.2%)	5 (20.8%)	
3. Distressed	Yes=262	190 (72.5%)	72(27.5%)	2.58 0.108
	No=130	84(64.6%)	46 (35.4%)	
4. Scared	Yes=327	226 (69.1%)	101(30.9%)	0.28 0.598
	No=79	57(72.2%)	22(27.8%)	
5. Depressed	Yes=121	83 (68.6%)	38 (31.4%)	0.81 0.776
	No=257	180 (70.0%)	77 (30.0%)	
6. Angry	Yes=76	55(72.4%0	21(27.6%)	0.38 0.538
	No= 307	211(68.7%)	96 (31.3%)	
7. Unsure/Uncertain	Yes=319	219 (68.7%)	100(31.3%)	1.98 0.160
	No =70	54 (77.1%)	16 (22.9%)	

Note: All chi-square tests had one degree of freedom

The relationship between being "afraid" and HSB almost approached significance (Chi-square = 3.083, d.f. = 1, p = 0.079) (Table 6.10). The majority of women (85%; n=356) reported being afraid on symptom discovery, of whom 71.3% (n=254) sought help promptly. Whereas, of the women who were not afraid (n=63) a smaller percentage (60.3%; n=38) sought help promptly.

6.8.5 Hypothesis # 4 There is a relationship between social factors and HSB.

Sub Hypothesis # 4.1 There is a relationship between women's symptom disclosure and HSB.

Results for symptom disclosure were collapsed into two categories "Yes" (disclosure to someone i.e. husband/ family member, friend/ GP/ other) and "No" (disclosure to no-one). In the entire sample (n = 449), only 24 women did not confide in another person regarding their symptom, of whom 62.5% (n = 15) were in the delay group (Table 6.15a). A significant relationship was evident between disclosure of the symptom to another person and HSB (Chi-square 21.05; d.f. = 5; p < 0.001), suggesting that women who disclose the symptom were more likely to seek help and non disclosure of the symptom predisposed to delay (Table 6.15a).

Table 6.15a Symptom disclosure cross tabulated with Delayed HSB

Who did you first talk to when you discovered / experienced your symptom?	n	Prompt HSB 314 (69.9%) n (%)	Delayed HSB 135(30.1%) n (%)	Pearson Chi-Square	d.f.	P value
Symptom Disclosure				12.69	1	< 0.001*
No-one	24	9(37.5%)	15(62.5%)			
Someone	425	305 (71.8%)	120(28.2%)			

*** p < 0.05**

Sub Hypothesis # 4.2 There is a relationship between role obligations (i.e. caring for children and /or older relatives; work commitments) and HSB.

No significant relationship was found between HSB and social constraints overall. Analysis of individual items detected a relationship between HSB and the item 'taking care of my family (children / older relative) prevented me from going to the GP' (Chi-square 7.56; d.f. =2; p = 0.023). Almost half (46.7%) of the women who said 'yes' to 'taking care of my family prevented me from going to the GP' delayed, compared to 24.8/30.1% of those who said 'not applicable/no' (Table 6.15b: Appendix 12). This suggests that the presence of family constraint increases risk of delay.

Therefore, hypothesis # 6 was supported since disclosure of the symptom to another person and the presence of family commitments were both significantly related to HSB.

6.8.6 Hypothesis # 5 There is a relationship between Health Seeking Habits and HSB

This hypothesis was unsupported but relevant findings are presented in view of their clinical importance.

Sub Hypothesis # 5.1

There is a relationship between women's frequency of breast self examination and HSB.

The relationship between frequency of BSE and HSB did not reach significance. However, evidence of a trend between overall frequency of BSE and delayed HSB was noted (linear-by-linear association 3.65; d.f. = 1; p = 0.056), suggesting that there

was an increased risk of delay with each reduced frequency of BSE (the less often women performed BSE the more likely they were to delay) (Table 6.16).

Sub Hypothesis # 5.2

There is a relationship between frequency of mammography and HSB.

No significant relationship was identified between frequency of mammography and HSB. Delay occurred amongst 31.4% (n=104) of women who never had a mammogram (n=331) (Table 6.16).

Table 6.16 Health Seeking Habits cross tabulated with HSB

How often do you examine your breasts?	**n**	**Prompt HSB 314 (69.9%) n (%)**	**Delay HSB 135 (30.2%) n (%)**
Monthly	160	120(75.0%)	40(25.0%)
Every Two Months	80	56(70.0%)	24(30.0%)
Rarely	165	109(66.1%)	56 (33.9%)
Never	39	25(64.1%)	14(35.9%)
Pearson Chi-Square; d.f.; p value	3.75	3	0.290
How regularly do you have a mammogram?			
Never	331	227(68.6%)	104 (31.4%)
Once ever	53	40(75.5%)	13(24.5%)
Once every 3 years	9	6(66.7%)	3(33.3%)
Every 2-3 years	34	26(74.3%)	9(25.7%)
Every 4-6 years	14	11(78.6%)	3(21.4%)
Pearson Chi-Square; d.f.; p value	1.92	4	0.751

6.8.7 Hypothesis # 6 There is a relationship between Health Service System Utilisation (HSSU) and HSB.

Sub Hypothesis # 6.1

There is a relationship between women's perceived access to health services and HSB.

The HSSU scale rated responses on a four point Likert scale from 'strongly disagree' to 'strongly agree' (Table 6.4a). Independent samples t-tests established that there was no significant difference between prompt and delayed help seekers regarding perceived access to health care, overall (t = 0.15; d.f. = 427; p = 0.884). Responses were collapsed into two categories 'yes' ('agree/strongly agree') and 'no' ('disagree/strongly disagree') (Table 16a: Appendix 12) following which, no significant relationships were found between individual items on the HSSU scale and HSB. The item 'sometimes I go without the medical care I need because it is too expensive' approached significance (Chi-square 2.83; d.f. =1; p = 0.093). Notably, of the women (n=145) who agreed with this item, 35.2% (n=51) delayed help seeking. (Table 6.16a: Appendix 12).

Sub Hypothesis # 6.2

There is a relationship between women's perceptions of experienced prejudice (PEP) and HSB.

No significant difference was detected between women who sought help promptly and those who delayed regarding perceptions of experienced prejudice, overall. (t =1.47; d.f. = 423; p = 0.154).

As above, responses on the PEP subscale were collapsed into two categories 'Yes' ('agree/strongly agree') and 'No'('disagree/ strongly disagree') and no significant relationships were found between individual items and HSB (Table 16a: Appendix 12). However, in the delay group (n=135), 32.6% (n=44) of women disagreed with the item (i.e. 'no' group) 'my own health has never been affected by discrimination' suggesting that their health was affected by discrimination at some point. In addition, of the women who agreed ('yes' group) that they had 'not always been treated respectfully by doctors and nurses' (n=86), delay occurred amongst 26.7% (n=23) (Table 6.16b: Appendix 12).

In summary, no significant relationships were found between either women's perceived access to health services or their perceived experienced of prejudice and HSB. However, the item 'sometimes I go without the medical care I need because it is too expensive' approached significance ($p = 0.093$).

Summary

This section presented findings relating to the testing of the hypotheses for HSB. The variables found to be significantly related to HSB were knowledge surrounding the presenting symptoms of a 'breast lump' ($p < 0.001$) (which facilitated prompt HSB) and 'breast pain' ($p = 0.043$), and 'nipple indrawn/ changes' ($p = 0.002$), both of which were associated with delay. Additionally, a significant relationship was evident between responding 'no/ don't know' to the item 'a clear drainage from one nipple' (Chi-square = 4.27; d.f. = 1; $p = 0.039$) on the breast cancer knowledge scale, which was associated with delay. In relation to women's beliefs about their breast symptom, a significant difference was detected between women who sought help promptly and those who delayed. Beliefs in the alternative help seeking behaviours of 'I used

alternative therapies/ home remedies to make it better' ($p = 0.017$) and 'I ignored it and hoped that it would go away' ($p < 0.001$) were significantly related to delayed HSB. Finally, social factors including symptom disclosure to another person was significantly related to HSB ($p < 0.001$) as a facilitating factor whereas, 'taking care of my family prevented me from going to the GP' ($p = 0.023$), was associated with delay. Further statistical analysis was performed using logistic regression which will now be described.

6.9 Univariate Logistic Regression

In order to examine the effects of the independent variables on delayed HSB, logistic regression was used (Polit and Beck, 2008). Initially, simple univariate analysis was performed to determine the association between each individual significant variable from the previous analysis and HSB (Eliott and Woodward, 2007). In order to ensure that all variables of statistical and clinical importance were included (Hosmer and Lemeshow, 2000) and to avoid disregarding any individual variables that were of borderline significance, variables having an association with HSB at the $p < 0.1$ level were selected for univariate regression. Throughout all logistic regression analyses, odds ratio greater than 1.00 ($OR > 1.00$) indicates increased likelihood of delayed HSB. Conversely, odds ratio less than 1.00 ($OR < 1.00$) indicates decreased likelihood of delayed HSB.

At first, univariate logistic regression was performed on the categorical (nominal and dichotomous) independent variables found to be significantly related to HSB at the $p < 0.1$ level, in the previous analysis. These variables included breast symptom type (four items); two items from the breast cancer knowledge scale (a breast lump never noticed before and clear drainage from nipple); alternative help seeking behaviour

(three items); symptom disclosure (yes/no); social constraints (one item: taking care of family) and health seeking habits (BSE frequency: monthly versus bi-monthly, rarely, never) (Table 6.17). Continuous (ordinal) independent variables included symptom belief relating to duration of the symptom (all three dimensions of the subscale) and consequences of symptom (one dimension of this subscale); symptom emotional distress (one item) and health service system utilisation (one item).

6.9.1 Univariate logistic regression results for categorical variables and delayed HSB

Knowledge of breast symptom identity, breast cancer knowledge, belief in alternative HSB, symptom disclosure and the social constraints relating to family commitments item were examined using a step by step approach, in order to determine which variables impacted most on delayed HSB (Table 6.17). Results demonstrated that women with a breast lump were less likely (OR = 0.54; $p < 0.001$) to delay whereas women presenting with breast pain (OR 1.47; $p = 0.043$) and nipple indrawn/changed (OR = 3.58; $p = 0.004$) were more likely to delay. Using the 'no' response as a reference point, univariate regression was performed on two items from the breast cancer knowledge scale. A significant relationship was evident between having a positive response to the items 'a clear drainage from one nipple' ($p = 0.040$; OR = 0.63), while the relationship between 'a breast lump I never noticed before' almost approached significance ($p= 0.055$; OR = 0.61). Results demonstrated that women who responded with 'yes' to the items 'a breast lump I never noticed before' and 'a clear drainage from one nipple', as being breast changes associated with breast cancer, were less likely to delay.

In relation to alternative help seeking behaviours, women who 'ignored the symptom and hoped it would go away" were far more likely to delay help seeking (OR = 9.07; p < 0.001). Using non-disclosure of symptom to another person as a reference point, the odds of women delaying decreased for women who confided in another person (OR = 0.24; p < 0.001). Examination of social constraints and taking care of family, women who answered 'not applicable', to this item, were markedly (62%) less likely to delay help seeking (OR = 0.38; p = 0.007). In relation to breast self examination, although not reaching statistical significance, an increased risk of delay was noted with each reduced frequency of BSE i.e. the less often women performed BSE, the more likely they were to delay (OR = 1.21) (Table 6.17).

Table 6.17 Logistic Regression for categorical variables and delayed HSB

Variable	Odds ratio	95% CI	p
Symptom Identity*			
Breast lump	0.54	0.36-0.84	**< 0.001**
Breast pain	1.47	0.95-2.27	**0.043***
Nipple indrawn or changed	3.58	1.44-8.90	**0.004***
Change in breast shape	1.95	0.89-4.28	0.098
Breast Cancer Knowledge **			
A breast lump I never noticed before	0.61	0.39-1.01	0.055
A clear drainage from one nipple	0.63	0.41-0.98	**0.040***
Alternative HSB ***			
Checked symptom periodically	1.79	0.95-3.36	0.70
Used alternative therapies	1.80	0.26-12.55	0.552
Ignored the symptom	9.07	4.65-17.70	**< 0.001***
Symptom Disclosure******			
Yes	0.24	0.10-0.55	**< 0.001***
Social constraints			
Taking care of my family *******			
No	0.49	0.26-0.94	**0.031***
Not applicable	0.38	0.19-0.77	**0.007***
Habits: BSE********			
Bi monthly, rarely, never	1.21	1.00-1.48	0.056

***p < 0.05**

Reference groups: * women without the symptom; ** no/ don' t know response
*** no/ n/a responses; **** women who did not disclose the symptom;***** yes response;
******monthly BSE

6.9.2 Univariate Logistic Regression for Continuous (ordinal) Variables and Delayed HSB

6.9.2.1 Beliefs Relating to the Breast Symptom

Symptom Duration

Logistic regression for the duration subscale demonstrated a statistically significant relationship between perceptions of symptom duration overall, and HSB (p= 0.013). Specifically, a one point increase in the total score (3-15) of the duration subscale score, indicating a belief that the symptom will last for a long time/ be of a permanent duration, suggested an increase in the risk of delay (OR =1.14; 95% ;CI = 1.03-1.27).

6.9.2.2 Symptom Consequences

Logistic regression demonstrated a weak association (p = 0.081), between the item 'my breast symptom has strongly affected the way others see me' and HSB. Women who 'neither agreed nor disagreed' with this item were less likely to delay HSB (OR= 0.60; 95% CI=0.34-1.07)

6.9.2.3 Symptom Emotional Distress

Logistic regression analysis was carried out to determine if being 'afraid' was strongly associated with delayed HSB. The relationship between being 'afraid' and delayed HSB was not statistically significant (p = 0.081). Results demonstrated that women who were afraid were less likely to delay (OR = 0.61).

6.9.2.4 Health Service System Utilisation

Regarding health service system utilisation (HSSU), while the relationship between 'agreement' with the item 'going without medical care I need because it is too

expensive' and delayed HSB was not significant, the odds of delaying help seeking increased by 1.44 for women who agreed with the statement.

6.9.3 Multiple Logistic Regression

6.9.3.1 Simultaneous entry approach

Multiple logistic regression was carried out to ascertain which variables had most impact on women's HSB and therefore, were most important in predicting delayed HSB. As in the case of the above univariate regression, to ensure that all variables of statistical and clinical importance were included (Hosmer and Lemeshow, 2000) and to avoid disregarding any individual variables that were of borderline significance, all variables found to be significant at the level $p < 0.1$ on univariate regression, were initially entered simultaneously into a multiple regression model (Table 6.18). These variables included symptom identity (four items); breast cancer knowledge (two items); beliefs relating to duration of symptom (all three dimensions of the subscale); consequences of symptom (one dimension of this subscale) and alternative HSB (three items); symptom emotional distress (one item); symptom disclosure (yes/no); social constraints (one item); health seeking habits (one item i.e. BSE: Yes: monthly/ bimonthly/ rarely versus No: never) and health service system service utilisation (one item) (Table 6.18).

Table 6.18 Multiple Regression model using simultaneous entry approach predicting the likelihood of delayed HSB

Variable	Response	Odds ratio	95% CI	*p*
Symptom Identity				
Reference Group	No			
Breast lump	Yes	0.61	0.32-1.17	0.134
Breast pain	Yes	0.97	0.52-1.81	0.913
Nipple indrawn or changed	Yes	3.60	1.04-12.45	**0.044***
Change in Breast shape	Yes	1.82	0.51-6.44	0.353
Breast Cancer Knowledge				
Reference group	No/don't know			
A breast lump I never noticed before	Yes	1.39	0.56-3.44	0.474
A clear drainage from one nipple	Yes	0.85	0.45-1.60	0.619
Symptom Beliefs				
Symptom Duration (subscale)		1.15	0.99-1.33	0.066
Consequences (one item)				
My breast symptom has affected the way others see me				
Reference group	Strongly disagree			
	Disagree	1.33	0.68-2.60	0.406
	Neither agree nor disagree	0.62	0.26-1.46	0.276
	Agree	0.00**		
Alternative HSB				
Reference group	No			
Checked symptom periodically	Yes	2.07	0.90-4.75	0.085
Used alternative therapies	Yes	0.29	0.02-4.63	0.372
Ignored the symptom	Yes	10.66	4.72-24.07	**<0.001**
Symptom Emotional Distress				
Reference group	No			
Afraid	Yes	0.32	0.14-0.71	**0.006***
Symptom Disclosure				
Reference group	No			
To another person	Yes	0.59	0.17-2.01	0.398
Social Constraints				
Reference group	Yes			
	No	0.71	0.27-1.84	0.477
	N/A	0.36	0.12-1.07	0.065
Breast Self Examination				
Reference group	No			
	Yes	0.92	0.30-2.79	0.885
Health Service System Utilisation				
Reference group	No			
Going without medical care due to expense	Yes	1.40	0.76-2.59	0.286

***p < 0.05;** ** no participants in this group delayed

Results demonstrated that the items most significantly related to delayed HSB were a presenting symptom of “nipple indrawn / changed” ($p = 0.044$), the alternative HSB of “ignoring the symptom and hoping that it would go away” ($p < 0.001$) and the symptom emotional distress item of “being afraid” on symptom discovery ($p = 0.006$). The model reiterates that women who presented with a “nipple indrawn or changed” were more likely to delay (OR = 3.60) as were those women who initially “ignored the symptom and hoped that it would go way” (OR = 10.66). Being afraid following symptom discovery was associated with less delay (OR = 0.32). Believing the symptom to be of longer duration almost approached significance ($p = 0.066$) indicating a trend towards increased risk of delay (Table 6.18).

6.9.3.2 Forward stepwise approach

In order to further ascertain reliability and robustness of the overall findings, variables reaching $p < 0.1$ in the univariate analysis were entered into a multivariate model using a forward stepwise approach. Results verified that the variables most significantly associated with HSB were a presenting symptom of ‘nipple indrawn / changed’ ($p = 0.005$), the alternative HSB of ‘ignoring the symptom and hoping that it would go away’ ($p < 0.001$) and the symptom emotional distress item of being ‘afraid’ on symptom discovery ($p = 0.005$). In this instance, a significant relationship was established between the belief that the symptom would be of longer duration ($p= 0.023$). Results demonstrated that the longer women perceived their symptom to last the more likely they were to delay help seeking (OR = 1.18) (Table 6.19). The process of logistic regression is summarised diagrammatically in Appendix 13.

Table 6.19 Multiple Regression model using forward stepwise approach predicting the likelihood of delayed HSB

Variable	Response	Odds ratio	95% CI	*p*
Symptom Identity				
Reference Group	No			
Nipple indrawn or changed	Yes	4.80	1.60-14.40	**0.005***
Symptom Belief				
Duration subscale		1.18	1.02-1.36	**0.023***
Alternative HSB				
Reference Group	No			
Ignored the symptom	Yes	10.72	5.06-22.70	**< 0.001**
Symptom Emotional Distress				
Reference Group	No			
Afraid	Yes	0.37	0.19-0.74	**0.005***

***p < 0.05**

6.9.4 Performance of the Multiple Regression Model

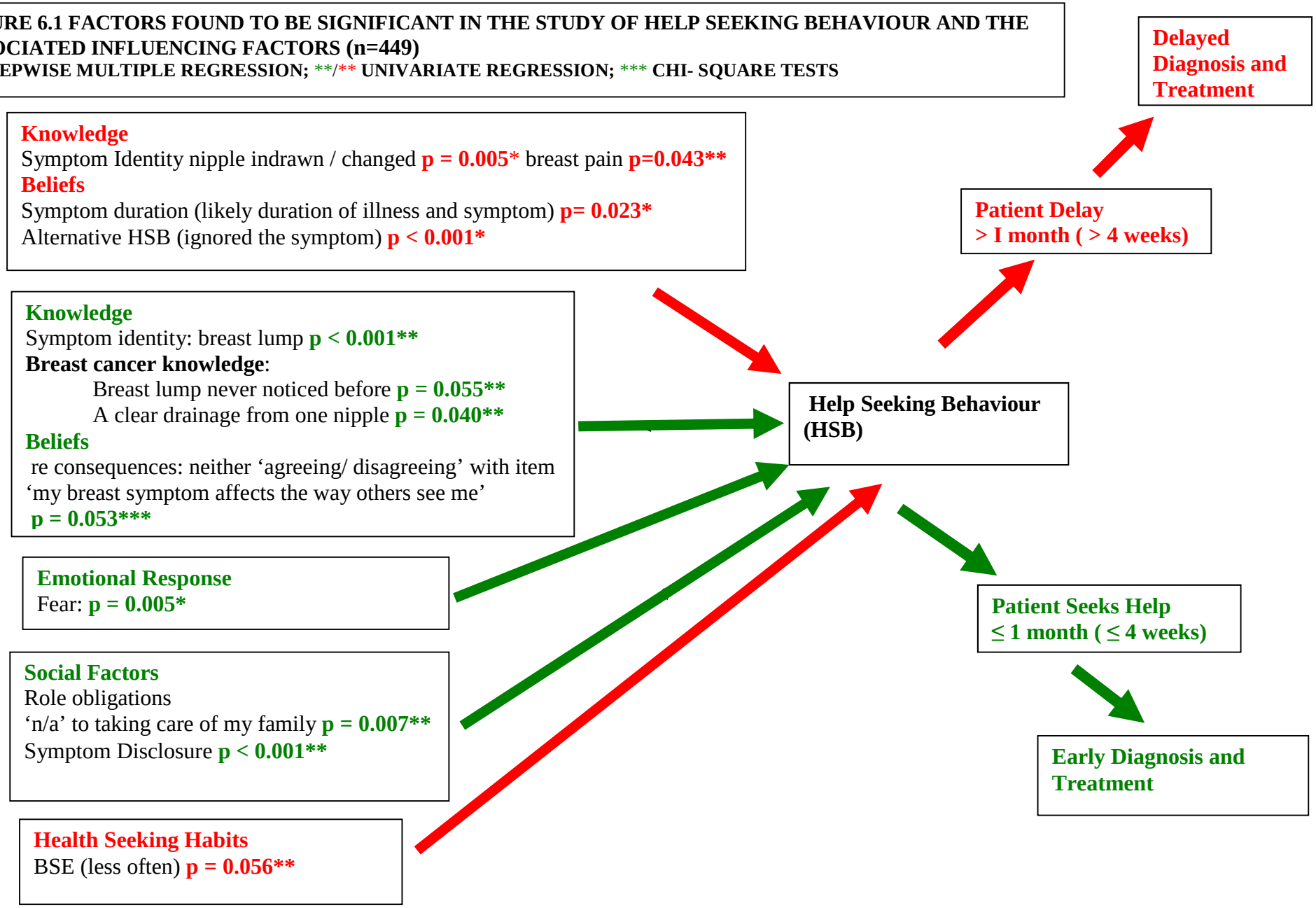
The Omnibus Test of Model Coefficients and the Hosmer-Lemeshow Test were used to assess the overall performance of the multiple regression model. The Omnibus Test of Model Coefficients provides an overall indication of how well the model performs (Pallant, 2007). Since a significant value ($p< 0.05$) is recommended for this test, results in this study (Chi-square = 84.12 d.f. = 20; $p < 0.001$) indicated that the model provided a fair representation of the data. The Hosmer-Lemeshow Test determines the model fit where a good fit is indicated by a significance value greater than 0.05 (Pallant, 2007). The result for this test (Chi-square = 7.497 d.f. = 8; $p = 0.484$) was not significant (as desired). This indicates that the model effectively describes the outcome variable (Hosmer and Lemeshow, 2000) ie women's HSB

Summary

This chapter presented findings on the study of the help seeking behaviour (HSB) of women on self discovery of a breast symptom and the associated influencing factors, in an Irish context. Findings on the relationships between independent categorical

variables and HSB ascertained using chi-square tests, were detailed. Results of t-tests, which assessed the difference between women who sought help promptly and those who delayed in relation to continuous variables, were then described. Throughout the chapter, findings were reported to reflect the variance in women's responses. Finally, findings from univariate and multivariate logistic regression, used to determine the strength of the relationships between variables (at the $p < 0.1$ level) and HSB are summarised in Table 6.20 (Appendix 13). The key findings are depicted diagrammatically in Figure 6.1.

FIGURE 6.1 FACTORS FOUND TO BE SIGNIFICANT IN THE STUDY OF HELP SEEKING BEHAVIOUR AND THE ASSOCIATED INFLUENCING FACTORS (n=449)
***/*STEPWISE MULTIPLE REGRESSION; **/** UNIVARIATE REGRESSION; *** CHI- SQUARE TESTS**



Red arrow and text denote the factors which are linked to delayed HSB (i.e. > 1 month); green arrow and text denote prompt HSB (i.e. ≤1 month)

Chapter 7 Discussion of Findings

Introduction

In this chapter, the findings of the study on the help seeking behaviour of a sample of women (n = 449) following self discovery of a breast symptom are discussed. The key factors found to impact on women's HSB in terms of facilitating and acting as barriers will be highlighted. The discussion will focus on the significant findings from a statistical and clinical perspective and how they relate to the current body of knowledge on HSB for self discovered cancer symptoms generally and breast cancer symptoms specifically.

7.1 Profile of Participants

A sample of 449 women participated in the study which took place in the breast clinics of two urban based hospitals in the Republic of Ireland. Data were collected over a period of four months. All women who participated in the study met the inclusion criteria of having a self discovered breast symptom and no previous history of breast cancer. To the author's knowledge this is the first large study undertaken on women's actual HSB on self discovery of a breast symptom utilising the conceptual framework (Figure 4.1) developed from the empirical and theoretical literature.

7.2 Help Seeking Behaviour (HSB) and Influencing factors

A review of the literature on the concept of help seeking led to the definition of help seeking as "a response to health changes and part of the broader process of health seeking behaviour" (O'Mahony and Hegarty, 2009a, E182). This operational definition was used in the current study which found that, 30.1% (n=135) of women delayed help seeking for more than one month. Prompt help seeking (within one

month / four weeks) was demonstrated by 69.9% (n=314) of women and of those who delayed, 13.4% (n=60) sought help within five to eight weeks and 16.7% (n=75) delayed for three months/twelve weeks or more. These findings indicate that while the majority of women sought help promptly, a considerable number (n=135) delayed for more than one month of whom 55.6% (n=75) delayed for three months or more. This is a cause for concern as it is highlighted that prompt help seeking for breast symptoms results in more favourable outcomes for women who are diagnosed with breast cancer (Richards et al 1999b; Richards, 2009a).

A qualitative study which explored the HSB of ten women who had self discovered breast symptoms (O'Mahony et al., 2011) confirmed that the "Help Seeking Behaviour and Influencing Factors" framework (Figure 4.1) provided an appropriate conceptual framework to guide the current study. The relationships between the variables within the framework and HSB were subsequently explored using a descriptive co-relational design. The final multiple regression model (Table 6.19) demonstrated that the four items most significantly related to HSB were: the presenting symptom of 'nipple indrawn/changed' ($p = 0.005$), 'ignoring the symptom and hoping that it would go away' ($p < 0.001$), the emotional response of 'being afraid' on symptom discovery ($p = 0.005$) and the belief in longer symptom duration ($p = 0.023$). It was verified that women who presented with nipple related symptoms were more likely to delay (OR = 4.80) as were women who ignored the symptom and hoped it would go away (OR = 10.72). The longer women believed that their symptom would last, the more likely they were to delay (OR = 1.18). Conversely, being afraid following symptom discovery was associated with less delay (OR = 0.37).

Univariate logistic regression established that prompt HSB was significantly related to breast cancer knowledge i.e. responding "yes" to the items 'a clear drainage from one nipple' being a breast change associated with breast cancer ($p = 0.040$) and the social factors of symptom disclosure to another person ($p < 0.001$) and the 'not applicable' response to social constraints relating to family commitments ($p = 0.007$). A positive response to the breast cancer knowledge item 'a breast lump I never noticed before' almost reached significance ($p = 0.055$) and was associated with less likelihood to delay HSB. Therefore, from a holistic perspective, of the influencing factors studied those impacting most significantly on women's HSB were knowledge and beliefs and emotional responses (Figure 6.1). These findings will now be discussed together with any findings of clinical importance.

7.3 Socio-Demographic Factors and HSB

While no significant relationships were identified between socio-demographic factors and HSB, commentary on data for delayers and non-delayers (Table 6.7) will be included as deemed relevant. Similar to previous studies on women with self discovered breast symptoms (Meechan et al., 2002; Friedman et al., 2006; O'Mahony and Hegarty, 2009b) the age profile of women in the current study ranged from18 to over 80 years and the majority (84.7%) were under 50 years. In addition, amongst the delay group (n=135) delay was more common (31.9%; n = 43) in the 31-40 age group which corroborates with previous findings (Friedman et al., 2006 and O'Mahony and Hegarty, 2009b). Although, the reverse was found in other studies where older age was associated with more delay (Burgess et al., 2000; Bish et al., 2005; Burgess et al., 2008; MacLeod et al., 2009). Younger age profiles are to be expected in studies on self discovered breast symptoms as opposed to symptoms being identified through

mammography screening. In Ireland, the Breast-Check screening programme currently in operation nationwide advocates that all women aged between 50-64 years be invited to attend for breast screening (Department of Health and Children, 2006). While breast cancer is more common in the 50+ age group, figures from the National Cancer Registry Ireland (NCRI) indicated that of the 2,740 women diagnosed with breast cancer in Ireland in 2009, 38.7% (n=1,060) were under 50 years (personal communication with NCRI, February 2011), which is reflective of a cohort of women who will not be routinely called for mammography, as in the current study. This highlights the need for all women regardless of age, to seek help promptly for self discovered breast symptoms.

The majority of women in both the 'delay' and 'prompt help seeking' groups were in a relationship and living with another person, suggesting that they had someone to whom they could disclose their self discovered symptom. Additionally, the majority in both groups were employed, had health insurance and were educated to third level. In relation to education, 50% (n=68) of women in the delay group were educated to third level which is consistent with a previous study (O'Mahony and Hegarty, 2009b) on the same topic. Conversely, other studies (Facione et al., 2002; Montazeri et al., 2003; Friedman et al., 2006; MacLeod et al., 2009; Waller et al., 2009), have reported that delay was associated more with lower educational levels. Nevertheless, figures in the current study reflect educational trends in Ireland, where it is reported that women are more likely to have a third level education than men (Central Statistics Office, 2011). Moreover, previous studies are indicative of HSB amongst diverse populations (United States; Iran; United Kingdom) whereas the majority of women (86.6%) in the present study were of Irish nationality.

While not significant, the above findings provide some insight into the socio demographic profile of women who delayed versus those who sought help promptly, in the current study.

7.4 Knowledge and Beliefs

Symptom knowledge

Women's symptom related knowledge was ascertained by asking them to identify their presenting symptom(s). It was found that 'nipple indrawn/ changed' was the symptom most significantly related to HSB. In addition, univariate logistic regression confirmed significant relationships between HSB and the presenting symptoms of a breast lump, and breast pain. Delay was less likely to occur for women with a breast lump whereas women with breast pain or 'nipple indrawn/ changed' were more likely to delay. Similarly, in the qualitative validation study (O'Mahony et al., 2011) while women's knowledge about breast symptoms varied, most women were aware that a lump in the breast was significant.

Previous studies also highlighted that the nature of the breast symptom impacted on women's HSB. Nosarti et al., (2000) noted that a presenting symptom of a breast lump was associated with less delay amongst a sample of women with self discovered symptoms attending a breast clinic in London. Limited knowledge of non lump symptoms was also highlighted by Grunfeld et al., (2002) amongst women (n=996) from a random sample of the general population in Britain. Similarly, identification of potential symptoms was found to be an important factor in predicting help seeking intentions across all age groups of women (Grunfeld et al., 2003) and found to be the variable within the Common Sense Model of Self Regulation that most strongly predicted the intention to seek help (Hunter, Grunfeld and Ramirez , 2003).

The ‘nature of the symptom’ (as in breast lump or non lump symptoms) was significantly related to prompt HSB for self discovered breast symptoms in a previous study by the researcher (O’Mahony and Hegarty, 2009b). Similarly, discovery of a breast symptom other than a breast lump was identified as the most significant determinant of patient delay amongst a sample of women (n=185) already diagnosed with breast cancer (Burgess et al., 1998). This study reported that delay of three months or more occurred amongst 41% (n=23) of women who had noticed a non lump symptom (e.g. pain, nipple changes or discharge, distortion of the breast) compared with 10% (n=13) who had noticed a breast lump (Burgess et al., 1998) Additionally, women have linked the “seriousness” of a breast symptom with how closely it matched their expectations of what a breast cancer symptom should be i.e. “a painless breast lump” (Burgess et al., 2001). Bish et al., (2005) also highlighted that the type of breast symptom found by women impacted on their HSB. Meechan et al., 2002 concluded that “what” women discovered impacted on HSB more so than how they discovered it. Additionally, a recent Australian population based study (Jones et al., 2010), found that women were more likely to seek help for a breast lump, thickening of the breast or swelling in the armpit. Conversely, Unger-Saldana and Infante-Castaneda (2011) identified that pain was the most common symptom to trigger help seeking for breast symptoms amongst a sample of Mexican women. While women need reassurance that nine out of ten breast lumps are benign (Irish Cancer Society, 2011), this finding highlights the importance of encouraging women to seek help promptly for both lump and non lump related breast symptoms.

Symptom beliefs

Women's beliefs surrounding the cause, duration, consequences, cure/control (Leventhal et al., 2003) and outcome of their breast symptom were ascertained using an adaptation of the Illness Perception Questionnaire (Weinman et al., 1996) and two questions adapted from Burgess et al., (1998). Overall, responses to the items on the symptom perception questionnaire subscales varied and a significant relationship was found only for the duration subscale and HSB and one item on the consequence subscale. Additionally, the neutral response was endorsed in a lot of cases, suggesting that women were uncertain about their breast symptom as would be expected.

A significant relationship was found between beliefs regarding symptom duration and HSB ($p = 0.023$) indicating that the longer women perceived their symptom would last the more likely they were to delay (OR = 1.18). This finding is surprising as one would expect the reverse to be the case. Possibly, some women were more pessimistic or fatalistic (Wong-Kim et al., 2003 and Kishore et al., 2007) in outlook and resigned to the belief that their symptom would last for a long time. Additionally, perhaps the more women perceived their symptom to be associated with a long term illness (such as breast cancer) the more likely they were to delay. Alternatively, this finding could be linked to denial and avoidance, where women postponed help seeking and decided to "wait and see" and monitor their symptom (Tjemsland and Soreide, 2004). Conversely, previous research confirmed that women's belief in 'the earlier I got it seen to the better' facilitated help seeking and considering the symptom as 'harmless' both facilitated and deterred help seeking (O'Mahony and Hegarty, 2009b).

Scott et al., (2007) (who also utilised the dimensions of the cognitive element of the Self Regulation Model in a qualitative study of symptom interpretation amongst a

sample of patients (n=57) with potentially malignant oral symptoms) reported that uncertainty about symptom identity made it difficult for patients to interpret their symptoms initially. It was only when symptoms persisted beyond the expected timeline that patients were forced to reappraise the symptom and reconsider their beliefs concerning symptom attribution (Scott et al., 2007). Similarly, persistence of breast symptoms was one of the factors to trigger help seeking amongst a sample of Mexican women with self discovered breast symptoms (Unger-Saldana and Infante-Castaneda, 2011)

In relation to women's beliefs concerning the consequences of their symptom, a trend was noted between the item "My breast symptom has strongly affected the way others see me" and HSB (linear- by- linear association: $p = 0.053$ following chi-square test.). Univariate logistic regression found a weak association ($p = 0.081$) between women 'neither agreeing or disagreeing' with this item and HSB, where women were 60% less likely to delay. In addition, a review of women's responses to individual items on this scale highlighted that 36.7% (n =159) of women disagreed that the symptom "is easy to live with". Similarly, 39.7% (n =175) disagreed that the symptom had not 'had much affect' on their lives, suggesting that the symptom was problematic for these women as would be expected.

Since the study was focusing on symptom discovery and HSB, the consequences subscale was adapted to examine women's beliefs surrounding the consequences of the symptom at that point in time, as opposed to the prospective consequences or final outcome of the symptom. The literature reviewed on knowledge and beliefs concentrated more on women's beliefs relating to the outcomes of their symptom,

where associating symptoms with cancer were identified as stimulating HSB (DeNooijer et al., 2001a).

An earlier study focusing on African-American women's (n=352) intentions to seek help, (Facione et al., 1997) found that women's failure to consider the negative consequences of not seeking help promptly (such as 'more serious disease'; 'more extensive surgery'; 'possible increased risk of death') was associated with delayed help seeking. In addition, having positive beliefs about the consequences of help seeking was found to be a significant predictor of intention to seek help, amongst older women in a sample from the general population (n=546) (Grunfeld et al., 2003), while one of the best predictors of intentions not to seek help were beliefs that breast cancer would have negative economic implications. Although no relationship was established between beliefs relating to the consequences of the symptom and HSB in the current study, it could be argued that this could have been influenced by the fact that this study focused on actual HSB for a self discovered breast symptom as opposed to intended HSB for hypothetical symptoms, where women might be more objective in their responses. This reiterates the suggestion of uncertainty surrounding women's beliefs about their self discovered breast symptoms.

Beliefs in alternative help seeking behaviours

What women did when they found the symptom prior to seeking help was titled 'Alternative Help Seeking Behaviour' and addressed women's beliefs in behaviours such as 'checking the symptom periodically'; 'praying to God'; 'ignoring the symptom' and 'listening to the advice of others'. Multiple logistic regression determined a significant relationship between 'ignoring it and hoping that it would go away'($p < 0.001$) and HSB. As expected, women who ignored the symptom were

more likely to delay (O.R. 10.72). This echoes findings from the qualitative validation study, where the four women who delayed help seeking all mentioned being "in denial" of their breast symptom (O'Mahony et al., 2011).

Similarly, women mentioned 'avoidance and fear' as barriers to HSB in an earlier study by Lauver et al., 1995. Later, in an Irish context, Kennedy et al., (2000) reported that 12% (n=25) of women from the sample (n=199) delayed HSB because they wanted to "avoid thinking about it as they were afraid". Choosing "to wait a while before making an appointment" was also found to be significantly related to delayed HSB for self discovered breast symptoms by O'Mahony and Hegarty (2009b). Additionally, denial was also reported to be a common coping strategy amongst Mexican women with breast symptoms who delayed help seeking (Unger-Saldana and Infante-Castanda, 2011). These findings corroborate with an earlier Australian study (Margarey et al., 1977), suggesting that delayed HSB was related to "unconscious avoidance defence mechanisms" such as denial and suppression of feelings following breast symptom discovery. While denial and avoidance can be seen as coping strategies, they are maladaptive if the outcome leads to a delayed diagnosis of breast cancer.

Breast Cancer Knowledge

Women's breast cancer knowledge was ascertained by the 15 itemed Breast Cancer Knowledge Scale (Facione et al., 2002), which required women to indicate whether or not they considered any of the breast symptoms listed to be changes that might be indicative of breast cancer. Knowledge levels ranged from low (score 0-4: 31.5%; n=141), medium (5-9: 31.5% n=141), to high (score 10-15: 37.1% ; n=166) (M = 7.5; SD = 4.4). Conversely, Facione et al (2002) reported knowledge scores ranging from

extremely poor (14% identified breast lump only) to well informed (10% correctly identified all or all but one symptom) amongst a multiethnic sample (n=699) of asymptomatic women in the San Francisco bay area. Unlike Facione et al.'s (2002) findings, where women who were likely to delay scored significantly lower on the breast cancer knowledge scale than women who were not likely to delay ($p < 0.001$), in the current study, no significant relationship was found between overall level of knowledge relating to breast changes associated with breast cancer and HSB. However, the fact that at least 11 items were not recognised as breast changes associated with breast cancer by 31.5% of the current sample is a cause for concern.

Additionally, a review of women's responses to individual items, indicated that the majority of women (84.8%; n=369) considered a breast lump or a lump under the arm (73.5%; n=316) to be changes associated with breast cancer. Constant pain in one area of the breast was the next most common breast change that women (65.7%; n=286) associated with breast cancer. Univariate logistic regression confirmed that women who responded 'yes' to 'a clear drainage from one nipple' were less likely to delay (OR = 0.63; $p = 0.040$) as were women who responded 'yes' to the item ' breast lump I never noticed before' (OR = 0.61), which almost reached significance ($p = 0.055$). Therefore, it was apparent that women recognised these breast changes as being symptoms associated with breast cancer and discovery of such symptoms was found to be more likely to facilitate prompt help seeking. Although, it would be ideal if all breast changes were endorsed as possible signs of breast cancer, it is reassuring to know that the majority of women were aware that lump associated changes are associated with breast cancer and indicate the need for prompt HSB. Nonetheless, the fact that knowledge levels were low amongst a considerable number of women cannot be ignored. This finding corroborates with findings relating to symptom identity

(discussed in the previous section) where women with a breast lump were less likely to delay.

Women's interpretation of symptoms has been highlighted previously to determine HSB where women (n=38) diagnosed with breast cancer were found to be unaware that their breast pain or nipple symptoms could be a breast cancer symptom (Facione and Dodd, 1995). Interpreting the potential threat of breast symptoms was also a theme that emerged from Facione and Giancarlo's (1998) study on narratives of women (n=80) around breast symptom discovery and cancer diagnosis.

In relation to other cancer symptoms, an English study (Pullyblank et al., 2002) highlighted lower levels of knowledge regarding colo-rectal cancer (CRC) as opposed to breast cancer knowledge ($p < 0.0001$) amongst a sample of patients (n=75) attending clinics for breast and colorectal screening. Lack of knowledge leading to failure to attribute symptoms to oral cancer have also contributed to delayed HSB amongst samples studied in the UK (Scott et al., 2006; Scott et al., 2007; Scott et al., 2008a; Scott et al., 2008b). Similarly, lack of knowledge and the vague nature of symptoms relating to CRC (Pullyblank et al., 2002), ovarian cancer (Koldjeski et al., 2004) and lung cancer (Corner, 2006; Smith et al., 2011) were associated with delayed help seeking. Thus, knowledge of breast changes associated with breast cancer needs constant reiteration to the public in order to promote prompt help seeking and early diagnosis.

Findings from the current study, reiterate that inadequate knowledge about breast symptoms and breast changes associated with breast cancer, are factors affecting women's initial appraisal and interpretation of a self discovered breast symptom. Subsequently, women will either, misinterpret, deny or avoid the symptom resulting

in delayed HSB. Alternatively, recognition, identification and acknowledgment of the problem has potential to lead to prompt help seeking. This finding is surprising in view of the continuous media attention and public health campaigns (Irish Cancer Society, Marie Keating Foundation, Ireland) currently promoting early detection of breast cancer through encouraging women to seek help for self discovered breast changes. In addition, current HSE guidelines recommend that women, presenting with breast symptoms be referred urgently (in the case of a breast lump in women over 35 years of age) and early referral is suggested (for breast lump in women under 35 years and "not" blood stained nipple discharge) (HSE, 2009). This highlights the need for women to be breast aware and knowledgeable about all breast changes associated with breast cancer.

7.5 Emotional Response(s)

A significant relationship was detected between the item 'being afraid' on symptom discovery and HSB ($p = 0.005$). This item was associated with less likelihood of delay (OR = 0.37) whereas, women who were not 'afraid' tended to delay. Similarly, another Irish study found that anxiety surrounding initial symptom discovery correlated with prompt HSB (O'Mahony and Hegarty, 2009b). This was reiterated in Meechan et al's (2003) New Zealand study where initial symptom distress amongst a sample of women (n=85), was significantly related to less delay. De Nooijer et al., 20001b identified that fear acted as both a stimulus and a barrier to HSB for women. This was also highlighted by GP's who participated in the study and reiterated in women's narratives relating to breast symptoms and HSB (Facione and Giancarlo, 1998). Similarly, fear both accelerated help seeking for Mexican women who wanted

to receive a diagnosis and delayed help seeking for those who preferred to avoid confirmation of diagnosis (Unger-Saldana and Infante-Castaneda 2011).

Fear was also related to help seeking intention ($p<0.05$) (Facione et al., 1997) and the variables of affective response to the symptom and expected treatments, (though not tested) were included in the J-delay Model (Facione et al., 2002). Thus, highlighting that emotional responses to symptom discovery are best studied in retrospect to the actual event (as in the current study) where participants can recall and describe how they really felt when they discovered the symptom as opposed to the hypothetical situation, where it is difficult to describe emotional responses to potential symptoms.

Conversely, Nosarti et al., (2000) found that psychological distress (indicated by an expression of fear of cancer) was linked to delay amongst women with breast symptoms. This corroborates with research already mentioned above in the case of avoidance of symptoms and HSB due to fear (Kennedy et al., 2000; Lauver at al., 1995). While the initial emotional response to finding a breast symptom was not significantly related to delay amongst a sample of women with breast symptoms attending a clinic in Houston Texas (Friedman et al., 2006), some of the most frequently cited psychologically related reasons for waiting to seek help were "worry that it might be cancer" (39%; n = 40); "worry regarding cancer treatment" (13%; n=13); "fear of breast loss" (15%; n=16) and not "wanting to think about it" (10%; n =10).

Bradley (2005) reported no relationship between worry and delay (delay was minimum with 86% of the sample seeking help within one to four weeks of symptom discovery) amongst a sample of African American women (n=60) who were diagnosed with breast cancer. However, as would be expected, 67% (n=40) reported

high levels of anxiety following diagnosis. In contrast, Iwamitsu et al., (2005) found that women with a benign diagnosis (who were highly anxious) reported significantly more psychological distress on their first visit to the breast clinic compared to their second visit when their diagnosis was confirmed. Tjemsland and Soreide, (2004) concluded that delayed help seeking was due more to the degree of control of symptom related anxiety rather than the level of anxiety experienced amongst women with self discovered symptoms who were diagnosed with breast cancer

Conversely, Burgess, et al (1998) reported that women's initial emotional response depended on the nature of the presenting symptom with women whose symptom included a breast lump being significantly more likely to experience fear (p= 0.02). This was supported by Scott et al., (2007) who reported a feeling of general unconcern about their symptom at the time of discovery amongst a sample of patients diagnosed with oral cancer (n=57), which was likely to have impacted on the HSB for some of the 24% of patients who delayed.

While findings in the literature on the impact of emotional responses on HSB are inconsistent, the individual nature of the emotional response to cancer symptom discovery generally and breast cancer symptoms, more specifically is apparent. In relation to breast cancer symptoms, as found in the current study, fear at the time of symptom discovery is likely to encourage women to seek help promptly (particularly in the case of a breast lump) while in some cases, fear can militate against help seeking. Thus, reiterating that the nature of the presenting symptom, the resultant emotional response and subsequent HSB, are inextricably linked.

7.6 Social Factors

Symptom Disclosure

Univariate logistic regression determined a significant relationship between disclosure of the symptom to another person and HSB ($p < 0.001$), where women who disclosed the presence of a symptom to another person were more likely to seek help promptly (OR = 0.24). This corroborates with previous findings that disclosure of symptoms to another person or somebody close facilitated help seeking (Burgess et al., 1998; De Nooijer et al., 2001a; Bish et al 2005; Burgess et al., 2008; Gulatte et al., 2010; Unger-Saldana and Infante Castaneda, 2011). Conversely, some women in the validation qualitative study (O'Mahony et al., 2011) had reservations about telling significant others about their symptom, for fear of causing them undue worry.

Meechan et al., (2003) reported that disclosure of the symptom to a partner or another person was unrelated to help seeking. However, 79% of women in the sample (n=85) talked to their partner, family member or a friend about the symptom, which could have impacted on prompt help seeking for the 69% (n=67) of women who visited their GP within 30 days of symptom discovery. Interestingly, while symptom disclosure to another person generally results in positive outcomes, it has also been reported to have the negative effect of reaffirming misinterpretation of symptoms amongst some Mexican women who delayed help seeking (Unger-Saldana and Infante Castaneda, 2011). Nonetheless, it can be concluded that disclosure of breast symptoms to another person is a significant facilitator of prompt HSB.

Social Constraints

A significant relationship was found between HSB and the item 'taking care of my family (children / older relative) prevented me from going to the GP' (p = 0.023). Univariate logistic regression demonstrated that women who endorsed the 'not applicable' response to this item, were markedly (62%) less likely to delay help seeking (OR = 0.38; p = 0.007). Therefore, it could be surmised that lack of family commitments (due to absence of family/ presence of support) could have facilitated help seeking. Both family and work commitments contributed to delayed HSB amongst four women interviewed in the qualitative validation study (O'Mahony et al., 2011). Similarly, a more recent series of British studies identified practical issues (being too busy; having other things to worry about) as barriers to help seeking for actual cancer symptoms (Simon et al., 2009) and hypothetical cancer symptoms (Robb et al., 2009;Waller at al., 2009).

Previous studies also highlighted that competing social roles (e.g family commitments and work commitments) acted as barriers to help seeking (Facione 1993; Lauver et al, 1995; Facione et al., 1997; Facione and Giancarlo, 1998; Burgess et al., 2001; Facione et al., 2002; O'Mahony and Hegarty, 2009b). Facione et al., (2002) reported that while perceived constraints relating to role obligations were rare, they were endorsed significantly more often by women who were likely to delay as opposed to those not likely to delay (t = 6.83, P < 0.001). However, this difference was more obvious for constraints relating to the employee role (22.2%; n=155), compared to spouse/partner (14.7%; n=102) or child/ elder care provider roles (16.6%; n=116). In relation to family commitments, the "moral obligation" of help seeking (i.e. the extent that one considers it an obligation to themselves and their family to seek help for cancer

symptoms) was found to be significantly related to intentions to seek help ($p < 0.01$) (DeNooijer et al., 2003). Thus, social factors relating to work and family commitments have potential to impact both positively and negatively on HSB for self discovered breast symptoms.

7.7 Health Seeking Habits

Health Seeking Habits focused specifically on the regularity of BSE and mammography. Chi-Square test results found evidence of a trend between overall frequency of BSE and delayed HSB (linear-by-linear association 3.65; d.f. = 1 $p = 0.056$), which was upheld on univariate logistic regression, suggesting that the less often women performed BSE the more likely they were to delay (OR = 1.21). In addition, frequency of BSE performance ranged from 'monthly' (36%; n=160) to 'two monthly' (18%; n=80) to 'rarely/ never' (46%; n=204).

These findings support previous research (Meechan et al., 2002, 2003) on delayed HSB among New Zealand women (n=85), where no difference in delay was reported between those who performed BSE and those who did not. However, a trend ($p=0.07$) for women, whose presenting symptom was pain, to wait longer before seeking help than women who discovered the symptom by chance or through BSE, was noted, suggesting that BSE was more likely to facilitate HSB (Meechan et al., 2002, 2003). Although 65.7% (n=65) of women in O'Mahony and Hegarty's (2009b) study (n=99) regularly performed BSE, no significant relationship was found between women's health seeking habits which included BSE (together with frequency of visit to GP, and mammography) and HSB.

Earlier, Margarey et al., (1977) identified that amongst a sample (n=90) of women with breast cancer symptoms, those who did not practice BSE were more likely to

have a malignant outcome. In a sample (n=60) of women diagnosed with breast cancer, Bradley et al (2005) reported that breast symptoms were found through BSE for 43% (n=26) of women. While the evidence surrounding the effectiveness of BSE is limited, many studies focusing on knowledge and beliefs and HSB also included the concept of BSE. In a sample of women (n=712; aged 67-73), Linsell et al (2008) reported that almost one third of women (n=220; 31.1%) indicated that they were not confident in detecting a breast change with 15% (n=108) not confident about how their breasts normally felt and 19% (n=137) of women rarely if ever checked their breasts. Surprisingly, women who were more highly educated were less likely to check their breasts compared to women with no education, although this finding was significant only for the most highly educated group ($p = 0.024$) of women. Subsequently, Burgess et al., (2008) included 'confidence in detecting a symptom' in their framework for development of a psycho-educational intervention encouraging women to seek help promptly. BSE was also found to be low amongst a younger sample of Iranian women (n= 1402; 20-80 years) (Montazeri et al., 2008), although it's performance was associated more with having higher education and being informed about breast cancer generally. Thus, highlighting that women need to be equipped with the knowledge and skills necessary to detect breast symptoms.

Conversely, Facione (1999) found that lower perceived access to health services was associated with less frequent performance of BSE. In addition, lower BSE rates were associated with having a male practitioner (Wu et al., 2006). While there is continuing debate concerning the appropriateness of BSE, it is reiterated that the best strategy for reducing cancer is early detection, which in the case of breast cancer includes breast awareness and early HSB (National Cancer Forum, 2006; Irish Cancer Society, 2011).

Moreover, the national cancer registry (NCRI) clearly stipulates on their website that "women need to examine their breast once a month" (NCRI, 2011) as one of the ways to lower the risk "of developing or dying from cancer" Thus, promotion of breast awareness through women having the confidence to "look at and feel" their breasts, (Irish Cancer Society, 2011) is vital.

7.8 Health Service System Utilisation

Access to health services

No significant relationship was found between women's perceived access to health care and HSB. However, findings are discussed in relation to their clinical relevance to HSB. Overall, women's perceptions of access to health services (their GP, in this instance) were positive. These findings were supported by the qualitative validation study where women were complementary of the health services overall and commented that access to services was good (O'Mahony et al., 2011). Although one woman commented that regardless of the type of 'medical cover', at times access can be problematic due to difficulties within the health care "system". These findings corroborate with previous studies where women reported good access to health care services overall (Facione 1999; Facione et al., 2002). In addition, help seeking intention has been significantly related to perceptions of good access (Facione, 1999) and likelihood to delay was significantly related to lower perceived access *(*$p < 0.001$*)*. Preference for a female HCP influenced both intentions to seek help (Facione et al., 2000) and actual help seeking (Nosarti et al., 2000). The majority of women (67.9%; n=290) in the current study also agreed that having a female GP makes it easier for them to attend.

Expenses

Following re-categorisation of responses to items on the PAHS scale into 'Yes' and 'No', statistically significant relationships were not detected. However, it is important to note that of the women who responded 'yes' (n=145) to the item 'sometimes I go without the medical care I need because it is too expensive', 35.2% (n=51) delayed help seeking. In addition, delay occurred amongst 31.6% (n=30) of women who responded positively (n=95) to the item 'It is difficult for me to go to the GP as I do not have a medical card'. Therefore, although not significant, expense was an issue for some women in the current sample in relation to accessing the health services

As already highlighted, Facione et al., (1997) found that help seeking intention was positively and significantly related to perceptions of health care access. In addition, narratives surrounding breast symptom discovery (Facione and Giancarlo, 1998) and cancer diagnosis highlighted that poverty was an inhibiting factor for help seeking amongst many women. In addition, perceived access to health care was significantly related to family income level ($p < 0.001$), having money to spend on healthcare ($p<0.001$) and being insured ($p < 0.001$) (Facione, 1999). Anticipated cost was also a perceived barrier to help seeking for a sample of women (n=99) with breast symptoms, in Houston, Texas (Friedman et al., 2006), although it is suggested by the researchers that this cost could be related to indirect expenses associated with help seeking as opposed to paying for the health provider's visit. These findings although not significant in the current study, highlight the impact of monetary issues on perceived access to health care, which has potential to impact on HSB in the event of breast symptom discovery.

Personal Experience of Prejudice

In relation to women's perceptions of experienced prejudice, 19.5% (n=86) of women indicated that they had 'not always been treated respectfully by doctors and nurses', of whom 26.7% (n=23) delayed help seeking. In addition, 32.1% (n=141) of women disagreed with the statement 'my own health has never been affected by discrimination' of whom 31.2% (n=32) delayed. These responses, while they did not have a significant impact on women's HSB, are a cause for concern. Additionally, two women in the qualitative validation study mentioned incidents of perceived prejudice relating to the experiences of family members as opposed to their own personal experiences. (O'Mahony et al., 2011).

In a study on cancer beliefs (Wong-Kim et al., 2003), personal experiences of discrimination in the community (due to a belief in the contagiousness of cancer) occurred when it became known that participants had cancer. Prejudicial treatment (both general and personal) has previously been reported amongst multi-ethnic samples of women in the United States (Facione, 1999; Facione et al., 2002; Facione and Facione, 2007). In testing the adequacy of the Judgement to Delay model (n=699), personal experience of prejudice was associated with likelihood to delay for both Latino (p<0.001) and black (p<0.001) women (Facione et al., 2002). Additionally, lesbian women were likely to experience significantly more prejudicial treatment than either heterosexual or bisexual women (Facione, 1999; Facione and Facione, 2007). Although sexual orientation was not examined in the current study, as already alluded to, discrimination and lack of respect by HCPs were experienced by some women in the sample, which does give cause for concern. The 'Helpseeking

Behaviour and Influencing Factors' conceptual framework used to guide the current study will now be evaluated.

7.9 Evaluation of the conceptual framework guiding the study

According to Fawcett (2005) the terms conceptual model and conceptual framework are synonymous. Therefore, Fawcett's (2005) framework for analysis and evaluation of nursing models will be used to evaluate the "Help Seeking Behaviour and Influencing Factors" framework (Figure 4.1) used to guide the current study. The key issues to be addressed are the purpose, origins, comprehensiveness, generation of theory, logical congruence and credibility of the framework.

The purpose of the conceptual framework was to outline the factors which act as facilitators and /or barriers to help seeking behaviour (HSB). The framework (Figure 4.1) was developed from an amalgamation of the empirical and theoretical literature (Facione et al., 2002; Meechan et al., 2003, 2002; Leventhal et al., 2003 and O'Mahony and Hegarty, 2009b). In particular, The Judgement to Delay Model (Figure 1.2) (Facione et al., 2002) which highlighted the factors influencing women's intentions to delay HSB for hypothetical self discovered breast symptoms, guided development of the framework. Additionally, the cognitive elements of the Common Sense Model of Self Regulation (Figure 1.3) (Leventhal et al., 2003) allowed for the operationalistion of women's knowledge and beliefs surrounding their breast symptom in terms of it's cause duration, consequences and curability/ controllability. The framework is comprehensive in that it outlines the key factors impacting on HSB following self discovery of a breast symptom, as identified in the literature. These factors can facilitate prompt HSB the outcome of which is early diagnosis and treatment if necessary. Conversely, the factors can act as barriers to HSB resulting in

delay in visiting a HCP and ultimately delayed diagnosis and treatment, where necessary.

According to Fawcett (2005) it is expected that a nursing model leads to the generation of theory. Therefore, this criterion seeks to determine the theories that have been generated from the framework (Fawcett, 2005 page 68). The purpose of the framework was to outline the factors known to facilitates or inhibit help seeking behaviour for self discovered breast symptoms. This led to the formulation of hypotheses which were subsequently tested. Knowledge emanating from the study describes and explains the help seeking behaviour of the sample and can be used to predict potential delayers. In addition, it is anticipated that further refinement of the framework based on the current findings will lead to an intervention to promote prompt help seeking for self discovered breast symptoms amongst women, in an Irish context.

Logical congruence is evaluated by addressing whether or not the components of the framework reflect logical reformation of diverse perspectives (Fawcett 2005). The framework was developed from an amalgamation of the theoretical and empirical literature from the perspective of both women's intentions to seek help for hypothetical breast symptoms (Facione et al., 2002) and women's help seeking for actual symptoms (Meechan et al., 2003, 2002; O'Mahony and Hegarty 2009b). Furthermore, the appropriateness for the framework for the current study was confirmed by a qualitative descriptive study (n=10) (O'Mahony et al., 2011) which also helped the researcher to further understand women's experience of symptom discovery and subsequent HSB. In addition, it influenced the structure of the questionnaire package (Appendix 1b) to reflect the sequence of events from symptom

discovery to HSB as logically and realistically as possible. Additionally, the "Help Seeking Behaviour and Influencing Factors" framework provides an holistic representation of the factors likely to impact on women's HSB for actual self discovered breast cancer symptoms.

Finally, credibility of the framework is evaluated through determining its social utility, social congruence and social significance (Fawcett, 2005). In terms of social utility, the framework was used to depict the key factors impacting on HSB. Review of the literature identified the key dimensions and variables linked to HSB (Figure 5.1) from which testable hypotheses were proposed (Chapter 5). Social congruence assesses whether or not the framework leads to outcomes that meet the expectations of the public and health care professionals of various cultures and diverse geographical regions (Fawcett, 2005). The study identified the key factors facilitating HSB (i.e. fear on symptom discovery) and inhibiting HSB (knowledge relating to the non lump symptom of 'nipple indrawn/changed'; the belief in the alternative HSB of 'ignoring the symptom and hoping it would go away' and belief in longer symptom duration (Figure 6.1). This knowledge is helpful to HCPs who are involved in promoting the message of breast awareness, prompt HSB and early diagnosis initiatives for all cancers globally. In addition, the framework and statistically significant results (Figure 6.1) could be used to predict potential delayers.

Finally, social significance addresses whether or not application of the framework makes any difference to the well-being/ health status of the public. The conceptual framework guided the current study which identified that delayed help seeking continues to occur amongst some women who self discover breast symptoms. The framework also facilitated clarification of the key factors associated with delay. This

knowledge will lead to refinement and further development of key messages and interventions designed to promote prompt help seeking for self discovered breast cancer symptoms. Prompt help seeking has potential to lead to early diagnosis and better outcomes for women who are diagnosed with breast cancer. The study is important as it advances the science of nursing around HSB following actual symptom discovery and reiterates the value of more research measuring the extent of delay and the contributing factors, in different countries as advocated by Richards, 2009b.

Summary

In summary, this chapter has discussed findings of the study on the help seeking behaviour and associated influencing factors, of a sample (n=449) of women, following self discovery of a breast symptom. Key findings were discussed in the context of their statistical and clinical significance and their overall relationship with the current body of knowledge on HSB for self discovered breast cancer symptoms. (Figure 5.1)

Findings verify the relevance of the 'Help Seeking Behaviour and Influencing Factors' framework developed from an amalgamation of the empirical and theoretical literature (Facione et al., 2002; Meechan 2003, 2002; Leventhal, et al., 2003 and O'Mahony and Hegarty, 2009b) (Figure 4.1), to women's HSB following self discovery of a breast symptom. In addition, analysis and evaluation of the framework using Fawcett's (2005) evaluative criteria for nursing models, proved it to be comprehensive, logical and credible.

Overall, findings from the study are important as they highlight that despite the emphasis on breast awareness and early detection of breast cancer, delayed HSB of

more than one month continues to occur which (when longer than three months) has potential to result in increased morbidity and mortality for women who are diagnosed with breast cancer. In addition, the key factors associated with delay were knowledge relating to symptom identity, belief in both the use of denial (ignoring the symptom and hoping that it would go away) and longer symptom duration. The emotional response most significantly associated with prompt help seeking was ‘being afraid’ on symptom discovery. The overall conclusion to the study will now be presented.

Conclusion

Breast cancer has been identified as the most common malignancy amongst women in the developed world. In Ireland, breast cancer was the most common female cancer diagnosed during 2000-2004 with an average of 3,095 cases reported annually and an average of 947 deaths (Donnelly et al., 2009). However, despite improved survival amongst women who are diagnosed with breast cancer; it continues to be one of the cancers for which survival estimates in Ireland are slightly lower than the European average (Verdecchia et al., 2007; DOH&C, 2010). The earlier the diagnosis of breast cancer is made the more likely it is that women will have a favourable outcome (Richards et al, 1999a, Richards et al, 1999b, Richards 2009b; Gulatte et al., 2010; Jenner et al., 2011). Evidence suggests that women themselves detect most breast tumours (Arndt et al, 2002; Facione et al, 2002; Richards, 2009b). However, despite the association between prolonged delay and survival, as reiterated in this study, a considerable number of women wait for more than one month (Burgess et al, 1998; Nosarti et al., 2000; Burgess et al, 2001; O'Mahony, 2001; Arndt, 2002; Meechan et al, 2002; O'Mahony and Hegarty, 2009b) before presenting to a HCP with a breast symptom. Additionally, there is lack of consensus in the literature regarding what constitutes delay, although "a wait of three months or more" (Pack and Gallo, 1938) was taken to be the general definition of "undue delay".

Efforts are being made internationally to control the incidence of cancer and improve cancer outcomes through the promotion of early detection and diagnosis. The need for more research, measuring the extent of delay and the contributing factors, in different countries, has recently been highlighted (Richards, 2009b). In addition, in view of the lower survival rates from breast cancer, the study of women's HSB for self discovered breast symptoms in an Irish context, was timely.

Chapter One presented a review of the literature on help seeking from an empirical and theoretical perspective. The concept of help seeking was defined together with an exploration of the literature on HSB for cancer symptoms. The review highlighted that help seeking for self discovered cancer symptoms is an area in need of further research as much of the research focused on preventive behaviours such as help seeking intentions in asymptomatic situations as opposed to help seeking in the event of actual symptom discovery. In addition the need for more theoretically driven studies on HSB (Scott and Walter, 2010) was emphasised. The Judgement to Delay Model (Facione et al., 2002) although, focusing on help seeking intentions was considered to be broad and holistic and to offer the most relevant framework to guide further study on women's help seeking in the event of breast symptom discovery. Leventhal et al's (2003) Common Sense Model of Self Regulation was also deemed relevant due to its focus on illness representations (identity, cause, time-line, risk factors, curability/controllability) inherent in the occurrence of symptoms/ threats such as breast symptoms. This chapter concluded with presentation of a preliminary model to guide the study on the HSB of women and the associated influencing factors, in an Irish Setting (Figure 1.1).

Chapter Two reviewed studies relating to knowledge and beliefs and HSB for various cancer symptoms including breast cancer. It was highlighted that symptom discovery stimulates the process of symptom appraisal. Symptom appraisal is dependent on an individual having the necessary knowledge to identify the symptom together with their beliefs surrounding the symptom. Knowledge in relation to symptom identity, breast changes associated with breast cancer and the presence or absence of a family history of breast cancer was identified as important to HSB. Beliefs were highlighted as being mediators between knowledge and behaviour. The Common Sense Model of

Self Regulation Model (Leventhal et al., 2003) was reiterated as a suitable framework to ascertain women's beliefs concerning the key dimensions of their breast symptom (cause, time-line, risk factors, curability/controllability) and determine how they impact on women's HSB. In addition, cultural and fatalistic beliefs together with beliefs in the use of "alternative help seeking behaviours" were seen to impact on symptom appraisal and interpretation and ultimately on HSB.

In Chapter Three studies on individuals' emotional response to cancer symptom discovery and HSB were reviewed. The complexity of women's emotional responses to threatening situations such as potential breast cancer symptom discovery was apparent. Emotional responses were seen to vary and either stimulated or deterred HSB. The use of defence mechanisms of avoidance and denial were also seen to effect emotional responses and subsequent HSB. The need to explore the emotional response of women to breast symptom discovery, particularly in the context of actual HSB, was clarified. The recently adapted (O'Mahony and Hegarty, 2009b) 'Emotional Distress' scale (Meechan et al., 2003) was deemed an appropriate instrument to use in this regard

Chapter Four focused on the literature regarding socio-demographics, social factors, help seeking habits and health service utilisation factors and HSB. The key dimensions of these variables pertinent to the study of women's actual help seeking behaviour for self discovered breast cancer symptoms were identified. These include socio-demographics (age, nationality, relationship status, occupation, health insurance/medical card and education level); social factors (living arrangements (recorded with socio-demographic factors), role obligations and disclosure of symptoms); health seeking habits (BSE and mammography) and health service system

utilisation (perceived access to health care i.e.: cost, convenience, relationship with HCP and personal experience of prejudice). These variables and their dimensions were outlined in the help seeking behaviour and associated factors conceptual framework (Figure 4.1) used to guide the study.

Overall, the literature review identified a large amount of theoretical and empirical literature on help seeking behaviour from the perspective of cancer in general, specific cancers and breast cancer. However, much research focused on intentions to seek help and in many cases, data were collected on a limited set of concepts and from specific cultural perspectives. A gap was identified in the study of HSB for self discovered breast symptoms from a theoretically based, holistic perspective. In view of the unfavourable outcomes of delayed HSB for self discovered breast cancer symptoms, coupled with the slightly lower than average European rates of survival from breast cancer in Ireland, further study of women's HSB in an Irish context was deemed necessary. Thus, a study to identify the HSB and the associated influencing factors, of women with self discovered breast symptoms was carried out.

In Chapter Six the methodology used for the study of women's help seeking behaviour and the associated influencing factors on self discovery of a breast symptom, was presented. Initially, the conceptual framework (validated by a qualitative descriptive study (O'Mahony et al., 2011: Appendix 1a) was described. This was followed by an outline of the research design, aim, objectives, operational definitions and hypotheses The development of the study instrument was described followed by a discussion on the validity and reliability and description of the pilot study and its implications. Details pertaining to the population, sample, access to the

sample and ethical considerations were addressed. Finally, procedures for data collection, management and analysis were described.

Chapter Seven presents findings on the HSB of a sample of women (n= 449) ranging in age from 18-80+ years following self discovery of a breast symptom. Results support the declarative statement that 20-30% of women would delay help seeking for one month or more, in that delay occurred amongst 30.1% of women. Findings revealed that 69.9% (n = 314) of women sought help within one month, 13.4% (n = 60) within two months (five to eight weeks) and 16.7% (n = 75) delayed for three months or more.

Multivariate regression established that the variables most significantly related to delayed HSB were: knowledge relating to breast symptom identity i.e. a presenting symptom of 'nipple indrawn/changes' ($p = 0.005$), belief in longer symptom duration ($p = 0.023$) and belief in the alternative help seeking behaviour of 'ignoring the symptom and hoping it would go away' ($p < 0.001$). Conversely, prompt HSB was associated with the emotional response of 'being afraid' on symptom discovery ($p = 0.005$).

In addition, univariate logistic regression established that prompt HSB was significantly related to knowledge of breast symptom identity i.e. the presenting symptom of a breast lump ($p < 0.001$); breast cancer knowledge i.e. responding 'yes' to 'a clear drainage from one nipple' being a breast change associated with breast cancer ($p = 0.040$), the social factors of symptom disclosure to another person ($p < 0.001$) and the 'not applicable' response to social constraints relating to family commitments ($p = 0.007$). A positive response to the breast cancer knowledge item 'a breast lump I never noticed before' almost reached significance ($p = 0.055$), with

results (O.R. 0.61) indicating that these women were less likely to delay. Conversely, two items of clinical relevance approached significance demonstrating that the less often women performed BSE the more likely they were to delay (OR=1.21; p = 0.056). Additionally, although not significant, the odds of delaying help seeking increased by 1.44 for women who agreed with the item 'sometimes I go without medical care I need because it is too expensive'.

Chapter Eight presents a discussion of the statistically and clinically significant findings from the study in relation to the current body of literature. The discussion highlighted that consistent with previous literature, delayed HSB for self discovered breast symptoms continues to be a problem. While much of the literature has focused on older women and delay, the younger age profile of women in the current study is to be expected as symptoms were self discovered as opposed to being discovered through routine mammography (advocated in the 50-64 age group). In contrast to most previous studies, 50% of women who delayed were educated to third level. However, it was highlighted that this may be reflective of educational levels amongst women in Ireland generally.

Similar to previous studies (Burgess et al., 1998; Nosarti et al., 2000; Meechan et al., 2002; Bish et al., 2005; Jones et al., 2010) in the current study, knowledge relating to symptom identity was found to be significantly related to HSB. Women with a presenting symptom of breast lump were likely to seek help promptly whereas the symptoms of 'nipple indrawn/ changes' and 'breast pain' were barriers to help seeking.

In relation to symptom beliefs, a new finding to this study was the significant relationship between women's perceptions / beliefs in the duration of their symptom

and HSB. The longer women believed their symptom to persist the more likely they were to delay HSB.

In contrast to previous studies (Facione et al., 1997; Grunfeld et al., 2003), no significant relationship was found between women's beliefs surrounding the consequences of their symptom. However, the trend between the neutral response to the item 'my breast symptom has strongly affected the way others see me' and delayed HSB, suggests that women had not thought much about their symptom affecting how others see them. Conversely, they were more inclined to connect with the personal effects of the symptom as indicated by their disagreement that the symptom 'is easy to live with' and that it had not 'had much affect' on their lives, as would be expected. In addition, belief in the use of the alternative HSB of denial inherent in 'ignoring the symptom and hoping that it would go away' was significantly related to delayed HSB as highlighted previously (Margarey et al., 1977; Lauver et al., 1995; Kennedy et al., 2000; O'Mahony and Hegarty 2009b; O'Mahony et al., 2011; Unger-Saldana and Infante-Castanda, 2011).

Regarding knowledge of breast changes associated with breast cancer, in contrast to previous studies (Facione and Dodd, 1995; Facione et al., 2002), overall women's knowledge levels ranged from high (37.1%) to medium (31.5%) to low (31.5%). Univariate logistic regression established that responding 'yes' to the items 'a clear drainage from one nipple' ($p = 0.040$) and 'a breast lump I never noticed before' ($p = 0.055$) indicated less likelihood to delay HSB. While, results relating to symptom knowledge were good overall and it is comforting to know that the three breast lump related symptoms on the breast cancer knowledge scale were endorsed as potential signs of breast cancer, by the majority of women. However, higher levels of

knowledge on non lump breast changes associated with breast cancer would have been more optimal. Limited knowledge of non lump symptoms was previously highlighted amongst a sample of women from the general population in England (Grunfeld et al., 2002) and identification of potential symptoms was found to be an important factor in predicting intentions to seek help HSB (Grunfeld et al., 2003; Hunter et al 2003) amongst asymptomatic women. Findings reiterate that knowledge of breast changes associated with breast cancer is crucial if women are to appraise and interpret self discovered breast symptoms. In addition, the importance of breast awareness in empowering women to identify any changes associated with breast cancer is reiterated.

In relation to emotional responses, consistent with previous studies (DeNooijer et al., 2001b; Meechan et al., 2003; O'Mahony and Hegarty, 2009b ; Unger-Saldana and Infante Castaneda, 2011) fear on symptom discovery was a significant stimulus to HSB. Conversely, fear and anxiety surrounding symptom discovery have also been associated with delayed HSB (Nosarti et al., 2000; Unger-Saldana and Infante Castaneda, 2011). Regarding social factors, as previously highlighted (Burgess et al., 1998; De Nooijer et al., 2001a; Bish et al 2005; Burgess et al., 2008; Gulatte et al., 2010), symptom disclosure to another person was significantly related to prompt HSB. Consistent with previous studies (Facione 1993; Lauver et al, 1995; Facione et al., 1997; Facione and Giancarlo, 1998; Burgess et al., 2001; Facione et al., 2002; O'Mahony and Hegarty, 2009b), social constraints in terms of family commitments significantly impacted on women's HSB. Univariate logistic regression established that women who endorsed the 'not applicable' response to the item 'taking care of my family prevented me from going to the GP' (suggesting that they had no commitments or that if so, the commitments did not deter their HSB), were less likely to delay.

In discussing health seeking habits, the trend noted between frequency of BSE and delayed HSB (suggesting that the less often women performed BSE the more likely they were to delay) supports previous studies (Meechan et al., 2002; 2003) and is important in terms of promoting breast awareness and confidence in detecting breast symptoms (Linsell et al., 2008; Burgess et al., 200; Montazeri et al., 2008 and Linsell et al., 2009), and subsequent prompt HSB. As expected, due to the predominantly younger age of the sample, frequency of mammography was not significantly related to HSB.

Positive perceptions of access to health services were reiterated by women overall, in relation to health service system utilization issues. Although not significantly related to HSB, expenses relating to access were an issue for some women, as highlighted in previous American studies (Facione et al., 1997; Facione and Giancarlo, 1998; Facione 1999; Friedman et al., 2006). Similar to other studies (Facione et al., 2000 and Nosarti et al., 2000), the majority of women voiced a preference for a female GP. While women's perceptions of experienced prejudice were not significantly related to HSB, the fact that women indicated experiencing discrimination and lack of respect from HCP's echoes findings of previous studies amongst multi-ethnic samples of women of varying sexual orientation in the United States (Facione, 1999; Facione et al., 2002; Facione and Facione, 2007), and was highlighted as being a cause for concern. Finally, the 'Help Seeking Behaviour and Influencing Factors' framework was evaluated using Fawcett's (2005) framework of (purpose; origins; comprehensiveness; generation of theory; logical congruence and credibility) for evaluation of nursing models. The overall usefulness and credibility of the framework for the current study was re-confirmed.

In conclusion, utilising the empirical and theoretically driven 'Help Seeking Behaviour and Influencing Factor' framework, this study examined the HSB of a sample of women (n=449) with self discovered breast symptoms. It was found that while the majority (69.9%; n = 314) of women sought help within one month, delayed HSB of more than one month occurred amongst 30.1% (n=135) of women. Multiple logistic regression confirmed that the factors most significantly associated with delay were knowledge relating to the presenting symptoms (nipple indrawn/changed); beliefs concerning symptom duration and ignoring the symptom. The factor most significantly related to prompt HSB was fear on symptom discovery. In addition, univariate logistic regression established that social factors in terms of both disclosure of the symptom to another person and endorsing the 'not applicable' response to the item 'Taking care of my family (children / older relative) prevented me from going to the GP' and knowledge of the breast changes (i.e. 'breast lump' and 'a clear drainage from a nipple') associated with breast cancer also impacted significantly on prompt HSB. Whereas, knowledge around symptom identity (breast pain) was associated with delay.

The study is important in that it utilized an holistic framework to investigate the actual HSB of women with self discovered breast symptoms, thus providing an holistic perspective of the symptom discovery experience and the complex nature of the help seeking process as suggested by Scott and Walter, 2010. Additionally, it advances nursing knowledge on women who self discover breast symptoms and the factors most associated with HSB. Completion of this study in an Irish context is timely in responding to the recent call for more research, measuring the extent of delay and the contributing factors, within different countries (Richards, 2009b). The limitations of

the study will now be addressed followed by an outline of the future recommendations for nursing practice, education and research.

Limitations

The study is limited in that a larger sample size might have resulted in more significant relationships, however the sample of 450 was based on a power analysis which recommended that a sample of 430 women would have 80% statistical power to identify a characteristic to be significantly associated with delayed help-seeking at the 5% level of statistical significance. Therefore, the sample of 450 women was deemed appropriate in view of its power and the time available to the researcher for data collection. However, the homogenous nature of the sample may limit generalisation of findings to other settings and cultural contexts.

Regarding clinical outcomes, since longer delay in help seeking is associated with a lower survival rate from breast cancer, the final diagnosis was confirmed for women who delayed for three months and more. Knowing the outcomes for the majority of women (69.9%) who sought help promptly (within one month) would have further enhanced the study.

In addition, it would have been useful to interview a sample of women who delayed for three months or more. However, qualitative data was provided from four women who delayed for periods of one to three months (n=2) and over three months (n=2), in the qualitative validation study (O'Mahony et al., 2011). These findings helped to confirm the appropriateness of the study framework, facilitated in the development of the study questionnaire and added to the researcher's overall understanding of women's experience of symptom discovery and subsequent delayed HSB, thus augmenting the validity of the current findings.

To the author's knowledge, this is the first study to utilise an adaptation of the Illness Perception Questionnaire to determine women's beliefs relating to actual self discovered breast symptoms. While few items on the adapted symptom perception subscales were significantly related to HSB, the scales provides an insight into women's beliefs about their breast symptom prior to their meeting with a consultant in the breast clinic.

Despite these limitations, as far as the researcher is aware, the study is the first to examine the HSB of a large sample of women following self discovery of a breast symptom. Thus, data was collected retrospective to actual symptom discovery as opposed to a prospectively or hypothetically which was in the case in much of the literature reviewed. Additionally, the study is unique in that it utilised the empirical and theoretically based 'Helpseeking Behaviour and Influencing Factors' as a conceptual framework to guide the study.

Recommendations

In view of the findings of the study the following recommendations are made for nursing practice, education and further research. Throughout this section, the term health care professionals (HCP's) refers to all members of the multidisciplinary team who have contact with women before, during and after their symptom discovery experience.

Nursing Practice

Help Seeking Behaviour

Since delay continues to occur amongst women who self discover a breast symptom, the message promoting early detection and treatment of breast cancer through prompt presentation of all breast symptoms to a HCP needs continuous reiteration. ..

Knowledge and Beliefs

Breast Symptom knowledge

Although the majority of women seek help promptly for a self discovered breast lump, the importance of prompt HSB for non lump symptoms (Irish Cancer Society, 2011) also needs to be emphasised to women.

Knowledge of breast changes associated with breast cancer

While the intention is not to alarm women or impose further on an already over burdened health service, the necessity for women to be breast aware and have knowledge about breast changes associated with breast cancer is reiterated. Thus, facilitating women to seek help promptly in the event of self discovery of a breast symptom. This has implications for continued public health and media campaigns promoting breast awareness and early detection and treatment of breast cancer amongst women of all ages.

Beliefs relating to cause, duration and consequences of symptom

Women need continuous reminders (by HCP's and policy makers) of:

- the risk factors associated with breast cancer and that the absence of family history is not a reason for complacency

- the importance of early detection and prompt diagnosis regardless of beliefs on the duration of the symptom

- the earlier the diagnosis of breast cancer the more favourable the outcome.

Beliefs in the use of alternative help seeking behaviours

While the belief in the use of denial (ignoring the symptom and hoping it would go away) may help some women cope following discovery of a breast symptom, the message that prompts help seeking is a more effective way of dealing with the symptom needs to be emphasised.

Emotional Responses

All HCP's need to be cognisant of women's level of emotional distress surrounding symptom discovery and assessment, particularly on women's first visit to the GP's surgery and the breast clinic.

Social Factors

Symptom Disclosure

The likelihood of women disclosing the symptom immediately depends on whether or not they live with another person or have somebody in whom to confide. Therefore, it

is important for HCP's to note women's relationship status and their access to social support around the time of symptom assessment and diagnosis.

Health Seeking Habits

Breast awareness through women being confident to look at and feel their breasts (Irish Cancer Society, 2011) needs continuous promotion and could commence amongst adolescents at secondary school level. This needs to be promoted by community based HCP's who have access to asymptomatic women

Health Service System Utilisation

Waiting time incurred in women visiting a HCP should be kept to a minimum in view of additional expenses relating to family and work related commitments. In addition, the need for HCP's to treat all women with dignity and respect regardless of race, creed or sexual orientation is emphasised. Sensitivity to these issues particularly around the time of symptom assessment when women are likely to be more vulnerable is vital.

Nurse Education

In order to ensure that the above recommendations are in place, the messages of breast awareness, prompt help seeking for breast changes, that outcomes are more favourable for early diagnosis of breast cancer and recognition that the cumulative

risk for developing breast cancer in Ireland before age 75 is 1 in 11 (National Cancer Registry, Ireland 2009) needs continuous promotion at both undergraduate and post graduate nurse education level.

Additionally, these message need to be promoted amongst nurse practitioners in clinical, community and general practitioner settings through continuing education and in service education on their role as health promoters in relation to breast health.

Despite the current shortages in the health services, nurse practitioners need to be encouraged and supported in attending relevant nursing conferences, study days and in service education sessions (in particular those held locally and nationally) as a means of updating their knowledge on breast cancer and current breast health related practices.

Nursing Research

The extent to which women deny or avoid the presence of their symptom needs further exploration together with their tendency to be optimistic or fatalistic generally.

The current study highlighted the relevance of the 'Help Seeking Behaviour and Influencing Factors' framework to guide the study, however, further qualitative research with women who self discovered a breast symptom is necessary in order to develop a theory on HSB for self discovered breast cancer symptoms, focusing particularly on women who delayed for three months or more. This theory would augment the current findings and add to the body of knowledge around HSB for self discovered breast cancer symptoms. Such knowledge would facilitate the

development and/or refinement of an intervention to promote prompt HSB amongst women of all ages, who self discover breast symptoms.

At this point, it should be emphasised that use of the term ‘delay’ could be interpreted as being pejorative towards women, since it suggests that women were negligent towards their health. However, the term is widely used in the literature in relation to HSB and it is recognised that women’s HSB is influenced by a wide array of factors some of which are beyond the woman’s control. Nonetheless, use of another less judgmental term such as ‘postpone’ or ‘defer’ might be more appropriate for future studies.

In conclusion, this study makes an important contribution to knowledge on HSB for breast cancer symptoms in that it provides a theoretically driven, holistic perspective to the HSB of a large sample of women (n=449) with self-discovered breast symptoms. It identifies the key facilitators and barriers to women’s HSB. Findings provide theoretically based evidence to underpin future interventions to promote breast awareness among women of all ages.

Finally, to quote from Richards (2009a)

> “if we can promote awareness and early diagnosis” of cancer “the size of the prize is very substantial”(page 53).

Thus, the researcher is confident that this study on women’s help seeking behaviour and the associated influencing factors will contribute in some way to this “prize” in relation to breast cancer.

References

Arndt V, Sturmer T, Stegmaier C, Ziegler H, Dhom G, Brenner H.(2002) Patient delay and stage of diagnosis among breast cancer patients in Germany: A population based study. British Journal of Cancer 86(7), 1034-1040.

Abdel- Rahman, M. Stockton, D., Hakulinen, T., Coleman, M.P. (2009) What if cancer survival in Britain were the same as in Europe: how many deaths are avoidable? British Journal of Cancer 101, S115-S124.

Ajzen, I. and Fishbein, M. (1980) Understanding Attitudes and Predicting Social Behaviour, New Jersey: Prentice Hall.

Ajzen,I. and Madden, T. J.(1986) Prediction of goal-directed behaviour: Attitudes, intention, and perceived behavioural control. Journal of Experimental Social Psychology 22, 453-473.

Ajzen, I. (1991) The Theory of planned behaviour Organizational behavior and human decision processes 50,179-211.

American Cancer Society (2009) Cancer Facts and Figures, Atlanta Georgia: American Cancer Society.

Andersen, B.L. , Cacioppo, J. and Roberts, D.C. (1995), Delay in seeking a cancer diagnosis: delay stages and psycho-physiological comparison processes. British Journal of Social Psycholology 34, 33–52.

Bandura, A. (1977) Self-efficacy: toward a unifying theory of behavioral change. Psychological Review, 184,191-215.

Becker, M.H. (1974) The Health belief model and personal health behaviour. Health Education Monographs, 2, 324-473.

Bish, A., A. Ramirez, Burgess C, Hunter M, (2005). Understanding why women delay in seeking help for breast cancer symptoms. Journal of Psychosomatic Research. 8(4), 321-326.

Botoroff, J. L., Johnson, J. L., Bhagat, R., Grewal, S., Balneaves, L. G., Clarke, H. and Hilton, B. A.(1998) Beliefs Related To Breast Healh Practices: The Perceptions Of South Asian Women living. Canada Social Science Medicine 47(12), 2075-2085.

Bradley, P. K. (2005). The Delay and Worry Experience of African American Women with Breast Cancer. Oncology Nursing Forum 32(2), 243-249.

Burgess, C.C., Ramirez, A.J., Richards, M.A., and Love, SB. (1998) Who and what influences delayed presentation in breast cancer? British Journal of Cancer 77,1343-1348.

Burgess, C. C., Ramirez, A. J., Smith, P., Richards, M.A. (2000) "Do adverse life events and mood disorders influence delayed presentation of breast cancer?" Jornal of Psychosomatic Research 48(2), 171-5.

Burgess, C., Hunter, M.S., and Ramirez, A.J. (2001) A qualitative study of delay among women reporting symptoms of breast cancer. British Journal of General Practice 51, 967-71.

Burgess, C.C., Bish, A.M.,Hunter, H.S.,Salkovskis, P.,Michell, M.,Whelehan, P., and Ramirez A.J.(2008) Promoting early presentation of breast cancer: development of a psycho-educational intervention.Chronic Illness 4(1), 13-27.

Burgess CC, Linsell L, Kapari M, Omar L, Michell M, Whelehan P, Richards MA, Ramirez AJ.(2009) Promoting early presentation of breast cancer by older women: a preliminary evaluation of a one-to-one health professional-delivered intervention. Journal of Psychosomatic Research 67(5),377-387.

Burns, N. and Grove, S.K. (2005) The Practice of Nursing Research Conduct. Critique and Utilisation. (5th Edition), St Louis: Elsevier.

Cameron, LD. and Leventhal. H. (2003) Self- Regulation, health and illness an overview in Cameron, L. D. and Leventhal, H. (eds) The Self-Regulation of Health and Illness Behaviour. London: Routledge.

Campo, J., Comber, H., and Gavin, A. (2004) All-Ireland Cancer Statistics 1998-2000, Second Report, Ireland: National Cancer Registry and Northern Ireland Cancer Registry.

Carmines, E. G. and Zeller, R.A. (1979) Reliability and Validity Assessment: Series: Quantitative Applications in the Social Sciences. London: Sage Publications.

Central Statistical office (CSO) Women and Men in Ireland 2010 available at www.cso.ie (Accessed July 28th, 2011)

Cockburn, J., Paul, C., Tzelepis, F., McElduff, P., and Byles, J.(2003) Delay in seeking advice for symptoms that potentially indicate bowel cancer American Journal of Health Behaviour 27,401-7.

Comber, H., and Walsh, P.M. (2008) Patterns of care and survival of cancer patients in Ireland 1994-2004: A Summary Report. Ireland: National Cancer Registry.

Cornally N, and McCarthy G. (2011) Help-seeking behaviour: A concept analysis. International Journal of Nursing Practice 17(3), 280-288.

Corner, J., Hopkinson, J., and Roffe, L. (2006) Experience of health changes and reasons for delay in seeking care: a UK study of the months prior to the diagnosis of lung cancer. Social Science Medicine 2, 1381-91.

de Nooijer, J., Lechner, L.,and De Vries, H. (2001a) Help-seeking behaviour for cancer symptoms: perceptions of patients and general practitioners. Psychoncology 10, 469-478.

de Nooijer, J., Lechner, L., and de Vries, H.(2001b)A qualitative study on detecting cancer symptoms and seeking medical help; an application of Andersen's model of total patient delay. Patient Education and Counselling 42, 145-57.

de Nooijer. J., Lechner, L., and de Vries, H. (2002a) Early detection of cancer: knowledge and behavior among Dutch adults. Cancer Detection and Prevention 26, 362-369.

de Nooijer. J., Lechner. L., and de Vries, H. 2002(b) Tailored versus general information on early detection of cancer: a comparison of the reactions of Dutch adults and the impact on attitudes and behaviours. Health Education Research 17,239-52.

de Nooijer, J., Lechner, L. and de Vries, H.(2003) Social psychological correlates of paying attention to cancer symptoms and seeking medical help. Social Science Medicine 56,915-20.

Department of Health (2007) Cancer Reform Strategy. London: Department of Health.

Department of Health and Children (DoHC) (2006) The National Cancer Forum: A Strategy for Cancer Control in Ireland, Dublin: Government Publications.

Department of Health and Children (2010) Health in Ireland: Key Trends 2010 Dublin: Government Publications.

DeVaus, D. (2005) Surveys in Social Research (5th ed) New York: Routlege.

Dooley, D. and McCarthy, J. (2005) Nursing Ethics; Irish Cases and Concerns. Dublin: Gill & Macmillan.

Donnelly, D.W., Gavin, A.T. and Comber, H. (2009) Cancer in Ireland 1994-2004: A Comprehensive Report. Ireland: National Cancer Registry/ Northern Ireland: Cancer Registry.

Facione, N.C. (1993) Delay versus help seeking for breast cancer symptoms: a critical review of the literature on patient and provider delay. Social Science and Medicine 36,1521-34.

Facione, N. C. (1993) The Triandis model for the study of health and illness behaviour: a social behaviour theory with sensitivity to diversity. ANS Advanced Nursing Science 15(3), 49-58.

Facione, N.C. and Dodd, M. (1995) Women's narratives for helpseeking for breast cancer. Cancer Practice, 3, 219-225.

Facione, N. C., M. J. Dodd, Holzemer, W., Melesis, A.I. 1997. Helpseeking for self-discovered breast symptoms. Implications for early detection. Cancer Practice 5, 220-227.

Facione, N.C. and Giancarlo, C.A. (1998) Narratives of breast symptom discovery and cancer diagnosis: psychologic risk for advanced cancer at diagnosis. Cancer Nursing 21, 430-40.

Facione, N. C. (1999). Breast cancer screening in relation to access to health services. Oncology Nursing Forum 26(4), 689-96.

Facione, N.C., Giancarlo, C., and Chan, L. (2000) Perceived risk and help-seeking behavior for breast cancer. A Chinese-American perspective. Cancer Nursing 23, 258-67.

Facione, N.C., Miaskowski, C., Dodd, M.J., and Paul S.M. (2002) The self-reported likelihood of patient delay in breast cancer: new thoughts for early detection. Preventive Medicine 34, 397-407.

Facione, N. C. (2002) The J-Delay scale: a measure of the likelihood of patient delay in breast cancer. Research and Theory Nursing Practice 16(2), 103-118.

Facione NC, (2002) Perceived risk of breast cancer: influence of heuristic thinking. Cancer Practice 10(5), 256-262.

Facione, N. C. and P. A. Facione (2006) The cognitive structuring of patient delay in breast cancer. Social Science Medicine 63(12), 3137-1349.

Facione, N. C. and P. A. Facione (2007) Perceived prejudice in healthcare and women's health protective behaviour. Nursing Research 56(3), 175-184.

Fawcett, J. (2005) Analysis and Evaluation of Contemporary Nursing Knowledge: Nursing Models and Theories. (2nd ed) Philadelphis: F.A. Davis Company.

Friedman, L. C., M. Kalidas, et al. (2006) Medical and psychosocial predictors of delay in seeking medical consultation for breast symptoms in women in a public sector setting. Journal of Behavioral Medicine 29(4), 327-334.

Gollwitzer, P.M. (1993) Goal achievement: the role of intentions, European Review of Social Psychology, 4, 141-185.

Grunfeld, E.A., Hunter, M.S., Ramirez, A.J., and Richards, M.A.(2003) Perceptions of breast cancer across the lifespan. Journal of Psychosomatic Research, 54, 141-146.

Grunfeld, E. A., Ramirez, A.J., Hunter, M.S. and Richards, M.A (2002). Women's knowledge and beliefs regarding breast cancer. British Journal of Cancer 86(9), 1373-1378.

Gullatte, M. M., O. Brawley, Gullatte, M. M., O. Brawley, , Kinney A, Powe B, Mooney K. (2010) Religiosity, spirituality, and cancer fatalism beliefs on delay in breast cancer diagnosis in African American women. Journal of Religious Health 49(1), 62-72.

Hardin, C., Pommier, S, Pommier, R.F.(2006) The relationships among clinician delay of diagnosis of breast cancer and tumor size, nodal status, and stage. American Journal of Surgery 192(4), 506-508.

Health Information and Quality Authority (HIQA) (2006) National Quality Assurance Standards for Symptomatic Breast Disease Services, Dublin:HIQA.

Health Service Executive (HSE), 2009 National Breast Cancer GP Referral Guidelines Dublin: HSE.

Hosmer, D. W. and Lemeshow, S (2000) Applied Logistic Regression. (2nd ed) Wiley and Sons: New York.

Howell, D.A., Smith, A.G.,and Roman, E. (2007) Help-seeking behaviour in patients with lymphoma. European Journal of Cancer Care 16, 529-532.

Hunter, M.S., Grunfeld, E.A., and Ramirez, A.J.(2003) Help-seeking intentions for breast-cancer symptoms: a comparison of the self-regulation model and the theory of planned behaviour. British Journal of Health Psychology 8,319-33.

Irish Cancer Society (2011) Breast Awareness-Action breast Cancer Available at http//www.cancer.ie/action/breastawareness .(Accessed 14th April, 2011).

Iwamitsu, Y., K. Shimoda, Abe, H. et al., (2005) Anxiety, emotional suppression, and psychological distress before and after breast cancer diagnosis. Psychosomatics 46(1), 19-24.

Jemal, A., F. Bray, et al. (2011) Global Cancer Statistics. CA Cancer J Clin 61 (2), 69-90.

Jones, S.C., Gregory, P., Nehill, C. Barrie, L., Luxford, K., Nelson, A., Zorbas, H., Iverson, D. (2010) Australian women's awareness of breast cancer symptoms and responses to potential symptoms. Cancer Causes Control 21 , 945-958.

Katapodi, M.C.,Facione, N.C.,Humphreys, J.C.,Dodd. M.J., (2005) Perceived breast cancer risk: heuristic reasoning and search for a dominance structure. Social Science Medicine 60(2), 421-432.

Kennedy P, Quin S, Murphy-Lawless, J. Hickey, E., 2000. Survey of views and perceptions of women who attended Symptomatic Breast Clinics. Ireland: The Women's Health Council.

Kishore J, Ahmad I, Kaur, R. and Mohanta, P. K. (2008) Beliefs and perceptions about cancers among patients attending radiotherapy OPD in Delhi, India. Asian Pacific Journal of Cancer Prevention 9(1), 155-158.

Koldjeski, D., Kirkpatrick, M.K., Everett, L. Everett, L., brown, S., Swanson, M. (2004) Health Seeking Related to Ovarian Cancer. Cancer Nursing 27(5), 370-378.

Lauver , D .,Coyle, M., and Panchmatia, B.(1995) Women's reasons for and barriers to seeking care for breast cancer symptoms. Women's Health Issues, 5(1), 27-35.

Lazarus, R.S. and Folkman, S. (1984) Stress, Appraisal and Coping. NewYork: Springer.

Leventhal, H., Meyer, D. and Nerenz, D (1980) The common sense representation of illness and danger in Rachman, S (Ed.) Medical Psychology (p.7-30). New York: Pergamon Press.

Leventhal, H., Nerenz, D.,Steele, D.J. (1984) Illness Representations and Coping with Health Threats in Baum, A.Taylor, S.E., Singer, J.E. (Eds) Handbook of Psychology and Health, Vol 1V Social Psychological Aspects of Health (p.219-252) Hillsdale (NJ): Erlbaum.

Leventhal, H. and Nerenz, D. (1985) The assessment of illness cognition in Korely, P. (Ed) Measurement Strategies in Health Psychology (pp. 517-554) New York: Wiley.

Leventhal, H., Leventhal, E. A. and Cameron, L. (2001) Representations, Procedures, and Affect in Illness Self-Regulation: A Perceptual- Cognitive Model (Chapter 2) in Baum, A., Revenson, T.A. and Singer, J. E.(eds) Handbook of Health Psychology, LEA Publishers: London.

Leventhal, H., Brissette, I. and Leventhal, E. A. (2003) The common-sense model of self-regulation of health and illness (Ch 3) in Cameron, D. C. and Leventhal (eds) (2003) The Self-Regulation of Health and Illness Behaviour, London: Routledge.

Linsell L, Burgess CC, Ramirez AJ. (2008) Breast cancer awareness among older women. British Journal of Cancer 99(8), 1221-1225.

Linsell L, Forbes LJ, Kapari M, Burgess C, Omar L, Tucker L, Ramirez AJ.(2009) A randomised controlled trial of an intervention to promote early presentation of breast cancer in older women: effect on breast cancer awareness. British Journal of Cancer. 3,101 Suppl 2:S40-8.

Macleod, U., Mitchell, E.D., Burgess, C., Macdonald, S., Ramirez, A.J. (2009) Risk factors for delayed presentation and referral of symptomatic cancer: evidence for common cancers. British Journal of Cancer 101(Supplement 2): S92-S101.

Maltby, J., Williams, G., McGarry, J., Day, L. (2010) Research Methods for Nursing and Healthcare Essex: Pearson.

Mason, O.J. and Strauss, K. (2004a)Testicular cancer: passage through the help-seeking process for a cohort of U.K. men (part 1). International Journal of Men's Health 3, 93-110.

Mason, O.J. and Strauss, K. (2004b) Studying help-seeking for testicular cancer: some lessons from the literature (part 2). International Journal of Men's Health 3, 111-27.

Margarey, C. J. Todd, P. B.., Blizard, P. J. (1977) Psycho-social factors influencing delay and breast self-examination in women with symptoms of breast cancer. Social Science Medicine 11, 229-232.

McMenamin, M., Barry, H., Lennon, A.M. Purcell, H., Baum, M., Keegan, D., McDermott, E., O'Donoghue, D., Daly, L., Mulcahy,H. (2005) A survey of breast cancer awareness and knowledge in a Western population: lots of light but little illumination. European Journal of Cancer 41, 393-397.

Mechanic, D. (1986). The concept of illness behaviour: culture, situation and personal predisposition. Psychological Medicine 16(1),1-7.

Meechan, G., Collins, J., and Petrie K. (2002) Delay in seeking medical care for self-detected breast symptoms in New Zealand women. New Zealand Medical Journal. 115,U257.

Meechan, G., Collins, J., and Petrie, K.J. (2003) The relationship of symptoms and psychological factors to delay in seeking medical care for breast symptoms. Preventive Medicine 36, 374-378.

Montazeri, A., M. Ebrahimi, et al. (2003). Delayed presentation in breast cancer: a study in Iranian women. BMC Womens Health 3(1), 4.(available from www.biomed.com/1472-6874/3/4).

Montazeri, A., M. Vahdaninia, et al. (2008) Breast cancer in Iran: need for greater women awareness of warning signs and effective screening methods Asia Pac Fam Med 7(1) 6 (Published online 2008 December 20).

Mor, V., S. Masterson-Allen, et al. (1990). Pre-diagnostic symptom recognition and help seeking among cancer patients. Journal of Community Health 15(4): 253-266.

National Cancer Registry Ireland (2005) Women and Cancer in Ireland 1994-2001, Ireland: Women's Health Council/National Cancer Registry (Available at: http//www.ncri.ie/cancerinfo (Accessed 23rd June, 2011)

National Cancer Registry (2009) Cancer in Ireland 1994-2007 Annual Report of The National Cancer Registry, Dublin: Stationary Office.

National Cancer Registry Ireland (2010) Personal Communication (November 2010)

National Cancer Registry Ireland (2011) Personal Communication (February, 2011)

Neal R.D. (2009) Do diagnostic delays in cancer matter? British Journal of Cancer. 3(101), Suppl 2:S9-S12.

Nosarti, C., Crayford, T., Roberts, J.V., Elias, E., McKenzie, K., and David, A.S.(2000) Delay in presentation of symptomatic referrals to a breast clinic: patient and system factors. British Journal of Cancer 82,742-748.

O'Mahony, M. (2001) Women's lived experience of breast biopsy: a phenomenological study. Journal of Clinical Nursing10, 512-520.

O'Mahony, M. and Hegarty, J., 2009a. Help seeking for cancer symptoms: A review of the literature. Oncology Nursing Forum 36 (4), E178-84.

O'Mahony, M., Hegarty, J., 2009b. Factors influencing women in seeking help from a Health Care Professional on self discovery of a breast symptom, in an Irish context. Journal of Clinical Nursing 18 (14), 2020-2029.

O'Mahony M, Hegarty J, McCarthy G. (2011) Women's help seeking behaviour for self discovered breast cancer symptoms. European Journal of Oncology Nursing 15, 410-418.

Pack, G.T. and Gallo, J.S. (1938) The Culpability for Delay in the Treatment of Cancer. American Journal of Cancer 33, 443-462.

Pallant, J. (2007) SPSS Survival Manual: A step by step guide to data analysis using SPSS for windows, Maidenhead: Open University Press.

Parahoo, K. (1997) Nursing Research: Principles, Process and Issues. London: Palgrave Macmillan.

Polit, D. F., C. T. Beck, and Owen, S. V. (2007). Is the CVI an acceptable indicator of content validity? Appraisal and recommendations. Research in Nursing and Health 30(4), 459-67.

Polit, D. E. and Beck, C. T. (2008) Nursing Research Generating and Assessing Evidence for Nursing Practice (8th ed) Philadelphia: Lipincott Williams and Wilkins.

Powe, B. D. (1995). Cancer fatalism among elderly Caucasians and African Americans. Oncology Nursing Forum 22(9),1355-9.

Pullyblank, A.M., Cawthorn, S. J. and Dixon, A. R. (2002) Knowledge of cancer symptoms among patients attending one-stop breast and rectal bleeding clinics. European Journal of Surgical Oncology 28, 511-515.

Ramirez, A.J., Westcombe, A.M., Burgess, C.C., Sutton, S., Littlejohns, P., and Richards, M.A.(1999) Factors predicting delayed presentation of symptomatic breast cancer: a systematic review. TheLancet 353,1127-1131.

Richards MA, Smith P, Ramirez AJ, Fentiman IS, Rubens RD. (1999a) The influence on survival of delay in the presentation and treatment of symptomatic breast cancer. British Journal of Cancer 79(5-6), 858-64.

Richards MA, Westcombe AM, Love SB, Littlejohns P, Ramirez AJ. (1999b) Influence of delay on survival in patients with breast cancer: a systematic review. The Lancet 353(9159), 1119-1126.

Richards MA. (2009a) The National Awareness and Early Diagnosis Initiative in England: assembling the evidence. British Journal of Cancer 101 Suppl 2,S1-4.

Richards MA. (2009b) The size of the prize for earlier diagnosis of cancer in England British Journal of Cancer.101 Suppl 2, S125-129.

Reifenstein. K. (2007) Care-Seeking Behaviours of African American Women with Breast Cancer Symptoms, Research in Nursing and Health 30, 542-557.

Ristvedt, S.L.and Trinkaus, K.M. (2005) Psychological factors related to delay in consultation for cancer symptoms. Psycho-Oncology 14, 339-50.

Robb K, Stubbings S, Ramirez A, Macleod U, Austoker J, Waller J, Hiom S, Wardle J. (2009) Public awareness of cancer in Britain: a population-based survey of adults. British Journal of Cancer 101 Suppl 2, S18-23.

Rosenstock, I. M. (1990) The health belief model: explaining health behaviour through expectations in Glantz, K., Lewis, F.M. and Rimer, B.K. (Eds) Health Behaviour and Health Education Theory, Research and Practice, San Francisco: Jossey-Bass, pp.39-62.

Schulman, C. S., Roger, K. and Fitzpatrick, J. M. (2003) Awareness of Prostate Cancer among the General Public: Findings of an Independent International Survey. European Urology 44, 294-302.

Scott ,S.E., Grunfeld, E.A., Main, J., and McGurk, M. (2006) Patient delay in oral cancer: a qualitative study of patients' experiences. Psychooncology15, 474-485.

Scott, S. E., M. McGurk, and Grunfeld, E.A. (2007). The process of symptom appraisal: cognitive and emotional responses to detecting potentially malignant oral symptoms. Journal of Psychosom Research 62(6), 621-630.

Scott SE, Grunfeld EA, Auyeung V, McGurk M.(2008a)Barriers and triggers to seeking help for potentially malignant oral symptoms: implications for interventions. Journal of Public Health Dentistry 69(1), 34-40.

Scott, S., M. McGurk, Grunfeld (2008b). Patient delay for potentially malignant oral symptoms. European Journal of Oral Science 116 (2), 141-147.

Scott, S. and Walter, F. (2010) Studying Help-Seeking for Symptoms: The Challenges of Methods and Models, Social and Personality Psychology Compass 4(8), 531-547.

Sheikh, I. and J. Ogden (1998). The role of knowledge and beliefs in help seeking behaviour for cancer: a quantitative and qualitative approach. Patient Education and Counselling 35(1), 35-42.

Smith, L.K., Pope, C., and Botha, J.L. (2005) Patients' help-seeking experiences and delay in cancer presentation: a qualitative synthesis. The Lancet 366, 825-831.

Smith SM, Campbell NC, MacLeod U, Lee AJ, Raja A, Wyke S, Ziebland SB, Duff EM, Ritchie, L.D., Nicolson MC.(2011) Factors contributing to the time taken to consult with symptoms of lung cancer: a cross-sectional study. Thorax 64 (6), 523-31.

Simon AE, Waller J, Robb K, Wardle J.(2010) Patient delay in presentation of possible cancer symptoms: the contribution of knowledge and attitudes in a population sample from the United Kingdom Cancer. Epidemiol Biomarkers Prev 19 (9), 2272-2277.

Stubbings, S., K. Robb, et al. (2009). Development of a measurement tool to assess public awareness of cancer. British Journal of Cancer 101 Suppl 2, S13-7.

Spurlock, W. R. and L. S. Cullins (2006) Cancer fatalism and breast cancer screening in African American women. ABNF Journal 17(1), 38-43.

The Breast Cancer Network News BCNNews.com (Accessed March 1st 2011).

The National Breast Cancer Coalition (NBCC) BreastCancerDeadline2020.org (Accessed March 1st 2011).

Thomas, E. C. (2004) African American women's breast memories, cancer beliefs, and screening behaviours. Cancer Nursing 27(4), 295-302.

Tjemsland, L. and J. A. Soreide (2004) Operable breast cancer patients with diagnostic delay--oncological and emotional characteristics. European Journal of Surgical Oncolology 30(7), 721-727.

Triandis, H.C. (1979) Values, attitudes and interpersonal behaviour in M.M. Page (ed) 1979, Nebraska symposium on motivation 195-259. Lincoln, NB: University of Nebraska press.

Tromp, D.M., Brouha, X.D., Hordijk, G.J., Winnubst, J.A., Gebhardt, W.A., van der Doef, M.P., and De Leeuw, J.R. (2005) Medical care-seeking and health-risk behavior in patients with head and neck cancer: the role of health value, control beliefs and psychological distress. Health Education Research 20, 665-675.

Unger-Saldaña K, Infante-Castañeda CB. (2011) Breast cancer delay: a grounded model of help-seeking behaviour. Social Science and Medicine72 (7), 096-104.

Verdecchia, A., Francisci, S., Brenner, H., Gatta, G., Micheli, A., Mangone, L., Kunkler, I. (2007) EUROCARE-4 Working Group. Recent cancer survival in Europe: a 2000-02 period analysis of EUROCARE-4 data. Lancet Oncology 8(9),784-96.

Villanueva, E. V., S. Jones, et al. (2008). The 2003 Australian Breast Health Survey: survey design and preliminary results. BMC Public Health 8, 13 (Available at http://www.biomedcentral.com/1471-2458/8/13)

Waller J, Robb K, Stubbings S, Ramirez A, Macleod U, Austoker J, Hiom S, Wardle J.(2009)Awareness of cancer symptoms and anticipated help seeking among ethnic minority groups in England. British Journal of Cancer 3,101 Suppl 2, S24-30.

Weinman, J., Petrie, K.J., Moss-Morris, R., and Horne, R. (1996) The illness perception questionnaire: a new method for assessing the cognitive representation of illness, Journal of Psychology and Health 11, 431-445.

Wong-Kim, E., Sun, A., and DeMattos, M. C. (2003) Assessing cancer beliefs in a Chinese immigrant community Cancer Control 10(5 Suppl), 22-28.

Wu, T.Y., West, B., Chen, Y.W., and Hergert, C. (2006) Health beliefs and practices related to breast cancer screening in Filipino, Chinese and Asian-Indian women. Cancer Detection and Prevention 30(1), 58-66.

Appendix 1a

Qualitative Validation Study (O'Mahony et al., 2011)

Reproduced with permission from Publishers (attached)

Appendix 1b Questionnaire Package

CODE						
DATE						

Confidential Patient Questionnaire

WOMEN'S HELP SEEKING BEHAVIOUR
ON SELF DISCOVERY OF A BREAST SYMPTOM.

Nurse Researcher: Máirín O'Mahony
MSc. BNS, RGN, RM, RNT

College Lecturer, PhD Student
School of Nursing and Midwifery
Brookfield Health Sciences Complex
University College, Cork.

WHAT THIS QUESTIONNAIRE IS ABOUT

This questionnaire explores the factors that aided you in seeking help from your general practitioner (G.P.) after you found a breast symptom.

I ask that you please take into account the following while answering the questionnaire:

- There are no **right** or **wrong** answers to these questions, please be as honest as possible in completing the questionnaire. An answer is correct if it is true for you.

- I am most interested in **your own personal views** rather than those of your family, friends or medical practitioner.

- To ensure the maximum utility of this research, it is important that you try to answer all the questions.

THIS QUESTIONNAIRE IS COMPLETELY CONFIDENTIAL

It will only be seen by the nurse researcher and not by any of the staff at the clinic.

If you have any further questions about this study or questionnaire, please do not hesitate to ask me (Mairin O'Mahony, here in the breast clinic) or
I can be contacted at the following number: 021- 4901458

Thank you for taking the time to complete this questionnaire.

Please tick or answer the following questions:

Section 1: Socio- Demographic Information

1. What age group are you in?

16-20 ☐ 21-30 ☐ 31-40 ☐ 41-50 ☐ 51-60 ☐ 61-70 ☐ 71-80 ☐

Over 80 ☐

2. What is your Nationality? ☐

3. What is your current relationship status?

Single Married Separated Widowed
Divorced Partner

4. Do you live alone? Yes No

5. What is your occupation?
(e.g. homemaker, teacher, farmer, student, unemployed) ☐

If retired or unemployed what was your previous occupation? ☐

6. Do you have: A medical card Yes No

Health Insurance Cover Yes No

Other (please specify) ☐

7. What is your highest educational qualification level?
Please tick <u>one</u> box only.

Primary School level
Second level (up to leaving certificate**)**
3rd Level (University or College)

Section 2: Breast Symptom Details, Help Seeking Behaviour, Symptom Disclosure and emotional response to symptom discovery

This section of the questionnaire relates to the symptom discovery, and how you felt when you discovered the symptom.

8. What symptoms caused you to visit your General Practitioner initially?
Please tick as many as apply to you.

Breast lump Nipple discharge Breast pain Nipple indrawn or changed

Skin changes Change in shape of my breast

Other (please specify) _____

9. Who discovered your breast symptom?
Please tick the appropriate box.

Yourself Your partner

Other (please specify) _____

10. The following statements describe what some women do when they find a breast symptom.

Please tick yes/no as appropriate to what you did when you found your breast symptom.

Please tick your response to <u>each statement below</u>:

	YES	NO
1. I prayed to God about the breast symptom		
2. I consulted a wide variety of people to see what I should do		
3. I checked it periodically myself to make sure it did not change		
4. I took medicine to make it better		
5. I listened to the advice of others about whether to go to the GP		
6. I used alternative therapies/ home remedies to make it better		
7. I ignored it and hoped that it would go away		
8. I meditated / reflected about the breast problem to try and heal it.		

(Alternative Help Seeking Behaviour Scale, adapted from "Self Care Scale, Facione et al., 2002)

11. Below are a number of words that describe different feelings and emotions.

Please indicate to what extent you felt this way when you first noticed your breast symptom(s):

Please tick your response to <u>each of the feelings/ emotions</u> below:

WHEN I FIRST NOTICED MY SYMPTOM(S), I FELT	NOT AT ALL	A LITTLE BIT	MODERATELY	QUITE A BIT	VERY MUCH
1. Afraid					
2. Anxious					
3. Distressed					
4. Scared					
5. Depressed					
6. Angry					
7. Unsure/ Uncertain					

(Symptom Emotional Distress Scale adapted from Meechan et al., 2003).

12. **Who did you <u>first</u> talk to when you discovered/ experienced your symptom?**
(*Tick <u>One</u> only*)

No one My Husband/ partner A family member A friend A colleague

General Practitioner Action breast cancer helpline

Other (please specify) ☐

13. How long after discovery of the breast symptom did you visit your General Practitioner (G.P.)?
Be specific about this time frame. A calendar is attached to the back of this questionnaire, for your convenience.

Less than 1 week 1 to 2 weeks 3 to 4 weeks

5 to 6 weeks 7 to 8 weeks 9 to 12 weeks

If over three months, please specify the length of time ☐

Section 3: Health Seeking Habits
In relation to breast self examination and frequency of mammography, please indicate:

14. How often do you examine your breasts?
Monthly Every 2 months Rarely Never

If rarely/ never, please indicate reasons for not examining your breasts:

I do not know how to do it
I forget
Fear of finding a breast lump
I do not have time
Other reason

If other reason, please specify: ☐

15. How regularly do you have a mammogram?

Never Once ever **Once every year** Every 2-3 years Every 4-6 years

Section 4: Health Service System Utilisation

This section relates to your views about accessing the health care services.

Thank you, once again for your participation in the study.

16. The following statements describe your views on accessing the General Practitioner (GP). ***Please indicate how much you agree or disagree with the following statements in relation to your own experience:***				
	Strong No			**Strong Yes**
	STRONGLY DISAGREE	**DISAGREE**	**AGREE**	**STRONGLY AGREE**
1) Sometimes I go without the medical care I need because it is too expensive.				
2) The GP office should be open for more hours than it is.				
3) The GP office is conveniently located.				
4) GP's often do not listen to people				
5) I have easy access to my GP				
6) I have a female GP which makes it easier for me to attend				
7) Prior to the occurrence of this breast symptom, I have not been to see my GP for at least two years				
8) When it comes to health care visits, transportation is a big problem for me				
9) I see a different GP almost every time I get an appointment.				
10) I have a GP with whom I feel comfortable talking to when I need medical care				
11) It is difficult for me to go to the GP as I do not have a medical card				
12) Sometimes I have been ignored by a GP because I am a woman				
13) I have not always been treated respectfully by doctors and nurses				
14)I have experienced discrimination in a GP's office				
15) My own health has never been affected by discrimination.				
Perceived Access to Health Services (PAHS) Scale (items 1-11) adapted from Facione et al., 1997 and Perceived Experience of Prejudice (PEP)subscale (items 12-15) adapted from Facione and Facione, 2007).				

17. The following statements describe possible constraints to your visiting the GP when you found your breast symptom. ***Please read each statement and indicate "Yes"/"No"/"Not Applicable" to indicate whether or not the statement relates to your own personal situation.***			
	Yes	**No**	**Not Applicable**
1) Taking care of my family (children / older relative) prevented me from going to the GP			
2) Work commitments prevented me from going to the GP			
3) I had nobody to talk to about the symptom			
4) My spouse/ partner did not like me having my breasts examined by the GP			

(CONSTRAINT scale adapted from Facione et al., 2002)

Section 5: Knowledge and Beliefs

This section of the questionnaire relates to your knowledge and beliefs/views about breast cancer generally. I realise that this is a sensitive issue for you at this time.

I appreciate your participation in the study and sharing your views about this topic.

18. Has any member of your family had breast cancer ? Yes No

If yes, please indicate:

Mother Sister Daughter Grandmother Aunt Others

If others, please specify:

At this stage, the questionnaire is almost complete.

Please continue on to next page

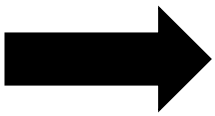


19. ***I am interested in your <u>own views (beliefs)</u> about your <u>breast symptom</u> and what it means to you. Please indicate how much you agree or disagree with the following statements about your <u>breast symptom</u>:***

	Strong No		**No opinion/ Not applicable**		**Strong Yes**
My views/beliefs about my breast symptom are that	**STRONGLY DISAGREE**	**DISAGREE**	**NEITHER AGREE NOR DISAGREE**	**AGREE**	**STRONGLY AGREE**
Cause					
1) The symptom was caused by a germ or virus					
2) Diet played a major role in causing the symptom					
3) Pollution in the environment caused the symptom					
4) The symptom is hereditary- it runs in my family					
5) The symptom occurred just by chance					
6) Stress was a major factor in causing my breast symptom					
7) My breast symptom was caused by my own behaviour					
8) Other people played a major role in causing My breast symptom to occur					
9) My state of mind played a major role in causing my breast symptom					
Duration					
10) My breast symptom will last for a short time					
11) My breast symptom is likely to be permanent rather than temporary					
12) My breast symptom will last for a long time					
Consequences					
13) My breast symptom is a serious condition					
14) My breast symptom has a major effect on my life					
15) My breast symptom is easy to live with					
16) My breast symptom has not had much effect on my life					
17) My breast symptom has strongly affected The way others see me					
18) My breast symptom has had serious economic & financial consequences for me					
19) My breast symptom has strongly affected the way I see myself as a person					
Cont.					

Cont.	**Strong No**		**No opinion/ Not applicable**		**Strong Yes**
My views/ beliefs about my breast symptom are that	**STRONGLY DISAGREE**	**DISAGREE**	**NEITHER AGREE NOR DISAGREE**	**AGREE**	**STRONGLY AGREE**
Cure/ Control					
20) My breast symptom will improve in time					
21) There is a lot I can do to control my breast symptom					
22) There is very little that can be done to control my breast symptom					
23) Recovery from my breast symptom is largely dependent on chance or fate					
24) What I do can determine whether the symptom gets better or worse					
Outcome of symptom					
25) My breast symptom could be due to breast cancer					
26) My breast symptom could be due to a non-threatening/less serious/benign breast problem					
(Adapted from The Illness Perception Questionnaire (IPQ), Weinman et al., 1996)					

Please continue on to next page



20. Below is a list of changes that can occur in the breast.
Please indicate an "X" in the box that best describes whether these changes might be signs of breast cancer, <u>in general</u>.

Please tick your response to <u>each of the breast changes</u> outlined below:

YES	NO	Don't Know	BREAST CHANGES
			1) Persistent itching of the skin
			2) A breast lump I never noticed before
			3) A lump under my arm
			4) A hot reddened painful area
			5) Constant pain in one area of the breast
			6) A darkening of the skin
			7) A little blood coming from one nipple
			8) A thickened area in one breast
			9) One nipple beginning to sink inwards
			10) A sore or scab on one nipple
			11) A clear drainage from one nipple
			12) A change in the shape of one breast
			13) A lump becoming larger
			14) A dimpling in the skin of one breast
			15) One breast getting larger

(**Breast Cancer Knowledge Scale adapted from Facione et al., 2002)**

Please continue on to next page

21. ***Are there any other comments that you wish to make about finding your breast symptom and what influenced you in visiting your GP after finding the breast symptom? Please use the back of the page if necessary.***

AGAIN, THANK YOU FOR TAKING THE TIME TO COMPLETE THIS QUESTIONNAIRE. YOUR PARTICIPATION IS VERY MUCH APPRECIATED

Please ensure that you

- *Have signed the consent form*
- *Return the completed questionnaire to the researcher or to the receptionist at the check in desk.*

Source of Questionnaire package: Adapted with permission from (Weinman et al., 1996; Burgess et al., 1998; Facione et al., 1997; Facione et al., 2002; Facione and Facione 2007, Meechan et al, 2002, 2003; Mc Menamin et al., 2005 Montazeri et al., 2008).

Appendix 2 Letters of permission to reprint models and utilise research scales

Appendix 2a(i) Permission to reprint the J-Delay Model (Facione et al., 2002) and utilise scales.

From: NFacioneMR [nfacione@measuredreasons.com]
Sent: 29 July 2009 19:47
To: O'Mahony, Mairin
Subject: RE: Permission to use model and scales

Hello Mairin:
Yes things are well here. I hope your summer has been a fine one. I usually feel most creative and productive during the daylight so summer is a favorite time, but it seems to be racing by.

I'm happy to have you use these measures in your study (as outlined below). All of these scales are in the public domain and you should have no trouble with copyright. In terms of the J-Delay model, there should be no problem with the publisher here either.

I will be interested to see whether you observe similar relationships or not in your own study sample. It's nice to hear that you are moving forward and I hope that you enjoy this part of the project.

Best regards,
Noreen

Noreen C. Facione, PhD, FAAN
Executive Consultant
Measured Reasons
919 Sunset Dr.
Hermosa Beach, CA 90254
Ph: 650-743-8631
Fx: 310-379-5358

Appendix 2a(ii) Permission to reprint the J-Delay Model (Facione et al., 2002) from publishers

ELSEVIER LICENSE
TERMS AND CONDITIONS

Jul 30, 2009

Supplier	**Elsevier Limited** **The Boulevard,Langford Lane** **Kidlington,Oxford,OX5 1GB,UK**
Registered Company Number	**1982084**
Customer name	**Mairin O Mahony**
Customer address	**School of Nursing and Midwifery** **Cork, other XXXXX**
License Number	**2238821394497**
License date	**Jul 30, 2009**
Licensed content publisher	**Elsevier**
Licensed content publication	**Preventive Medicine**
Licensed content title	**The Self-Reported Likelihood of Patient Delay in Breast Cancer: New Thoughts for Early Detection**
Licensed content author	**Noreen C. Facione, Christine Miaskowski, Marylin J. Dodd and Steven M. Paul**
Licensed content date	**April 2002**
Volume number	**34**
Issue number	**4**
Pages	**11**
Type of Use	**Thesis / Dissertation**
Portion	**Figures/table/illustration/abstracts**
Portion Quantity	**1**
Format	**Print**
You are an author of the Elsevier article	**No**
Are you translating?	**No**
Order Reference Number	**pfCase:97240, pfTicket:5118727]**
Expected publication date	**Sep 2010**
Elsevier VAT number	**GB 494 6272 12**
Permissions price	**0.00 EUR**

Elsevier hereby grants you permission to reproduce the aforementioned material subject to the terms and conditions indicated

Appendix 2b. Permission to reprint 'Parallel Response Model'

Order Details

Handbook of health psychology

Billing Status:

Not Billed

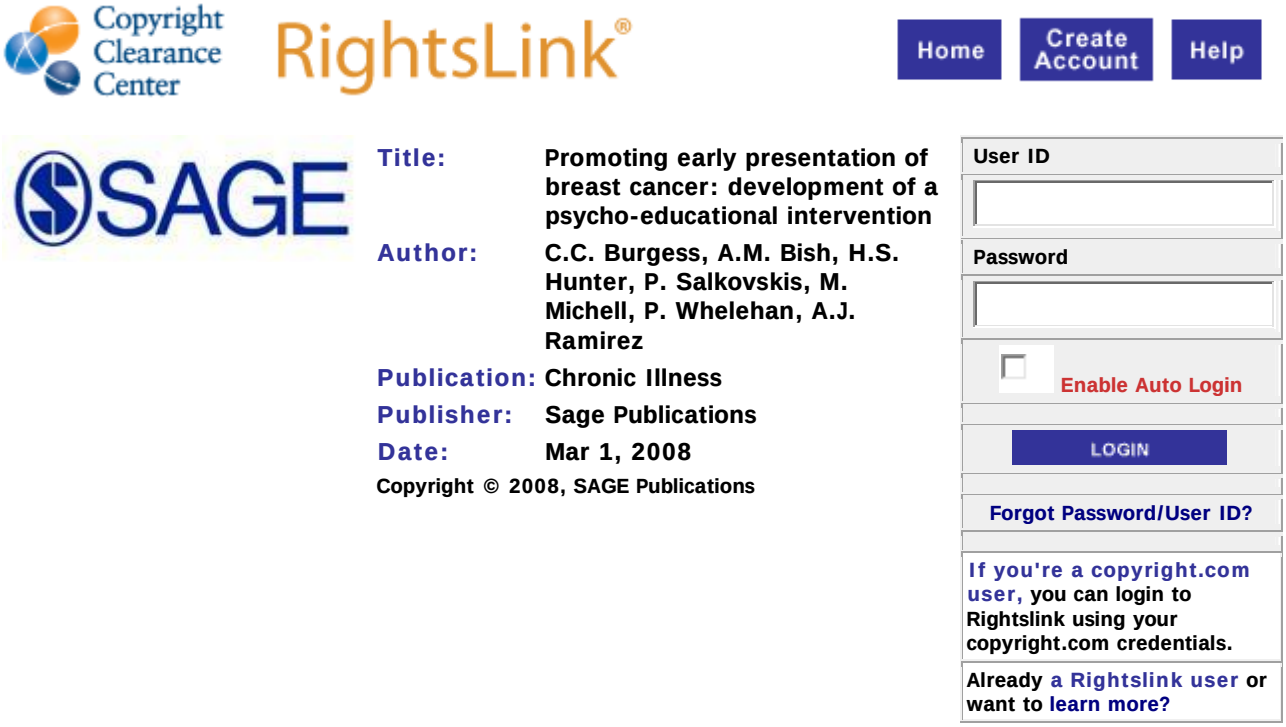
- Order detail ID: 55240403
- ISBN: 978-0-8058-1495-8
- Publication year: 2001
- Publication Type: Book
- Publisher: LAWRENCE ERLBAUM ASSOCIATES, INCORPORATED
- Rightsholder: TAYLOR & FRANCIS GROUP LLC - BOOKS
- Author/Editor: Leventhal et al., 1991
- Your reference: Mairin's thesis Chapter 1
- Permission Status: Granted
  Comment: Please make sure the appropriate source line is credited under the requested material.
- Permission type: Republish or display content
- Type of use: Dissertation
- Requested use: Dissertation
- Republication title: Women's help seeking behaviour and the associated influencing factors on self discovery of a breast symptom
- Republishing organization: University College Cork
- Organization status: Non-profit 501(c)(3)
- Republication date: 08/01/2011
- Circulation/ Distribution: 5000
- Type of content: Figure/ diagram/ table
- Description of requested content: Parallel Response Model
- Page range(s): page 21
- Translating to: No Translation
- Requested content's publication date: 01/01/2001
- Cancel
- Copy
- Edit

Appendix 2c. Permission to reprint 'Model for understanding delayed presentation with breast cancer' (Bish et al., 2005).

ELSEVIER LICENSE
TERMS AND CONDITIONS Jul 06, 2011

Supplier	Elsevier Limited The Boulevard,Langford Lane Kidlington,Oxford,OX5 1GB,UK
Registered Company Number	1982084
Customer name	Mairin O Mahony
Customer address	School of Nursing and Midwifery Cork, other XXXXX
License number	2702970291426
License date	Jul 06, 2011
Licensed content publisher	Elsevier
Licensed content publication	Journal of Psychosomatic Research
Licensed content title	Understanding why women delay in seeking help for breast cancer symptoms
Licensed content author	Alison Bish, Amanda Ramirez, Caroline Burgess, Myra Hunter
Licensed content date	April 2005
Licensed content volume number	58
Licensed content issue number	4
Number of pages	6
Start Page	321
End Page	326
Type of Use	reuse in a thesis/dissertation
Portion	figures/tables/illustrations
Number of figures/tables/illustrations	1
Format	both print and electronic
Are you the author of this Elsevier article?	No
Will you be translating?	No
Order reference number	
Title of your thesis/dissertation	Women's help seeking behaviour and the associated factors on self discovery of a breast symptom
Expected completion date	Jul 2011
Estimated size (number of pages)	260
Elsevier VAT number	GB 494 6272 12
Permissions price	0.00 EUR
VAT/Local Sales Tax	0.0 USD / 0.0 GBP

Appendix 2d. Permission to reprint 'Framework to promote early help seeking'



Copyright Clearance Center RightsLink®

Home | Create Account | Help

SAGE

Title: Promoting early presentation of breast cancer: development of a psycho-educational intervention

Author: C.C. Burgess, A.M. Bish, H.S. Hunter, P. Salkovskis, M. Michell, P. Whelehan, A.J. Ramirez

Publication: Chronic Illness

Publisher: Sage Publications

Date: Mar 1, 2008

Copyright © 2008, SAGE Publications

User ID

Password

Enable Auto Login

LOGIN

Forgot Password/User ID?

If you're a copyright.com user, you can login to Rightslink using your copyright.com credentials.

Already a Rightslink user or want to learn more?

Gratis

Permission is granted at no cost for sole use in a Master's Thesis and/or Doctoral Dissertation. Additional permission is also granted for the selection to be included in the printing of said scholarly work as part of UMI's "Books on Demand" program. For any further usage or publication, please contact the publisher.

Appendix 2e. Permission to adapt Illness Perception Questionnaire

From: Weinman, John [John.Weinman@iop.kcl.ac.uk]
Sent: 29 July 2009 14:55
To: O'Mahony, Mairin
Subject: RE: permission re IPQ

Mairin

Please go ahead and adapt the IPQ for your study, and I hope that your study is successful,

best wishes

Prof John Weinman

Appendix 2f. Permission to utilise question on Breast self examination (BSE)

From: Dr. Ali Montazeri [montazeri@acecr.ac.ir]
Sent: 28 July 2009 19:24
To: O'Mahony, Mairin
Subject: Re: permission re questionnaire
Dear Mairin,

Thank you for your e-mail asking permission to adapt and use the Q15 of our questionnaire in your study. Your are very welcome to adapt and use not only the Q15 but also the whole questionnaire as you wish.
Please do not hesitate to contact me if you need further assistance.
Kind regards
Ali Montazeri

-----Original Message-----
From: "O'Mahony, Mairin" <mairin.omahony@ucc.ie>
To: <montazeri@acecr.ac.ir>
Date: Tue, 28 Jul 2009 17:27:41 +0100
Subject: permission re questionnaire

Dear Professor Montazeri,

Recently you very kindly forwarded me a copy of the questionnaire that you used in the study: Montazeri, A., M. Vahdaninia, et al. (2008). "Breast cancer in Iran: need for greater women awareness of warning signs and effective screening methods." Asia Pac Fam Med **7**(1): 6.

I am now request your permission to adapt and utilise the options listed for Q 15 re BSE in my questionnaire on delayed help seeking in an Irish context.

I look forward to hearing from you,

Kind regards,

Mairin O'Mahony

Appendix 3a Content validity of questionnaire items and scales

Content Validity Index for questionnaire items (I/CVI) and for scales (S-CVI)
Note for items content validity (I-CVI) recommended index: ≥ 0.78;
For scales S/CVI recommended value : 0.90 (Polit and Beck, 2008 pg 459)

Question Number	Questionnaire Section and Variable Title	Scale Title	I-CVI	S-CVI
Section 1 : Socio-demographics				
1.	Age		1.00	
2.	Nationality		0.63	
3.	Relationship status		0.88	
4.	Living Alone		0.88	
5	Occupation		1.00	
6	Education level		1.00	
Section 2: Breast Symptom, help seeking details and emotional response to the symptom				
7	Breast Symptom identity		1.00	
8	Who discovered the symptom		0.86	
9.	Help seeking behaviour		1.00	
10.	Who did you first talk to		1.00	
11.	Alternative help seeking behaviour (ALT HSB)	ALT HSB (8 items)		0.78
12.	Psychological Factors	Symptom Emotional Distress (7 items)		1.00
Section 3 : Health Seeking Habits				
13.	Breast Self examination		1.00	
14 &15	Mammography		1.00	
Section 4: Health Service System Utilisation and Social Constraints				
16a	Perceived Access to Health Services	Perceived Access to Health Services (11 items)		0.9
16b	Personal Experiences of Prejudice	Personal Experiences of Prejudice		0.85
17.	Social Factors: Constraints	CONSTRAINT (4items)		0.88
Section 5: Knowledge and Beliefs				
18.	Knowledge regarding presence or absence of a family history of breast cancer		1.00	
19.	Symptom Perceptions/ Beliefs relating to:	Symptom Perception Questionnaire		
	Cause of Symptom	Causes Subscale (9 items)	0.80-1.00	
	Duration of Symptom	Duration subscale (3 items)		0.80
	Consequences of Symptom	Consequences subscale (7 items)		0.90
	Cure/ control of symptom	Cure/ Control subscale (5 items)		0.90
	Outcome of symptom	Researcher adapted questions (2 items)	1.00	
20.	Knowledge of breast changes associated with breast cancer	Breast Cancer Knowledge scale (15 items)		0.85

Appendix 3b Document sent to reviewers regarding face validity of questionnaire

Having reviewed the questionnaire package, I would be very grateful if you would take the time to complete the questions below regarding their overall relevance with the aim and objectives of the study in mind.

PhD study entitled "Women's help seeking behaviour and the associated influencing factors, on self discovery of a breast symptom": Phase Two

Aim of study: To describe women's help seeking behaviour (HSB) and the associated influencing factors on self discovery of a breast symptom.

Objectives:

1. To identify the factors that influence women's HSB on self discovery of a breast symptom.
2. To ascertain the extent of delay in women's HSB on self discovery of a breast symptom.
3. To determine the relationships between HSB and the following variables: knowledge and beliefs, psychological factors, social factors, health service system utilisation factors, health seeking habits and socio-demographics
4. To compare women who delayed help seeking for one month or more with women who sought help within one month of finding the breast symptom(s).

Validity of the questionnaire

1. Does the questionnaire package address the aim and objectives of the research study:

Aim :	Yes	☐	No	☐	Unsure	☐
Objectives:	Yes	☐	No	☐	Unsure	☐

If no or unsure please elaborate:

2. In your view, does the content of the questions listed below meet the aim and objectives of the study?

Issues	**Addressed very well**	**Addressed well**	**Addressed fairly well**	**Not adequately addressed**
Q1-6 Socio-Demographic information				
Q 7. Breast symptom details				
Q8. Breast symptom discovery				
Q9. Time lapse from symptom discovery to visit to GP				
Q10. Time lapse from visit to GP to consultant visit				
Q11 Symptom Disclosure				
Q 12 Alternative help seeking behaviour				
Q13 Women's emotional responses to symptom discovery				
Health seeking habits Q14-15 Q14 Practice of BSE				
Q15 Frequency of mammography				
Q 16 Health service system utilisation Scale				
Q17 Constraints in accessing GP				
Q 18 Family History details				
Q 19 Beliefs about the breast symptom				
Q20 Knowledge about breast cancer symptoms				

As help seeking behaviour following women's self discovery of abreast symptom is the focus of the study, in your opinion are there any other possible issues/ questions which should be added to the questionnaire? If so, please outline below:

Reliability of the questionnaire

3. Are the questions or statements clear and unambiguous enough for a respondent to understand and to respond to them in the same way <u>each time</u> they are presented to them?

Yes ☐ No ☐

If no, highlight the questions which are "**unclear"** in the attached questionnaire

4. Are the questions or statements clear and unambiguous enough for all respondents to interpret and understand them in the <u>same way</u>?

Yes ☐ No ☐

If no, highlight the **questions** which are "**unclear or ambiguous"** in the attached questionnaire:

5. Do you think that it is likely that all respondents will <u>interpret</u> the instructions given by the researcher in the same way?

Yes ☐ No ☐ Unsure ☐

If no or unsure, please highlight on the questionnaire the **instructions which are unclear**.

Are there any other comments you wish to include:

Thank You for your time in reviewing this questionnaire.
Mairin O'Mahony
PhD Student/College Lecturer

Appendix 4 Letter of Approval from Ethical Committee

Appendix 5 Letters of Approval from Consultants

Appendix 6a Letters of Approval from Director of Nursing

Appendix 6b Letter of approval from Board of Directors

Appendix 7a Letters to Breast Care Nurse Specialists

Appendix 7b Letter to Cancer Care Co-ordinator

Appendix 8 Information leaflet for women attending the breast clinic

STUDY INFORMATION LEAFLET FOR WOMEN VISITING THE BREAST CLINIC

Research on women's help seeking behaviour on self discovery of a breast symptom

What is this study about?

This study is about the factors that helped you in visiting your GP after you found your breast symptom. In order to take part it is necessary that you found your breast symptom **yourself.**

What is involved in the study?

The study involves completion of a questionnaire about your demographic details, finding your breast symptom and the factors that helped you and/or made it difficult for you to visit your general practitioner concerning your breast symptom. The questionnaire will take approximately 10 minutes of your time, and will be completed here in the breast clinic, before you meet with the consultant. Your decision to take part in the study will not in any way affect your place in the queue to visit the consultant to-day.

Should you wish to take part, the researcher (Mairin O'Mahony) will meet with you and answer any questions about the study and obtain your consent. You will also be asked to for consent to contact you by letter or telephone, to arrange for a follow up interview, with the researcher, if necessary. Finally, you will be asked to give permission to the researcher to access your case notes to confirm the outcome of your breast symptom assessment.

Will this information be confidential?

All information provided will remain confidential. Your name and address will not be included on the questionnaires or any publications following completion of the study.

What are the benefits of the study?

The study will investigate women's help seeking from their GP, and identify the factors that helped and/or made it difficult for women to go to their GP when they found their breast symptom. This information will be helpful to health care professionals involved in planning and developing breast health promotion programmes for women.

Do I have to take part in this study?

There is no obligation to participate. Should you decide not to take part, this will not in any way affect your care or restrict your access to health care services. Even if you agree to take part initially, you have the right to subsequently withdraw.

Does the researcher have permission to carry out this study?

Yes, the researcher has sought and been granted permission from the Hospital Management, Consultants and the Clinical Research Ethics Committee of the Cork Teaching Hospitals.

Thank you for taking the time to read this leaflet, Mairin will now meet with you, if you are interested in taking part in her study.

Appendix 9 Consent Form

CONSENT FORM

Research on women's help seeking behaviour on self discovery of a breast symptom

Researcher: Mairin O'Mahony **Phone**: 021-4901458

This is to confirm that I have been informed about the above study concerning women's help seeking behaviour on self discovery of a breast symptom.

Mairin, the nurse researcher, has informed me about the study, and I know that there are minimal risks to my taking part in the study. I know that the study involves me completing a questionnaire in the breast clinic before I meet with the consultant. I am aware that Mairin may contact me if necessary, for follow up interview, in my own home. I am also aware that Mairin will access my case notes to review the results of the assessment of my breast symptom.

I know that Mairin is available to answer any questions that I may have about the study. I know that my name will not be recorded on the questionnaire. A code number will be used to identify my participation in the study. The information that I give in the questionnaire, in any additional interview and the results of the assessment of my breast symptom will be kept confidential. I also understand that the study may be published in a nursing journal but it will be impossible for me to be identified from what will be written.

Mairin has explained to me that my participation is voluntary and that I may withdraw at any time if I so choose.

I am happy that any questions I have asked Mairin about the study have been answered to my satisfaction. I am aware that if I have any further questions I can contact Mairin at 021-4901458.

X_____ _____

Signature of Participant **Date**:

_____ _____

Signature of Nurse Researcher **Date:**

*If necessary, Mairin may contact me for a follow up interview following her initial review of the questionnaire, at the following address **(Please Print)** or telephone number:*

Name: _____

Address: _____

_____

Telephone Number: _____

Appendix 10 Code book for data Interpretation

Variable	SPSS Variable Name	Coding Instruction
Identification Number	**ID**	Number assigned to each questionnaire
1. Age	**Age**	1 = 16-20 2 = 21-30 3 = 31-40 4 = 41-50 5 = 51-60 6 = 61-70 7 = 71-80 8 = over 80
2.Nationality	**National**	1 = Irish 2 = English **99 = Other**
3.Relationship Status	**Relstatus**	Single =1 Married =2 Separated = 3 Widowed = 4 Divorced = 5 Partner = 6
4.Live alone	**Livealone**	Yes =1; No = 2
5.Occupation	**Occup**	Homemaker =1 Professional =2 Non-professional =3 Student = 4 Unemployed =5 Retired=6 Retired Professional =7 Self-employed =8
6.Medical Cover	**Medcover**	Medical card =1 Health Insurance=2 No cover =3
7.Educational Qualification	**Education**	Primary school =1 Secondary School = 2 University/ 3rd Level = 3
8.Symptom Type	**Symtype**	Breast lump =1 Nipple Discharge =2 Breast pain = 3 Nipple indrawn or changes = 4 Skin changes =5 Change in shape of breast = 6 Mastitis =7 Axillary swelling = 8 **Other =99**
9.Who discovered symptom	**Whodisc**	Yourself = 1 Your partner =2

Variable	SPSS Variable Name	Coding Instruction
10.Alternative help seeking behaviour scale items 1-8	**ALTHSB1-8**	Yes =1; No =2
11. Symptom Emotional distress scale items 1-7	**SED scale 1- 7**	not at all =1 a little bit =2 moderately =3 quiet a bit =4 very much =5
12.Who first talked to	**Talkfirst**	No One = 1 Husband = 2 Family Member = 3 Friend = 4 Colleague = 5 General practitioner = 6 Action breast cancer helpline = 7 Gynaecologist = 8 VHI Helpline=9 **Other =99**
13. How long after discovery of symptom to visit GP	**Time to GP**	**Coded as number of weeks** Less than 1 week =1 1-2 weeks = 2 3-4 weeks = 4 5 to 6 weeks = 6 7 to 8 weeks = 8 9-12 weeks = 12 (3 months) **Other i.e.** **4 months=16** **5 months=20** **6 months =24** **9 months =36** **12 months =52** **24 months=104**
14aHabits	**BSE**	Monthly 1 Every 2 months =2 Rarely =3 Never = 4
14b Reasons for not doing BSE	**Rarelynever**	I do not know =1 I forget = 2 Fear of finding a lump = 3 I do not have time = 4 **Other reason = 99**

Variable	SPSS Variable Name	Coding Instruction
15. Mammogram	**Mamogram**	Never =1 Once ever 2 Once every year 3 Every 2-3 yrs 4 Every 4-6years 5
16. Health Service System Utilisation **Subscale Perceptions of prejudice**	**HSSU 1-11** **PEP 12-15**	strongly disagree = 1 disagree = 2 agree = 3 strongly agree = 4 strongly disagree = -2 disagree = -1 agree = +1 strongly agree = +2
17. Constraints to visiting GP	**Constraint1-4**	Yes = 1 No = 2 Not applicable = 3
18a Family History	**Famhistry**	Yes = 1 No = 2
18b If yes , indicate who	**Famembr**	Mother =1 Sister =2 Daughter =3 Grandmother = 4 Aunt =5 **Other = 99**
19.Symptom beliefs/ views/ perception scale	**SPQ 1-26**	strongly disagree =1 disagree = 2 neither agree nor disagree =3 agree = 4 strongly agree =5
20. Breast cancer knowledge scale	**BCKS 10-15**	**Yes = 1; No =2; don't know = 3**
21. Any other comments		**Yes=1; No=2**

Note to data manager: missing data: <u>enter 100 for all questions</u>

Appendix 11 Hypotheses, data measurement and statistical tests

QUESTION	INDEPENDENT VARIABLE	DEPENDENT VARIABLE	PARAMETRIC STATISTIC	NON-PARAMETRIC STATISTIC
Q.19 Is there a relationship between women's HSB (prompt versus delayed) and their beliefs re: cause/ duration/ consequences/ control/curability / attribution, of their breast symptom?	**Women's beliefs: Ordinal/ Continuous**	**Question 9** Prompt HSB Delayed HSB (Yes/No) **Nominal/ dichotomous variable as two values yes/ No**	Independent sample T-Tests	Chi- square test for individual items on scale and HSB
Q10. Is there a relationship between women's HSB (prompt versus delayed) and their beliefs in alternative help seeking behaviours?	**Women's beliefs**: **Nominal Yes/No Categorical**	Prompt HSB Delayed HSB (Yes/No): **Nominal**		Chi- square test
Q.20 Is there a relationship between women's HSB (prompt versus delayed) and their knowledge about breast changes associated with breast cancer?	**Women's knowledge Nominal Yes/No** **Categorical**	Prompt HSB Delayed HSB (Yes/No): **Nominal**		Chi- square test
Q.13. Is there a relationship between women's HSB (prompt versus delayed) and their emotional responses to their breast symptom discovery?	**Women's emotional response**: **Ordinal/ Continuous**	Prompt HSB Delayed HSB (Yes/No): **Nominal**	Independent sample T-Tests	Chi- square test for individual items on scale and HSB

QUESTION	INDEPENDENT VARIABLE	DEPENDENT VARIABLE	PARAMETRIC STATISTIC	NON-PARAMETRIC STATISTIC
Q.17 Is there a relationship between women's HSB (prompt versus delayed) and social factors /constraints?	**Social factors/ Constraints Nominal Yes/No Categorical**	Prompt HSB Delayed HSB (Yes/No): **Nominal**		Chi- square test
Q. 16 **items 1 to 11** Is there a relationship between women's HSB (prompt versus delayed) and their perceived access to health services?	**Access to health services Ordinal/ Continuous**	Prompt HSB Delayed HSB (Yes/No): **Nominal**	Independent sample T-Tests	Chi- square test for individual items on scale and HSB
Q. 16 **items 12 to 15** Is there a relationship between women's HSB (prompt versus delayed) and their perceived experience of prejudice within the health services?	**Perceived experience of prejudice within the health services Ordinal/ Continuous**	Prompt HSB Delayed HSB (Yes/No): **Nominal**	Independent sample T-Tests	Chi- square test for individual items on scale and HSB
Q. 14-15 Is there a relationship between women's HSB (prompt versus delayed) and their engagement in health seeking habits?	**Health seeking habits**: **Nominal/ Categorical**	Prompt HSB Delayed HSB (Yes/No): **Nominal**		Chi- square test
Socio demographic Factors				
Q. 1 Is there a relationship between women's HSB (prompt versus delayed) and their age?	**Age** **Nominal/ Categorical**	Prompt HSB Delayed HSB (Yes/No): **Nominal**		Chi- square test

QUESTION	INDEPENDENT VARIABLE	DEPENDENT VARIABLE	PARAMETRIC STATISTIC	NON-PARAMETRIC STATISTIC
Q. 2 Is there a relationship between women's HSB (prompt versus delayed) and their nationality?	**Nationality** **Nominal/ Categorical**	Prompt HSB Delayed HSB (Yes/No): **Nominal**		Chi- square test
Q3 & Q4 Is there a relationship between women's HSB (prompt versus delayed) and their relationship status?	**Relationship status** **Nominal/ Categorical**	Prompt HSB Delayed HSB (Yes/No): **Nominal**		Chi- square test
Q.5 Is there a relationship between women's HSB (prompt versus delayed) and their employment status?	**Employment status** **Nominal/ Categorical**	Prompt HSB Delayed HSB (Yes/No): **Nominal**		Chi- square test
Q6 Is there a relationship between women's HSB (prompt versus delayed) and their medical insurance cover?	Medical card/ Insurance cover **Nominal/ Categorical**	Prompt HSB Delayed HSB (Yes/No): **Nominal**		Chi- square test
Q7 Is there a relationship between women's HSB (prompt versus delayed) and their educational level?	**Educational level** **Nominal/ Categorical**	Prompt HSB Delayed HSB (Yes/No): **Nominal**		Chi- square test

QUESTION	INDEPENDENT VARIABLE	DEPENDENT VARIABLE	PARAMETRIC STATISTIC	NON-PARAMETRIC STATISTIC
Q8. Is there a relationship between women's HSB (prompt versus delayed) and the type of symptom discovered?	**Symptom Type Nominal/ Categorical**	Prompt HSB Delayed HSB (Yes/No): **Nominal**		Chi- square test
Q18. Is there a relationship between women's HSB (prompt versus delayed) and family history of breast cancer	**Family History Yes/No Nominal/ Categorical**	Prompt HSB Delayed HSB (Yes/No): **Nominal**		Chi- square test

Appendix 12 Additional Tables

Table 6.9b Breast cancer knowledge and HSB
Table 6.10 Family History and HSB
Tables 6.12a-f Beliefs about breast symptom and HSB
Table 6.15b Social Constraints and HSB
Table 6.16a Health Service System Utilisation and HSB
Table 6.16b Perceptions of Experienced Prejudice and HSB

Table 6.9 b Breast Cancer Knowledge: Changes associated with breast cancer cross tabulated with HSB following amalgamation of "No" and "don't know" responses into one "no" category,

BREAST CHANGES ASSOCIATED WITH BREAST CANCER	Yes/N0 (No/ Don't know) n	Prompt HSB n (%)	Delay HSB n (%)	Chi-square & p value
1) Persistent itching of the skin	Yes = 90	63(70.0%)	27(30.0%)	0.00 0.963
	No = 357	249 (69.75)	108 (30.3%)	
2) A breast lump I never noticed before	Yes = 368	264 (71.7%)	104 (28.3%)	3.72; 0.054*
	No = 79	48(60.8%)	31(39.2%)	
3) A lump under my arm	Yes = 316	219(69.3%)	97(30.7%)	0.13 0.72
	No = 131	93(71.0%)	38(29.0%)	
4) A hot reddened painful area	Yes = 155	110 (71.0%)	45 (29.0%)	0.15 0.695
	No = 292	202 (69.2%)	90 (30.8%)	
5) Constant pain in one area of the breast	Yes = 286	195(68.2%)	91(31.8%)	0.99 0.321
	No = 161	117 (72.7%)	44 (27.3%)	
6) A darkening of the skin	Yes = 179	131 (73.2%)	48 (26.8%)	1.62 0.203
	No = 268	181(67.5%)	87 (32.5%)	
7) A little blood coming from one nipple	Yes = 230	165(71.7%)	65(28.3%)	0.65 0.358
	No = 217	147(67.1%)	70 (32.3%)	
8) A thickened area in one breast	Yes = 254	178 (70.1%)	76 (29.9%)	0.02 0.88
	No = 193	134 (69.4%)	59 (30.6%)	
9) One nipple beginning to sink inwards	Yes = 215	150 (69.5%0	65 (30.2%)	0.00 0.989
	No = 232	162 (69.8%)	70 (30.2%)	
10) A sore or scab on one nipple	Yes = 133	94 (70.7%)	39 (29.3%)	0.07 0.79
	No = 314	218 (69.4%0	96(30.6%)	
11) A clear drainage from one nipple*	Yes = 161	122 (75.8%)	39 (24.2%)	4.27 0.039*
	No = 286*	190 (66.4%)	96 (33.6%)	
12) A change in the shape of one breast	Yes = 254	176 (69.3%)	78 (30.7%)	0.07 0.79
	No = 193	136 (70.5%)	57 (29.5%)	
13) A lump becoming larger	Yes = 320	225 (70.3%)	95 (29.7%)	0.14 0.707
	No = 127	87 (68.5%)	40 (31.5%)	
14) A dimpling in the skin of one breast	Yes = 192	140 (72.9%)	52 (27.1%)	1.55 0.21
	No = 255	172 (67.5%)	83 (32.5%)	
15) One breast getting larger	Yes = 182	130 (71.4%)	52 (28.6%)	0.39 0.534
	No = 265	182 (68.7%)	83 (31.3%)	

***Significant relationship detected with HSB; Note: All chi-square tests had one degree of freedom.**

Table 6.12a & b Beliefs about Symptom Cause: Internal and External cross tabulated with HSB

My views/beliefs about my breast symptom are that:	STRONGLY DISAGREE		DISAGREE		NEITHER AGREE NOR DISAGREE		AGREE		STRONGLY AGREE		Chi-Square & *P* value
a. Internal cause	n (%) P	D	n (%) P	D	n (%) P	D	n (%) P	D	n (%) P	D	
1)The symptom was caused by a germ or virus	147 (64.5)	81 (35.5)	86 (72.9)	32 (27.1)	71 (78.0)	20 (22.0)	5 (83.3)	1 (16.7)	3 100.0	0 (0.0)	8.36 0.079
2) Diet played a major role in causing the symptom	92 (67.6)	44 (32.4)	108 (66.3)	55 (33.7)	85 (74.6)	29 (25.4)	26 (83.9)	5 (16.1)	1 100.0	0 (0.0)	5.85 0.210
4)The symptom is hereditary- it runs in my family	73 (69.5)	32 (30.5)	99 (68.8)	45 (31.3)	65 (71.4)	26 (28.6)	60 (72.3)	23 (27.7)	14 (73.7)	5 (26.3)	0.51 0.972
7) My breast symptom was caused by my own behaviour	109 (71.7)	43 (28.3)	128 (68.4)	59 (31.6)	58 (65.9)	30 (34.1)	13 (86.7)	2 (13.3)	2 100.0	0 (.0)	3.95 0.413
9) My state of mind played a major role in causing my breast symptom	131 (72.8)	49 (27.2)	109 (66.9)	54 (33.1)	34 (61.8)	21 (38.2)	24 (75.0)	8 (25.0)	4 (80.0)	1 (20.0)	3.69 0.45
b. External cause											
3)Pollution in the environment caused the symptom	89 (66.9)	44 (33.1)	104 (67.1)	51 (32.9)	93 (74.4)	32 (25.6)	16 (69.6)	7 (30.4)	4 (80.0)	1 (20.0)	2.51 0.643
5)The symptom occurred just by chance	21 (84.0)	4 (16.0)	41 (78.8)	1 (21.2)	82 (65.6)	43 (34.4)	144 (69.2)	64 (30.8)	17 (63.0)	10 (37.0)	6.09 0.19
6) Stress was a major factor in causing my breast symptom	39 (73.6)	14 (26.4)	100 (66.2)	51 (33.8)	85 (66.4)	43 (33.6)	67 (75.3)	22 (24.7)	16 (80.0)	4 (20.0)	4.21 0.38
8) Other people played a major role in causing my breast symptom to occur	153 (69.2)	68 (30.8)	118 (69.4)	52 (30.6)	31 (72.1)	12 (27.9)	8 (80.0)	2 (20.0)	1 (50.0)	1 (50.0)	1.02 0.91

P= Prompt HSB; D=delayed HSB Note: All chi-square tests had four degrees of freedom

Table 6.12c Beliefs about symptom duration cross tabulated with HSB, P= Prompt HSB; D=delayed HSB

My views/beliefs about my breast symptom are that:	STRONGLY DISAGREE		DISAGREE		NEITHER AGREE NOR DISAGREE		AGREE		STRONGLY AGREE		Chi-Square & *P* value
Duration	n (%) P	D	n (%) P	D	n (%) P	D	n (%) P	D	n (%) P	D	
10) My breast symptom will last for a short time	13 (65.0)	7 (35.0)	34 (68.0)	16 (32.0)	150 (65.8)	78 (34.2)	96 (78.0)	2 (22.0)	15 (75.0)	5 (25.0)	6.27 0.180
11) My breast symptom is likely to be permanent rather than temporary*	50 (87.7)	7 (12.3)	86 (64.7)	47 (35.3)	140 (69.0)	63 (31.0)	27 (67.5)	13 (32.5)	2 100.0	0 (0.0)	11.43 0.022*
12) My breast symptom will last for a long time	53 (89.8)	6 (10.2)	81 (65.9)	42 (34.1)	139 (67.5)	67 (32.5)	27 (67.5)	13 (32.5)	2 100.0	0 (0.0)	13.71 0.008*

***p< 0.05; Note: All chi-square tests had four degrees of freedom;* significant relationship detected with HSB**

Table 6.12d Beliefs about symptom consequences cross tabulated with HSB, P= Prompt HSB; D=delayed HSB

My views/beliefs about my breast symptom are that:	STRONGLY DISAGREE		DISAGREE		NEITHER AGREE NOR DISAGREE		AGREE		STRONGLY AGREE		Chi-Square & *P* value
Consequences	n (%) P	D	n (%) P	D	n (%) P	D	n (%) P	D	n (%) P	D	
13) My breast symptom is a serious condition	25 (71.4)	**10 (28.6)**	69 (62.2)	**42 (37.8)**	141 (72.3)	**54 (27.7)**	57 (69.5)	**25 (30.5)**	12 (80.0)	**3 (20.0)**	4.38 0.357
14) My breast symptom has a major effect on my life	41 (68.3)	**19 (31.7)**	118 (65.6)	**62 (34.4)**	75 (72.8)	**28 (27.2)**	56 (71.8)	**22 (28.2)**	14 (77.8)	**4 (22.2)**	2.60 0.619
15) My breast symptom is easy to live with	18 (64.3)	**10 (35.7)**	91 (69.5)	**40 (30.5)**	102 (74.5)	**35 (25.5)**	83 (65.9)	**43 (34.1)**	6 (54.5)	**5 (45.5)**	3.862 0.425
16) My breast symptom has not had much effect on my life	29 (82.9)	**6 (17.1)**	98 (70.0)	**42 (30.0)**	61 (68.5)	**28 (31.5)**	108 (66.3)	**55 (33.7)**	11 (78.6)	**3 (21.4)**	4.36 0.36
17) My breast symptom has strongly affected the way others see me	108 (67.9)	**51 (32.1)**	113 (65.7)	**59 (34.3)**	78 (78.0)	**22 (22.0)**	6 100.0	**0 (.0)**	N/A	**N/A**	7.42 0.060*
18) My breast symptom has had serious economic & financial consequences for me	105 (69.1)	**47 (30.9)**	116 (65.6)	**61 (34.5)**	71 (75.5)	**23 (24.5)**	9 (75.0)	**3 (25.0)**	6 100.0	**0 (.0)**	5.75 0.22
19) My breast symptom has strongly affected the way I see myself as a person	107 (73.8)	**38 (26.2)**	110 (64.0)	**62 (36.0)**	56 (75.1)	**18 (24.3)**	30 (66.7)	**15 (33.3)**	6 (85.7)	**1 (14.3)**	6.142 0.189

***trend detected with HSB. Note: All chi-square tests had four degrees of freedom**

Table 6.12e Beliefs about symptom cure/control cross tabulated with HSB, P= Prompt HSB; D=delayed HSB

My views/beliefs about my breast symptom are that:	STRONGLY DISAGREE		DISAGREE		NEITHER AGREE NOR DISAGREE		AGREE		STRONGLY AGREE		Chi-Square & *P* value
Cure/ Control	n (%) P	D	n (%) P	D	n (%) P	D	n (%) P	D	n (%) P	D	
20) My breast symptom will improve in time	4 (66.7)	2 (33.3)	8 (66.7)	4 (33.3)	111 68.5	51 (31.5)	153 69.5	67 (30.5)	32 76.2	10 (23.8)	1.03 0.906
21) There is a lot I can do to control my breast symptom	18 (73.8)	5 (21.7)	61 (64.9)	33 (35.1)	130 (68.8)	59 (31.2)	89 73.6	32 (26.4)	11 68.8	5 (31.3)	2.76 0.599
22) There is very little that can be done to control my breast symptom	35 71.4	14 (28.6)	120 71.9	47 (28.1)	106 66.3	54 (33.8)	37 69.8	16 (30.2)	5 71.4	2 (28.6)	1.34 0.855
23) Recovery from my breast symptom is largely dependent on chance or fate	51 (70.8)	21 (29.2)	115 (73.2)	42 (26.8)	83 (68.0)	39 (32.0)	52 (66.7)	26 (33.3)	6 60.0	4 (40.0)	1.92 0.750
24) What I do can determine whether the symptom gets better or worse	15 (78.9)	4 (21.1)	56 (73.7)	20 (26.3)	103 (74.1)	36 (25.9)	103 (64.4)	57 (35.6)	23 65.7	12 (34.3)	5.00 0.283

Note: All chi-square tests had four degrees of freedom

Table 6.12f Beliefs about symptom outcome cross tabulated with HSB, P= Prompt HSB; D=delayed HSB

My views/beliefs about my breast symptom are that:	STRONGLY DISAGREE		DISAGREE		NEITHER AGREE NOR DISAGREE		AGREE		STRONGLY AGREE		Chi-Square & *P* value
Outcome of symptom	**n (%) P**	**D**	**n (%) P**	**D**	**n (%) P**	**D**	**n (%) P**	**D**	**n (%) P**	**D**	
25) My breast symptom could be due to breast cancer	14 (87.5)	**2 (12.5)**	41 (67.2)	**20 (32.8)**	127 (67.6)	**61 (32.4)**	111 71.6	**44 (28.4)**	10 71.4	**4 (28.6)**	3.28 0.512
26) My breast symptom could be due to a non-threatening/less serious /benign breast problem	3 (75.0)	**1 (25.0)**	11 (78.6)	**1 (25.0)**	87 (73.1)	**32 (26.9)**	175 (68.6)	**80 (31.4)**	32 (65.3)	**17 (34.7)**	1.82 0.769

Note: All chi-square tests had four degrees of freedom

Table 6.10 Family history of Breast Cancer tabulated with HSB

Family History	n	Prompt HSB n (%)	Delayed HSB n (%)	Chi-Square *d.f.* *P* value
Yes	149	106 (71.1%)	43 (28.9%)	0.13
No	295	205 (69.5%)	90(30.5%)	1
Missing	1			0.720

Table 6.15b Social Constraints to HSB cross tabulated with HSB

Social factors **Please tick yes/no as appropriate to what you did when you found your breast symptom.**	**Prompt HSB**	**Delayed HSB**	**Chi-square & *p* value**
1) Taking care of my family (children / older relative) prevented me from going to the GP * **Yes**	24(53.3%)	21(46.7%)	7.56
No	190(69.9%)	82(30.1%)	0.023*
N/A	97(75.2%)	32(24.8%)	
2) Work commitments prevented me from going to the GP **Yes**	39(60.9%)	25(39.1%)	3.23
No	219(70.4%)	92(29.6%)	0.199
N/A	53(74.6%)	18 (25.4%)	
3) I had nobody to talk to about the symptom **Yes**	8(47.1%)	9(52.9%)	4.41
No	249(70.9%)	102(29.1%)	0.110
N/A	55(70.5%)	23(29.5%)	
4) My spouse/ partner did not like me having my breasts examined by the GP **Yes**	0	0	0.860
No	238(71.0%)	97(29.0%)	0.353
N/A	73(66.4%)	37(33.6%)	

Note: Chi-square tests for items 1-3 had two degrees of freedom; item 4 had one degree of freedom;*P < 0.05

Table 6.16a Health Service System Utilisation cross tabulated with HSB

Please indicate how much you agree or disagree with the following statements in relation to your own experience:	Yes/NO N	Prompt HSB n (%)	Delayed HSB n (%)	Chi-square & *p* value
1) Sometimes I go without the medical care I need because it is too expensive.	Yes = 145	94 (64.8%)	51 (35.2%)	2.83;
	No = 289	210 (72.7%)	79 (27.3%)	0.093
2) The GP office should be open for more hours than it is.	Yes = 186	132(71.0%)	54 (29.0%)	0.36;
	No= 246	168 (68.3%)	78 (31.7%)	0.550
3) The GP office is conveniently located.	Yes = 396	274 (69.2%)	122 (30.8%)	0.84;
	No = 38	29(76.3%)	9 (13.7%)	0.361
4) GP's often do not listen to people	Yes = 97	70 (72.2%)	27 (27.8%)	0.41;
	No= 336	231(68.8%)	105 (31.3%)	0.520
5) I have easy access to my GP	Yes = 398	277 (69.9%)	121(30.4%)	0.28;
	No= 38	28 (73.7%)	10 (26.3%)	0.600
6) I have a female GP which makes it easier for me to attend	Yes = 290	197 (67.9%)	93 (32.1%)	1.89;
	No = 137	102 (74.5%)	35 (25.5%)	0.170
7) Prior to the occurrence of this breast symptom, I have not been to see my GP for at least two years	Yes = 49	36 (73.5%)	13 (26.5%)	0.33;
	No=390	271 (69.5%)	119 (30.5%)	0.567
8) When it comes to health care visits, transportation is a big problem for me	Yes =30	22 (73.3%)	8 (26.7%)	0.17;
	No = 410	286 (69.8%)	124 (30.2%)	0.680
9) I see a different GP almost every time I get an appointment.	Yes =54	35 (64.8%)	19 (35.2%)	0.77;
	No= 385	272 (70.6%)	113(29.4%)	0.381
10) I have a GP with whom I feel comfortable talking to when I need medical care	Yes =407	290 (71.3%)	117 (28.7%)	1.35;
	No= 37	23 (69.2%)	14 (37.8%)	0.246
11) It is difficult for me to go to the GP as I do not have a medical card	Yes = 95	65 (68.4%)	30 (31.6%)	0.11;
	No = 342	240 (70.2%)	102 (29.8%)	0.742

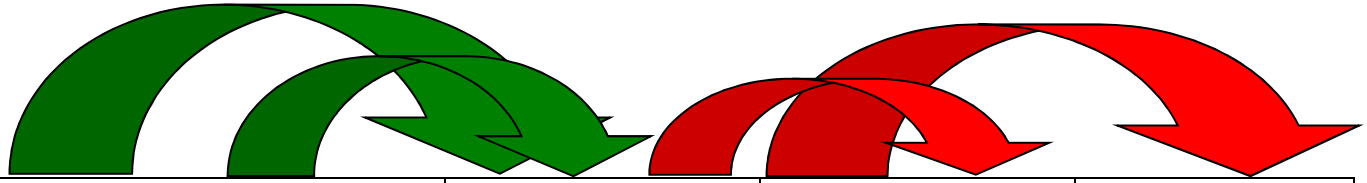
Note: All chi-square tests had one degree of freedom

Table 6.16b Perceptions of Experienced Prejudice cross tabulated with HSB

Please indicate how much you agree or disagree with the following statements in relation to your own experience:	**Yes/NO n**	**Prompt HSB n (%)**	**Delayed HSB n (%)**	**Chi-square & *p* value**
12) Sometimes I have been ignored by a GP because I am a woman	Yes = 16	13 (81.3%)	3 (18.8%)	0.10; 0.318
	No = 421	293 (69.6%)	128 (30.4%)	
13) I have not always been treated respectfully by doctors and nurses	Yes = 86	63 (73.3%)	23 (26.7%)	0.65; 0.422
	No= 356	245 (68.8%)	111(31.2%)	
14) I have experienced discrimination in a GP's office	Yes = 13	11(84.6%)	2 (15.4%)	1.32; 0.250
	No = 424	296(69.8%)	128 (30.2%)	
15) My own health has never been affected by discrimination.	Yes = 298	211 (70.8%)	87 (29.2%)	0.19; 0.67
	No =141	97 (68.8%)	44 (31.2%)	

Note: All chi-square tests had one degree of freedom

Appendix 13 Logistic Regression Procedure: selection of variables



1Variable	Following initial inferential analysis		Univariate Logistic Regression p <0.05*	Multivariate regression variables entered simultaneously to model p <0.05*	Multivariate regression forward stepwise approach p <0.05*
	Significant p <0.05*	Approached Significance p <0.1			
Symptom Identity					
Breast Lump	$p < 0.001$*		$p < 0.001$*		
Breast Pain	$p = 0.043$*		$p = 0.043$*		
Nipple indrawn/ changed	$p = 0.002$		$p.= 0.004$*	$p = 0.044$*	$p= 0.005$*
Change in breast shape		$p = 0.093$	$p = 0.098$		
Breast Cancer Knowledge					
A breast lump I never noticed before		$p = 0.054$	Yes response $p= 0.055$		
'a clear drainage from nipple'	$p = 0.039$*		Yes response $p = 0.040$*		
Symptom Beliefs					
Duration subscale	$p = 0.006$*		$p = 0.013$*		$p = 0.023$*
Consequences : one item					
'my breast symptom has affected the way others see me'		$p= 0.053$	$p= 0.081$		
Alternative HSB					
ignoring the symptom	$p < 0.001$*		$p < 0.001$*	$p < 0.001$*	$p < 0.001$*
using alternative therapies	$p = 0.017$*				
'checked it periodically to make sure it did not change'		*p=0.074*			
Psychological Factors					
Afraid		$p = 0.079$	$p = 0.081$	$p = 0.005$*	$p = 0.005$*
Social Factors					
Disclosure of symptom: yes	$p < 0.001$*		$p < 0.001$*		
Constraints: Taking care of family					
'N/A' to 'Taking care of my family'	$p = 0.023$*		$p = 0.007$*		
Health Seeking Habits					
Bi monthly/ rarely /never		*p =0.056*	*p =0.056*		
Health Service System Utilisation					
Go without medical care as too expensive		*p=0.093*			

Note: Significance level for the study was set at $p< 0.05$*. The level for entry to logistic regression was $p< 0.1$.