

# Freedom or isolation?

The impact of discharge from breast cancer follow-up

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## Abstract

The study was conducted following a systematic review of 38 articles (Collins et al 2004), which failed to find strong evidence for the optimum duration and frequency of follow-up, or the personnel best placed to provide it. Against this background of lack of evidence for ongoing follow-up, on the grounds of limited resources and an ever increasing population of breast cancer survivors; the level and nature of service provision for the patients attending a regional breast unit was changed. What was unknown was the impact this may have on the quality of the care and support and future health and well-being. Primary aim: To investigate the experience of being discharged from follow-up breast care services and evaluate the impact of the proposed changes from the patient's perspective. This thesis reports on interviews with 20 women from the time they were discharged from the service to 2 years post discharge. In addition, 4 participants who developed recurrent disease gave interviews to discuss their experiences. 3 major themes emerged: 1. "Close shave" or "marked woman"? describes the approaches adopted by the women towards their disease, treatment and risk of recurrent disease; 2. A "blessing" or a "curse"? encompasses views of the value of follow-up care; 3. "freedom" or "isolation"? is the account of the impact of discharge from the service on future health, care and well-being. Creating a network of services and working collaboratively with other sectors may well provide the scope and quality of care that women in long-term recovery from breast cancer want and need from the survivorship care of the future.

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# Chapter 1

## Introduction

This thesis is concerned with women's experiences post treatment for their breast cancer and considers how they deal with long term follow-up care. It documents a study which followed a group of women who have visited a regional breast cancer unit annually, for 5 years or more, as an integral part of the follow up care after their diagnosis and treatment for breast cancer. The regional policy has changed and the service is no longer available in its previous form.

Some of the women who were recently discharged from their regular clinic appointments expressed feelings of anxiety and abandonment. On questioning the healthcare professionals who ran the clinic, gave explanations of the rationale given for the policy change at regional level and the national guidelines and literature it was based on. Variations in the women's reactions to the change were evident – a broad spectrum of behaviour, from euphoric relief through blind acceptance, deference and resignation; to fear, distress and outrage. Further investigation seemed warranted to elicit why this was, to explain why women reacted in the way they did and why there were a variety of responses.

The literature demonstrates that both the optimum duration/type of long-term follow-up care for women with breast cancer and the personnel best placed to provide it – have yet to be established. This would then help to increase the understanding of the health care professionals working in the clinic to optimise the care of women in this situation.

- **Primary aim**

To investigate the experience of being discharged from follow-up breast care services and evaluate the impact of the changes in service delivery from the patient's perspective.

- **Objectives**

- To describe how women feel about the change in service provision
- To examine how the change in service provision affects women's views of fear/risk of disease recurrence
- To identify the impact of being discharged from follow-up on quality of life, including psychological distress, adjustment and coping.
- To explore anxieties and concerns once patients are discharged from regular outpatient follow-up care

The study was designed to incorporate the investigation of possible influential factors for reactions to the change in service provision as well as explore women's experiences. The original design of the study reported in this thesis included 100 women who were recruited to take part in a questionnaire survey, which was designed to examine factors highlighted in the research literature as influential in long-term recovery of breast cancer/cancer. These were: coping strategies, social support, anxiety and depression and quality of life.

Despite the best efforts of the researcher, the questionnaire data collected, illustrated that the instruments chosen were very limited in their ability to answer the research questions posed. This was despite the fact that they were all widely used and the results of previous research using these instruments have been published in the literature; or designed and validated for use in oncology patients. In any event, they proved to be too narrow in their focus for what transpired to be very complex issues.

The women surveyed for this study appeared to use a wide range of coping styles in a spontaneous way in their assessment of stressful events. The study illustrated that coping with long-term stressors may be far more complex than we imagine and the assumption that an individual may adopt a dominant strategy may be unfounded. This complexity warrants an in-depth exploration of the nature and influencing factors of a process which may be dynamic and not fixed and therefore not easily measured.

The data generated from the survey questionnaires were very limited in their ability to inform the aims of the research. This was due to a combination of the variety of experiences and approaches to dealing with breast cancer demonstrated by the women who took part and the unexpected influential factors which contributed to them. The complexity of the concepts and behavioural adaptation involved, meant that the instruments chosen were ineffectual in their ability to determine why the women in the study behaved the way they did. There were no "trends", the original factors postulated were not the only influences and the interview data proved to be the most effective way to answer the research questions.

However, the data collected during the course of the study was generously given by the women involved and has contributed to the knowledge related to coping strategies, quality of life and the emotional well-being of this group of patients, at this stage in their recovery. For this reason the quantitative data collected will be reported elsewhere and published separately.

Twenty of the original 100 participants agreed to take part in semi structured interviews designed to elicit their views and concerns. Data was collected from these participants at the time of discharge from regular outpatient follow-up care and then 12 and 24 months later. The interviews provided a wealth of data, which became the main focus of this thesis. The findings are presented in 3 separate chapters covering the experiences of the

women recruited. The first explores their experience of diagnosis, treatment, their approach to dealing with both of these and their perceptions of their future risk of recurrent disease. The second chapter describes their perceptions and the value they attached to their follow-up care. The third considers how they dealt with the impact of the changes imposed on them and their plans and expectations for their future care and well-being.

The study findings highlighted the variety of beliefs; approaches and strategies women have regarding breast cancer and its treatments. There was a broad spectrum of perceptions of the risk the disease might pose to future health and this did not correspond to clinical estimates. The findings also illustrated the differences between the perceptions and expectations of follow-up care from the women's perspective and the conventional, accepted, preconceptions of healthcare professionals and the medical research literature. For some women, the emphasis on the surveillance, monitoring and early detection of recurrent disease for physical well-being was seen to be at the expense of psychosocial care and well-being.

The conclusions reached, relate to the value of the adoption of an individualised, patient-centred approach to long term care and support in this patient group. Recommendations are made for the reconfiguration of follow-up care rather than the withdrawal of it. Suggestions are made for a network of flexible, accessible, services, a collaborative approach incorporating the skills and expertise of a range of disciplines and sectors, including social services and the voluntary sector.

Further research may be best served by building on the research and findings of the National Cancer Survivorship Initiative test communities. The challenge will be to design and evaluate interventions and services to provide optimum care for a patient group whose numbers are growing exponentially both in incidence and duration of survival each year.

## Chapter 2 - Literature review

### 2.1 Introduction

This chapter outlines the previous work and current theories related to the long-term care of women with breast cancer. The first section describes the disease and its physical impact on the women it affects. It also examines the risk factors, incidence and prevalence rates for the disease.

Breast cancer has effects other than physical harm. The second section deals with the psychosocial impact of breast cancer, the responses to it, the psychological problems and impact on quality of life which may result. The psychosocial effects can be far-reaching, extending beyond the woman herself to her close friends and family. It may impact on her ability to maintain her social roles, her social commitments, her social networks and her sense of self. It may affect her relationships with other people and her place in society.

Coping with the diagnosis, treatment and long-term recovery from breast cancer is a complicated process and can take months; or even years to achieve. Women choose to cope with this traumatic event in a variety of ways, based on their appraisal of the threat it poses and the resources available to them. Some are more successful than others in achieving their aim, to either regain their prior sense of self and feel able to function as they would wish; or assimilate the experience and reinvent themselves.

Long term survival in breast cancer is a relatively new phenomenon and the chapter will explore the issues and topics which are currently debated in the literature. Largely due to the improvements in treatments over the last 25 years, cancer and breast cancer in particular; is now being seen by many as a *chronic* rather than a *terminal* illness. This has highlighted previously unanticipated problems – having to deal with the long term

effects of treatment, the effects of increasing age on reconstructive surgery and living for many years with the anxiety of possible recurrent disease.

Despite the efforts of recent research in this area, there is no clear answer to the question of the optimum level, format and duration of follow-up in the long-term care of women with breast cancer. This is discussed both from the women's and the clinician's perspective. What is apparent is that the aims, benefits and criteria of follow-up care; identified by health care professionals working in the field of breast cancer; do not necessarily match those of the patients using the service. Several alternative models of care, to those used routinely in the past have been suggested and there are a variety in use around the world; but none have been shown to be close to meeting the requirements of both patients and clinicians. An outline and summary of the recommendations of the care of future patients – from both professional bodies and associations; as well as government policy, are included.

## 2.2 Search strategy

The aim of the literature review conducted for the purposes of this study was an attempt to identify and understand previous work/knowledge in the area under investigation. Not only to discover, what had already been done, but how, what the key issues were and the significance of previous findings.

The strategy adopted was necessary, in order to answer questions relating to the theoretical foundations for this knowledge, how they had been applied and developed; and to enable the researcher to decide on the most appropriate perspective to answer the research question.

Important influential factors relevant to the topic were identified, together with established, validated, methods and techniques used for the collection and analysis of

the data. This assisted the researcher to justify the approach chosen. Investigating the historical work conducted by others raised awareness of current issues and debates and enabled the researcher to identify areas requiring further investigation and more importantly; avoid duplication and demonstrate that the current study contributed new information to the body of knowledge

There was a reciprocal relationship between the literature review and the research conducted with each used to inform the other. The research question was intended to investigate the experience of being discharged from follow-up breast care services and evaluate the impact of the proposed changes in service delivery from the patient's perspective.

Consequently, the literature search was intended find evidence to ascertain what other women with breast cancer felt about being discharged from their routine follow-up care. What might influence women to react in one way or another? What value did breast cancer patients attribute to their follow up care? What did they feel they might lose? What existing knowledge was there relating to risk/fear of recurrent disease and ways of identifying/allaying anxiety and distress?

The potentially important influential factors for reactions to changes in follow-up care identified in the literature were coping strategies, social support, quality of life, anxiety and depression. These were used to inform the research objectives, to describe how women felt about the change in service provision and examine how the change in service provision affected women's views of fear/risk of disease recurrence. It was important to identify the impact of being discharged from follow-up on quality of life, including psychological distress, adjustment and coping and explore anxieties and concerns once they were discharged from regular outpatient follow-up care

In addition the review was used to inform:

- the study design– for example the structure of the interview guide
- the methods of data collection – the use of semi structured interviews, open questioning
- the provisional analysis – the use of the constant comparison method, labelling of initial themes and categories and the adoption of the NVIVO programme for data management

The review was instrumental in identifying the different perspectives/expectations of follow-up care from clinicians and patients. It also highlighted the absence of longitudinal research looking at long term survival in women with breast cancer and the longitudinal aspects of coping with stressful life- events .

In order to make an assessment of the quality of the research, the review of journal articles, book sections/chapters for the current study was conducted using the Critical Appraisal Skills Programme (CASP) toolkit (CASP International Network, 2011). This was adopted as a guideline to assess the research for its trustworthiness. Each publication reviewed was assessed as follows:

- The review attempted to identify a clear statement of the aims and the researcher's assertion of the study's importance and relevance.
- Was there a discussion around the justification of the methods and the appropriateness of using a qualitative, quantitative, or combined approach?
- The ethical issues and considerations were identified and the report examined for evidence that the researcher had addressed these by ensuring informed consent, confidentiality and Local Research Ethics Committee approval.
- Information relating to the setting, recruitment and sampling strategies; as well as the inclusion/exclusion criteria of participants was ascertained, to assess transferability of the data.

- Details of the mode of data collection, the process of analysis (e.g. derivation of the themes/categories) were investigated, to see if the data presented gave sufficient detail to support the findings.
- Did the researcher consider negative cases/contradictory data? Or discuss the potential influence on the data of non-participants?
- Did the findings relate to the original research question?
- Was the issue of credibility adequately addressed?

Other aspects included:

- The researcher's attempt to examine potential sources of bias,
- Researcher role/influence,
- The relationship between the researcher and participants,
- Efforts to adopt a reflexive approach to the work and incorporate changes during the course of the study.
- Did the researcher acknowledge the limitations of the study design, the findings and the subsequent influence on transferability?

Finally at the end of the discussion/conclusions an explanation was sought, of how the research fitted into existing knowledge and the contribution it made to the understanding of the area of interest. What in the researcher's opinion was its potential influence on current thinking or policy and were there suggestions for further research?

It was essential to use validated established methods when searching the research literature for this study. Initially 3 databases were used MEDLINE, EMBASE and psycINFO. In addition, within the first year of my doctoral studies the host institution provided access to the SCOPUS database (Elsevier, 2011) . Scopus was launched in November 2004 and contains sources from over 18,000 titles with access to peer-reviewed research literature and quality web sources. It covers published material from the scientific, technical, medical and social sciences fields as well as the arts and

humanities with 45.5 million records which go back as far as 1823 and 350 million scientific web pages. This is the largest and most comprehensive database to date and provided a wealth of high quality reference material for the literature review conducted for the current study. Due to the fact that Psycho-oncology is a relatively new specialism, specific, specialist, journals i.e. the back issues of Psycho –Oncology journal and the Journal of Psychosocial Oncology were searched for relevant articles.

### 2.2.1 Search methods employed

Initial review started with 2 recently published systematic reviews of the literature related to the effectiveness of routine follow-up care for women with early stage breast cancer. In addition the national guidelines for the provision of follow-up care for the USA (Institute of Medicine) , UK (NICE, British Association of Surgical Oncologists, Cochrane Collaboration) and Australia (National Breast and Ovarian Cancer Centre - now Cancer Australia) were also reviewed.

The research from papers included in these systematic reviews provided a basis for the review for the study and highlighted the current issues and topics related to follow-up care. The papers featured in the review were examined in detail and the keywords and search terms from those papers were used to broaden the scope of the search.

The search strategy for the research related to follow-up care was designed to capture the literature published since the systematic reviews and so initially included the search terms "cancer" and "follow-up" from 2002 until the current date. The search results were then limited by the search terms "breast cancer" and "follow-up", plus "breast neoplasms" and "follow-up". A further search was conducted using these results and the search limited by the terms "physician-led care" and "nurse-led care".

Survivorship as a concept in the literature is referred to under a variety of terms and so a broad search using "cancer" and "psychosocial" was used and then the results searched again and limited to "breast cancer". In addition searches using "cancer survivor"/"survivorship" and "breast cancer survivor"/"survivorship" as search terms were performed. Finally, a search using "breast cancer" and "recurrence/recurrent disease" was conducted to try to capture research which highlighted this as an important issue in the long-term recovery phase in breast cancer.

The literature search related to coping and appraisal was conducted both to investigate the theoretical basis of coping strategies and also to describe and explain the coping strategies adopted by those individuals with cancer and particularly women with breast cancer. For that reason the initial search was conducted using the search terms "coping theory" and then "appraisal" with no limit to the year as literature specific to coping theory was first published in the 1980's. The body of work of Richard Lazarus and Susan Folkman - the originators of the theory - was reviewed. Both authors also published retrospectives of the work conducted in coping theory since their initial publications which proved invaluable. Susan Folkman also highlighted the need for longitudinal research looking at coping over time which. "Uncertainty" was also identified by the review as a relevant concept to coping and coping strategies and so was included in the search terms.

In addition the search then proceeded to include "cancer" and "coping and "breast cancer" and "coping" to look at the variety of ways individuals dealt with their diagnosis and treatment and elicit influential factors which may give an indication of the strategy they might choose.

The search term "psychosocial", also provided references for literature related to social support. However to ensure the literature in this area was adequately reviewed the following search terms were also used:

"cancer" and "psychological distress"/"breast cancer" and "psychological distress"

"cancer" and "psychological support"/"breast cancer" and "psychological support"

"cancer" and "support groups"/"breast cancer" and "support groups"

"cancer" and "social support"/"breast cancer" and "social support"

Again social support is a relatively recent concept and so; no limitations of year of publication were employed.

The literature review was structured in this way because the research reviewed, demonstrated that there were 3 common standpoints related to follow-up care in breast cancer adopted by other researchers in the field: effectiveness, models of care and attribution of meaning.

- Effectiveness was invariably an attempt to find measurable variables to justify the method of follow-up or cast doubt on its effectiveness
- Models of care were an assessment of alternative methods – often to prove they were more cost-effective (cheaper)
- Attribution of meaning, examined the life experience of dealing with a breast cancer diagnosis, treatment and finding a way to live life after active treatment is complete.

During the course of the 4 years it took to complete my doctoral studies Macmillan Cancer Support and the National Cancer Survivorship Initiative; conducted research projects around the UK investigating the concept of survivorship and the long-term needs of those recovering from cancer (Macmillan Cancer Support, 2008b, Department of Health UK, 2008). This work revealed that many cancer patients were uncomfortable with the term "cancer survivor" and so the term "living with and beyond cancer" was created as a more appropriate phrase.

The literature also revealed that differences in the perspective of clinicians versus women with breast cancer related to follow-up care were also reflected in their perceptions of the problems of dealing with long-term recovery of the disease: The clinicians were concerned primarily with the psycho-social impact – symptoms and perceived dysfunctional behaviour – e.g. anxiety, depression, hyper-vigilance, "over-anxious" patients. In contrast, work conducted exploring views and emotions of women with breast cancer highlighted issues such as the need to avoid distress in others, stigma, loss of role and social status and management of fear of recurrent disease. This was borne out by the data collected for the current study via the interviews. The influence of social support and the coping strategies adopted, to deal with breast cancer and its treatments were evident throughout the literature and did prove to be influential on the behaviour of the women who participated in the study.

In summary, the review of the literature was never intended to be a comprehensive systematic review due to the vast volume of literature available and the limitations of the resources of my doctoral studentship. However, it was extensive and concentrated primarily on the literature relevant to the aims of the study conducted, with emphasis given to the empirical research relating to follow-up care and the perspective of the women who receive it. The review was divided by perspective i.e. clinician vs patient and this was informed by the research question. It was also divided by the physical vs

the psychological well-being of women with breast cancer and this was informed by the previous research conducted in this field.

## 2.3 Breast cancer

Breast cancer is the most common cancer affecting women in the United Kingdom (UK). Each year, there are over 44,000 new cases diagnosed in the UK, it accounts for almost one in three of all cancer cases in women, and the lifetime risk is one in nine. In the UK, death rates for women of all ages, have fallen by a fifth in the last ten years (Cancer Research UK, 2007). The mortality rate for women aged 50-69 years with breast cancer fell by 33-36% between 1989 and 2005. However, approximately 12,400 women still die from breast cancer each year in the UK (Northern Ireland Cancer Registry, 2007, ISD Online, 2007, Office for National Statistics, 1997, Office for National Statistics, 2006). In the UK, women aged 50 years and over, are offered three yearly mammographic surveillance, via the National Breast Screening Programme. The advisory committee to the NHS Cancer Screening Programme estimate that 50% of breast cancers in women aged 50-70 years, are detected via routine mammography, approximately 10,000 per annum (NHS, 2006). However, not all women take up the opportunity to participate and the remaining 50% constitute women who do not attend for screening; or present within the 3 year interval between mammograms. The committee also estimate that the screening programme prevents 1400 deaths per annum in women of this age group. In addition the cancers it detects are smaller and less likely to require mastectomy.

Women often present with breast cancer either, because they or their GP detect something they perceive to be abnormal/unusual about their breast tissue, or via an abnormal result from routine mammographic screening. However, many breast cancer tumours are detected by the women themselves. They may notice increased lumpiness,

thickening, dimpling, peau d'orange (skin which has the appearance of orange peel), inverted nipple, discharge, crusting or abnormal axillary lymph nodes.

Early detection has proved to be beneficial, for example in the US, screening has made a significant impact on breast cancer mortality, resulting in a 23.5% decline in the number of deaths from 1990-2000 (National Cancer Institute, 2007).

In the UK, it has been estimated that mortality has fallen 1-2% per year since the introduction of the National Screening Programme in 1988 and survival has increased as a result of earlier detection and improved treatments (Blanks et al., 2000).

It has been suggested that clinical breast examination alone identifies approximately 5% of breast cancers, with 54% sensitivity and 94% specificity (Macdonald et al., 2004) and the US National Cancer Institute points out that up to 10% of breast cancers may be clinically evident by physical examination whilst undetectable by mammography (Mincey and Perez, 2004). However it is difficult to assess its contribution due to the lack of standardisation of the technique (Knutson and Steiner, 2007). In contrast, mammographic imaging alone, generates results with only 80-85% sensitivity (Given-Wilson et al., 1997). Mammography, clinical examination and breast self examination (BSE); all go some way to providing the benefits of early detection.

### 2.3.1 Prognosis and recurrent disease

The estimated prognosis for women with breast cancer and their risk of recurrent disease is related to a variety of factors. These include stage and grade of disease, effectiveness of treatment and type of tumour. Once initial diagnosis is made and surgical treatment administered (to those women with early, primary, breast cancer), the risk of recurrence is highest in the first 5 years. The risk then reduces with every 5

years of disease-free survival (Early Breast Cancer Trialists Collaborative Group, 2005). The UK Association of Breast Surgeons guidelines state that Breast Units should achieve less than 10% recurrence rates following surgery and <5% at 5 years post surgery (The Association of Breast Surgeons @ BASO, 2005)

There are 2 main hypotheses related to localised disease recurrence, documented in the literature. The first that it is an indication of incomplete removal of the tumour and the second, that it is the first sign of dissemination of the disease (Fisher et al., 2002). Jatoi and colleagues (Jatoi et al., 2005) identified 2 peaks in the hazard of recurrence. One at 2 years post diagnosis and another at 5 years and suggest that the magnitude of the hazard peak is affected by the patient's age, tumour size, menopausal status and whether the tumour is node positive. They acknowledge that in earlier research there is evidence to suggest that the psychological response to breast cancer can influence the risk of recurrence and death from the disease (Greer et al., 1979). They also refer to the work of Watson and colleagues and the relationship between depression, the reduced chance of survival and the detrimental effects of feelings of hopelessness and helplessness at 5 years post diagnosis (Watson et al., 1999). Watson and colleagues revisited the same group of patients 5 years later (Watson et al., 2005). Their results indicated that the same psychosocial responses were still evident at 10 years of follow-up. Fighting spirit had a positive effect on survival and they suggested that the possible reasons for the negative effect of feelings of hopelessness/helplessness may be:

Impact on immune status

Effect on stress hormones

Behavioural changes may impede treatment

(avoidance/non-compliance, delay or termination of treatment).

It would seem that psychosocial responses to a diagnosis of breast cancer have long term effects on physical well-being and may influence survival – although the mechanisms of action have yet to be established.

Methods of detection of recurrent disease are commonly via mammography, physical examination at routine clinic visits, or self-detection, i.e self-examination by the women between these visits (Chen et al., 2003).

In their study, Chen and colleagues point out that women diagnosed with early stage breast cancer are 5.9 times more likely to present with a tumour in the other breast, than women with no history of breast cancer. Furthermore, not all contralateral tumours are diagnosed via the same method as the ipsilateral tumour, or have the same characteristics. The authors propose that a combination of all three modalities, provides the most effective method of detection of recurrent disease. The routine clinic visits which create the opportunity for surveillance using mammography and physical examination, therefore achieve tangible benefit in the form of both clinical investigation and reassurance/respite from anxiety (this will be described in more detail, later in the chapter).

Although influential factors for recurrent disease have been highlighted, it is at present impossible to predict which women will develop recurrent disease, or when it will happen. This can create uncertainty, feelings of unpredictability and lack of control. Women may continue to be fearful of recurrent disease long after initial treatment has been completed. The following section will now review the literature related to follow-up care for women with breast cancer, its effectiveness, its meaning for both patients and clinicians and the models of care currently in use.

## **2.4 Follow-up care provision for Primary Breast Cancer**

Once an individual completes their treatment for cancer, they move into the follow-up phase of their care. The aim of follow-up care for women recovering from the diagnosis

and treatment of primary breast cancer is two-fold. It enables the healthcare professionals who care for them to provide regular surveillance for early detection and treatment of recurrent disease (Rojas et al., 2005), as well as access to ongoing psychological support and information (NICE, Aug 2002). International and national guidelines have been published to outline the nature of this provision and numerous studies conducted investigating, assessing and evaluating the care provided. These will be described and reviewed in the following section.

The US Institute of Medicine's (US IOM) report "Cancer patient to cancer survivor: lost in transition" (Institute of Medicine, 2006) suggests follow-up care is planned and coordinated so that patients are made aware of their heightened risk and given a follow up plan of action. This allows follow-up visits to become an opportunity to promote a healthy lifestyle, manage lasting effects of the experience of having cancer, as well as checking for recurrent disease. There are over 10 million survivors in the US and lasting effects become evident shortly after completion of treatment or can arise years later.

The US IOM outlines the following essential components of survivorship care:

Prevention – of recurrent, new or late effects

Surveillance – to detect spread, recurrence of disease,  
assessment of medical and psychosocial late effects

Intervention – physical problems (lymphoedema, sexual), pain, fatigue,  
psychosocial distress, employment, disability

Coordination – between specialists and primary care

According to the UK National Institute of Clinical Excellence (NICE) Improving Outcome Guidance (NICE, Aug 2002), the primary aim of clinical follow-up after breast cancer treatment is threefold: to identify and treat local recurrence, identify and treat adverse effects of therapy and for routine follow-up in the context of clinical trials. (Page 58)

The guidelines also recommend that patients should have continuing access for an indefinite period to a breast care nurse and that health care professionals should be able to offer support and arrange counselling for patients – including those released from follow-up - who develop psychological problems linked with their experience of cancer. (Page 62)

NICE (National Institute for health and Clinical Excellence), recommends that routine hospital follow-up is discontinued after 3 years unless the patient is participating in a clinical trial, or is currently receiving treatment. NICE suggests follow-up is maintained in the community with a system for rapid referral back to the Breast Unit via the Breast Care Nurse Specialist if disease recurrence is suspected. This is based in part on the views of the clinicians, professional societies and associations listed below, who remain unconvinced that early detection of local or systemic recurrence improves survival and assert that randomised, controlled trials, show little or no benefit from intensive surveillance (ASCO, 1997, The GVIVIO Investigators, 1994, Joseph et al., 1998, Wheeler et al., 1999, Ciatto, 1995, Turco et al., 1994, Gulliford et al., 1997).

The current recommendations would suggest that some form of follow-up is necessary in order to fulfil the physical and psychological needs of patients following diagnosis and treatment for breast cancer. The successful treatment and extended survival for this group of patients has resulted in a dramatic increase in their number over the last three decades. This is likely to increase exponentially over the next ten years and there is a pressing need to address how best to manage their care in an effective and appropriate way. For this reason we need to explore what constitutes effective follow-up provision

### 2.4.1 Effectiveness of follow-up care:

There have been two recent systematic reviews looking at the effectiveness of follow up care for women with early stage breast cancer (Rojas et al., 2005, Collins et al., 2004). Collins et al (2004) included 38 articles in their review and concluded that survival and quality of life were not affected by the frequency of the follow-up, or its location. Patients valued their follow-up care and had a positive attitude towards it but high levels of psychological distress were evident regardless of where the care was provided. The authors assessed the published research based on quantitative measures: years of survival, disease free interval, i.e. time to recurrence, method of detection. Survival was unaffected by location of follow-up care and most recurrences were identified at routine visits with a large proportion of patients being asymptomatic. Their data suggested that routine follow-up may be more effective in diagnosing contralateral tumours, than recurrent disease in the affected breast. Follow-up conducted by GPs was found to be more frequent and the consultations of longer duration than those in oncology outpatient clinics. Patients found follow-up visits stressful but still valued them.

Collins et al (2004) noted that the quality of the research they assessed was poor, with inadequate research designs, or measures of effectiveness. They were unable to draw any broad conclusions for best practice to reduce morbidity, provide cost-effective care, or work in partnership with patients to satisfy their needs. They highlighted the need for further studies "to ascertain whether or not there is an optimum care package for patients treated for breast cancer and under what circumstances ... the components of this package vary". They also concluded that "identifying techniques to reduce any further distress should be a focus for future research in this area."

Rojas and colleagues' review published a year later under the auspices of the Cochrane Collaboration, reviewed only six studies from the last 20 years (Grunfeld et al., 1999, Grunfeld et al., 1996, Gulliford et al., 1997, Palli et al., 1999, The GVIVIO Investigators,

1994, Turco et al., 1994)., all of which were randomised controlled trials, with no qualitative element involved in the study design. They looked at survival rates, time to recurrence and quality of life measures, but not distress levels, patients' views, needs or preferences. Again they found no difference in outcomes either related to frequency of follow-up, location, or personnel.

In a mixed methods study employing observation, interviews, as well as survey questionnaires, the authors (Beaver and Luker, 2005) observed over 100 consultations with a range of Health Care Professionals (HCPs), including doctors, clinic nurses and a breast care nurse specialist. The observational data revealed that physical examination to look for recurrence or metastasis was the most common constituent of the consultation. However on questioning, the HCPs doubted its value and were of the opinion that the women were more likely to notice abnormal changes themselves before they came to the clinic. They felt that the visits served as a source of reassurance and comfort to their patients. Doctors concentrated on mammogram results, physical examination and compliance with treatment. They did not address patients' issues and concerns and the tone was one of optimism which centred on short-term progress. Nurses usually addressed informational needs and clarified and explained information initially discussed by the doctor during the course of the consultation. The nurse specialist felt there was insufficient time available during the clinic to provide psychosocial support and that the most productive time for this was outside the clinic environment.

There are conflicting views about the value and purpose of follow-up with clinicians and patients often differing in their views of the purpose and value of prolonged follow-up care. Clinicians appear to doubt the effectiveness of traditional follow-up to diagnose recurrence and consider it to be expensive, time-consuming and potentially give patients false hope that it will increase their chances of a cure (Collins et al., 2004, Wheeler et al., 1999, Tomiak and Piccart, 1993). Alternatively patients appear to value the

reassurance and peace of mind provided by the follow-up visit, as well as the sense of relief and euphoria reported following these visits despite the problem of anticipatory anxiety prior to outpatient visits which is well documented (Tate et al., 1989, McLaren and Wynne, 1996, Brada, 1995).

Anxiety around the time of and after discharge from routine follow-up is less well researched. An audit of 65 long-term survivors of cancer (63% with breast cancer) attending an oncology outpatients clinic assessed their levels of anxiety related to being discharged from routine follow-up care, using the Hospital Anxiety and Depression HAD Scale. Twenty eight per cent of the patients refused to be discharged and 75% of those had clinical anxiety, according to the HAD scale results. The number of years of follow-up and levels of anxiety were predictive factors for refusal to be discharged from follow-up. Of those who agreed to be discharged, a substantial proportion re-attended several months later, via their GP. They were assessed again 4-5 months later and in fact their anxiety levels had further increased. This would appear to suggest that anxiety in cancer survivors is persistent and may not necessarily be simply related to clinic visits (Thomas et al., 1997).

In an attempt to address the issues highlighted, a number of studies have been conducted which examine a variety of models of follow-up care and these are reviewed in more detail in the following section.

## 2.4.2 Models of follow-up care

Due to the increasing numbers of individuals moving into follow-up care and the policy initiatives to provide on-going support, a number of approaches to providing follow-up after cancer treatment is complete have been evaluated. Many of these seek to use alternative models to the traditional medical hospital-based mode of follow-up and seek to utilise more flexible approaches delivered by other members of the health care team. These include, nurse led follow-up, open appointments and community based follow-up.

Nurse-led follow-up in breast cancer patients, has been shown to be effective and acceptable to patients as long as there was continued access where needed to medical support (Earnshaw and Stephenson, 1997, Grunfeld et al., 1999, Adewuyi-Dalton et al., 1998, Broyn and Froyen, 1982, Pennery and Mallet, 2000, Marcus et al., 1998).

For example Koinberg and colleagues (Koinberg et al., 2001, Koinberg et al., 2002), evaluated a system of patient-initiated, nurse-led follow-up compared to their traditional physician-initiated/physician-led programme of care. The women opted voluntarily for the system, (there was no randomisation) and they were strategically sampled to encompass the variation in the clinic population. The women chose when they came to the clinic to see a specialist nurse, who provided breast examination and palpation including assessment of lymph node involvement, yearly mammography and referral to a physician where necessary. The nurse also provided psychosocial care, monitoring of compliance with medication, assessment of treatment side effects, teaching breast self-examination technique.

Patients were also given the opportunity to discuss psychological and social problems, offered education both to the woman and her relatives either, on an individual basis or, as a group. The patients felt that their access to a physician was not compromised as the nurse could arrange this if they needed it. They highlighted the fact that needs varied from individual to individual and they valued flexibility and the option of being able to pick up the phone and ask for help when they needed it.

For some women, the yearly mammogram was sufficient to reassure them that their disease was stable. They had faith and trust in its ability to pick up recurrent disease and did not feel the need to contact the nurse for other issues. Others wanted confirmation that everything was fine, despite the absence of symptoms and normal mammography; and some women used their network of friends and family to talk over their concerns

and get the reassurance they needed. Women also sought information to help them understand their disease and treatments – to help them assess what was considered “normal” or common to women with breast cancer to allay their fears. The study raised the issue of empowerment and choice and their affect on feelings of control and confidence for women with breast cancer. It also confirmed that women vary widely in their needs and expectations and need flexible and individualised follow-up (Koinberg et al., 2001, Koinberg et al., 2002).

In another study of patients considered to have a low risk of recurrence, written information on the signs and symptoms of recurrence was given at discharge, patients were offered a yearly mammogram and given a contact telephone number to speak to a breast care nurse if they had any concerns. The authors (Brown et al., 2002) collected data via survey questionnaires and interviews and concluded that patient-initiated follow-up was a safe, cost-effective alternative to traditional follow-up arrangements.

However the study design was inherently flawed as any patients with anxiety or “personal problems” were screened out by the clinical staff before the researcher could approach them. Only 50% of the patients then deemed eligible, agreed to take part and then they were randomised to traditional or telephone follow-up. Consequently only 30 women out of a possible 123 (plus the women screened out) were involved in the new model of care.

The authors concede that the generalisability of their findings is very limited and emphasise the convenience and cost effectiveness of their model; while accepting that the burden of care may then pass to the patient’s General Practitioner; and have financial implications in the primary care sector.

Follow-up in primary care is an area which remains under-researched. In a recent study patients were discharged from an oncology out-patients clinic to their General

Practitioner with an information pack, (outlining treatment side effects and signs of recurrence) and a rapid re-referral fax form for both the patient and their family doctor. Patient's contact details and tumour characteristics were kept on a database for future reference. The authors concede that this arrangement has its limitations, requires additional training and resources for GPs and is not suitable for all patients, nor does it address all of their needs. It served only to reduce the workload for the oncology team and they suggest that this care should be provided outside of the traditional oncology outpatients clinic (Vanhuysen et al., 2007).

In other studies, patients considered their GP to be over-burdened and lacking in specialist knowledge about breast cancer and was often the least preferred option in terms of mode follow-up care (Pennery and Mallet, 2000, Adewuyi-Dalton et al., 1998).

In summary, several alternative models of follow-up care have been developed: nurse-led, telephone help lines, open appointment systems, GP-led follow-up care. As the evidence base demonstrates each has its attractions and limitations; as well as resource implications. It would appear however that women value continuity and good relationships with clinical professionals with expertise in the field, whom they can access easily. Those studies that have examined women's views on follow-up care would suggest that they need reassurance as well as routine surveillance to detect recurrent disease. They also want psychological support to continue long after their physical needs have been met. The literature demonstrates that the knowledge around the benefits of follow-up care (other than that of surveillance and early detection), is limited and so therefore is the knowledge around the impact of withdrawing it. This seems to elicit vehement objection in some women, but there is no evidence to suggest why this might be, or the most appropriate way to address it.

So far, this review has encompassed follow-up care from the biomedical perspective. The meaning women with breast cancer attribute to their follow-up care and their perceptions of its aims and benefits will be explored in the next section.

### 2.4.3 The meaning of follow-up care for women with breast cancer

The empirical work conducted related to the value of follow-up care for women diagnosed with the female cancers – breast, gynaecological and ovarian cancers was included in the review. This body of work indicates that there are similarities in the perspectives of women regardless of the site of the cancer, as well as similarities in their needs and wants during the period of recovery of their disease from the first year of treatment to long-term survival.

Follow-up care fulfils a whole host of needs and wants for the women who receive it. To many it represents an evidence-base, concrete “proof” that they are currently cancer-free. This is provided via mammograms, physical examinations and the verbal information given within their outpatient consultations. Prevention/early detection of recurrent disease via regular surveillance is seen as its primary aim (Allen, 2002, Bock et al., 2004, Koinberg et al., 2001, Kew et al., 2007). The confirmation and reassurance they crave relieves the anticipatory anxiety they experience prior to the consultation and the reward for this, is the relief and euphoria they feel afterwards. However there is little information available, on how long this euphoria lasts, the influence of the time interval between visits, or length of time since diagnosis (Kiebert et al., 1993).

Women appear to value the opportunity to gain information and advice about their risk of developing recurrent disease as well as the risk to other members of their family (Cox et al., 2008, Bock et al., 2004). Information-seeking has been shown to be influenced by a variety of factors. For example women currently being treated with hormone or

chemo-therapy, those under the age of 65 years, women who experience anticipatory anxiety, or have a higher anxiety level (Hospital Anxiety and Depression Scale score) or a reduced level of quality of life and those who express fears of recurrent disease are all more likely to need information to answer concerns and relieve anxiety (Bock et al., 2004). The level of social support available has also been shown to mediate information needs, the cultural context is influential and as the interval from initial diagnosis is extended, information needs are reduced (Vivar and McQueen, 2005). One area which seems to be neglected and has been reported in a study of women with ovarian cancer is that of sexual intimacy. Despite the fact that women highlight the importance of sexual and relationship issues, they are not routinely discussed in consultations and this is thought to be the result of lack of privacy, lack of time, lack of resources and the perception of clinicians that they are not trained to address these issues (Cox et al., 2008)

Other short-comings of follow-up care identified by women with breast cancer are long waiting times, rushed appointments which result in unanswered questions and an inappropriate environment for discussion of psychosocial problems (Pennery and Mallet, 2000).

There is now a body of work which has attempted to establish preferences for follow-up of women with a breast cancer diagnosis. For example, Pennery and Mallet (Pennery and Mallet, 2000) demonstrated that 50% of the breast cancer patients they studied felt "cast aside" once they are discharged from follow-up. They preferred regular follow-up rather than open access appointments, as they thought fear of recurrence would prevent them from making an appointment and the subsequent delay may impact adversely on their prognosis. Flexibility and accessibility in follow-up care is attractive for those in long-term recovery for a variety of reasons – it accommodates a range of coping strategies and beliefs about risk of recurrent disease and enables those with family

commitments and full-time employment to fit their follow-up care around the other priorities in their life (Koinberg et al., 2002, Brown et al., 2002).

Women's satisfaction with their care also appears to be associated with continuity and establishing relationships with individual health care professionals as well as the perceived quality of the consultation (Adewuyi-Dalton et al., 1998, Gaudine et al., 2003, Renton et al., 2002, Koinberg et al., 2001).

Who provides the follow-up care is also considered to be important to many women. This seems to be related to their perceptions of levels of expertise and the faith and trust they place in particular individuals. Hospital doctors are often seen as having a higher level of expertise than a general practitioner and doctors to have greater depth of knowledge than nurses. This would account for the importance attached to continuity of care (Kew et al., 2007, Koinberg et al., 2002, Renton et al., 2002).

The needs and wants of women with breast cancer do not seem to change over time. Alice Gaudine's phenomenological study (Gaudine et al., 2003) investigated the perceptions of women in long-term recovery and showed that the type and level of need remained unchanged and suggested that data generated from longitudinal research provides useful information in helping to understand longer-term follow-up needs (Gaudine et al., 2003).

The table included in the following pages is intended to give the reader a chronological overview and allow comparison of the studies discussed in the preceding text. It encompasses empirical research conducted over the last 20 years which investigated follow-up care from the patient's perspective.

## 2.4.3.1 Cancer Follow-up Care from the Patient's Perspective – an overview

Reference	Design	Sample	Comments
Kiebert, Welvaart et al (1993)	Questionnaire survey	127 women with breast cancer	Anticipatory anxiety followed by relief and reassurance after follow-up visits. Not clear for how long this persists or the influence of frequency or time since diagnosis. Indicated the importance of providing reassurance in addition to the detection of recurrent disease.
Thomas, Glynne-Jones, et al. (1997)	Questionnaire survey	252 men/women with cancer	65 women (28%) refused discharge from follow-up. Need to address anxiety prior to discharge. Identified disparate needs and suggest individualised follow-up
Adewuyi-Dalton, Ziebland, et al. (1998)	Qualitative interviews	109 women with breast cancer	Anxiety not necessarily related to hospital visits. Open appointments and fast-track access to nurse specialists not enough to allay anxiety related to recurrent disease. Lack of confidence in the specialist knowledge of GPs
Pennery, and Mallet (2000)	Qualitative interviews	24 women with breast cancer	Suggest patient-focused follow-up. Identified the need for flexibility in frequency, location and personnel involved. 50% had unmet needs and 75% thought the consultation too hurried.
Koinberg, Holmberg, et al. (2001)	Qualitative interviews	20 women with breast cancer	Women vary in the value they give to different aspects of follow-up. Identified need for routine, accessibility, security, continuity, confidence in the system and individualised information.
Allen, (2002)	Qualitative interviews	6 women with breast cancer	Hospital-based follow-up does not meet the need for psychosocial support – insufficient time, inappropriate environment.
Lyons, Jacobson, et al. (2002)	Qualitative interviews	20 women with breast cancer	Conducted within one year of diagnosis. Identified 3 phases: Diagnostic – 6 themes: bad news, fear, being strong, persistent thoughts, multiple stressors, spiritual awareness. Treatment – 4 themes: making choices pain and suffering, determined to fight, social support, Post-treatment – 3 themes: fear of recurrence, behavioural changes, personal growth
Renton, Twelves, et al. (2002)	Questionnaire survey	134 women with breast cancer	Clinician-led follow-up does not fulfil the need for psychosocial support. Need to address fear of recurrent disease, treatment effects, family risk, alternative treatments, mood disturbance, body image issues. Prefer hospital follow-up = specialist knowledge

Reference	Design	Sample	Comments
Gaudine, Sturge-Jacobs, et al. (2003)	Qualitative interviews	9 women with Breast cancer	After 2-7 years of follow-up. Highlights that time since diagnosis does not seem to change the level or type of need. Identified 4 themes: life-changing experience, a sense of belonging, uncertainty and needing to know. Access to information is essential no matter how long since diagnosis.
de Bock, Bonnema, et al. (2004)	Questionnaire survey	84 women with breast cancer	2-4 years post-treatment. 88% believed early detection of metastases would contribute to cure, self examination not highly valued, 18% warranted psychiatric evaluation, 7% had anxiety/depressive disorders. 50% desired 6 monthly lifetime follow-up.
Beaver and Luker (2005)	Mixed methods: Observations/interviews/questionnaire survey	104 women with breast cancer	Physical examination most common constituent of follow-up valued by patients, but not clinicians insufficient time to address psychosocial issues Suggest follow-up care creates a culture of dependency in women with breast cancer
Kew, Galaal, et al. (2007).	Questionnaire survey	96 women with gynaecological cancer and 32 HCPs	Women (92%) and HCPs (73%) preferred hospital-based follow-up by a doctor. HCPs valued the consultation, women valued the physical exam, HCPs thought addressing concerns was the primary aim, women thought it was the detection of recurrent disease
McCaughan and McSorley (2007)	Non-participant observation 7 consultations 21 Qualitative interviews	21 women with breast cancer	Fear of recurrent disease and a need reassurance were the main issues. Many psychosocial needs remained unaddressed. Nurses under-used as a potential source of support
Cancer Services Collaborative Improvement Partnership and Macmillan Cancer Support (2008)	5 Focus groups (4 cancer patient and 1 carer)	Group 1 = 9 women with breast and gynae cancer	Desired rapid access to specialist medical care, hospital-based for first 12-24 months, holistic approach to care, diet, lifestyle etc., tailored psychological support, continuity, information/advice to facilitate self-management, information for employers. Need rationale for follow-up in order to manage expectations. No confidence in GP follow-up. Patient-managed and group follow-up not enough to address all of their needs.

Reference	Design	Sample	Comments
Lydon, Beaver, et al. (2009)	2 Focus groups = 6 women 7 HCPs	6 women with ovarian cancer	Women wanted reassurance information, support and alternative approaches to follow-up. HCPs wanted to optimise the identification of recurrent disease and facilitate self-management
Allen (2009)	Focus group interviews	47 women with breast cancer	The clinic does not fulfil the need for psychosocial support not enough time, inappropriate environment, seen as a place primarily to identify recurrent disease
Frew, Smith et al (2010)	Questionnaire survey	604 cancer patients 22 carers 2302 HCPs	Consensus between 3 groups for reasons for follow-up: monitoring early complications, detecting late effects of treatment, detecting recurrences early, managing medication, providing information and support. Service users had higher expectations in relation to detecting recurrences early and preferences for models of follow-up care were dependent on previous experience. Service users also consider follow-up provides support for research and education for the medical team.
Beaver, Williamson et al (2010)	Qualitative interviews	28 women with breast cancer 4 breast cancer nurse specialists	Views of telephone follow-up: not suitable for all patients, suggests individual patients choose different approaches at different time-points in the disease trajectory. Requires specially trained, experienced nurses, regular clinical supervision and sufficient time and resources to provide appropriate levels of care.

## 2.5 Long-term recovery and the concept of survivorship

### 2.5.1 Living with and beyond cancer

In the US alone, over one million people are currently breast cancer survivors. UK statistics published by Cancer Research UK (2003) estimate that women with primary breast cancer, aged 50-69 years, have an 85%-90% chance of survival at 5 years post-diagnosis. It is likely from information collected over the last twenty years that as treatments both surgical and pharmacological improve; these numbers will continue to grow exponentially (Jemal et al., 2007).

#### **2.5.1.1**

#### **Macmillan Cancer Support and the Two Million Reasons Report**

In a recently commissioned UK report it has been estimated that by the end of 2008, approximately two million people in the UK were living with, or beyond cancer and the numbers are rising by more than 3% per year (Macmillan Cancer Support, 2008a). The report set out the views and concerns of cancer patients and recommended ways in which their long-term care might be improved.

Current follow-up care aims to provide support from clinicians, assist in the management of symptoms as well as detect recurrent disease. In addition to this, the report suggests that the full range of needs – emotional, financial as well as physical, need to be assessed at regular intervals; with a partnership approach to care between patient and clinician; and a mutually agreed care plan. This may include self-management tools, information on local support groups, or individualised support. The report identified the need for flexibility both in the location and personnel providing the care; and called for improved management of late effects of treatment, as well as accessibility and self-referral back into the system. It highlighted the differing informational needs of patients

and carers especially around decision-making and provision of practical and emotional support for carers. Returning to work was also a priority for many cancer patients, who called for a cancer-orientated return-to-work model, access to occupational health services and improved awareness amongst employers of their obligations under the Disability Discrimination Act.

### **2.5.1.2 The National Cancer Survivorship Initiative**

The Two Million Reasons report led to the launch in September 2008 of the National Cancer Survivorship Initiative (Department of Health UK, 2008), a joint venture between Macmillan Cancer Support and the UK Dept of Health -intended to establish a range of approaches to the care of cancer survivors and tied in with the aims of the Cancer Reform Strategy (Department of Health UK, 2007) to provide care which is tailored to the needs of individual patients. The Initiative is comprised of seven work-streams:

- Assessment, care planning, immediate post-treatment approaches to care
- Managing active and advanced disease
- Late effects of treatment
- Children and young people
- Self-care and self-management
- Work and finance
- Research

Since its inception it has conducted a scoping exercise to identify existing knowledge, current good practice around the UK as well as the gaps in provision. The research work stream aims to work with the others in order to identify a research agenda during its first year of operation and then identify funding in order to commission research by the third year. One of its aims is to develop interventions to alleviate or manage the long-term psychosocial impact of cancer.

## 2.5.2 The psycho-social impact of breast cancer

The previous section in this literature review has concentrated on the nature of breast cancer, its treatment and potential for recurrence. As noted earlier, women diagnosed with the disease are often diagnosed early and can expect to survive the disease. The outlook therefore for women with breast cancer is very positive with many women achieving long periods of disease free survival (Peto et al., 2000). However, it is well established that a diagnosis of breast cancer has an impact beyond the purely physical (Knobf, 2007, Frost et al., 2000).

The concept of Quality of Life (QoL) is closely linked with coping strategies, anxiety and depression and the role of social support. These may also influence women's reactions. Review of the literature reveals how this construct is commonly used in the field of Oncology to assess effectiveness. Measuring quality of life enables the self-assessment of physical, psychological and social well-being (Aaronson et al., 1993, Fallowfield, 1990, Moinpour et al., 1989). This is likely to become more relevant in the future as breast cancer is perceived as a chronic illness rather than a terminal disease (Ferrell et al., 1997, Ferrell et al., 1998)). It incorporates the aspiration of health care professionals, to provide holistic modern health care.

Recovery after cancer treatment can be slow and emotionally challenging (Schnipper, 2001). However, a number of studies suggest that the majority of women adjust well to living with their breast cancer and report high levels of quality of life (Frost et al., 2000, Shapiro et al., 2001, Ganz et al., 2002, Land et al., 2004).

Some of the women in these studies viewed their cancer diagnosis as a positive experience and found benefit in it. They reported appreciating life more than they did before and felt they had changed for the better as a result. These women tend to be hopeful, optimistic, like to find the positive aspect to things, be better educated and be

several years into the survivorship period. An optimistic approach, adequate social support and adopting a problem-solving coping strategy seems to result in less distress and supported long term recovery and rehabilitation (Sears et al., 2003, Edgar et al., 2000). The concept of Quality of Life assumes more importance as the duration of long-term cancer survival increases as it attains societal (resource), as well as personal implications.

A diagnosis of cancer which may, or may not be anticipated, depending on the method of detection, has psychological and social consequences for individuals in relation to the threat to life (Mages and Mendelsohn, 1979, Lyons et al., 2002). Subsequent treatment may be difficult to deal with and can often result in long term side effects (Spiegel, 1997, Meyer and Aspegren, 1989). In order to understand the consequences psychologically, emotionally and socially for these women the following section focuses attention on the literature relating to coping with life threatening illness, which can be long term. It seeks to explore some of the common psycho-social responses to breast cancer, in particular psychological distress and some of the theoretical perspectives on coping, dealing with uncertainty in illness and perceptions of risk.

### 2.5.3 Common psychosocial concerns

Psychological distress is a common response to a cancer diagnosis and the US National Comprehensive Cancer Network has published guidelines on the management of distress in people with cancer. The guidelines define distress in cancer as "*.....a multifactorial, unpleasant, emotional experience of a psychological (cognitive, behavioural, emotional), social and/or spiritual nature, that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness and fears - to problems*

*that can become disabling, such as depression, anxiety, panic, social isolation and existential and spiritual crisis” (National Comprehensive Cancer Network, 2007).*

The literature in this area would suggest that responses to a breast cancer diagnosis and subsequent treatment are many and varied and unique to each individual. Previous work has provided evidence to show that a multitude of factors dictate how each individual responds to their diagnosis. These factors include age at diagnosis, levels of social support, ethnic/cultural background, coping style, personality traits and spirituality/belief systems (Degner et al., 1997, Ward et al., 1989, McFarlane and Sony, 1992, Cotton et al., 1999, Ferrell et al., 1998).

R Janoff-Bulman’s extensive body of work with survivors of emotional trauma: rape, earthquake survivors, war veteran’s and cancer patients (Janoff-Bulman, 1979, Janoff-Bulman, 1985a, Janoff-Bulman, 1985b, Janoff-Bulman, 1989a, Janoff-Bulman, 1989b, Janoff-Bulman, 1992, Janoff-Bulman and Lang-Gunn, 1989, Janoff-Bulman and Timko, 1987, TImko and Janoff-Bulman, 1985), illustrated that regardless of the type of trauma, age, time since the event, or demography the psychological effects persist long after the event. The impact of the event challenges core beliefs and shatters basic assumptions about the world, disrupting well-used tried and tested ways of managing everyday life Janoff-Bulman (Janoff-Bulman, 1992) p18, asserts that there are 3 fundamental assumptions held by the majority of people:

- the world is benevolent
- the world is meaningful
- the self is worthy

We learn these basic assumptions in childhood - our emotional and physical needs are met, we establish trusting relationships and consistency. Feelings of safety and security follow as a result of our experiences. We start to believe that life is predictable and everything will be fine. This confers an illusion of protection and we assume that negative events are unlikely to happen to us.

In short, she says we over-estimate and over-generalise as part of our adaptive approach to dealing with everyday situations. This leads to the formation of schemas – categorisations, rule books or sets of criteria for making sense of the world we live in. These incorporate not only “facts” or “evidence”, gleaned along the way but also generalisations and abstractions from previous experiences. Event schemas are known as “scripts”, presumptions are made that in a given scenario, a chain of events is likely to take place. Janoff-Bulman suggests that our basic assumptions about the world produce our grandest schemas and are the most resistant to change. We are more likely to assimilate rather than accommodate new information. We may try to make the new information “fit” or ignore or even misremember it. That is to look for and prioritise information which reinforces and confirms our beliefs rather than change them.

When this is no longer possible due to sudden and over-whelming threatening events the changes have two distinguishing characteristics

- change occurs at a narrower level than one might expect –“mini” schemas rather than at the “meta” level of fundamental assumptions
- change is incremental, gradual rather than sudden or swift (Janoff-Bulman, 1992) p41-42.

Janoff-Bulman’s work with breast cancer survivors (Timko and Janoff-Bulman, 1985) illustrated the dualism between the biological and the symbolic self, acknowledging the fragility and the vulnerability of the physical self and how deeply it affected psychological well-being. She says “those individuals diagnosed with cancer are forced to see the world as it truly is and the effect is terrifying and induces feelings of shock, disbelief, helplessness and confusion” (Timko and Janoff-Bulman, 1985). They feel fearful and uncertain of the future - in particular pain, recurrent disease, disease progression, loss of independent living and death. Cancer survivors experience what she terms a “double dose of anxiety” – insecurity because survival can no longer be assumed, the world is a

frightening place, fraught with danger and “cognitive disintegration” that is – everything previously taken for granted no longer holds true. Assumptions are shattered, there is no “rule book” schemas fall apart. Both external and internal worlds fall apart – all is chaos. Janoff-Bulman calls this the psychological equivalent of physiological arousal. She maintains that victims of trauma are subject to hyperarousal and hyperactivity which may make them hypersensitive to stress so that quite minor levels of stress set off major autonomic arousal (Janoff-Bulman, 1992) p65.

It would seem logical that those with prior experience of traumatic events should be predisposed to reacting in this way. However, Janoff-Bulman points out that those individuals with the most positive pre-existing core assumptions are the most deeply affected by the disintegration of their core schemas (Janoff-Bulman, 1992) . She states that this positivity gives them coping skills to adapt and manage their new circumstances and they achieve a more successful long-term recovery. Those individuals who bring negative views and reduced coping skills to the current traumatic event are likely to experience both short term and long term distress. She also suggests that exposure to moderate levels of stress may reduce the impact of a traumatic event as long as there is an adequate time interval to re-establish the equilibrium.

Schemas may already be partially reconstructed, core assumptions re-evaluated and the world viewed as less benevolent than before. Otherwise the reverse may be true and the situation exacerbated by a cumulative stress effect – this leads us again to the concept of hyper-arousal.

Janoff-Bulman noted 3 major strategies used by the survivors in her studies (Janoff-Bulman, 1992):

Comparison with others – in particular downward comparisons,

this helps to minimise the threat

Role evaluation – self-blame/control, creating the illusion of

control and predictability

Interpretation of meaning – benefit-finding, personal growth by

transforming/ reversing the concepts and restoring core assumptions via

- Malevolence back to benevolence
- Randomness to meaningfulness
- Self-abasement to self-worth

Janoff-Bulman's findings and theories were borne out by the findings in the present study and used to inform and describe the principal themes in the analysis. The concepts of "close shave" and "marked woman" (described later in the findings chapters) are directly related to the women's varied attempts to attribute meaning to and explain the disruptions to their core beliefs and assumptions about the world and the situation they find themselves in. Breast cancer diagnosis generates strong emotional responses: fear of death, fear of recurrent disease, feelings of hopelessness/helplessness, loss of control, as well as intrusive thoughts and anxieties related to the illness and its treatments (Institute of Medicine, 2004). Once women have come to terms with the immediate implications of their diagnosis and recovered from the effects of surgical treatment, many individuals experience low self esteem and sexual dysfunction due to their altered body image (Pelusi, 2006, Schover et al., 1995, Kalaitzi et al., 2007). This in turn may affect their relationships with those closest to them. They feel vulnerable, less attractive, less desirable, fearing they may lose esteem in the eyes of others. (Pitceathly and Maguire, 2003, Mellon and Northouse, 2001).

The practicalities of being unable to work, or fulfil family commitments in the short or long-term, can create difficulties. Changes in social roles and unemployment can have a devastating affect on personal, or family financial circumstances (Carter, 1994, Hoffman, 1991). Future health status becomes uncertain, with the fear of recurrent disease bringing with it existential concerns and the need for readjustment in belief systems. Life can no longer be taken for granted, planning for the future can seem difficult and for some, death is contemplated for the first time. (Muzzin et al., 1994, Northouse, 1981)

The prevalence of long-term psychological distress in patients with cancer ranges from 20% to 66%, according to the few available estimates (Bodurka-Bevers et al., 2000, Sharpe et al., 2004, Maguire, 1999) While most people with cancer experience symptoms of anxiety, evidence suggests that 12%-30% experience clinically significant anxiety problems (Zabora et al., 2001).

Previous studies have outlined some of the characteristics of those women most likely to develop problems with distress in the long-term these are set out in the table below:

Age (younger women)
Dependent children younger than 21 years
Economic adversity
Cumulative stressful life events
History of alcohol or other substance abuse
Infertility concerns
Sexual dysfunction
Pre-existing mental illness (including anxiety/depression) and psychological morbidity
Physical co-morbidities
Inadequate social support
Single, separated, divorced, widowed
Living alone
More treatment side-effects
Experiencing lymphoedema
Experiencing chronic pain
Fatigue

taken from "From Cancer Patient to Cancer Survivor: Lost in Transition" (Institute of Medicine, 2006)

We know very little about when and if distress may become a problem at given points along an individual's journey, or how the level of that distress may vary by phase or treatment.(Omne-Ponten et al., 1992, Ganz et al., 1993, Maunsell et al., 1992, Schag et al., 1993). We do know, that women with early breast cancer are twice as likely to develop anxiety and/or depression in the year after diagnosis than their counterparts in the general female population (20-30%) and that the risk factors for depression and anxiety are related to the patient rather than the disease or treatment (Burgess et al., 2005).

Anxiety has been shown to be particularly related to key points in time – including the end of treatment and people with cancer are also more likely to be depressed than the general population (Spijker et al., 1997), the prevalence is between 20-50%. Depression in cancer reduces quality of life, prolongs hospitalization and increases the risk of treatment non-compliance (Ashbury et al., 2003). It is therefore important that assessment and treatment are effective and timely.

Identification and assessment of the individuals affected, results in positive changes in their mental health and adjustment to their disease (Bailey et al., 2005, Raison and Miller, 2003, Jacobsen and Hann, 1998).

Cognitive-behavioural therapy has proved to be useful. It can be tailored to deal with the symptoms unique to each individual, problems related to control and quality of life issues (Bailey et al., 2005). It is also more readily accepted as a means to develop strategies to cope and manage the burden of treatments, as it centres around the concepts of self-advocacy and personal control (Jacobsen and Hann, 1998).

### **2.5.3.1 Uncertainty**

Uncertainty has a direct effect on quality of life for women with breast cancer. It can be due to the side effects of treatment, doubts about the effectiveness of the treatment, or fear of its long term side effects. It may also be related to a fear of disease recurrence. According to Mishel's Uncertainty in Illness model, (Mishel, 1988) uncertainty becomes a problem when there is a lack of understanding of the meaning of an event due to its complexity, ambiguity, or a mismatch between an individual's own expectations and the "real" world. This is likely to affect an individual's appraisal of stress, their coping strategy and consequently how they adapt to it, i.e. their adaptation outcome. This concept originates from the work conducted on stress appraisal and coping (Lazarus and Folkman, 1984), who describe uncertainty as "the adjustment of somatic health, morale or life satisfaction; and the ability to function at the work-place, and social living".

Mishel (1988) identifies 4 characteristics of uncertainty:

- Changing signs and symptoms of illness
- Unfamiliarity
- unpredictability
- incongruence between expectations and reality.

Uncertainty is created when circumstances change, once a situation ceases to become predictable and there is a perceived loss, or reduction in control.

Studies have identified "flash-points" or phases in the disease trajectory at which women with breast cancer are particularly vulnerable to distress, uncertainty and depression.

The US Institute of Medicines report "Meeting the psychosocial needs of women with breast cancer" (Institute of Medicine, 2004) acknowledges that breast cancer may be only part of the psychological burden in women's lives affecting their ability to cope, their sense of well-being and quality of life. They recommend levels of psychosocial

distress are understood in the context of socio-economic, cultural factors, levels of available social support, difficulties in accessing healthcare, as well as co-morbidities and other life crises. They state that for each woman, the type and extent of psychosocial concerns may vary depending on the phase of the breast cancer experience.

They describe these distinct phases as:

Diagnosis
Primary treatment
Special issues, not related to invasive cancer
Genetic risk and its psychological management
Completing treatment
Re-entry to usual living
Survivorship
Recurrence
Palliation for advanced cancer

(Institute of Medicine, 2004)

For example if the expectation is that treatment will bring about cure and then the disease recurs this represents a new threat and induces uncertainty about the possible outcome and effectiveness of future treatments.

Fallowfield et al (Fallowfield and Clark, 1992) demonstrated in their work with women diagnosed with breast cancer that some women perceive that if psychological interventions such as visualisation techniques and relaxation therapy can have a positive effect on their physical well-being, then the psychological impact of stress, depression, or negative thinking can conversely increase their risk of developing a physical problem, or recurrence of disease. The idea that there is no known cause and therefore no way of preventing the disease instils the fear and anxiety that accompany uncertainty.

Individuals describe needing to assign blame and/or find a causal link between their disease and something tangible they have done, or not done. This originates from a

basic human need to elicit an element of control or predictability from the situation. (Fallowfield and Clark 1992).

Women discharged from regular follow-up are not acutely sick, but not cured either; and have no way of knowing which of them is likely to experience recurrent disease. Therefore they are likely to experience uncertainty which in turn influences coping strategies and affects quality of life (Wonghongkul et al., 2006).

### **2.5.3.2 Perceptions of risk of recurrent disease**

Uncertainty is related to perceptions of risk. The higher the perceived threat or risk of harm, the more uncertain an individual perceives their future to be. If prognosis is perceived by an individual to be poor, recurrent disease likely, or metastatic spread inevitable at some time in the future – the uncertainty of the situation generates feelings of loss of control i.e. fear and anxiety; and existential concerns. Assessment tools such as the Nottingham Prognostic Index (Galea et al., 1992) allow clinicians to look at the known risk factors and attempt to predict the likelihood of recurrent disease. Whilst health care professionals look to the research literature, relevant statistics and their clinical experience to inform their predictions; women with breast cancer use their beliefs about health prior to diagnosis and their perceptions of their personal susceptibility to physical ill health in their assessments.

This is evident in the work of Leventhal and colleagues who investigated the factors individual's take into account when assessing risk.

Leventhal’s Common Sense Model (Leventhal et al., 1992, Leventhal et al., 1997, Weinman et al., 1996) defines 5 characteristics or attributes which are used to investigate an individuals own understanding of risk:

identity/label of the health threat (i.e. the name of the condition)
timeline of the health threat (e.g. acute, chronic, or cyclic)
consequences of the health threat -physical, economic, psychological, or social
causes of the health threat (e.g. inheritance or environment);
the control or cure of the health threat (e.g. health behavior or surgery)

(Leventhal et al., 1992, 1997; Weinman et al., 1996).

These characteristics may influence an individual’s perception of risk, how they express it and relate to how these perceptions dictate their behaviour. It gives a framework to enable researchers to gain an understanding of how individuals form their estimates of risk and “conceptualize risk and what information individuals use to form their own subjective estimates of risk” (Kelly et al., 2005).

Leventhal suggests that the factors which influence health behaviours can be investigated to see how they communicate with each other, in order to develop effective, efficient, usable, interventions. By assessing intra-individual changes it may be possible to see how the strategies adopted for coping with difficulties are translated into health beliefs (Leventhal et al., 2008).

Other researchers (Burgess et al., 1998), identified triggers for health-seeking behaviour. When they compared patient-driven visits to healthcare providers, with routine annual examinations – they found they were distinguished by somatic changes. These were new symptoms and the perceptions of the relevance; or significance of these symptoms as threatening to physical function. For example: finding a new breast lump, versus back pain, as an indicator of recurrent disease in breast cancer. This is relevant to the strategies for self-identification of recurrence, or metastatic spread, for women discharged from regular out-patient follow-up. They are expected to recognise when a

symptom is of appropriate significance to warrant investigation. This requires a set of heuristics or mental rules to differentiate between inconsequential changes and serious illness.

Leventhal divides these into 4 components:

1. A spatial/temporal map – this identifies the location, duration and severity of symptoms and is reinforced by healthcare professionals during consultations when they ask where the problem is situated, how long the symptom has been present for and what it feels like.
2. Patterns – this is based on prior experience (e.g. chest pain=heart problem) novelty, trajectory (Is it getting worse? Does it fluctuate?), control e.g. does it respond to self care?
3. Cultural beliefs – is there a relationship between age and illness, gender stereotypes, the relationship between stress and illness, and that feeling good is thought to equal good health.
4. Active social comparison – the prevalence or severity in one's own community; a similarity in exposure, temperament or physical characteristics.

These mental rules attribute meaning to the somatic changes, so for example if the changes are of long duration and high severity this may imply a serious threat to function and/or life. Leventhal also found that if symptoms were grouped into concepts (e.g. sweating+arm pain+chest pain=heart attack ) they were more likely to generate care-seeking behaviour. Leventhal and colleagues suggest that research into the understanding of the significance of symptoms and embodied experience would generate information around how individuals answer the questions "am I sick, or am I well?" "is it a threat to life?". For many people, it is considered necessary to be symptomatic in order to be sick and this influences perceptions of the significance and level of threat attributed to the illness as well as its susceptibility to control or cure. Investigating the chronic illness representations of patients and practitioners and how this relates to their treatment experience both in the clinic and the community, may help to improve the effectiveness of health interventions (Leventhal et al., 2008).

Leventhal et al's theory of illness representation corresponded to the findings of the interview data in the current study, where women described how they either viewed themselves as well or sick – "I have breast cancer"/"I had breast cancer" and

consequently how they viewed their follow-up care. This led to the construction of the theme (described later in the findings chapter), of attendances for routine follow-up care as either a "blessing" or a "curse". This helped to explain why some women welcomed their discharge from follow-up care and others did not.

Mira Cohen in her work with Israeli women also investigated risk and its relationship to early detection practices and breast self-examination (Cohen, 2006). She randomly selected women from the general population and found a connection between raised anxiety and distress levels, early detection practices (EDP) and over performance of breast self-examination (BSE). Regardless of their family history the women performed EDP in similar ways and similar frequencies, age was not significant. Over-performance of BSE was associated with a family history, or having more cancer worries, or feeling more susceptible to the disease. She suggests that adherence to EDP has more to do with health belief than actual risk and that BSE may be self-assuring/self-calming behaviour and a sign of distress.

The decision to actively seek out information about risk is influenced by communication and coping styles. This applies both to the individual and their family members (Mellon et al., 2006). Some families openly discuss inherited risk with all family members, seek out information via the internet and exchange it via email, while others are more selective, or do not discuss the issue at all. Mellon et al, found that this was related to the (perceived) control exerted by identifying behaviours which may reduce risk such as surveillance. It was also negatively associated with the fear of finding out the risk, increasing stress or distress for other family members and uncertainty of effective treatment options (Mellon et al., 2006).

Being closely related to someone diagnosed with breast cancer can also have a profound effect on risk perceptions. Watching a close relative go through diagnosis and treatment and knowing that a family history of the disease increases one's own risk, creates

feelings of vulnerability,. In the case of a daughter involved in a caring role for a mother with breast cancer, this may expose her to various aspects of the disease she may otherwise have not known. This prior first hand knowledge brings with it an acute awareness of personal mortality, fearfulness, a loss of hope and doubts about what is possible in the future (Raveis and Pretter, 2005). Leventhal points out that both experience and somatic changes perceived in the self and the observations and exposure to information about illness in others; are used by individuals to form illness representations and design effective strategies to prevent and control chronic illness (Leventhal et al., 2008). Watching someone else experience a deterioration in their health, or even die, from cancer can be traumatic and have long term psychological effects; informing beliefs about treatment/survival and influencing health behaviours such as hypervigilance; or watchful-waiting .

Time does not seem to diminish the anxiety and fear around risk from cancer. In a study of older, long-term survivors of cancer (Deimling et al., 2006), the 5 year anniversary often considered by some to represent the likelihood of a "cure" was not seen to be a guarantee of immunity from recurrent disease. Worries were not only related to recurrent disease but also to the possibility of other cancers and diagnostic testing. Deimling et al (2006) observed that even after several decades of disease-free survival, worries about cancer persisted and were associated with anxiety and depression; with the potential to reduce quality of life.

#### **2.5.4 Social Support**

Previous research has noted that women with close relationships in which there is open and mutual communication have lower levels of distress (Helgeson et al., 2004, Boyle, 2006, Ballenger et al., 2001, Jones, 2001, Friedman et al., 2006, Lewis et al., 2001). Furthermore, lack of social support has been noted as a risk factor for anxiety, depression, Post-Traumatic Stress Disorder (PTSD) and a higher mortality rate (Amir and Ramati, 2002, Kroenke et al., 2006).

Naturally occurring social networks are widely held to be beneficial. Support from significant others is seen as an indication that they are aware of; and sensitive to; the stress experienced by their loved one. These networks include spouses or partners, siblings, (grown-up) children, close female friends, fellow church members. The support they give is assumed to reduce the levels of distress and alleviate practical problems associated with it.

Bolger and colleagues (Bolger et al., 1996) reviewed the literature to look for evidence to support this assumption. Their findings showed that studies conflicted in their reports and that the nature of the support, as well as the approach and motivation of the supporter had greater impact and relevance. The authors point out that those closest to people with a chronic illness, may experience support fatigue, feeling overwhelmed by their loved one's distress and difficulties. Supporters may understand recovery from the physical impact of the illness, better than its long-term emotional implications. Physical symptoms may be seen as beyond the control of the support recipient but expectations of controlling the symptoms of distress may result in the supporter, seeing it as a weakness or simply as a negative attitude. For this reason those who are chronically ill may hide symptoms of distress, for fear of driving the significant other away. Bolger et al, suggest this is why many form close external relationships and turn to peer support groups to alleviate their distress.

The nature of support required varies greatly from person to person. Based on data gathered from the Inventory of Socially Supportive Behaviours (ISSB) and Cancer Evaluation System Short Form (CARES SF) questionnaires, Reynolds and Perrin (Reynolds and Perrin, 2004) looked at social support and psychosocial functioning and identified 4 categories of support that women with breast cancer desire:

- Reassurance: from several different sources which centred on the idea, that everything would be ok and eventually return to normal.
- Normalcy: the opportunity to be treated normally, autonomy, with no pressure to talk about their breast cancer, or have information, or advice forced upon them.
- Information: facts, information and advice as much of; and whenever they needed it.
- Talking: emotional expression, story-telling, sharing of experiences, but no advice.

Women asked for some or all of these things on an individualised basis. They reported distress when what they desired, was not what they received. When there was a mismatch between support wanted but lacking, or there was receipt of unwanted support, this was due to the assumption by both parties that there was an unspoken agreement on what constituted good support and assumptions made about the good intentions of the supporter. Negative support behaviours such as minimisation, changing the subject, avoiding discussion of difficult issues and not understanding the recipient's perspective were all reported by Reynolds and Perrin in their review of previous work as eliciting distress.

The stress imposed on close relationships was well illustrated by Holmberg and colleagues (Holmberg et al., 2001) in their interviews with couples and single women in their first year following diagnosis of breast cancer. The diagnosis challenged the relationship no matter how strong it was prior to diagnosis. It resulted in both members of the dyad (couple) having to find new ways to operate within the relationship. Those couples who were previously in conflict terminated their relationship as a result of having to cope with the diagnosis. Conflict occurred when differing coping strategies were adopted by supporter and the supported. Communication broke down due to an inability to discuss grief, loss, death, or if conflict resolution was managed differently, or even avoided altogether. Some of the problems arose because of the women's negative

perceptions of themselves – fears about loss of sexual allure, loss of intimacy and the change in their role in the relationship. Their partners were more concerned about the possible death of their significant other and did not consider the issue of altered physical appearance as important. However, partners did report feeling anxious, lonely and afraid.

There is evidence to endorse the view that support from naturally occurring social networks can be beneficial, as long as it is provided in the form needed and desired by the recipient of that support. Unwanted support may actually increase stress levels and those closest to the recipient may feel overwhelmed and fatigued when support is needed in the long-term.

This raises the issue of identifying the available alternatives when the most valued source of support is no longer available. What might the alternatives be? How well do they provide what is needed? How does this affect the quality of life for the individuals concerned?

### **2.5.5 Coping with breast cancer**

Coping as a concept has been defined as “constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as, taxing, or exceeding the resources of the individual” (Lazarus and Folkman, 1984). Lazarus and Folkman suggest that the way a person copes, is determined by their resources, existential beliefs, commitments, problem-solving skills, social skills, social support and material resources. Conversely they may be constrained by: cultural values which proscribe ways of behaving, psychological deficits, competing demands and agencies/institutions which thwart their coping efforts. Coping is impaired when threat rises to a level where arousal is so high it interferes with cognitive functioning and information processing (Lazarus and Folkman, 1984).

In a phenomenological study of the experiences of twenty women, during the first year following a diagnosis of breast cancer, Margaret Lyons and colleagues (Lyons et al., 2002), explored what it was like to be diagnosed with breast cancer, cope with the treatments, the emotional aftermath and its effect on the lives of the individuals affected. The study identified a process characterised by the authors as gradual having aspects that were both private and social; as well as spiritual. The women experienced initial trauma, a period of re-traumatisation, followed by resolution/healing.

They encountered 3 overlapping phases:

diagnostic – the impact of diagnosis,

treatment – which required resilience

post-treatment – which resulted in resolution and healing.

The diagnostic phase encompassed 6 themes: receiving the news, fear, being strong, persistent thoughts, multiple stressors and spiritual awareness. The period during which they received treatment was characterised by: making choices, pain and suffering, determination to fight and support from others.

Once treatment was complete, fear of recurrent disease, behavioural changes, personal growth and spirituality were identified as common themes. Despite having faith and hope, all of the women feared the cancer would return. They made lifestyle changes to promote, or preserve good health, took more exercise and ate a healthier diet in order to improve their sense of control over the disease. They created more opportunities to relax with family and friends. They felt they were more patient with others, kinder, appreciated small things which previously, would have had less significance for them and learned not to take their good health for granted. They re-prioritised and attached greater importance to the significant relationships in their lives. All of the women reported becoming more spiritual, either via personal prayer, reading scripture, discussions with their pastor, support from their church community or meditation; as a

means of re-assessing their beliefs and creating meaning for the events they were experiencing.

Although it documents the experiences of a small group of women, this study describes in detail the rollercoaster of emotions and situations women with breast cancer may have to face and the variety of ways they might choose to cope with them. It also highlights the fact that breast cancer is an emotionally, as well as physically, traumatising experience. In particular, the way in which the women in the main, chose to cope by being strong, thinking positively, finding benefit from the experiences, illustrates the culture of women with breast cancer to adopt, or appear to adopt these strategies. The fact that as a group the women in this study chose to turn to their religious, or spiritual beliefs may also have contributed to their choice of approach.

Reaching the end of treatment can produce a range of emotions. Treatment is often viewed as something positive to contribute to well-being and an attempt to stop the disease returning (Lethborg et al., 2000). Stopping treatment can therefore induce feelings of uncertainty, vulnerability, loss of control and ambivalence. Often family and friends no longer see a need for continued physical or psychological support. In many instances quality of life is at its lowest at this point, with individuals describing feeling isolated and abandoned, (Ganz et al., 2004, Deshields et al., 2005, Land et al., 2004).

The social construct of "good" and "bad" coping has been adopted by both health care professionals and the general public. The notion that there is a "right" and a "wrong" way to cope and that it may have a positive; or negative effect on physical and emotional well-being; seems to be universally accepted. Coping theory has a long history. Festinger in the 1950's, observed that individuals use comparison with others to help them make sense of their own situation and generated the social comparison theory. This theory is still currently used in experimental work by Stanton, Buunk and others (Festinger., 1954) in (Stanton et al., 1999) (Buunk et al., 2002).

Women with breast cancer have been shown to use social comparison to minimise their level of threat, using for example the size of their tumour, or the treatment options offered to them at diagnosis, to gauge their risk of recurrent disease (Stanton et al., 1999).

To paraphrase Leon Festinger, the concept of cognitive dissonance is based on the theory that individuals crave that their world is consistent, harmonious, congruous with all that they believe in and attribute value to, how they “know” their world and their attitudinal approach to it (Festinger, 1962), they want above all consonance (consistency) in thought, deed, belief, opinion, versus inconsistency (dissonance). That is, Festinger says believing one thing but one’s actions are the reverse – for example – knowing smoking is bad for you, but smoking anyway.

Cognitive dissonance almost always exists once a decision has been made between 2 or more alternatives i.e. related to the negative aspects of the chosen alternative and the positive aspects of the rejected one. Festinger goes on to say that dissonance almost always exists if threat or reward is used to elicit public behaviour (behaviour observed by others) which is at odds with private opinion. Forced or accidental exposure to new information may create new cognitive elements which are dissonant with existing knowledge (Festinger, 1962).

There is a human need to resolve the resulting discomfort and discord. This is achieved via several methods:

- Changing one or more of the cognitive elements in the decision making process
- Adding new elements which are consonant with existing opinion
- Reducing the importance of the elements (Festinger, 1962)

The concept of cognitive dissonance was evident during the course of the present study. Some of the women interviewed were at pains to explain that they were now disease-free and risk of recurrent disease was minimal if not impossible now their treatment was complete as their tumour was small and detected at an early stage. However, these same women argued for re-instatement of their routine follow-up appointments and more regular mammograms, directly contradicting their declared confidence in their slim risk of developing metastases.

Alternative theories related to stress appraisal and strategies for coping with stressful events were later proposed by Lazarus and Folkman in the 1970s. Lazarus et al's attempts to explore this concept proved difficult, as they discovered that there were a variety of reactions to the same stressful situation (Lazarus and Eriksen, 1952a, Lazarus et al., 1952b). They were forced to acknowledge that individuals responded in different ways and that motivation and cognition were important factors in the response to stress.

Lazarus and Folkman (Lazarus and Folkman, 1984) further developed Janis and Mann's (Janis and Mann, 1977) appraisal-based theory model, which was concerned with choices between courses of action and considered emotion as "an interference with information searching and decision-making processes".

According to the research literature based on the theories of Lazarus and Folkman around stress, appraisal and coping (Lazarus and Folkman, 1984) coping strategies are constructed as a result of cognitive appraisal.

In the beginning, during "primary appraisal" of an event, it is assessed to determine whether it is irrelevant, benign-positive, or stressful. If perceived as stressful – "stress appraisal" determines whether the event is perceived by the individual to represent harm/loss, threat or challenge. During "secondary appraisal" an assessment is made to see what can be done. The individual evaluates the coping options available, their likely

effectiveness, whether they will accomplish their aims and what the consequences might be.

The interaction of primary and secondary appraisal influences the resulting emotional reaction. The interpretation of an event as a challenge is dependent on the level of perceived control and effort required to master it. "Reappraisal" of the event occurs when new information or feedback from reaction becomes available, for example anger as a reaction may lead to guilt, shame, righteousness or fear. "Defensive reappraisal" (cognitive coping) is the effort to *re-interpret* the past more positively, or to deal with present harms and threats, by viewing them in less damaging and/or threatening ways. Defensive reappraisals are self-generated, originating from needs within the person, rather than pressure from outside – a form of self-defence. Cognitive appraisal is not only affected by the reality of the situation but also how the individual *chooses* to perceive it. It is phenomenological in nature and consists of private thinking, relying on the individual's subjective interpretation of an event (Lazarus and Folkman, 1984).

Lazarus and Folkman (Lazarus and Folkman, 1984), identified 2 important determinants of appraisal: commitments and beliefs.

Commitments are described as those aspects of an individual's life which are deemed to be important, give meaning and are at stake or risk of loss in times of threat or harm. They are motivational and influence the choices made to reduce threat. So, the greater the strength of the commitment, the more vulnerable the person is to psychological stress in the area of that commitment, but this also determines the amount of effort a person is willing to invest in warding off the threat.

The more "public" a commitment, i.e. the more people who know about it, the more threatening it is, to have it challenged. Therefore, the more the person will strive to avoid the threat. Conversely, people may "announce" a commitment to the world and

put pressure on themselves to fulfil the commitment, by creating a sense of obligation, or the threat of embarrassment/social disapproval. In the context of the study we might include close family relationships, social roles, the pressure to fight cancer, be strong, think positive as commitments in the sense that Lazarus and Folkman intended.

Beliefs are described by Lazarus and Folkman as "personally-formed or culturally-shared, cognitive configurations". They are pre-existing notions about reality and determine what is "fact" for an individual and shape their understanding of its meaning. Beliefs include concepts such as mastery and vulnerability and are partly constructed in childhood. Lazarus and Folkman differentiate between what they term primitive and higher order beliefs. That is, those which are a "given", beyond reproach, taken for granted and those which are as a result of experience and inductive reasoning, even questioning external authorities. Over time higher-order beliefs may take on the qualities of a primitive belief and be accepted without question.

Beliefs Lazarus and Folkman assert, are concerned with what one thinks is true, whether or not, one likes or approves of it. Commitments reflect values, what one prefers, or considers desirable. They have an emotional-motivational quality, whereas beliefs are effectively neutral. The way a person copes, is determined by their resources (including health and energy), existential beliefs (about God or control), commitments, problem-solving skills, social skills, social support and material resources. It is also determined by constraints - cultural values and values which proscribe ways of behaving and psychological deficits.

Environmental constraints may be demands which compete for the same resources and agencies/institutions which thwart coping efforts. High levels of threat can also prevent a person from using coping resources effectively, by heightening arousal - cognitive functioning and information processing skills become impaired.

So rather than categorise responses according to personality traits, or styles Lazarus theorised that individuals assessed and evaluated; or *appraised* a situation as being harmful, threatening, challenging, or benign. He called this primary appraisal and identified two ways of coping which he called "problem-focused" and "emotion-focused". He suggested that problem-focused coping was used when the individual felt able to change a situation, or exert some control over it and emotion-focused when this was not the case (Lazarus and Folkman, 1984). These concepts of problem-focused and emotion-focused coping were based on the idea of "stress inoculation" – that is, that people can be trained to cope with upcoming stressful situations (Meichenbaum and Novaco, 1978).

Lazarus's work on coping resulted in a belief that reactions to stress can not be wholly explained by the physiological responses to it, but that emotional response shapes its meaning and therefore the behaviour employed to deal with it (Lazarus, 1993).

Individuals use both the way they think and the way they feel about a situation to create an effective coping strategy; each informing the other and assisting in adaptation to a change in circumstances.

Since then, the social constructs of "benefit-finding", "positive re-appraisal" and "post-traumatic growth" have all emerged in studies that have attempted to investigate and describe the way individuals deal with traumatic events in their lives (Carver et al., 1989, Sears et al., 2003, Fredette, 1995, Franks and Roesch, 2006).

Against this back-drop of theory development in relation to coping with stressful events within health care, there has been a plethora of research conducted over the last two decades. This work has intended to assess women's ability to cope with their breast cancer, the design of a multitude of instruments to measure it (Endler and Parker, 1990, Folkman and Lazarus, 1988, Carver et al., 1989, Moos, 1993) and psychotherapeutic interventions to attempt to modify it (Vos et al., 2006, Arving et al., 2006)..

However, Folkman and Moscovitz's recent review of the coping literature (Folkman and Moscovitz, 2004) acknowledges that there is a dearth of data on within-person prospective and longitudinal coping. Folkman and Moscovitz (2004) encourage the use of mixed methods – combining the data from inventories (self-reported, multi-dimensional, situation-specific) with information from narrative research. Thus enabling researchers to overcome the limitations of questionnaire research and in addition find out what is being coped with; whilst identifying ways of coping not listed in inventory based questionnaires. Mixing methods in this way enables not only the investigation of which coping strategies are adopted in stressful situations, but why they are chosen, whether this changes over time, as well as identifying the influencing factors involved in the choice.

Richard Lazarus (Lazarus, 2000) highlights the importance of investigating both within-person and between person psychological changes over time in diverse situations. He sees prospective, longitudinal research in this area as a vehicle to extend theoretical knowledge in the field of coping theory and link it to clinical practice. He uses the work of Tennen and colleagues (Tennen et al., 2000) who followed a group of HIV patients and their carers, as an example of how this can be done.

The study undertaken for this thesis is an attempt to add to the knowledge in this particular area by asking women with breast cancer prospectively, about their experiences of long term recovery. The findings (via the interview data), will describe how the variety of coping strategies employed by the women, relate to the reactions to discharge from routine follow-up care. Reappraisal and assessment of threat proved to be an important aspect of their adaptation to the change in circumstances and perceived level of threat was crucial to their assessment of the implications of the changes imposed on them.

## 2.6 Summary

Over 44,000 women are diagnosed with breast cancer in the UK every year (Cancer Research UK, 2007) and have to cope with the demands of their treatment. Women with primary breast cancer, aged 50-69 years, have a 85%-90% chance of survival at 5 years post-diagnosis and these numbers are likely to grow exponentially over the next ten years (Coleman, 2000, Jemal et al., 2007). The societal and resource implications of this, mean that it is important to investigate how they cope with the recovery phase, long-term survivorship and the anxiety associated with the risk of recurrent disease.

One element of this is the role of follow-up care in providing this support. However whilst there is a wealth of guidance available, there are conflicting views about what and how to deliver it. Women appear to have a range of opinions about what they want and need, but an increasingly resource-aware National Health Service means that follow-up practices are evolving and changing.

In addition, there is little empirical evidence for the effectiveness of outpatient follow-up to detect disease recurrence. It does seem to provide psychosocial support and this appears to be valued by the women. Several different models have been developed to address these needs.

It is against this backdrop that the present study was undertaken. It presented an opportunity to collect data from a group of women whose mode of follow-up was to be changed and women were to be discharged from outpatient care (with an open appointment) 5 years or more post-diagnosis. The impact this had on the women and how they coped with what was happening to them was of interest to me as a researcher.

As treatments improve for other cancers and the prognosis and recovery phase become extended; the same issues and problems may arise for other groups of patients. The

information collected may be useful not only for the future care of women with breast cancer but also for other patient groups creating the opportunity to collect information to contribute to the provision of optimum care.

The next chapter will outline how this study was designed to collect views and information from women recently discharged from annual outpatient follow up care.

## Chapter 3 - Research Design

### 3.1 Introduction

This chapter describes in detail the conduct of the study. It outlines the study's aims and the research questions it sought to address. The study design is summarised with an explanation of the research methods employed and how and why the participants were chosen; as well as the method of recruitment. It describes the data collection and the methods of analysis adopted. Strategies to ensure trustworthiness and credibility are covered as well as the approach adopted to address ethical considerations and issues. It also includes reflection on the role of the researcher and the approach used in the interpretation of the data.

The previous chapter presented an overview of the literature relating to breast cancer, its diagnosis and treatment, the psychological and social impact of the disease and issues relating to follow-up. The review highlighted a number of issues in relation to the lack of clarity around the appropriateness of follow-up, uncertainty about timing and length of follow-up; and the purpose that follow-up served. There was also a concern noted in the difference between what services offered and what women said they wanted.

In addition there are a number of policy guidelines that are suggesting changes to the way women with breast cancer are followed up in the long term. The literature review also encompassed the role of coping mechanisms and the adaptive behaviour necessary to deal with stressful situations. This study was designed to explore these issues further and gain greater insight into the views and experiences of women at this stage of recovery from breast cancer.

## **3.2 The Context: follow-up care in a regional breast cancer centre**

This thesis considers these issues in the context of examining follow-up for women with breast cancer in a regional treatment centre. The region where this work was being conducted was undertaking a review of its policy in relation to the follow-up care of women and as such this provided a unique opportunity to undertake a case study.

This prompted an interest in conducting a piece of research which investigated the impact of these changes from the women's perspective. The aim was to collect detailed information from the women regarding their feelings towards their follow-up care, what they needed in the future and how the changes had affected them psychologically and emotionally.

The changes to follow-up procedures were examined as they occurred. Women's experiences of follow-up, their thoughts on what a change to their follow-up plans meant to them and how they experienced follow-up over a period of time were investigated prospectively.

In order to provide the context to the research presented in this thesis I shall first outline the follow-up process that was previously undertaken and the changes that ensued.

### **3.2.1 The local context 'the case'**

Prior to 2006, patients under 70 years of age with primary breast cancer attending a regional specialist breast cancer unit were routinely seen in the post-operative results clinic 3 weeks post surgery. They were then followed up at 3 monthly intervals for the first year and then annually in the outpatient department for the duration of their lifetime; or until their disease recurred. Patients having wide local excisions for breast

tumours were offered yearly mammography prior to their clinic visit for 4 years and then 2 yearly mammograms thereafter. They also received 2 yearly mammography of the contra-lateral breast. Patients having mastectomy received 2 yearly mammography of the contra-lateral breast for the duration of their follow-up.

On the grounds of limited resources, an ever increasing population of breast cancer survivors and the recommendations of the NICE guidelines for improving outcomes in breast cancer (NICE, Aug 2002); the NHS Trust for this group of patients decided to change the level and nature of service provision for the patients attending the unit.

Under the new proposals, patients were categorised according to their level of risk for disease recurrence and the level of clinical follow-up was allocated, as considered appropriate, according to a predetermined protocol as follows:

Women attending the primary breast cancer follow-up clinic:

- 5 years or more post-diagnosis
- At moderate risk of recurrence with an NPI score of 3.4-5.4

(Galea et al., 1992)

- No abnormality observed via routine mammogram
- Physical examination revealed no evidence of disease recurrence
- Discharged from out patient follow-up with an open appointment to return if necessary and given contact details for the Breast Care Nurse Specialist Team to discuss any concerns they may have in the future.

What was unknown was the impact this would have on the quality of the care and support women received and their future health and well-being. The changes were made without prior consultation with the women themselves.

Nurse practitioner and medical colleagues reported that during the discussion at the discharge appointment, women responded with a variety of reactions - extending from jubilation and relief, through deferential acceptance, to outraged indignation and petitions to reinstate the traditional follow-up care.

Adjuvant hormone therapy was at that time recommended for 5 years post diagnosis (Blamey and the ZEBRA Trialists Group, 2001, Early Breast Cancer Trialists Collaborative Group, 1998). So women discharged from follow-up at 5 years had dual concerns: the end of pharmacological treatment, as well as a change in their care provision.

Women who are discharged from long term follow-up services are likely to be faced with a number of challenges. These include the psychological impact of leaving on-going follow-up, on-going surveillance, information, support and decision-making support and the requirement to cope and adjust to the impact of potential future recurrence, all of which can impact on their quality of life.

### 3.3 Aim and objectives

#### Aim:

- To investigate the experience of being discharged from breast cancer follow-up services and evaluate the impact of the proposed changes in service delivery from the patient's perspective

#### Objectives:

- To describe how women feel about the change in service provision
- To examine how the change in service provision affects women's views of fear/risk of disease recurrence
- To identify the impact of being discharged from follow-up on quality of life, including psychological distress, adjustment and coping.
- To explore anxieties and concerns once patients are discharged from regular outpatient follow-up care

## 3.4 The Philosophical Approach

Historically, philosophical theory has enabled us to explore a variety of perspectives on the world and the way societies operate and evolve within it. There are differing views on how this knowledge is generated. Adopting a particular philosophical perspective helps create a point of reference from which to view the social world in which we live. It creates an anchor point for the researcher, based on clear theoretical thinking, a framework from which to begin in order to shape a coherent and structured approach to the research question. The next section explains why a pragmatic perspective was chosen as the philosophical approach for this study.

### 3.4.1 Pragmatism as a philosophical perspective

Although pragmatism may seem at first to be a single approach, it has throughout its history been an umbrella term, with many philosophers building and extending on the views of their predecessors. It is considered an approach and not a methodology. The following section will outline its proponents and their divergent views.

The verification of belief Misak says "occurs within an elaborate socially inherited system of knowledge. The techniques of verification, the supporting conditions of an act of testing a claim, the working standards of procedure and control are all, for Peirce, the creation and possession of the scientific community as a whole.....that community is active in and through the activities of its individual members inquiring into facts". (Misak, 1998) p104. The relevance of beliefs and their nature when undermined by doubts will become more apparent during the course of this thesis and will be discussed in more detail in the findings and discussion chapters.

William James had a pluralistic view of pragmatism, one which allowed for diversity of views between and within individuals – an acknowledgement of multiple selves, multiple realities, in varied circumstances (Rescher, 1999). Women in long term recovery from breast cancer have the same pluralistic approach to their disease. They have a broad spectrum of experiences and belief systems and the research questions and the methods designed to address them needed to encompass this variety

In John Dewey's view, truth is not fixed, but what is endorsed and accepted by the community who believe it. He sees it as linked to societal needs and once it no longer satisfies them it is replaced by another, with social consensus as the creator of truth. He characterised his version of pragmatism as "instrumentation" and saw beliefs, suppositions, ideas, as intellectual tools to make sense of the world. He considered that cognitive resources were chosen on the basis of the necessity to operate in the practical, everyday world. Peirce and Dewey agreed on the need to settle beliefs and remove doubt to re-establish a sense of equilibrium but diverged in their views on whether the consensus was rooted in objective states and processes (Peirce) or societal, or political conditions (Dewey).

For Dewey knowledge is ongoing, undergoing constant refinement, orientated to the future, nothing is fixed or, forever "known" and fulfils the requirements of the community for whom it is relevant at that point in time.

This does not mean that he did not believe in the endeavours of the scientific community rather that theory and practice, thought and action and knowledge and evaluation were inextricably linked. (Rescher, 1999) p24. Frequent, rapid, advances in the treatment of breast cancer over the last 3 decades, support this view; and the rationale for the need to re-think and re-evaluate the approach to healthcare for this group of women.

### 3.4.2 Neo-pragmatism

More recently, philosophers such as Richard Rorty, Hilary Putnam, Donald Davidson and many others have taken their own paths to pragmatism. The wide variety of stances and slants on pragmatism are too great to study in detail in the context of this chapter and so I will concentrate on those of Christopher Hookway and Nicholas Rescher who both acknowledge the influence of pragmatism's "founding fathers" and its relevance to modern day philosophy and research methodology.

In his chapter (7) "Doubt: Affective states and the regulation of inquiry" cited in (Misak, 1998), Christopher Hookway highlights the influence of cognition, which he says enables problem-solving, responsible and effective discovery of truths, collection of evidence, devising/carrying out experiments, dialogues with fellow inquirers and decision-making about the accuracy of results.

He links affective states with practical rationality and asserts that in planning our conduct and carrying out plans it is possible to assess both the rationality of goals and desires and examine the role of emotions and attitudes, reminding us that emotions can serve to aid rationality as well as impede it. His definition of doubt is "insufficient evidence to warrant acceptance or rejection of a proposition". In his opinion, instinctive judgements of rationality are to be trusted more than philosophical reasoning. We use our beliefs – he says to guide our desires and shape our actions, they prompt actions to promote our goals. He points out that actions resulting from beliefs are conditional – we may act on a belief only if we wish to satisfy a desire. He goes further than Peirce in relation to doubt, seeing its role as not only stimulating inquiry but also monitoring it and taking responsibility for assessing how successful it is. It is the driving force without it, our inquiry will lack conviction, problems may remain unsolved and questions answered ineffectively (Hookway, 1998). The reactions of women discharged from the service created doubt around the belief of healthcare professionals that outpatient

follow-up care is needed only in the short-term and fulfils their needs. For this reason, collecting thoughts, opinions and beliefs from the women in this study and exploring the reasons for them allows pragmatic inquiry via qualitative methods such as interviews and field notes. Evidence in the form of healthcare guidance and policy would lead us to believe that the service provided what the women needed, whereas clinical experience demonstrated dissatisfaction.

Hookway then goes on to talk about what he calls cognitive habits. He defines these as "habits of inductive reasoning, standards of plausibility, judgements of what stands in need of defence, what goes without saying, reflect and determine patterns in systems of belief and cognitive practice". He sees them as habits of evaluation, guiding us so we might decide when we have sufficient evidence to establish a belief, differentiate when an inference is useful and disregard implausible hypotheses. They are however difficult to pin down and explain or describe. Hookway advocates a sense of self-trust, a confidence in our instinctive cognitive habits even though they may be flawed what he calls "responsible rationality" (Hookway, 1998) p215.

Hookway would have us incorporate self-trust into our inquiries. Emotional responses he asserts, in some cases are the more trustworthy because they are based on extensive experience and he suggests that what is needed is a more balanced view – "a combination of the mechanical application of rules and the manifestation of judgements is needed to make cognitive evaluations and eliminate doubt". He quotes from C S Peirce: "Doubt is a hybrid state – a state of suspension of judgement and a desire to resolve it" in (Hartshorne and Weiss, 1934). This acknowledgement of the influence of emotion and intuition on perceptions of truth and knowledge; fits in with the concept of collecting information via narrative data and experiential knowledge. The idea that the way people feel about a situation, their perceptions of it and its meaning for them is a valid form of "truth" or knowledge.

I have drawn on Rescher's theory related to the pragmatic approach to methodology. The acceptability of claims relates, he says, to the success of their implementation. This goes back to the pragmatist maxim of practice taking priority over theory (Rescher, 1999). The methods of verification of these claims are what makes the approach pragmatic. A knowledge claim is judged by its method, which should be fit for purpose and achieve its aims. In Rescher's view methodological pragmatism should strive for an effective way to attain description (what), explanation (why, how), prediction (inference) and control (intervention)

This reverses the concept of methods being valid as a result of the accuracy of their truth claims and instead truth claims are judged on the validity of the methods employed to obtain them. In addition pragmatism allows for and encourages; complex approaches to complex problems, attempting to expand horizons, rather than adopting a reductionist approach (Rescher, 1999). It provides the opportunity to find out what women feel, why they might feel this way and how they formulate their beliefs.

The pragmatic standpoint acknowledges that beliefs are just that and rejects the notion of absolute truth, instead the concept of fallibilism describes the limitations of using belief as an anchor point for knowledge.

### **3.4.3 Fallibilism**

A best available estimate of the truth may well describe the pragmatist's view of validity claims. Whilst endorsing the value of scientific inquiry, pragmatism acknowledges that a proposition may be believed until proven otherwise. However close we may think we are to the "truth", it is still possible that it may, at some time in the future, be deemed to be untrue. Without the wisdom of hindsight it is impossible to predict the nature and likelihood of false assertions. Though provided in good faith, they may simply be the result of improved experimental techniques, more powerful means of observation or detection, or superior methods of data processing. Fallibilism is not to be confused with

scepticism – not all truth claims are held to be false. It is the realisation that knowledge is not absolute truth and although we are unable to make it so, we can still strive for as close an approximation as we can muster and continually try to improve upon it (Rescher, 1999). For example inferential statistics used to provide evidence in the healthcare research literature illustrate this point - when they employ probability values and confidence intervals to point estimates. In this way, results from experimental data are quoted with the caveat of the estimated probability that the results may be the result of chance. In the realm of modern healthcare, methods of obtaining “truth”, via clinical evidence (e.g. results of X-rays, blood tests) are constantly changing, evolving, being updated and it is generally accepted that they are fallible – false negatives, false positives, but they are still considered to be practically useful and accurate enough to provide benefit. By using “fallible” data in the form of the self-trust and emotional rationality of interview data, this study allies itself with the pragmatic philosophical tradition.

### 3.4.4 Pragmatism and modern health services research and healthcare

Modern health services research is often designed to generate results which may have a possible practical application. Studies are likely to be an attempt at problem-solving, investigating the influences, factors and causes of an identifiable problem; and addressing practical issues. Modern healthcare aspires to be orientated towards providing a service which fulfils the needs, as far as possible of the people who use it. Government policy guidance encourages a consumer-led, patient-centred approach to healthcare (NHS, Sep 2000). This study is no exception – the research question originated from an observed change in circumstances which created a variety of reactions to it – both positive and negative. The paradox of an increase in need (more women surviving breast cancer for longer), the reduction in the level of the service due to limited resources, and the differing aims and agendas of the key stakeholders

warranted detailed investigation. A practical problem dictated the methods used, based on what was “known” and this was an issue which was clinically relevant and considered important to the women concerned. A research question was required, which would provide answers of interest to both Health Care Professionals and their patients, as well as a perspective and methodology which would improve understanding and be appropriate to answer the questions effectively.

### 3.5 Study design

In order to address its aim and objectives the study employed an exploratory, prospective, longitudinal design. This meant that experiences were assessed as they were taking place, thereby minimising recall bias and monitoring changes over time. The study followed the women’s progress over the 2 years following discharge from the service, to investigate how the women felt over time and if that changed from the baseline data.

The study spanned a 3 year period and involved the recruitment of 20 women recently discharged from the outpatient clinic. Each participant was approached 3 times. In addition, any of the women recruited, who developed recurrent disease during the course of the study, were invited to give an interview to describe their feelings and experiences as close to the time of diagnosis as possible.

The table below indicates the time-points for data collection

Numbers of participants	Baseline (discharge)	12 months later	24 months later
20	interview	interview	interview
	Disease recurrence		
Up to 10 women	Interview		

Women attending the clinic, from which the sample was drawn, were aged between 50 and 70 years. As a group they had experienced a variety of treatments: lumpectomy, mastectomy, radiotherapy, chemotherapy and endocrine therapy. They varied in duration of follow-up, as the policy prior to the changes, was to follow up women until their disease recurred – when they would move to a different clinic, or died from other causes.

### 3.5.1 Interviews as a method of data collection

Qualitative analysis of semi-structured interview data was chosen as an approach for the study described in this thesis. This was based on the theoretical concept of narrative, as a valuable tool to elicit understanding of events and feelings considered significant by the author of the narrative.

One of the most well-known proponents of narrative in the 20<sup>th</sup> century as a valid and useful method in healthcare is Arthur Frank. Both his work over many decades as a sociologist at the University of Calgary and his own personal experiences of serious illness, shaped his belief that “story-telling” and the sharing of the experience of illness fulfils a need and has therapeutic value for those who suffer ill health. In his paper “The Standpoint of Storyteller” (Frank, 2000) Frank explains his views on what he considers are the important aspects of “story-telling” in the form of narrative:

In the analysis of narratives he differentiates between the study of the structure and the study of their content and cautions against sacrificing one for the other. Whereas the structure may be of interest we may lose the aspects of most importance to the storyteller if it becomes our sole focus.

Frank sees narrative story-telling in terms of the creation of a relationship. They are not told in a vacuum, the story requires a listener and the listener has an influence on what and how it is told.

Narratives can serve as a method of recuperation. When times are difficult, stories can help to create distance between the event and the experience of it.

When used purely as data for analysis, the relationship built during the course of the narrative can be lost and the original intentions for recounting it may be mis-interpreted. Frank advises that the analyst should concentrate on the problems of the respondent not the investigator.

Story-telling - Frank insists, is primarily a call to be heard and for other stories to be told, experiences to be shared; to find common ground with others and build relationships through storytelling. The opportunity for improved understanding by healthcare professionals, seems to be aptly explained by Frank when he says:

“Stories address the problem of how we can live different forms of life within the same social world. Stories deriving from different forms of life are like Gestalt drawings: The same lines depict two different images simultaneously. And more than that, one person can not teach another how to see the image in the drawing (the first image is usually seen immediately). The only way to see the other image is to keep looking until suddenly the other way of seeing is *there*: The duck becomes a rabbit, the young woman turns into the old crone, or the vase becomes two profiles. When perception switches back to seeing the initial image, the other configuration remains as a background possibility, not presently seen but now an immanent possibility in what is seen. How much of this process can be “analyzed” without first having the experience is questionable. Any analysis seems to depend on an experience that is prior to and always somewhat outside the analysis” (Frank, 2000).

As Frank says: "Each needs to hear the other's stories to make sense of why the other is, as he, or she is: why physicians seem patronizing or patients seem to be non-compliant. Until these stories are heard, clinics will remain tense places. The drawing that is the other's life will remain an unintelligible squiggle, or be configured as a shape that makes sense in the viewer's life but is not the shape that the other understands his, or her, life to be. Only when the story-telling relation is entered can the duck become a rabbit: only then can each see the shape of the other's life as the other experiences it." (Frank, 2000) p361-362

To paraphrase Arthur Frank (Frank, 1995): telling stories, or recounting a narrative of past events, is a way of bearing witness to personal experiences. It offers a form of testimony to previously unknown or suppressed, truths or reality. It is a way of expressing what it is to "be" in a particular circumstance, a subjective, personalised, account. Unlike the testimony of the witness in the court-room, it has more to do with feelings, emotions and perceptions than technical facts. Not only does it offer an opportunity to create order from the chaos of illness and a re-ordering of the life-story, but communicates what it feels like to be ill - to those who provide healthcare. It gives a voice to suffering and enables those most affected by it to express it. However the most important aspect of recounting a narrative is not to influence the design of healthcare, but the chance to be heard and understood (Frank, 1995) page154-155.

Narrative inquiry is a useful way of illuminating and investigating the life-worlds of others. It enables the researcher to gain insight and understanding they may not otherwise be party to. Denzin and Lincoln define it as "retrospective meaning-making, shaping or ordering past experiences" (Denzin and Lincoln, 2005) p640. It may also provide a "voice" and draws attention to *what* is being communicated and *how*; as well as the social location from which it is being said" (Gubrium and Holstein, 2002).

Narrative research offers the opportunity not only to listen to the “voice” of one individual but to compare it with those of others within a group.

It enables researchers to examine personal perspectives, situations and explanations, however indistinct or intricate they may be. A narrator may link particular details of their life story with the resources and limitations of their world. This gives the researcher an insight into how their life experience has shaped them as individuals, whilst acknowledging that identities constantly shift, change and evolve.

A researcher’s interpretation of a narrative allows description of the aims of the story-telling and make explicit; aspects the narrator takes for granted. In particular the language used - be it cultural or institutional in origin, can be illuminating, as can the use of analogy or metaphor.

Denzin points out that this approach can be at the expense of the narrator (Denzin, 1997). The researcher has a responsibility to take precautions to guard against this and preserve the diverse nature of stories; to ensure that all relevant perspectives are addressed including the narrator’s responses or oppositions to the researchers interpretations (Czarniawska, 2002) pp 742-744.

Narrative enquiry creates the opportunity to explore the reasons for the divergence, between the way the women felt about the change in policy and what was considered by the health care professionals in the clinic; to be the “appropriate” response. It allies itself to modern day pragmatism by acknowledging the value of multiple realities and dispenses with the idea that there is a universal truth, only one way to view a particular situation, only one perspective. It encourages and helps to describe the pluralistic, reality of social life.

Choosing semi-structured interviews provides rich, textual data, allowing investigation of pre-determined themes of interest documented in the literature, in addition to unexpected questions or issues raised by the participants.

In-depth qualitative interviews allow interaction and dialogue between researcher and participant which is relatively informal, what Burgess calls "a conversation with a purpose" (Burgess, 1984 pg. 102). They allow the exploration of themes and topics, biographical story-telling or narrative accounts. Even if the researcher has a list of topics to be covered or an interview schedule, they may still create the opportunity for flexibility and fluidity to allow the emergence of unexpected themes.

However, it would be foolish to assume that they generate "truth", accurate representations of a fixed social reality. They are more likely to generate a construction, or reconstruction of knowledge which is jointly created by both interviewer and interviewee during the course of the interview (Mason, 2002).

An interview schedule was designed, (attached as appendix 2) to frame the scope of the interviews and encompass the original aims of the research questions. It was used as a guide for the interviewer (researcher), but the intention was, that interviewees would lead the discussion and the interviewer would explore and clarify additional issues raised by the women within the interviews. The interview schedule consisted of a series of broad open questions, allowing exploration of the reasons for anxiety, coping strategies and aspects of quality of life, the extent and scope of social support relationships, the value of follow-up for the patients and how that correlated with the value placed on it by current health care policy. The women were asked to describe where they felt they were "at" after 5 years or more post diagnosis, issues they felt were important, concerns they had, their opinions and needs at this stage of their breast cancer recovery.

### 3.5.2 Ethical considerations and approval

Approval for the project was granted by Local Research Ethics Committee (LREC) and NHS Trust Research and Development Dept prior to recruitment. LREC approval was also granted to approach up to a maximum of 10 women who presented with recurrent disease following discharge from the service, during the course of the study. These women were invited to give their account of the events surrounding the diagnosis of their recurrence and express their views and concerns.

The ethics committee were keen to know the method of recruitment and to ensure there was no pressure to participate; or element of coercion. The committee were also concerned that distress may be caused by approaching patients at yearly intervals, without first checking that they were not deceased. To overcome this, the nurses working in the clinic agreed to inform the researcher of all patients who returned to the clinic with recurrent disease, or who they know to be deceased. It was agreed that contact would be made with the patient's GP each year to check they are still at the same address and that nothing unfortunate has happened to them in the interim. The Local Research Ethics Committee asked for assurances that the issue of potential harm would be addressed and approved patient information leaflets and informed consent forms which specifically address access to medical records, digital recording of interviews, verbatim transcription and publication of direct quotations. They also gave advice related to the NHS Trust's Loan Worker Policy when conducting home visits, for the researcher's own personal safety.

Being aware of the potential for exploitation, misrepresentation and the burden of research for the participants (time, cost, emotional burden) is central to preserving participant autonomy. Combined with the acknowledgement of bias, scientific rigor, creating rapport, and observing confidentiality; they are all essential components of an ethical research relationship (Hewitt, 2007).

Using patient names or initials as a method of identification may breach confidentiality. Strict confidentiality was maintained by allocating each participant a unique identity number known only to the researcher. The data collected for the study was stored in a locked cupboard in a locked room with restricted access. Digitally recorded data was stored in a password protected file, on the main server of the University computer, accessible only by the researcher. This ensured that any verbal information was kept in the strictest confidence and was not available to any member of the healthcare team.

### 3.5.3 Collaboration and consultation

This type of research study requires consultation and collaboration not only with the proposed participants, but also with the gate-keepers in the health care system and the communities of whom they are a part. This helps to ensure that the research is ethical and assess its acceptability and relevance to the participants and area of interest. For this reason, once Local Research Ethics Committee approval was obtained, the views of the Professionals and Patient Partnership (PPP) group (a combination of clinical staff and consumers of cancer healthcare services) were solicited. The project outline was presented to the Primary Breast Cancer (PBC) Support Group (set up by patients for the benefit of patients with breast cancer in the locality). The study was also presented to the multidisciplinary breast care team at their regular lunch-time meeting. This raised awareness of the study, answered questions and addressed any concerns; before recruitment was initiated.

The Professionals and Patient Partnership (PPP) group were supportive of the aims of the study and raised no objections. A meeting was arranged with the Primary Breast Cancer support group, who asked for reassurances that confidentiality would be maintained and that all women discharged from the clinic would be given the opportunity to take part;

otherwise they were enthusiastic about the study and welcomed the chance for women to be listened to and given the opportunity to give their views.

### 3.5.4 Gaining access to patients and issues of coercion

Discussions with the Breast Care Nurse Specialists and Nurse Practitioners working in the clinic resulted in a personal introduction to the women by the health care professionals and a strategy for initial contact.

This was done in order to address the clinical staff's concerns that, women may be wary of research staff who are unknown to them. It was agreed that participants would be approached by health care professionals who are known to them, in a familiar environment, at their usual clinic visit. It was also envisaged that they may have reservations about divulging to the researcher, information or opinions, which may adversely affect their relationship with their usual healthcare team. This was addressed by arranging to conduct the visits away from the clinic in a private interview room in another building.

By seeking consent and collaboration from the "gatekeepers", i.e. the doctors and nurse specialists caring for the patients; the recruitment strategy was designed, to try to minimise the possibility of participants feeling coerced or obliged to take part, while at the same time offering the maximum opportunity to gain information and access to the study.

The effect on the findings of approaching the patients before their consultation, was considered. This may have meant that they had limited information on which to form an opinion. Explanations about the need and value of follow-up and the progress/course of their disease; together with reassurances and estimates of risk; were likely to have been discussed during the course of the consultation. The patients may well have felt differently after the consultation. Approaching women after their consultation meant they

had an opportunity to ask questions of the healthcare professionals, time to assimilate the information and its potential impact for them as an individual. They also had time to consider whether they wanted to take part in the research and decline to participate without having met the researcher.

### 3.5.5 Avoiding distress

The literature demonstrates that patients attending oncology/breast cancer clinics are invariably anxious prior to their follow-up consultation (Jacobsen et al., 1993, Lampic et al., 1994b, Lampic et al., 1994a). It was agreed that questionnaires would be completed and interviews conducted, after the discharge consultation. This was after discussion with the nurse practitioners/breast care specialists and breast surgeons who were responsible for the follow-up care given in the clinic. It was suggested that writing to patients in advance of their clinic visit may cause distress in patients, who were not yet aware that they may be discharged.

Alternatively, women may be diagnosed with recurrent disease during review in the clinic and then not be eligible for discharge. This would be upsetting and confusing for them. By mutual agreement it was decided that if a woman expressed interest in the study, the researcher would give a verbal explanation of the design and aims/purpose of the study, hand her a patient information sheet, her name and phone number, arrange to contact her over the next 1-2 weeks for her decision on participation and the opportunity to ask further questions. Then at the baseline visit ask for written consent prior to the initial interview.

A protocol was also put in place, for fast track referral to the nurse specialist and psychiatric nurse teams if participants experienced distress during the course of the interview.

### 3.5.6 Addressing issues of confidentiality

A patient log listed participants by name, date of birth and hospital number. A separate data log recorded study identification numbers, dates of consent and participation. This was stored securely and allowed audit of source data if necessary, by documenting the link between the patient's number and their hospital notes.

### 3.5.7 The process of recruitment

The recruitment strategy aimed to collect a variety of views, concerns and experiences from the women in the breast cancer follow-up clinic and to gather information on the characteristics of the population from which the interview participants were drawn.

All women deemed eligible to be discharged from the primary breast cancer follow-up clinic, who were aged 50 years and over and at least 5 years post diagnosis; were approached consecutively and offered the opportunity to take part in the study.

Recruitment was conducted within the primary breast cancer follow-up clinic, on the same afternoon of each week, with the researcher accompanying the breast care team to the clinic and sitting with them in the clinicians office while they worked – reviewing and updating their patients medical notes prior to and immediately after their consultations.

The rationale for this was to raise awareness of the study on a weekly basis and remind the staff that the study was actively recruiting. Patients were identified by a member of the clinic team as eligible for discharge from outpatient care. This meant that both mammogram and physical examination revealed no abnormality – this was then followed by an explanation and discussion around the change in the follow-up care protocol and any questions were answered; followed by a brief explanation of, who the researcher was and why she wished to talk to them. If the patient verbally consented this opportunity was arranged prior to leaving the clinic.

As the researcher had no knowledge of the participants prior to the study, it was important to make a formal introduction and explain the aims and background to the study.

### 3.5.8 Conducting pilot work

It was also considered appropriate to conduct two separate pilot interviews, both observed and reviewed by the academic supervisor of the researcher; who has personal experience of interview technique. The interviews were intended both to assess the interview technique of the researcher and pilot the interview schedule.

Arrangements were made to conduct two mock interviews with an actor experienced in clinician-patient role play. The first interview was set up to simulate a dialogue with a participant who was very satisfied with her discharge arrangements. This tested the ability of the researcher to draw out interesting data about her views/ opinions of follow-up care, her risk of recurrent disease and the way she coped with her breast cancer.

The 2<sup>nd</sup> simulated an interview with a participant who was very angry and upset, because she had developed recurrent disease 6 months after being discharged from the clinic. This proved more difficult because it proved almost impossible to conduct the research when what the woman really wanted was answers to her questions related to her disease recurrence.

After discussion with my supervisor and a breast care nurse specialist working in the clinic it was agreed that it would be unethical and unfair to interview women under these circumstances, before their return to the clinic. It would be important for them to have their clinical consultation first. This would allow assessment of their disease, create an opportunity to ask questions and plan/initiate treatment prior to the interview. It was envisaged that creating the opportunity to address these issues first, would mean the

focus would be on their feelings and opinions, rather than the perceived impending risk to their physical health. This pilot work was invaluable and avoided potential pitfalls as well as distress to the participants.

### 3.5.9 Data collection experiences

Once a woman expressed an interest in participating in the study and took away an information leaflet, written informed consent was obtained several days /weeks later, after the clinic consultation and an initial meeting with the researcher and once all questions and concerns had been addressed. The participant was given a copy of the information sheet and consent form to keep for their own records (a copy of each is attached as appendix 1). A mutually convenient meeting was then arranged face to face in a room allocated for the purpose away from the clinic, in the participant's own home, or via the telephone according to the preference of the participant.

Once interview data were obtained, the participants medical notes were requested by the researcher (consent for this was included on the consent form). The medical notes were used to collect demographic information, i.e. age, marital/employment status, details of surgery and drug treatments and duration of follow-up care. A copy of the information sheet and consent form together with details of study participation were recorded in the notes, together with a request to contact the researcher if the participant should present with recurrent disease during the course of the study.

The women who agreed to be interviewed were self-selecting. Each woman was offered the opportunity to participate, until the quota of 20 was fulfilled. However, after the initial 4 interviews, the data was reviewed to assess the ability of the researcher's interview technique and the interview schedule to elicit useful, appropriate, data.

The interviews were digitally recorded and followed a pattern of initial open-ended questions which encouraged women to describe their experiences and gave them the

opportunity to set out which aspects were of greatest significance and their feelings about them. The interviews then became more structured as the women were asked more specific questions.

The baseline interview – conducted shortly after discharge from the clinic, aimed to record the women’s stories, the discussion centred around:

- Each woman’s breast cancer history , how they got to the clinic to begin with, how and when diagnosis occurred, the way they coped with initial diagnosis and treatment
- Their views of the follow-up care they received were elicited, the frequency and duration of follow-up clinic visits and the personnel encountered during the visits; as well as the value they placed on it. Women’s expectations of the clinic visits were explored and anything they felt might be lacking as well as how well supported they felt and their views on long-term recovery.
- Finally the women were encouraged to express their feelings about being discharged from the service and why they felt the way they did. They were asked to describe the impact the change in policy had for them personally and consider how they might deal with breast cancer related issues in the future.
- They were asked to give potential reasons which might prompt their return to the clinic via their open appointment. They were requested to estimate their personal risk of recurrent disease, discuss their beliefs about breast cancer and potential problems in the future; and describe their ideal long-term follow-up care.

The interviews allowed exploration of possible contributory factors to women’s reactions to discharge from the clinic in more depth and their relationship to each other. They also helped to describe previously unidentified issues, concerns and views. The women could explain how they formulated their beliefs, the value of them, as well as outlining the needs they had – emotional, psychological and social.

The second interview, approximately one year later, dealt with significant events that had occurred in the lives of the women, in the intervening 12 months and how they coped with them. They could discuss how they felt about the policy change then, compared to the previous year and how they coped without their annual clinical consultation. In addition, they were asked if they had consulted anyone formally (professionally), or informally, about their breast cancer in the previous year. Their beliefs and estimates of risk could also be recorded and compared to those of the previous year.

The final interview was intended to ask very similar questions to see if views, beliefs, reactions, were sustained or changed over time. It also provided the opportunity to collect information about reasons for participation and any additional value that participants received from taking part.

The baseline interviews provided a wealth of data and proved very informative. Interviews 2 and 3 provided useful information but were of much shorter duration because they were in effect an annual update and served to document whether attitudes and opinions had remained the same or changed and therefore created the opportunity to elicit why they had changed. Face to face interviews were more popular and the level of attrition was partly due I feel to the lack of personal contact when in year 2 – interview 3, telephone interviewing was adopted to accommodate the time and resource constraints of a study conducted under the auspices of a PhD dissertation. Some of the women felt they had nothing new to say if their attitudes remained unchanged and doubted the value of a further interview, whilst others were keen to explain why they felt differently over the course of the study.

This is reflected in the quotations used in the findings chapters which follow, the majority were from the baseline interviews and quotations from visit 2 and 3 are used to illustrate

either attitudes which are constant or those which changed and the reasons why this was the case.

### 3.5.10 The Process of qualitative data analysis

#### **3.5.10.1 Phase 1 of the analysis**

The initial plan for analysis of the qualitative data collected from the semi-structured interviews was based on a combination of:

- issues and views voiced by women with breast cancer, gleaned from personal clinical practice (e.g. distress, abandonment, confusion, fear)
- anecdotal evidence from fellow health care professionals (attribution of negative reactions to discharge from follow-up to women with particular personality characteristics or coping styles)
- current economic/political/scientific debate around self-management of long-term health problems
- previous research literature related to follow-up care for cancer/breast cancer

The review of the research literature conducted for the purposes of this study suggested potential influential factors which may contribute to the way women coped with their breast cancer diagnosis and treatment and their expectations of their follow-up care, i.e. levels of social support, perceived quality of life and personal preferences for the style of follow-up care received. The interview schedules (which are attached as appendix 2) incorporated this combination of factors within the questions posed to the interviewees.

Initially the literature review informed the themes and categories adopted for the analysis but later the data, themes and categories began to inform the literature review. This will be discussed in more detail later in this section.

The interviews were recorded via a digital recorder by the researcher and transcribed verbatim by a trained, experienced, transcriber, employed by the host university. The researcher made notes (with the participants consent) if appropriate during the course of the interview and offered the participant the opportunity to write down any additional points of interest or importance these were also used to inform the analysis.

The researcher then listened to the interview once to immerse herself in the interview, then again for a second time making supplemental notes. Analysis was then conducted line by line using the NVIVO programme, with the first interview used to construct a series of provisional codes. Then each subsequent interview was coded in the same way and additional codes elicited and added to the list. Once each of the visit 1 interviews had been coded, an index of thematic categories was created and then groups, hierarchies and sub-themes generated. These were matched with pre-conceived theories from the research literature and the research questions posed for the study.

Appendix 3 illustrates the method of analysis employed using the NVivo software to create themes and categories. The NVivo programme allows the researcher to link themes together using a hierarchical coding system. The screen shot used for appendix 3 shows the appearance of the computer screen when the programme is in use. The horizontal section across the top of the screen shows the tool bar.

The column running down the left side of the screen includes a window which gives access to the hierarchy of codes created by the researcher. Alternatively the researcher may create free nodes – stand alone codes which are considered to be independent of the tree nodes. Below this window are the other facilities offered by the software to manipulate the data to assist the researcher with the analysis. This includes the ability to retrieve data from a variety of sources, search for grouped data within and between data sets, generate reports, create models and sort/file large amounts of data.

In the centre of the screen is a window divided horizontally in two. The upper window allows review and access to the data stored under the nodes. It shows the hierarchy of nodes which can be collapsed or expanded to show all of the nodes in the tree.

For example provisional codes created for the interview data relating to discharge from follow-up resulted in the following tree nodes:

Discharge

    Reaction

        Positive

        Negative

        Self-sacrifice

        Resignation

    Meaning

    Reasons

    Future needs

        Prosthetic service

        Knowledge/Understanding

    Legitimate opportunity

    Problems

    Support

    Strategy

The lower window shows text from the dialogue from the interview with the ability to view coding "stripes" via the window to the right. The window on the right represents each of the nodes by a different coloured "stripe", which extends line by line for the duration of the coding. The coding stripes illustrate which nodes are attributed to a particular line or paragraph of text.

The first phase of the analysis generated a plethora of categories which are attached as appendix 4. This index of provisional codes, incorporated the factors perceived by the researcher likely to be influential in attitudes to discharge from follow-up but also included the chronological nature of the stories women told. This wealth of themes and categories whilst complex and overwhelming, illustrated the wide variety of experiences, views, expectations and emotions within the study sample. Themes around coping and follow-up in particular proved to be diverse and multi-faceted. Time was a significant factor for both. There were variations in strategies for coping and expectations of follow up at different time-points. The data also illustrated the relationship between coping, social support and quality of life.

#### **3.5.10.2 Phase 2 of the analysis**

The next phase of the analysis involved referring back to the literature to look at the findings in the light of the work of other researchers looking for similarities and differences. There was a positive relationship between the findings of others and related accounts in the interviews for this study of coping strategies, quality of life, social support. So the analysis initially concentrated on these three themes (see appendix 5)

Time relationships seemed significant and analysis identified possible influencing factors for the choice of strategy. Attempts were made to investigate why women chose a particular strategy and what they achieved by preferring one strategy to another. The strategies seemed to be an attempt to create a sense of self, achieve control, manage change, or risk reduction/ risk appraisal, rebuild their place in the world or their lifestyle, or adopt a positive attitude with the perceived benefits it conferred.

Particular time points influenced how much and who provided the support and the type of support needed. There were also negatives associated with social support:

- Avoiding distress in others
- Adoption of differing coping strategies from close supporters
- Spousal distress/needs
- Fears for others future well-being

The coding used to describe aspects of quality of life was largely around the situation of self in relation to others and related to social acceptance and avoiding rejection and included:

- Social roles/status,
- social networks,
- lack of self-esteem,
- impaired body image,
- reclamation of self,
- re-invention of self and social role

Discharge from outpatient care and follow-up care were then examined as separate issues because they related to the primary research question. The themes generated related to follow-up and described a range of needs and expectations. They also identified factors for increased need or expectations or importance for follow-up. In addition they highlighted negative aspects, or the negative impact of follow-up.

### **3.5.10.3 Phase 3 of the analysis**

At this point in the study, the categories and themes chosen by the researcher, either appeared at times to be at odds with the perspective of the women interviewed, or not adequately descriptive to encompass it. After a discussion between the researcher and her supervisor it was decided that in an attempt to avoid the possibility of the researcher imposing categories and themes on the data, the researcher would go back to the data and the original index of provisional codes. The intention would be to find a way to map

them out, looking for new connections and a more naturalistic explanation of the data, which was not so reliant on pre-conceptions and the limitations of previous research reported in the literature.

Data had been collected related to attitudes to follow-up. These attitudes appeared to be based on beliefs either acquired from others – parents and other significant relationships, or as a result of past personal experiences, as well as societal and cultural expectations: via friends, other women, the media etc. So a great deal of the variation in the data and in women's behaviour seemed to be explained by the fact that the *meaning* of follow-up varied from one woman to another. It meant different things to different women, their expectations of it varied, the value they attached to it varied and so consequently their attitude to discharge from outpatient follow-up care varied.

This necessitated a re-examination of the research literature, to identify some theoretical under-pinning of how in the face of adversity, women with breast cancer cope when their beliefs are challenged. In addition, how they create meaning from a novel situation when they are under threat. Two authors emerged from the review: Leon Festinger and the body of work he conducted which generated his theory of cognitive dissonance (Festinger, 1962) and the extensive research conducted by Ronnie Janoff-Bulman (Janoff-Bulman, 1989a, Janoff-Bulman, 1992), some of which was specifically with women with breast cancer. Festinger's theory helped to explain why some women might minimise the perceived threat from breast cancer in comparison to their peers. Janoff-Bulman's insights into how people deal with challenged core beliefs and shattered basic assumptions helped to situate the data in terms of her work and offer possible reasons why there was a variety in attitudes and behaviour. This is discussed in more detail in the findings chapters

The following codes illustrate the views of the women interviewed regarding the *purpose* of outpatient follow-up care:

Prevention of recurrent disease (early detection = better prognosis/cure)

Detection of recurrent disease

Advice – breast cancer/general health/financial

Information - breast cancer and its treatments

Familial risk of breast cancer

Fear of recurrent disease

Mood disturbance – anxiety, depression, mood swings, loss of libido, etc.

Body image – loss of self esteem

Reassurance – cancer-free

Confirmation – cancer-free

Self-care - learning how to recognise signs and symptoms of recurrent disease

Continuity of care - was always valued, being seen by a familiar face who knew their medical history

Access to specialist care

Quality of consultation – time for questions and discussion and access to the expertise of the personnel involved.

Many women perceived that hormone therapy/chemotherapy prescribed in the 1<sup>st</sup> year following diagnosis may lead to the increased need or importance of follow-up.

Anticipatory anxiety was often viewed as a positive – as the pay-off was a feeling of euphoria and relief from anxiety. The research literature raised the question of how short-lived this euphoria might be. How was this influenced by duration of survival and the visit interval?

There were several negatives which may have influenced women's attitudes and possibly account for a positive reaction to discharge from follow-up care. There were some women who identified that they may have disparate needs which would necessitate individualised care. They complained of rushed appointments creating an inappropriate environment for discussion, sexual issues in particular were neglected and left women generally with unanswered questions. The lack of flexibility and accessibility to the clinic was a disadvantage to some women. They wanted more choice in the mode of follow-up care provided, the personnel who provided it and the frequency it was offered. This was in contrast to the assumptions of clinic staff and the researcher who had made the presumption that a positive reaction to discharge was a sign that women had a positive view of the service.

In contrast the data was examined to try to identify why for other women discharge from follow-up care was perceived in a negative way and is summarised by the following categories:

Cast aside – feelings of abandonment, fear of delayed presentation – fear of avoidance of seeking help for recurrent disease, or assumptions of cure. Patient-initiated open appointments = unwanted responsibility and assumptions about the motivation for the change in policy being due to the cost benefits – to the NHS and not patient-centred or consumer-led

#### **3.5.10.4 Phase 4 of the analysis**

##### ***The meaning of discharge from the clinic***

There was a feeling of dissonance/tension between choosing to analyse the interviews using influential factors, or a cause and effect approach - which created a sense of discord when dealing with emotions and beliefs. This did not reflect the chronological nature of the stories the women told. The analysis seemed to suggest that there was a

link between the level of perceived risk, the coping strategy adopted and attitudes to discharge from follow-up. Dichotomous categories emerged:

At risk versus cured

Detection versus reassurance

Early versus long-term survival

Hospital doctor versus GP/Nurse etc.

The analysis was then focused on trying to describe the meaning of discharge and themes around beliefs and their relationship to the emotions it elicited; its psychological impact. By acknowledging that this dichotomy may exist, whilst linking feelings with beliefs, with behaviour and attitudes; it was possible to generate the over-arching themes "Close shave" and "Marked woman" and "Blessing" and "Curse" and finally "Freedom" and "Isolation" (see appendix 6).

The Close shave and Marked woman themes encapsulated the influence of beliefs and prior knowledge, coping with adversity and meaning making.

Blessing and Curse described the experience of breast cancer follow-up care.

Freedom and Isolation attempted to summarise the impact of discharge from the clinic and managing the future.

The issues of open-appointments and self-management were met with a mixed reception. Welcomed by some women and seen as an unwelcome responsibility by others. Education, self-confidence, expectations and appraisal of breast cancer as factor; either an ever-present threat, or a minor risk, were all significant factors. One of the most interesting sub-themes in this aspect of the analysis were the barriers to access to the open-appointment system: confusion, rejection, shame, sabotaging patient/clinician relationships, lack of confidence, anxiety, fear of recurrent disease, fear of confirmation

– delay – early death. None of these had been accounted for in the literature or expected by the researcher.

Each theme described a process rather than a group of women, each pair of themes linked to each other and then linked to another chronologically. That is, the suggestion that beliefs and experience influenced how a diagnosis of breast cancer might be dealt with. This in turn would have a bearing on experience and expectations of follow-up care.

Finally, all of these related to the impact of discharge and attitudes towards the open appointment system and the responsibility of self-management, this appeared to be more representative of the data.

Although the dichotomy of the themes suggested rigid categorisation in fact they were a metaphorical device for a continuum, for a process, a transition would be a more accurate description. A linear approach was applied to a phenomenon which was in effect could be quite nebulous in character.

#### ***3.5.10.5 Phase 5 of the analysis***

In the final stage of the analysis the influence of expectations and the variety evident within the sample was evident with strong links to appraisal of risk/threat from breast cancer running through all 6 themes.

The mode of detection of the initial breast tumour was highly influential in persuading women that 3 yearly mammograms were an adequate method of monitoring for recurrent disease and the interviews demonstrated that coping strategies are dynamic and evolving; not fixed.

The importance of metaphor was acknowledged and harnessed as it had appeared many, many times in the transcribed interview data. It was used by the researcher and the participants as Miles and Huberman suggest (Miles and Huberman, 1994), to paint pictures and encompass feelings and emotions which otherwise might prove difficult to describe. Metaphorical language proved invaluable as a way to reflect back and verify meaning in the interviews. It was responsible for illustrating complex concepts in a very succinct and clear way and generated several "light bulb" moments for the researcher in particular.

### 3.5.11 Issues of trustworthiness/reliability in this study

Validity/reliability in qualitative research is related to perceptions of how consistent and trustworthy the data collection and analysis are considered to be (Kvale, 2007). Kvale makes the connection between validity and truth and in particular the assertion that the methods employed, investigate the intended phenomenon; and the observations made by the researcher reflect the aims of the research.

We can, Kvale states (Kvale, 2007) Chap 2, increase confidence in the quality of the knowledge we produce and the claims made based on that knowledge. This is achieved by increasing the quality of what he refers to as the *craftsmanship* of qualitative research, by continually checking, questioning and theorizing and to a large extent playing devil's advocate with our methods and findings.

Jane Elliott, in her book "Using narrative in social research" (Elliott, 2005) p22, differentiates between internal and external validity. The aim of internal validity being, that there is sufficient confidence in the data to allay any fears that the findings might simply be due to the design of the research study. External validity relates to the applicability of the findings of a particular sample, to a broader population.

Using narrative as a form of data collection, rather than a structured interview with standardised questions, facilitates internal validity. By empowering the interviewee, this form of interview allows them to set the agenda of the interview, use their own words, highlight issues of personal importance, give their own version of events and use their own conceptual framework (Elliott, 2005).

Narrative data is useful when the focus of the research is the meaning of experiences and allows reflection and sense making during the course of the interview; giving the researcher insight into the perspective of the interviewee. However truthfulness and trustworthiness are not always the dominant issues in narrative research. When asking for opinions and personal experiences, the data will by nature, be subjective and open to argument and interpretation. Consequently the meaning and reasons for the views and perspectives of the interviewee may take precedence and become the focus of the research. The researcher is interested in not only what the interviewee has to say, but why.

The issue of validation/reliability is relevant at every stage of a qualitative research study. Kvale and Brinkmann (Kvale and Brinkmann, 2009) p248, propose that the qualitative researcher consider the steps to be taken to promote the validity of their research at 7 stages of the research process:

- 1 Thematizing
- 2 Designing
- 3 Interviewing
- 4 Transcribing
- 5 Analyzing
- 6 Validating
- 7 Reporting

In his paper "Strategies for ensuring trustworthiness in qualitative research projects" (Shenton, 2004), Shenton acknowledges Kvale's ideas and also draws on Guba's four constructs of Credibility, Transferability, Dependability and Confirmability (Guba, 1981) to propose a framework for trustworthy research studies.

The following section will describe the approach taken to promote trustworthiness and reliability in the conduct of the current study using these constructs as a framework.

### **3.5.11.1 Credibility**

The research questions for the current study were based on a thorough review of the research literature in the field, current health policy and topics hotly debated by clinicians and policy makers; as well as anecdotal reporting from women attending the clinic and the healthcare professionals responsible for their care. The theoretical concepts on which the previous research were based were examined and the possible influencing factors for women's attitudes and behaviour towards changes in the follow-up care were considered. Theories were then proposed for the reasons for the women's attitudes and behaviour related to the change in their follow-up care and these were incorporated into the study design.

Established methods were used for both the conduct of the interviews and the data analysis – for example - the interviewer underwent training in interview technique organised by the host academic institution, participated in role play exercises and was observed conducting mock interviews by her supervisor. Strauss and Corbin's constant comparison method was adopted when coding interview data for thematic analysis (Strauss and Corbin, 1990).

Prior to the start of the study there was consultation with members of the Public and Professional Partnership PPP group who reviewed the protocol and made comments and

suggestions as well as a presentation at a meeting of the Primary Breast Cancer Support Group who also made a useful contribution and raised relevant issues such as - assurances of confidentiality and possible sources of dissemination of the findings. Participants were randomly sampled to avoid bias in recruitment. None of the women who attended the clinic were excluded from the invitation to participate.

The style and content of the interview questions chosen, reflected the aims of the research and the data was analysed/interpreted accordingly. For the purposes of the current study, the interview guide was primarily an open question "can you tell me how you came to be in the breast cancer clinic?". This invariably prompted story-telling, a chronologically structured account of the time period from the first indication that there was a medical problem which warranted investigation, to the point of recent discharge from the outpatient clinic. The interview guide is attached as appendix 2 and includes prompts relating to expectations and value of follow-up care, relationships with health care professionals and views and concerns around being discharged from regular outpatient consultations. In addition the interviewee's view of her future care needs was elicited.

These prompts were designed based on the research questions posed and the aims of the research - to investigate the experience of being discharged from breast cancer follow-up services and evaluate the impact of the proposed changes in service delivery from the patient's perspective. In particular to describe how women felt about the change in service provision and explore anxieties and concerns once patients were discharged from regular outpatient follow-up care.

Qualitative research "creates a deeper richer picture of what is going on in particular settings" (Elliott, 2005) p26. Therefore it may not be realistic to pronounce that the findings/conclusions are applicable or likely to hold true across a range of contexts. Elliott suggests the adoption of a "common sense" view of generalisability, where the

reader makes up his/her mind of how far the findings can reasonably be extrapolated to other settings is therefore more appropriate.

However it is possible to make legitimate comparisons with findings from other studies a form of qualitative meta-analysis or meta-ethnography – comparing other settings, other samples etc. An example from the present study is Allen et al's study (Allen et al., 2009) of women in the first year of breast cancer diagnosis and treatment and Lydon et al's study qualitative and quantitative approaches (Lydon et al., 2009) which collected data from women with ovarian cancer both of which produced data which corresponded to the findings of the current study of women in long term recovery from breast cancer. In this way readers can decide whether the findings are likely to be transferable to their own setting. Qualitative research may also - as in the case of the present study be exploratory in its aims. Its intention - to provide data for further investigation means it has inherent value regardless of its ability to be applicable to a range of settings.

Ensuring participants gave written informed consent and understood that their participation was voluntary helped to promote honesty in their answers. The intention was that they chose to be interviewed because they wanted to tell their story. By establishing a rapport, ensuring confidentiality and making it clear that they could withdraw from the study at any time the researcher encouraged frank and open discussion during the interview. Participants were recruited and interviews continued until no new data emerged in order to avoid bias

There were monthly debriefing sessions between the researcher and her supervisor and during the course of the research there was discussion /scrutiny by a range of other researchers: the panel of experts who granted the funding via Cancer Research UK, an eminent researcher in psycho-oncology and her team, presentation of the project to other PhD students and the UK Oncology nurses national conference.

Direct quotations from the interview transcripts have been used extensively to illustrate the findings and justify the conclusions. All of the interviews recorded for the purposes of the study were included in the analysis with transcript quotes from each, included in the report of the findings.

### **3.5.11.2 Transferability**

The sample population has been described, as has the number of participants and their demographic characteristics. The “process of data analysis” section included in the methods chapter describes the number and length of data collection sessions, the time period over which the data were collected and the detail of how the analysis was conducted to assist the reader in assessing the similarities and differences between this study, its setting and their own population/situation/setting.

### **3.5.11.3 Dependability**

Kvale’s concept of the interview is as “Inter-View” that is, a social co-construction of knowledge between interviewer and interviewee (Kvale and Brinkmann, 2009). However it would be unrealistic to assert that there is equality in the power relationship between the two parties. The power relation is weighted on the side of the interviewer and so the onus is on the interviewer to acknowledge and address this asymmetry and attempt to minimise its impact. For the purpose of the current study the following strategies were employed:

- The interviewee chose the time, date and location of the interview.
- The open question approach allowed the interviewee to talk about issues of interest and personal significance and dictate the direction of the interview within jointly agreed boundaries.
- The interviewee dictated subjects which were “out of bounds” to the interviewer.
- Probing questions, clarification and reflection were used to assist with the accurate interpretation of dialogue.

- The Local Research Ethics Committee reviewed the study and gave approval of the design and the written information given to participants.
- Healthcare professionals responsible for the clinical care of participants acted as “gatekeepers” in an attempt to avoid any sense of coercion to participate

#### **3.5.11.4.1 The Interview Environment**

“A semi-structured life world interview attempts to understand themes of the lived daily world from the subjects’ own perspectives.” (Kvale, 2007) p10-11. The interviews conducted during the course of the present study, provided the researcher with an opportunity to describe the life world of the interviewee, from their own perspective and using their own words.

The recruitment process occurred in stages:

- Initial approach by the participant’s usual healthcare practitioner to request permission for the researcher to broach the subject of the research and provide oral and written information,
- Introduction to the researcher,
- Creation of a rapport, explanation of the research and then permission to arrange a further contact
- Telephone contact to obtain a decision for participation or declination.
- Consent appointment – opportunity to request further information before signing the consent form

### **3.5.11.4.2 The physical environment**

A designated room was negotiated for the purposes of the interviews if participants wished to visit the researcher (in preference to a home visit, or telephone interview).

The room was deliberately located away from the clinic and an attempt made to create a more relaxed, informal, atmosphere. The chairs were different in appearance, with pictures, plants, coffee table, tea and coffee offered on arrival. The interview appointment was booked for the interviewee's convenience and transport costs offered.

#### **Setting the scene**

Before the interview started an explanation of the duration of the interview, the aims of the research etc. was given. The quotes below illustrate a typical start to the interviews:

#### **Patient 38 "Irene" - 12/6/07 - 1st Interview**

*Interviewer:*

*"So I've explained to you who I am and what I'm going to do haven't I, earlier on?. So the idea of the interview is really so I get an idea about you personally. So, how you feel, what you think and the interview will be around what you want to talk about. What I might do, is if you say something, I might ask you for more clarification, I might say "what do you mean by that?" or "can you tell me a bit more?" or whatever. If there's anything you don't want to talk about, you're not happy to, then we can..... you just say and we don't go any further with it. So it's under your control, I'm not going to ask you to do anything you don't want to do. Okay? So, some of the questions I'm going to ask you will be around the sorts of things I've asked you in the questionnaire, so it won't be unfamiliar territory, you will have thought about it already. If it's alright with you, I might write a couple of things down, usually I'm so interested in what people say I don't, but now and again I think, oh I must write that, and it'll be because I'll think well you're in the middle of what you're talking about and I don't want to interrupt you and I'll ask you later. Is that alright? Okay, so, I don't know much about you at all really, so do you want to just tell me how you came to be in the clinic in the first place?"*

#### **Patient 84 "Rita"- 19 Nov 2007 – 1st Interview**

*Interviewer:*

*So I've explained to you that everything is confidential and that I won't divulge anything to anybody else?*

*Respondent:*

*Yes*

*I And you're only known by a number*

*R Yes.*

*I Now this is for you, to give you the opportunity to say what you want to say and to talk about the things that you think are important*

- R *Right*  
 I *Now I've got things that I'd like to know*  
 R *Yes*  
 I *And probably in the course of the conversation they'll come out anyway.*  
 R *Right*  
 I *And what I might do is just let it very naturally unfold as a conversation, and then if there's anything that we haven't covered that I would have quite liked to have known I'll ask you at the end.*  
 R *Ask specific questions yes, no that's fine.*  
 I *Are you happy for me to take any..... for me to write things down and take some notes?*  
 R *Perfectly happy.*  
 I *I'll show them to you before I go so you can see what I've written.*  
 R *Yeah, no thats quite alright.*  
 I *So they won't be anything other than reminders for me really and sometimes I don't like to interrupt you when you're in full flow*  
 R *Full flow yes.*  
 I *And I'll think of something, oh I'll ask her that in a minute and I'll write it down. So thats all I'm doing.*  
 R *Yes, no that's alright.*  
 I *Alright, so I don't know a lot about you, because we haven't met other than for this research so can you tell me a little bit about you, about how you came to be in the breast clinic and a little bit about you?*

The concept of accuracy in quantitative research methods relates to measurement and quantification. In qualitative methods, it is the precision and detail of the description and the rigorous attempt to accurately represent the meaning; which is the primary aim. Reflection/clarification were often used to avoid ambiguity and bias in the current study. This act of reflection is a useful way of clarifying and checking the accuracy of the researcher's interpretation of the meaning. The quotes below illustrate how this was adopted:

**Patient 025 "Elizabeth" 1<sup>st</sup> interview 15 June 2007**

- R *So that is why I decided to have a mastectomy.*  
 I *So you, so the idea of having the mastectomy then, was to try and reduce the risk?*  
 R *To reduce the risk*  
 I *Of the disease coming back?*  
 R *Yes, of it coming back because I didn't want it back you know I just thought.....*  
 I *But you were more confident that, that wouldn't be the case if you had your mastectomy?*  
 R *Yes, yes and I had my operation on the Monday*

**Patient 002 "Anne" 1<sup>st</sup> interview 16 July 2007**

- R *So I do keep myself busy.*  
 I *Mmm, sounds like it.....and that helps?*  
 R *Yeah it does, and I also have this very weird mind - I can switch off. It's not actually a very good thing I mean I can actually totally switch off.*

- I Are we talking about stressful things that you switch off from?*  
*R Yeah, I mean I'm normally positive but sometimes when something is too much, you make it disappear.*  
*I What, forever? Or just for a time?*  
*R No, for the time being, you know and then when you feel you can handle it then you bring it back but I can...I am a happy go lucky person, I can make it go.*  
*I Yeah? So is this...were you like this before your breast cancer or is this something.....?*  
*R I've always been a happy go lucky person, but I think that the breast cancer has made me look at things because you suddenly...you are made aware that you are mortal after all. Which you don't think about really, if life goes on in the normal way you don't think I'm going...I could die...tomorrow you know...*  
*I Mmhmm.*

The method employed to terminate the interview was just as important, in order to check whether the interviewee felt she had been provided with the opportunity to address all of the issues of personal significance and set the scene for the next interview as illustrated by the following quotes:

***Patient 047 "Nancy" – 4 July 2008 1<sup>st</sup> interview***

- I Oh that's good. Well I've really appreciated you talking to me, thanks very much, it's very good of you to spare me the time.*  
*R That's okay. Do we do this again at some other time or is this it?*  
*I Well with your permission I'd like to see you in a year's time.*  
*R Okay right.*  
*I I would find it helpful to talk to ladies round about the time that they would be coming for their appointment but they're not - to see how they feel and to see if they feel any different a year later.*  
*R Okay fine.*  
*I So if you're happy with that I'd like to do that.*  
*R Yes.*  
*I Thank you very much.*

***Patient 010 "Cathy" 1<sup>st</sup> interview - 8 March 2007***

- I Okay do you want to stop there? or is there something else you wanted to say or want to cover? Have we covered everything that you wanted to?*  
*R I think so yes as long as you're happy with....?*  
*I Yes, if you are?*  
*R Yes, thats fine.*  
*I Thank you very much, I've really enjoyed talking to you.*  
*R Thats good.*

During the course of the interview the discussion sometimes revealed new aspects of the point of discussion, or provided new insights for the interviewee they were previously unaware of, with the interview as a learning process. It is not unusual for the process of

meaning- making resulting from the process of a research interview to result in changes in the behaviour, or views of the interviewee. Two examples from the present study are:

**Example 1.** A woman who divulged that sexual relations with her husband had stopped because of the negative impact her mastectomy operation had on her body image and her assumption that her husband would find her no longer sexually attractive. I asked the question did she know this for sure? Had she raised the question? How did she feel about her sexual allure?

She considered this and admitted maybe it was her own feelings which were the problem. One year later when I interviewed her again, she revealed after the previous interview that she had initiated a discussion of the subject with her husband, he had reassured her this was not the case and their sex life had returned to normal.

**Example 2.** A woman who had missed the opportunity to take part because she was discharged from the clinic several months before the study started and volunteered to be interviewed. She was anxious about being discharged and wanted to give her views. When I interviewed her again a year later she told me that it was the first opportunity she had ever been given to talk about her experience of breast cancer and its treatments. She was surprised at how much her anxiety had been reduced just by being able to talk for over an hour to someone who had some insight into her experiences and was sympathetic to her anxieties.

The interviews were transcribed verbatim by a trained, experienced, independent, transcriber to avoid bias by the researcher, who used content analysis to interpret the dialogue. Listening to the recorded dialogue, whilst reading the transcription, enabled the researcher to correct transcription errors and omissions; therefore improving the accuracy of the data.

The transcribed data was then systematically reviewed and categorised using the constant comparison method (Strauss and Corbin, 1990) to elicit emergent themes. All of the categories were grouped, linked and arranged into a hierarchical structure.

None of the interviews were excluded from the analysis and all of the data from each interview were included, again to avoid reporting bias. The researcher then moved from categorisation to thematic analysis to interpretation using pre-existing theoretical concepts and research literature. The findings were then compared with previous work and similarities and differences identified, differences in the present study, or newly emergent data not previously reported were explained/justified.

Kvale and Brinkmann describe the process of analysis/interpretation as “craft” (Kvale and Brinkmann, 2009) and assert that analysing and interpreting qualitative data requires time, training and practice. In the case of a research study conducted as part of a doctoral thesis, the necessary knowledge, skills, expertise and experience required are a collaboration between the doctoral student and his/her supervisor.

### **3.5.11.5 Confirmability**

This aspect of trustworthiness aims to foster confidence that the findings emerge from the data, rather than the researchers own presuppositions. Miles and Huberman suggest that this confidence comes from “the extent to which the researcher admits his or her own presuppositions” (Miles and Huberman, 1994).

The presuppositions of the influencing factors for the women’s beliefs and behaviours and their influence in the choice of data collection methods was openly acknowledged for the current study, as was their inability to capture the full extent of the significant issues. The discussion section of this thesis explores the sophisticated and complex nature of the contributory factors.

The process of the analysis has been described in detail earlier in the chapter. The research questions were revisited and applied to the data during the process.

Discussions between the researcher and her supervisor resulted in a re-examination of the focus of the analysis and a broader approach using the women's perspective to guide the interpretation of the data.

Various methods of validation have been touched upon in this section – illustrating themes and categories of data with transcript quotes, finding multiple instances of themes across interviews from a variety of participants, using reflection/clarification to probe participants during interviews, using previous research and established theories as a measuring stick for the findings, peer scrutiny of the methods/findings etc.

Ultimately it is the reader of the research who will judge the validity - initially the external examiner of the thesis and subsequently the readers of papers and conference presentations elicited from it, who will decide whether the findings are likely to be representative, free from bias and based on sound theoretical foundations.

### **3.5.12 Reflective practice and the role of the “insider” researcher**

Participants may have received unexpected benefits from the research process – talking through personal experiences may have had a therapeutic effect and the researcher party to unintended revelations. It was important in order to avoid potential harm to participants, to prepare for and deal with “difficult” situations and moral problems. Being able to anticipate and pre-empt possible situations where the competence of the researcher comes into question; meant the ability to recognise limitations and be able to refer to those who have the relevant expertise - without losing the respect and trust of the participant; was essential.

The opinions of the respondents to questions were likely to be "situated", that is, influenced by wanting to please the researcher, to avoid offending the clinical team who cared for them, address a personal agenda, or by the aims of the study itself. Strategies were developed to try to minimise this. One of these involved meeting with the women beforehand and chatting with them, in an attempt to create a rapport – as one woman to another and to trying to express the intention to record their perspective.

The interviews were a result of dialogue, a two-way interaction between researcher and the researched, each bringing their history, past experiences, cultural background and personal perspective to the interview.

The traditional method of trying to remain distant from the participant in order to remain objective is being replaced with the acknowledgement that the researcher affects every aspect of the research process, "from conception to final interpretation" (Coffey, 1999). Qualitative research is "layered and interwoven" (Sherif, 2001) not a simple report of facts, but an attempt to elicit meaning and understand the experience of the other.

Being both a nurse and a researcher by training and having extensive experience in both roles could be a double-edged sword. Attempting to live in both worlds whilst purporting to be completely impartial and objective would be implausible. It was preferable to admit the limitations of the "insider-researcher" role, attempt to minimise the effects this may have both on the data and the research relationship; and embrace the advantages it conferred.

The researcher needed to be aware of the perceptions of the researcher by both groups (breast cancer patients and health care professionals) and elicit expectations of her role and the research. Explaining the motivation and perspective of the study helped to gain acceptance and reduce suspicion and feelings of threat.

“Insider-researchers” can provide useful insight into the situational aspects of the research, they have developed a kind of “shorthand” which others would not have access to, may have experience/knowledge of others in a similar situation to the participant and consequently a deeper level of understanding. They may be able to see the gaps in knowledge on both sides and differences in perceptions of the same situations, creating a bridge between the two groups.

It would be unethical to conduct a study of this kind and subject the participants to in-depth examination of their personal history and illness experiences; without the assurance that the researcher was appropriately trained and equipped to perform the research. The researcher in the case of this study, had ten years clinical nursing experience and seventeen years experience of working in health services research in a variety of therapeutic areas, the last three years working on research projects in the advanced breast cancer setting. In addition, during the course of the first few months of her doctoral project, she received formal training in the conduct of qualitative interview technique and was closely supervised by both her clinical and academic supervisors.

The influence of the researcher is important to consider. As a white, middle-class, well-educated woman, a nurse, as well as a researcher, caution was exercised to avoid bias in the results, due to a priori assumptions or theories. There is a position of power inherent in the role of researcher and lay perceptions of the researcher as professional expert. However, the insider-researcher needs to be able to step back; and look critically at both the data and her own attitudes agenda and values; and attempt not to affix these to the findings. By examining a priori assumptions, the influence of the researcher role and research process, it is possible to critique them. , Recording and reporting thoughts, feelings and experiences enables the researcher to make changes and evaluate unexpected events. It also helps to describe how the researcher is changed by the research and acknowledge the effect this has on the data; and the researcher as part of

the data. Finally, the potential experience of loss for the researcher and the researched when the study ends; is an important issue to address.

## Chapter 4 – Findings – Interview Data

### 4.1. Introduction

Twenty of the women recruited to the original study, who consented to be interviewed provided the data for this thesis. They provided a wealth of useful information and the next 3 chapters (chapters 4, 5 and 6); will illustrate in detail the content of the semi-structured interviews conducted over a period of 2 years.

The qualitative data collected during the course of the study described the variation in behaviour towards a given situation and attempted to examine the perspective of women related to the changes imposed on them. The interviews provided the opportunity for the examination of their feelings, emotions and adaptive behaviours.

The data produced by the interviews also explored and documented the experiences of a variety of women, generating understanding of not only what, but how and why the behaviour manifested itself.

### 4.2. Recruitment/Sampling

The inclusion/exclusion criteria for recruitment were very broad in order for the study to be as inclusive as possible. All women discharged from the breast follow-up clinic during the 12 month period of 2007 were invited to participate and were recruited consecutively. That is, at year 5 or more of follow-up with normal mammography and able to give written informed consent. Over the period of 12 months from January-December 2007, 20 women were recruited and agreed to give interviews and contribute to the study described in this thesis.

Those who declined and gave reasons for their reluctance to participate gave the following reasons:

- Not interested in research
- Happy with the new arrangements and saw no need to give their views
- Wanted to put breast cancer and the clinic behind them and participation would interfere with this
- Others did not give reasons

Of the original 20 participants, 18 agreed to be interviewed at visit 2 and 14 participants at visit 3.

### 4.3 Participant characteristics

Participants were aged 50-70 years (median 65 years). They had received regular surveillance via mammography and follow-up care via outpatient clinic visits for 5-18 years (median 8 years). All of the women had breast surgery following diagnosis for primary breast cancer: 9 had mastectomy and 11 had wide local excision (lumpectomy).

Table 1 the characteristics of the group of participants studied:

	<b>N</b>	<b>Median</b>	<b>IQR</b>
Age (yrs)	20	65	59-69
Survival (yrs)	20	8	6-11
NPI*	20	4.3	3.2-4.5
	N		
Married	15		
Widowed	3		
Divorced/separated	2		
Single	0		
Employed	6		
Not employed	14		
Wide Local Excision	11		
Mastectomy	9		

\*Nottingham Prognostic Index

Women's risk of recurrent disease was assessed using the Nottingham Prognostic Index prior to discharge from the service. On closer inspection of their medical history, the variation in the NPI scores reflected changes in their circumstances since diagnosis. This was either recurrent disease, or further surgery, which either increased, or reduced their risk in the intervening 5 years.

Of the 20 participants 15 of the women were married, 3 were widowed, 2 were divorced or separated and none were single. 6 were in regular employment.

### 4.3.1 Comparison of participants and non-participants

Both participants and non-participants were aged 50-70 years. This is specifically because women under 50 years of age, are not discharged from the follow-up clinic as they are estimated to be at higher risk of recurrent disease and those women over 70 years are seen in a different clinic. Both groups were noted to be living in a wide variety of postcodes and therefore more likely to be from a variety of socio-economic backgrounds.

The women attending the clinic come from a variety of ethnic backgrounds, currently 10% are Asian/Afro-Caribbean with the remainder of white European descent. Although all women discharged from the clinic in 2007 were invited to participate, the women who agreed to participate were all white Europeans.

Previous research (Hussain-Gambles, 2003, Kristie Long et al., 2006), suggests that the methodology chosen for this study (survey questionnaires and interviews) is more acceptable in some cultures than in others. The methodology is more common in; and therefore more acceptable in western cultures; and this may well be the reason for this bias in recruitment.

## 4.4 Interview data – Theme 1 - “A close shave?” or a “marked woman?”

There were three major themes which emerged from the data and deemed to be influential in describing and explaining the women’s concerns, fears and behaviour:

The current chapter (Chapter 4) covers the first theme “Close Shave” or “Marked Woman” which describes the women’s attitude towards their breast cancer diagnosis, treatment and perceptions of risk of recurrent disease. Chapter 5 relates to the second theme “Blessing” or a “Curse” where women described the value of follow-up care for them personally and their reaction to the withdrawal of regular outpatient clinic visits. Finally Chapter 6 (“Freedom”? or “Isolation”?), encompasses the women’s feelings about their future care and well-being and records how they feel about the expectations of imposed self-management having been outside the hospital follow-up system for two years. These themes follow the chronological nature of the interviews. The natural flow of the storytelling approach the women adopted was to reflect on the past, raise issues related to present events and then contemplate/plan for their future.

Theme 1 (“Close Shave” or “Marked Woman”) emerged from descriptions of what the diagnosis of breast cancer meant to each of the women interviewed. It includes expectations of its impact on their lives and subsequent experiences of surgical treatments and follow-up care. The theme relates to the core beliefs and basic assumptions, that the women have about breast cancer and its treatments; and explores the concepts of curative intent; versus prevention or early detection. The descriptions encapsulated the emotional, psychological as well as physical effects (*‘breast cancer beliefs’*), attitudes to the risk of recurrent disease (*‘risk beliefs’*) and the variety of coping strategies adopted (*‘coping beliefs’*). Each of these will be addressed later in the chapter.

The effects of the diagnosis of breast cancer guided women's strategy for dealing with their *illness* as opposed to their *disease*. Many of the women interviewed, appeared to construct their beliefs in conjunction with the beliefs of others. Their beliefs were constructed over time and in conjunction with those they were emotionally closest to. They discussed their experiences and compared them with "comrades-in-arms" that is, their peers, women who had also been diagnosed with breast cancer and had their own personal experience of the treatments. The women in this study also reported talking to other women who were members of self-help, or health care professional-led support groups, as well as family members and friends. They compared their histories, feelings, concerns and looked for similarities and justification and confirmation of their own beliefs. This social comparison and confirmation of "sameness", appeared to help them map out the "usual" path to recovery and created an air of predictability. It also gave some clues to the socially accepted mode of coping with a new and frightening situation. Women reported needing to feel they were doing the "right thing" and wanted to avoid the possibility of rejection and labelling by others, particularly those they were closest to and whose approval and esteem, they most valued.

The two metaphors ('close shave' and 'marked woman') describe very succinctly the polarity between the beliefs of women in this study who were in long term recovery from breast cancer and their confidence in the effectiveness of treatment and surveillance in preventing recurrent disease. Women's estimates of their risk of recurrent disease seemed to span the full spectrum of possibilities from zero to 98%. They based this on personal experiences and their knowledge about the stage of the disease and the available treatments prescribed for them. The women interviewed in this study fell into 2 groups, one group believed that their treatment was in effect curative and that it conferred either no risk; or relatively low risk of recurrent disease, in effect they had, had "a close shave" with the threat of breast cancer, but now the threat had passed and was negligible.

Another group of women saw treatment only as a risk-reducing strategy these were the “marked women”, who felt they constantly carried the threat with them after treatment was complete and would never be free of it. Often this group included women who had experienced the death of others with cancer either in the past, or within the last few years and expressed fears of potential pain, suffering and isolation. This was particularly true if the women knew of other women who had either, developed recurrent breast cancer, or died from breast cancer, more than 5 years after diagnosis. The interviewees were self-selecting. They opted into, or out of, the interview group by personal choice and made up 20% of the 100 participants.

There were 10 (50%) of interviewees in each group – ‘close shave’ and ‘marked woman’. This was a chance finding and unknown at the time of recruitment. These two views are described in more detail below. Please note all quotes used in this chapter and following chapters are identified by the interviewee’s allocated pseudonym to preserve anonymity, followed by the age of the interviewee, the number of years in follow-up and the interview number for example:

#### **Kathryn (aged 67, 9 years) interview 1**

##### **4.4.1 A “close shave”**

For the women who believed the treatment had affected a cure, their desire was to resolve their health status, restore the status quo and return to daily life as it was before diagnosis; as soon as possible. They used minimisation, social comparison and created the illusion of control and predictability. Their prior knowledge and beliefs about breast cancer allowed them to put their faith and trust in the healthcare system and the concept of preventative medicine. Their beliefs about the advantage of early detection and timely treatment; fed into their conviction that they had a good prognosis. They used indicators such as a small tumour, no spread to their lymph nodes, no family history of breast cancer, or lumpectomy versus mastectomy. For example:

*"Oh no, I didn't feel in any danger at all really and I thought what's to be will be, we've got to die sometime if it is threatening, you know. I didn't sort of get myself all wound up, ooh am I going to die? no, because I didn't think like that. I didn't think like that, because to me it just seemed trivial to what other people were going through when they had mastectomy and taking tablets and, and chemo and losing your hair. I mean I didn't have a fraction of that so I mean I hadn't got anything to worry about had I?"*  
*".....because well, the reason that was, as it were, were because I thought it was such a small thing, I mean I didn't think there was anything to worry about, you know, really. Because they'd found it, and they said if you have it out now it'll save you problems later. So, I mean you're not going to walk away from it and say "No I'm not having it done are you?" You're going to have it done while it's small, so I mean to me, it weren't no big thing really, do you know what I'm saying?"*

**Kathryn (aged 67, 9 years) interview 1**

They viewed the fact that they were not prescribed treatment with chemotherapy or radiotherapy to mean that their chances of developing recurrent disease were minimal.

#### 4.4.2 A "marked woman"

In contrast for these women, their appraisal of breast cancer was that of a major, immediate and constant threat, life-changing, and/or life-threatening. Often their personal experience of others with, or dying from cancer, brought with it real fear of pain, suffering, isolation and death. While she was an inpatient having initial breast surgery, Anne (aged 65, 8 years) met a woman admitted with advanced breast cancer:

*".....You know there are so many women have got to go through this sort of trauma. How it's affected me? I suppose its left me a little bit worried because it's always at the back of your mind. And you know I've got a crumbling spine and one of the things is, that if it comes back it tends to come back in your back, I mean I just remember that when I was in hospital, there was one woman in a bed and she was in agony and her cancer had spread to her back. Those sorts of things always stay in your mind don't they? I'm normally a very jolly person and I can put things in the back of my mind but they are there."*

**Anne (aged 65, 8 years) interview 1**

A diagnosis of cancer entails an adjustment to the prospect of a life-threatening disease, what Ronnie Janoff-Bulman (Janoff-Bulman, 1992) calls "a jarring awareness of the fact of death" (p57) when confronted with one's own mortality. Once initial treatment is complete and the immediate danger appears to be over, adjusting to recovery can be difficult, particularly when there is direct experience of family, friends or peers who have not survived cancer. Individuals construct schemas - personal books of "rules" which create order and meaning to make sense of the world they live in and once these conflict

with contradictory experiential evidence - survival can no longer simply be assumed or ignored.

Consequently some women interviewed as part of this study experienced long-standing emotional trauma and unresolved grief. These women described how they felt insecure, vulnerable, dependent and trapped. They viewed themselves as being in a constant state of transition, unable to move forward - in a kind of limbo. They used "watchful-waiting" and clung to their belief in the healthcare system and regular surveillance as a means of (temporary) control. They felt contaminated by the disease and this forced them to re-evaluate their lives, re-examine their identity and even re-invent themselves as "breast cancer patient" or "breast cancer survivor".

The different approaches to the experience of breast cancer, evident in the data, can be explained by the theory of illness representations described in Leventhal's Common Sense Model (Leventhal et al., 1997, Leventhal et al., 1998, Leventhal et al., 2008) which was described earlier in Chapter 2.

To recap, three of the dimensions of the model: identity, consequences and timeline are evident in the way women view the impact of breast cancer.

- Identity – the labelling given to the illness by an individual, in this case the concepts of close shave, or marked woman,
- Consequences – the individual's evaluation of its impact on their life and activities. For the women in this study, this was a minor threat to be treated and resolved (close shave); or an ever-present threat to be monitored and feared (marked woman).
- Timeline – perceptions of the course of the illness and control – either personal or via treatment and the strategies available to influence the illness. Breast surgery, mammographic screening, self-examination and clinic visits would fit into this

category. Expectations of cure or recurrent disease, illustrate perceptions of the course of the disease.

Initially for all of the women interviewed, diagnosis evoked feelings of shock and disbelief followed by an appraisal of the level of threat it represented to each individual. Appraisal of threat was described in Chapter 2 as a concept proposed by Lazarus and Folkman (Lazarus and Folkman, 1984) as the first step in their theory of the coping process. Their work differentiated between problem-focused and emotion-focused coping. Low levels of threat or some level of predictability/control enabled individuals to view situations as problems to be solved (close shave), whilst high levels of threat accompanied by lack of control and uncertainty; generated emotional responses such as anxiety, avoidance, denial and hyper-vigilance (marked woman).

Leon Festinger's Theory of Cognitive Dissonance (Festinger, 1962) also goes some way to explaining the unease and uncertainty associated with the adopted "marked woman" approach and may account for the behaviour of some of the women interviewed in this study. Beliefs are formulated, assumptions made about breast cancer, its treatments and the steps necessary to prevent, detect, or monitor recurrent disease. When these no longer hold true there is dissonance between prior cognitions and new information relating to the changes in their follow-up care.

Festinger asserts that the magnitude of post-decision dissonance *reduces* as the number of cognitive elements identical to characteristics of chosen and unchosen alternatives increases. That is, as more evidence is collected to support the decision. The magnitude of dissonance *increases*, when the importance of the opinion of others is greater, the relevance of the opinion to others is greater, or the attractiveness of those voicing disagreement.

Therefore, women may use their faith in the expertise of the healthcare professionals responsible for their care to *reduce* dissonance, or experience an *increase* when they feel insecure because their beliefs are contradicted by the "experts".

The major sources of resistance to change of a cognitive element are its responsiveness to "reality" and the extent to which it exists in consonant relations with many other elements (Festinger, 1962).

Interview data collected for this study implies that anecdotal evidence, (that is - the views and opinions of others outside the healthcare system) and experience of others with cancer; shapes beliefs about causes of breast cancer and the level of risk or threat it poses. It also provides information for assessment of effectiveness of the treatments offered and the expected prognosis. Clinical evidence (as provided by healthcare professionals) fosters hope, positive regard towards treatments and faith and trust in the healthcare system.

Conflict between anecdotal evidence, or personal experience and clinical "evidence"; to support a reduction in levels and frequency of disease surveillance; are an example of a challenged "reality" in the context of the study. Festinger's theory acknowledges the variation between individuals in their reaction to and tolerance of; dissonance. This is likely to be reflected in the beliefs, perceptions and behaviours of women when confronted with the experience of breast cancer and is borne out by the themes revealed in the interview data. These two views, 'close shave' and 'marked woman', will be explored in more detail in the next section.

## 4.5 Breast Cancer Beliefs

The women interviewed for the study, highlighted the mode of detection, the type of treatment they received, their understanding about risk factors and their own perceived risk of recurrent disease as the things most likely to inform their beliefs about breast cancer.

### 4.5.1 Detection

Analysis of the interviews suggested that the mode of detection for breast cancer is influential in the formulation of women's appraisal of its threat to health. Detection may be via routine mammography, physical examination in the primary setting via a General Practitioner, or by the woman herself.

Routine mammographic screening via the national screening programme, raises awareness of the prevalence of the disease and so women who attend have already considered the possibility of its detection. However, the perspectives of the healthcare team; and those of the women who attend for screening, conflict. For the HCPs, the women attend so that breast cancer can be detected. For the women, attendance is intended to reassure them that they *do not* have breast cancer. There is misconception and misunderstanding amongst the general public, who presume that a strong family history of breast cancer is the most influential risk factor for developing the disease, when in fact risk is directly related to age and menopausal status in the majority of women.

Detection via mammography vindicates regular attendance but is often still shocking to many women:

*"Well when I had my...., it was picked up on a mammogram, a routine mammogram and I just came back for the repeat mammogram thinking they'd forgot to put the film in, you know..... there is no way. And it came as an initial shock, as quite a shock when*

*they said right we've got to, we're doing the biopsy. And then it began to gradually sink in". **Blanche (aged 63, 13 years) interview 1***

Breast cancer screening attendance is seen by some, as a formality, a public obligation, a cultural and societal expectation with a negative outcome perceived as highly unlikely:

*I ".....how did you find out to start with, who noticed things weren't right, was it you, or your doctor or.....?"*

*R No, mammogram*

*I Picked up on the mammogram?*

*R When....., you'll need to put Hospital X, and one of them cabins used to come every year*

*I Oh, a mobile unit came round yeah?*

*R Mobile unit used to come round and park up at Hospital X, and they sent for you to go and have one there.*

*I And you went regularly?*

*R So I used to go every time they sent for me to go and it was always in the cabin in the yard; and I just had a letter back saying things weren't right, I needed to go to Nottingham for another one. There were a slight error". **Kathryn (aged 67, 9yrs) interview 1***

Self-detection had a two-fold effect, it provided women with reassurance that they could rely on their own instinct and knowledge of their own bodies to identify when they should seek medical help, but also highlighted, that mammograms were not a fail-safe way of detecting breast cancer at an early stage. This creates dissonance between the belief that their regular attendance for mammography was necessary and their personal experience of its limited efficacy:

*"I found a lump, I went to my GP who referred me to the clinic....."*

*Oh one thing that you need to know as well - my cancer did not show up on mammogram". **Rita (aged 55, 5 years) interview 1***

Failure to detect the tumour via mammogram may create the misconception that the disease has progressed at a rapid rate, rather than revealing its limitations as a mode of detection:

- I* "Okay the other thing you said to me was, that you'd had a mammogram and then it was clear and it was normal; and then how many months after that were you diagnosed with breast cancer?"
- R* I had a mammogram in the November and I was diagnosed with..., that was 1999 I had.... November, I had a mammogram. That was diagnosed clear, I was then..... felt a lump in my breast in July, I went to the City Hospital, had a mammogram, I'd got breast cancer.
- I* So, within eight months the mammogram had gone from normal to.....?
- R* Yes, I was operated on very quick, I was diagnosed 4th July and I had my operation 4th August in 2000". **Teresa aged 64, 7 years interview 1**

Data generated from the interviews indicated that self-detection may also create confidence in personal intuition, belief in self-determination as a strategy and a sense of control over future events. The assumption may be that, if recurrent disease develops – women will intuitively know if something is wrong and have the opportunity to be proactive and seek expert help. Consequently, mammograms are believed to be of limited value. Physical examination by a healthcare professional, or self-detection, is rated more highly than routine screening. Trusting in intuition and familiarity with one's own body is felt to be of paramount importance.

Self examination could be controversial as a strategy. For those women who chose to take a passive role in the management of their illness there was a reluctance to assume this responsibility and in a sense of inadequacy in their ability to recognise abnormality. There was fear that a symptom of recurrent disease may be overlooked through lack of expert knowledge. Delayed detection in turn, may confer a disadvantage by resulting in a poorer prognosis. With responsibility for detection remaining firmly with the health care professionals, women were able to compartmentalise their breast cancer and concentrate on day to day living. It was then possible to continue with life as before – they were "well" until proven "sick". For the 'marked woman', this was one way of managing the anxiety and fear related to the prospect of recurrent disease.

## 4.5.2 Treatment beliefs

The women who believed their breast cancer was a 'close shave' held a positive attitude towards the effectiveness of their treatment. They saw it as a solution to their problem (breast cancer). They viewed the treatment period as time-limited which when complete, enabled them to move forward and regain their previous status as "well". Those in the 'marked woman' group viewed treatment as limited in its effectiveness and anticipated that it was only a matter of time before the disease came back. Consequently vigilance was necessary to identify when the treatment had ceased to be effective. This vigilance was assumed to be a joint responsibility, between the woman herself and the healthcare professionals responsible for her care. This relationship was considered to be an ongoing source of help, unlimited by time.

In order to make an informed decision regarding surgical treatments, as well as information received from the healthcare team, the women interviewed, appeared to assemble information from a variety of other sources: other women with breast cancer, friends, the media – television programmes, news reports, newspapers, magazines and via the wealth of information available on the internet. The decisions about treatment are reached in relation to the amount of control over the disease they are believed to bestow. This is in combination with the impact they are perceived to have on self-esteem and body image.

Perceptions and beliefs related to treatment options are reflected in the reasons women give for their choices about treatment. Those who opt for wide local excision for example, do so either because they feel they are at low risk of recurrence, or place greater importance on body image – fearing loss of sexual allure and rejection. It is not unusual for women to regret their decision later and feel guilt or fear; that they have put themselves at risk of recurrent disease later on.

Those who choose mastectomy may presume the surgery is risk-reducing or even curative, or want to avoid more than one surgical procedure if they should require re-excision and/or mastectomy later:

R *"I felt absolutely fine until I was told I was going to have a mastectomy and that was a big shock because I didn't really know much about cancer, it surprised me, but I don't know a lot about it and I thought that mastectomies were only for people who had advanced cancer and the treatment was usually a wide incision if it was in the early stage and the mastectomy was only for advanced cancer. Of course I know that's not the case now but that's how I interpreted it. So when I was told that, that was a tremendous shock because then I thought immediately it was far more serious than I first thought and I was very, very worried about that. As well as what it meant in terms of surgery.*

I *Oh right, so you were worried because you felt that it meant that it was more serious, the disease was more serious?*

R *Yes.*

I *As well as the effect it would have on you physically?*

R *Yes, yes so I just thought mastectomy, advanced cancer, lymph node involvement, I'll die in two years".*

**Dorothy (aged 57, 7 years) interview 1**

Although often onerous, both in the amount of time spent as an outpatient at the hospital and the side effects experienced, pharmacological treatments are tolerated for the sense of control and predictability they confer. They are often viewed as a safety net, an additional means of fighting the disease as the following quotation from Dorothy's interview illustrates.

R *".....I was here all the time, I had fifty appointments in the first year.*

I *Really?*

R *Mm, well if you count the twenty five radiotherapies.*

I *Oh I see what you mean, yes.*

R *And then because I had breast reconstruction.*

I *Oh, so it was a busy year?*

R *I was, seemed to be, always here.*

I *And was that a bad thing, or a good thing?*

R *It was a good thing*

I *Did you find it helpful?*

R *Yes, well it was very painful the process of having the saline implants which is what happened, so I had to come here for all these injections with that and then I had to have another operation in January, that was seven months later to have that replacement silicone implant. And so there was follow ups from plastics on the one side. Oh and I had injections, that's why I kept coming back, I just remembered that.*

I *So there was lots of contact in the first year.*

R *Yes so I had to be here every four weeks for the injections and I, I found that quite hard because I just got depressed in the clinic, I just didn't like to be here surrounded by people who'd had breast cancer.*

I *So often?*

R *And it was every four weeks so it was just a constant reminder".*

**Dorothy (aged 57, 7 years) interview 1**

Once treatment was complete, women described how they experience mixed feelings of relief and insecurity. The onus is now on them to self-monitor and there are expectations from both healthcare professionals and friends and family to resume the life they had before their diagnosis. Worrying about recurrent disease is then perceived by many women to be detrimental to both physical and psychological well-being:

*R You've got to accept it because if you don't you'd just, to me you'd just worry, you'd fret and it's no good to your health is it?*

*I It would have a detrimental effect on it?*

*R Its no good to your health at all".*

**Elizabeth (aged 65, 7 years) interview 1**

This is particularly common for the women in the "close shave" group. They invariably endeavour to resume their employment or family duties as soon as possible and try to forget about their breast cancer.

For those in the "marked woman" group, treatment gives them confidence and is seen as a way of delaying recurrent disease, consequently completing treatment leaves them feeling vulnerable:

*".....it was difficult because as I say you're suddenly told that right that's it, your five years is up and your treatment, and your tablets are suddenly stopped and I thought that was quite, that's quite a shock to the system. So I think that, I think that is difficult because I think while you're taking tablets you always feel that you've got that little back up that, you know they're going to keep you sort of free for as long as possible I suppose". ".....you used to come, it was like part of your daily life anyway you just get so used to it. And I think once it finishes it's quite strange because you sort of think ah you know I'm sort of, you know that's it and then I'm on my own now you know, because I think you sort of, it's a prop isn't it while you're being treated?" ".....So I suppose after the treatment had finished I think you sort of pick yourself up and just try and get on with things really. And you've got your family I think, I mean I think that's the hard thing that I think the problem a lot of the time, especially when you've got children, although mine are quite grown up, you're actually putting on a brave face for them, so you're actually trying to be you know, I feel great all the time and you actually probably don't".*

**Cathy (aged 61, 5 years) interview 1**

To summarise the beliefs held by the women interviewed relating to breast cancer treatment:

The decision-making process around choice of treatment entailed the gathering of information from a variety of sources other than health care professionals and decisions were often heavily influenced by the views and approvals of significant others. When asked to make the choice between wide local excision (WLE) and mastectomy (Mx) , the decision appeared to relate to whether distorted body image and loss of sexual allure were significant factors (WLE), or whether the aim of the surgery was deemed to be an opportunity to obtain a cure/reduce risk of recurrent disease or avoid further surgery.

Whatever the intention, the aim was to gain some level of predictability and control. Those women who chose to view their diagnosis as a "close shave" believed that their treatment was an effective solution to the "problem" of breast cancer. They saw the treatment period as time limited and believed once the treatment was complete they would then be "well".

Those women who identified with the "marked woman" approach acknowledged the limitations of treatment from the beginning. They stressed the importance of vigilance to detect recurrent disease and saw this as a joint responsibility with health care professionals. They believed that recurrent disease was inevitable.

The women's choice of treatment reflected both their perceived level of threat and their confidence in its effectiveness in reducing the risk of recurrent disease. Many viewed it as "ammunition" to fight the disease and tolerated the onerous side effects in order to achieve this.

The end of the treatment period brought either feelings of relief, a time to regain independence and resume normal daily life for the 'close shave' group, or induced fear, anxiety and insecurity because the safety net had been removed and some level of control lost, creating feelings of vulnerability and abandonment for the 'marked woman' group.

### 4.5.3 Cancer in Others

Some of the women interviewed for this study, described how experiencing the effects of cancer on a loved one and their eventual death, had far-reaching long-term effects on them personally. These women felt their perspective of their own diagnosis was unlike that of women with no prior intimate knowledge of the disease. Their prior experiences brought entrenched, pre-conceived ideas and beliefs related to risk and prognosis. They also had an altogether negative attitude and lower expectations. Experience of others dying from cancer hindered the ability to believe that its threat would ever be eradicated. Cancer was perceived as life-threatening even after treatment and often these women lived with a sense of dread that one day their fate would be the same as that of their loved one.

This morbid fear creates conflict – dissonance, between what they want to believe, (the information received from healthcare professionals, i.e. clinical “evidence”) and personal experiences. For some women this leads to severe anxiety, excessive worrying, “watchful waiting” and obsessive fixation on a perceived impending death. These are the “marked women”.

In the case of Irene (aged 69, 8 years), watching her step-father die of stomach cancer and then being diagnosed with breast cancer herself, resulted in constant self-monitoring for symptoms of advanced disease. She told me about the traumatic effect when she was a teenager, of the news that her step-father had stomach/bowel cancer. He was nursed at home and she remembers how swollen his abdomen became and the devastating effect of watching him die from cancer. It has left her with this overwhelming fear that the same thing may happen to her even though she realises family history is not an issue as he was not a blood relative. She accepts that her fears are irrational but are real and intrusive and at times quite disabling. They have a profound effect on her emotional well-being. When I met her she had even bought and wrapped next year’s Christmas presents in case she wasn’t around and made and frozen

the food for her funeral guests. All of this with no evidence that she currently had active disease:

R *".....but as I said to my husband, I won't be here next year to worry about my seventieth birthday, you see that's how I feel. You know, he said, we'll have to do something special next year for your seventieth, I said, Oh I shan't be here. And he said, why, where are you going? I said I won't be here, I know I won't." ".....but I never felt, after the first initial, when they said you've got cancer or a pre-cancer and I said in the car going home, I'm going to die, that was my first reaction, and then after a while I thought well that's silly, you know, we'll go along and see how things went on. And I never felt as bad as I do now. I'm seriously worried about this. I mean if I go and have this colonoscopy (she is having periods of diarrhoea) and they say there's nothing there, it's the tablets that causing it, or it's irritable bowel, then you know I'll be swinging from the stars, and my husband says, yes, until the next time, because that's how I am."*

I *"So you don't think the fear's going to go away really?"*

R *"No, because when something else hurts I shall think its spread to there hasn't it? Yeah. And I'm sure there's not only me feels like that." ".....I mean all my family will tell you, I mean I've got all my Christmas presents now, and basically some of them are even wrapped up ready for Christmas (the interview was in April)." "....And my first thoughts was well if I'm going to die, I need to do this, I need to buy my husband a gold St Christopher, I need to get the boys something on a similar line, the girls there's plenty of jewellery for them, I don't really want them to go to a pub after, so I could make the sandwiches and make the cakes and put them in the deep freeze."*

I *"So you're even planning for your funeral, is that what you're saying?"*

R *"Yeah, and when we go to funerals I listen to the different sorts of music and think, yeah, I like that one." ".....but I don't want to die" ".....but the fear of dying and leaving everybody and they're all going to go on with their lives, it's an awful feeling. It's just, it's just me."*

**Irene (aged 69, 8 years) interview 1**

The fear and trauma induced by cancer in others should not be overlooked or underestimated. Irene views her breast cancer as a perpetual threat and unlike other women who perceive their risk to be minimal; she is unable to put her fear to one side.

Women who convinced themselves that their risk was minimal more readily accepted that they didn't need frequent surveillance once they were discharged from regular outpatient follow-up. This just wasn't possible for others like Irene. Watching others go through a similar experience can help women prepare for what is to come, whilst also making them fearful for the future.

Nancy (aged 55, 15 years) supported her mother-in-law through the progress of her disease and her eventual death, before her own diagnosis. Since she was discharged

from her own outpatient follow-up, she has been supporting her sister-in-law through her diagnosis and treatment. She told me:

R *"This all happened in the summer holidays, my mother in law had died in the June, of secondaries from breast cancer. So I'd just finished taking her to the clinic and within about six weeks I was coming for myself." ".....So I've been coming to this clinic since 19, oh gosh 19, grandma (mother-in-law) died in 1992 and I must've been bringing her for 5 or 6 years before that so sort of mid (1980's) 80s I should think, so I've been coming fairly regularly since about the mid 80s one way or another with her first and then with me and now with X. So...."*

I *"X? That's your sister?"*

R *"That's my sister in law yes." **Nancy (aged 55, 15 years) interview 1***

The women in her family are successively following a similar journey and based on her own experiences, she feels it is only a matter of time before it is her turn to face recurrent disease and death from cancer.

The experiences of these women demonstrate that it proves to be very difficult to believe that their treatment/surgery is likely to have long-term or permanent benefit when they have witnessed first-hand, the ravages of recurrent and advanced disease in others. One of the factors that influence their ability to minimise the threat from breast cancer is the belief in the value of the concept of preventative medicine. This is incorporated into women's assessment of their risk of death, or recurrent disease.

In contrast to the 'marked woman' group, either women in the 'close shave' group had little or no experience of cancer in others to challenge their beliefs; or found a reason to differentiate their experience from others - "my tumour was very small they caught it early", "I didn't need chemotherapy". This was done to minimise their threat and distance themselves from others with advanced disease.

## 4.6. Risk Beliefs

Beliefs about risk related to the possible *causes* of breast cancer, personal *estimates of risk*, the factors women believed to be influential in increasing the risk of recurrent disease and the possible *risk-reducing strategies* they might employ.

The literature review chapter, outlined how the research literature related to the risk of recurrent disease, demonstrated that the risk is highest in the first 5 years following surgery and that the risk reduces with every 5 years of survival (Early Breast Cancer Trialists Collaborative Group, 2005).

UK guidelines currently suggest that breast cancer units achieve targets of 10% of women with recurrent disease post surgery and <5% after 5 years (The Association of Breast Surgeons @ BASO, 2005). According to clinical evidence documented in the literature (Jatoi et al., 2005) risk is directly related to age, size of tumour, menopausal status and lymph node involvement, but there is no way of knowing which of the women will be affected, or when.

Some of the women interviewed, believed that recurrent disease would be more significant, than their original diagnosis. It may mean a poorer prognosis – treatment may be unsuccessful, a shortened life-span – they foresee the stigma and side effects associated with chemotherapy and fear pain. They have already witnessed first-hand, the value of early detection and fear they will “miss the boat” next time.

For the women who assumed their risk was minimal and their treatment was curative (a “close shave”), this was not a major issue. They trusted their beliefs in the system and moved forward; leaving their fear behind in their quest to resume the life they had before. They perceived their risk to be related to the kind of surgery, or treatment

prescribed (e.g. wide local excision versus mastectomy) and the extent of their disease (e.g. absence of lymph node involvement):

*"I don't dwell on it, in fact nine out of ten times I don't think about it at all. It was there, it's gone, and hopefully, it won't come back."*

**Helen (aged 75, 5 years) interview 1**

The modality of detection of their original tumour was also influential. The way in which the disease was initially detected seemed to influence women's confidence in the health care system. Faith in mammographic screening as a means of effective early detection, is either confirmed when it successfully identifies their disease, or undermined when a tumour is found by physical examination by a health care professional, or even by the woman herself, particularly within 3 years of a routine mammogram. Regular surveillance was viewed as a means of regaining some level of control or predictability. If mammographic screening successfully revealed disease, they had confidence that as long as they were screened regularly, any recurrence would be identified at an early stage, but still felt recurrent disease to be an unlikely event.

For the "marked" women, fear of recurrent disease was often linked in the interviews with death, pain and suffering. Being told that breast cancer is evident in their body when they have not found anything amiss or feel perfectly well, is very frightening to some women. It highlights the fact that their own sense of well-being and reliance on personal intuition; is not fool-proof and this is very disconcerting. It can be unnerving to acknowledge that they may have a life-threatening disease and not even feel unwell. This challenges basic assumptions and the women believe they are marking time until the disease inevitably returns; they feel vulnerable and insecure:

*".....I think if you've had a touch of cancer, you automatically think every time you've got something wrong with you it's come back. And I think whoever you are and however strong you are, if you've had a touch of it, next time you get something you automatically think, well this is it, I've been lucky with the first time, how lucky am I going to be this time?"* **Irene (aged 69, 8 years) interview 1**

### 4.6.1 Causes of Breast Cancer

The women interviewed, often voiced their perceptions of the *cause* of their breast cancer. They needed to attribute blame, in order to create the illusion of predictability and a sense of control over the disease. This generated a variety of beliefs related to the possible causes of breast cancer: stress, physical injury, Hormone Replacement Therapy (HRT) and food additives; which are not documented in the research literature as medically accepted causes of the disease. However, more importantly for the women they were things they had personal control over and so the belief was - if they could be avoided, maybe so could recurrent disease.

For women in the 'close shave' group, causality tended to be attributed to factors which were avoidable, controllable, treatable or not applicable to them. Those in the 'marked woman' group held the opposing view – that the disease was unavoidable and beyond their control.

These diametrically opposed views correspond with the "cause" domain in Leventhal's Common Sense Model of illness representation (Leventhal et al., 2008). The need to make sense of the illness experience and find meaning in it helps women adjust and adapt and reduces levels of uncertainty.

Kay Toombs (Toombs, 1992), suggests that the priorities of patients when trying to make sense of their illness are:

- an adequate explanation
- curative treatment
- a prediction of what may be expected to happen next.

This is distinguished from the clinician's priorities of:

- identifying an accurate diagnosis,

- prescribing an effective treatment
- making an assessment of a possible prognosis.

Other women I spoke to, attributed the cause of the breast cancer to a variety of events/situations:

"I bumped my breast"

"I fell and landed on that side"

"I was under a lot of stress at work"

"My husband died 6 months before"

Attributing "blame" appears to allay feelings of anxiety, fear and loss of control. For example, Frances (aged 70, 5 years) felt it was her own fault she developed breast cancer, she thought taking HRT was a strong contributory factor:

*R ".....in a way I kind of blamed myself taking HRT for so long. I shouldn't, you know I just thought I was tempting providence really by taking that. Because I'd read things in the papers which some advised you it would be okay and some didn't, some said it wasn't okay but....."*

*I "So you blamed yourself?"*

*R "In a way, yes well not completely, but I thought, I just thought, I shouldn't have been taking that. It was a shock but I think because of, my doctor reassured me it was rated at number one (grade I tumour) I think she said so don't, she said don't worry about it, we've got it in time."*

**Frances (aged 70, 5 years) interview 1**

In contrast Anne (aged 65, 8 years), refused to give up her HRT despite possible risks, to maintain her quality of life:

*I "What risk do you think there is of it coming back? Had you considered it, do you have a handle on it?"*

*R "Yes I have considered it because of the hormone replacement therapy, but Dr X said it had not been proved that it is a risk, so again I'm taking these HRT tablets knowing that it might give me breast cancer again but only might, because it's not proven that it does. You have to make a choice. I would have been in a wheelchair by now if I hadn't, so my quality of life is so much better because of it." **Anne (aged 65, 8 years) interview 1***

Phyllis (aged 54, 9 years) was convinced that the research project she took part in and the "extra" mammograms she had as a result, were responsible:

*R "....but I was on the programme for the mammogram of, mammogram in, ladies over a certain age for so many years."*

*I "What, like a research project you mean?"*

*R "Mm, then I felt that they've gave me the breast cancer because I'd been exposed to mammograms every year." ".....because I mean let's face it we all, it*

- can, well I think it can trigger it off and that's how I felt, as if I was given it by going on this programme."*
- I* "So you had them more frequently?"
- R* "Mm."
- I* "For how many years?"
- R* "I can't really remember, it's probably maybe about five, six, I don't know." ".....I feel as if, because I'd read an article or something about somebody in America saying that, I don't know, it could be dangerous for women to be mammogrammed too much. Yes, so I sort of blame it on the hospital, that's why I got it. So I don't know." ".....I mean like, I had a problem with my rib and I had awful pain in this rib and then when I spoke to the breast nurse, then they was explaining it's the effect of the radiotherapy. I don't know that and I've been thinking I've got cancer of the bones." ".....well I think, well the way I think, I think yes, I am going to get it back. If I've got the cancer gene in me then I'm going to get it back."
- I* "So not a matter of if, it's a matter of when?"
- R* "Mm." **Phyllis (aged 54, 9 years)interview 1**

For Phyllis, her healthcare has become a threat as well as a benefit. She now distrusts the system and its treatments.

Those women who attributed their diagnosis to a family history of cancer, the will of God (a punishment, a warning), or chance/bad luck assumed their diagnosis was unavoidable and were more accepting and philosophical about their future. Margaret (aged 66, 16 years, interview 1) told me how she adopted a pragmatic, practical, approach to dealing with her breast cancer. She felt she had very little control over events – so she must accept her lot and dealt with whatever happened in a very logical and practical way. She found comfort in her religious beliefs, prayed and meditated in church, placed her faith in God – this helped when things got difficult. She chose to adopt a passive role and felt she had limited control or influence over her future, therefore avoiding the anxiety and dissonance experienced by other women.

#### 4.6.2 Risk Perceptions

Beliefs related to causality influenced perceptions of risk of recurrent disease. It would seem from the interviews that, beliefs about breast cancer and its treatments are very carefully constructed over time, in conjunction with the views and experiences of others.

It would seem that the aim, of attributing causality, is to enable women to bring a greater sense of understanding and control to their experiences.

Cathy (aged 61, 10 years interview 1) was given a 65% survival estimate at diagnosis (i.e. 35% risk of recurrence) and still self examines regularly. She formed close friendships with two women while an in-patient for breast surgery – they have both since died and a third has developed recurrent disease since being discharged from the clinic. This has made her very anxious for her own well-being and she declined to discuss the possibility that her own disease may recur, or estimate her risk. She thinks that her risk increases with time but consoles herself with the fact that she has survived for 10 years.

Dorothy (aged 57, 7 years, interview 1) witnessed the death of 3 friends recently, one from breast cancer and takes the opposite view. She has reduced her personal risk of recurrent disease over time from 50% to 35% and now feels it is probably about 5%. Being able to put a number on it and quantify her risk has acquired great significance for her and being able to predict or at least estimate her risk gives her comfort and the illusion of control.

It seems to be a matter of perspective. Some women take comfort from the fact that nothing bad has happened since their diagnosis and tick off each year as another year free from breast cancer, while others feel the longer time goes on ..... the more likely it is that their luck will run out.

Part of the carefully constructed schema or personal rule book, includes each woman's belief about their risk of recurrent disease and the factors which have a strong influence over their chances of experiencing it. Personal estimates of risk obtained from the women interviewed in the study at discharge from annual outpatient follow-up, ranged from 0 - 100% and often bore little resemblance to the clinical risk estimates made at the time of diagnosis:

I "So how do you view your risk now?"

R "I'd be very low, probably 5% that I will get breast cancer again because I know there is still a chance, I've been told that there is a chance that I could still get it. But I don't think it, in my mind it's not a high risk."

**Jane (aged 63, 13 years) interview 1**

I "and how do you perceive the risk of it coming back, what's your, in your mind what risks do you think you've got? We can do it on a percentage basis?

R "The same as it was the first one isn't it? I've got just as much chance of getting it again."

I "But if I asked you to quantify it would you able to do that? would you like? do it on a percentage basis, or from 1 to 10, or..."

R "Chance of?"

I "I know it's a difficult question."

R "I suppose it must be as high as 50%."

**Blanche (aged 63, 13 years) interview 1**

Jane and Blanche demonstrate the influence of beliefs on personal estimates of risk.

They are both 63 years old and 13 years post-surgery but vary greatly in their personal estimates of risk of recurrent disease, 5% and 50% respectively. For Jane it is a slight possibility, for Blanche a definite threat.

Linda, Phyllis and Teresa's views illustrate the "Marked Woman" philosophy on recurrent disease:

".....because up to that I was being given a mammogram, not every year but every other year, now I have to wait three years and to me, that's too long, for me. Not too long for the women who haven't had breast cancer, because if they've never had it that's, but how can I be put in the same thing as them? because I have had it. And what really worries me now is, I've only got one bust you know. I mean when I had two that's how I found my breast cancer because I compared one with the other. I can't do that now, them other women can if they're checking their self but I can't. And because I have had it I feel in my head, that I am more at risk of it coming back. I mean I hope... I don't live from day to day that it will come back, but I feel, I feel that my risk is greater than theirs, that it might.... having already had it....."

**Linda (aged 58, 10 years) interview 1**

R ".....I mean like, I had a problem with my rib and I had awful pain in this rib and then when I spoke to the breast nurse, then they was explaining it's the effect of the radiotherapy. I don't know that and I've been thinking I've got cancer of the bones." ".....well I think, well the way I think, I think yes, I am going to get it back. If I've got the cancer gene in me then I'm going to get it back."

I "So not a matter of if, it's a matter of when?"

R "Mm." **Phyllis (aged 54, 9 years) interview 1**

- I "So if I said to you on a score of 1 to 10 or a percentage 1 to 100 what do you think your chances of risk are what do you say, how would you estimate it yourself based on what you feel?"
- R On my gut feeling I've got now?
- I Yes your gut feeling?
- R 98
- I What 98% chance of it coming back?
- R Yes." **Teresa (aged 64, 7 years) interview 1**

The women's estimates were heavily influenced by their understanding of risk factors.

These were often well-informed evaluations based on size of tumour, lymph node involvement and the treatment prescribed. Many women were aware that larger tumours, timing of detection – "they caught it early", lymph node involvement "it hadn't spread to my lymph nodes", having chemotherapy, radiotherapy, mastectomy, endocrine therapy, or a strong family history, equated with a higher risk of disease progression:

*"So he went out and came back in, got the results over the phone and read these. "Da um da dam, right you've got a very aggressive carcinoma, spread to the nodes, and it's Class 3 or something, malignancy. So you've got, you've got breast cancer, you may as well have it off." **Blanche (aged 63, 13 years) interview 1***

Risk beliefs (for recurrent breast cancer) influence expectations of treatment and appear to be constructed from a combination of a priori information, information obtained from the "bad news" and 6 week post surgery consultations and the assumptions and schemas, or personal rule books, created at that time. During long-term recovery women look to healthcare professionals to reassure them that their beliefs still hold true and to give them *long term* estimates of their risk:

*"Well I think simply Dr X said seven years. He said, if you don't have a recurrence in seven years it won't happen and so the nearer to seven, getting to the seven years the better I felt, simple as that."*

**Dorothy (aged 57, 7 years) interview 1**

*".....well, going back to the clinic about four years ago, when I, on one of my appointments I saw, he wasn't, I think it was the gentleman there I saw and I think it was after I'd been going six years and I said to him what's the risk, let me get this right, oh what chances are there of the, of the cancer coming back? Because I'd gone six years, does that raise my chances of it not coming back? And he says, do you want me to be honest with you? and I says, yes I do. And he says, not really, no. So he thought it could come back, because I was of the opinion that the longer you get away from it*

*then maybe the risk lowers, or it maybe didn't come back but that wasn't his, he said, do you want me to be honest? I said yeah, he said no, it doesn't lower the risk."*

**Linda (aged 58, 10 years) interview 1**

It would seem that clinician's estimates of risk are also variable. Women doubt these statistical predictions of their future when they encounter others who are not so fortunate:

R *".....and as I say I suppose I do get sort of support from this group that I'm with, so you know, but of course you do get, I mean someone in that group has just had a mammogram; and found that it's spread into her other side, so I mean that's, as soon as you hear that sort of thing you think - oh my God! So I mean, I've just had a mammogram and I mean the, you know the worry of waiting for the result to come back; and of course when it came it was okay; and that was a real relief. But....."*

I *"Does that happen? Sorry can I just stop you? Does that happen with every mammogram, or just because this friend of yours who's recently had a negative result?"*

R *"Well I suppose with every one I suppose, but I think it was particularly worse, because she'd been signed off after her five years; and then of course, she had the mammogram; and it was picked up of course on this, so you tend to think that's a bit of a worry, because the mammograms are sort of, what? Every three years I think aren't they?"*

I *"Yes that's right."*

R *"So I think obviously this had happened, what if it hadn't been picked up then? You know I think that was, as she said you know, when would it have been picked up after that? It would probably have been quite a long way along the line you know. So of course, she's had to have her other breast removed and is just recovering from that now. So obviously, I think these are always little hiccups along the way, because you know, because you hear, I mean several people I know in this group, have actually died. I mean people that I was being, that were being treated at the same time as me. One lady has died and another one in the group she died as well. So that's, I think it always brings it to the fore really I suppose. I mean as much as you try to get on with your life as well."*

**Cathy (aged 61, 5 years) interview 1**

Women invariably looked to healthcare professionals to give them long-term predictions, or estimates of their risk of recurrent disease. This quantification equates in their view with an element of control and gives comfort and reassurance. This reassurance is challenged when their peers (women with similar clinical characteristics, treatment, or duration of follow-up) go on to develop recurrent disease.

### 4.6.3 Risk-Reducing Behaviours

The strategies the women employed to try to reduce the risk of the disease returning and regain control varied. They ranged from changing or restricting their diet, being knowledgeable about breast cancer, avoiding stress (changing or giving up their job),

developing a positive attitude – to finding ways to obtain more frequent mammograms, or contact with healthcare professionals. The existing policy of a combination of clinic attendance, mammographic screening and physical examination was considered by many women to be an effective way to closely monitor disease and detect recurrence at an early stage. Some women valued mammograms over physical examination, for others the reverse was true. Some women valued the opportunity for discussion with breast care nurses others did not see the need. By using this combination, all of the women's criteria were satisfied, regardless of which of the three methods they had the most confidence in.

Women interviewed in this study described how they had tried to find various ways to reduce their risk of recurrent disease as soon as they had been diagnosed. This is illustrated by one woman who describes how she decided to have radical surgery to treat her breast cancer. Elizabeth (aged 65, 7years), describes how she insisted on mastectomy rather than a wide local excision. She notes how she felt this would reduce her risk of developing recurrent disease and assumed that if she had all of her breast tissue removed; it would ensure that the disease would be unlikely to return:

R *"So I came in on the 16<sup>th</sup>, came in on the Sunday, they came round on the Monday morning, they said Xxxxxx Xxxx? I said Yes? Lumpectomy? I says No, no, no! and they said yes! I says "No, no, no! I says, I want a mastectomy. I says, just take it away because I don't want to know, because I was talking to other patients in the hospital and one or two of them, and there was one lady there, this was her third visit and her lump had come back and I thought well I don't need this, I don't want it. I mean I haven't got a very big bust anyway so you know it's nothing to me. And I hadn't got a man in my life at the time I must admit; and I thought I don't want it. So that is why I decided to have a mastectomy."*

I *"So you, so the idea of having the mastectomy then, was to try and reduce the risk?"*

R *"To reduce the risk."*

I *"Of the disease coming back?"*

R *"Yes of it coming back, because I didn't want it back, you know I just thought....." ".....but I know it is very, very hard for a lot of people to accept. I mean I know we've got cancer in the family"*

I *Yes*

R *"My grandma died of it, my nephew died, he died of leukaemia when he was four, my brother died of it in 1996, he was riddled with cancer so we had accept that it is in the family." ".....my brother he died 1996 and they gave him nine weeks, they couldn't even operate, they couldn't give him chemo, he'd gone too far and he died of cancer. And thought you're not bloody having me yet mate because I*

*ain't ready to come. But X (brother) would have, he would've, he died, he wouldn't have felt the same, he would have supported me. They only give him nine weeks from diagnosing it to when he passed on yeah. So I was determined, I was determined that I wouldn't want to join him because I'm not ready yet so....." Elizabeth (aged 65, 7 years) interview 1*

Elizabeth opted for mastectomy in the belief that this reduced her chances of an early death from breast cancer and considered her prognosis to be much less threatening than that of her brother as a consequence.

Nancy's (aged 55, 15 years) describes how her beliefs swing from fearing a genetic predisposition increases her risk (her mum died from breast cancer), to trying to reassure herself that discharge from regular outpatient follow-up means her risk is fairly low, so she has mixed feelings and is confused about her risk:

*I "So if I asked you to gauge it on one to ten or a percentage what do you think the risk is of you having problems in the future, do you mind if I ask you that?"*

*R "It probably isn't that much more than someone who's not had breast cancer I suppose after all this time, you know after fifteen years. I suppose genetic, I mean I don't know whether my cancer was one of these BRCA1 and 2 gene jobs or not, because I don't think they'd got that far in looking into it necessarily then and I don't think they've done any further tests on me to find out so I don't know. I mean the fact that my mum died of it probably predisposes me to it more than if she hadn't. She was an only child, my father was an only child so we don't have very many relatives to talk about as to whether anybody else in my family suffered that way or not, I don't know. As I say I don't honestly know whether, I mean presumably they wouldn't discharge me if they felt that my risk was that much greater than anybody else in the general public these days, so you know I think that's an encouraging sign really I suppose."*

***Nancy (aged 55, 15 years) interview 1***

Many changed their diet and instigated an exercise regime, while some put their faith and trust in alternative therapies and natural supplements:

*R "My friend....., a lot of people at our church have had cancer in the bowel, a lot. Perhaps I'll feel a bit different now once I get into my seventies an awful lot... it's one after the other have fallen off the boat. I can't believe it. But my friend doesn't like cooking and she's had a lot of meals where she buys them and sticks them in the oven and somebody was saying that on (local radio station) that preservatives in some foods weren't a good idea, you know to be having fresh things was a lot better. But when I see some of the veg that comes into supermarkets and it's been flown from Kenya and this, that and the other they don't seem to have very much shelf life, even when they're within the date on the thing.*

*I Yes.*

*R And I think we ought to go back to cutting that out. And I mean I belong to the WI (Women's Institute) anyway, we don't well we don't approve of ferrying things right round the world when we could get them on our own doorstep, even if we have to pay a little bit more. And the purity of your food, and I was just thinking this the other day she doesn't, whenever we go out she's always shovelling her salad onto my plate and you know you're bound to think I wonder what's caused*

*this, I wonder if she's had too many food with preservatives in, not enough five veg, fruit and veg you know. So I do try to have that. And I persuaded me husband to have a Weetabix some time ago because he used to say you know he wasn't going to have any breakfast and things like that years ago and after I'd had the cancer I did look at nutrition and stuff like that. You know yeah a friend of mine cut out all red meats altogether and I haven't got as far as that, I like a nice steak but suppose we should, we ought to eat more fish. I'm not very keen on fish, I think it leaves the house smelling so much but you know I think an awful lot of people my age just give up on cooking and stuff like that and I still enjoy it, even though I don't find it easy to stand and stuff like that."*

**Queenie (aged 70, 7 years) interview 1**

Being well-informed, actively seeking information related to breast cancer, having a positive attitude to life and attempting to avoid a stressful lifestyle; all contributed to feelings of control over the disease and an ability to take personal responsibility for their own well-being. These were the elements of the new "schema" (as opposed to the old "schema" – that breast cancer was unlikely to happen to women like them):

*R     "....and obviously she's had cancer and sort of she said that a dairy free diet was, she thought that was a good idea and she'd sort of carried out all this research so I thought well why not try that which is what I've been doing. Whether it's helped or not I don't know."*

*I     "Did it help you though, do you think?"*

*R     "I think it helps me because I think that in a way I think that's something positive that you can take responsibility for."*

**Cathy (aged 61, 5 years) interview 1**

These strategies proved effective as a way to keep fears and concerns at bay for the majority of the time. However, stories in the media (newspapers, magazines, television) of women recently diagnosed or with recurrent disease triggered old anxieties, and existential concerns.

Women described feelings of uncertainty and lack of control which they had thought were long buried; but came flooding back:

*R I thought that's terrible really, because at the time Paul McCartney's wife.....*

*I Was in the news, yes?*

*R Yes it was all in the media and every time you put the television on it was about Paul McCartney's wife and I thought, and then she died and I thought well what chance have I got? She's got a vast amount of money, she's got the best care in the world and what chance have I got and that's all I thought about....."*

***Phyllis (aged 54, 9 years) interview 1***

This also happened when they had what they termed a "scare", a potential disease recurrence which after investigation, was found to be benign. These episodes were seen as a "dry run" for the real thing. That is, the women experienced the same level of trauma and went through the same emotional turmoil, as if they had received the news that there was a further malignancy. This left them with residual anxiety regardless of the level of information or reassurance given at that time.

Teresa explained to me the extent of her anxiety and her chosen solution:

*I "...so, you said to me (before the tape started running), that you've been trying to get an appointment to go back to the clinic to see a consultant because there's some things you want to talk about. You explained to me that you've had a couple of scares since you had your breast operation and it's worried you about your risk of the disease coming back. And although they've amounted to nothing and you've been told they're normal it's worried you."*

*R "That's right."*

*I And so you think the answer might be to have a, what we call a prophylactic, a preventative mastectomy on the other side?"*

*R "That's correct."*

*I "And that would help you feel that you'd reduced your risk as much as you could and you wouldn't worry so much, is that right?"*

*R "That's right, that's correct." ".....you know what I mean, I'd had them scares that, oh yeah, well it was in my head, yes, the cancer was back, do you know what I mean? It was like, oh God! here I go again and it's like well a month down the line I went up and I seen Dr X. Do you know who I mean?"*

*I "I do, yes."*

*R "And he just held my hand he said, you've been through hell but you haven't got breast cancer and I just didn't believe him. I just looked at him and went what? You know and....."*

*I "Because you'd convinced yourself that it was going to come back positive?"*

*R "Oh God yeah."*

*I "So I'm just going to clarify this for the tape. So you, there was some suspicion that the cancer might have come back and you had biopsies and investigations and then everything was alright?"*

*R "Mm."*

*I "...but you'd convinced yourself by that time that it wasn't alright?"*

*R "Yeah."*

- I ".....and then even though you'd been told that, it's left you insecure that it might come back because you know you went through all that."
- R "Yes, yes."
- I ".....So if I said to you on a score of 1 to 10 or a percentage 1 to 100 what do you think your chances of risk are what do you say, how would you estimate it yourself based on what you feel?"
- R "On my gut feeling I've got now?"
- I "Yes your gut feeling?"
- R "98."
- I "What 98% chance of it coming back?"
- R "Yes."
- Teresa (aged 64, 7 years) interview 1**

This constant reappraisal of threat creates cycles of anxiety, re-evaluation and control. The coping strategy adopted during the recovery phase and personal experience of others with cancer, assist the formulation of these beliefs about risk.

Assessments are made by the women of personal risk and the factors and strategies which may maintain or reduce that risk. New information from professionals, social comparisons, personal contacts, media-derived information, is compared and then assimilated or rejected. This enables an individual to create the illusion of predictability and control; thus reducing levels of distress in an attempt to increase their level of emotional and social function.

The broad spectrum of factors illustrated by the women interviewed: health behaviour, surveillance methods, other cancers, duration of survival and the ability to quantify risk; are evident in their differing approaches to the way they cope with long term recovery and will be outlined in the next section.

## 4.7 Coping Beliefs

The previous two sections help to illustrate how pre-existing and acquired beliefs about breast cancer relate to personal estimates of risk of recurrent disease. In turn, the third section will describe how beliefs and fears help to shape the coping strategies adopted of *contamination* and *restitution*. The constantly changing, adaptive nature of coping in the

context of breast cancer is explored, together with the *role of social support* and its ability to enable women to manage its psychological impact.

Cultural and societal expectations for the appropriate way to manage life-threatening illness and breast cancer in particular; mean that there is social pressure on women with breast cancer to be "strong", "think positive" and to use a popular World War II slogan "keep calm and carry on". The expectation is that the disease will be managed psychologically and emotionally and make as minor impact on daily life as possible (Cohen and Lazarus, 1973, Low et al., 2006, Merluzzi and Sanchez, 1997, Petticrew et al., 2002, Sears et al., 2003) .

However, the interviews captured the variety in the coping strategies employed by women recruited to the study. The differences seemed to be related directly to the differences in their belief systems. The aims of each coping strategy appeared to be three-fold:

- To manage fear, threat and anxiety by either minimising the threat or creating the illusion of control over it.
- To continue with daily living

Either by attempting to get back to normal, that is regain the life they had before (restitution) (Frank, 1995) or, reinvent themselves and create a new life (contamination) (McAdams and Bowman, 2001)

- To maintain significant relationships

Some women placed great value on the preservation of their credibility, their status and their role within the social world they lived in. The potential loss of these and the resulting rejection, social stigma and discrimination were to be avoided at all costs.

Gladys (aged 63, 11 years, interview 1) suffered discrimination at work. When her work colleagues visited her in hospital, she felt obliged to put on a show and be "a pleasure to visit". She described feeling betrayed by her boss who was very unsympathetic and told

her colleagues she wasn't up to her job. She took early retirement because she felt so unsupported.

Rita (aged 55, 5 years, interview 1) avoided this by maintaining her role as a teacher. She re-organised her surgery date to coincide with the school holidays and her radiotherapy for when she wasn't teaching in class. She taught in the morning and had her radiotherapy sessions in the afternoon. This ensured that there was minimum disruption to her working day and she was seen to be contributing to the work of her team.

For Cathy (aged 61, 5 years, interview 1), the fear of rejection and loss of status was from within her own family. She told no-one but her husband of her diagnosis and treatment; for fear that other members of her family would pity her and avoid her company.

A variety of coping strategies were used to deal with long-term recovery from breast cancer and the withdrawal of annual outpatient clinic visits. The influencing factors for the adoption of a particular strategy were beliefs relating to risk of recurrent disease, locus of control and the level of social support available in the long-term. Adapting to the changes in care provision required that the women confront challenged basic assumptions and carefully created schemas to recreate them and move forward psychologically. This was achieved with differing levels of success.

Their strategies and tools for coping with this significant life-event varied enormously. To a large extent the information collected from the interviews followed the well-documented patterns and findings of previous research conducted in this area. Their stories were often those of either "redemption" or "contamination" as described by McAdams and Bowman (McAdams and Bowman, 2001). Their work highlighted the distinctions made by those who reach a crossroads in their life, between their choice to

view events as a positive or, a negative experience. They represent how an individual makes sense of what “really” happens and how they choose to remember and understand it. An individual’s adaptation to the present is often shaped by past events, a joint psychosocial construction by the individual and the culture in which they live.

#### 4.7.1 Redemption

In the redemption narrative, negative events are seen as problems to be solved, as a drive to achieve a kind of salvation, to liberate oneself and rise like a phoenix from the flames (McAdams and Bowman, 2001), these are the women in the “close shave” group. Finding benefit in negative events brings hope and the exertion of *interpretative* control over uncertain circumstance (Rothbaum et al., 1982).

Sarah (aged 65, 6 years, interview 1) explained to me that she had learned to become more assertive and independent. She felt stronger having coped with her diagnosis and treatment and was determined to get as much fulfilment out of life as possible. She felt she appreciated her life more. Her breast cancer diagnosis, has given her life more value she feels, she now has different priorities, finds beauty in small things and dismisses materialistic values. She gets angry and frustrated when she hears other people complaining about things she feels are unimportant; or if they give more priority to what she sees as a materialistic way of life.

#### 4.7.2 Contamination

Alternatively, others construct a contamination narrative (the “marked woman”), viewing the event as a blight on their life, a permanent stain, which dictates a negative perspective on future events. Irene is constantly afraid and feels under constant threat:

- R     *"..... I'm afraid I'm a very, very big worrier, I do worry about it. I mean the least little thing that happens I think, oh it's gone somewhere else now, you know...."*  
 I     *So, you're still living with the fear of it coming back, even after all this time?*  
 R     *Oh yeah.....".....and, I mean, I just said to my husband, "This is it, its spread" and "this is it, I'll not get a second chance, I've had my first chance." And I went*

*to see my doctor last week and I had a sample take, sent away, and it came back negative, there was no blood in it, which I'd had one show of blood a fortnight before that, I hadn't had any since, but he says "We need to do a colonoscopy, just to make sure that everything's as it should be." So I'm dying, you know in my mind I am dying and it doesn't matter how much my husband says to me you know, they're going to check it....", ".....So until I've been there I don't know, but I mean, as far as I'm concerned this breast cancer that I've had that was really nothing compared to what some ladies have, has now spread into my bowels....." ".....Mm, so the, so the, the thing that I find is if anything, anything happens, that involves my body of any description, I've got cancer".*

*I "You don't think the fear's actually going to go away?"*

*R No, because when something else hurts I shall think its spread to there hasn't it, yeah. And I'm sure there's not only me".*

***(Irene aged 69, 8 years) interview 1***

### 4.7.3 Restitution

Many women provided what Arthur Frank calls a "restitution narrative" (Frank, 1995).

That is, an emphasis on both personal desire and societal expectations to restore their previous lifestyle and status as an individual free from ill-health. Illness is viewed as an obstacle to be overcome and assumes that control and self-determination are a "given".

The body is viewed as a machine which has broken and needs to be fixed, restored to its original level of function. The cultural expectations of healthcare professionals working in modern medicine facilitate this approach. If this is achieved, there is the presumption that the same solution can be applied (successfully) again and an element of predictability is achieved.

Rita is a school teacher and used this approach to maintain her social role throughout her treatment period:

*R The one thing that I was concerned about was going back to school in September because we were having a new teacher start and I was working part of the time in her classroom to help her to settle in and I wanted to be there on the first day of term to help this new teacher. They sent me a letter to say my surgery date would be mid September, towards the middle of September so I rang through to the appointments desk and I explained that being a teacher I would have nine weeks off in the summer holiday, I said "But you've sent me this appointment," I says "and it's about a week after we started back at school. Is there any chance that it could be brought forward a little bit so that my surgery actually takes place during the time that I'm off work so that I don't have to have time off for the surgery.*

*I So you really tried to slot it into your life instead of the other way around didn't you?*

R *Mm I did". ".....And I was originally going to go in as a day case, go in first thing in the morning and come home that day, provided obviously that I got over the anaesthetic alright but she said that it would be an evening surgery time and therefore I would have to spend one night in the hospital. That was quite acceptable but it meant that I could have my surgery and I made it to school on the first day of term. So I was quite happy about that. Yes and it all slotted in around my lifestyle. But I wasn't, I can't ever remember unduly concerned about the fact that I had cancer because I'd had so much reassurance from all the staff at the hospital. On the Friday after I'd spoken to the doctor the breast care nurse took X and myself down to see some ladies who had had breast cancer, I think one was about 15 years before me, one was about 20 years before. And they made us a drink and they sat us down and just had an informal chat about, yes you've got cancer but we had it, we've had the surgery, we've had all the after treatment and look we're still here, large as life. So there is hope afterwards".*  
**Rita (aged 55, 5 years interview 1)**

Anecdotal evidence challenges traditional coping theory categories: "avoidant" copers, "information seekers", etc. Coping skills and strategies are learned and adapted. They are dynamic and organic and not fixed. Sometimes this comes from prior experience – health "scares", sometimes from other members of their family – parental, or friends. Things that work are retained and used again. Things that don't, are discarded and the strategies employed are directly related to the perceived level of threat and the impact on significant others at that point in time.

#### 4.7.4 The Role of Social Support

The women interviewed consider social support to be of paramount importance and incorporate it as a valuable component of their coping strategy. Relationships outside the immediate family with other women often seem to be the most useful. This is primarily because partner distress prevents them from communicating their own. Women describe hiding their own distress to protect family members, not wishing to burden them and cause them distress; but also express anger at poor communication from partners and other close family members. Women "keep strong" and shield others from their distress out of fear of withdrawal, or rejection from others, or erosion of their status/role/credibility. 8 of the 20 women interviewed, highlighted the fact they had deliberately chosen to avoid distressing other close members of their family. They wanted to avoid burdening their families with more distress than they already had and

also avoid having to support others when they were already struggling psychologically themselves.

Wanting to protect loved ones from distress, not wanting to be the cause of this distress, places a terrible burden on an individual when they most need support. They feel isolated from the very people they need love and understanding from. Gladys (aged 63, 11years, interview 1) experienced this conflict within her own family situation. She was not permitted to discuss her worries within the family. She told me that her husband and 3 daughters refused to talk to her about her breast cancer. She and her husband coped by being "busy" all the time. She stayed with her sister periodically and was able to relax at her house. Her grandson gave unconditional love, warmth and physical affection. One daughter used her friend's mum to talk to, this made her feel hurt and displaced and created a barrier between them. Another daughter – shut it out completely. Her sister-in-law was in the terminal stages of liver cancer. She found this very upsetting. It made her very fearful and acutely aware of her own mortality. Her sister-in-law wanted to talk and expected she was willing, but she found it difficult because they were at different stages of disease. She experienced distress and had already started to grieve for the loss of her sister-in-law.

Nancy (aged 55, 5 years, interview 1) always felt her husband was her confidante but talking about her breast cancer instilled such fear and distress that she was unable to discuss it with him.

Selective disclosure as a coping strategy (Bolger et al., 1996, Holmberg et al., 2001, Wellisch, 1985), was used as a delay tactic to assimilate information, create meaning and assess the impact of diagnosis and treatment. This appeared to be done in order to wrest some form of control and a sense of self determination from an uncertain circumstance. This avoided distressing others unnecessarily, or having to deal with their distress out of fear of rejection from loved ones, or social stigma, loss of status, role and

credibility. In addition it helped avoid negative effects on relationships both at home and at work as well as an individual's financial situation.

For example. Irene hid her fears that her disease had recurred for many months, before she sought help – to avoid distressing her family. She told me she preferred to delay the investigation of possible recurrent disease in order to prolong happy, times with her family and was loathe to disrupt them regardless of the effect on her health:

*"The only problem I had was I think it was the, about 18 months ago I found this lump. And I didn't say anything for a while because my husband was retiring and it was Christmas and I didn't want to upset the family. Then we were going away in February and I didn't want to spoil that holiday and I kept this under my bonnet for a while. And then we came back from holiday and I said to my husband "I think I've got a lump". I rang the clinic on the Monday morning."*

**Irene (aged 69, 8 years) interview 1**

Phyllis went to great lengths to hide her diagnosis from her daughter and damaged their relationship as a consequence. Her husband hid what he perceived to be distressing information from her. I also asked Phyllis if she and her husband were able to support each other during the initially period of diagnosis and treatment:

R "Well, he didn't really."

I "Did you talk about things?"

R "Not a lot, it was because we was frightened. Like I'd come home, he'd come home from work and he'd bring the daily paper and after dinner in the evening I would look at the daily paper and I'd think oh there's something wrong, and there'd be pages taken out of it."

I Anything to do with breast cancer?

R "So he'd taken it out so I wouldn't see it."

I "So he tried to protect you."

R "Yes, he did yes."

I "So you said you couldn't talk to anybody, but you didn't want to talk to the family?"

R "No."

I "So what would you have liked, would you have liked to be able to talk to somebody?"

R "Yes, yes somebody who I didn't know, so I knew they wouldn't worry about me because they don't know me and I wouldn't give them you know any worry."

I "And what sort of things would you have wanted to talk about, what would have been helpful?"

R "Well to understand the illness more, I don't really understand. I mean if you get a lump, how long can the lump be there before it travels through your system and.....?"

I "So the way that breast cancer works, you would like to have talked about that?"

R "Yes ." **Phyllis (aged 54, 9 years) interview 1**

Nine years after her diagnosis, Phyllis is unsure of what to expect and how vigilant she should be. She knows her husband is likely to downplay any problems or worries she may have, out of a sense of trying to protect her. So she is unlikely to voice her concerns to him. Selective disclosure was not as helpful as she imagined it would be. It created barriers between family members and left her feeling isolated:

R *".....I never told my family, only my husband, I never told my friends at work, never told no one."*

I *"Why was that?"*

R *"Because it's the way I am, I'm a private person, I think well why should I give friends or family something to worry about when they've got enough to worry about."*

I *"So it was out of not wanting to burden other people?"*

R *"Yes that's right."*

I *"So are you quite self sufficient, is that the way you deal with things?"*

R *"Yes I'm a very independent person, I don't kind of show my feelings, I keep everything bottled up and I'm very hyperactive person, I think its because I've got to be busy doing things, because when you're busy doing things you're not thinking about things."*

I *"So you had this shock so you told your husband, did you tell your daughter?"*

R *"No."*

I *"Does she know now?"*

R *It come to a head just after the.... after I'd had the operation and I was having the radiotherapy. She was at school and she was doing exams and she, something was going off at school and she wanted something to be done, I think a pair of trousers taken up or something and I'd not long come back from the hospital and I used to walk to the hospital and walk back and I just didn't feel too good this day and I says, Oh I'll sew the trousers tomorrow. No I want them now, you know teenagers and she said, I don't know what's the matter with you just lately, you always seem to be tired and.... and then I thought, I left it for a while and I thought this is causing arguments between me and my daughter and it, that shouldn't be. So I thought I've got to come clean with my daughter. Well bearing in mind I knew she'd finished, she'd sat her exams, she'd done them, they was out the way so I spoke to my daughter about it and then that caused another problem, she was annoyed with me because I didn't confide in her. But I couldn't make her understand that I did it because I didn't want her to make her worry, why should she be worried about me because she's doing her exams and I'm in the hospital and so that's why."*

I *"Has she forgiven you?"*

R *"No she says she'll never forgive me, but I tried to make her understand that she did come home about six months before I had the breast cancer, her friend's mum had died of breast cancer and that's another one of the things I didn't want to tell her and because she was at a young age where she needed her mum. But she still hasn't forgiven me to this day." "...but that will, she will alter as she gets older, when she has children of her own and then..."*

I *"You think she'll forgive you one day, she'll understand?"*

R *"Yes she'll understand. But I do know it had a big effect on my husband because he did age a lot because he'd got all that on his shoulders and of course he couldn't talk to any member of his family because I didn't want the family to*

*know. So he'd got nobody to talk to and it was difficult, we couldn't talk together unless we went out for a walk with the dog."*

*I "Because your daughter was at home?"*

*R "Yes." Phyllis (aged 54, 9 years) interview 1*

Psychological support via health care professionals was an important aspect of follow-up care, again often because social support networks which seemed apparent on the surface were actually unavailable. The reasons for this were either, because there was poor communication between family members/friends, or their refusal to acknowledge and discuss the long term impact of breast cancer. Many women found their choice of coping strategy conflicted with that of others. This left them feeling frustrated, lonely and isolated.

Breast cancer is not always seen as the issue which warrants the highest priority within a family. Circumstances may dictate that other members of the family, or other issues take precedence.

Frances,(aged 70, 5 years), finds life difficult because she is unable to acknowledge breast cancer as an aspect of her everyday life. She has subjugated her own needs to those of her husband. He has current health problems and needs her to support him both physically and emotionally. So Frances spends her time trying to be understanding and accommodate her husband's problems because they are more immediate and more visible - where as her breast cancer, is seen as a *potential* problem:

*R "...and my husband has been diagnosed with Parkinson's, he's diabetic, he's had a knee operation, he's had a lot of problems. But he's a very negative person, I mean I shouldn't be saying that."*

*I "It's alright it's not a problem, it won't go any further."*

*R "So it's been hard anyway living with him [laughs]"*

*".....He's been so good, I mean he's a lovely person as well - you know what I mean?"*

*I "Yes."*

*R "Very high principles and all the rest of it, but he's just that kind of person and he can be very difficult to live with. And I get very agitated about things so any problems that I've got seem bigger because of this. It's hard to explain it really."*

*I "But it, well I would imagine that it makes things difficult if two people live together and they have different ways of approaching the same thing?"*

*R "Mm."*

*I "Is that what you're trying to say to me?"*

- R "Yes, yes it is yes."
- I "If you both have problems, one would choose to deal with it one way and one would choose to deal with it in another; that must make it difficult?"
- R "Yes but I'm always thinking of him and how he feels and you know what I mean?"
- I "So you tend to downplay your own problem, is that what you're saying?"
- R "Oh yes, yes I just try not to have any problems but I can't help it."
- I "Not easy is it?"
- R "No."
- I "You're entitled to have your own."
- R "I know, but he's just you know..... I know."
- I "Does he rely on you, does he depend on you, emotionally depend on you?"
- R "Yes I think he does really. But at the same time he won't let me have any opinions. It's hard, it's really hard to explain."
- I "Yes, it's his way of coping though?"
- R "It is yes and the fact he's been diagnosed with Parkinson's it must be so hard for him because he's a big strong bloke you know and now he's got to rely on me even more, so that's really hard for him."
- Frances (aged 70, 5 years) interview 1**

The sense of isolation, of breast cancer creating distance between themselves and others was evident in the conversation I had with Sarah (aged 65, 5 years). When I asked if she found it difficult to talk to people about her breast cancer, she said people only wanted to talk to her when they were afraid they might find themselves in the same position:

*".....I don't find it difficult to talk to people about it, people just don't like me talking about it, they find it difficult". ".....They don't give you the opportunity, your friends. I've got very close to one young lady and she had a lump in her breast; and she came running to me, and I said, what can I do? Go to the hospital. I can't tell you, I can't say you've got breast cancer, or you haven't, you've got to go straight up there. I'm not going, I'm not going. I said, Yeah come on I'm going to drag you up. And that was it you see, I said, right you get up there. Lucky enough she hadn't got breast cancer but if I hadn't drug (sic) her up she wouldn't have gone."*

**Sarah (aged 65, 6 years interview 1)**

To counteract this, women often described how they formed relationships with other women they met as inpatients having breast surgery at the same time. When describing these relationships, they made comparisons with the camaraderie of the trenches in WWI. During the pre/peri/post surgery period, they bonded like soldiers fighting a battle together, used "trench" humour and formed friendships. Through shared experiences, the women helped and supported each other, followed each others progress and discussed issues they were unable to discuss with others.

The advantages seemed to be that they were all going through the same experiences at the same time and could sympathise and empathise with each other and offer suggestions for coping skills and strategies.

The downside occurred when one or more of the group members developed recurrent disease, or died. This caused ripples of fear, anxiety and panic creating feelings of threat and vulnerability and increased awareness of their own mortality and shortened life span. This was heightened because the affected member was diagnosed at the same time and was at exactly the same stage in their recovery as other members of the group. They were then forced to acknowledge and accept that they may be at risk themselves.

This happened to Cathy. Three of her breast cancer peers have died and she sees the benefits derived from her support group as a "double-edged sword". She described the anxiety she experienced when one of her peers developed recurrent disease:

- R     *".....and as I say I suppose I do get sort of support from this group that I'm with, so you know, but of course you do get, I mean someone in that group has just had a mammogram; and found that it's spread into her other side, so I mean that's, as soon as you hear that sort of thing you think - oh my God! So I mean, I've just had a mammogram and I mean the, you know the worry of waiting for the result to come back; and of course when it came it was okay; and that was a real relief. But....."*
- I     *"Does that happen? Sorry can I just stop you? Does that happen with every mammogram, or just because of this friend of yours who's recently had a negative result?"*
- R     *"Well I suppose with every one I suppose, but I think it was particularly worse, because she'd been signed off after her five years; and then of course, she had the mammogram; and it was picked up of course on this, so you tend to think that's a bit of a worry, because the mammograms are sort of, what? Every three years I think aren't they?"*
- I     *"Yes that's right."*
- R     *"So I think obviously this had happened, what if it hadn't been picked up then? You know I think that was, as she said you know, when would it have been picked up after that? It would probably have been quite a long way along the line you know. So of course, she's had to have her other breast removed and is just recovering from that now. So obviously, I think these are always little hiccups along the way, because you know, because you hear, I mean several people I know in this group, have actually died. I mean people that I was being, that were being treated at the same time as me. One lady has died and another one in the*

*group she died as well. So that's, I think it always brings it to the fore really I suppose. I mean as much as you try to get on with your life as well."*

**Cathy (aged 61, 5 years) interview 1**

Cathy experienced first hand what *could* happen to her, just at the time when her regular follow up appointments were withdrawn. So she received what she sees as contradictory information on risk. Her clinician assured her it was appropriate to be monitored less frequently and yet her friend has experienced disease recurrence after the same disease-free interval; causing confusion and anxiety. This raises several questions for her: What should she believe? What will happen to her? Is it safe for her to place her faith and trust in the judgement of her clinician? Despite this, because of her husband's distress and his inability to discuss it with her, Cathy is still gaining beneficial support from her monthly meetings with the group. She has access to reassurance, understanding, a sounding board for worries and concerns, at least once a month outside her family circle – 5 years after her original diagnosis, she still feels the need to use it on a regular basis.

I also had two requests for a support group, or follow up support, for husbands/partners who felt that they needed help to support their loved one to cope with breast cancer. One woman's husband pointed out at the recruitment discussion, that he had wanted more information and needed support for his own distress; as well as guidance on how to manage, or alleviate the distress of his wife. Phyllis (aged 54, 9 years) wished more help had been available for her husband. When I asked what she thought her husband would have found useful, what he would have liked to have talked about, who she thought he would have liked to have talked to. She said simply, "You know, somebody, just to let all his feelings out." Support for her husband outside of her immediate family she feels, would have helped them as a couple deal with the situation more effectively, support each other and put less of a strain on their relationship.

Not everyone finds outside support useful. Many women reported mixed reactions to support group input at the time of diagnosis. Some women were outraged and distressed by being expected to talk to complete strangers at a very vulnerable time. Some just felt the timing was inappropriate, that it forced them to think and talk about things before they were ready. They felt unable to refuse because it seemed to be the routine. Others found the experience invaluable. There were suggestions that this could be a flexible option with a wider window of opportunity, with women able to take this up when and if they were ready.

Nancy has found another way to gain support during long-term recovery. She used her role as mentor as a "legitimate" opportunity to discuss breast cancer issues. She transformed her need to talk through her feelings, into advice for others and discovered the benefits and freedom of being able to discuss topics previously reserved for self-contemplation:

R *"My husband I suppose really, that's about all really. I'm not a person who tends to pour out their troubles to lots of people. I don't really talk about it very much with him either. He's not good with hospitals at all, doesn't like coming to hospitals, doesn't like doctors so....."*

I *"So you're quite self sufficient?"*

R *"I'm pretty self sufficient I would say yes." ".....I think if anything, because I had breast cancer so early quite a number of people I know have developed it since and so I've found myself in a mentoring role if you like, for quite a lot of other people. A number of friends at church and X, Y's sister in law, amongst, you know amongst others. I mean as I say there's several other people that I know through social activities, church and so on, and school and stuff like, you know I've found myself going and talking to them and saying oh well this is what happens when you have chemo and this is what happens and so on, you know and so rather than me talking about my problems with other people - it's been more a case of me offering perhaps advice is a bit strong but you know at least...."*

I *"Support?"*

R *"Support if you like, to other people who've found themselves in the same position I suppose."*

I *"So do you see that as a positive thing or not?"*

R *"Yeah I do yeah, yeah. Yes I mean I suppose you know talking about it probably helps me as well as helping other people. You'd hope it helps other people, you know wanting to know what might happen but yeah."*

**Nancy (aged 55, 15 years) interview 1**

Social support from others is used to help women construct both coping beliefs and meaning; but both the source and level of support needed changes over time as their circumstances change.

#### 4.7.5 Coping over time

The issues to be coped with and the strategies adopted seemed to be time-related. At the time of diagnosis and the first few weeks whilst treatment is established, women talked about how they relied on the support of close friends and family and the Health Care Professionals who care for them. They described feeling severely threatened, vulnerable and fearful. They looked for information, advice and reassurance. They placed great faith and trust in the judgement of the clinical team responsible for their care this is echoed in the work of others who studied women at this point of their breast cancer experience (Lethborg et al., 2000, Stanton et al., 2002, Vachon, 2006).

The first year after diagnosis brings new experiences, new challenges and often brings them into contact with other women with breast cancer, either as inpatients in the hospital ward, or in the outpatient clinic. This peer support can be very helpful both to allow them to express their fears and concerns and to pick up useful information and strategies. It can also provoke anxiety as they hear of other women's negative experiences.

For many women, religion and spirituality helps to make sense of things. They feel safe knowing that their fate is in the hands of someone else. This corresponds with Lazarus and Folkman's theory of coping - the appraisal of a threat as benign or dangerous, to well-being and choosing to adopt an appropriate approach to manage it. L & F acknowledge that when a person feels unable to control or predict their own fate - they may adopt an emotion-focused coping strategy to deal with it (Lazarus and Folkman, 1984).

Some of the women interviewed for the study used distraction to manage fear and distress in the early years following their diagnosis and have a need for "projects" to take up their time and focus on. They use significant family events – weddings, birth of grand-children, long trips, a "holiday of a lifetime". This enables them to delay facing difficult, emotionally distressing situations until they have the emotional resources to cope and avoid low mood and depression. There is a commonly held belief that worrying, "going to pieces", feeling depressed, "not coping", "giving up", will result in a deterioration in their physical health and contribute to a poor prognosis and a hastening of advanced disease as well as socially isolating them. Women seem to know intuitively that anxiety and depression will reflect negatively on their survival. They are genuinely afraid of it and attempt to avoid it at all costs. They equate hopelessness with poor survival. This has been documented in the research literature following studies of women with clinically diagnosed anxiety and depression in ovarian and early breast cancer (Bodurka-Bevers et al., 2000, Burgess et al., 2005).

Elizabeth (aged 65, 7 years, interview 1), changed her strategy over time. She told me how initially when she felt under threat she avoided talking about her breast cancer, then once she felt she had some sort of control over the disease, she found benefit in being open about it and has now incorporated it and made it part of who she is. Later, several weeks after surgery, once she felt the threat had passed - she changed her strategy. She now makes jokes about her mastectomy, she has given herself a nickname relating to the fact she only has one breast and tells every one she meets about her situation. She has incorporated it into her identity.

Another example of changing and evolving coping strategies was a woman who participated in the study, who was 16 years post diagnosis and getting on with her life. During my interview with her she described how she had always shielded her family from her distress, never talked about it and had a psychological need for frequent surveillance/follow-up to give her "peace of mind". When I met her for the first time she

had been recently widowed – 7 months before. This time she completely changed her modus operandi and talked about her grief to anyone who would listen, expressed her emotions openly and frequently. She now has a potential aortic aneurysm – at the time of the interview she was waiting for an appointment for a scan to confirm this and was currently using avoidant thinking – “its probably nothing.....I’m not thinking about it, not telling anyone.....they will only worry”. Each time she has dealt with a stressful event in her life, she has adapted her coping strategy to suit her needs at that time.

The way women talk about concepts such as a “marked woman”, living on “borrowed time”, having a “close shave”, “I was lucky this time”, have already been described. During the long-term recovery phase, they often use tactics to manage this anxiety, which on the surface seem contradictory. For instance, one woman told me “I no longer have breast cancer, its gone, I’m better now”, but when I asked for her views on the change in outpatient follow-up, she told me she felt she needed annual mammograms “just in case”. This brings us again to what Festinger would term cognitive dissonance (Festinger, 1962), an attempt to consciously self-deceive and hold contradictory beliefs when the belief results in an inability to control a particular circumstance and reduce the level of threat.

The present example of dissonance, is women who believe that they need annual surveillance to prevent recurrent disease but no longer have access to it and feel powerless to change the situation. Then there are those women, who experience conflict between their anecdotal evidence of knowing women who have died from breast cancer more than 5 years after diagnosis; and the “scientific” evidence provided by their clinicians that they do not need annual follow-up. They also use minimisation and social comparison (Stanton et al., 1999), to convince themselves that their risk is lower than those of other women; for the same reasons.

The adoption of either the redemption, contamination or restitution narrative dictates the coping behaviour. Positive thinking is seen as a defence against depression and a poorer prognosis. Being pro-active and making life changes such as increased levels of exercise or a dairy free diet helps elicit a sense of control. Avoiding distress in others is a great and unwelcome additional burden, so finding an effective source of social support means anxiety and distress can be expressed and resolved without any cost to significant relationships

Previous studies have shown that women with breast cancer construct a coping strategy over time, it evolves and changes with the changes in circumstances (Knobf, 2007) (Deshields et al., 2005). "Flash points" force the women to re-evaluate and re-construct their strategies i.e. end of regular follow-up; or when they develop recurrent disease.

The interview data demonstrate that following the completion of their treatment, women lose the frequent contact with the healthcare team that they have become accustomed to. They often feel isolated and insecure and have the time and opportunity to think about the impact of their diagnosis on their long-term well-being. They try find meaning in it, need to put faith and trust in either the healthcare system, or their own intuition to recognise problems in the future. They renegotiate their sense of self or re-establish the life they had before. Close friends and family do the same, often trying to position the breast cancer in the past and expect their loved one to behave "as normal". This can create barriers to communication and leave women feeling isolated, unable to discuss deep emotional concerns. These different ways of approaching and coping with breast cancer, were influential in the way women interpreted the impact of the change in their follow-up care. I asked them to describe how they felt about being discharged from regular outpatient follow-up and this forms the basis for the second theme in the following chapter.

## Chapter 5 – Findings – Interview Data

### Theme 2 - A “blessing” or a “curse”?

#### 5.1. Introduction

The theme of “blessing” or a “curse” illustrates the women’s perceptions of the value of follow-up care - its benefits and its costs. The theme also explores the four reactions to the changes in follow-up care: positive acceptance, dissatisfaction, self-sacrifice and disempowerment.

During the interviews women’s views on their follow-up experiences were explored as well as their reactions to the change in their long term follow-up in terms of being discharged from this service. Some of the women interviewed, viewed their follow-up clinic visits as a “safety net” and had a positive attitude to their annual attendance. Others resented the anxiety and inconvenience they associated with the visits and viewed them in a negative way. Consequently when the annual visits were withdrawn, some women felt cheated and abandoned, while others were relieved and reassured that they were no longer required to be followed up on an annual basis. Regular, routine, follow-up clinic visits and the withdrawal of them have therefore been categorised as a “blessing” or a “curse”. These labels were intended to encapsulate the women’s perceptions of the changes in follow-up care as a gain - in terms of independence and self-responsibility or as a loss - of contact and support as well as feelings of safety and security.

During the interviews a variety of benefits of regular outpatient follow up care were identified, some intended, as well as many others that were unintended. There was a significant difference between the aims of follow-up as presented in the original aims of the service and articulated by clinical staff working in the clinic and those benefits perceived by the attendees to the clinic.

The vast majority of women interviewed viewed follow-up appointments as a positive aspect of their care and treatment and tolerated the negative aspects in order to receive these benefits. They gave a sense of peace and respite by providing transitory relief from anxiety and a short-lived euphoria. One woman explained she was always very apprehensive before her clinic appointment, just heard "everything is fine" then hurried out of the clinic, didn't want to stay and ask any questions but the euphoria only lasted for a couple of days. Another always had anxiety prior to appointments – this never went away, it happened every year she attended. She wanted reassurance that every thing was ok – ie no recurrent disease. She wanted to be in and out of the clinic as soon as possible then get on with her life in between.

Some women reported criticisms of the staff, the system, or the logistical aspects of the clinic, but in the main, they felt well-supported by the healthcare team responsible for their care. The value of breast cancer follow-up care and the positive and negative elements were explored in the interviews. Women explained how they used the annual visits as part of their strategy for coping with their long term recovery. They differentiated between the 3 different elements of follow-up care: *physical examination*, *mammography* and the *consultation*. They attached different values to these 3 elements depending on their personal circumstances and the way their disease was originally detected. The next section will describe how the women interviewed perceived the outpatient follow-up care they received in the context of the clinic environment and describes in detail why women varied in their preference for each element.

## 5.2 The Value of Follow-up Care - The Women's Perspective:

Analysis of the interview data would suggest that for the women in this study follow-up care was not simply viewed as an opportunity for regular monitoring for recurrent disease, they highlighted the benefits (and limitations) of the surveillance techniques

employed and their ability to attribute responsibility for this to the healthcare team. In addition to this, follow-up also appeared to provide a wealth of other, unintended benefits. Women valued the support and advice they received and explained how the clinic provided a form of sanctuary, an opportunity to compartmentalise their breast cancer and use the visits as time-markers or milestones.

Women also identified the perceived costs of attending the clinic:

- anticipatory fear and anxiety
- inconvenience
- lack of continuity in the healthcare professional they saw each time,
- dissatisfaction with the healthcare professionals' approach to pain management,
- maintaining dignity and privacy
- the burden of supporting those who accompanied them to the clinic.

### 5.2.1 Benefits of Follow-up care

The three elements of surveillance provided by follow-up care: mammography, physical examination and face to face consultation each appeared to provide value to women attending the outpatient clinic. For the women interviewed in this study, the method of detection of the original breast tumour seemed to influence how women felt about their breast cancer and the value they placed on the various aspects of follow-up care.

Koinberg et al (Koinberg et al., 2001) in their study , also identified variation in the value attributed to various aspects of follow-up and the need for individualised care to address this variation. Of the 20 women interviewed for the current study, mammographic screening was the mode of detection for 6 of the women and 2 women were diagnosed via a physical examination by their GP. The remaining 12 women self-detected a problem although not all of them had considered that breast cancer would be the diagnosis. Each of these methods of detection will be explored through quotes from the interviews.

## 6.2.1.1 Mammographic screening

Women who were completely unaware that they had a problem and were diagnosed via the routine screening programme – set great store by the regular mammograms that were provided as part of the follow-up programme. For example:

R *".....and you think well they're doing that all day so they must know what they're doing and if there is anything they'll look into it. But I mean right, on my own I examine myself, but I probably wouldn't find anything. In any case mine was too small to feel anyway.*

I *So it was picked up on the mammogram?*

R *It was picked up on the mammogram yes. So you do feel a little bit, well you try not to think about it actually, you just put it to the back of your mind.*

**Ursula (aged 70, 12 years) interview 1**

They were distrustful of the assumption that their risk is equal to their peers in the general population and resented the extended interval from 2 yearly to 3 yearly mammographic screening:

I *".....you said to me earlier when we were chatting informally, before we started the tape, that you feel different to women who haven't got breast cancer. You don't feel like you've, you said to me "I'm different."*

R *Yes because I've had breast cancer and I've had a mastectomy and I am different.*

I *And you feel you should be treated differently, is that what you're saying?*

R *Yes, yes.*

I *So what is it you think you've lost, what is it that makes you feel this way about you know you're not comfortable with the discharge, what is it you think that you're not getting that they're depriving you of?*

R *Because up to that I was being given a mammogram, not every year but every other year, now I have to wait three years and to me that's too long, for me. Not too long for the women who haven't had breast cancer because if they've never had it that's..... but how can I be put in the same thing as them because I have had it? And what really worries me now is I've only got one bust you know. I mean when I had two that's how I found my breast cancer because I compared one with the other. I can't do that now, them other women can if they're checking their self but I can't. And because I have had it, I feel in my head that I am more at risk of it coming back. I mean I hope..... I don't live from day to day that it will come back but I feel, I feel that my risk is greater than theirs, that it might..... having already had it.*

I *So... it makes sense to you that you should be monitored more closely than they are?*

R *Yes, I'm not bothered about going for the examination because I can examine myself to a certain extent, although I haven't got another bust to compare it with, but I would still like to be seen every two years at least.*

**Linda (aged 58, 10 years) interview 1**

The lack of confidence in mammograms to detect recurrent disease by some women, while others set great store by them has already been highlighted in the quotes above by Ursula and Linda. Frances and Rita had greater confidence in digitally recorded

mammograms. They perceived they were more accurate and able to detect smaller "deeper" tumours:

*".....I was expecting the mammogram which they'd explained and then I would have an examination just to make sure, because I think in those days everything didn't really show up, not that long ago is it but I think with a mammogram if it was very, very deep things didn't show up did it?"*

**Frances (aged 70, 5 years) interview 1**

*".....however, having said that when I went this September for my final check up, oh I've always mentioned it to the radiographer that the original didn't show up and this time she was using a digital machine and she said that's why it's more, that's why it's really important that you use the digital machine because it will show up. So that reassured me."* **Rita (aged 55, 5 years) interview 1**

There was a common fear of rapid progression of the disease. Some women believed that the disease could grow from a tiny tumour to extensive metastases in a matter of weeks or months – so a 3 year interval for mammography seemed irresponsible to them, as Teresa explained:

R *".....you see I've never done that, I've never been left three years. In fact when I first had my breast off I was every six months*

I *So how did that make you feel that it's now every three years?*

R *It's terribly wrong, in my eyes it's terribly wrong".*

**Teresa (aged 64, 7 years) interview 1**

### 6.2.1.2 Physical examination

Interestingly, mammograms were considered by many of the women interviewed to be of limited, or no value to detect recurrent disease. This was true particularly for those women with tumours identified by other methods (self-detection or physical examination), for these women there was little, or no confidence in mammography:

*".....I've been along for mammograms and once year it's just the left side, the affected side and then the following year it's both sides. But I don't, I don't feel very confident because it didn't show up on the original mammogram and yet I had cancer, it didn't show up therefore it follows, it's logical to me that it won't show up if it happens again." ".....so I haven't got that much confidence in a mammogram."*

**Rita (aged 50, 5 years) interview 1**

- I* ".....you've been coming to the clinic for these seven years then what did you get out of it, what did it give you?"
- R* Well it didn't give you nothing really because you went for your mammogram, it was always in my head I've been for my mammogram but it's a waste of time because you get cancer anyway.
- I* Right so you don't hold great store by the mammograms then?
- R* No and then I talked this through, it was a lady with nice grey hair
- I* Oh the nurse practitioner?
- R* And she's really, really nice person and she said a mammogram is only as good as the day you take it and I thought Christ I don't...you know what I mean?
- I* You found yours yourself didn't you?
- R* Yes
- I* You found a lump after you'd had a normal mammogram?
- R* Yes." **Teresa (aged 64, 7 years) interview 1**

Teresa perceived mammograms to be unreliable, she felt it was still possible to have breast cancer even if the result was normal, "only as good as the day you take them". The value of the follow-up appointment for her was she had a regular opportunity to discuss her feelings and concerns and, have a physical examination. Consequently, with the change in follow-up procedures with patients being discharged from follow-up she felt she had no effective means of early detection now that she no longer regularly visited the clinic and had lost access to physical examination as an aspect of her care.

Women who were diagnosed via clinical examination had great faith in this method particularly if they had a negative mammogram result less than 3 years before diagnosis. They had unrealistic expectations of its effectiveness as a method of early detection of recurrent disease. They valued the human input and the intimate nature and power of touch:

- R* ".....but you see there is nothing like somebody sort of feeling all over to make sure you are all right .....
- I* So you feel that the fact that they have had their hands on you....is that extra reassurance for you?
- R* "Mmm." **Anne (aged 65, 8 years) interview 1**
- I* ".....so what about when you came for your checkups then, when you came and you had your follow up appointments and you started to come to the clinic, what was that like?"
- R* Well, good.
- I* What did you get from it? What did it provide?
- R* Well just I think the knowledge, because they, even though you're coming, you always have that little doubt that you think okay, well I know everything is

*alright, but this is it really? so them checking me and examining me I just thought you know the satisfaction was enormous that I'm still okay and it was nice to be told and you know .....and I don't know really.*

*I Yes, so was the hands on, you know the physical examination, is that, was that, important to you?*

*r Yeah I still find that. I think this is what I'm going to miss*

*I Yes.*

*R That, you know, the fact that somebody is doing that, because although other times I did have, since after the first time I went, I had a double mastectomy, because it can return and just although I know the risk is now very much lower I'm still satisfied, you know someone, someone other than yourself telling you that, yes."*

***Jane (aged 63, 13 years) interview 1***

*I "...what were you expecting, when you got there what did you think it was for (follow-up clinic visits) and what, what did you expect to get?*

*R Well, I expected to have a mammogram if I needed one, and a full, an examination of me boobs to make sure there were no lumps in them.*

***Kathryn (aged 67, 9 years) interview 1***

They were less confident than the other women in the interviewed in the ability of a mechanical object (mammography), to influence their diagnosis. This may relate to the fact that medicine has evolved from an art into a science and the changing role of the doctor from a healer to a biomedical scientist/technician.

### 6.2.1.3 Face to face consultation

Those women interviewed who valued the face to face contact with the healthcare team gained reassurance that their physical health was good, that the disease had not recurred. They were able to ask "difficult" questions of healthcare professionals. They felt that the staff were able to give truthful honest replies about levels of risk, without minimising or sanitising their answers. The visits were used as milestones, women "ticked off" another year without any problems. Many understood that the first 2 years were the most crucial and that most disease recurrence occurs during this period. They were also aware that if they manage to achieve 5 disease free years, they have a better prognosis.

Some women felt the appointments were purely intended to deal with physical problems and anxieties about risk of recurrent disease, others expected psychological care and support:

*I "So how was that, how was the follow up appointment, how were the follow up appointments for you?*

*R Er alright, I was just convinced I was alright.*

*I And what did you get out of them?*

*R It was just a pain coming down and finding parking and messing up the day.*

*I So you found them inconvenient, did you find anything positive out them or not? What did you think they were for?*

*R Well I didn't think there was anything emotional, no emotional support, I wasn't expecting that I was just expecting confirmation that everything was alright.*

*I In a physical sense.*

*R In a physical sense yes." **Blanche (aged 63, 13 years) interview 1***

*I " .....so what do you think you're losing?*

*R I'm losing that, that, I have a regular appointment every year and I know I will be going up either to be examined or it's every two years your mammogram because it's not every year a mammogram. But one time of the year you went up and you sat down and you discussed what was happening with you, you discussed your feelings.....*

*I So it's an opportunity.....?*

*R .....had your examination, do you know what I mean, you can examine your body, examine under your arms, examine your scar and everything. The next year you go for your mammogram and then go for the results of that; plus you then talk to somebody."*

**Teresa (aged 64, 7 years) interview 1**

*".....you have little questions in your mind and you jot them down and then when you go for your yearly appointment you can ask them and that's sort of reassuring. **Anne (aged 65, 8 years) interview 1***

Blanche was looking for confirmation that she was physically "well" from her appointment whereas Teresa and Anne wanted the opportunity to talk through their feelings and anxieties. These quotes illustrate that despite the fact that each of these women were in long term recovery they had different requirements of the clinic and surveillance was not their only concern.

Dorothy felt she had missed out on the opportunity for psychological support and advice and explained why she thought her care was lacking in this respect:

*R ".....and then I suppose I'm not quite sure how we, ..... how the nurses deal with the sort of psychological impact .....*

*I Okay*

*R Because again that is usually considered to be their area*

- I Yes
- R *I just felt there's an awful lot of practical things going on here,*
- I *Right*
- R *Come in, lie down, give you an injection, that kind of thing but nobody ever says how are you feeling? really.*
- I *So, you would have preferred to have the opportunity to express yourself more?*
- R *I think so yes, yes. And I know that takes time and you've got a lot of people to process*
- I *Do you think, if that wasn't the case, do you think if the clinics were smaller it would be more likely to happen? or do you think it's something that's like a training need?*
- R *I don't think it's a training need, I think this is such a busy hospital*
- I *So, it's a resource.....?*
- R *I think it's a resource thing, I think people have got an enormous amount to do and there's so many patients and so many people to deal with so I think probably from the nurses point of view they may want to give more care and attention to their patients and they can't, it's just not possible with the time available. So no I don't think it's a training need. It might be but it feels more like a resource thing.*
- I *I was just trying to figure out then if you felt there had been, if you felt the nurse would have had more time, whether that would have helped you ask for support that you wanted, or to talk about the things that you wanted to talk to the nurse about, if you'd have felt it was less pressured in the clinic?*
- R *I think so yes.*
- I *So, what sort of things do you think you would have wanted to express? What sort of things didn't get addressed at the time?*
- R *I think probably the worries and the anxieties because you can talk a lot about them to people who are close to you, but then, but you also want to talk to people with the medical knowledge as well.*
- I *To give you information?*
- R *Yes.*
- I *.....and worries around recurrence, or what?*
- R *Just anything why is it hurting?, why is this implant hurting so much and how long is it going to be like this? and I don't know ..... anything really.*
- I *Just the opportunity?*
- R *Just the opportunity.*
- I *In case you needed it?*
- R *Yes." Dorothy (aged 57, 7 years) interview 1*

Dorothy perceived the consultations to be short and hurried. She felt that due to time and resource constraints, the staff did not have the time to devote to answering questions and her needs and concerns; were not being met. She felt intimidated by health care professionals in the clinic and did not feel confident to ask for psychosocial support.

For some women the clinic created a sense of community and they gained social support from their yearly visits via other women in the waiting room. One woman explained: "you feel like you belong to an exclusive club, but not one you want to belong to". The

women met the same people in the waiting room every year, sometimes the women they were inpatients with at the time of their surgery. This offered the opportunity for peer support and advice – discussions with other women in the waiting room and a chance to catch up with old friends. However, this could be a double-edged sword – when they no longer saw familiar faces, they wondered why – had their cancer come back? Had the person died? This created more fear and distress.

The face to face consultations were also a valuable source of information and advice. Expert knowledge was valued and the consultant breast surgeon or oncologist was seen as the source of this. There were concerns that General Practitioners would not have this knowledge. Anxiety arose when women became confused. What is normal after breast cancer? What is a result of treatment? What constitutes early detection of an abnormality?

The clinic allowed women to keep in touch with health care professionals, maintain valued relationships, creating the opportunity for “legitimate” access. This meant that women “saved up” worries and concerns for their annual appointment so that they were not viewed as “worriers”, or “time wasters”. They also used their appointments for information and discussion prior to decision-making - for example if they wished to request reconstructive surgery.

Gladys (aged 63, 11 years, interview 1) felt the clinic enabled her to keep up to date with new developments in treatment and provided access to advice/products such as prosthetics and appropriate clothing – bras, swimsuits, etc., specifically designed for women following mastectomy. She requested that the clinic staff raise awareness of the prosthetic service. She felt the onus was on the women to seek out information.

#### 6.2.1.4 Attribution of responsibility

Attributing responsibility for detection of new or recurrent disease, was a very important part of the coping strategies for the women in the study who felt they lacked the skills and expertise to self-monitor their disease.

The clinic visits allowed them to allocate this responsibility to the healthcare team:

- R *".....I think you feel, oh well I shall be okay for another twelve months, I think that's the kind of feeling you get because alright you can examine yourself but you're never 100% sure that you're right. And you think well people here know exactly what they're looking for and I think when they've given you that examination it sets your mind at rest and you think oh well I'm alright for another twelve months. But now you think well it's up to me, you know they obviously said well you'll get another mammogram but I don't know if it will be here or at a local place or what?"*
- I *Well I don't know, you could find out.*
- R *Yes.*
- I *.....my understanding is, that it's probably here but you'll have to check.*
- R *But yeah that's it, you feel a bit out on a limb actually.*
- I *So a sense of responsibility that it's your responsibility?*
- R *Yeah it's your responsibility now, nobody else's.*
- I *And then you wonder whether you're up to the job, is that what you're saying?*
- R *Yes you do.*
- I *To use a phrase, that you know it's your responsibility but you don't feel*
- R *You don't feel.....*
- I *.....well-trained enough to have it?*
- R *No, no I mean when you know a nurse, a nurse has got, knows exactly..... and when they're doing it every day....."*

#### **Ursula (aged 70, 12 years) interview 1**

A study conducted in Holland (Everdingen et al., 2008) revealed that 56% of the 169 women they studied had moderate to strong levels of fear of recurrence and this was unrelated to the time since diagnosis and Lampic et al's study (Lampic et al., 1994a) showed 33% of 197 women felt unable to self-detect symptoms of recurrent disease.

The findings from the Dutch study correspond with the interview data from the present study, which show that women vary in their confidence in their ability to self detect a problem and rely heavily on the skills and expertise of health professionals to identify potential recurrent disease.

### 6.2.1.5 The clinic as sanctuary

Women also described the visits almost as places of safety/sanctuary that they lurched to, from year to year on a stormy sea of uncertainty. The visits to the clinic for follow-up care seem to relate to Arthur Frank's analogy of the broken clock which stills tells the correct time twice a day (Frank, 1995).

One woman explained:

*"It's the one day each year when you can say, you don't have breast cancer today – that's invaluable and worth all the anxiety beforehand. Regardless of the physical benefits, the psychological benefits of that one day of certainty are immeasurable. 3 years is too long to wait for that".*

Another told me: *"I know it doesn't mean you won't get breast cancer again, but at least you know you didn't have it last year".*

### 6.2.1.6 Time-markers/milestones

Clinic visits were sometimes used as a way of marking time. Creating distance (in time) between the point of diagnosis and the number of disease-free years seemed to give comfort to some women. Each year without signs of recurrent disease gave hope that the disease may not return:

R *".....obviously odd days you feel a bit down, I suppose you wonder what the future is going to hold. But having come through the five years and sort of feel*

*.....*

I *....so you feel that the five years is a bit of a milestone really, it sounds like you do?*

R *Yes, well, I suppose each year is actually.*

***Cathy (aged 61, 5 years) interview 1***

R *".....and when I come out (of the clinic), I thought great that's another year gone and another year to go and that was it.*

I *So it's like ticking off you know....?*

R *Yeah tick if off.*

I *Tick it off, it's a milestone, you've reached it, gone past it, you're on, a bit further on.*

R *Yeah." Elizabeth (aged 65, 7 years) interview 1*

In her book, *"Good Days, Bad Days"*, Kathy Charmaz (Charmaz, 1991) suggests the usefulness of time markers – they fulfil the need for comparison and measurement – to see how far one has come. Anniversaries of events can be used as periods of reflection and points of reference. Outpatient clinic visits represent the milestones women crave to mark their progress and increase their perceived levels of predictability and control over the disease. Annual visits create the opportunity to re-visit the time of diagnosis and reflect on the positive aspects of their journey through the treatment period and into long-term recovery. Each year which passes without recurrent disease is viewed as a small victory and gives reassurance that for the moment at least, one is "safe" from the ravages of serious illness. The clinic environment gives comfort when women recognise women from previous visits who are also free from disease. Even the number of women attending the clinic provides hope and encouragement that recurrent disease is unlikely.

Time is important as a way of situating "self". Charmaz (Charmaz, 1991), relates perceptions of lived time to strategies for managing chronic illness. Her work with people living with chronic illness, gave rise to her assertion that people situate themselves in the past, present, future or everlasting future (immortality, life after death). They use the present, if the future is threatened or uncertain. This may well be the case for women with breast cancer and may be dependant on their adopted coping strategy and how they view their future.

#### 6.2.1.7 Compartmentalisation of illness

One woman explained that the clinic gave her breast cancer a geographical location. She described having somewhere to leave her breast cancer while she had regular clinic visits. She knew where to find it if she needed to but if not, she could leave it behind. Now she has been discharged from regular follow-up and no longer attending the clinic, she has to take it home with her. There is a need for this particular woman to compartmentalise the breast cancer experience in order to cope and move forward

emotionally, intellectually and geographically; so that it does not intrude on daily life. Many women talked about being able to put their breast cancer to one side, and get on with life in between visits. This enabled them not only to carry on with life as normal and but also concentrate on close family relationships.

The visits created the opportunity to revisit the possibility of recurrent disease at an allotted time in a "safe" environment. Visits were used as a touchstone, an opportunity for some women to bring breast cancer to the forefront of their thinking - having buried it for the rest of the year, to ask questions, gain information and address anxieties. Many of the women I spoke to schedule their annual holiday the week following their yearly appointment so that they can relax and feel "safe" for at least a couple of weeks each year knowing (their mammogram is normal, physical examination reveals no abnormality), they don't currently have recurrent disease. They crave reassurance, control, predictability and peace of mind, respite from fear and anxiety.

For some women, incorporating clinic appointments into an active action plan and their chosen coping strategy; helps to create the illusion of predictability and control. The broad spectrum of benefits quoted by the women interviewed, illustrate that there can be a wide variation in what individual women want and need from the same appointment. However, they also described the negative aspects - the "costs" of follow-up care as outlined in the next section.

### 5.2.2 "Costs" of follow-up care

There was often a downside to attending the follow-up clinic. The negative aspects of the clinic visits, although tolerated were significant none the less. There were descriptions of anticipatory anxiety prior to appointments, because they triggered fears of recurrent disease and loss of control. The biggest fears expressed by those interviewed were pain, suffering and early death. For some women - high levels of background anxiety, hyper-vigilance, watchful waiting, were not relieved by their annual visits. They continued

despite attempts by health care professionals to provide information, reassurance and clinical/scientific "evidence". They disliked the anxiety prior to the visit but relished the euphoria when they left, having been told that there was no sign of recurrent disease.

Practical things like long journeys to the hospital, parking difficulties, long waiting times and crowded waiting rooms increased these feelings of anxiety. Many women accommodated the inconvenience of transport difficulties and having to take time off work; or other commitments. Although these problems created resentment, they were tolerated for the relief the appointments provided and the transitory euphoria the women felt when they were told that no signs of recurrent disease had been found.

Anticipatory anxiety prior to routine clinic visits, related to fear of recurrent disease, is well documented in the literature (Renton et al., 2002, Vanhuysen et al., 2007). It is tolerated by women who attend because they value the post visit euphoria and relief so highly and feel it helps them to cope with the fear in the long-term:

*".....I'm not a great worrier, but it is there, it is always there so I think although you have to wait a bloody long time at these follow up visits I think that they are marvellous because they set your mind at rest." ".....you go in and you think will...will it be alright? And they say yes you're fine and you think ooh great whoopee! And you go....."*

**Anne (aged 65, 8 years) interview 1**

Kiebert et al's study (Kiebert et al., 1993), highlighted this phenomenon and the lack of data available relating to how long the euphoria lasts, the influence of the interval between visits, or time since diagnosis. The data collected for this study illustrates that the anxiety from the threat of recurrent disease and the relief given by follow-up clinic visits is evident many years after diagnosis.

Sympathetic care by doctors in the clinic was appreciated but a lack of continuity in staff meant the women felt unknown by the health care professionals and wanted to see their breast care nurse as a familiar face:

- R "..... I think that the breast care nurses are very nice and very helpful if you require them, they are always there and they are quite willing to take their time to talk to you. The one thing that...the doctors were very nice but to this day I don't think that I have seen the same one twice.
- I .....and that would have been important to you? To have got to know the doctors?
- R To me it would be. To have some continuity because you sort of feel that they look at the notes and its nothing personal anymore.
- I Mmhmm.
- R But I mean I can understand that you know that that happens."
- Anne (aged 65, 8 years) interview 1**

Women report placing high value on being reviewed by a medical practitioner who is already familiar with their medical history, and subsequently have more confidence in the process (Koinberg et al., 2001, Pennery and Mallet, 2000). Pain management skills were perceived by one woman interviewed in the study, to be lacking in doctors and nurses and she considered privacy to be inadequate. She related an incident when she was waiting in a consultation room and was able to hear the "bad news" consultation in the room next door and was very distressed by this. She suggested segregation of patient groups to ensure confidentiality and prevent unnecessary distress; as well as the opportunity to disrobe in private for as short a time as possible in order to maintain personal dignity.

Accompanied visits could be a double-edged sword. Significant others provided badly needed support, but may also provoke more anxiety when role reversal necessitated the need for the woman to provide support when spousal needs and distress remained unaddressed:

- I ".....and who supported you during that time, outside the hospital, who did you have to talk to and support?"
- R "My husband I suppose really, that's about all really. I'm not a person who tends to pour out their troubles to lots of people. I don't really talk about it very much with him either. He's not good with hospitals at all, doesn't like coming to hospitals, doesn't like doctors so....."
- I "So you're quite self sufficient?"
- R "I'm pretty self sufficient I would say yes."
- Nancy (aged 55, 15 years) interview 1**
- R ".....I think they should do more for husbands when the wives are diagnosed with breast cancer, they should do something for the husbands. He should be seen as well and you know asked if he, you know like a service where he could phone up and say "I need somebody to talk to, I don't understand this," support for the

*husband. Because he's just left, he's supporting his wife but nobody is looking after the husband.*

*I Okay*

*R And if it's a young man and he's got a family to support then he's got to go to work and he's got, he's got also his wife, children to worry about, a job.*

*I A lot of responsibility.*

*R Mm yeah so I do feel they need help."*

***Phyllis (aged 54, 9 years) interview 1***

Pitceathly and Maguire's review (Pitceathly and Maguire, 2003) and subsequent prevalence study (Pitceathly et al., 2004) ; of the impact of cancer on the relatives, of those diagnosed with cancer, identified that those who adopt a negative approach to their relatives illness and related events; are more likely to develop high levels of distress and psychological ill-health themselves. This further increases the psychological burden for the cancer patient and consequently the need for alternative sources of support.

This section has described the 'value' given to clinic attendance on an annual basis, what it means to these women, what it offers and the challenges it creates for them. The views quoted highlight the 'unintended' benefits of the clinic – attribution of responsibility for the detection of recurrent disease,, a place of sanctuary, a source of accurate, truthful, information and advice, an opportunity to air concerns and voice fears without the cost of distressing others and a geographical location to 'visit' their illness to enable compartmentalisation and resumption of normal daily life.

The value the women interviewed attached to their follow-up care, strongly influenced their reactions to the change in policy. The following section describes these reactions in greater detail and explores the possible reasons behind them.

## 5.3 Reactions to change

When questioned about their views and concerns regarding their discharge from the follow-up clinic, women's reactions fell into four main categories:

- The changes were viewed as a positive move forward – from sick to well and fitted in with previously adopted coping strategies of believing that the treatment was intended to be curative or that levels of risk were low or non-existent.
- Some women exhibited anxiety and anger; based on a belief that the changes would be detrimental to health and were an irresponsible attempt to reduce the burden on ever-diminishing resources and save money.
- Alternatively the view was taken that the judgement of the healthcare team was to be trusted and that the changes would not have been implemented unless there was minimal chance of detriment to health.
- Other women either sacrificed their needs for others they perceived to have greater need of the service, or resorted to silent resignation that although the changes were unwelcome the individual was powerless to change them and it would be hopeless to protest.

### Positive (close shave) versus a negative (marked woman) approach

Some women were relieved not to have to come to the clinic every year and described a sense of restitution, normality, an absence of threat. Those women who believed that early detection and treatment improve prognosis but have lost family members/friends to cancer, clung to regular follow-up visits as a means of avoiding an early death. They incorporated it into their coping strategy in order to reduce anxiety levels, to be able to cope with daily life and for these women only then could they bring some normality into their existence. Many felt cheated – they were told at the time of their diagnosis, that they would have lifetime follow-up and saw the changes as a cost-cutting exercise at the expense of their well-being.

### 5.3.1 The “positive” approach

For the women who saw the changes to their care as a positive - it confirmed beliefs about risk – it fitted in with their chosen coping strategy. Women who minimised their risk and chose to believe that recurrent disease was unlikely – in effect that they were cured (the “close shave” group) – were accepting of their discharge from regular clinic visits. It facilitated their change of role from sick to well and provided an opportunity for the reclamation of self. It provided feelings of relief from anticipatory anxiety and was seen as a prompt to move on and get on with the life they had prior to their breast cancer diagnosis:

R *“...yeah and then when I came in March and they said “Right so you’ve been discharged but, you know the clinic will always been here for you.” I thought it were great. I went home, rang my daughter. In fact no, I went up to see her because she’s, no I didn’t I rung her; and I says “Right that’s it, your mother has got the all clear so watch it, I’m back*

I *So does it feel like you can get on with life now?*

R *Yeah, I got on with my life anyway !*

***Elizabeth aged 65, 7 years interview 1***

Rita (aged 55, 5 years) perceived her situation in this way:

R *“.....Dr X then said what options were open, the fact that it was operable and he didn't think that I'd need chemo, that I would more than likely need radiotherapy and he didn't think that I would need any follow up drugs because of the type of cancer that it was. And also I think it's the size of the cancer, I'd caught it very early. He also said that yes I needed an operation to have it removed but it wasn't urgent, I'd probably had it growing inside my body for about 20 years, so he says “I'm not going to wheel you down to the theatre today or tomorrow”, so he says “We will remove it but it's non-urgent,” which you know I was quite happy with that because he'd said that. I think that had it been life threatening or more urgent I'm sure that he would have said sign the form here you're going down to theatre now”. “.....no I'm not anxious at all. I mean I've had cancer, its past, it's behind me and I don't think that I'm going to get it back”. “.....five years ago I had breast cancer, I'm alright now.”*

*“.....I think I've had my cancer scare, I don't think I'm going to get it back again.” “.....but no I don't think I'm going to get it again...I mean whether that's being too optimistic or not I don't know”. “.....I'm sure they would not have discharged me had they thought that it was going to come back.” “.....that's why I see this, being discharged as a positive thing.”*

***Rita (aged 55, 5 years) interview 1***

Dorothy (aged 57, 7 years) was also happy with the new arrangements for her follow-up care:

- I* ".....Okay so how did you feel then when they told you that it was going to be changed - your follow up then, it wasn't going to be face to face any more, that it was going to be via mammogram with an open appointment?
- R* I felt fine
- I* You did?
- R* Yes I felt it was time for me to go.
- I* So are we saying there was a sense of relief or what?
- R* A bit yes, yes.
- I* It was something, it sounds like you were prepared for?
- R* Yes.
- I* Did you know in advance before you came that it was a possibility?
- R* Well the previous appointment I'd seen Dr X and I'd heard from a friend who'd also had breast cancer that there had been this change and I mentioned this to him and he just said "Don't take any notice, just because they're putting in these new rules doesn't mean to say you can't come. If you want to come to see me come and see me and I'll make another appointment in the usual way," which he did. But then of course when I came back this time he'd retired so I didn't see him.
- I* And how was that seeing someone different and have things been different, how did you feel?
- R* I was a bit disappointed he wasn't here, I would have liked to have rounded the thing off really because it's just like he's disappeared. You develop a little bit of a relationship with somebody don't you when you see them every month over a period of time
- I* Yes.
- R* But I think I saw nurse X and she was, she was great yeah, answered all my questions
- I* Good.
- R* I was quite happy to talk to her, didn't particularly need to see a doctor, you know there weren't really any issues that needed discussion.
- I* So you feel things were dealt with as you would have wished?
- R* Yes."

**Dorothy (aged 57, 7 years) interview 1**

Both of these women no longer view their breast cancer as a current threat and this appeared to help them accept the changes to their care.

Linda was less sure, she was uncertain whether discharge from the clinic was a good thing or what the alternatives might be:

- I* ".....Yes, so were you, were you aware when you came for your last appointment that they might change the arrangements, did you have any warning or any preparation?
- R* No.
- I* So it was a bit of a surprise to you?
- R* Yes.
- I* Okay so how did you feel about it?

- R *I don't think shock is the right word but whether let down might be a better one, thinking well what am I going to do now, I haven't got to come here any more. But then again I was thinking well that's it, you know I'm cured, but do I still need to come here, do I want to come here? I thought".*  
**Linda (aged 58, 10 years) interview 1**

### 5.3.2 The "negative" approach

In contrast, other women viewed the changes in a negative way. Regular outpatient follow-up care was seen as a "back-up system", or a "safety net". Many women believe: rapid referral, direct access, prompt investigation, early detection and timely treatment lead to a speedy recovery and delay death. So "time is of the essence":

- I *".....what is it you think you get from it that's so important to you that you'd like to continue with it?*
- R *Well because I think it could return at any time. You always feel that once you've had it it could return, if that one has gone but you don't know if another one is going to appear and you've always got that sort of at the back of your mind haven't you, you know? Or I think you must have, I know I have. So you would feel it would be found quicker*
- I *So it's early detection, you feel that that would be the benefit of it?*
- R *Yes. " **Frances (aged 70, 5 years) interview 1***
- R *".....I think, I suppose it is a worry that you only sort of come once a year, I think that was.....*
- I *Did that feel not frequent enough?*
- R *No I think because at one time I think it was three months, six months and then a year I think; wasn't it? So I was told by.... I think and then of course it was cut just recently.*
- I *So the yearly internals seemed a long time to you?*
- R *Mm... yes, I think so, because I think a year is a long time if you are worried about anything, because I think it's alright you know I think like when you've finished with your five year one say, you know just keep a check on yourself etc but it's very difficult to know yourself whether, well is this how it should be? you know or whatever.*  
**Cathy (aged 61, 5 years) interview 1**

The loss of annual clinic visits was seen by some women as a missed opportunity and a potential source of delay in the process of detection, casting doubt on the ability of the system to do this and created anxiety about increased risk. Some of the women interviewed were concerned that they would delay presentation with possible symptoms of recurrent disease out of fear, if they did not have regular appointments. The women interviewed in Pennery and Mallet's study (Pennery and Mallet, 2000), stated that they preferred regular follow-up rather than open appointments because they were concerned

they would put off the consultation and delay presentation with clinically relevant symptoms, therefore worsening their prognosis.

Women who felt they were at substantial risk, resolved to find alternative strategies to circumvent the system and obtain more frequent surveillance:

*I* ".....okay, so how are you going to feel now then, that you're not able to do that any more (attend for annual mammograms)? Now that you don't come so regularly?

*R* *I don't think, I don't think that'll worry me, because I know next year it'll be the mammogram comes into the village (mobile unit in another county), so I won't be missing three years, I'll only be missing one, well I won't be missing one, because I had it April this year and I think my next door neighbour said "It's either July this year or July next year so I'm not going to miss out, I'm not just going to get my regular three years like everybody else, but I shall get mine this year or next year or, so that'll not worry me."*

**Irene ( aged 69, 8 years) interview 1**

Linda had decided on another strategy:

*R* ".....in fact I'm thinking about, I don't see why I should pay for a mammogram but I'm thinking about doing that in between the three years.

*I* *Yes, for your own peace of mind?*

*R* *Yes, yes because I think three years is a totally, is not, is too long for me. I mean I had the disease. and she (nurse practitioner) said "We'll send for you in three years." But I'm not happy about that, I don't know what I'm going to do about it but I'm not going to wait three years*

*I* *You'll find some other way?*

*R* *Yes."* **Linda (aged 58, 10 years) interview 1**

Women who experienced a previous trauma which remained unresolved, found the resulting stress and uncertainty of discharge from follow-up care unacceptable. That is, it created a cumulative stress effect. One woman used the analogy of a house of cards to describe how she incorporated her follow-up appointments into her coping strategy. She saw the clinic appointments as one of the cards which when removed, meant the house of cards fell flat and had to be painstakingly rebuilt.

### 5.3.3 Self-Sacrifice and Disempowerment

Some women would have preferred to continue visiting the clinic but felt they should sacrifice their own needs for others either because other women were more sick, or more recently diagnosed; with growing numbers of women needing the services of the clinic and limited resources. They used social comparison to justify it to themselves and accommodate the changes. The women who dealt with the changes in follow-up care in this way, felt guilty that they were a burden on the system and that they should give up their clinic attendance in order to provide quality care for others who they thought may be perceived as more deserving:

- I* ".....she (nurse practitioner) just said "We don't see people any more now. They used to see them for a lifetime but we don't do that any more." And I thought well why not, because it's this new thing. But I could accept that there's so many more people, so many more woman have got breast cancer obviously there's hundreds and thousands of women need to be seen and I thought well I have been seen and I've been cured so I tried to accept that part of it.
- I* And see it as a positive?
- R* It's still a bit of a break, you know after going there for 10 years thinking oh but at the end of the day they had saved my life and you know if I've got to go out of the system well so be it.
- I* Almost sacrificed yourself for someone else, is that what you mean, is that how it feels?
- R* Yes probably, probably." **Linda (aged 58, 10 years) interview 1**

Other women felt the changes were imposed and that they were powerless to challenge them, with no real way to change the system.

Anne (aged 65, 8 years) was scathing about the standard of care within the NHS and felt it was directly related to a lack of resources:

- R* ".....So the national health service is a bit dire at the moment.
- I* So you feel it is under-resourced is that what you mean or of a low standard, what do you ....?
- R* Yes that's what I mean! Because it is under-resourced the standard is low. Did you see that programme on TV about the "superbugs" and how they cope with it in Holland? Now I know that I am Dutch .....
- I* So you may be slightly biased?
- R* Yes I am slightly biased, but it is a real "eye-opener".
- I* I don't know the health system in Holland. Is it private medicine? Is it.....?
- R* They actually have a sort of National Health Service, but that is for the people who are so poor that..... for the poorest of the poor.....
- I* So a bit like the American system maybe?
- R* Ye...e..s, probably, but if you go with a pain in your stomach and you have ulcers, they would probably give you an aspirin or something, no, no its not, not good, so most people have private health insurance. In this country if you want private

*health care, when you reach my age you've had it, because all the things that can go wrong, you have had a bit wrong so they're exempt. But I think that they are trying to do their best, it's just that they are under-resourced, and I do think that things are so costly nowadays, my son-in-law has got myeloma, and the treatment is sky-high, but – I don't see the solution really."*

**Anne (aged 65, 8 years) interview 1**

Each of these reactions related to risk beliefs and coping strategies. Some of the women described how the changes challenged sophisticated coping strategies constructed over many months or even years and were an unwelcome imposition which forced them to re-think their feelings about breast cancer, treatment and the value of surveillance; in order to re-construct their coping mechanisms. This often created anxiety, insecurity and dissonance between what they had previously held to be true and what they were now being told.

Each woman's approach to the changes in service provision was related to the core beliefs and illness representations constructed around their breast cancer diagnosis. It relied upon their appraisal of the threat it posed and the meaning they attributed to it. As with their estimate of risk it depended on whether they viewed themselves as marked women and perceived their lives to be contaminated by the disease or restored to their former health status ('close shave') Dealing with the changes in the service and being discharged from regular clinic visits, meant that the women re-evaluated their health status and the alternative healthcare provision they were offered. There was no element of choice and the psychosocial needs of each individual woman were not accounted for. The decision (by the healthcare team) was based on clinical assessment of risk, using the Nottingham Prognostic Index and the duration of survival – 5 years or more since diagnosis. The impact of discharging women from regular outpatient clinics was as varied as their experiences and methods of coping with the disease. Each seemed to be related to the other and as the next theme will illustrate, this variation extends to the way the women interviewed for the study assimilated the changes and made personal decisions about how to manage their future care and well-being.

## Chapter 6 – Findings – Interview Data

### Theme 3 - Freedom or isolation?

#### 6.1. Introduction

The final theme articulates women's views and behaviours towards the concept of self-management. It divides into the two disparate standpoints of feeling free to move forward - or feeling isolated from much needed care and support. Asking women what they feel they might need, once they are discharged from the service, was intended to help inform planning of future services.

The longitudinal design of the study enabled the description of changes over time of attitudes and needs for individual women. This was as opposed to assumptions that at the same point in time and stage of recovery, as a group - their needs would be similar. The variety of reactions indicates that the present system may not fulfil the needs of all of the women using the service. Exploring the reasons for this variety may help identify how those needs might be met.

##### 6.1.1 Freedom

For the women who readily accepted the open appointment system, no longer having to attend the clinic on an annual basis was seen as a transition to independence and self-care, to take responsibility for their own health - freedom from the label of breast cancer patient and the world of the "sick". However, this was only possible if the level of threat was perceived as minimal (close shave) and women were confident in their ability to recognise a 'problem'. It lent itself to a pro-active, self-directing, form of coping. Acceptance necessitated a belief in the value of self determination and the ability of the healthcare system to engender some level of control and predictability.

### 6.1.2 Isolation

For those women who were doubtful of the ability of the open appointment system to fulfil their needs, the change in policy generated fear, anxiety, uncertainty, unwanted responsibility. Dissonance between what they were told by healthcare professionals and what they believed - that recurrent disease continued to be a significant threat (marked woman) lead to a lack of confidence in the healthcare system. Women in this group described feelings of abandonment, helplessness, resignation.

*Open appointments* and 3 yearly mammograms, were seen by some as a valued and welcome "back-up system", which gave them reassurance and comfort that support would be available to deal with recurrent disease if needed. However, others foresaw barriers to access and doubted the appropriateness of the system to help them monitor their disease and detect recurrence early enough to improve prognosis.

Not all of the women interviewed, complied with, or accepted the open appointment system and developed strategies to circumvent it to obtain what they felt they had lost, by other means. This is described later in the chapter.

*Long-term and late effects of treatment*; both physical and psychological were prevalent in the group studied. The quantitative data collected demonstrated that 33 of the 100 women recruited, reported a range of problems still present at 5 years or more since diagnosis.

The final section of the theme, explores the experiences of women taking part in the study, who developed *recurrent, or metastatic disease*. Their descriptions of their feelings and attitudes once the worst case scenario, their greatest fear is realised - documents their views of the success, or failure of the new system of care.

## 6.2. Attitudes towards the open appointment system

The open appointment system was designed to create the opportunity for patient-initiated, rapid, access to the breast cancer clinic and the advice and expertise of the breast cancer team. Women were told they could initiate contact and ask for assistance. They could telephone the clinic or a breast care nurse at any time for information and advice and any breast cancer-related problems would be dealt with promptly without the necessity for GP referral.

### 6.2.1 First Port of Call

Despite the assurance that the open appointment system was available to them, the women interviewed for this study were divided about who would be their first port of call to ask for help and advice relating to breast cancer following discharge from outpatient follow-up.

Of the 20 women interviewed, 15 asserted that they would be happy to telephone the clinic and ask for an open appointment. Most of these women stipulated that a new breast lump or breast pain would be the "trigger" to ask for help but seemed unaware of other signs or symptoms of recurrent disease.

Two women said they would telephone the breast care nurse they had an established relationship with and three women felt unable to contact the breast care team directly and preferred to consult their General Practitioner in the first instance.

Those who were happy to ask for an appointment felt confident they would know if their problem was breast cancer-related and that they would get a positive, helpful response and an expert opinion.

This group of women tended to have more confidence in the health care system and their own judgement. They were happy to have the breast cancer team and the open appointment system as back-up if they needed them.

Some women believed they would not need it and didn't foresee any necessity to use either the open appointment system or direct referral to the Breast Unit in the future.

This was based on their self-assessment of their risk of recurrent disease as very low or even zero:

*I ".....so what needs do you think you'll have in the future, what, I mean you have an open appointment...."*

*R Mm*

*I What do you think you might use it for?*

*R I think I would only use it if there was some sort of cause for concern, which I can't envisage at the moment. I can't see me using the open appointment for what's happened to me in the past because I don't think there is any need for that. So I could only see the appointment being used if I'd had, if I got breast cancer in the other breast.*

*I Okay is that what you would want it for?*

*R I'd probably want it for that, if I got some anxieties yes.*

***Dorothy (aged 57, 7 years) interview1***

*I Would that be the first port of call? Is that the first place you'd go? Would you feel happy to just ring the girls (breast care nurses) up for a chat and....?*

*R No, because I think I'd go to the doctors first with that, see what they said it were first.*

*I ...and then if you thought it was to do with your breast cancer then you'd ring the nurses?*

*R Then I might suggest to the doctor that it were, could it be that, you know, but it'd have to be a lot of years away I should imagine, because I hadn't got galloping sort, well what I call galloping, you know what I mean....."*

***Kathryn (aged 67, 9 years) interview1***

Several women who used their spirituality and religious beliefs to guide and comfort them, chose to believe that a higher power would protect them from harm. There is therefore a possibility that they may have unrealistic expectations of treatment and ignore symptoms of recurrent disease because they have convinced themselves that the threat no longer exists.

Others see benefit in the open appointment system as it corresponds with their belief that early detection and rapid referral back into the system will lead to timely treatment and therefore a better prognosis. They value the expertise of the breast care team and doubt the skills and specialist knowledge (of breast cancer) of their General Practitioner:

*I* "...what would prompt you to ring the breast care nurse, what sort of "problems" do you think they mean?

*R* I think when you self examine, and you find anything remotely amiss, you can ring them up but I think that they would prefer you to go and see your doctor (GP), but personally I would not go and see my doctor about things like this because basically your doctor (GP) knows a little bit about everything and I would prefer to go and see someone who knows a lot (about breast cancer). I wouldn't go and see my GP if I thought something was wrong – I would ring the clinic. That's what I would use it for."

**Anne (aged 65, 8 years) interview1**

*R* "...and as I say just knowing that there is someone here that I can come and talk to if I'm worried about something and that it's someone who has you know a specialism here whereas you know if you go to talk to your GP or whatever they don't have that specialist knowledge shall we say.

*I* So you're happy for it to be the first port of call?

*R* Yes, yes I think so yes." **Nancy (aged 55, 15 years) interview 1**

Studies by Grunfeld et al (Grunfeld et al., 1995) Thomas et al (Thomas et al., 1997) and Kimman et al (Kimman et al., 2007) all demonstrated that hospital specialists, GPs and patients alike; identified additional training needs of GPs and community nursing staff as an issue - if patient-initiated follow-up was to be considered as a feasible alternative to standard hospital care.

*I* "...so what sort of problems do you think you would use your open appointment for, what can you envisage that you would.....?"

*R* I suppose only if it was things like I was talking about before, if you get probably lots and lots of headaches or something like that that didn't go away or I suppose unexplained pains and things that's all and I think apart from that, only something that you couldn't really put a finger on ??

*I* So like a suggestion that something.....?"

*R* Yes a suggestion that something wasn't quite right

*I* Or come back?

*R* Although I suppose you could, I could go to the doctor first and speak to her. But then again I suppose she isn't obviously quite as qualified to deal with that sort of thing is she so I mean I know they say you can come along here so....."

*I* To the fast track service?

*R* Yes I think sort of, that sort of, I mean I do get headaches, I think it's just worry sometimes you know and I suppose you do get stressed....."

**Cathy (aged 61, 5 years) interview 1**

Women who would choose to speak to a breast care nurse valued talking to a familiar face who knew their medical and social history and either wanted reassurance that their worries were unfounded or confirmation that their concern was breast cancer-related and warranted further investigation before coming back to the clinic. Nearly all of the women interviewed, stated that breast pain or a breast lump would be the trigger for a request for help:

*I* ".....so you've got this open appointment haven't you?

*R* Yes.

*I* What sort of things would you use it for do you think, what are you likely

*R* If I found another lump I'd be back.

*I* Right if you got some sort of physical sign?

*R* Mm

*I* And you thought you were ill from your breast cancer.

*R* Mm

*I* And you feel completely happy to come straight here, not go anywhere else?

*R* Oh yes.

*I* Oh that's good, that's good.

*R* I would, I've got my hospital number and everything so I'm alright, still got my card, I know where it is.

*I* Yes that's good and that gives you confidence that.....?

*R* Yes, yeah it does." **Elizabeth (aged 65, 7 years) interview1**

*I* ".....and if you did have a problem, if you were suspicious that you know something wasn't quite right where's your first port of call? Where would you go?

*R* Probably ring the breast clinic

*I* You would?

*R* Mm

*I* Okay and discuss with them first?

*R* Yes and hopefully they would see me.

*I* So do you see, what else would you use them for? So let's say you found a lump or a thickening, is there anything else that you would consider ringing them for?

*R* Other than that? No.

*I* That's what you feel the appointment is for?

*R* Yes." **Linda (aged 58, 10 years) interview1**

*I* ".....and your open appointment that they've given you.....

*R* Yes

*I* What? what do you think you might use it for? What sort of things do you think you.....?

*R* Well I shan't use it at all shall I, unless I get a lump

*I* Right, so if you got a lump then you'd ring?

*R* I should have to find a lump or have pains, because I have to say my aunty died of it you know and she had a lot of back pain, she had ever such a lot of back pain, we thought it was lumbago. And then my neighbour over here that were the same, and she had a lot of back pain, so I mean I might consider being looked at if I got a lot of chronic back pain, because....."

**Kathryn (aged 67, 9 years) interview 1**

Women described how bonds and relationships with health care professionals (HCP's) are built into coping strategies and fulfil several needs. Psychosocial support in the form of information, advice and emotional support have already been identified from their interviews. Their belief, faith and trust in an individual, team, or system appeared to offset the uncertainty, unpredictability and loss of control they experience when in long term recovery from breast. It helps allay their feelings of vulnerability and existential concerns. It allowed the women to feel safe, move forwards, make progress, lead a more "normal" life, make plans, achieve goals and gave relief from anxiety:

- R *"....but I mean even now if I was to examine myself now and find something I'd be on the phone first thing in the morning to one of the lists, one of the numbers on the list*
- I *Right so you wouldn't go to your GP first, you would automatically go to the breast unit?*
- R *Yes*
- I *Right*
- R *because that's what I was told to do upon discharge. I was given the leaflet. Any worries ring one of these numbers. So if I go to the doctor I've got to go through to the GP, who's got to contact the hospital, who's then got to contact me, so I'm just.....*
- I *So it makes sense to you to do it that way?*
- R *So I'm just cutting out the GP yes and the receptionist. But yeah for me to know that I can go straight through to the breast institute and talk to a breast care nurse who will then decide either yes she does need a bit of reassurance but yeah everything is okay and that's quite normal or I think we'd better have a look at you, can you come in on and give me an appointment. I mean I'm quite happy with that.....*
- I *Mm good.*
- R *I'm quite happy. And on the leaflet there were several things to look out for which some of them I knew anyway you know the shape and lumps and everything and anything untoward about your breast but shortness of breath I think was one of the, one of the symptoms and there was any unexplained illnesses or something like that.*
- I *Anything that persists or gets worse.*
- R *Yes." Rita (aged 55, 5 years) interview 1*

One woman I spoke to, attached great importance to the ability to speak to an HCP who had "shared" her cancer experience – watched and supported her and "knew" what she has been through. She explained that this means every important detail does not have to be remembered, there is no necessity to recount it (relive it) over and over. In addition there are no worries that something significant or relevant may be forgotten in the telling. Continuity of care has been reported in the literature as an important aspect of follow-up care in breast cancer by Adewuyi et al (Adewuyi-Dalton et al., 1998). The

sense of “freedom” these women gained from discharge from the service came from their conviction that either they had access to expert help from the breast care team without having to rely on the skills and knowledge of their GP or that the service was for other women because they did not see a personal need to use it. Women who anticipated they may require help in the future were convinced they would know if their disease had returned but some cited a breast lump or breast pain as the reason. Others seemed to recognise that the signs of recurrent disease may relate to other body systems – back pain, symptoms which did not go away or got worse over time. However some women described how they felt “isolated” by the losses or gaps created by the limitations of the open appointment system.

One woman raised the concern that time may create a barrier to access to her open appointment and highlighted the need to feed the relationship she had with the breast care team with regular contact and exchange of information and experiences:

- I* "...well I've not..... not been to my doctor because the last time I did go I mean he sort of said you know go to the clinic.....
- I* Mm, you have an open appointment.
- R* Yes I do but you know you sort of, you feel you're not welcome any more.
- I* Oh that's a shame, you really feel that way?
- R* Yes that's how you feel, I think how you feel because you know the pressure is on, you know there's so many people there that you know you sort of think well
- I* You think twice
- R* Yeah you think well you know you just go in there and hopefully it's for nothing and you're wasting people's time so yes. You know when you had an appointment that's it isn't it?
- I* Yes.
- R* If you're keeping your appointment
- I* So it was permission to do all these things.
- R* Yes it was permission to do these things but you don't feel like you can do that. I mean you know if I sort of really got really panicky I would but I don't know I mean you're a bit like you know you're sitting on a seesaw, shall I, shan't I.
- I* Is it important enough? Is it serious?
- R* Yes, yes.
- I* So you have to make all the decisions yourself about those things?
- R* Yes and when you have the appointment you see that was, that was not an issue because you just went
- I* Yes and it was alright.
- R* Yes." **Anne (aged 65, 8 years) interview 1**

Anne's quote describes how infrequent or loss of contact may mean a reticence to re-establish contact. HCPs move on, change jobs and talking to strangers is not an attractive prospect. HCPs unfamiliar to the women are seen as an unknown quantity and therefore women are unsure of the response they will get.

Some of the women interviewed for this study made the point that making contact to ask for support or advice, takes courage. There is a risk involved. Women need to feel that the individual they speak to, will be known to them and have knowledge of them as an individual. They risk being made to feel foolish, that they may be wasting the professional's time with insignificant concerns. They risk a negative, unhelpful response and the possibility that they may jeopardise the valued relationship by "crying wolf". The fear is then that, they may be ignored or feel unable to voice concerns. This may result in wasting valuable time and then it may be too late – disease progression may be more advanced and lead to a poorer prognosis. Not all of the women are happy to use their open appointments. One woman was concerned that if no-one rang, to ask for help on a regular basis – would the service be deemed unnecessary and be lost altogether?

The research literature regarding patient-initiated follow-up has shown some positive results (Brown et al., 2002). However, Brown et al's study showed positive results for the 61 women who participated, but out of 123 women approached to take part – 23 declined initially and another 39 refused after reading the study patient information sheet. This was in addition to an undisclosed number of women who were excluded by clinic staff, due to "anxiety" or "personal problems".

This would suggest that it is an attractive prospect to a proportion of patients and unacceptable or inappropriate for others:

- R* Yeah and just I think I feel once you've been on a regular basis like that and made so many trips to the hospital you feel part of, it's like doing something on a regular basis and then you don't do it any more, you miss doing it.
- I* So, you've incorporated it into your routine?
- R* Yes, yes that's right it was only once a year but it was a nice once a year although you know the parking is horrific up there, I didn't miss that.

- I And I know that you said that it wasn't always a pleasant experience to go but no you just felt better for it afterwards?
- R Yeah knowing that you've been.
- I So, what's it like in between, when you were going like once a year what was it like in between?
- R I didn't really think about it because I know I was going to do.....and this....
- I So, did you put it to one side then?
- R Yes, yeah
- I And now that you can't do that how do you cope with that?
- R I think it makes you more anxious because only a few, two or three weeks ago I started feeling my chest and thinking oh is that something there and I think whether I'd felt it that much I'd made it sore
- I Yes
- R And I kept feeling it and trying to grab it and move it and thinking oh is there something my chest? So it does make you more anxious I think.
- I Because you're not able to put it to one side you mean?
- R Yes probably.
- I You want somebody to go...." it's alright" for a bit?
- R Yeah I think it gives you reassurance when you go up there to clinic, you know not being seen by anybody, I mean I suppose I could go up to the clinic if I wanted but it's better for them to contact you, your appointment is so and so and you just take it for granted and you go.
- I So it's better if you get sent an appointment?
- R Yes.
- I Why is that?
- R Because I suppose you could be on the phone to them every so many weeks you know if you let everything worry you. So you do have to tell yourself.....
- I So do you collect it altogether and deal with it once a year is that what you mean?
- R No, throughout the year. I mean like I thought I had this thing in my chest, I could have gone down the doctors or phoned the hospital up you know and then you have to tell yourself to stop it.
- I Oh I see what you mean yes.
- R But if you knew, maybe you're looking for something, if you knew you was going there still once a year
- I You wouldn't be constantly looking for something.
- R No
- I Ah I understand now. So you feel you have to do the looking and the.....
- R I always did do the looking before but maybe now it makes you more anxious because you're not going up there. I think it does make a difference, definitely it's made a difference to me not going.
- I Yes.
- R And now I'm thinking well, do I go back to the doctors again? How do I get another mammogram? Or have I got to wait another three years? Because I think it's every three years which to me seems a long time for me."
- Linda (aged 58, 10 years) interview 1**

Anxiety was also an influencing factor in Thomas et al's study (Thomas et al., 1997). Out of 65 patients considered suitable for discharge after 5 years or more of regular follow-up clinic visits, 28% of their patients refused to be discharged, 75% of these, were deemed to be suffering from anxiety using the HAD Scale (Zigmond and Snaith, 1983) and many found their way back into the clinic via referral from their GP.

Contacting their GP was the preferred option for those women who had already established a good relationship with their GP. Unlike the women who preferred to ring the clinic, they trusted their GP to ascertain whether or not their problem was breast cancer-related and refer them on. This they felt, avoided bothering the breast cancer team with unnecessary concerns.

- I* ".....you don't, you don't have a problem with it? (being discharged from outpatient follow-up).
- R* No, I've got no problems. I mean if I find, if I do start getting anything, or anything, I should contact the doctors straight away.
- I* So, where would you go? Your own doctor? Or would you come to the.....
- R* No I should go to my own doctor first, just to, I mean I wouldn't want to come on a false mission if you know what I mean?"
- Helen (aged 75, 5 years) interview 1**

So the women are faced with a dilemma:

If contact proves to be a "fool's errand", it may jeopardise the relationship, if contact is avoided - they may lose the relationship altogether, or risk late intervention for recurrent disease.

Some women also felt they had lost access to the prosthetic advisor (who was attached to the follow-up clinic) who also provided advice and information on bras, swimsuits and clothing specifically designed for women following mastectomy:

- I* ".....so you said you still miss the comfort of the annual check up, they're reassuring and the ability to ask questions and you want to see the prosthesis advisor because you're not happy about swimming in a normal costume?"
- R* No because you know I've lost a lot of weight and.....
- I* I noticed when I came in you're looking very slim.
- R* Yes and it sort of, it has reduced my boobs so I mean it's much more noticeable, to me you know anyway and I'm not happy about it. And they have a prosthesis nurse at Hospital X (her local hospital) but she says they don't, she doesn't do swimming costumes."
- Anne (aged 65, 8 years) interview1**

Those women who felt the open appointment system did not fulfil their needs (those in "isolation"), were not prepared to accept responsibility for self-detection of breast cancer-related problems or symptoms of recurrent disease. They felt the system had

failed them and left them feeling abandoned. They doubted whether they would have the courage to act in a timely fashion, did not relish the loss of contact and valued relationships with the clinic staff. One woman doubted if she returned to the clinic, that anyone would even know who she was. Others feared the stigma of being labelled as "worriers" or "time wasters". These women were more likely to go to their GP for confirmation that their problem was breast cancer-related before taking this risk. Finally there was the fear that the service would be deemed unnecessary and be lost altogether

### 6.3. Strategies to circumvent the system

Some women developed strategies to obtain the service by other means during the course of the study. They used the following to maintain contact with the service and regular surveillance:

- well woman clinics
- practice nurses
- their GP,
- the mobile mammography unit in another county
- private consultations
- participating in research projects
- accompanying others to the clinic,
- volunteering for peer support
- helping in the coffee shop
- seeking further breast reconstruction procedures
- not refusing "extra" mammograms when transferring from the clinic for their mammography to the National Breast Cancer Screening Programme.

This was possible because the two systems are independent with computer generated appointments. Some women have deliberately avoided pointing out the duplication. This was done in order to re-instate regular physical examinations, obtain more frequent mammograms, or just maintain regular contact.

Variations in levels of acceptance of the open appointment system, may relate to whether it complied, or conflicted with the chosen coping strategy. For example those women who appraised the future threat from breast cancer as low, were more accepting of the concept of self-care/self monitoring, whereas those who perceived the threat to be high were more likely to want to put the responsibility firmly in the hands of health care professionals.

Franks and Roesch's (Franks and Roesch, 2006) meta-analysis of long-term coping in cancer patients, illustrated that re-appraisal of threat and problem-focused coping was more likely, the longer the time from diagnosis. The studies included in their analysis showed that women with breast cancer in particular, used strategies aimed at improving physical well-being and identifying and treating disease – this has traditionally been the realm of healthcare professionals.

When asked what they wanted from the health care system in the future, some women wanted close surveillance, regular physical examination, more frequent mammograms (they refused to believe they should be treated in the same way as their age-related peers) as well as regular contact with the breast cancer team. Hospital follow-up was seen as a source of *physical* care but women were undecided as to where they should go to talk over *psychological* issues. This needed to be in a place where they could go when - and if - they needed it. Somewhere they would not feel foolish, where they could ask questions and talk things through. This was sometimes because they did not always feel they had this kind of support from immediate family and friends. There was pressure to get on with life and put their experience of breast cancer behind them.

Linda (aged 58, 10 years) felt that hospital appointments were clinical, medical matters, not for reassurance or peace of mind. She has heard of "Maggies Centres" (a UK charitable organisation who provide psychological support) and thinks they would be very useful for this, both for people like her and people like her husband. She would like to just be able to pop in and be with other people who understand, not necessarily just when she has a problem. Several women wanted support for significant others as well and felt this was lacking in the present system.

## 6.4. Late/Long term effects

The late and long term effects (both physical and psychological) of breast cancer treatments are common and persist for many years after the completion of treatment (Wyatt and Friedman, 1996, Dubray et al., 1997, Carpenter et al., 2004, Mrozek and Shapiro, 2005, Knobf, 2006, Cheville and Tchou, 2007). This was the case for over 30% (33/100) of the women recruited to the study who highlighted the problems they were experiencing more than 5 years after diagnosis during their interviews.

Some women felt stronger, more assertive, more confident, after recovering from breast cancer. These attributes are included in the research literature within the concepts of benefit-finding and personal growth (Carver and Antoni, 2004, Tomich and Helgeson, 2004, Helgeson et al., 2006).

In contrast, others described negative feelings particularly towards their body image. Although this is also described in the literature (Schover et al., 1995, Fentiman and Hamed, 2006, Kalaitzi et al., 2007), the women in the present study still felt this way up to 10 years after surgery – hating scars, hating to look at their body, resentful of other women's ability to wear close-fitting or revealing clothes – bikinis or sunbathe topless on

the beach – this didn't recede over time. Unconditional love from their significant other was very important to help with this: "the person I was before, no longer exists, a change took place". Reconstructive surgery does not resolve all of these issues and may bring problems of its own:

Linda aged 58, 10 years, explained to me that adapting to an implant reconstruction occurs on several levels. She needed to be happy with the cosmetic result – the "look" of it, it needed to "feel right", to feel "natural". This included the weight, the way it moved in tandem with her own movements, the sensation when she put pressure on it/rolled over in bed, as well as being able to accept it as part of her, as part of her body. If it didn't "feel right" then no matter how good it looked, incorporating it into her sense of self became difficult and it then acquired its own separate identity as a "foreign body", it became unwanted, an intrusion.

Women may now be disease-free for much longer intervals than ever before; and experience the prospect of taking this experience through their life-cycle. Ageing following breast surgery and reconstruction brings with it novel problems. For instance a woman may now require surgical replacement of her prosthesis and need to come to terms with the physical changes in her own ageing body compared to the constancy of the appearance of the reconstructed breast. Age brings with it a change of perspectives and priorities and the need to renegotiate identity, role and sense of self.

Linda recounted what happened to her:

*I ".....right, well can we go back to the implant thing because we didn't get it on the tape to start with so when I first arrived you showed me some photographs because you had a problem with your implant and you told, - tell me if I don't get this right, but initially when you opted to have breast reconstruction you were concerned about the effects of silicone implants if they should rupture....."*

*R Mm*

*I .....and the health implications, so you particularly chose an implant that wasn't silicone and was sugar and water, is that what you said?*

*R Yes Hydrogel*

*I Hydrogel, to try and avoid that.*

- R Yes.
- I And then by about three years after you had it inserted - it ruptured.
- R Yes.
- I So you tell me your story after that.
- R Well it was about 3½ years, 4 years down the line and I was aware that I'd got a swelling above the implant and it didn't take long before it was a very big swelling and I lived with it for quite a few months really thinking that you know implants do change and move and it was just normal so I put up with it. And then I happened to show a friend of mine who'd had her, both her breasts off and she said "Oh I'd go to the hospital and let them have a look at it." So I decided to go and, but before then I'd had other problems in as much as I was getting pins and needles in my arm, quite a few times a day but never related it could be due to the swelling. Anyway I went to the breast clinic and it was there that they told me that it had ruptured and within a few weeks I'd gone back into the City Hospital and had the, that particular implant removed and opted for silicone one which I didn't really want in the first place but it's the one that's been longest on the market and so
- I It's the one you've got most confidence in.
- R Now yes, yes
- I Oh I can understand you being wary.
- R Yes.
- I And you've had that one in for how long now?
- R I think this has been in, did I have it in 2002 or 2001?
- I You'd had it a little while.
- R Yes.
- I You said you're reasonably happy with the cosmetic effect of it but you're still concerned about.....
- R Yes, yes I know it's not, it's never going to marry up to the other one or it's never going to be the same as the other one. It's funny really because I've got a friend and she's had both her bust off at various times, her cancer came back again and she's been in and out of plastic surgery, plastic surgery quite a bit because she said you know she's not happy with them they don't, they don't match up, one is bigger than the other and I thought well you're never, they tell you this when you have an implant in in the first place, it's never going to be normal but it will look okay in a bra. And I accepted that, I can accept that. So you're never going to have your boobs back like they were before, never ever, no matter what you do because they won't make them look the same. But I think when you've got only one off there is a significant difference as opposed to having both of them off and two implants. I mean you've got two implants that are here and there, they don't move but if you only have one of them off there is a big difference because the other one is hanging down and the other one will be up there." ".....so yeah, and I've become that I am getting more older with my body as well and it's become more apparent this last year because I've got my implant in on this side, the right side, which I had my breast removed the left side is sagging more
- I Oh right yes.
- R So that's come to mind and so I suppose there's not much I can do about that other than if I went to have an uplift or I didn't want to do that but so I've become aware of that.
- I And you hadn't considered that when you had your reconstruction to start with, that hadn't occurred to you?
- R No, no but obviously as a woman as you get older your boobs, everything sags, but obviously my right one is not going to sag but the other one is sagging more.
- I And do you feel when you're clothed that you can address that or not?
- R Yes, yes.
- I So it's when you're undressed that that's more of an issue to you?
- R Yes, yes." **Linda (aged 58, 10 years) interview 1**

Ten years after her initial diagnosis, Linda is still adjusting to the way she looks, following reconstructive surgery. She has undergone one replacement of her implant and presumes she will live long enough to need a second. She didn't consider, ten years ago that her natural breast would "age" (i.e. change shape and position) whilst her reconstructed breast would not. Her body image and sense of sexual allure has been challenged many years after her decision regarding her choice of surgery – a situation which would not have arisen 20 or 30 years ago when survival was of much shorter duration.

Other long-term physical effects of surgery and other treatments are more functional in nature and include pain, restricted movement (Caffo et al., 2003, Raj et al., 2005), hot flushes and poor sleep pattern (Carpenter et al., 2004).

Years after the original surgery women are unable to continue to perform normal daily activities:

*I* ".....but when you came last time, were your needs any different? Were you wanting anything any different from the appointments than you did then?

*R* No! just wanted reassurance and erm...I normally make a list of questions because I am still baffled by the fact that it hurts and I mean you know it hurts all the time.

*I* Really?

*R* And erm...one "kind" (.....) doctor that I saw once, I asked him why it was still hurting and he said....what do you think? We are just like butchers you know! I mean that was not very reassuring.....(laughs)

*I* No,no

*R* Yeah, it still baffles me that it hurts..." ".....I have mentioned that I am still anxious, at the back of my mind, I mentioned that it still hurts.

*I* Do you have to take medication for that? Does it hurt that much, that you need to take something for it?

*R* Its alright as long as nobody touches it, I mean if I lie on the bed and the cat jumps on me.....Oooh! I mean he weighs 9 pounds, ooh it hurts and its weird because the operation was on this side - but it hurts here

*I* In the middle?

*R* I mean this is what the doctor told me.....he said "we are like butchers really, we just chop a bit off you." **Anne (aged 65, 8 years) interview 1**

".....and I suppose that's the only problems I've had since that occasionally I don't sleep particularly well. But then I get hot because I'm getting sort of hot flushes and things at night, I can get quite hot so, but that's variable, some nights it's fine."

**Cathy (aged 61, 5 years) interview 1**

R ".....well it should have been my six monthly visits I had to come back the three months after because I was getting a lot of pain under my arm and that's when they said that what we've probably done is damaged, because I was getting like shooting pains up my body into where my bust was and what they said was it's because it's your nerves going up and the nerves that normally goes into your bust it's going there and there's nothing there so it's got to find somewhere to go so it had got to, and it took a while to sort it out.

I So the surgery gave you some nerve damage, yes?

R Yes damaged my nerves yes.

I Sorry.

R Which I've accepted, I mean it's been seven years now, well seven and a half years now, I still do get pain, I still do get a little bit of swelling under my arm and I do find that, I mean I've got to admit I do find it sometimes very uncomfortable if I wear a bra.

I You were telling me earlier on about when you have a bath, you suffer with pain for several hours afterwards?

R Yes when I have a bath, if I have a hot bath the pain, it's, I don't, ?? it just feels, it's not like a sharp pain, it's a dull pain but it's there and I want to scratch it off. So whether it's the hot water, I don't use anything in my bath, I don't use

I Yes you can't use perfumed products you told me earlier.

R I can't use perfumed soap, I cannot use deodorant with perfume in and I cannot with my perfume, and if I wear perfume, I do wear perfume obviously but I never put any on my right hand side.

I So what happens when you do?

R I'd scratch, it's terrible.

I Oh it irritates?

R It really, really irritates?

I What like an allergy type of thing?

R Yeah, yeah but I don't come out in a rash or anything like that, it's just

I It itches, and it's painful yes?

R Itches and painful yes.

I Oh right, even after all this time?

R Even after seven years, yeah." **Elizabeth (aged 65, 7 years) interview 1**

I ".....the other thing that you've got a problem with is that you've got pain around the scar from your mastectomy from before and it gets very severe

R Very.

I And you have to take Paracetamol for it every day and it lasts for 10 minutes.

R Sometimes more.

I Sometimes more and it's very severe when you get it and when it's gone you feel drained and you need to rest.

R Totally drained, totally drained .

I So I wanted to get that on tape because I think that's important.

R And I end up screaming sometimes.

I Do you, it's that bad?

R It's that bad.

I So you're waiting for an appointment to go and talk to the consultant about your risk and whether a preventative mastectomy on the other side would be a good idea and to talk about your pain and how you can manage your pain because you take Paracetamol for it regularly and then Tramadol if it gets very bad, you don't feel that's enough.

R Mm.

I And that you find it difficult to cope with because it happens a lot.

R Yes.

I And it doesn't seem to be getting any better.

R *No, yeah it happens quite so badly when I'm travelling in the car, you know if we go over a bump in the road, you know like we've got these bumps*

I *Yes speed bumps yes*

R *Oh*

I *That really hurts you.*

R *And I'm hanging on and oh crickey.*

I *So very uncomfortable on a frequent basis?*

R *Oh definitely, yes.*

I *Okay.*

R *I can't go shopping because I can't carry, if I try and carry a carrier bag or anything then I get the pain, it's like I'm dragging down and I'm getting*

I *And this is seven years after your mastectomy isn't it?*

R *Yes*

I *So it's quite a long time after the surgery.*

R *Yes.*

I *Okay.*

R *In fact it's got worse this last couple of years.*

I *So it wasn't, did you have it from the very beginning and but then it's got worse?*

R *I had it from the very beginning but I didn't notice it because when you've had the operation that side is numb, it's like dead isn't it till all the feelings come back and it, roughly I'd say the feeling has come back maybe a year, maybe a little bit less or a bit over a year before everything didn't feel absolutely dead, numb. But since then yes gradually I've had niggly pains, I've reported it at the hospital when I've been up for my ?? and just take your Paracetamol or take a Tramadol.*

I *Yes so it's been considered, so when you've asked about it it's been considered to be just the after effects of surgery*

R *Yes*

I *And it's a matter of trying to manage it with pain relief, is that what you've been told?*

R *Yes mm."*

R *".....it interferes with sexual relationships with my husband.*

I *Does it?*

R *Because I'm very, I mean he can see my scar, he can touch it anything but since this thing with the right side what's, it's like*

I *Since the worry you might have it in the other side?*

R *Yeah*

I *That's affected your sex life with your husband?*

R *Yeah*

I *On whose side?*

R *Now he's not allowed*

I *Oh right on your side.*

R *On my side, oh yeah it's me, I said "No leave it, don't touch me there, don't," you know what I mean which is hard on him.*

I *Yes well you said to me, because you showed me your scar earlier and you said, you called it ugly.*

R *It is ugly.*

I *So you're obviously it's affected how you feel about yourself about how attractive you feel and how sexually attractive you feel and all that sort of thing so it's had that effect on you as well even after all this time. And was it always like that or has that just happened as the*

R *No that's only just happening.*

I *So immediately afterwards things*

R *The norm.*

I *Was alright?*

R *We had sex and he just used to rub my scar and he's been brilliant, he's absolutely been brilliant but I mean now it's me.*

I *So it's to do with how you feel about yourself.*

- R Yeah mm and I've noticed, you know since I had the mammogram then the biop, whatsit, this breast has actually gone, it's flat
- I What it's dropped.
- R Well it ever used to be like that.
- I So it looks different.
- R Like a piece of liver?) it feels terrible
- I It feels different?
- R Yes
- I It feels different and the shape is different.
- R Well yeah where before I'd get undressed and just put my nightie on or whatever and get out of the shower no matter what, now I won't.
- I You feel much more self conscious about the way you look?
- R Yes, yes
- R ".....and it still worries me because I've still got that little thing there, still get quite a bit of discomfort and I do my breast Examination
- I Examination
- R Yeah so I mean yeah I don't worry 24/7, it's when you have a shower and it still worries me because I've still got that little thing there, still get quite a bit of discomfort and I do my breast Examination
- I Examination
- R Yeah so I mean yeah I don't worry 24/7, it's when you have a shower, because I can't have a bath, I can get in a bath but I can't lift myself out because I can't get out.
- I Oh you were saying as well you'd got really restricted movement in your left shoulder
- R Shoulder where I had my left breast off.
- I And then after your surgery that improved, and then as time has gone on it's got worse and worse and worse
- R No you've got that wrong
- I Oh go on then tell me.
- R I didn't have trouble with my left shoulder before I had my surgery.
- I You didn't.
- R No whilst I'd had my surgery the hospital explained to me, in fact it was X (breast care nurse), that if you don't move your arm you'll get a stiff shoulder and over the time I've been alright because I've always done my exercises and got it to move. This last twelve months it's deteriorated, I can't do what I used to be able to do where I put two arms up in the air, I can put one up and then push the other one up, I can't keep it up, like that.
- I And it's painful when you do as well isn't it?
- R Very painful, very painful, I get a lot of cramp here in my scar, a lot of pain in my scar, puffiness and I've had some like, scurfy if you want to call it
- I Like dry skin?
- R Yes, yes you know what I mean, but I've put cream on and
- I That's helped?
- R Massaged it but yes I get a lot of cramp there, a lot of pain there."
- Teresa (aged 64, 7 years) interview 1**

These quotes illustrate how common and incapacitating late and long-term effects of treatment can be 5-8 years after diagnosis. Pain, skin sensitivity, restricted movement, negative body image and the resulting effects on self-esteem and quality of life persist for many years and were highlighted as significant issues for women interviewed for the study.

These long-term problems seemed to make it difficult for women to “move on” and leave their breast cancer patient identity behind. They were unsure how to manage them, who to go to for help and whether they would be considered an appropriate reason to make use of their open appointment.

## 6.5. Two years on.....the final interviews

The interview data collected from visit 3 the final visit – 2 years following discharge from the outpatient clinic demonstrated the same variety in women’s views. However views changed according to the coping strategies and circumstances of each of the women.

The following 3 quotes from Frances, Anne and Cathy illustrate acceptance, rejection and use of the appointment system respectively, two years after their initial interview:

- I        "...and if I said to you what do you think you're going to need in the future, do you feel that your needs are catered for, do you think you'll have what you need or do you think there's anything else that could be provided that would improve things for you in the future?*
- R        Well I think everything is probably provided, I mean as I say obviously if you know that, if you know that a problem might crop up that you know help is available. And I think it is and I've never found a problem speaking to anyone, yes I would think that, I would think I was probably catered for yes.*
- I        And if you didn't have your CHAT group (peer support group) what would you do instead do you think?*
- R        Oh well I don't know, I don't think you do anything instead, I mean you obviously, I mean with it sort of being a local little area I suppose if there was a problem and I needed to talk to someone then I suppose I know the people to talk to here that have been through the same thing.*
- I        Yes so you would just access them individually as opposed to a group, that sort of thing?*
- R        Yes, yes.*
- I        So how do you feel about the changes in the clinic system then now compared to how you did before, do you feel the same, do you feel different?*
- R        Well I think because mine was such a mild one not really and they did such an excellent job with it and it was caught very, very early I don't really worry about it at all.*
- I        No so you don't have a problem with the changes?*
- R        Not really no and I do believe if I had any problems I could ring the hospital and I could ring the hospital and have a mammogram I think.*
- I        You can definitely ring up and speak to a breast care nurse and have a chat to them and they'll give you advice?*
- R        Yes, okay yes but I've, I mean touch wood I haven't had to. I don't really worry about it at all now.*
- I        It's at the back of your mind, right at the back?*

R *I know, I'm aware of it but I don't have to worry about it I don't think. And just now and again I get a little bit of slight pain underneath but I think it's where the glands were removed, not the breast, I think it's more where the glands were taken out.*

I *So what it's just a bit uncomfortable now and again?*

R *It's a little bit uncomfortable now and again yes and then it eases, it goes back to normal. **Frances (aged 70, 5 years) interview 3***

Frances uses her peer support group to talk through psychological issues, sees the breast care nurse as her first point of contact for physical problems and trusts her own knowledge and judgement to identify the significance of signs and symptoms.

Women who were accepting of the system at this time point, believed they were cured, or that the risk was minimal, that 3 yearly mammograms meant their risk was the same as their age-related peers and they would not have been discharged if they were at risk from recurrent disease. One woman found comfort in her religious beliefs and trusted in God's plan for her and this she felt helped her to cope. Another coped by living in the present and considered breast cancer to be part of her past. "I *had* cancer, its in the past, I've put it behind me, I've had it, I'm alright now".

Anne remains unconvinced that the system is adequate for her needs and does not foresee that this is likely to change:

I *"...yes so if I ask you now to tell me how you feel about being discharged from the clinic what would you say?*

R *I've actually written it down you see.*

I *Have you, oh good, oh that's good.*

R *On the last page*

I *So that, yeah the open page.*

R *So I have put I still feel the same about the follow up care from breast cancer, it was like a safety net for me. I felt that I would be checked out once a year and that the following year etc this would also happen which gave me a feeling of security. Now with the open appointment I do not have this feeling of security because one's worries are not always logical and so you do not want to trouble the doctors. And actually, I said, I feel the same about the follow up care, or rather the lack of follow up care, that if it's not true I feel more and more anxious as times goes by.*

I *"...yes okay and if I said to you if you could design your care in the future what would you do? You mentioned a bone scan, what else do you think would make you feel better?*

R *Well I mean a regular yearly, annual check up would make me feel better.*

I *So basically to go back to what you had before, is that what you mean?*

R *Yes what we had before." **Anne (aged 65, 8 years) interview 3***

The women at visit 3 who concurred with Anne's view, believed that the risk of recurrent disease was still a significant threat and that they were at increased risk of developing recurrent disease compared to their age-related peers. They believed their risk *increased* over time and it was a matter of when, not if - they developed a recurrence.

They wanted "legitimate" contact (i.e. healthcare professional initiated). Because they lacked confidence in their ability to self-identify a problem, or they did not have confidence in mammograms they valued physical examination as a method of detection, or felt 3 yearly mammograms were too infrequent. For some there was confusion about what might be a "breast cancer problem" and what might be age-related i.e. signs of age.

For those who initially accepted the open appointment system they changed their view for the following reasons:

- One woman was admitted with a ruptured implant – this entailed 3 surgical procedures and eventual removal. Old fears and anxieties re-surfaced during her admission when she came into contact with women with advanced disease.
- Another became fearful when one of her breast cancer peers developed metastatic disease after bilateral mastectomies.

On a positive note - Cathy has changed her mind and is now happy with the new arrangements. This is primarily due to the fact she has had occasion to use her open appointment. She developed problems with lymphoedema and contacted her breast care nurse to ask for help. She was referred to specialist physiotherapy care and her problem she feels was dealt with quickly and effectively:

- I* "...okay and if I asked you to tell me now how you feel about the changes, you know about not being able to come to the clinic once a year how do you feel about it now?
- R* Well I mean initially when I was told that it was a sort of, I think I said to you before like a sort of, your crutch being knocked from underneath you really. I

- think when you're sort of told that your sort of treatment has finished I suppose as such and the once a year visit I suppose initially you sort of feel a little bit less out on a limb I suppose really. But I think because they always say that you can actually go along if you think you have a problem I think it's probably okay because as I say like this problem with the lymphodema I mean obviously getting in touch with the right person and I was contacted very quickly so there's not a problem. And as I said there is always the follow up with that all the time, people do keep in touch so I don't really think it's, you know I don't think it's been a particular problem."*
- I "...do you think the fact that you've actually experienced what is available, you know because you've had a problem and you dipped into the service and you've found that it's actually what you feel that it's quite a good service so that's coloured your judgement now, you've thought oh well I thought this but now actually when I've needed help I've got it so maybe it's not so bad.*
- R Yes.*
- I Do you think if you'd not have had that, do you know what I mean, do you think that.....*
- R If I hadn't had to go along you mean?*
- I What I'm trying to say is that some ladies have gone along nicely and haven't needed to contact anybody*
- R Mm*
- I Whereas you've, actually the need has arisen and you've experienced it and you've had a positive experience of it, do you think that's coloured how you now view it?*
- R I think it has.*
- I Do you know what I mean?*
- R Yes.*
- I You've worried that it might be a problem and then found out it wasn't*
- R That's right yes so I was wrong.*
- I And so therefore you've changed your view. Do you see what I mean?*
- R Yes, I think it was only they just as I say the initial reaction you sort of, you've been going once a year and then all of a sudden it stopped so you think oh dear you know I'm sort of on my own now. But obviously they always said that if there's ever a problem in the future you know we're always here and you can ring up and you can come along so as I say*
- I And you've got, you've had proof of it because had occasion to use it, yes?*
- R So I don't think it is a problem really because I think, my feeling is that you've got to get on with your life and not concentrate on the negatives, you've got to try and be positive and move on really and just really carry on with as normal a life as you can I think and just put the bad bits to the back of your mind I suppose or not really even try to think about them. I mean this for me has just been a sort of a nuisance but you know it's just something you've just got to accept sometimes happens and get on with it really.*
- Cathy (aged 61, 5 years) interview3***

The women's accounts of the 2 years following their discharge from the clinic, clearly illustrate that there are no hard and fast rules about how women in this situation cope and accommodate the changes in their follow up care. Time does not necessarily have a positive influence on their anxieties and concerns and there are a variety of influencing factors to account for attitudinal changes over time.

## 6.6 When cancer comes back (women with recurrent disease)

Four of the women who participated in the study developed recurrent or metastatic breast cancer during the course of the study. The final section of the chapter describes their experiences.

The first of the four women I met, was not part of the group of interviewees, but had agreed to complete sequential questionnaires. I will call her "Esther" for the purposes of this chapter and when I saw her a year after the initial meeting, (during the course of completing the second questionnaire), she mentioned she had been admitted to hospital for a second mastectomy in the interim. Despite this, she had maintained a positive attitude towards being discharged from the clinic, because she felt it was proof that the system worked. She had returned to the clinic via her open appointment and further investigation had detected a second primary tumour. She was now back in the regular outpatient follow-up clinic being monitored more closely with annual reviews by the healthcare team.

"Dulcie" was also recruited to the questionnaire-only arm of the study but had the exact opposite experience. She found a mass in her breast and tried to get an open appointment. The staff in the breast unit suggested she contact her GP and her GP insisted that she should see the breast cancer team. She was confused and frustrated and decided she was elderly so maybe that was why no-one was interested in helping her and gave up. Several months later she had an appointment with the practice nurse at her local GP surgery for another health problem and recounted her story. The practice nurse called the breast cancer team the same day and facilitated her referral back into the system. She was diagnosed with metastatic disease 2 years after being discharged.

“Yvonne” was unaware she had a problem until her employer – an optician noticed she had a facial palsy. She did not connect this with her breast cancer but he encouraged her to seek help and further investigation and she was diagnosed with brain metastases within 2 years of discharge.

Finally, Sarah’s (aged 65, 6 years) story might have been considered the nightmare scenario for this group of women. When she was interviewed shortly after her discharge from the follow-up clinic, she assured me this signified her breast cancer was “cured” – she was diagnosed with metastatic breast cancer 9 months later.

When I met Sarah for the second time, she was an inpatient waiting for the start of the first cycle of her chemotherapy treatment. She was distraught, frightened and angry but still keen to conduct the interview as planned. She told me how 2 months after our last meeting, she went to her GP complaining of a cough, breathlessness and feeling unwell. She was treated unsuccessfully for a chest infection with several courses of antibiotics. Then referred to a respiratory physician and investigated for asthma – this was not the case so then referred back to her GP. She became so ill and breathless that she was admitted to hospital as an emergency and the admitting physician requested a CT scan – which showed pleural and liver metastases from her breast cancer.

Her coping strategy since diagnosis had been to try to carry on as normal and soldier on. Her breast cancer had been one of several stressful situations she had to deal with over the last few years.

She was very shocked and angry and felt let down by the system. It had not occurred to her either, that her breast cancer would return, or that her symptoms might be related to recurrent disease:

".....I just feel terribly let down by the medical profession - with knowing my history, I feel that they should have investigated further because that's what they did when I came this last time, they just looked at....I'd been sent.... "just looking at the history with you having cancer, we're going to send you straight away for a scan." Why didn't they do that 9, 10 months ago - and it would have been picked up then? I just feel that I've missed out on a lot of time to have chemo, which would have probably given me more time".

".....I just feel angry with the whole....with the whole thing and upset, I've got my own business, I can't carry on doing that, there's all sorts of things that..... I've got so many things I planned to do".

".....The shock is unreal, I just couldn't believe, I can't believe that it's happened to me again, I just can't believe it".

".....I'm just in limbo and I'm just getting more and more depressed every minute that goes by; and I'm just sleeping a lot because there's no point in doing anything else. I have to just try to hide myself away, until something has been done about it. Nothing is being done about it - because they don't care".

".....It just never occurred to me that.....I just so..... I've just been so.....I have had things happen during my life physically, but different things like my hip and TB and all that; but I've always managed to get through it. And then, when I had the breast cancer the last time, you know my husband..... I was looking after my husband who was terminally ill with cancer then....."

".....and then I had the breast cancer, you know recovered from it really quickly, because that's what I'm like really and then it just never occurred to me that it would come back, it just did not ever occur to me that it would come back. And that's been the biggest shock - that it's come back and I don't know.....I honestly don't know how to cope with it and you know my sons and my family, my youngest son, both my sons but my youngest son particularly has found it incredibly hard to cope with."

**Sarah (aged 65, 6 years) interview2**

She had tried everything in her power to try and wrest some control over her life and now felt completely helpless and overwhelmed. Sarah's experience brings us back to Janoff-Bulman's concept of shattered assumptions and challenged core beliefs and the devastating effect this has on psychological well-being.

Kenne Sarenmalm et al's study (Sarenmalm et al., 2009) of women coming to terms with recurrent breast cancer describes the transitional nature of this life-changing event. They termed it "living under the shadow of death". Coping with recurrent disease involved not only dealing with its treatment but also the implications for other aspects of daily life – role, status, self-esteem, relationships, fear of death. As Sarah's quote illustrates, there is a need to know not only what has happened, but why it happened and what the future may hold.

The concept of "living under the shadow of death" would be very familiar to many of the women who took part in the present study and whose fear of recurrent disease is real and ever-present.

The apparent dichotomous nature of the identified theme categories, although descriptive and a useful analytical tool; may be altogether too simplistic to encompass the scope and nature of the course of events for individual women. Rather than choosing to position themselves in one category or another, women are situated along a continuum of beliefs, coping strategies and self-identities.

The women who related their breast cancer experience to a "close shave" were also likely to be the women who saw their discharge from the follow-up clinic as a "blessing", the opportunity to self monitor/self-manage their care as a kind of "freedom" and affirmation of their belief that life could on as before (breast cancer).

By the same token, many of the "marked" women did not welcome their discharge from the clinic viewing it as a negative change, a "curse", which conflicted with their beliefs and coping strategies and left them feeling condemned to imposed "isolation".

## 6.7 Summary

The longitudinal data collected for this study demonstrate that as circumstances change, so do beliefs, strategies and attitudes to follow-up care. Women travel up and down the continuum to wherever they find a "fit" for their current situation. For example, they may re-evaluate their "close shave" when a peer develops metastatic spread of her breast cancer, experiencing unexpected fear and feelings of insecurity.

The "Close shave"/"Marked woman" theme described the variety in the ways women cope with the traumatic experience of diagnosis, treatment and managing their long-term recovery. The "Blessing"/"Curse" theme explored the value of follow-up care for the women who receive it and its relationship to the psychosocial support they need and expect. The third theme "Freedom"/"Isolation" documented the anxiety, fears and concerns which emerge for some women when follow-up care is withdrawn; and the re-evaluation and self-management techniques adopted by other women in the same situation.

The three themes in this chapter chart the progress of the women from diagnosis through treatment and long-term recovery; and for some to recurrent disease, but highlight that their story does not end with discharge from outpatient follow-up care.

The next chapter will discuss the implications of their experiences and how they might inform the design of care and management of women in long term recovery from breast cancer.

## Chapter 7 Discussion and concluding remarks

### 7.1 Introduction

The aim of the study was to investigate the experience of being discharged from breast cancer follow-up services and evaluate the impact of the proposed changes in service delivery from the patient's perspective. The study objectives were to describe how women felt about the change in service provision, examine how the change in service provision affected women's views of fear/risk of disease recurrence, identify the impact of being discharged from follow-up on quality of life, including psychological distress, adjustment and coping and explore anxieties and concerns once patients were discharged from regular outpatient follow-up care

Before the start of the study described in this thesis, informal discussion with clinical colleagues involved with the care of women in recovery from primary breast cancer; indicated that they felt that women who held negative views of the proposed changes to routine follow up care; would be characterised by those they termed "the worried well", "over-anxious", "information-seekers", "control seekers". Clinical staff predicted that women who volunteered to participate in the study would invariably be suffering from anxiety disorders and/or depression or be psychologically unwell in some way and this would result in a skewed, biased sample of the population of women who attended the clinic. They felt only women who were dissatisfied with the proposed changes would wish to take part. These women would be in contrast to the women who conformed to the positive role models evident in contemporary breast cancer patient culture of "positive thinkers", those who were keen to move from the "sick" to the "well" role and move forward; returning to the lives they had before. This was considered by many clinical colleagues to be the appropriate and healthy response to the changes in follow-up care.

This led to the generation of possible influencing factors to try to explain the variation in the women's reactions. These were: undiagnosed anxiety and depression, reduced quality of life, little, or no social support and the use of particular coping strategies.

An initial review of the literature revealed that previous work had documented there were a variety of responses to diagnosis. These were influenced by age at diagnosis, the coping strategies adopted and the level of social support available. Previous research also provided evidence to suggest that higher levels of distress were evident in the long-term for those women with co-morbidities, chronic pain, chronic fatigue, lymphoedema, diagnosed anxiety and depression, side effects from breast cancer treatments, a lack of social support and those who were unmarried/living alone. In particular this was related to the nature of social support available – dependent on who provided it, what it consisted of and how long it lasted. Uncertainty and its association with perceptions of threat and risk of recurrent disease was also deemed to be influential regarding the levels of distress experienced by women with breast cancer. In particular this occurred at certain flashpoints the most pertinent were those related to end of treatment and re-entry to usual living.

This led to the adoption of several survey instruments to test these assumptions in the group of women recruited to the present study, namely:

The COPE questionnaire to investigate coping strategies, its addendum the Significant Others Scale to look at the level and nature of social support, the EORTC's QLQ-C30 questionnaire to assess quality of life, the BR23 breast module to assess late and long-term effects of treatments and the HAD scale to obtain scores for anxiety and depression. These were in addition to in-depth semi-structured interviews to elicit not only what the women felt but collect additional information about why they felt the way they did.

These assumptions turned out to be limited in terms of their ability to explain responses and behaviours in relation to discharge from long term follow-up. The study findings from the questionnaire data provided no evidence to support the initial ideas regarding influential factors. Coping strategies were dynamic and evolving not static and a range of styles were used by the same participant. Social support was often available but not effective or even detrimental and the quality of life data demonstrated too much variation to be of help. Long term/late effects of treatment were evident in 33% of the participants but not correlated with reactions to discharge from follow-up care. HADS scores for anxiety and depression were not directly correlated with negative reactions to discharge from follow-up care. Consequently this thesis has focused on the findings from the interview data.

The influential factors seemed to be more closely related to the following:

- prior experiences and beliefs
- traumatic events (cancer-related)
- social support that was theoretically available but in reality inaccessible
- the fact that follow-up care was used as an integral part of coping strategies as opposed to the style of coping adopted.
- the mode of detection of disease
- dissatisfaction with the reliance on either self detection, or mammograms, for the identification of recurrent disease

In addition, the new style of follow-up care was adopted based on chronology of recovery ( $\geq 5$  years post diagnosis) and prognostic status and did not appear to meet individual needs.

Analysis of the interviews was in effect, an examination of the combination of the development of the social process of adapting to change and the way in which the process worked. It was apparent from the interviews with the women that they held

divergent views on whose responsibility it was to monitor for recurrent disease and how big a threat it posed in the long-term. These views differed according to whether they chose to remain in the 'world of the sick' or the 'world of the well' and the advantages or disadvantages they saw in this.

For this reason the analysis centred on

- belief systems –what they constituted and their influence on behaviour
- the *scope* of follow-up care
- perceptions of future care and well-being

The interviews highlighted the presence/role of the feelings of dissonance, which some of the women in the study experienced, when confronted with the clinical evidence provided by the healthcare professionals to support the withdrawal of regular outpatient follow-up care. This was in conflict with the experiential evidence of other people they knew with, or had died from, cancer. This resulted in an increase in their perceived level of threat. Festinger's Theory of Cognitive Dissonance helped to explain why this was and consequently was adopted for the analysis and interpretation of the data.

The influence of core beliefs and basic assumptions about breast cancer, its treatments, the level of threat it posed, the way it was dealt with and assimilated into the life experience of the women in the study was also emphasised in the interviews. Beliefs about risk and self-determination; and the role of the various modes of detection of breast cancer; had a major influence on views and behaviour related to reactions to follow-up care. Ronnie Janoff-Bulman's theories on the effects of emotional and physical trauma on belief systems, helped to explain what happens, when belief systems are challenged and the threat of cancer creates existential concerns.

Lazarus and Folkman's work around coping strategies (particularly emotional vs problem-solving coping); contributed to the development of the "Close-shave"/"Marked Woman" themes used to describe the data from the interviews.

Leventhal's Theory of Illness Representation is incorporated into the interpretation of the data related to the value of follow-up care. Specifically how women created meaning and made sense of the changes and new information; and then adapted their coping strategies and behaviour, this led to the themes of "Blessing" or "Curse" described in chapter 5.

The changes over time described in the findings related to whether women felt they **have** breast cancer/**had** breast cancer/are likely to develop further recurrence of breast cancer in the **future**; and fit with Kathy Charmaz's ideas of people with chronic illness *situating themselves in time*. Choosing to view themselves either as sick or well, under threat, or free from it.

All of these theories were then linked and incorporated into a theory of cyclical change and adaptation, a perpetual re-evaluation characterised by periods of equilibrium, interspersed with episodes of crisis, confusion and rebuilding.

This final chapter focuses on my explanation and interpretation of the views, concerns and behaviour of the women who participated in the study in the light of existing theories and in particular:

- the reasons behind the differences in reactions to the change in follow-up care provision
- perceptions of the value of follow-up care
- the variation in perceptions of risk of recurrent disease

- the wants and needs of women in this situation for their future care and management.

The final section of the chapter will discuss suggestions for possible options and alternatives for models of care for this group of women.

## **7.2. Key themes and major findings**

Discharge from the clinic was initially intended to be the main focus but as women told their story, past experiences seemed to play an important part both in how they approached their diagnosis and how they chose to manage their lives thereafter.

The women's interpretations of the significance of the type of treatment they were offered, the extent of their disease and its implications for their future well-being seemed to influence their reactions to the change in their follow-up care. The women's appraisal of the level of threat from breast cancer (regardless of that of their clinician), was the key to the feelings and emotions they had towards the changes.

The value the women in this study attached to follow-up care rather than their satisfaction with it was important. It was the perceived unintended benefits/ losses which invoked negative reactions to discharge from follow-up care. The variety in needs and expectations seemed to explain the variety of responses rather than those factors presumed by the researcher.

### **7.2.1 The experience of discharge from routine out-patient clinic follow-up care**

Reactions to discharge from regular follow-up care and attitudes to self-care and long-term management of breast cancer; appeared to be generated as a result of personal interpretations and beliefs. This appears to be based on the experiences of the

individual: not related to the level of education, or information the women received about breast cancer risk or follow-up care. Neither was it related to clinically significant levels of anxiety and depression, poor quality of life, or personality trait. The interview data demonstrated links between the beliefs and assumptions the women held about breast cancer and its treatments, the effectiveness/usefulness of follow up care and the level of risk it posed on their future health and well being.

The broad spectrum of reactions/responses documented in the interview data illustrated that there was no usual response, no common reaction to the changes in follow up care in the 20 women interviewed.

The women either viewed the change to their follow-up care as a positive event, or just trusted in the expertise and intentions of the clinicians responsible for their care. Others resigned themselves to the change despite the fact they were unhappy with the change because they felt powerless to influence or overturn the decision, or were angry, fearful and felt they had been cheated out of the care they needed and deserved.

### **7.2.2 Reasons for the reactions to discharge from follow-up**

Whether the women reacted in a positive or negative way to their discharge from follow-up was heavily influenced by their prior beliefs about breast cancer and the effectiveness of treatment. Women referred to what Janoff-Bulman calls their "life schemas" or personal rule-books (Janoff-Bulman, 1992), using their experience and knowledge related to breast cancer, to guide their appraisal of the change in circumstances.

Conventional sources of social support: significant others, family, friends were not always available. This was sometimes due to differing methods of coping, the expectations of others to "be strong", "think positive", "move on". This is not always possible and societal expectations make it difficult to express these feelings outside the

clinic environment. Witnessing the ravages of metastatic cancer in others also appears to interfere with the appraisal of breast cancer as a treatable disease.

Faith in the expertise of Health Care Professionals/the Health Care system, facilitated the transition from discharge from outpatient follow-up to self-management and was welcomed by those women who believed in and embraced the concept of self-determination.

Due to the longitudinal nature of the research, it was possible to monitor the original responses and look for changes over time. This was dependent on the experiences of individual women during the course of the two years of data collection for the study. Those women, who maintained their original views on the discharge from this clinic either positive or negative, did so because there were no significant events to challenge their views during the study period. Positive views of the change were challenged when family members or peers, developed recurrent, metastatic disease or died from cancer and fears re-emerged with breast cancer once more viewed as a significant threat. Negative views subsided for the women who over time had reappraised the threat and used social comparison to minimise the risk of recurrent disease and convinced themselves that for this reason outpatient visits were now unnecessary.

The concepts of "close shave" and "marked woman" emerged from the interview data during the course of the study and have been described in detail in earlier chapters. The choice of approach both at diagnosis and at discharge from follow-up appeared to be linked to the appraisal of the threat posed by breast cancer.

#### 7.2.2.1 Characteristics of women who choose the "Close shave" approach

The women in this group perceived the level of threat and the risk of recurrent disease to be low. Women came to this conclusion based on their belief in the value of early

detection of the disease. The assumption was that their tumour was small in size with no lymph node involvement. Therefore they did not require chemotherapy, radiotherapy and were offered lumpectomy, not mastectomy. This combined with the fact that there was no family history of breast cancer, engendered belief in the effectiveness of their treatment.

In addition women who adopted this approach tended to place greater faith in self-determination, favour self-management of their long-term care and had greater confidence in their ability to detect a breast cancer related problem. They believed the open appointment system gave them rapid access to effective treatment for recurrent disease. The original mode of detection used to diagnose their breast cancer was invariably mammography or self-detection of a lump. They had no prior experience of others dying from cancer. They successfully minimised the physical and psychological impact of their disease and used upward social comparison as a coping strategy to distance themselves from others who they perceive to be at higher risk.

Consequently discharge from outpatient follow-up care was welcomed by these women as it corresponds with perceptions of self as "well". Annual follow-up visits clash with these perceptions and result in unwanted re-visiting or reminders of the status of "breast cancer patient". The open appointment system is accepted as the women in this group presume they will never need it.

#### 7.2.2.2 Characteristics of women who choose the "Marked woman" approach

In stark contrast the women in this group perceived breast cancer to be a constant ever-present threat. They believe it is a matter of when, not if, disease recurs. This is often based on previous experience of cancer in others, either breast cancer peers, or from nursing terminally ill relatives. They were less likely to have faith in their ability to self-detect breast cancer problems, or self-manage their long term care and preferred to abdicate this responsibility to specialist health care professionals.

This was related to their belief that they lacked the necessary skills to detect recurrent cancer and it required the expertise of clinicians. Often their disease had gone unnoticed and was detected by others – GP, practice nurse, well-woman clinic –they were completely unaware of any physical changes which were sometimes undetectable by mammogram. Consequently 3 yearly mammography, was viewed as ineffective as a means of detecting recurrent disease, and some of the women had unrealistic expectations of physical examination as a mode of detection. They needed to have faith in the abilities and expertise of healthcare personnel.

These women disliked and distrusted the open appointment system. Regular outpatient follow-up had created a legitimate opportunity for revisiting, re-evaluation and provided relief and respite from anxiety, which they now felt was lost to them. There was a real fear of sabotaging valued relationships (with healthcare professionals) with false alarms. The women also dreaded the stigma of being viewed as “whittlers”, “worriers”, “neurotic” and wanted to avoid being labelled and discriminated against.

The variations in perceptions of risk of recurrent disease seemed to be related to either, the belief in self detection of recurrent disease and its early detection as a means to a favourable prognosis, or fears of undetected progressive disease and an early death. In short, whether the women understood “a breast cancer problem” to mean another small treatable breast lump or widespread bone metastases.

These two scenarios contributed to either the sense of freedom or feelings of isolation once the women were discharged from regular follow-up. Those who believed the risk was significant constructed alternative strategies to circumvent the system to maintain their contact with the healthcare system, via well-woman clinics, mammograms in another county via the mobile unit, consultations in the reconstruction clinic, visits to their practice nurse or GP.

This resulted in resources and costs being merely moved from one part of the NHS to another, disguising/hiding the problem of discontent and unfulfilled need in this group of patients. In part this is a result of cultural and societal expectations that once treatment is complete women should return to the physical and psychological state they had before diagnosis. Some women interviewed for the study, feared the stigma and intolerance to their long-term fear and anxiety and their inability to come to terms with a life-threatening illness. This in turn, engendered a sense of failure and a need to hide their true feelings.

### 7.2.3 The Value of Follow-up Care

The medical research literature over the last 20-30 years has reported the value of follow-up care for breast cancer in terms of improvements in physical well-being, the monitoring and surveillance of disease and the detection of local, or metastatic spread of the original tumour. In Rojas et al's Cochrane Review of breast cancer follow-up (Rojas et al., 2005) they reviewed only 6 randomised controlled trials from the previous 20 years and failed to include any qualitative studies in their analysis. Collins et al's structured review (Collins et al., 2004) was only able to assess 38 studies out of the 4,418 they identified - due to poor study design/research quality. What the Collin's review was able to reveal, was that despite the heterogeneity of the studies which made statistical comparisons almost impossible - duration of survival and quality of life; did not appear to be affected by the intensity, or location, of follow-up care. Levels of psychological distress were high regardless.

Despite the volume of research conducted, there was insufficient evidence to support recommendations for patient involvement, cost effectiveness, or reductions in morbidity. Beaver and Luker's study (Beaver and Luker, 2005) highlighted that the doctors in their study concentrated on mammography results, physical examination and compliance, whilst the nurses in the same team felt that psychosocial care was an important aspect

of follow-up care. The nurses in this study felt time was too limited within the consultation and dealing with these issues outside the clinic environment would be beneficial.

The data collected from the interviews in this study revealed that for many of the women in the study - the medical model of follow-up care, is only one aspect of the benefits gained from regular attendance at the outpatient follow-up clinic. Thus discharge from outpatient follow-up care, results in the loss of these unexpected and under-reported benefits.

The women in the study appeared to gain useful information and advice about their physical health and breast cancer in general. They looked for reassurance that they were disease free and respite from the fear and anxiety of possible disease recurrence. They needed to create the illusion of control and predictability over the disease in order to feel safe and free from the over-whelming sense of threat posed by their original diagnosis.

The clinic represented an environment which allowed compartmentalisation of their breast cancer status. It created a sense of place, a geographical location for their breast cancer, where they could be with others who understood what it meant to be diagnosed with breast cancer. There was a sense of "belonging" "fitting-in" which may be lacking in their relationships with other people. The clinic was an opportunity for "legitimate" contact with health care professionals. There was no need to draw attention to themselves, raise their head above the parapet, to risk feeling foolish and admit they needed help. The clinic appointment was in effect an invitation to do so. As all of the women attended the clinic once a year, there was no necessity to fear being singled out, or seen as "different", "difficult" "needy" or "over-anxious".

The annual appointments were an opportunity for these women to measure their progress, reflect on the time of diagnosis and make comparisons, both with their own

situation and social comparisons with others. The clinic visits were in some instances ritualistic, used as a touchstone creating feelings of safety, security, and being cared for. Women used their clinic visits to share their feelings and experiences with other women they met in the waiting room each year. This enabled them to give meaning to their personal experience of breast cancer and to try to understand what is "usual", "expected", "normal for breast cancer". They needed to gauge the "right" way to manage, the "right" way to behave within breast cancer culture in order to fulfil their perceptions of societal expectations and feared stigma, labelling and discrimination by others.

#### 7.2.4 Looking to the future

The needs and wants for their future care and management articulated by the women who participated in the study depended on their view of the threat it posed to their future well-being.

The women who chose to believe their experience of breast cancer was a "close shave", desired the freedom to return to the life they had before their diagnosis, to return to the world of the "well", to leave their experience of breast cancer behind, to self-manage their health and well-being. They felt able to do this either because they believed they had rapid, easy access to the healthcare system for timely treatment and consequently a favourable prognosis or because they believed themselves to be cured and were convinced they would not need to return to the clinic at all.

The "marked woman" on the other hand, wanted regular life-time surveillance – this was assumed to comprise of a combination of physical examination, mammogram and face to face consultation to address the needs of all of the women, regardless of which mode of detection they placed their confidence in. They also felt that follow-up care should be individualised to address the needs of women regardless of the length of time since diagnosis.

Women wanted their follow-up to be flexible both in frequency and availability and easily accessible - with a choice of venue. There were variations in perceptions of what kinds of issues should be addressed in the clinic environment. Some women wanted the clinic to address purely physical problems, others felt that psychological issues were important but found the clinic environment too intimidating and wanted access to help and support outside of the traditional hospital setting. One woman suggested that out of hours support would be useful – she felt the need to talk late in the evenings when she felt most alone, or at the weekends when she didn't have her work to distract her. Some of the women interviewed, described how close family members and friends struggled to support them and often needed support themselves. This led to distancing in their relationships with each afraid to distress the other. There were several requests for support for others –women felt with outside help they would be better able to support one another within their close relationships.

## 7.3 The Cycle of Reappraisal and Adaptation

The theoretical concepts adopted for the analysis and interpretation of the data collected for the study appear to be linked, forming a cycle of events, a process by which the women move from “triggers” which disturb the equilibrium of their psychological well-being through a series of meaning-making steps to achieve a level of understanding and psychological status quo.

The “triggers” are diverse and individual to the woman concerned and often relate to contradictions of previously held beliefs. For example – the belief that the size of tumour and consequent treatment she received confers a minimal risk of recurrent disease is challenged when a peer with a similar breast cancer history develops metastatic disease.

Other examples of challenged assumptions that recurrent disease is unlikely, are media coverage of female celebrities diagnosed with breast cancer or unexpected/unexplained aches and pains which result in increased levels of anxiety and insecurity.

These “triggers” create dissonance between core beliefs and assumptions and contradictory “evidence”. This necessitates a period of reflection, cognitive reasoning and meaning-making.

This subsequently results in readjustment of schemas or rule-books related to breast cancer, its treatments and prognosis. Coping strategies are then constructed and developed to deal with changing circumstances and assimilated into daily life and pre-existing roles and responsibilities.

Finally women arrive at a satisfactory (to them) conclusion with regard to the influence of the trigger and the threat it poses to their future well-being. They then decide how they will manage its implications, how they will choose to situate it in the chronology of their life experience.

## 7.4 Theoretical foundations and the interpretation of the data

The next section will explain how the study findings relate to the theoretical concepts. These concepts help to illustrate the significance of the findings and in addition I will describe how the findings may contribute to theory in this field of research.

The women interviewed for the study, chose to view the impact of their breast cancer in different ways. This was related to their assessment of the risk of recurrent disease. They based their assessment on prior knowledge of the implications of a breast cancer diagnosis, their beliefs about the effectiveness of treatment and the experiences of

others within their social circle. If the threat was perceived to be overwhelming, they chose to avoid dealing with the threat, or attempted to deny its existence. This led to the emergence of the themes of close shave or marked woman which incorporated the theoretical concepts of illness representation proposed by Leventhal's Common Sense Model (Leventhal et al., 1997, Leventhal et al., 1992) and the emotional response to challenged core beliefs and basic assumptions illustrated in Janoff-Bulman's work with those affected by emotional trauma (Janoff-Bulman, 1992).

### 7.4.1 "Triggers" and Dissonance

Cognitive dissonance is a state of disequilibrium which ensues when convictions and "truths" – no longer hold true. Some of the women who participated in the study, chose to adopt a self-delusional approach due to their perceptions of lack of control or self-determination. The need to carry on with daily life and maintain social roles meant there was a need to pretend that everything was fine. Information and advice didn't help because the issue related to belief systems – emotional not cognitive responses, feelings not logic. Dissonance between information given and pre-existing beliefs resulted in a plethora of emotions - threat, fear, anxiety, uncertainty, insecurity, inadequacy, isolation and loss.

The anxieties and concerns expressed by the women once they were discharged from regular outpatient follow-up care could be explained by, or appear to be based on, their unease and discomfort with the sense of responsibility and level of faith and trust in the healthcare system. Leon Festinger's theory of cognitive dissonance (Festinger, 1962) as detailed in the literature review (section 2.5.5, page 53) is a possible explanation.

This sense of dissonance and the strategies described to manage it were evident in the interviews conducted for the study and described in the findings (chapter 4, section 4.4.2, p130 ). Not only at the time of diagnosis, but at the end of the treatment period,

at trigger points (cancer in others, death of peers, "scares") and for some women - at the point of discharge from regular outpatient follow-up or diagnosis with recurrent disease. I spoke to women who said they believed they were cured, that they believed their breast cancer would not come back but insisted that their follow up care should continue and include yearly mammograms.

Then there were the women who wanted to believe that recurrent disease was unlikely but viewed the clinical "evidence" provided by healthcare professionals as suspect, flawed, because it was contradicted by the "trigger" of personal experience of others diagnosed with metastatic disease. Women who valued physical examination because they believed it was instrumental in the prevention/early detection of recurrent disease, were then told it was unnecessary and were denied access to it.

Those women who developed recurrent disease as a "trigger", experienced dissonance when their beliefs about the causes of cancer were challenged and they found they were unable to control or predict the progress of the disease and had to reconstruct/rebuild disrupted coping strategies

## 7.4.2 The Meaning-Making Process

Illness representation - how the way women view the implications of a breast cancer diagnosis on their well-being relates to the formulation of their beliefs. One of the objectives of the study was to examine how the change in service provision affects women's views of fear/risk of disease recurrence.

Leventhal's Common Sense Model and Theory of Illness Representation (Leventhal et al., 1997, Leventhal et al., 1992, Leventhal et al., 1998, Weinman et al., 1996), as outlined in the literature review (section 2.5.3, p54) and highlighted in the findings (chap 4, section 4.4.2, p129); have been used to explain how women varied in their perspective and approach to dealing with a diagnosis of breast cancer; and the treatment and

recovery period that ensued. The Common Sense Model defines 5 characteristics or attributes which are used to investigate an individual’s own understanding of risk:

- the identity of the threat to health – in this case breast cancer
- its timeline – whether the women perceive it to be an acute or chronic event
- the consequences of being diagnosed with the disease – physical, psychological, economic and social
- causation - whether there is an identifiable factor(s) which contributed to the diagnosis
- control or cure – elimination of the disease, or prevention or reduction in the likelihood of recurrent disease

The role of fear of disease recurrence and its influence on how women with breast cancer view their future has already been flagged. The women’s perceptions of the cause of their breast cancer, the level of control and the possibility of cure relate to their beliefs about its implications for their health now and in the future.

The constitutive elements of the two themes of close shave and marked woman link closely with the attributes identified in the model as shown below:

<b>“Close shave”</b>	<b>“Marked woman”</b>
<b><i>Identity/labelling</i></b>	
Well	Sick
Cured	Threatened
Curse (of follow-up care)	Blessing (of follow-up care)
Freedom (from regular clinic visits)	Isolation (loss of follow-up)
 <b><i>Timeline</i></b>	
Acute	Chronic
Finite (curse, freedom)	Ongoing (blessing, isolation)
 <b><i>Consequences</i></b>	
Minimal	Significant, extensive
 <b><i>Causation</i></b>	
HRT, diet, trauma, stress	Random, bad luck, age, family history
 <b><i>Control</i></b>	
Predictable, resolvable, controllable (via healthcare systems and treatments)	uncertain, unpredictable, uncontrollable

The women in each category chose to adopt completely opposite attributes when evaluating the risk posed by their breast cancer

Time-markers and being "situated" in time – were often used as a means of measuring, evaluating progress and making sense of major life changes in relation to a personal chronology of illness and life in general. Even those women who maintain a disease-free recovery, experience dissonance and find it difficult to come to terms with the idea that breast cancer is part of their past when they continue to experience late or long term effects of treatment.

Clinic visits when used as time-markers provided a useful opportunity for some of the women in the study, to chart a steady advance towards anticipated recovery. The annual visits enabled a self-reflection on past events and a way of measuring their progress. Kathy Charmaz describes this as creating a "chronology of illness". By treating dates of diagnosis or surgery as anniversary dates they were able to re-visit and re-evaluate the treatment and follow-up period and create meaning/generate understanding from it (Charmaz, 1991, Charmaz, 1995, Charmaz, 1999, Charmaz, 2000, Charmaz, 2002, Charmaz, 2006).

### **7.4.3 Behavioural adaptation and the management of change.**

Ronnie Janoff-Bulman's ideas on the influence of challenging significant stressful events on core beliefs and basic assumptions were explored in the literature review (chap 2, section 2.5.3) and linked to the reported findings (chap 4 section 4.4.2). This illustrates that individuals are forced to adapt their behaviour and manage the change using a variety of coping strategies and fits with women's reactions in the study to the changes in their follow-up care. Women either made the information "fit" – assimilated it into their personal schema of breast cancer reinforcing and confirming their previously held beliefs or felt challenged by it - previously held beliefs no longer held true and changes in strategy and schemas were necessary to accommodate the change in circumstance. It

may also explain why some women reacted so vehemently against the change in their follow-up care – a form of what Janoff-Bulman calls “hyperarousal” (Janoff-Bulman, 1992) - following the traumatic impact of diagnosis and treatment, or the experience of others with cancer. Some of the women in the study had experienced the death of a loved one from cancer, or a breast cancer peer, or a “scare” (a potential disease recurrence which turned out to be benign). Each of these circumstances induced fear and anxiety which was not easily overcome and left a sense of residual threat which resurfaced when routine outpatient follow-up care was withdrawn.

Coping theory is used to explain and describe how strategies for dealing with changing circumstances are formulated and evaluated. The women in the study chose to cope with the change in follow-up care in different ways. Coping strategies took many forms and were used to process the new information and rebuild schemas. Each of the phases of appraisal outlined in the theoretical concepts of Lazarus and Folkman (Lazarus and Folkman, 1984), is evident in the dialogue of the interviews for the current study. The process of primary and secondary appraisal was described during the period immediately following diagnosis. The assessment of level of threat and risk to physical well-being; and the strategy chosen to manage it, was apparent in the descriptions women gave of their feelings and behaviour at that time. The outcome depending on whether breast cancer was viewed as a challenge or a threat, dictated whether women adopted the attitude of “close shave” or the role of “marked woman”.

Reappraisal occurred at the time of discharge from regular outpatient follow-up and also at “trigger” points, the progression of disease in others or the death of a friend or relative from cancer for example.

Defensive reappraisal emerged in the form of minimisation and social comparison – “it was a small tumour”, “they caught it early” “ I didn’t need chemo like some women do”.

Commitments and beliefs were strongly influential in shaping the reactions of the women to the changes in their follow-up care. Long-term management of recovery from breast cancer included attempts to preserve important relationships, social roles, avoid stigma and rejection. Pre-existing ideas about cancer, its treatments and the potential level of control and predictability were all a result of carefully constructed beliefs (both primitive and higher order) which were resistant to change, regardless of information or clinical "evidence" offered by health care professionals.

The variation in the appraisal of the threat and differences in individual's experiences and beliefs may account for the spectrum of coping strategies encountered in the interviews.

The situational factors included in Lazarus and Folkman's coping theory (Lazarus and Folkman, 1984) were also relevant to the findings in the interview data. The sense of predictability, provided by annual clinic visits created the opportunity for women to prepare in some way for the anticipated stress and the ability to gauge when they were "safe" from the stressor (breast cancer) giving them periods to relax (for a year) until the next appointment. This was lost once the appointments were withdrawn.

Lazarus and Folkman acknowledge the immobilising effect of uncertainty on anticipatory coping processes and the mental confusion that ensues by having to consider first one possible outcome, then another and not being able to decide which course of action is best. This means "closure" is unavailable, this can lead to excessive worrying and rumination and eventually anxiety. This interferes with cognitive functioning ".....not knowing whether an event is going to occur, can lead to a long drawn out process of appraisal and reappraisal generating conflicting thoughts, feelings and behaviours which in turn create feelings of helplessness and eventual confusion". This accurately describes the period following completion of treatment and before disease recurrence and explains

why the change in follow-up care caused turmoil and anxiety in those women in the "marked woman" group.

McGrath 1970 and Appley and Turnbull 1967 in (Lazarus and Folkman, 1984) point out that time may be one of the most important parameters of stressful situations.

Imminence – ".....the interval during which an event is anticipated" the more imminent an event, the more intense its appraisal, particularly if it is likely to include harm, danger or opportunity for mastery or gain. Time for decision-making affects its quality and allows for evaluation of information and advice – weighing up all the pros and cons of each alternative before making a choice. If insufficient time is allowed or available, a hyper-vigilant approach may be adopted: ".....obsessive, nightmarish fantasies of what might happen, failing to notice evidence indicating the improbability of their occurrence.....constantly aware of pressure to take prompt action to avert catastrophic losses. Superficially an individual scans the most obvious alternative open to him/her and may then resort to a crude form satisfying hastily, choosing the first one that seems to hold the promise of escaping the worst danger." (McGrath, 1970)

For the women who believed the threat from recurrent breast cancer to be imminent or an ever-present threat, (the "worried-well") hyper-vigilance, "watchful-waiting" seemed to be an important aspect of their management of the perceived threat.

For the women who reacted negatively towards the change in follow-up care, this followed on from the choice of coping strategy and the appraisal of the threat from breast cancer. Those women who viewed the changes to follow-up care in a negative way appeared to be more likely to rely on formal surveillance methods to fuel their belief that they reduced the level of threat from recurrent disease and wanted to attribute responsibility for this aspect of their management to the healthcare team.

Women in the “marked woman” group perceived a higher level of threat from their breast cancer than their “close shave” counterparts and viewed their health status as uncertain, unpredictable, incurable, beyond their control or that of the healthcare team. These women used compartmentalisation as a way of coping and viewed the clinic as a place of sanctuary where they could obtain understanding, information, advice, reassurance and voice fears and concerns without emotionally distressing the other. These were the anticipated losses which prompted feelings of abandonment and isolation.

The changes in health policy disrupted coping strategies and challenged beliefs and meaning-making carefully constructed over time. This created the feelings of insecurity, abandonment and isolation. The “marked women” were afraid and anticipated undiagnosed untreatable disease recurrence, with palliative care the only option. These women feared pain, suffering and death and believed that close surveillance and frequent follow-up care may help them avoid or at least delay this possibility.

As alluded to previously the data from this study suggests, that this is not a static state of affairs but a cycle of events. The status quo remains until the next “trigger” which acts as a catalyst for the next cycle of re-appraisal and adaptation.

It is the emergence of this process from the data, which led to the strong suggestion that ongoing psychological support and care are an essential element of long-term management in breast cancer. The broad spectrum of needs and the moveable feast of who needs what, when and how - necessitates a flexible, accessible, individualised, program of care throughout the disease trajectory.

## 7.5 The significance of the study findings and implications for clinical practice

The interview data collected for this study illustrate that the women gained far more than the clinicians may have anticipated from their annual clinic visits. Unlike the aims of follow-up documented in the research literature, their priorities were not always physical well-being, effective disease surveillance and early detection of recurrent disease.

Negative reactions to discharge from regular follow-up care can not simply be written off as signs of anxiety and depression, hyper-vigilance, and a need for "reassurance", which is viewed as an ill-defined, unnecessary aspect of the provision of care. It is often minimised, trivialised and given low value by healthcare professionals who feel it has no place in modern health surveillance and is not within their remit of care.

Although open to interpretation and difficult to define, it would seem to represent some level of predictability, control and self-determination. For some women this is gained through information – knowledge is power, they use logic, education, action, cognition, problem-focused coping. For others coping is primarily emotion-focused with a need to attribute responsibility to healthcare professionals in order to feel safe. This group of women rely on trust, faith, hope, belief as a means of managing uncertainty.

"Reassurance" appears to incorporate all of these things and is invaluable as a means of managing long-term recovery from breast cancer.

Review of the literature identified similar results from two recent studies. One conducted using a focus group comprising of women with breast cancer at the end of their chemotherapy treatment in the first year of follow-up (Allen et al., 2009) and the other also using focus groups to investigate views of follow-up care in ovarian cancer from the perspective of both patients and the healthcare team responsible for their care.

The data generated from both of these studies although conducted in women with either a different site for their cancer, or at a different time-point in their cancer journey – mirrored the feelings fears and concerns of the women in the present study. Some women used benefit-finding and felt empowered by their breast cancer experience, others were constantly fearful of recurrent disease this equates to the close shave/marked woman dichotomy described in the present study. They expressed emotional distress and had difficulty in achieving normality that is returning to the psychological state they had prior to diagnosis. They felt a sense of loss at the end of their treatment period and feared the sense of responsibility which came with the role of self-monitoring for recurrent disease. They resented the expectations of others to think positive and move on before they were ready (Allen et al., 2009).

The health care professionals in A Lydon et al's study of women in recovery from ovarian cancer (Lydon et al., 2009) placed emphasis on monitoring and detection of recurrent disease and the need for self-management in long term recovery, they wanted "modernisation" of the system of care i.e. less frequent visits, doubted the efficacy of detection via routine appointments and felt there was no evidence to support physical examination as a mode of detection. This was in direct contrast to the views of their patients who valued "hands on" care at regular intervals and wanted reassurance that all was well via information and support. This proved harder to ask for over time, through fears of time-wasting. They also requested alternatives to the present system to enable a system of more individualised care. The striking similarities between all three studies illustrate that time and site of disease are immaterial and experiences are more common and universal than recorded previously in the literature. The women who participated in the studies were either within 12 months of their breast cancer diagnosis and had completed chemotherapy in the case of Allen et al's study, in the present study the women were in long-term recovery from breast cancer and in Lydon et al's study the women were in long-term recovery from ovarian cancer. Regardless of these differences the women had similar fears, concerns and expectations. All three studies illustrate that

reassurance is an essential part of follow-up care and psychological support is required long after treatment is complete throughout the trajectory of cancer care.

## 7.6 Models of follow-up care and their relationship to the study findings

The literature review chapter outlined a variety of follow-up options. The data from the study lead us to believe that each model of care is attractive and successfully fulfils the needs of a proportion of women but there is no “one size fits all” model which is universally acceptable or universally effective. All have demonstrated benefits and disadvantages, but the variety of needs and experiences of women in long-term recovery would appear to necessitate a flexible accessible, range of options to suit individual needs.

The data would suggest that patient-initiated, nurse-led or telephone-based follow-up may be a welcome alternative to traditional, clinic-based, care for some women (i.e. the women in the “close shave” group). Those who estimate the threat of recurrent disease to be minimal and have faith in the open appointment system to give them rapid access to treatment should they need it – this approximates to the close shave concept. These models allow a greater degree of freedom and independence, whilst still offering the opportunity for psychological support and access back into the system, should the need arise. However previous research has demonstrated that healthcare professionals consider this model to be unsuitable for women with personal/psychological problems and symptoms of anxiety or depression (Brown et al., 2002).

For the “marked woman”, physician-led, hospital-based care may satisfy the need to feel safe, as greater faith and value is conferred on those perceived to possess knowledge and expertise. However, the availability of resources may restrict the ability of the

healthcare system to provide this in the traditional setting and so alternative strategies may need to be explored to manage the physical/psychological well-being of this group.

Both healthcare professionals and patients alike seem to have reservations regarding attributing long-term follow-up care to General Practitioners. For the patients, their uneasiness centres on the limitations of knowledge and expertise of GPs (Adewuyi-Dalton et al., 1998, Renton et al., 2002) , whilst for the healthcare professionals, the concerns relate to the financial burden on primary care services, in addition to issues around the training needs of GPs (Grunfeld et al., 1995, Collins et al., 2004, Grunfeld et al., 2006).

### 7.6.1 Alternative models of care

McMurty (McMurtry and Bultz, 2005) asserts that there is a need to measure indicators of emotional distress - a significant aspect of the cancer experience. Despite the plethora of evidence-based research which demonstrates high prevalence rates of emotional distress, current health care policy continues to focus on biomedical aspects of care. This he says is unlikely to change unless healthcare professionals routinely address comprehensive aspects of their patient's experience and are committed to affecting change via cancer agencies as well as government policy.

McMurty criticises current health policy because he says, it fails to reflect the human and social consequences of economic activity and its effects on the natural environment, health status and social cohesion. He also criticises what he terms "reductionist thinking" the higher value/status attributed to biomedical products and consequently providing e the main, if not only, focus of advances in care.

McMurty's solution to these issues is to elicit the global determinants of health and their relationship to psychosocial status in health and disease and routinely seek, measure, report and act on determinants of psychosocial realities of disease

There are already established, dedicated, one stop, survivorship clinics in the USA (Yale Cancer Center, 2010) and the US National Cancer Institute has piloted a national training programme for survivorship care which is in the process of being evaluated and rolled out in centres across the US (Grant et al., 2007, Ferrell and Winn, 2006).

The voluntary sector, have already created innovative models of care provision designed to complement the current biomedical hospital-based model for those in long-term recovery from cancer.

Maggies Centres (UK), Breast Cancer Haven (UK) and the Wellness Community (US) each offer a community-based, accessible, drop-in service to provide resources for information, advice and education related to a variety of useful coping strategies, self-management techniques as well as signposting to other services. These are available not only to those living with and beyond cancer but also those with whom they have close relationships.

It would seem prudent to work in collaboration with the voluntary sector and build on established successful models to work towards an effective and satisfactory programme of care within the NHS.

Current strategies proposed for survivorship care by the UK National Cancer Survivorship Initiative (NCSI) (Adult Cancer Survivorship Initiative, 2010) include assessment of individual needs, screening for psychological problems, improvements in ongoing education (patients and Health Care Professionals), and individualized, planned, care using a survivorship care plan to identify patient-centred priorities for long-term support.

A report outlining their programme of research - conducted in test communities around the UK has recently been published by NHS Improvement. The research was in response to 5 key shifts in cancer care identified by the NCSI:

- cultural/attitudinal shift towards health and recovery in cancer
- improvements in information
- assessment and care planning
- tailored care pathways addressing future problems
- improved measurement via patient reported outcomes and experience measures

The data from the present study adds to this debate by highlighting the issues and concerns of women having to deal with the longer-term effects of breast cancer and the need to re-think and re-design their care to accommodate the changes in their treatment and expected duration of survival.

The new models of care tested by the NCSI include:

- a project which attempts to bridge the gap between health, social and community care by using the voluntary sector to facilitate communication between them
- another using community based "agents" who bridge the gap between social services, health services and the voluntary sector
- tele-care project using telephone-based support and motivational interviewing to provide assessment support signposting and referral to other agencies
- specialist nursing care via a new primary care cancer nurse role to support patients in the community during their cancer treatment
- self-management via information, support education – coping skills, Cognitive Behavioural Therapy
- continuous assessment and care planning using the distress thermometer routinely in outpatient clinics

Although these exciting strides forward have yet to be evaluated, they indicate the strong desire by those who work in the field of cancer care to provide the high standard of care expected by their patients.

However the work conducted so far is still predominantly with those patients recently diagnosed or recently having completed treatment (Adult Cancer Survivorship Initiative, 2010) and the design of the survivorship care plan continues to adhere to the biomedical model (Ganz and Hahn, 2008, Ganz et al., 2008). Psychosocial support is eluded to, but the detail of what is provided, by whom and for how long in long term recovery is not explicit.

The study findings identified the need for individualized psychological support and this may well be best served by forging links with the UK government's Improving Access to Psychological Therapies (IAPT) initiative (Department of Health UK, 2010). The IAPT programme aims to provide training to create a national, skilled, community of health care professionals able to provide low level psychological therapies. This was with the aim of improving the psychological well-being of communities at large, to improve productivity, help more people stay in employment and reduce the social and economic impact of psychological ill-health. This is part of a hierarchy of care with each practitioner referring upwards if the problems identified increase in severity and require the care of professionals with greater expertise. It may be helpful if women living with and beyond breast cancer were able to utilize this service as an integral part of their routine care.

## 7.7 The limitations of the study design

The ages of the study participants ranged from 50-70 years and were also a heterogenous sample with regards to their social circumstances, prior experience of breast cancer, treatments, and duration of follow-up.

This study was conducted in a relatively small number of women in a regional unit providing specialist care for patients with breast cancer and therefore generalisation to other contexts and other groups of patients with cancers other than breast cancer is not possible. As with many studies collecting data over time - this issue was compounded by the level of attrition. At the point of discharge from the service 100 women were recruited to the original study, 20 of whom provided interview data in addition to questionnaire data. Two years later the number of participants had reduced to 66 of whom, 14 provided interview data. However the interview data provided a wealth of information both in depth and breadth as well as variety. The three findings chapters which capture this information are testament to the value of the data collected and the worthwhile nature of the study.

The data are culturally/socially situated, and the study recruited middle-aged Caucasian women who are responding to the influences of European western culture where consumer involvement in a collaborative approach to healthcare is encouraged. The concept of self-determination and a belief in the power of positive thinking to influence one's own health is central to the culture the women are immersed in, but may be completely alien in other cultural and social settings.

However, the longitudinal nature of the research enabled the observation of behavioural changes and attitudes over time. Through this approach the study highlighted the shifting, evolving nature of coping mechanisms and change management in these particular circumstances.

The study enabled the women who participated to raise issues of relevance and importance to them as individuals and as a group. The findings may also be relevant to other settings, patient groups with other cancer sites and may be taken further to

improve our understanding of living with cancer in the long-term and the scope and standards of care provided.

## 7.8 Concluding remarks

The study reported in this thesis aimed to improve understanding in relation to long-term follow-up care for women recovering from breast cancer. By documenting and interpreting the experiences of the women who agreed to participate it has demonstrated that women diagnosed with the same disease:

- have different beliefs about their disease and treatment
- have different approaches to dealing with its implications
- have different needs as regards care and support

Time is not always a relevant factor their needs may vary at the same points in time. There is no "one size fits all" approach to caring for women in this situation. Although previous research has indicated that certain "flashpoints" (diagnosis, end of treatment, discharge from hospital follow-up, recurrent disease), are periods of increased need for many women, there are many other "triggers" which impact on psychological well-being. These may occur at any time and women are often at a loss to know to whom to turn for help, particularly if they occur after physical treatment is complete.

The impact of the trauma of caring for and grieving for others who have died from cancer would appear to be underestimated, under-reported and largely unaddressed. For some of the women in the study its effects were psychologically devastating, lasted for many years after the event and made dealing with their own situation extremely difficult. The same was true if this happened to women after their own diagnosis and was one of the reasons the women changed their approach from "close shave" to that of "marked woman".

The concept of follow-up care does not appear to mean the same thing to all women they have differing expectations (from each other) of what it should provide and from the healthcare teams who provide it. For some women it represents "evidence" that they are disease-free, for others it is a "touchstone" and represents faith, belief and trust in the expertise of their clinicians, for other women the human contact is valued, the "laying on of hands" and being able to discuss their feelings and concerns is paramount. The ritual of the regular visits, the familiarity of seeing HCPs they know and who know them - is helpful. In addition for some the clinic creates a geographical location, a legitimate place to leave their breast cancer and revisit, re-evaluate it when they need to, leaving space to resume daily life without the anxieties it elicits.

The women who participated in the study varied in their views of their future, whilst some were comfortable with the concept of self-management – others were not and developed alternative strategies to get what they wanted. The medical research literature would seem to indicate the consensus that once physical well-being is achieved our work is done – I would argue strongly that it is not. The incidence of late and long-term physical effects of treatment, anxiety and depression indicate the need for ongoing support and care to help women live with the "Sword of Damocles" of breast cancer. The emphasis on physical well-being and the monitoring and surveillance of the physical implications of the disease is at the expense of the psychological and emotional needs of this group of women.

The expected exponential increase in the number of women diagnosed, treated and surviving cancer over the next ten years will demand a creative and innovative approach to their care. Creating a network of services and working collaboratively with other sectors may well provide the scope and quality of care that women in long-term recovery from breast cancer want and need from the survivorship care of the future.

Recognition of the variation of both their needs and the approach to their recovery of this patient group and the reasons for them is essential if there is to be improvement in their care. Assessment of their psychosocial well-being at diagnosis and periodically thereafter will help to highlight issues and needs early on and create the opportunity for them to be addressed prior to discharge from regular outpatient follow-up care.

Understanding the reasons for behaviour avoids the labelling and stigma some of the women in the study described related to being viewed as "worriers", "over-anxious" "hyper-vigilant" "not coping".

It would seem constructive to acknowledge the limitations of the current system of care and fill the gap either with:

- appropriate training
- an extension of the service provided
- adopt a policy of shared care with the appropriate multidisciplinary teams.

This would ensure that psychosocial care is integral to the service in order that women do not feel targeted or "different".

Psychological therapies such as cognitive behavioural therapy have been shown to be useful in oncology patients (Greer, 2008, Kissane et al., 2004, Kissane et al., 2003) and there is already a growing community of specialist psycho-oncology teams in the UK. Stress-reduction techniques such as mindfulness therapy (Ledesma and Kumano, 2008, Sears and Kraus, 2009) have also been systematically evaluated as a way of managing anxiety in cancer patients.

Future research will need to address the needs of those who are in long-term recovery, specifically building on the findings of the NCSI test communities and extend the goals and objectives to adapt the model of care to suit their needs by:

- Using community based facilitators to improve the accessibility and flexibility of care
- Improving assessment and care planning by using a holistic approach to include emotional, social, psychological and spiritual as well as physical care needs
- Specialist psychological support utilising the skills and expertise of nurses, general practitioners, cognitive behavioural therapists, psychologists and psychiatrists
- Collaborative working within health and social services and the voluntary sector

The challenge researchers will face will be to design and evaluate the interventions to fulfil these needs.

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## Appendices:

### Appendix 1: Patient Information Leaflets and Informed Consent Forms

#### **Patient Information Sheet – questionnaire and interview data**

##### **Study title: (The IMPS Study)**

**A prospective, longitudinal, study to investigate the IMPact of changes in Service provision, for the follow-up of women (over 50 years) with primary breast cancer.**

##### **Introduction**

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish. Ask us if there is anything that is not clear, or if you would like more information. Take time to decide whether or not, you wish to take part.

##### **What is the purpose of the study?**

The National Institute for Clinical Excellence (NICE), recently issued guidelines for the follow-up care of patients with breast cancer. Our regional centre is changing the level and nature of follow-up for breast cancer patients, based on these guidelines. Patients will now be categorised according to their level of risk and clinical follow-up will be given accordingly as considered appropriate. This will affect the majority of women at Year 5 of follow-up. We want to collect information on the impact of this on the care/support women receive and their future health and well-being.

This project will explore the needs of women following treatment for their primary breast cancer. We propose measuring their quality of life and assessing levels of anxiety/depression experienced by women between Year 5 and Year 7 of follow-up. We will also explore women's views and concerns by interviewing a smaller representative group discharged from follow-up care, at Year 5, Year 6 and then again at Year 7.

The project will also form part of a PhD qualification for one of our nursing staff. Pauline Hyman-Taylor has worked as a Breast Care Research Nurse here at the Nottingham City Hospital for 4 years and has 16 years experience of working in health services research. Her supervisors will be Professor John Robertson and Karen Cox, Professor of Nursing, Queens Medical Centre. This PhD offers the opportunity, not only to enable Nottingham to view follow-up care from the patient's perspective, but also to provide the optimum long term service to patients and add valuable information to the NICE guidelines regarding depth of patient involvement.

We will investigate the experience of being discharged from follow-up breast care services and evaluate the impact of the proposed changes in the service, from the patient's perspective. We will do this by asking women how they feel, what affect it has on their views of their future, their quality of life and how they adjust and cope with the changes.

**Why have I been chosen?**

You have been approached because you have regularly attended the outpatient clinic at the Nottingham Breast Institute for follow-up for your breast cancer. This will now change. As it is now 5 years or more since your breast surgery, you will now be transferred to surveillance by mammogram, with open access to a breast care nurse should you need follow-up care in the future.

**How many other participants will be studied?**

100 women with primary breast cancer will be surveyed by questionnaires at year 5, year 6 and year 7. From these 100 women, we will ask 20 to allow us to conduct interviews, in addition to their questionnaires, at the time of discharge from the clinic, 12 months later and 12 months later at year 7. In addition, we will ask up to 10 women, whose disease returns, to allow us to interview them about their experience.

**Do I have to take part?**

No. It is up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and be asked to sign a consent form. You are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

**What will happen to me if I take part?**

We will either send you written information prior to your clinic appointment to allow you to consider the information in advance, or give you written and verbal information at your clinic appointment and invite you to come back on another day to give written consent.

If you would like to know more, the researcher (Pauline Hyman-Taylor) will be available in the clinic after your appointment, to discuss the study with you and answer any questions you may have. If you need more time to consider whether you would like to take part, or wish to return on an alternative day – we can arrange this for you.

If you decide to participate, we will ask you to sign a consent form. We will then ask you to complete 5 questionnaires which ask about your quality of life at the present time, your mood and ability to live your usual lifestyle; and how you cope and adjust to your breast cancer, this will take approximately 30 minutes. We will ask you to do this, in a years time and again a year later, so 3 times in all. We will look to see if things change over time and compare how you feel with other women in the same situation.

We will ask 20 of the women who agree to complete the questionnaires, to allow the researcher to conduct interviews with them. These will be recorded on audio tape but only available to the researcher and her supervisor. No other member

of the breast care team will be allowed access. Participants will have the right to reconsider any taped material. We may decide to use written quotations from the taped interviews in our publications, but they will be anonymised, so no one will know the identity of the person they originate from. We will repeat the interviews 12 months later and again 12 months later at Year 7, so again 3 times in all. The interviews will be conducted in private, away from the clinic at your convenience. If you request it, they may be conducted in your home. Each interview will last between 30 and 60 minutes. The researcher will ask several key questions but in the main, the interviewee will discuss the issues and views they feel are important to them. If at any stage you need to discuss issues raised in more depth or need support to deal with them, you will have prompt access to the support of the specialist nursing team to help you.

We will ask up to 10 women to share their experiences with us if their disease comes back during the course of the project.

You may take part in all, or part of the project, as you wish.

**What are the possible benefits of taking part?**

There is no intended clinical benefit to the participants from taking part in the project. The information we get will be used to improve the support care and treatment of patients with primary breast cancer in the future.

**What if there is a problem?**

If you have a concern about any aspect of this study, you should ask to speak with the researcher (Pauline Hyman-Taylor tel: 0115 823 1959) who will do her best to answer your questions. If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from Nottingham City Hospital.

If your problem relates to your breast cancer please contact your breast care nurse - a leaflet with contact details is attached. Alternatively, contact the Cancer BAcup helpline: 0808 800 1234.

Will my taking part in this study be kept confidential?

Yes. We will preserve the anonymity and confidentiality of all the interviewees. The research information will be stored in a locked cupboard in a locked room and will not be identified by name, only by an identification code. The survey questionnaires will not identify you by name only by your personal identity number which will be recorded by the researcher. The survey information will be held on a secure computer and only accessible by the researcher and her supervisor. Procedures for handling, processing, storage and destruction of the data are compliant with the Data Protection Act 1998.

**What will happen to the results of the research study?**

It is intended to submit and publish the results in a reputable scientific/medical/nursing journal and/or conference. However you will not be personally identified in any way.

**Who is organising and funding the research?**

Cancer Research UK have reviewed, approved and agreed to fund the project and the researcher for 3 years until its completion.

**Who has reviewed the study?**

Approval for this project has been given by a Local Research Ethics Committee prior to the start of this project. All patients approached about taking part in this study have either been provided with written information by post, prior to attending their clinic appointment, or given written and verbal information at their clinic appointment and invited to return to give written consent on another day. You will have an opportunity to ask questions of the researcher before agreeing to participate. If you choose not to be involved, you will not be troubled further. Systems have been put in place to address the issues of anonymity, confidentiality and data protection to safeguard your rights as a participant.

**You will be given a copy of the information sheet and a signed consent form to keep.**

Patient Initials and Identification Number for this trial: \_\_\_\_\_

### CONSENT FORM

**Name of Researcher: Pauline Hyman-Taylor**

**Title of Project: The IMPS Study**

**A prospective, longitudinal, study to investigate the IMPact of changes in Service provision, for the follow-up of women (over 50 years) with primary breast cancer.**

#### Please initial box

I confirm that I have read and understand the information sheet (version 1.2b 06/11/06) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

I understand that relevant sections of any of my medical notes and data collected during the study, may be looked at by the researcher, regulatory authorities, or the NHS Trust, where it is relevant to my taking part in this research.

I give permission for these individuals to have access to my records.

I consent to the use of digital recording of face to face or telephone interviews, for the purpose of this study, with possible use of verbatim quotation.

Name of Patient

Date

Signature

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Researcher

Date

Signature

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**Thank you for reading this – please ask any questions if you need to.**

## Appendix 2: Interview schedules

### **Interview 1, Interviews 2 & 3, patients with recurrent disease**

#### **Interview Topic guide Interview 1**

**Study title: A prospective, longitudinal study to investigate the impact of changes in service provision for the follow-up of women with primary breast cancer.**

How long ago were you diagnosed with breast cancer?

How long have participants been in follow-up?

How often do you attend the clinic?

Are they regular attenders? Do they attend more than annually?

i.e. do they have pre-existing problems?

Who normally conducts your consultation?

Do they have an established relationship with the Breast Care Nurse team?

What do you think you have gained from your outpatient follow-up?

Has their follow-up care been of positive benefit?

In which respect?

Did it fulfil your expectations?

Was it lacking in any way?

What was missing?

How do you feel about your discharge from the clinic, with open access to the Breast Care Nurse team?

Do they see it in a positive, or a negative light?

What issues, or concerns, would prompt you to approach them for help or support?

What are their perceptions of potential problems in the future?

What is your interpretation of your risk of the disease recurring?

How do they rate their risk? How much do they understand?

Describe for me, your ideal follow-up care

What do they feel follow up care is for?

### **Interview Topic guide interview 2/3**

**Study title: A prospective, longitudinal study to investigate the impact of changes in service provision for the follow-up of women (over 50 years) with primary breast cancer.**

How have things been since the last time we spoke?

Any issues or concerns? How did you deal with them?

Have you accessed formal support services?  
Informal support – family/friends/support group?

How do you feel about your discharge from the clinic, with open access to the Breast Care Nurse team?  
What helped? Would have helped?  
Do they feel differently, 12 months later?

How are you coping/adjusting?

What is your interpretation of your risk of the disease recurring?  
How do they rate their risk compared to a year ago?  
Has anything changed?

Any other issues?

Reflect on previous visit/interview and issues raised so far

## **Interview Topic guide (recurrent disease)**

**Study title: A prospective, longitudinal study to investigate the impact of changes in service provision for the follow-up of women (over 50 years) with primary breast cancer.**

The aim and design of the study and particularly the aim of the interviews will be reintroduced to the participant:

To collect information about the views, issues and concerns of women surviving breast cancer for 5 years or more and how they feel about the change in service provision.

The participant will be asked to tell the story of their diagnosis, treatment and follow-up care.

The participant will then be asked to recount the circumstances leading up to recurrence of their disease:

How was it diagnosed?

How do they feel about it?

What has happened since?

What happens next?

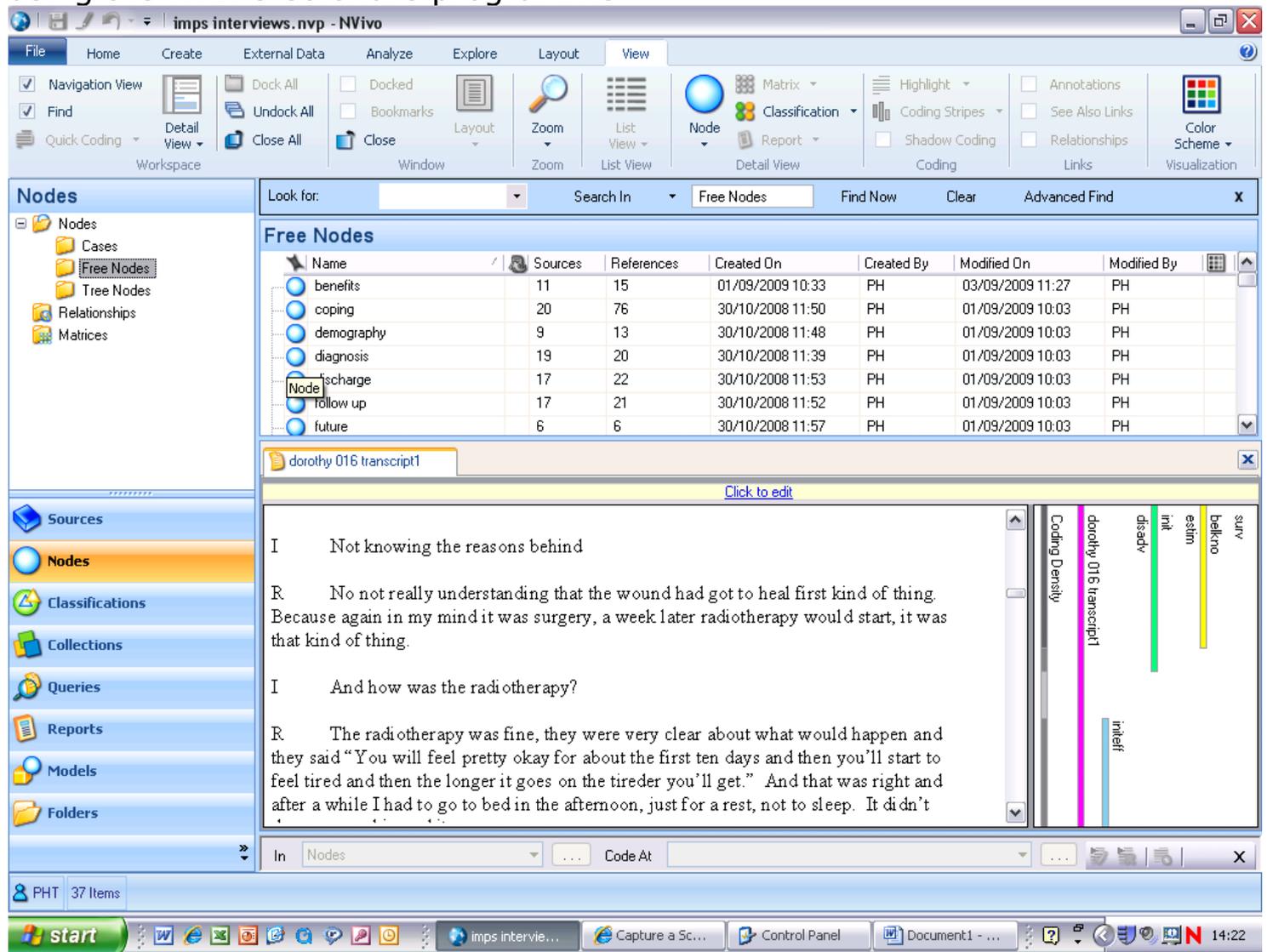
How do they feel about the care they received in the past?

How do they feel about the changes to their follow-up?

How do they feel about their current follow-up care?

What do they feel they need now?

### Appendix 3 Screenshot of the method and structure adopted for the coding of the interview data using the NVIVO software programme



## Appendix 4 :Provisional coding for analysis of interview data

Visit 1 - End of Follow-up visit

Demography

Age

Family

Marital status

Employment status

Survival status

The beginning

Point of change/moment of transition

A priori beliefs and knowledge

Prompt for action

Diagnosis

Identifying the problem

Screening

Self detection

GP

Other

Reaction

Acceptance

Fear

Death

Children

Explanation

Future care

Anger

Expectations

Blame/causation

Treatment decisions

Initial surgery/treatment

Beliefs/knowledge

Initial effects

Milestones

Long term effects

Coping

Results coping

Initial coping

1<sup>st</sup> year coping

Survival coping

Finding meaning

Faith/trust

Mammogram

Clinical exam

HC system

Religious faith

Previous coping  
Strategies

- Normalisation
- Minimisation
- Social comparison
- Cognitive dissonance
- Attributing responsibility
- Control/predictability
- Selective disclosure
- Sanctuary
- Avoidance
- Facing disfigurement
- Worst case scenario
- Watchful waiting
- Intuition
- Mentorship/informant

Beliefs

Milestones

Dynamic/evolving coping

- 2<sup>nd</sup> episode coping
- Age related coping
- Inherited coping
- Recurrence coping
- Scare coping

Social support

Results support

Inpatient support

Survival support

- Peer support

- Family support

- Professional support

Other support

Negative support

Avoiding distress in others

Differing strategies

Fears for others

Spousal distress/needs

QOL

Social status

Social network

Self esteem

Body image

Old self

Reinvention

Initial follow-up  
Expectations  
Perceptions of disease  
    Fear of recurrence  
        Death, pain, suffering  
Anxiety  
    Fear of the unknown

Subsequent follow-up  
Value  
Primary benefits  
Information  
    Confirmation  
    Reassurance  
    Support

Relief  
Peace  
Respite  
Unintentional benefits  
Revisiting  
Milestones  
Compartmentalisation  
Familiar faces (patients)  
Sanctuary  
Disadvantages  
Prior anxiety  
    Fear of recurrence  
Negative reminder  
HCP attitudes  
    Resource issues  
Insufficient time  
    Afraid to ask  
Accompanied visits  
    Advantages  
    Disadvantages  
    Significant others needs

Discharge  
    Reaction  
        Positive  
        Negative  
        Self-sacrifice  
    Meaning  
    Reasons  
    Future needs  
        prosthetic service  
        knowledge/understanding  
Legitimate opportunity  
Problems  
Support  
Strategy

Open appointment

Reaction

Benefit

Disadvantage

1<sup>st</sup> port of call

Ideal follow-up

Detection

Frequency

Personnel

Value

Future

    Planning

Risk perception

    Estimate

    Beliefs/opinions

        Marked woman

    Strategies

    Family cancer

    Cancer in others

Analogy/metaphor

Recurrence

    Anger

Wrongly discharged

    Financial constraints

Fear

    Death

    Children

        Explanation

        Future care

Confusion

Disappointment

Failure

Expectations of treatment

Wrong treatment

    Sub-standard treatment

    Sub-standard care

Expectations of follow-up

Expectations of discharge

## Appendix 5: Subsequent coding

Coping

Time related –

Results/initial

Yr 1/treatment

Survival/long-term

finding meaning

faith and trust

sense of self

milestones

Influential factors

age-related

previous trauma

inherited/learned

“scares”

2<sup>nd</sup> episode/recurrence

Dynamic/evolving

Social support

Coping beliefs

Coping strategies

Minimisation

Normalisation

Finding sanctuary/respite

sense of self

Facing disfigurement

Informant/mentor role

Attributing cause

Attributing responsibility

Control/predictability

Avoidance

Selective disclosure

Social comparison

Cognitive dissonance

management of change

Intuition (value/faith in)

Watchful waiting

Worst case scenario

Finding benevolence, meaning and self worth

Social support

Time-related

Results/initial

In-patient

Survival

Peers

Family

Professional

Others

Negative

Quality of Life

Social roles/status

Social networks

Lack of self-esteem

Impaired body image

Reclamation of self

Re-invention of self and social role

## Appendix 6: Final thematic structure (adopted and used for findings chapters)

Close shave or Marked woman

Breast cancer beliefs

Detection

Treatment beliefs

Cancer in others

Risk beliefs

Causes of breast cancer

Risk perceptions

Risk-reducing behaviours

Coping beliefs

Redemption

Contamination

Restitution

Role of social support

Coping over time

Blessing or Curse

Value of follow-up

Benefits of follow-up

Mammographic screening

Physical examination

Face to face consultation

Attribution of responsibility

Clinic as sanctuary

Time-markers/milestones

Compartmentalisation

Costs of follow-up

Reactions to change

The positive approach

The negative approach

Self-sacrifice and disempowerment

Freedom or Isolation

Attitudes towards the open appointment system

1<sup>st</sup> port of call

Strategies to circumvent the system

Late/long-term effects

Two years on - the final interviews

When cancer comes back.....