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**UNIVERSITY OF SOUTHAMPTON**

Faculty of Health Sciences

**The Experience of Living with  
Metastatic Breast Cancer**

by

Elizabeth Reed

Thesis for the degree of Doctor of Philosophy

March 2012



## ABSTRACT

Thesis for the degree of Doctor of Philosophy

### **The Experience of Living with Metastatic Breast Cancer**

By Elizabeth Reed

Over the last 10-15 years the medical management of metastatic breast cancer has improved survival, so women are living longer with progressive disease. Little is understood about women's problems and needs and how they live their everyday lives.

This study aimed to explore the experience of women with metastatic breast cancer by applying three phases: a cross-sectional survey exploring quality of life, experience of care and where they turned for support; exploration of the narratives of 30 women considering the social consequences of living with progressive breast cancer on identity; and finally triangulating medical and nursing documentation, a measure of physical functioning and ten women's narratives to define the illness trajectory of metastatic breast cancer.

Phase1: Quality of life was found to be poor with women experiencing a significant symptom burden. Experience of care was poor with unmet information and support needs. There was little evidence of General Practitioner or palliative care involvement in care.

Phase 2: In weathering the oscillations of progressive disease, women faced threats to their social identity. Women sought ways to maintain their social roles and social order to avoid social isolation. To do this they adopted contingent identities: stoicism or absolved responsibility. Women used these contingent identities to mediate any discontinuity between the self, the body and social order. These self-representations were used by women to maintain their social roles and social order and in doing so avoiding being discredited and socially isolated.

Phase 3: Mapping women's illness trajectories identified three typical trajectories. The illness trajectories demonstrated the complexity of living over time with progressive disease, through phases which give definition to a previously ill-defined pathway.

Living with metastatic breast cancer challenges the personal resources of the individual and poses interesting questions about how healthcare professionals provide information, effective symptom control, and emotional and practical support to women.

Current models of care are not meeting women's needs and new approaches to care provision need to be considered.



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## DECLARATION OF AUTHORSHIP

I, Elizabeth Reed, declare that the thesis entitled *The Experience of Living with Metastatic Breast Cancer* and the work presented in the thesis are both my own, and have been generated by me as the result of my own original research. I confirm that:

- this work was done wholly or mainly while in candidature for a research degree at this University;
- where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
- where I have consulted the published work of others, this is always clearly attributed;
- where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
- I have acknowledged all main sources of help;
- where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
- parts of this work have been published as: Reed, E. Simmonds, P. Haviland, J. Corner, J. (2011) Quality of Life and Experience of Care in Metastatic Breast Cancer: a Cross Sectional Survey. *Journal of Pain and Symptom Management*. Nov 15. [Epub ahead of print].

**Signed:** .....

**Date:**.....12 March 2012.....

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# Introduction

The conception of this study emerged from informal discussions with women with metastatic breast cancer throughout the UK. At the time, part of my role as secondary breast care nurse for Breast Cancer Care<sup>1</sup> was to address the information and support needs of women with metastatic breast cancer. To do this I attended meetings and support groups with women across the UK, as well as entering into email correspondence with some who learned of my role. Many reported feeling isolated and unsupported by the healthcare system and were navigating the health and social care systems themselves with little or no support. A significant number were tolerating unpleasant symptoms with little or inadequate access to palliative care. This led to a review of the literature on the needs of women and a realisation that there was a paucity of psychosocial research about the experience of living with progressive metastatic breast cancer.

Breast cancer is the most common cancer in the UK. Each year around 47,700 women are diagnosed with breast cancer in the UK (Cancer Research UK, 2011) and 550,000 are estimated to be alive with a diagnosis of breast cancer (Maddam et al, 2008).

In the UK around 12,000 women die each year from breast cancer, although breast cancer deaths have fallen by a third since the late 1980s (Cancer Research UK, 2011). One third of the decline has been attributed to breast screening, which began in 1988, and two thirds is due to improved treatments such as Tamoxifen and chemotherapy, and possibly the health promotion messages of breast self-examination and breast awareness, although the true benefits of this are inconclusive (Catalano, 2003).

Despite developments in the detection and management of breast cancer, approximately 50% of all those with primary operable breast cancer who receive local regional treatment alone will have micrometastases at presentation and will go on to develop metastatic disease (Smith and Chua, 2006) and 6-10% will present with metastatic disease at diagnosis (Johnston and Swanton, 2006).

This indicates that of the 550,000 women in the UK estimated to be alive with a diagnosis of breast cancer a significant number will have metastatic disease. However, the exact number living with metastatic breast cancer is unknown since these data are not collected. When the first site of metastases is visceral, i.e. lung, liver or brain, the

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<sup>1</sup> Breast Cancer Care is the UK's leading provider of information, practical assistance and emotional support to anyone affected by breast cancer.

average life expectancy is relatively short. When the metastatic site is in the bone, the average life expectancy is approximately 24-36 months with up to 20% of cases surviving five years and beyond (Johnston and Swanton, 2006).

Despite breast cancer being the most common cancer for women in the UK, accounting for one in every three cancers, little is understood about the experience of living with progressive breast cancer. This is in stark contrast to the body of evidence on the experience of being diagnosed, treated and surviving early stage breast cancer (Landmark et al, 2002, Al Ghazal et al, 2000, Luker et al, 1996, Beaver et al, 2009).

A diagnosis of early stage breast cancer brings a new perspective on life with a focus on relationships, body image, mood changes and a need to search for meaning in identifying the cause, in particular the effect of lifestyle, for example stress (Arman et al, 2004). The will to live and the fight for existence become increasingly intense when there are periods of illness, particularly in the early stages of the disease (Landmark and Wahl, 2002), and the fear of recurrence is an enduring concern (Spiegel, 1983, Northouse et al, 2002). When cancer does recur there is evidence to suggest it is more traumatic than the early stage diagnosis (Cella, 1990). Quality of life has been found to be significantly poorer in those with cancer recurrence than those with early breast cancer or those with a serious medical illness, with poorer physical, functional and emotional health (Northouse et al, 2002).

The needs of those with metastatic breast cancer are increasingly receiving both national (Breast Cancer Care, 2008) and international attention (The Metastatic Breast Cancer Advocacy Group, 2008). Historically, research into the needs of those with metastatic breast cancer has been predominantly in response to treatment, with few studies reporting the global quality of life in relation to tumour response or relief of symptoms (Geels, 2000). Fatigue, pain and sleeplessness among other symptoms have been found to be a problem for women with metastatic breast cancer (Aranda et al, 2005) with many experiencing moderate to severe pain. Many appear unaware that they can have strong analgesia for pain and are reluctant to complain to health professionals (Arathuzik, 1991). Depression, anxiety and traumatic stress have also been found to be problems that require intervention in this population (Hopwood et al, 1991, Pinder et al, 1993). While there is national guidance to address the needs of those with progressive cancer (NICE, 2004), evidence suggests there is still unmet need for health information and psychological support (Aranda et al, 2005), in particular around the individual's own cancer and treatment options (Gray et al, 1998).

The prognosis of metastatic breast cancer has improved over the past decade as a result of the development of more effective and better tolerated therapies that can be

applied to a wider range of patients sequentially over time (Conlin et al, 2008, Pavlakis et al, 2002). Active treatment often allows women with metastatic breast cancer, even those with visceral disease, to have a prolonged illness trajectory; for many it may become a long-term illness. Yet little is understood about the everyday lives of women living with progressive breast cancer or the provision of care to address their multidimensional needs.

The purpose of this study was to explore the emotional, physical, social and practical effects of living with metastatic breast cancer and to identify the prevalence of problems and needs of women as well as practical measures that might be taken to meet these. It aimed to define the illness trajectory of metastatic breast cancer and explore the social consequences of living over time with progressive breast cancer.

The study aimed to yield information that may be used to improve the experience of living with metastatic breast cancer by informing those living with it, policy makers and those responsible for providing treatment and care.

## Background and rationale for the study

Evidence suggests that care for women with metastatic breast cancer is inadequate and that they do not receive the same attention and care as those with early stage disease. An audit of a breast care nurse survey in Australia showed that of 842 women seen by breast care nurses only 7% had metastatic breast cancer, despite the fact that this group represented 35% of those in the population audited (Aranda, 2002), indicating that nursing provision for those with progressive breast cancer is inadequate.

With the increase in treatment options and the potentially prolonged illness trajectory, over time the decisions to be made and the obstacles and problems to navigate have become more complex. There is little research considering either the prevalence of concerns and problems or the physical, social, emotional and practical impacts of living with metastatic disease for a prolonged period. The biomedical and personal illness trajectory of metastatic breast cancer has never been mapped.

The rationale on which this thesis is based arises from the literature review in chapter 1, which gives a detailed systematic approach to the search and retrieval of the literature, offers a critical appraisal of the evidence to date, and identifies gaps in methodological approaches and theoretical perspectives. Chapter 2 on methods sets out the approaches taken in the three phases and the reasons why, focusing on the purpose of the study and its aim and objectives. Within this chapter, I discuss the use of mixed methodology and its application in this study.



In total 234 women and one man took part in the study but for consistency throughout the thesis the population will be referred to as women. The study design is in three phases. The first is a survey of 235 women exploring their quality of life, experience of care and support needs. The second and third phases of the study applied a qualitative approach. Using a biographical narrative approach, a sub-sample of 30 women who took part in the survey was interviewed three times over one calendar year, at baseline, six months and 12 months. The second phase of the study explored the social consequences of living with progressive breast cancer on identity, while the third mapped the illness trajectory of ten women in order to define the metastatic breast cancer illness trajectory. The thesis concludes with a discussion on the implications of the findings for healthcare professionals and clinical practice and how the findings could influence the care and experience of those living with metastatic breast cancer.

Mapping the illness trajectory was not in the original study design but the need to explore this emerged through data collection in both the survey and narrative interviews.

To set the scene in understanding what was known about women with metastatic breast cancer and to determine the methodological approach the study would take, the literature was reviewed.

## **Chapter 1. Literature review**

In order to examine literature related to the experience of living with metastatic breast cancer, all the evidence published about the experience of metastatic breast cancer was reviewed to understand what the literature reveals about the day-to-day lives of women living with it. This approach would build an understanding of the multidimensional problems and needs women have, how living over time with a life-limiting illness impacts on their self-image and their social world, and how healthcare provision for women with metastatic breast cancer influences their ability to live with progressive cancer. A systematic approach to the search and retrieval of the literature into the experience of metastatic breast cancer was undertaken.

Through the development of this study and data gathering it became clear that, as women were living over time, sometimes for years with metastatic breast cancer, it was important to consider the chronic illness literature as well as the literature focusing only on the experience of metastatic breast cancer. Consequently, a retrospective review of the chronic illness literature was undertaken which would inform the understanding of the lives of women with metastatic breast cancer over time. The review is presented in three sections. Firstly, the findings of a systematic review of studies of women with metastatic breast cancer. Secondly, as those with metastatic breast cancer can have a prolonged illness trajectory, an overview of the literature on chronic illness was drawn from the social sciences. Lastly, the literature on illness trajectories was reviewed to inform the development of the study design into this area of investigation. The chapter concludes by identifying gaps in the evidence.

Predominantly, the research focus in metastatic breast cancer has been on medical management. Comparatively little has been undertaken into the psychosocial aspects of the disease, so all the literature was searched irrespective of the date of publication. This aimed to ensure all psychosocial research was captured to give as complete a picture as possible of what is known about the experience of living with metastatic breast cancer.

This review begins by outlining the systematic approach used to search and retrieve the evidence into psychosocial research and metastatic breast cancer, then goes on to critically appraise the literature presented.

Reflecting on the literature reviewed, the chapter concludes by identifying gaps in the methodology, theoretical perspectives and understanding of the experience of living

with metastatic breast cancer. This in turn informed the methodological approach used in this study.

## 1.1 Process of literature retrieval

A comprehensive review of the literature was initially undertaken in 2004 using the following databases: PSYCHinfo, AMED, CINAHL, British Nursing Index and Medline. It was repeated in 2009 and 2011 through the OVID search engine and Google Scholar. No time frame was used in order to capture as much as possible that has been written on the subject. The Cochrane database was also searched and a review of psychological interventions in metastatic breast cancer retrieved. Publications date from 1983-2011.

*Inclusion criteria* – all studies exploring the physical, emotional and practical aspects of metastatic breast cancer and intervention studies to address these domains. Also considered were studies which included caregivers and studies looking at all breast cancer patients where the experience of those with metastatic disease was significant.

*Exclusion criteria* – studies on the medical management of the disease, although those where the focus was the individual experience of treatment were included.

Key search terms were: secondary, advanced, metastatic and recurrent breast cancer and this was linked to: living with, experience, coping, adjustment, social and psychological. Table 1 shows the total number of papers retrieved under different search terms (including papers repeated under different terms).

**Table 1: Results of the terms used in the literature search on the experience of metastatic breast cancer**

Search terms	Papers identified	Number of papers retrieved	Number of papers included in review
Coping and advanced breast cancer	59	8	8
Adjustment and advanced breast cancer	86	27	11
Living with advanced breast cancer	25	6	4
Experience and advanced breast cancer	298	8	6
Psychological issues and advanced breast cancer	31	31	18
Social issues and advanced breast cancer	70	16	13
<b>Total</b>	<b>569</b>	<b>96</b>	<b>60</b>

*Updated in 2009 and 2011*

Only literature in English was retrieved although other languages would have been considered if relevant.

Full copies of all papers included in the review were retrieved other than one which was unavailable. For this paper the abstract was retrieved. Of the 569 papers identified despite the search terms many were about early stage breast cancer as well as studies about medical management. These were excluded from the literature retrieved. In addition, a number of papers were duplicated under different search terms.

Searches of authors known to have published extensively on psychosocial interventions were undertaken, for example, Spiegel, Classen and Koopman. Hand searches of reference lists from each paper were searched for other relevant papers. In total, 49 primary sources of psychological and social research were retrieved, with an additional five papers on studies of those with metastatic breast cancer and their partners/families and five which investigated different phases of breast cancer including metastatic disease. One Cochrane systematic review was included.

All papers were critically reviewed and scored using an adapted model from the Public Health Resource Unit, *Critical Appraisal Skills Programme* (<http://www.phru.nhs.uk/Pages/PHD/CASP.htm>) , 24.04.2009) to consider their eligibility and methodological approach (Table 2). This was used as I had not undertaken a substantial literature review before, and it was a useful tool in developing skills in critical appraisal. Quantitative papers were scored out of ten and qualitative out of nine. The Vancouver referencing system is used throughout the review of the literature on metastatic breast cancer and a table of all papers and their CASP scores can be seen in Appendix 1. The rest of the literature review and thesis use the Harvard referencing system.

**Table 2: Critical Appraisal Skills Programme (CASP) literature review questions**

Question	Yes	No
1. Was there a clear statement of the aims of the research?		
2. Was a quantitative or qualitative methodology appropriate?		
3. Was the research design appropriate to address the aims of the study?		
4. Was the recruitment strategy appropriate to the aims of the study?		
5. Were the data collected in a way that addressed the research issue?		
6. For qualitative only: Has the relationship between researcher and participant been considered?		
7. Have ethical issues been taken into consideration?		
8. Was the data analysis sufficiently rigorous?		
9. Is there a clear statement of findings?		
10. Is the research valuable?		
<b>Score</b>		

When all the literature had been scored, the body of literature as a whole was considered, including the theoretical and methodological approach, outcome measures used and the findings. Each paper was critiqued to establish if it did what it set out to do, and to identify any methodological flaws or concerns.

## 1.2 Literature review – the experience of metastatic breast cancer

Evidence of the experience of metastatic breast cancer is predominantly measured by statistical prevalence, correlation and association. Of the literature retrieved, 42 (74%) were quantitative studies focusing on measuring information need<sup>1</sup>, psychiatric morbidity<sup>7,13,20,23,26,31,53,60</sup>, response to a psychosocial intervention<sup>5,12,14,17,24,25,36,44</sup>, coping mechanisms<sup>9,11,33,46,52</sup>, symptom control<sup>2,8,33,34,43,59</sup>, physical impact<sup>6,10,19,20,30</sup>, treatment related studies<sup>29,32</sup>, social functioning and support<sup>4,33,48,52</sup>, end of life research<sup>19</sup> and caregiver burden<sup>51,55</sup>. Eight studies (12%) used qualitative measures examining the meaning of the experience of metastatic breast cancer<sup>15,49</sup>, detailing the daily activities of women<sup>16</sup>, determining the information needs<sup>27,38</sup>, investigating the meaning of quality of life<sup>37</sup>, aiming to understand the life of women with a focus on changing perspectives<sup>56</sup>, and self-management and transitions<sup>42</sup>. Six (9%) used mixed methodology aiming to characterise the prevalence of physical impairment and the appropriateness of treatment provision<sup>10</sup>, estimate the prevalence of anxiety and depression and its relationship with socioeconomic and disease status<sup>39</sup>, examine pain experience over time<sup>43</sup>, define the emotional concerns of newly diagnosed women<sup>47</sup>, understand the perceived challenges, barriers and potential influences of race and income on management of metastatic disease<sup>41</sup> and to explore the societal shift for women with metastatic breast cancer<sup>28</sup>. Two studies (3%) examined retrospective data from medical records to assess the intensity of diagnostic testing and treatment during the last months of life<sup>3</sup> and define the extent to which women accessed palliative care during the last six months of life<sup>22</sup>. One (2%) was a systematic review of psychological interventions and survival outcomes<sup>18</sup>.

Ten papers were randomised controlled studies reporting on psychological interventions, predominantly supportive-expressive group therapy<sup>5,12,14,17,24,25,44</sup>, an exercise programme on fatigue and quality of life<sup>30</sup>, the impact of treatment on quality of life<sup>32</sup>, and emotional adjustment<sup>33</sup>.

Overall, the dominant focus of the literature demonstrates the multidimensional needs of women with metastatic breast cancer, specifically the prevalence of symptoms (physical, psychological and social), interventions to address these (principally psychological interventions) and patterns of care.

While validated quality of life measures have been applied to this population<sup>1,6,32,35,41,59,60</sup>, these were limited to six different measures (EORTC, FACT-F, FACT-G, Medical Outcomes Study (SF36), QLQ-C30, RAND-36) commonly utilised in biomedical research and clinical trials. One study used a quality of life measure but did not specify which<sup>58</sup>.

The number of women alive with metastatic breast cancer is unknown in the UK and throughout the world, making power calculations of research populations problematic. However, the sample size in five papers was low in studies aiming to measure statistically significant outcomes<sup>14,17,19,20,30</sup>. Three of these were randomised control studies<sup>14,17,30</sup>. In addition, attrition rates for two studies were high<sup>30,31</sup>. The latter aimed to determine the prevalence and persistence of affective disorders and acknowledged that those withdrawing from the study may have had higher levels of affective disorder, thus influencing the findings.

The recruitment and representation of black and minority ethnic (BME) groups in research is acknowledged to be problematic (Hussain-Gambles, 2003). Thirteen studies excluded non-English speaking participants<sup>1,5,10,12,14,20,21,23,25,30,34,48,47</sup> and of those reporting the demographic profile of the study populations, two reported they were white, middle class and well educated<sup>8,14</sup>. Two studies explored how race and income affected the experience of metastatic breast cancer<sup>40,41</sup>.

While it is acknowledged that the organisation and running of intervention studies can be challenging, many of the intervention studies only selected English speakers and those who had easy access to the institution that ran the intervention. That this may exclude women from BME groups and women from diverse socio-economic groups raises questions as to how accurately the metastatic breast cancer population is represented in the research literature.

Comparatively few studies originated from the UK<sup>15,19,20,21,29,31,39</sup>. Of these, four examined psychiatric morbidity<sup>19,20,21,31</sup>, one looked at decision making on palliative chemotherapy<sup>29</sup> and one looked at the meaning of living with advanced breast cancer<sup>15</sup>.

The psychological impact of metastatic breast cancer dominates the evidence base of the experience of metastatic disease. The majority of psychological research is the use of psychological interventions<sup>5,12,14,17,25,24,36,44,46</sup>.

### 1.3 Theoretical perspectives

The research into the experience of metastatic breast cancer has predominantly been based on deductive and causal models of investigation by means of statistical

correlation and association. Of those studies using this theoretical approach only two have been explicit about theory and models applied to the research design: Roy's Adaptation Model<sup>30</sup> and a causal model<sup>4</sup>.

There has been much debate on the use of different approaches to research. This focuses on the importance of internal validity and rigour, argued by those utilising quantitative methods as being achieved by the structured use of adequate, calculated samples and statistical measurement which is undisputed evidence. Qualitative research uses an interpretative approach and is argued to be open to researcher interpretation (Tashakkori and Teddlie, 1998). As is clear in this literature review, the latter approaches appear to be more explicit in their description of the theoretical approach in order to demonstrate an adherence to an established method of analysis, so aiming to demonstrate attention to rigour. The four theoretical approaches are grounded theory<sup>15,40,41</sup>, feminist theory<sup>16</sup>, thematic content analysis<sup>27, 29,46,49,42,51</sup> and phenomenology<sup>37,56,57</sup>. One study used a case study approach<sup>6</sup>.

The studies using mixed methodology examined the relationship between physical impairment and rehabilitation status through qualitative interviews and statistical analysis<sup>10</sup>, measured the prevalence of psychiatric disorders<sup>39</sup>, aimed to define the key emotional concerns of women from a literature review, interviews and psychometric measures<sup>47</sup> and to understand the perceived challenges, barriers and influences of race and income<sup>40</sup>. None of these studies described the rationale of using a mixed method design, nor was the synergy of the methods clearly reported in the papers, therefore arguably this was not mixed methods research but studies applying two different methods within one study.

## 1.4 Review of the evidence

### 1.4.1 Psychological impact of metastatic breast cancer

Evidence of psychological morbidity in metastatic breast cancer reveals that up to 50% of women with metastatic breast cancer experience clinically significant levels of traumatic stress symptoms associated with their cancer<sup>7</sup> and around one third of women have an affective disorder which for a third of these is a persistent problem requiring intervention<sup>29,31,60</sup>. Similarly another study identified that 43% of women with metastatic breast cancer had a psychiatric disorder with 7% having a major depression<sup>26</sup>, while one study found that psychological outcomes could be predicted by assessing behaviours of suppression, repressive-defensiveness, restraint and distress separately<sup>23</sup>. One study considered the psychological reactions at the time of disease progression which were predominantly sadness, worry and acceptance<sup>46</sup>.

### **1.4.2 Psychosocial intervention studies**

The use of supportive therapy for women with metastatic breast cancer has been widely studied. Much of this has been done at Stanford University, California, under the leadership of Professor David Spiegel, using supportive-expressive group therapy. A seminal work in 1989 looking at the effect of weekly supportive therapy found incidentally that those in the therapeutic group lived an average 18 months longer than the control group<sup>44</sup>. Others, including Spiegel<sup>45</sup>, have since tried to establish whether this effect can be replicated. Although supportive expressive group therapy for women with metastatic breast cancer has been found to improve mood and the perception of pain, an increased survival time has not been found<sup>14,25</sup>. One study identified that those adopting self-management practices may have influenced survival<sup>14</sup>. To date, other studies into the use of supportive-expressive therapy in metastatic breast cancer have been found to help reduce distress<sup>12</sup>, with one study failing to find any benefit from psychosocial group therapy<sup>5</sup>. One longitudinal follow-up of an intense psychological intervention, with a battery of measures evaluating the effects, found psychological health improvements in the short term did not extend to long term, other than reducing feelings of helplessness, although the participants did experience more anxious preoccupation<sup>17</sup>. A Cochrane review of psychological interventions for women with metastatic breast cancer concluded that there was evidence to suggest short-term benefits of psychological interventions but the benefits are not maintained in the long term and effects of psychological interventions on increased survival time are not statistically significant<sup>18</sup>.

### **1.4.3 The physical impact of metastatic breast cancer**

The evidence highlights concern about the physical manifestations of metastatic breast cancer and symptom control management. The physical impact of metastatic breast cancer has been widely investigated over years. Symptoms such as fatigue, pain and sleeplessness have been found to be a problem for women with metastatic breast cancer<sup>1,2,59,34</sup>. Women have been found to experience moderate to severe pain with some being unaware that they can have strong analgesia and reluctant to complain to health professionals<sup>2</sup>. A correlation between pain experience and psychosocial factors has been identified<sup>43</sup>, women who experienced more pain also had more depression, fatigue, anxiety and confusion and the experience of pain has been associated with poorer coping (use of avoidance methods of coping) and social interaction<sup>4</sup>. Total mood disturbance, stress and belief about the meaning of pain have been associated with pain. Retrospective analyses of medical records reveal pain<sup>3</sup> and physical impairment<sup>10</sup> to be a persistent problem.



Pain is considered to be a subjective, individual experience; however, all the above studies used quantitative measures. Where interviewing was part of the methods applied, this was limited to the collection of physical performance data analysed using statistical methods<sup>10</sup>. While valuable and essential to quantify the magnitude of the problem of pain and other symptoms, it is timely to explore in detail the symptom experience of women with metastatic breast cancer using a qualitative approach. One study evaluated an exercise intervention resulting in improved physical functioning and wellbeing, although this was a case study report therefore not necessarily applicable to the metastatic population<sup>6</sup>.

#### **1.4.4 The consequences of social relationships**

In considering social relationships, evidence indicates that those with metastatic breast cancer receiving social support, both within the family and outside, have been found to report more satisfaction with their lives and their sense of fulfilment; fewer avoidance coping strategies were associated with better social functioning<sup>4</sup>, and those with a larger social network reported fewer avoidance coping strategies<sup>7</sup>. However, the authors note that lower avoidance was not significantly associated with high degrees of positive social support, so the effect may be due to quantity rather than quality of social support. Conversely, this may mean that being in receipt of numerous social interactions limits the time spent alone so could be considered an avoidance coping strategy<sup>7</sup>. However, others report that more people in the social support system of women with metastatic breast cancer is associated with less mood disturbance (the buffering hypothesis)<sup>33</sup> and the use of avoidance coping by caregivers has a detrimental effect on the women's quality of life<sup>52</sup>. The latter study suggests the higher the symptom burden, the use of avoidance coping behaviour allows the caregiver to distance themselves as a self-protective measure<sup>52</sup>. Social stress has been found to increase pain and mood disturbance and has been associated with isolation<sup>11</sup>. In addition, self-image and a decrease in sexual functioning challenge self-esteem and relationships at a time when support is most needed<sup>60</sup>.

But when considering social relationships in studies using qualitative or mixed methods, powerful insight into the experience of living with metastatic disease begins to emerge. The following two studies demonstrate this.

Davies and Sque<sup>15</sup> interviewed eight women with metastatic breast cancer who were in receipt of palliative care. They identified four categories using a grounded theory approach; firstly the time bomb, living with the fear of progressive disease. Second, the media effect, both positive reinforcement of inspirational stories of living with advanced cancer and the isolation experienced during Breast Cancer Awareness Month. Third,

professional waning, described as the failing relationship between healthcare professionals and the participants and the embodied knowledge the women had which was not acknowledged by those responsible for their care. Lastly rescuers, described as the search for individuals or situations that could release the women from their sense of isolation. These four categories coexist with a core category 'reconciling a different me'.

Using an interpretive approach, Arman et al<sup>58</sup> sought to interpret and understand the suffering experienced by 17 women with breast cancer (of who five had metastatic disease) in relation to healthcare. Three themes emerged. Firstly, the caring relationships which fail to materialise, where suffering was seen as a relationship with healthcare professionals failing to materialise or the woman not being seen as a unique human being. Second, not being regarded as a whole human being with experiences and needs, where the women felt they were regarded as a diagnosis or as a 'number' rather than a whole person with existential concerns. Third, an imperceptible call for help in a disintegrating, incomprehensible life: this was identified as the experience of total disintegration of life being a common problem and contributing to isolation, loneliness and a sense of vulnerability, with the women feeling they had to take responsibility for their cancer.

These studies demonstrate the individual accounts of illness, moving away from understanding illness experience as quantifiable outcomes and allowing it to become collective constructions of illness.

#### **1.4.5 Information needs**

Of the few studies looking at the information needs of women with metastatic breast cancer, a strong reliance on their doctors for information has been identified, although health professionals' engagement appeared to wane as the disease progressed and treatment options dwindled<sup>27</sup>, at a time when women with metastatic breast cancer have a high need for information in understanding their medical condition, treatment options and how to anticipate and address physical symptoms. Where the healthcare professionals are proactive in seeking up-to-date treatment the women felt safe<sup>27</sup>. One researcher found that although around 30% of the women with metastatic breast cancer in her study acknowledged that the information they received was at times distressing, only 5% of them felt too much information was provided<sup>38</sup>.

Two studies which considered supportive care as an outcome did not include palliative care in the list of health professionals, even though supportive care included the administration of analgesics and symptom control<sup>32</sup> and the detection of anxiety and depression being measured by contact with the multidisciplinary team<sup>20</sup>.

#### **1.4.6 The impact of medical management**

Research investigating the impact of medical management on the lives of women with metastatic breast cancer is timely and reveals that the number of diagnostic tests increase as death approaches and many women are receiving third line chemotherapy in the last six months of life<sup>3</sup>, with care predominantly given in the outpatient setting by oncologists and little evidence of general practitioner involvement or palliative care. The authors conclude that their findings explain high hospital death rates and low home death rates in their study<sup>22</sup>.

#### **1.4.7 Temporality and metastatic breast cancer**

Of particular interest to the development of this study are the everyday lives of women and how they live over time with metastatic disease. Studies into the temporality of metastatic breast cancer are few. All use only quantitative methods and look at the prevalence and detection of psychiatric morbidity over time from diagnosis of metastatic breast disease<sup>20</sup>, the physical and psychological symptoms before death<sup>19</sup>, and levels of depression over time compared to others with longer survival time<sup>39</sup>. Although these studies report using mixed methodology, the interviews were limited to gathering demographic data<sup>20</sup>, a standard psychological assessment, i.e. past psychiatric history<sup>30</sup>, or the collection of data on the outcome scales used<sup>19</sup>. The most recent publication into the experience of living with metastatic breast cancer described the experiences of self-management in the context of transitions among women with advanced breast cancer. The women in this study expressed a range of preferences for participation in self-management including developing skills, becoming empowered, and creating supportive networks. Barriers to self-management included symptom distress, difficulty obtaining information and lack of knowledge about the cancer trajectory. Shifts in transitions often prompted changes in self-management engagement and were experienced as positive, negative and neutral. Moments of disease progression often triggered changes in physical, emotional and social wellbeing<sup>42</sup>.

### **1.5 Methodological issues**

Methodological issues are found predominantly within the psychosocial intervention studies and the rigour of a number of studies calls into question the accurate reporting of findings of qualitative research.

One study aiming to examine levels of intrusion and avoidance symptoms recruited women who chose to take part in group psychotherapy before recruitment to the study, which may reflect a study population who are in particular need of support, so

influencing the findings. In addition, those using avoidance behaviour may decline to take part in such a study<sup>7</sup>.

Control groups contaminated the data in one study by seeking psychological interventions outside the trial<sup>14</sup>. Studies that advertised for participants could bias the study population with self-selecting participants who may be experiencing psychological problems thus seeking psychological intervention<sup>11,12</sup>. There are ethical concerns about the study by Edmonds et al<sup>17</sup> which assessed the effects of long-term psychological interventions using a series of interventions and a battery of outcome measures, and which demanded considerable time and commitment from participants. The intervention group experienced greater anxious preoccupation than the control group, questioning whether participation in a complex intervention study influenced this finding.

There may be limitations in qualitative research approaches. Silverman (2000) argues that reporting of methods in qualitative studies can be less rigorous. For example, the interviewees in one study<sup>15</sup> were all patients of a hospice and described as being in the palliative phase of their disease, although this phase was not defined. With no clear definition of their advanced stage, their perception of self in the world may be influenced by this, particularly if they were close to the end of their lives. These findings may not reflect the experience of women living over years with their disease although could be interpreted as being the experience of all women by the reader. Another study<sup>57</sup> aimed to understand the life worlds of women with breast cancer, focusing on changes in life perspective, but did not differentiate between those with early stage breast cancer and those with metastatic disease. It is assumed that there was no difference between groups in the analysis of the data although this was not alluded to in the findings. In another study which aimed to interpret and understand the meaning of patients' experience of healthcare, the authors had a choice to report the total experience of 'suffering' of care or focus on the negative effects of healthcare; they chose the latter<sup>58</sup>. Silverman (2000) contends that the validity of an explanation is in doubt if the researcher has made no attempt to deal with the contrary cases.

## 1.6 Review of the literature over the last ten years

Over the last ten years there have been considerable developments in medical management of breast cancer, with the development of different treatment modalities, for example, a new generation of endocrine therapies, the aromatase inhibitors, monoclonal antibodies such as trastuzumab and an increasing number of options for chemotherapy as a single agent and in combination (Johnston and Swanton, 2006). With this in mind it is appropriate to consider the literature over the last decade to

investigate whether there have been changes in the approach to psychosocial research in this time.

Thirty one of the 60 papers reviewed have been published in the last ten years. As with the complete literature review, the methodological approach to investigating the experience of living with metastatic breast cancer over this time has been predominantly quantitative, with 24 papers using this approach<sup>1,3,5,6,8,10,12,18,22,23,24,25,26,30,32,34,35,36,40,41,45,48</sup>, seven using a qualitative approach<sup>15,16,29,37,42,46,49</sup> and one using mixed methods<sup>47</sup>.

While the literature in the last ten years still focuses on the psychological impact of metastatic breast cancer<sup>8,24,26,41,42,46,47</sup> and interventions to address this<sup>5,36,45</sup>, there does appear to be a shift in focus to consider in more detail the temporal experience of progressive disease and the everyday experience of living with metastatic disease<sup>15,16,49</sup>. In addition, studies begin to consider a deeper understanding by using the language expressed in participants' experience<sup>35</sup>.

Earlier work focused predominantly on measuring the psychosocial impact of metastatic breast cancer while in the last ten years it appears to begin to acknowledge the different dimensions of living with it.

Advances in treatment for metastatic breast cancer which increases life expectancy are celebrated (Johnston and Swanton, 2006) but within the last ten years research begins to challenge the medical management and questions are posed about the impact of treatment on quality of life and decision making about palliative chemotherapy<sup>29,32,37</sup>, the unmet needs in information and support<sup>1</sup> and a lack of rehabilitation services needed to ameliorate physical impairment<sup>10,30</sup>. In addition, new challenges and concerns are emerging due to the convergence of palliative treatments and the end of life. This in turn may impact on the quality of end of life care and place of death<sup>3,22</sup>.

With a shift in healthcare practices in the UK towards promoting self-management, the study by Shulman-Green et al (2011)<sup>42</sup> is both current and timely. It is the first paper to indicate that those with progressive disease could be considered as cancer survivors who could take an active part in promoting their wellbeing.

From the literature over the last ten years it appears there is an acknowledgement of evidence to date and a shift towards beginning to focus on the identified need and importantly to address the less positive dimension of a life prolonged by treatment, specifically managing physical impairment and end of life. However, those from diverse backgrounds, by their ethnicity or social group, and those who are non-English speaking are still under represented in the literature.

While some studies considered the experience of living with metastatic breast cancer over time, this has been a statistical appraisal; an in-depth enquiry is still needed. Finally the social consequences of a potentially prolonged life dominated by sequential treatment have not been considered.

## 1.7 Summary of literature on the experience of living with metastatic breast cancer

The current evidence base into the experience of metastatic breast cancer predominantly quantifies the prevalence of problems and the impact of psychological interventions in metastatic disease using statistical prevalence, association and correlation. In its totality this evidence demonstrates a wide body of knowledge about aspects of the lives of women with metastatic breast cancer. However, in comparison with the vast body of evidence on the experience of early stage breast cancer, the evidence presented here is limited. To date, research into the experience of women with metastatic breast cancer has identified that they are experiencing significant symptom burden<sup>1,2,28,49</sup>. They can experience significant levels of traumatic stress<sup>6</sup> which highlights the level of distress a metastatic diagnosis brings. In addition, anxiety and depression may be a problem for a third of women and can persist over time<sup>28</sup>.

The importance of social support on women's lives has been well researched and overall evidence indicates that those receiving social support are more satisfied, use fewer avoidance coping strategies and experience less mood disturbance<sup>4,6,30</sup>, although these effects may be due to quantity of social interactions rather than quality. Conversely, the effect of high levels of social support could be considered an avoidance coping strategy as women may have little time alone to contemplate their disease and wellbeing<sup>6</sup>.

Over the last ten years, during which time increased options for treatments means women are living longer, the literature has begun to shift from exclusively identifying the physical and psychosocial problems and needs to considering the negative impact of life-prolonging treatment and its impact on women's lives and, importantly, the end of life.

The more in-depth investigations begin to shed light on the existential experience of metastatic breast cancer. There is however, little investigation of the temporal, everyday life of women, and while there is a large body of knowledge into the effect of social relationships and support, little is written about social identity.

This evidence to date is fundamental in informing an understanding of the lives of women with metastatic breast cancer by offering insights into their multidimensional

problems and needs, but understanding the experience of women over time, in the present day context of increased survival, is crucial in understanding the experience of living with metastatic breast cancer today.

A more detailed in-depth exploration of the multidimensional problems and needs of women with metastatic breast cancer is needed, but to do this in isolation without considering the social and biomedical present day context would be as limiting as focusing on the quantifiable evidence alone.

In addition, concerns about the validity of qualitative research methods may have made quantitative researchers downplay the value of qualitative research. When using qualitative methods, attention must be paid to the reporting of methods to clearly demonstrate equal validity and rigour, as is required of quantitative researchers. This is particularly crucial when the research aims to inform clinical practice and influence those who are likely to respond more favourably to quantifiable evidence.

Finally, overall there is a paucity of research exploring the experience of living with metastatic breast cancer. Little has been done in the UK.

As previously stated, women with metastatic breast cancer may live for a number of years and could be considered to have a chronic illness and there is debate as to whether metastatic cancer is a chronic illness (Tritter and Calman, 2002). Key works in chronic illness have informed the design and direction of this study so it is appropriate to review literature on chronic illness.

## 1.8 Chronic illness literature

Metastatic cancer has been considered a chronic illness (Tritter and Calman, 2002) and those with progressive cancer are now considered to be cancer survivors rather than necessarily at the end of life (Corner, 2008, Department of Health, 2010). As such, they live with the consequences of a progressive illness over time.

The decision to review the chronic illness literature developed from reading an overview and appraisal of work contributing to the understandings of lay experiences of health and illness during data collection of narrative interviews (Lawton, 2003). Key chronic illness theories (biographical disruption, loss of self and biographical reconstruction) cited in this paper resonated with the early themes emerging from the interview data. A subsequent review of the chronic illness literature centred around these key theories only and a focus on illness and identity, as the body of literature on chronic illness is vast and beyond the scope of this study. Search terms used were: identity and illness, self and illness and coping and chronic illness, as well as

biographical disruption, loss of self and biographical reconstruction. Hand searches of papers retrieved were also done.

The review of the social science literature on chronic illness presented here is not exhaustive, but selective to work which informed the development and understanding of the approach to researching and interpreting the effect of and response to living over time with an illness which could be considered both chronic and life limiting.

### **1.8.1 Biographical disruption**

The point of diagnosis of a chronic or long-term illness signifies an interruption to life, to before and after the event, with a disruption to the continuity and discontinuity of life referred to by Bury (1982) as biographical disruption. The 'taken for granted' future is disrupted which impacts on the self-image and biography; the ability to marshal resources to the altered life is reflected in the individual's ability to adapt. The illness and the ability to adapt and integrate it into life are dependent on societal and structural responses and the constraints of both. Many have applied the theory of biographical disruption in future research and despite the passage of time this is still an important and influential theory today. Interestingly Packard's (1991) investigation of the stressful illness-related experiences of 52 chronically ill women did not reflect on Bury's work but identified seven domains of chronic illness with the focus of disruption as a) direct disease effects, b) disruption of continuity, c) disruption of integrity, d) disruption of normalcy, e) social responses, f) treatment processes, and g) patient/provider transactions. The disruption of illness and societal and functional demands were concerns throughout the illness trajectory and the primary source of stress appears to be caused by the intrapersonal and environmental world around them. Women with breast cancer were part of the cohort. This author acknowledged limitations of her study in that the participants were asked to reflect back in time, so the findings are reliant on memory and their interpretation may have altered.

Three studies explicitly describe transitions in chronic illness (Brown et al, 2008, Kralik, 2002, Thomé et al, 2004) outlining phases individuals pass through in adjusting and adapting to chronic illness. Kralik (2002) described two transitional themes; firstly, the concept of extraordinariness. Participants faced turmoil and distress in the face of a diagnosis of chronic illness as a life-changing event, with the disruption of the taken-for-granted life and the self. There was a sense of alienation from familiar life and life events. The transition from extraordinariness to ordinariness was described as when the participants confronted life with illness and began to reconstruct their lives with chronic illness. The theory of biographical reconstruction was first described by Williams (1984) when investigating the lives of people who had lived with chronic



illness for over five years. He developed the theory of biographical reconstruction and genesis as being an attempt to repair ruptures between body, self and the world by linking up and interpreting different aspects of biography in order to realign present, past and self with society. Like Bury (1982), Williams's (1984) theory has been one of the seminal works in understanding the experience of chronic illness.

### **1.8.2 Presentation of self**

While enduring life and navigating through chronic debilitating disease, people may use narrative as a medium through which to represent themselves. One study explored the use of narratives of people with a progressively debilitating illness. Remaining positive and aiming for achievable goals while acknowledging the future of a slowly debilitating disease was described as a sustaining narrative storyline (Brown et al, 2008) while others in this study described an endurance of suffering and stoicism as an enduring storyline, sought opportunities to prolong life and physical functioning (preserving storyline) and ultimately a breakdown of self, with fear of the future, living in a surreal notion of time and living a quiet, sad reality (a fractured storyline).

### **1.8.3 Loss of self**

Loss was a central theme in a number of papers. A key work in the loss of self describes the loss of self over time, which erodes identity and self image. The accumulated loss of self without development of new self-perception can result in a diminished self-concept (Charmaz, 1983). Loss was described in numerous ways. Loss of bodily function, relationships, an autonomous life, an imagined life, social roles, activities, identity and uplifting emotions demonstrate that recurring losses can result in chronic sorrow (Ahlström, 2007). In life-limiting illness this loss can impact on the individual's response to illness and their relationship to their social world while fearing and acknowledging an uncertain future (Fife, 1994) particularly in the face of living a life of discontinuity (Little et al, 2002).

### **1.8.4 Coping strategies**

A significant proportion of the literature focused on coping strategies. Kralik et al (2002) aimed to understand the way in which people who lived with chronic illness constructed the notion of self-management. This study found that to create order from the disorder in their lives, participants used complex self-management approaches: recognising and monitoring boundaries, mobilising resources, managing the shifts in self-identity and balancing, pacing, planning and prioritising. A study which explored how adults integrate chronic illness into their lives found that the process was complex and challenging, requiring considerable effort. The everyday life of symptoms, physical functioning and changing emotions could be overwhelming and integrating illness into a

life could be an arduous task (Whittemore et al, 2008). In contrast, one study investigated those defined as 'resilient' individuals living with chronic illness (Hayes, 2008). This study identified that a strong faith and family support were the key mechanisms to successful coping: illness was not the focal point and there was a commitment to living life successfully. This study contradicts most of the literature on coping in chronic illness. Participants stated that, comparatively, things could be worse and personality make-up and role models are the key factors in being successful. However, there are some methodological concerns about this study. There was no definition of 'resilient individuals' or mention of how the cohort was selected and defined as resilient. If participants were told they were chosen because they were identified as resilient, this may have skewed the findings. This was not described. In addition, while other studies demonstrate a questioning of faith, strong faith was a key mechanism for coping in this study. It could be that the recruitment population was in an area where religious faith was important as they were described as holding Christian religious beliefs. This may not be considered a reflection of those living with chronic illness outside this population.

### **1.8.5 Cancer as a chronic illness**

In considering the literature on cancer as a chronic illness, the time of diagnosis was particularly stressful and served as the beginning of marshalling resources to develop coping strategies, although little support appeared available to assist this prior to diagnosis (Sægrov et al, 2004). The will to live and the fight for life were important for those newly diagnosed with breast cancer (Landmark et al, 2002) and breast cancer was seen as a challenge to be faced (Luker, 1996). Fear of the future and living in the 'shadowy light of death' represented crisis, loss, uncertainty and pain, and negotiating the socially constructed norms and stigma could lead to isolation (Colyer, 1996). While the latter investigation is interesting, ultimately only two participants chose to have their interviews used in the analysis, limiting the generalisability of the findings.

### **1.8.6 Older people and cancer**

Tritter and Calnan (2002) question whether cancer should be considered a chronic illness as its aetiology and trajectory is very different to chronic illness. For older people with cancer, the loss of capacity indicates a disintegrated existence where illness begins to restrict physical ability and age and ageing become a more conscious reality. Sudden awareness of the finiteness of life and a life lived meant reflection on and evaluation of life, so influencing the appraisal of future life. A worthwhile and fruitful life lived made it easier to endure the finite future. End of life concerns were less to do with a life ending and more about dying process. Overall the process of living and dying with cancer in older people was a transitional life described as a disintegrating existence

over time. The bodily signs of illness influenced the individual's ability to adapt, with the fear of dependence and loss of capacity and so dependence a significant concern (Thomé et al, 2004).

### **1.8.7 Temporality**

Time was a central concept in almost all studies; the past, present and future impact on the temporal experience of living with chronic illness. Following the theory of biographical reconstruction (Williams, 1984), one study explored the experience of men who were HIV non-progressors who sought to explain why they had lived so long (Pierret, 2001). They had grown confident over time in their stable disease and uncertainty was in the past. Four ways of living were identified with the past: going on day to day, keeping things the same, withdrawing into one's bad luck, and constructing an exceptional future. This work developed the theory of biographical reinforcement as individuals defined themselves as exceptional and/or privileged, able to live their lives in the present, plan ahead with an imagined future and reconstruct their past life. In contrast, other studies found that in order to integrate chronic illness into their lives participants had to confront loss, fluctuating emotions, making changes and gaining control of an altered life direction (Rush, 1996, Ahlström, 2007, Charmaz, 1983, Luker, 1996, Little et al, 2002).

### **1.8.8 Dying of illness**

Living and dying of a life-limiting illness was explored by three authors (Armstrong-Coster, 2004, Lawton, 1998, Thomé, 2004). A key work was undertaken by an anthropologist who worked in the hospice setting in a participant observation study (Lawton, 1998). From this the researcher developed the theory of the sequestration of the unbounded body. At the end of their lives individuals lose their cohesive identity when they no longer have a bounded body, when the diseased body disintegrates and selfhood disintegrates. Lawton (1998) poses interesting questions about disintegrated selfhood and the role of hospices in end of life care in stating that there was an increasing trend towards hospices sequestering specific types of dying, in particular those with unbounded bodies. Lawton argues that this phenomenon is 'glossed over' by referring to the care of the dying as purely symptom control and that hospices become a liminal place where individuals with progressive disease linger between an integrated whole self and death.

While the body of literature discussed above adds to the knowledge about the dying process, the women in this study are living prolonged lives with progressive disease. By applying a longitudinal approach the aim is to understand more of the day-to-day lives of people as they navigate a life lived with progressive breast cancer and to

consider the social consequences of this. One approach to this was to map the illness trajectory, the lives as they were experienced over time, the events, problems, the oscillations, to understand the transitions of progressive breast cancer. Illness trajectories have been considered in chronic illness and cancer. Considering this approach to investigating the experience of metastatic breast cancer might allow greater insight into the everyday life over time, the events, problems and needs of those living with progressive disease and offer ways in which this could be improved. The current literature on illness trajectories has been explored to consider the frameworks which could be applied to this population.

### **1.8.9 Illness trajectory**

In the context of developments in the management of metastatic breast cancer and the provision of care, or its inadequacies (Reed et al, 2010), little is understood of the temporal existence of those living with it. While survival is said to have increased and the illness trajectory prolonged, equally for some it can be a short trajectory with rapid progression of disease and little respite. Problems and needs are complex and different for each individual which influences the unfolding trajectory of illness. To understand and so consider the needs of a heterogeneous population, the illness trajectories would plot in detail lives over time.

Corbin and Strauss (1984) suggest that the course of illness can be managed by ameliorating events, such as uncontrolled symptoms, and maximising quality of life using an illness trajectory framework.

The main concept of the Corbin and Strauss Chronic Illness Trajectory Framework is 'trajectory', which is the course of illness that may be shaped by the individual, family and healthcare professionals. Kleinman (1988) differentiates between disease and illness, disease being a biomedical term and illness having a very different meaning.

*'By invoking the term illness, I mean to conjure up the innately human experience of symptoms and suffering. Illness refers to how the sick person and the members of the family or wider social network perceive, live with, and respond to symptoms and disability.'* (Kleinman, 1988:3)

It can only be mapped retrospectively and is usually unpredictable. The shape is determined by the individual, events which occur throughout an illness trajectory and the response to events.

Murray et al (2005:1007) described three trajectories in progressive incurable disease:

- a short period of relatively predictable decline in the last weeks or months of life

- slow decline punctuated by acute exacerbations of illness
- prolonged dwindling, a progressive illness with functional decline.

Murray et al (2005) stated that trajectories give us a framework with which to plan for the end of life appropriately and address the needs of each person. The seminal work of Kubler Ross (1970), who developed an early model of the dying trajectory, identified five stages in the response to dying; denial, anger, bargaining, depression and acceptance. Kubler Ross acknowledged that an individual may not go through a structured process to acceptance but may stay at one stage throughout the dying trajectory. However, criticism has been levelled at her model as it appears to assume that those dying go through the five-stage process without deviation. It has since been acknowledged that the process is not necessarily linear.

Two years after Kubler Ross described her model of the dying process, Glaser and Strauss published a then seminal book, *Time for Dying*, in which they proposed that the dying trajectory was formed of two elements – time and shape – and that there is a relationship between the expectations of death and the phases of dying.

An early trajectory of dying was developed by Glaser and Strauss (1968):

- certain death at a known time
- certain death at an unknown time
- uncertain death but at a known time when the certainty will be established
- uncertain death and an unknown time when the question will be resolved.

This study added significantly to the understanding of dying trajectory theory and provides important insights into dying trajectories. They described intensive field work involving a combination of observation and interviews in six hospitals, with the aim of giving maximum exposure to different dying locations. A strength of their approach was in their day-to-day immersion in patients' lives and interactions with them, an approach to exploring the illness experience which is still lacking today (Lawton, 2000).

Developing this work further Pattison (1977) described a living/dying model based in his clinical experience, which he says is from the point of *crisis of knowledge of death* to the *point of death*. The living-dying process is described in three phases; 1) the acute crisis phase, 2) the chronic living-dying phase and, 3) the terminal phase.

The role of the healthcare professional is to acknowledge and respond to the acute crisis to ameliorate the risk of disintegrated dying, respond to the need to adapt and assimilate in the chronic phase and assist in the acknowledgement and experience of the dying phase. Copp (1999) contends that while Pattison's model recognises that

integrated dying allows for the acknowledgement of the individual characteristics which influence the dying trajectory, it does not acknowledge that integrated and disintegrated dying can happen concurrently.

Pattison's work is derived from his many years in clinical practice and may be considered to be what Frank (1995) terms as surrendered narratives, in that the experience of people living with cancer is not represented in his methods or data collection.

While there are commonalities in each individual's response to dying, each reaction needs to consider the life experience both with and without disease and the emotional, physical, social and spiritual dimensions of that response. Buckman's (1998:145) three-stage framework of dying begins to address this. His model is based on two central principles.

Individuals facing death exhibit a mixture of reactions and response which are characteristic of the patient, not of the diagnosis or the stage of dying process.

Progress through the dying process is marked, not by change in the type or nature of emotions but by resolution of the resolvable elements of those emotions.

The initial phase *facing the threat* is when the individual first faces the threat of disease and the response to this: the chronic phase, being *ill* is the process of resolution of their initial response and the intensity of their initial response lessens. Buckman states that at this time depression is common following the high level of emotional response and social support associated with the initial threat and facing reality that they are going to die. Lastly, the final stage is *acceptance* of the situation and that they are going to die.

All the illness trajectory models discussed so far are dying trajectory. Copp (1999) acknowledged that there is an assumption that there is always a downward trend but that there may be times where the illness trajectory plateaus. Copp (1999) described the multidimensional aspects of dying by interviewing patients and nurses in a hospice. She found that redefinitions of the self occur at critical junctures over the illness trajectory. Nurses sought to gain insight into the experience of dying and in doing so, engage in the process of redefinition of self to support their patients. Conversely, there may also be upward trends on functional ability in progressive cancer; on occasion individuals may have some restoration of wellbeing so their functional ability may significantly improve to indicate an upward trend.

Current evidence suggests that illness trajectories of progressive cancer always follow a downward trend. Arguably, people living with progressive cancer are on a dying trajectory, but as the body can respond to active treatment this is not necessarily

always downward; there may be moments of significant restoration of health and improved physical functioning. While the models above begin to acknowledge that the illness trajectory has a psychological element, there is little understanding of the oscillation and extreme highs and lows of the physical and emotional response to progressive disease and treatment and how an individual may adapt and cope over time. This is particularly important in the current day healthcare context of metastatic breast cancer, when treatment can prolong the lives of women who may live for years with varying levels of functioning while facing the certainty of death at an unknown time in the future.

### **1.8.10 The breast cancer trajectory**

Investigations into the illness trajectories in breast cancer have to date focused on the trajectories of fatigue in women with breast cancer during and after radiotherapy (Dhruva et al, 2010), predictions of distress in the first year after a breast cancer diagnosis (Henselmans et al, 2010) and identifying distinct trajectories of adjustment to breast cancer over a four-year period (Helgeson et al, 2004). While some in the later study developed recurrent disease, these participants were excluded from the study. There is no investigation into the trajectory of metastatic breast cancer and as medical management aims to increase survival time it is timely to map the illness trajectory of women with metastatic breast cancer.

## **1.9 Summary of chronic illness literature**

In contrast to the evidence on the experience of metastatic breast cancer, the literature on chronic illness is almost exclusively qualitative. Key theories have informed the development of evidence in chronic illness; biographical disruption (Bury, 1982), the loss of self (Charmaz, 1983), biographical reinforcement (Pierret, 2001), biographical reconstruction (Williams, 1984) and the sequestration of the unbounded body (Lawton, 1998). All of these theories have also influenced and informed this study.

To date the evidence suggests that the diagnosis of a chronic illness is a disruption to an individual's life and biography (Bury, 1982). It can affect an individual's ability to function physically and so disrupt the integrity and continuity of life (Packard, 1991). Individuals with chronic illness pass through transitions from the distress and isolation of diagnosis to the integration of chronic illness into their lives through marshalling coping strategies or using their situation for its uniqueness as a quest or to identify themselves as privileged (Pierret, 2001).

To integrate chronic illness in everyday lives necessitated marshalling resources (Kralik, 2004) and using coping strategies to create order. While this could be an

arduous task, some used complex self-management approaches in the face of the uncontrolled symptoms, physical functioning and challenges of a life lived with and around chronic illness (Whittemore, 2008).

Temporality was a central theme in the exploration of the experience of chronic illness. Those living over years with chronic illness may reconstruct their biographies in order to integrate illness into their lives, so reconstructing the relationship between body, self and society (Williams, 1984).

For those living with a potentially life-limiting illness but looking well and feeling well for years, there was a need to reinforce their identities by describing themselves as privileged and exceptional. While still uncertain, the future could be considered and imagined rather than experienced as a loss of control and fear (Rush, 1996, Ahlström, 2007, Luker, 1996, Little, 2002). However, individuals could feel discredited by the social reaction to their limitations or visible disability and their opportunities for socialisation and previously held social roles were eroded leading to a loss of self (Charmaz, 1983).

In the studies that considered cancer as a chronic illness, a diagnosis signified a finite life, which reflected on both a life lived and an uncertain future. While a number of studies considered the fear of death, only two considered the process of dying and the impact of this on identity in chronic illness (Armstrong-Coster, 2004, Lawton, 1998, Thomé 2004).

Those with metastatic breast cancer specifically are not represented in the literature. This may reflect that the key theories precede advances in treatment over the last ten years which increases the survival time (Johnston and Swanton, 2006). Over this time breast cancer has been a part of investigations into the experience of chronic illness (Kralik, 2004, Landmark, 2002, Little, 2002, Sægrov, 2004) but only two included those with metastatic cancer (not specifically breast) (Armstrong-Coster, 2004, Thomé, 2004). These studies explore specific areas: the dying process and cancer in old age respectively.

Contrary to the evidence of the experience of metastatic breast cancer, while there is plentiful in-depth understanding of the lives of people with chronic illness from a sociological perspective there is little quantifiable evidence about the prevalence of the problems and concerns of those living with chronic illness. This is interesting but not within the realms of this study. However, this study in its entirety will add to the mixed method approach of the understanding of one illness which could be considered to be chronic.



Narrative research within the body of evidence is interpreted predominantly through the illness, and not the aspects of everyday life lived *with* an illness. In documenting the biomedical difficulties experienced with cancer treatment, its side effects and symptoms, the individual narrative is lost within the demands of the healthcare system. Lives outside the biomedical are not so apparent within the cancer literature and to see the whole experience as opposed to the separate parts which make it up through the individual narratives will add depth to the understanding of breast cancer experience.

Evidence into illness trajectories is predominantly chronic illness. Those exploring the trajectories of cancer are focused on the dying trajectory with little evidence into lives over time with progressive disease. The illness trajectory of metastatic breast cancer is complex and convoluted and in order to consider the medical and nursing management in the current day context of sequential treatments and prolonged lives, it is important to consider this as part of this study.

## 1.10 Gaps in the evidence and research recommendations

While there is a wide evidence base into the problems and needs of this population, no one study has set out to measure quality of life or the prevalence of problems and needs in the UK. A quantitative approach to measure quality of life in physical, emotional, social and practical domains would provide a present day benchmark and further the research.

In the context of prolonged life expectancy and the impact of the increased number of treatment options, perspectives on experience of care and the quality of healthcare would be a timely investigation.

A sociological perspective has not been applied to women with metastatic breast cancer. An investigation into the social context of women's lives, in particular the individual construction of identity and the social co-construction of identity, would be a significant addition to the body of knowledge.

It is timely to explore the temporal existence of women with metastatic breast cancer, considering both the biomedical and personal illness trajectories of women in detail over their lives with metastatic disease. In addition, mapping the illness trajectory over time would for the first time give a picture of the prevalence of treatment, problems and events in the life of those with metastatic breast cancer.

The chronic illness literature focuses on the emotional adjustment that has to be made in coping with a disintegrating body from a social perspective, while the current literature on illness trajectories predominantly focuses on the emotional response to the

knowledge of dying. What is absent from the literature is the exploration of the multidimensional response (emotional, physical, social) to living with a progressive and incurable illness alongside the physically disintegrating body.

In identifying the gaps in evidence and methodological approach in the investigation of women with metastatic breast cancer, this study aimed to use methodology which identified the prevalence of problems and needs and the extent to which healthcare services meet the needs of women in the present day context of multiple treatment modalities and potentially increased survival. In addition, reflecting on the evidence to date and the body of literature on chronic illness, it aimed to capture the experience of living with metastatic breast cancer day to day and further the understanding of this experience.



## Chapter 2. Methods

Drawing on the evidence base outlined in the previous chapter this study set out to explore in detail the experience of people living with metastatic breast cancer over time.

The aim was to first 'set the scene' of what the experience of living with metastatic breast cancer was like for the wider population and to understand the prevalence of problems and concerns in the context of present day healthcare, then to explore in more detail the everyday lives of those living with it. To do this a mixed method approach was used.

In this chapter the design of the study is explained and the research questions and objectives stated. The methodological approach and theoretical perspectives are explained and there is a discussion on the use of mixed methodology. The three phases of the study are described separately.

### 2.1 Objectives

- To identify the physical, emotional, social and practical problems for women living with metastatic breast cancer and the extent to which they are accessing services to meet needs they may have.
- To explore in detail the physical and social consequences of metastatic breast disease as illuminated through individual stories of illness experience and to examine how these may change over time as the disease progresses.
- To map participants' illness trajectory and develop a trajectory framework for metastatic breast cancer.
- To identify measures that might be taken to offer greater support to people with metastatic breast cancer.

### 2.2 Research questions

- What is the prevalence of problems and needs of people with metastatic breast cancer and to what extent does current service provision meet their needs?
- What are the social consequences of living over time with progressive breast cancer on identity?
- What does the illness trajectory of metastatic breast cancer look like and by mapping this, what does it add to the understanding of the experience of living with progressive breast cancer?

- What measures could be taken to improve the wellbeing and experience of women with metastatic breast cancer?

## 2.3 Study design

Lawton (2000) argues that the majority of studies focus on accounts of chronic illness and less about what she describes as the mundane daily aspects of ‘coping with’ the diseased body. She argues that there is a need to understand more about the body, self and society while focusing on the temporal experience of the individual narrative.

While the study design was defined at the outset, in reality there was an organic growth in the design in response to the literature and as data were collected for the first phase of the study.

From the identified aim and objectives, the study sought to understand everyday lives as women navigated their life course with metastatic breast cancer. In the early development of the study methodology, a qualitative approach alone was to be used. However, from reviewing the literature it became apparent that with recent developments in the medical management of metastatic breast cancer, women’s treatment options, decision-making and life course were evolving as medical management improved. Consequently, there was little quantifiable evidence on this population in the present day healthcare context. In addition, there is a dearth of evidence originating from the UK, with the current evidence focusing on psychiatric morbidity (Fulton, 1997, Fulton, 1998, Fulton, 1999, Hopwood et al, 1991), decision-making on palliative chemotherapy (Grunfeld et al, 2006) and the meaning of living with advanced breast cancer in hospice patients (Davies and Sque, 2002).

In view of this it was important to capture the reality of participants’ everyday lives in order to explore the influences and consequences of living with metastatic breast cancer. Subsequently, from interviewing women and reading their hospital documentation, it appeared that the illness trajectory of metastatic breast cancer was ill-defined and a third phase was added to the study. To achieve this, the study was undertaken in three phases (Figure 1). Recruitment and data collection in all phases of the study were undertaken concurrently. Participants who had completed the survey and consented to be interviewed were recruited and interviewed while the survey recruitment was ongoing. This was to ensure recruitment was done within the time frame of the research grant.

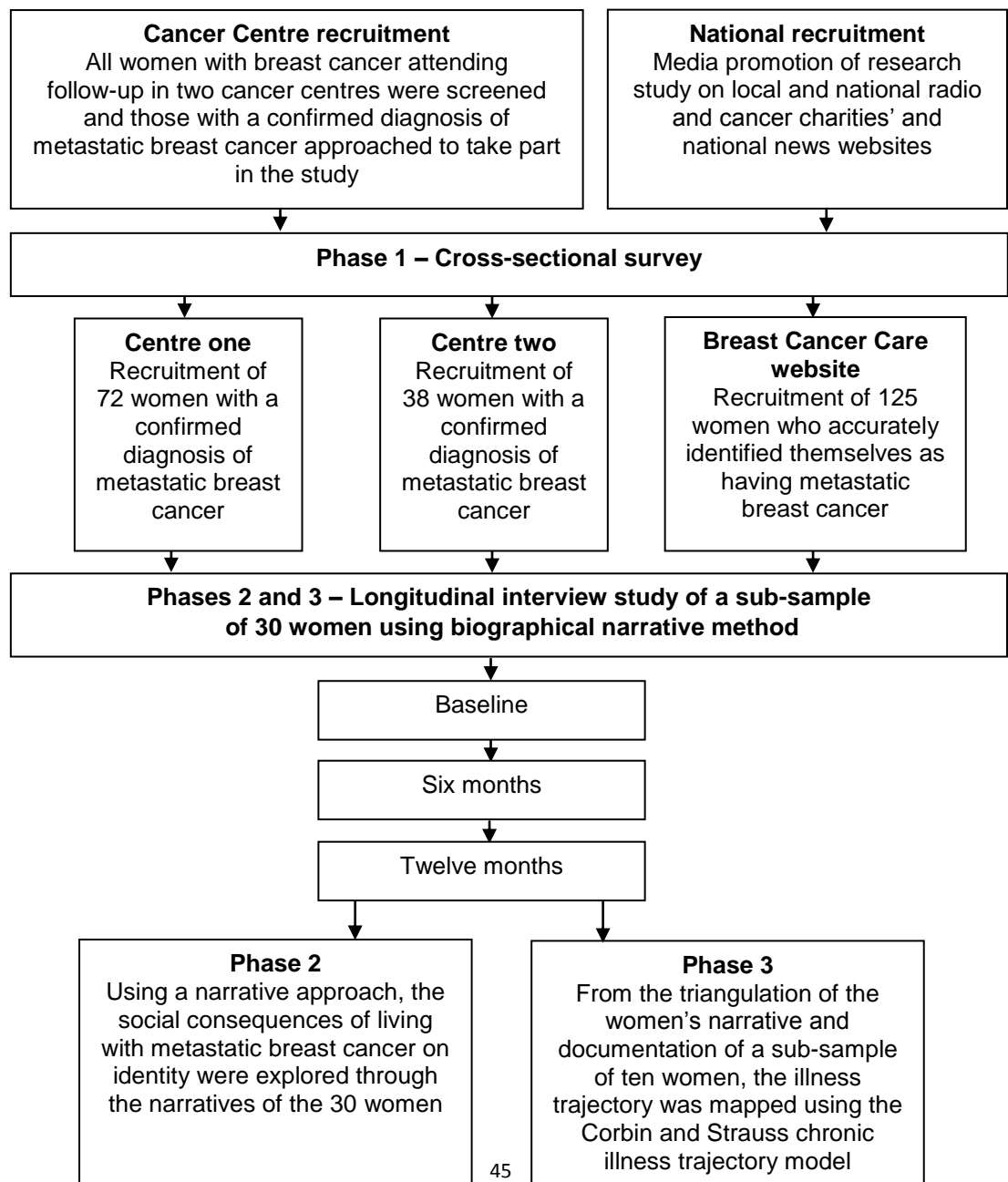
**Phase one** – a cross-sectional questionnaire study measuring the quality of life and experience of care in women with metastatic breast cancer and open questions

exploring their physical, emotional and practical concerns and where they accessed support.

**Phase two** – a longitudinal approach using narrative enquiry in 30 women who were interviewed three times over one calendar year, exploring the social consequences of living over time with progressive breast cancer.

**Phase three** – a longitudinal approach using narrative inquiry of ten women who were interviewed three times over one calendar year, triangulated with patient documentation (medical and nursing notes, investigation results, correspondence between healthcare professionals) in order to map in detail the metastatic breast cancer illness trajectory.

**Figure 1: Study design**



## 2.4 Methods used

A mixed method approach was applied to this study. Using mixed methods allowed a convergence of the broad quantitative picture from a survey with the more detailed exploration of a qualitative approach.

## 2.5 Mixed method approach

Paradigm purists believe that quantitative and qualitative methods are completely incompatible due to the underlying philosophies of each approach, and to use both compromises the rigour of the research. However, pragmatists have called for more understanding of the different methodologies available with the belief that integration of different methodological approaches makes for richer data, and that there are strengths and weaknesses in both quantitative and qualitative approaches (Tashakkori and Teddlie, 1998).

By utilising a mixed method approach the bias inherent in each method identified in the literature review is neutralised with the convergence of the survey and interview data (Creswell, 2003). A simple illustration of this would be to consider Koopman et al's (1998) study which demonstrated that adverse social support resulted in women with metastatic breast cancer experiencing mood disturbance using two psychometric measures, the Yale Social Support index and the Profile of Mood States measure. This finding was determined using multiple regression analyses. This gives a statistically generated fact that mood is influenced by the level of social support in women with metastatic breast cancer. What it does not tell us is what this means to the women, how it makes them feel. The interpretive approach used by Arman et al (2004) supports Koopman et al's (1998) findings and adds depth to the understanding of women's isolation by using individual narrative; *'...then the suffering when you feel that you don't get any help, any support, that there is nobody who understands...'* (p252). As Kleinman (1988:28) said, *'Symptoms scales and survey questionnaires and behavioural checklists quantify functional impairment and disability, rendering quality of life fungible. Yet about suffering they are silent.'*

Pope and Mays (2009) argue that many studies which state they use mixed methodology in fact keep the quantitative and qualitative methods separate and report them as such, as demonstrated in the literature review in the previous chapter. They state that to make the most of mixed methods studies the qualitative and quantitative approaches should be synthesised. For example, the survey in this study showed that around a third of women experience significant pain. The qualitative data reinforce this

finding with powerful insights into the pain experience of women living with metastatic breast cancer:

*'It's always there niggling in the background and it's sort of like ehrrm, I don't know because I'd never had a bad back before that so I wouldn't know what, what to compare it with, but it's not nice. Whether I'm sat, if I lay down, you know that it's constantly niggling, whether I'm laid, sat or standing.'* (40 year old woman living with bone, lung and liver metastases for 18 months)

Bryman (2012:633) states that by employing both quantitative and qualitative research approaches within one study, a more comprehensive account of the findings promotes a 'completeness' to the area of enquiry. Phase one applied quantitative and qualitative approaches (quantitative survey using validated measures and narrative responses to open questions) to provide a more comprehensive account of the problems and needs of women with metastatic breast cancer. This allowed a more in-depth enquiry to be undertaken from the prevalence of the problems identified in the wider population and the scene to be set from statistics and variate analysis with the more in-depth exploration of narrative responses. However, in the final, third phase, triangulation of mapped illness trajectories from medical and nursing documentation with a physical functioning scale and women's narratives integrated each approach in the study design and analysis.

A research proposal was submitted to Breast Cancer Campaign for funding of a three-year grant which was successful. Ethical approval was given by Southampton and South West Hampshire Local Research Ethical Committee.

While it was always the intention to write a doctoral thesis, there were tensions between meeting the requirements of the grant-awarding body to publish the study findings and writing the thesis. At times the preparation of publications dominated focus and time.

## 2.6 Phase 1 – the survey

The theoretical strength of quantitative methodology has been considered to be the best approach to uncovering the processes by which both physical and human events occur (Sarantakos, 2005). This is considered to be underpinned by a pragmatic and objective ontology, which asserts that reality is objective and rigid and research should focus on what can be observed and measured. A post-positivist approach, however, challenges that social reality can be subjective and independent (Tashakkori and



Teddle, 1998). The difference is that the post-positivist critical realist recognises that all observation is fallible and has error and that all theory is revisable.

In this study, by applying an empirical quantitative approach the aim was to explain the experience of living with metastatic breast cancer using both descriptive and inferential statistics in pre-determined sub-groups within that population. For example, those with indolent disease may have a different illness experience to those with more aggressive disease (independent variables) in relation to symptom burden or experience of care (dependent variables). Creswell (2003:120) describes quantitative theory as *'an interrelated set of constructs formed into propositions, or hypotheses, which specify the relationship among variables (typically in terms of magnitude or direction). The systematic view might be an argument, a discussion, or a rationale, and it helps to explain (or predict) phenomena that occur in the world.'*

In phase 1 a cross-sectional survey design was used to provide a picture of the profile of women using psychometric tools. This approach sought to develop a picture of the prevalence of physical, social and emotional problems of living with metastatic breast cancer in the wider population and the extent to which women accessed services to meet their needs. A quality of life (QoL) measure and patient experience of care measures were used as well as open text questions asking participants about their multidimensional needs and where they turned for support. This approach gave an understanding of the needs of the population in the UK with metastatic breast cancer and aimed to inform the second and third phases of the study, which explore individual experiences in more depth over time.

Recruitment to Phase 1 was completed in November 2006. Quantitative data were analysed using SPSS and the open text questions were analysed using the qualitative package Nvivo. The findings have informed the work of Breast Cancer Care's Secondary Breast Cancer Taskforce<sup>2</sup>.

### **2.6.1 Outcome measures**

Established and validated measures were used in this phase of the study.

### **2.6.2 Measuring health related quality of life**

The theoretical framework of health-related quality of life is predominantly based on the multidimensional viewpoint of health as physical, psychological and social functioning

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<sup>2</sup> <http://www.breastcancercare.org.uk/campaigning-volunteering/campaigning/current-campaigns/spotlight-secondary-breast-cancer/background-campaign>

and wellbeing (Bowling, 2001). The World Health Organisation (WHO) defines health related quality of life thus:

*'Quality of life is defined as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, and their relationships to salient features of their environment.'* (WHO, 1998)

Bowling (2001), however, contests that while the definition encompasses health-related quality of life, few measures cover all domains and those that do are lengthy and impractical.

Reduction in tumour size was until recent years the main measure of response to treatment in metastatic breast cancer. Studies have confirmed that chemotherapy can improve quality of life (QoL) and survival (Ramirez, 1998, Greenberg, 1996) although few clinical studies report global quality of life in relation to tumour response and relief of symptoms (Geels, 2000). Almost exclusively health-related quality of life measures used in cancer are designed to be used in clinical trials and are measuring ill health and the impact of illness and/or treatment rather than quality of health (Bowling, 1997). Arguably physicians are predominantly interested in measuring the physical functioning of quality of life while patients are more interested in the more psychosocial aspects (Sloan et al, 1998). To encompass the holistic multidimensional needs and problems of cancer populations in healthcare, a more subjective, qualitative approach to measuring health-related quality of life is needed (McCabe et al, 2008).

Some concerns about QoL measures need to be acknowledged. Those who fail to complete QoL questionnaires may be those who would have low scores, so affecting the accuracy of overall quality of life reported. In addition, participants may not complete the QoL measure accurately but rather seek to represent themselves favourably for health professionals who are responsible for prescribing their treatment and providing their care.

Despite these caveats, the lack of data on health-related quality of life outside a clinical trial means data are needed as a present day benchmark of the experience of living with metastatic breast cancer in the context of developments in treatment and a potentially prolonged metastatic breast cancer illness trajectory. It also serves to inform the second phase and third phases of the study.

For this study, FACT-B was selected as a health-related quality of life measurement as it incorporates the physical, emotional and practical aspects of living with breast cancer this study sought to investigate. The measure was developed empirically through interviews with patients and service providers and is appropriate to use in cancer patients (Davies, 2009). It was developed from the original FACT (Functional Assessment of Cancer Therapy) scale. In-depth interviews were conducted with fifteen breast care patients and five experts (doctors and registered nurses) with experience in treating breast cancer patients. Then 30 FACT-B naïve breast cancer patients (some with metastatic disease) used a four-point scale to rate the relative importance of the questions. The results were reviewed by the expert panel and compared to other FACT scales (lung and colon cancer). A three-year validation study derived a normative sample consisting of a 295 patient validation sample of people with breast cancer, of whom 20% had metastatic disease (Brady et al, 1997). The participants were recruited from two American cancer centres. They had to have a diagnosis of breast cancer at any stage, be over 18 years of age, and not have brain or central nervous system metastases or be taking psychotropic medication.

FACT-B was designed to be brief to complete (approximately 10 minutes), easy to understand (the reading age of 8-10 year olds) and sensitive to change in studies using the measure repeatedly over time (Brady et al, 1997).

FACT-B is a self-administered questionnaire. It has been widely used in breast cancer research (Fallowfield et al, 1999, Avis et al, 2005, Holzner et al, 2001) and has been tested for internal validity, reliability and score stability (Brady et al, 1997, Cella et al, 1993). This multidimensional instrument consists of domains this study sought to investigate: physical, emotional, social and functional wellbeing and a breast cancer specific domain (Appendix 5). The questionnaire has a total of 37 items asking participants to rate how true each one is for the period of the last seven days on a Likert scale. Response scales range from 0 (not at all) to 4 (very much). The total FACT-B score is calculated by adding the results for each domain, so the higher the score the better the quality of life.

### **2.6.3 Patient experience of care**

Over recent years there has been increased interest in measuring cancer patients' experience of health services. Government guidance promotes the need to measure the quality of care received by those using the health service and their satisfaction with it (NICE, 2004). Patient participation is now seen as the way forward in improving health service provision. In the palliative care setting patients and families believe it to be an important aspect of care including accessibility, co-ordination, competent

symptom management, comfort with dying, communication, education, emotional support, personalised care and support for decision making (Dy et al, 2008).

Measuring satisfaction with care is, however, not straightforward. It is often missing when measuring health status and is notoriously difficult to measure accurately (Bowling, 2001). There is a lack of clarity in the literature on the definition of satisfaction and its relation to other measures (Hudak et al, 2000) and whether the population sampled is indeed representative of the total population. Non-response bias needs to be considered as the fewer people returning the survey the less likely the satisfaction of the population is a true picture of patient satisfaction (Spooner, 2003). Those dissatisfied may choose not to respond and those dependent on healthcare professionals for care may feel less able to respond honestly on their satisfaction, or lack of it, with care received. The participants of this study were asked to complete a questionnaire which explored their experience as someone living with metastatic breast cancer, so not focusing on their experience of care. As the experience with care measure was embedded within the survey and not given to participants by the healthcare professionals involved in their care, it was hoped that the response rate would be better than surveys measuring only their experience with care.

The experience with care measure (Appendix 5) used was adapted by Moore et al (2002) from a medical interview satisfaction scale (Wolf et al, 1978) and used in a study assessing the effectiveness of nurse-led follow-up for lung cancer patients. This incorporated three validated domains; information and advice, personal experience of care, which considered the quality of communication with healthcare professionals and whether the participants felt valued and heard, and satisfaction with care, which considered the thoroughness of care and whether the participants felt their needs and concerns were addressed. Each individual item was rated on a five-point Likert scale. Lastly a visual analogue scale measured overall satisfaction from 0-10, 0 = dreadful and 10 = excellent. These domains contained the areas requested from the pilot study participants, in particular, information on quality of consultations with healthcare professionals and satisfaction with care.

Demographic variables were collected and also additional information around site of disease spread, treatments and time since diagnosis. Whether women from the cancer centres were defined as having metastatic breast cancer was determined through the medical notes for cancer centre participants and identification of metastatic site on investigation reports and other medical documentation. Website participants were asked to describe the site of their metastatic disease and time from diagnosis of metastatic disease. Disease specific data were collected from medical notes in the

cancer centres. Further open text questions aimed to elicit information about where participants turned to meet their physical, emotional and practical needs and why.

#### **2.6.4 Pilot study**

To pilot it, the survey was given to eight women with metastatic breast cancer who were part of a support group. The overall feedback was positive, other than their request to comment on their experience of care, or lack of care, and on their experience of healthcare services, which four of the eight felt was a significant aspect of the experience of living with metastatic breast cancer. The original survey did not incorporate an experience with care component but in response to the pilot study the experience with care measure was used.

#### **2.6.5 Recruitment**

In order to ensure participation of a large number of people with metastatic breast cancer, recruitment to the survey was done at two cancer centres and on the Breast Cancer Care website. This allowed a wider response from people from around the UK. This was the first time the internet was used to recruit individuals with progressive cancer in research in the UK. The aim of using these two very different approaches was to get a UK-wide population of women so as to be as representative a sample as possible within the constraints of the research grant. This approach also aimed to recruit those who may not be in follow-up or receiving active treatment.

#### **2.6.6 Cancer centres recruitment**

Over a 24-month period (November 2004-2006), all women attending treatment and follow-up clinics in two cancer centres were screened by hand searching their medical notes. The inclusion criteria were all those with a confirmed diagnosis of metastatic breast cancer. Once identified, all those with a confirmed diagnosis were approached (directly by me as the author in one cancer centre and by a research nurse in the second) to participate in the study, unless they were too unwell, or approach was deemed inappropriate by the oncologist. Some women were identified but not approached at the time due to a number of reasons, such as they were receiving information about disease progression, distressed by their situation at that time or making treatment decisions. In these cases, they were approached at a later, more appropriate time. Women were given the patient letter and study information sheet (Appendix 2) and at least 24 hours to consider study participation. Subject to consent (Appendix 4), they were asked to complete a questionnaire about their experience of living with metastatic breast cancer (Appendix 5).

Data were extracted from medical notes in the cancer centres relating to their diagnosis and treatment.

#### **2.6.7 Website recruitment**

In response to national and regional media promotion of the study inviting people to take part in the survey online, a self-selecting sample of women visiting the Breast Cancer Care website accessed the study information sheet (Appendix 3) and completed the same questionnaire online. The inclusion criteria were participants' accurate description of metastatic breast cancer.

#### **2.6.8 The internet and research**

An internet survey such as this had not been used in the UK before, but past experience of another on-line activity by Breast Cancer Care indicated a good response rate was possible.

The internet offers unprecedented opportunities for healthcare professionals, service providers and policy makers to access information on the needs and behaviour of those accessing their services locally, nationally or globally. To date, studies looking at the use of the internet in women with breast cancer are predominantly interested in the women's search for information (Satterlund et al, 2003) and their use of on-line support systems (Fogel et al, 2002, Hoybye et al, 2005, Pereira et al, 2000).

The limitations of internet research need to be acknowledged, although there are some benefits. As the use of the internet in research grows, there are concerns about its validity (Figure 2).

The comparison between face-to-face and on-line recruitment became an additional interesting area to explore and a paper on this has been published (Appendix 6).

**Figure 2: Advantages and disadvantages of on-line surveys**

**Positive features of internet research**

1. Time efficient – 50 website participants recruited in five weeks compared to the same number taking nine months in one cancer centre
2. Cost-effective
3. Easy to manage online
4. Anonymity - outside care setting, so response not influenced by contact with caregivers
5. Access to groups difficult to recruit, particularly those geographically isolated or those with physical disability
6. Access to large numbers of people nationally or internationally
7. Ease of access at any time

**Negative features of internet research**

1. Data protection - the researcher should have knowledge of the collection, storage and protection of the data
2. Ensuring informed consent – no opportunity to ask spontaneous questions of researcher
3. Security – anonymity cannot truly be assured since 'hacker' could reveal identity
4. IT competence and confidence of respondent
5. Volunteer effect
6. Selection bias, i.e. age
7. Potential fictitious responses
8. Limited access to support

All participants from both cancer centres and the website were asked if they would be willing to take part in a longitudinal interview-based study of their experiences by submitting their contact details at the time they returned the survey.

Postcodes were checked to ensure no one had taken part in both the cancer centre survey and the on-line survey, or had submitted more than one response to the on-line survey.

### **2.6.9 Sample size**

The incidence of metastatic breast cancer is currently not collected in the UK making power calculations in populations problematic. It was estimated from data on incidence of breast cancer in each cancer centre that 50-100 new cases of metastatic breast cancer were diagnosed in each centre per year. Therefore it was estimated that around 300 women may be available to be approached from the centres. Assuming a contact, consent and response rate to the survey of 60% we aimed to yield a sample of 180 women from the cancer centres. The number of likely cases from the website was unknown, but the target sample size was set at 100.

### **2.6.10 Statistical analyses**

All data on the quality of life and experience with care measures were entered into SPSS, and the data checked for errors. FACT- B subscale scores were calculated using standard methods (Brady et al, 1997) and summarised according to subgroups of survey participants using mean and standard deviation (SD). Mean scores of the quality of life and experience with care were calculated using subscales between groups using t-tests and one-way analyses of variance for the univariate analyses. In order to take into account associations between clinical and demographic characteristics all factors were entered into multiple linear regression analyses to determine independent associations with the quality of life and experience with care subscales. The chi-squared test was used to test associations between categorical variables, such as patient characteristics with place of recruitment and some elements of the experience with care questionnaire.

For the experience with care data, a positive response was defined for each item in the questionnaire by grouping the higher two categories (agree/strongly agree or very/completely satisfied) out of five options. Then for each patient the number of positive responses was summed within each of the three domains separately (information and advice, personal experience with care and satisfaction with care). The number of positive responses within each of the three experience with care domains was then converted to a percentage out of the number of questions within each domain in order to facilitate comparisons between the domains, since the domains were based on a different number of questions. These percentages therefore represent the proportion of items within an experience with care domain for which an individual participant gives a positive response. Mean (SD) percentages of positive responses for each domain of the experience with care questionnaire were used to summarise across groups of participants.

The categories of the variables were coded to ensure the number in each group was adequate to determine statistical significance. For example, there were 31 sites of metastatic spread identified, but for the analysis this was re-coded into two sites – bone metastases alone and all other sites of spread.

The p-value was adjusted from the initial analysis when  $p=0.05$  was used. To allow the analysis to account for multiple testing, a more conservative cut-off of  $p=0.01$  was taken to indicate statistical significance.

All participants' socio-economic status was measured using the Townsend deprivation score. These were calculated by a Townsend postcode database.



Participants were invited to respond to free text questions in the survey which aimed to elicit more information on the participant's cancer, frequency of interactions with health professionals and the physical, emotional and practical problems they may have and where they turned to help them cope with these. A final question asked the participants to tell us 'anything else you feel may be useful in understanding the needs of women with secondary breast cancer'.

Responses to the free text questions were transcribed verbatim and analysed using the qualitative research software NVivo. Analysis was undertaken by the author.

Categorical indexing was generated from the original themes of the open questions; physical, emotional and practical concerns and sub-categories generated within these identifying the key themes (Creswell et al, 2003).

Listening to what cancer patients have to say about their quality of life alongside a quality of life measurement could be considered to be the 'gold standard' approach (McCabe et al, 2008, Kowalski et al, 2008). Considering the limitations to measuring health-related quality of life in cancer care, in the overall analysis and conclusion of the study a mixed methods approach was used to provide greater meaning and understanding of the multidimensional problems and needs of this population.

## **2.7 Phases 2 and 3**

Qualitative research allows the chronological flow of events to be explored which facilitates a deeper understanding of experience and consequence (Miles and Huberman, 1994). The central theoretical approach to qualitative research applied in the second and third phases was biographical narrative.

### **2.7.1 Longitudinal study design**

The time and length requirements for a study to be described as longitudinal are unclear, but the discernment of change is fundamental to any investigation of this kind (Saldaña, 2003). Using a longitudinal approach of serial interviews a developing relationship may facilitate the discussion of emotive and emotional issues; more likely than in one interview where the interviewer and interviewee are unknown to each other. Serial interviews allow fluctuating physical, emotional and social responses to illness to evolve, revealing the complexity of life with illness and the influence of treatment and healthcare. In addition, it allows the typical and the atypical trajectories to unfold so bearing witness to the highs and lows of living over time with a progressive illness (Murray et al, 2005). Utilising time in an investigation allows change to be observed, but inevitably this will, in part, be a retrospective account of events in time and as such

subject to re-presentation (Riessman, 1993), although this is not exclusively an issue in longitudinal investigations.

There are, however, concerns about longitudinal interviewing. When investigating people with progressive disease, as in this study, participants may become vulnerable towards the end of life and to continue to include those towards the end of life in the longitudinal process may not be in their own interests. Murray et al (2009) also highlight the concern that the emotional burden on the researcher should be considered as relationships and attachments may develop. In addition, longitudinal investigations can generate large volumes of data (in the case of this study around 90 hours of interview data), which can be unwieldy and unmanageable. Good planning is essential in both data collection and analysis. While there appears little uniformity or shape to a body of longitudinal data, a logical, focused approach to analysis is essential to demonstrate its depth and complexity. In a longitudinal study such as this, the temporal experience of living with a progressive illness is central to the analytical approach.

In the approach to interviewing biographical narrative was used in both phase 2 and 3 so this will be discussed before considering the methods applied in each phase.

### **2.7.2 Narratives and illness**

Historically metanarratives shaped our understanding of health, illness and disease from a biomedical, scientific approach. Any reference to the individual experience in illness was through an interpretation of those responsible for their care from their perspective, rather than from the perspective of those with illness (see Pattison, 1977, Kleinman, 1988). However, the uniqueness of experience can be lost within this approach – what Frank (1995:6) refers to as '*narrative surrender*' – and the individual and the medical profession render the narrative a medical condition, so losing the subjective uniqueness of the illness narrative. In explaining the difference Sakalys (2003:231) says that illness narratives are '*stories told by patients about their experience of illness rather than about the disease process and its treatment*'. By passing the responsibility for narration to the individual with illness, a richer, unique story unfolds. Narration or story telling is universal to entertain, inform and, in the case of illness or adversity, to assist in the comprehension, repair and restoration of meaning (Bury, 2001).

Bal (2002:5) considers the form of narrative, saying that it has three distinct layers – text, story and fabula – fabula being '*a series of logically and chronologically related events that are caused by actors*'. Within this framework are events, actors, time and location. These elements constitute the material for a fabula and are organised with each other in a certain way into a story so that they produce the desired effect – for

example to inform, convince or move the reader. The principle of 'ordering' then allows the narrative to form a story. However, a narrative may not always be a temporal flow of events as narratives are rarely bounded and can switch from differing time frames and events to alter their shape and form (Riessman, 1993). Instead the narrative is a way of '*organising episodes, actions and accounts of actions*' (Crossley, 2000:47).

Narrative enquiry is increasingly being used in the study of the individual and collective experience of illness and has gained importance in the study of chronic illness. These developments have seen a shift in social science research from the study of healthcare practices and professional experience to the everyday experience of those living with illness from their perspective (Bury, 1982, Williams, 1983, Charmaz, 1983). This approach brings to the fore the voice of those living lives with illness and articulates the impact of illness, healthcare practices, healthcare professionals and society on that experience (Franks, 1995). While the interest in the individual experience has grown, it has become important to consider not only the individual narrative but the different narratives determined by a similar situation (Hyden, 1997). This point is particularly important when considering a heterogeneous population such as those with breast cancer, as in seeking a collective representation the disparity between different individuals within a population may be lost (Hyden, 1997).

### **2.7.3 Narrative in research**

Lieblich et al (1998:2) define narrative research as '*any study that uses or analyses narrative materials*'. It is increasingly used to understand the experience of cancer (Armstrong-Coster, 2004, Mathieson and Stam, 1995, Copp, 1999). To utilise narrative inquiry as a research approach, and particularly in this study, aims to represent in as true form as possible the 'experience' of those being studied to a wider audience. The overarching aim is to add significant evidence to the understanding of the lives of women with metastatic breast cancer but also to improve that experience for others in the future. However, the key words are 'as true a form' as Riessman (1993:8) reminds us that '*investigators do not have direct access to another's experience*'.

Mattingly and Garro (2000) contend that the concept of lives having a narrative shape has been argued by influential theorists such as Ricoeur, but they also reason that there may be discontinuity between stories told and lives lived, as much may be lost in trying to understand one in terms of the other. In using narratives as a means to collect data in research, the latter point is important as the individual story is always a retrospective interpretation of '*events, actors, time and location*', and as such there is a gap between the experience and the communication of it. In re-presenting the elements which make up the narrative account, using different language or intonation, or

favouring one aspect over another, the events, time and location may alter with the desire to give a better account. So the story told may be altogether different to the experience of it.

In undertaking narrative research I, as the researcher, bring with me my communication skills, actions, feelings and impressions which are all subjective and personal. As an experienced palliative care nurse I was confident that I would be able to 'stay with' the women when they talked about difficult, emotive thoughts and experiences. However, my interpretation of events and experiences all becomes data. My awareness and acknowledgement of personal biases, values and reflexivity as a researcher must be considered. In addition, I too become an 'actor' in the women's narrative accounts; my facial expression, tone and body language could influence the story told, which parts are omitted and which emphasised. Mason (1996) reminds us that as researchers we should practice critical self-scrutiny, being aware of our actions and their role in the research process. A reflexive researcher needs to acknowledge their personal biography and how it shapes the study (Creswell, 2003).

In this study the aim was that the women's narratives became a collective experience so that the personal narrative could add significant power to the wider study findings, and add significantly to the understanding of the experience of living with progressive breast cancer.

#### **2.7.4 Narrative enquiry approach**

Narrative inquiry in this study has the narrative as the central means of data collection to investigate the experience of living with metastatic breast cancer. This is opposed to other narrative research which investigates the narrative as the object of the research. This approach relies on the spoken (or written) word of individuals and in this study the narration tells of the experience of living with progressive breast cancer. Narrative inquiry is different from other forms of qualitative research in that the participants have more control over the direction and flow of the story told. The researcher does not influence the direction or content of the narrative, for this renders it a semi-structured interview, but follows the participant's narrative, only seeking clarification if needed without influencing the story told. Holloway and Freshwater (2007) say that a small number of questions may be asked but the researcher must allow the centre of flow to be controlled by the participant so their truth is told. The researcher must suppress the desire to speak so that the participant produces as spontaneous narrative as is possible.

It is important here to consider narrative representation. Is the story told a true account of experience or a crafted account of events which aims to piece together a fragile identity in order to re-present a cohesive, socially acceptable whole? The search for personal meaning may influence the telling of experience in the research interview. An advantage of the longitudinal approach may be that a projected image of a cohesive self is easier to maintain once but less so over time as the experience of progressive illness challenges the self in the face of deteriorating health and the social consequences of this deterioration.

In reality the interpretation of truth in representation in biographical narratives is a thorny problem (Riessman, 1993), and the layers of stories within stories make this a complex issue. However, Ewing (1990) argues that when experiencing a temporal flow of experience individuals constantly shift self-representations in response to internal and external stimuli. Rather than this being a methodological concern, it could be considered as part of the richness of the narrative in how individuals adapt and interpret their lives.

As part of the interviews for this study truth telling and representations of self were commonly discussed, never in the first interview but commonly in the second or third. As the relationship between interviewee and interviewer developed, the layers of representation began to fall away and, it is hoped, the narratives represent a truer form of the experience of living over time with progressive breast cancer. Although this cannot be scientifically verified, the developing relationship appeared to herald a more intimate and deeper exploration of the interviewee's experience of living with progressive disease and the experience of being interviewed about this.

### **2.7.5 Developing qualitative research questions**

In formulating my research questions for the qualitative phase of the study, I needed to first reflect on the evidence to date in order to establish what was known about the experience of living with metastatic breast cancer, the methodological approaches applied to this population and to identify gaps in both (the literature review). The evidence identified gaps in sociological theory applied to this population, specifically the effect of social roles and social order on identity in progressive illness. I wanted the questions and qualitative design to consider specifically the temporal experience of living with progressive breast cancer and to map the biomedical trajectory alongside the storyline. The research questions which apply to the second phase of this study are:

- What are the social consequences of living over time with progressive breast cancer and how does this affect the self and identity?

- What does the illness trajectory of metastatic breast cancer look like and by mapping this, what does it add to the understanding of the experience of living with progressive breast cancer?
- What measures could be taken to improve the wellbeing and experience of people with metastatic breast cancer?

### **2.7.6 Sample selection**

All those who took part in phase 1 were asked if they would like to take part in interviews. From those expressing interest in taking part, a sub-sample of 30 women from the two cancer centres and website were invited to participate in the longitudinal interview study. To do this they simply ticked a box on the consent form and gave their contact details. The sample aimed to select the women purposefully to ensure that women with visceral and bone disease as well as aggressive and more indolent types of metastatic disease were represented, and that the sample was sufficiently representative of age and, where possible, ethnic background. Women were selected using a sampling matrix in consecutive order, ensuring that as far as possible each of the cells/categories was filled. However, the constraints of time due to the funding of the study meant it was not possible to be as selective as intended (Table 3).

In phase 3, illness trajectories were mapped from a sub-sample of ten women selected from the original 30.

**Table 3: Purposeful sampling matrix for interview study**

Southampton 12						Breast Cancer Care website 11						Portsmouth 7					
Age						Age						Age					
<30-39	40-49	50-59	60-69	>70		<30-39	40-49	50-59	60-69	>70		<30-39	40-49	50-59	60-69	>70	
1	5	2	2	2		2	2	3	3	1		0	1	2	3	1	
Time since secondary diagnosis (yrs)						Time since secondary diagnosis (yrs)						Time since secondary diagnosis (yrs)					
< 1	1-2	2-5	5-10	>10		< 1	1-2	2-5	5-10	>10		< 1	1-2	2-5	5-10	>10	
3	5	3	0	1		5	4	2	0	0		1	2	3	0	0	
Site of spread						Site of spread						Site of spread					
SCLN	Bone	Lung	Liver	Brain	Multi	SCLN	Bone	Lung	Liver	Brain	Multi	SCLN	Bone	Lung	Liver	Brain	Multi
1	4	0	0	1	6	1	5	2	0	0	3	2	2	0	0	0	3
Marital status						Marital status						Marital status					
In relationship			No relationship			In relationship			No relationship			In relationship			No relationship		
10			2			8			3			7			0		
Ethnic origin						Ethnic origin						Ethnic origin					
White British			Other			White British			Other			White British			Other		
12			0			9			2			7			0		

### 2.7.7 Data collection – interviewing

Narrative interviews were selected as the qualitative research method for this phase of the study. Flick (1998) says that in some ways the objects under study can determine the methodological approach to take. If the design methods are so open, they do justice to the subjects being studied in their entirety in their everyday lives. Certainly, I wanted to capture the complexity of women's lives, but more than that I wanted them to share their life stories with me, constructing the personal and social experience of living with metastatic breast cancer. In attempting to do this I wanted them to share their inner thoughts and feelings in an open way, not determined by me or my direction as an interviewer. In using a narrative approach I aimed to get as close as possible to the everyday existence of the study participants over time. In narrative interviewing, the central object of the investigation is the story (Riessman, 1993).

Narrative inquiry differs from conventional interviewing in that variation in responses is as important as consistency and diversity in the narrative is sought through a less formal, more interactionalist approach where interviewers play a more active part in the interview rather than just asking predetermined questions (Potter and Wetherell, 1987).

At the first interview the opening question was *'tell me about yourself'*. If the woman did not then automatically go into her breast cancer experience, there was a prompt question, *'tell me about your cancer'*. Subsequent interviews began with an open question, *'tell me what has happened since we last spoke'*. As the interview progressed I aimed to follow rather than lead to explore what emerged from the interview using open statements such as *'tell me what that means to you'* or *'I wonder how that affected you at that time.'* If the need for emotional support was raised, for example, a question such as *'if you could have some support, what would that look like?'* would be used. If I needed clarification on a point I would say *'tell me if I have interpreted this correctly'*. With an awareness of the aims and objectives of the study, and the findings from phase 1, if areas had not been covered, towards the end of the interview I would ask open questions such as *'tell me about any physical problems you may have experienced'*.

Participants from the cancer centres were interviewed in their own homes while participants from the on-line survey were interviewed over the telephone. The website participants were interviewed over the telephone primarily for convenience as they lived all over the UK, but also my security may have been at risk from going into the home of someone unknown to any institution. This approach conforms to the University's Lone Worker Policy.



### **2.7.8 Data collection – records and documentation**

All interviews were tape recorded and transcribed verbatim; these were the central record of analysis for this phase of the study. However, other documentation informed the third phase of the study. Demographic data were collected on all participants and their biomedical trajectory was documented in detail from medical and nursing notes in order to collect data on dates and details of progressive disease, treatment regimens and the different services involved in their care. Metastories were constructed for each person from the interview transcripts to give their whole story form and field notes documented my reflections after each interview and where appropriate, when listening to each recording or reading each transcript for the first time. All these records and documents were used in the analysis of the interviews.

Having spent considerable time in the outpatient setting screening medical notes and recruiting patients and as a researcher and observer in a clinical area and in participants' homes, I kept notes of scenarios and reflections to use when writing up my research, in particular when considering my reflexivity as a researcher.

These notes have already proved valuable as my thoughts and feelings evolved over the time I was conducting the research; in particular my early field notes document my struggle from nurse to researcher.

### **2.7.9 Familiarisation with the data**

All interviews were transcribed verbatim and entered in the qualitative database NVivo. In using an audio recording, as in this study, the narrative is fixed in time and has with it the detail of the plot, the tone of voice, hesitations, emphases, unfinished sentences and emotion. There are differing schools of thought about the transcribing phase; some edit out the interviewee, others use the conversation and non-verbal cues (pausing etc) as part of the analysis. The transcripts in their entirety have been used, each one checked for accuracy while listening to the tape recording.

### **2.7.10 Narrative analysis**

Lieblich et al (1998) states that narrative research is suitable for researchers who are comfortable with ambiguity and who are able to adapt and change their interpretive conclusions as they immerse themselves in the narrative data. The researcher enters into an interactive process with the data and becomes familiar with the narrator's voice and meaning. Lieblich et al (1998) warn that this does not give the researcher freedom to speculate but to use integrity and skill, paying attention to the narrative and testing their intuition against the narrative data.

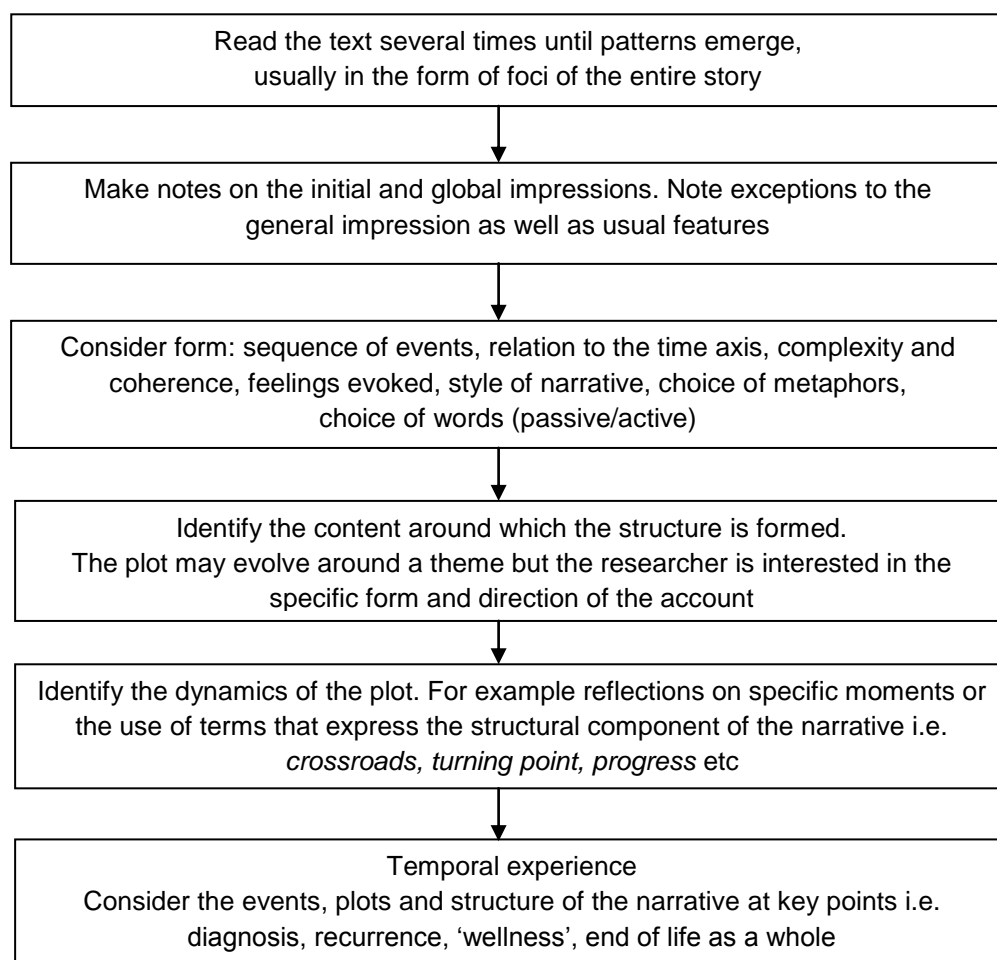
The individual interview transcripts were read and re-read several times then the three interview transcripts over one calendar year were formed into a metanarrative. This allowed the temporal dimension to emerge and give the narrative some continuity and form, so allowing the year to be seen as a whole in addition to the individual moments in time.

In the analysis of the narrative data, a framework was developed using Lieblich et al's (1998) holistic-form and holistic-content analysis approach in order to use the interviews in their totality to determine the plot and story over time, while analysing the content (Figure 3).

The whole body of data amounted to around 90 hours of narrative and the aim was to use the narrative in its totality to get as close as possible to the everyday lives of women living over time with progressive breast cancer. Lieblich et al (1998) describe four modes in narrative analysis: holistic, content, categorical and form. In using the holistic-content mode of analysis, the complete life story was used but the analysis focused on the content it presented. In reading the interview transcripts several times, and in developing the metanarrative, the plot, patterns and foci of the narrative story began to emerge. Notes were made on the global impressions of the narratives then major themes identified.

By using a holistic analysis of form approach the focus was on the style of the narrative and considered how the narrative is constructed to form a story. Lieblich et al (1998:89) describe this process as developing a 'prototype life course' when the plot axis of each metanarrative is considered. From here, the themes and plots are organised around the structure. Using this adapted framework to organise the data, the individual and global story began to emerge, allowing a more in-depth inquiry with a focus on the minutiae as well as the broader patterns and the typical and atypical within the women's narratives.

**Figure 3: A holistic content/form framework for analysis**



*Adapted from Lieblich et al, 1998*

### 2.7.11 Validation

The body of evidence produced from analysis aims to describe a coherent explanation of events and occurrences. However, as well as focusing on the collective concepts emerging from narrative analysis, exceptions were considered and informed the analysis and understanding of the phenomenon. Together the expected and exceptional create a richer so more valid account of the individual experience within a collective explanation. When examining narrative data to derive understandings or consistency in data, it is important not only for the researcher to determine this, but for it to be validated by those being studied.

Potter and Wetherell (1987) describe validation as 'fruitfulness'. This refers to the analytical approach and its ability to interpret a phenomenon and so add to its understanding and potential resolution.

In considering the assessment of validity and rigour in qualitative research, Bryman (2012) describes four criteria of trustworthiness: credibility, transferability, dependability and confirmability.

By exploring women's experience and considering the various viewpoints of different women, the credibility of the data is reinforced. There may be several accounts of women's experience of living with progressive breast cancer so the analysis and reporting of the findings should have some measure of validation. In paraphrasing, using sentences such as *'tell me if I have interpreted this correctly'*, the role of events, actors, time and location can be corroborated by the narrator. Summarising events described throughout the interviews aimed to validate the narratives as they unfolded. In addition, prior to each of the second and third interviews, I gave each woman a synopsis of the previous interview to build a picture of the story over the year and enquired if that was consistent with her experience. The triangulation of data sources in phase 3 added to the process of validation within that phase. As the women in this study were all living with progressive disease, it was not appropriate to return the analysis and findings to them. However, the ability to do this would have added to the validation of the findings.

When considering the transferability of the study findings, by exploring in detail women's everyday lives it is hoped that the depth and richness of the data obtained is more likely to be representative of the wider population of women living with metastatic breast cancer. Applying a longitudinal approach added to the depth of understanding so that the findings are transferable to the wider population. Applying a mixed methods approach reinforces this as the findings can be supported or challenged by the different research methods.

To establish the dependability of the study, an audit process is recommended. In this study, the timescale and significant amount of data made this process problematic. A level of auditing did take place, with peer review of two interview tape recordings and transcripts considering the interviewing technique and a level of analysis, as well as the supervision process.

Lastly, confirmability aims to establish whether the researcher has influenced the study. As stated on page 57, as the researcher self-scrutiny was essential to ensure I influenced the interviews as little as possible. By a research peer listening to two tape recorded interviews, feedback on my interviewing technique allowed me to hone and develop my interviewing skills, so conforming to the narrative inquiry approach.

To ensure the authenticity of the research the various viewpoints of participants were considered – the common and the less common as well as the typical and atypical – so that the findings represent a wider population of those living with progressive disease. As Silverman (2000) states, the research is flawed if researchers only report one side of a story and do not consider the contrary cases. The overall outcome of research is to inform others and in this study, to influence change in policy and care provision. Therefore authenticity is essential so that action can be taken based on sound evidence which allows a better understanding of the experience of women with metastatic breast cancer and so influences change in policy and care provision.

### **2.7.12 Transition from nurse to researcher**

As an experienced palliative care nurse yet novice researcher the conflict between these two roles became apparent in the early stages of data collection, both as an observer in the clinical setting and when interviewing women. My reflective diary described my internal struggle not to intervene when healthcare professionals did not see the distress of a woman standing in the middle of the outpatient department where she had just been told she had progressive disease. Another entry in my reflective diary describes my struggle to focus on the women's narratives during the interviews rather than their uncontrolled symptoms. As time went on I began to acknowledge both angles; for example, the frustration of seeing someone with no support and uncontrolled symptoms as well as the recognition that this brought rich data.

Colbourne's personal account of her struggle with the nurse–nurse researcher conflict encountered when conducting qualitative research (Colbourne and Sque, 2004) asked difficult questions. As a nurse, does the difficulty in letting go of that role depend on the individual's need for gratification in their role? That gratification can be instant – a symptom controlled or a fear verbalised. The same gratification in the research role is not instant – rather it can take years until the production of a thesis and publication.

Colbourne felt a loss of a valued role and hard earned skills. Her experience resonated with mine. I valued my experience and skills as a nurse and felt this role was eroded by leaving it behind. In addition, mutual support is instant as a member of a clinical team with colleagues who can listen to stories of emotionally difficult clinical situations, whereas the life of the researcher can be isolated, particularly if, like me, they are not part of a team but undertaking emotionally challenging research alone. Colbourne feels that acknowledging the conflict is the most important factor in resolving it. The skills of the nurse can be transferable to the role of researcher and, she argues, can be used to the researcher's advantage. In this study, knowing that the research findings would ultimately improve the care of women with metastatic disease eased the transition from nurse to researcher and was a constant reminder throughout.

While narrative was the central means of data collection in phase 2 and 3 of the study the approach to each differed so each will be described separately.

## 2.8 Phase 2 – the social consequences of living over time with progressive breast cancer

In order to address the research question considering the social consequences of metastatic breast cancer, narrative enquiry was used. This allowed an exploration of the relationship between the self with progressive cancer, the diseased body and how this influenced social interaction between the participants and those within their social groups.

Constructionists argue that actions are not limited by what is right or wrong, but are influenced through social interaction and discussion and that nothing exists in the world of people or objects until there are relationships (Gergen, 2009). As we communicate with each other we construct our daily lives and the world we live in. Life events mean different things to different individuals; one person's problem is another's challenge, for example chronic illness may be seen as either chaos, a quest or restitution (Frank, 1995).

Socially determined behaviour has evolved over time and we conduct ourselves in accordance to social rules by following a set of conventions about what is acceptable behaviour and what is not. In addition, by critical reflexivity we listen to alternate views of others and the argument for the multiple standpoints which influence our reality and so our socially constructed worlds. At times the majority influence the minority and social rules are applied. For example, when meeting or speaking to someone with incurable cancer socially constructed behaviour is to treat them kindly (even though the individual may wish to recoil). Some people who are unable to abide by socially constructed rules may choose to avoid this interaction by avoiding the individual with cancer. To deviate from the social order risks isolation. Illness has been considered 'deviant' behaviour in that those with it may not be able to fulfil their social obligations, thus disturbing the social order (Parsons, 1951).

Participants in this study used the word 'normal' often: *'I feel normal'*, *'I just want to be back to normal'*, *'I just want a normal life'* and *'I want to be treated normally'*.

Armstrong-Coster (2004) found that individuals with advanced cancer strived to contribute to a meaningful life within family and the wider social network, and in 'normalising' illness the social roles remained as intact as was possible even if the self-identity was stage managed. This social co-construction of identity between the

individual with illness and members of their social group can determine how each person in a social group behaves due to the influences on that group which become reality.

Within the post-modern context identity and self are independent components (Giddens, 1991). The self is described by Mead (1934:135) as:

*'...something which has a development; it is not initially there, at birth, but arises in the process of social experience and activity, that is, develops in the given individual as a result of his relations to that process as a whole and to other individuals within that process.'*

Identity is defined by embodiment, continuity and memory (Little et al 2002). In reality self and identity are inextricably linked by a constant negotiation of presentations of one's inner reality to an external social reality (Lawton, 2000). When faced with extreme experiences *'no aspect of identity is untouched'* (Little et al, 2002:176).

Berger and Luckman (1966) argue that society must develop procedures of reality maintenance to ensure there is equilibrium between objective and subjective reality. They distinguish between two general types of reality maintenance – routine and crisis maintenance. Routine maintenance is designed to maintain internalised reality in everyday life and crisis maintenance in the crisis situation. Firstly, the reality of everyday life is represented by daily routine and the reaffirmation of the individual's interaction with others and maintained by social processes which *'reflect the basic fact that subjective reality must stand in a relationship with an objective reality that is socially defined'* (Berger and Luckman, 1966:169). In addition, Berger and Luckman (1966) caution that it would be a mistake to assume that significant others serve only to maintain subjective reality; they are important in the ongoing element of reality we refer to as identity. So identity is crafted and driven by interactions with others:

*'To retain confidence that he is indeed who he thinks he is, the individual requires not only the implicit confirmation of this identity that even causal everyday contacts will supply, but the explicit and emotionally charged confirmation that his significant others bestow on him.'* Berger and Luckman (1966:170)

In crisis, reality confirmations must be more explicit and intensive. Berger and Luckman (1966) states that while the individual may improvise reality by maintaining routines in crisis, the wider social network uses procedures specific to reducing the risk of a disintegration of reality. While they do not consider that these may be adaptive or maladaptive realities, in the reality of this study both were used at times of disease

progression or crises. The biographical disruption (Bury, 1982) of cancer means the individual will almost certainly question their identity and their place in the world and reality. In moments of crisis in their 'taken for granted' world individuals are forced out of reality-maintaining routine and both the individual and their significant others have to develop contingencies to preserve the individual sense of self-identity to ensure they remain within their social worlds (Becker, 1997).

Social influence on identity in cancer has predominantly measured the adjustment and adaptation to diagnosis and treatment, using validated measures and statistical variance. Using qualitative research methods, and in particular the cancer narrative, as the central source of data allows a deeper investigation into the everyday lives of people with progressive cancer (Armstrong-Coster, 2004). Mathieson and Stam (1995) argue that a narrative approach to the cancer experience does not superimpose an inflexible model of analysis on the individual experience and reject the notion that an individual is a self-contained entity who is unable to represent a collective event (cancer). Instead, individuals articulate their own narratives and the threat that illness imposes on their identity and as such the individual contributes to the collective understanding of the impact of illness on identity.

One of the aims of this study is to inform policy makers and service providers to improve the experience of people with metastatic breast cancer. By using a quantitative approach it was hoped that those more familiar and comfortable with a positivist approach to research would be more inclined to respond to the findings of the survey, but in using a qualitative narrative approach, the study sought to understand the everyday lives of participants as they lived over time with progressive breast cancer.

This phase of the study considers the social consequences of living with metastatic breast cancer. In interviewing participants over time, the aim was to explore the everyday life of women as they navigated their lives with progressive breast cancer and in doing so, how they were able to navigate the social consequences of living with and around progressive breast cancer.

## 2.9 Phase 3 – mapping the illness trajectory of metastatic breast cancer

As previously stated, to map and understand the illness trajectory of metastatic breast cancer a sub-sample of ten women was selected from the original 30 women who were recruited and interviewed in phase 2. The ten were selected to ensure they represented different experiences of progressive breast cancer, such as age and site of metastatic spread as well as those with indolent disease and aggressive disease and



different experiences of treatment. In addition, the ten women selected had the more complete documentation, giving as detailed a picture as possible of their lives over time. Triangulation of women's narrative from interviews and documentation collected from their medical notes (including oncologist annotations of appointments, nursing notes, correspondence between healthcare professionals, investigation results and researcher field notes) aimed to map in detail the illness trajectory of metastatic breast. Over one calendar year eight women were interviewed three times; two women were interviewed twice but died before the final interview.

Each woman's illness trajectory was mapped in detail in terms of physical, psychological and social events. As women appear to function well despite progressive disease, the study aimed to measure physical functioning alongside the events which punctuated their lives. Scales used to measure physical functioning are designed as a biomedical tool to assess a patient's performance state for treatment and should be done face to face in a clinical setting. In the absence of any other means to map the physical performance of the women in this study the Karnofsky Performance Scale was used to estimate physical functioning (y axis) (Karnofsky and Burchenal, 1949) alongside the mapped events described from the individual narratives and documentation (x axis).

Other work on illness trajectories (Pattison, 1977, Murray et al, 2005, Copp, 1999) did not assess physical functioning, but were more influenced by the phasing of the illness trajectory. The Karnofsky scale is used primarily to compare effectiveness of different therapies and to assess the prognosis in individual patients and the assessment is done face to face, whereas the assessment of physical functioning in this study was done from medical and nursing documentation and the individual narrative. This scale was chosen because it is a ten-point scale and, as such, is able to show more subtle changes in functional ability in comparison with others such as the World Health Organisation scale which only has three levels of functioning. The scale is from 0-10: the lower the Karnofsky score, the worse the performance status and prognosis (Figure 4). The Karnofsky scale has been shown to have good reliability and validity in cancer patients (Schag et al, 1984).

The illness trajectories are not a complete picture of the lives of the ten women: there may be events and experiences the women did not disclose because they were too personal or they were so accustomed to living with them they did not mention them, as well as others which spanned the whole trajectory, making them problematic to depict in a graphical representation of someone's life. But they do aim to illustrate the complexity and unpredictability of the women's lives. In addition, this chapter aims to

illustrate the temporal experience of living with progressive breast cancer throughout individuals' illness trajectories.

**Figure 4: Karnofsky Performance Scale Index**

Value	Level of functional capacity
10	Normal, no complaints, no evidence of disease
9	Able to carry on normal activity, minor signs or symptoms of disease
8	Normal activity with effort, some signs or symptoms of disease
7	Cares for self, unable to carry on normal activity or to do active work
6	Requires considerable assistance, but is able to care for most needs
5	Requires considerable assistance and frequent medical care
4	Disabled, requires special care and assistance
3	Severely disabled, hospitalisation is indicated although death is not imminent
2	Hospitalisation is necessary, very sick, active supportive treatment
1	Moribund, fatal processes progressing rapidly
0	Dead

*Karnofsky and Burchenal (1949)*

To give the analysis of the illness trajectories structure, the revised Corbin and Strauss Chronic Illness Trajectory Framework (1998) was applied to the ten women's illness trajectories. This conceptual model was developed from the premise that chronic disease has an illness course which is varied and changes over time. By defining an illness trajectory, it can be shaped and managed to improve the illness experience (Corbin and Strauss, 1992). This framework has been applied in many different illness contexts, from diabetes mellitus (Walker, 1992) to HIV/AIDS (Nokes, 1992). In considering the framework in cancer care, Scott Dorsett (1992) argues that a course of recovery is a more appropriate trajectory when considering cancer as a chronic illness. She argues that the application of this framework in the cancer trajectory renders it a biomedical model, determined and influenced by medical management with the overall aim of restoring health, which she argues are short term aims not considering the needs and preparation for life after cancer. Scott Dorsett (1992) contends that the needs of those in remission with cancer are not within the Chronic Illness Trajectory Framework. Similarly Smeltzer (1992) suggests the Chronic Illness Trajectory Framework does not address the needs of those who are symptom free or whose disease is progressing slowly over years. Corbin (1992) answers the criticism as a

misunderstanding of the framework and argues that the very use of the framework would determine the appropriate management to ensure there are times when the illness plateaus, and that not all chronic disease trajectories (including cancer) have a downward trend. While the argument over the application of the framework in cancer is challenged, in this instance it was used to give structure to the metastatic breast cancer trajectory. Corbin's (1992) defence and explanation of using the framework to determine how to manage an illness trajectory and anticipate problems and needs reassured that this would be an appropriate framework to use in the absence of any other. Those previously used in cancer predominantly apply to the dying process and are influenced by phasing of illness rather than trajectory, which was the aim of this study.

A mixed method approach has been used in the first and third phase of this study. Within these phases the quantitative and qualitative data have at times been presented both in tandem and sequentially: the aim has been to integrate both approaches in the analysis, presentation of findings and discussion.

## 2.10 Ethical issues

The Medical Research Council guidance notes for good clinical practice in research (2005) aim to provide assurance that the rights, safety and wellbeing of research participants are protected. Within the guidance, those with incurable illness are considered to be a vulnerable group and as such these ethical principles are considered particularly important. It is argued that to involve those with advanced cancer who commonly experience fatigue and other debilitating symptoms in research may be unethical as they are unlikely to benefit and their time and energy may be better spent elsewhere. In addition, by involving vulnerable people in research about living with their illness, they may experience distress by talking about living with a life-limiting illness (Addington Hall, 2002). It could also be argued, however, that those with advanced disease may have an altruistic approach, wishing to use their experience to assist in the development of services to improve the experience of those diagnosed after them. However, their vulnerability needs to be considered. Each participant was given 24 hours to consider participation prior to consent and participation was assessed at each meeting with the reminder that they could withdraw at any time.

In this study an additional ethical concern was using the internet as a means of recruitment and data collection. Protecting the privacy, anonymity and confidentiality of participants is challenged by the use of an on-line survey. All individuals' data were kept in an encrypted file and contact details and data were stored separately, however, while participant details and data collected can be stored in secure, encrypted files, this

is not 100% safety proof since a 'hacker' could reveal the identity of participants. Knowledge of on-line data management is important to ensure all steps are taken in protection of participants' on-line data. Those who backed up the IT systems and had daily access had to sign a confidentiality agreement

There is concern about how informed participants are when taking part in an on-line survey since participant/researcher interaction is limited. In addition, on-line participants can complete the survey at any time of the day or night. Sleeplessness is known to be a problem for those with metastatic breast cancer (Koopman et al, 2002), consequently participants may respond to the survey at night when access to support is limited. Access to support services was documented on the patient information although services available outside office hours are limited.

To maintain confidentiality, all participants have been given pseudonyms and in places small details of stories which would have identified women have been changed, protecting their anonymity but without substantially altering the story.

## 2.11 Summary

This chapter states the study aim, objectives and research questions and describes the research approach which aimed to address them.

In seeking to explore the experience of living with metastatic breast cancer this study applied three phases. The first was a cross-sectional survey of quality of life and experience of care in those with metastatic breast cancer which aimed to determine the prevalence of problems and concerns participants had using validated statistical methods. The survey also used open text questions to identify participants' problems and needs in respect of their physical, emotional and social concerns and where they sought support.

Central to the data collection, management and analysis of phases 2 and 3 was a narrative inquiry approach, to explore in detail the experience of living with metastatic breast cancer over time. The second phase applied qualitative methods and the third phase of the study applied both qualitative and quantitative methods. The second phase applied a narrative approach to explore the social consequences of living with progressive breast cancer on identity and the third phase mapped the illness trajectory of ten participants using the Corbin and Strauss Chronic Illness Trajectory Framework (1998). The first phase aimed to set the scene for the wider study by identifying the problems and needs of those with progressive breast cancer by measuring women's quality of life and exploring the experience of care.



## **Chapter 3. Measuring quality of life and experience of care in women with metastatic breast cancer: a cross-sectional survey**

This, the first phase of the study, was a cross-sectional survey. It set out to measure quality of life and experience of care in women with metastatic breast cancer and to identify what physical, emotional, social and practical problems and concerns those with metastatic breast cancer had and where they sought support for these. The aim of the survey was to set the scene of the experience of women with metastatic breast cancer within the current healthcare context of advances in medical management in which women are living longer and more complex lives. This phase aimed to answer the research question:

What is the prevalence of problems and needs of people with metastatic breast cancer and to what extent does current service provision meet their needs?

### **3.1 Outcome measures**

Quantitative analysis of the survey applied the validated tool FACT-B measuring quality of life (Brady et al, 1997) and a patient experience survey to measure women's experience of care (Moore et al, 2002).

FACT-B is a multidimensional instrument with a total of 37 items covering five domains; physical wellbeing, social wellbeing, emotional wellbeing, functional wellbeing, breast cancer specific score and total score. Participants are asked to rate how true each one is for the period of the last seven days on a Likert scale. Response scales range from 0 (not at all) to 4 (very much). The higher the score the better the quality of life.

The experience of care scale aimed to determine the satisfaction women felt with the care received from the healthcare services. This measure incorporated three domains; information and advice, personal experience of care, which considered the quality of communication with healthcare professionals and whether the participants felt valued and heard, and satisfaction with care, which considered the thoroughness of care and whether the participants felt their needs and concerns were addressed. Each individual item was rated on a five-point Likert scale, the higher the score the greater the satisfaction. Overall ratings of support were measured on a ten point visual analogue scale (VAS) (0=dreadful to 10=excellent). The Townsend deprivation index quintiles were calculated from the total sample with available postcode data.

Using the framework previously described on page 56, the qualitative analysis of open text responses identified the principal themes within the free text responses; information and support, social support and employment and financial concerns. Central to all the themes was the underlying concept of self-management. By seeking supported self-management women appeared to seek ways to exert control over their lives. The chapter concludes with a summary.

## 3.2 Study population

All women with metastatic breast cancer attending for follow up or treatment in two cancer centres were approached to take part in the survey. Simultaneously, women with metastatic breast cancer responding to a media campaign asking women to take part completed the survey online through the Breast Cancer Care website.

### 3.2.1 Sample size

The number of women with metastatic breast cancer in the UK is unknown making sample calculations problematic. From the number of women estimated to attend each cancer centre the survey sample was calculated assuming a response rate of 60% (n=180). The website aimed to recruit 100 as numbers accessing the website were unknown. In total 235 women were recruited to the study from the two cancer centres (n=110) and Breast Cancer Care's website (n=125) (Table 4).

**Table 4: Recruitment of questionnaire participants**

Recruitment site	Number approached	Number recruited	Number completing survey
Cancer centres	188	136	110
Website	221*	135	125

*\*Number of women who looked at online survey*

### 3.2.2 Cancer centre recruitment

All those with a confirmed diagnosis of metastatic breast cancer in two cancer centres were approached to take part, a total of 188 women (the recruitment process is described fully on page 52). One hundred and thirty six consented to take part (a response rate of 72.3% of the 188 identified with metastatic disease) and 110 actually completed and returned the questionnaire (a response rate of 80.8%). Two women were not approached as their oncologist deemed them to be too ill (1) or with poor cognitive ability (1). When attending clinic to receive test results, making decisions about treatment or presenting due to new symptoms, women were identified and their diagnosis noted at the time but they were approached at a later appointment. The

timing for this was determined from discussions with the oncologist and other personnel such as the research nurses. The aim of this approach was to respect women's dignity at a difficult and anxious time and to maximise recruitment.

It has been suggested that those with metastatic disease may be more vulnerable and may feel coerced into taking part in research as they are dependent on those responsible for their care (Addington Hall, 2002). Their response may not be a true reflection of their experience but a self-representation they want their healthcare professionals to see. To lessen this potential problem, the study was presented as being conducted by Breast Cancer Care with the consent of the NHS Trust, with me as the researcher from an external organisation.

Fifty two women who were approached declined to take part. While some did not volunteer a reason for choosing not to participate, those who did gave reasons for their decline as follows; they had nothing to say, surveys were 'not their sort of thing', they were too distracted with their disease or making decisions about treatment, finding the questions too distressing. No data were collected on the characteristics of those who declined to take part so it is not possible to compare study participants to those who did take part in the survey.

A number of women who consented to take part did not go on to complete the survey and/or return it (26). It is not possible to know why they chose not to do so, but for those who did report their reasons, these were; finding the questions distressing, feeling too unwell and disease progression. For some it appeared that the magnitude of living with progressive breast cancer dominated their lives and they simply forgot to complete the questionnaire. Due to the sensitive and changeable nature of their illness, there was no formal reminder, although on occasion when I was attending clinic my presence reminded some women and they did then complete the questionnaire.

### **3.2.3 On-line recruitment**

Women responding to a media campaign about the study were asked to complete the survey online through the Breast Cancer Care website. The online survey was the exact replica of the survey given to cancer centre participants. It was one of the first of a kind in surveying those with progressive cancer via the internet.

A total of 221 women looked at the on-line survey; 135 completed it and 125 correctly described themselves as having metastatic breast cancer. Ten women thought they had metastatic breast cancer but described a second primary or loco regional recurrence, so were excluded. It was not possible to deduce the reasons for not taking part, but some of those looking and not taking part may have been interested in on-line



surveys rather than in completing the survey. Some women admitted they looked more than once before completing the questionnaire which may account for some of the numbers looking at but not completing the survey.

### 3.3 Population characteristics

The age range for women in the cancer centres was 25-84 and the mean age was 58. The design of the on-line survey did not allow the women to give their exact age as it was collected in ranges, so the overall mean age cannot be calculated. Forty two percent of website participants were aged between 45-55 compared with 27% from the cancer centres, whereas 35% of those recruited from the cancer centres were over 65 in comparison to 2% of website participants, so website participants were significantly younger ( $<0.001$ ). The age of the website participants is in stark contrast to the breast cancer population in the UK, as most cases (81%) of breast cancer occur in women aged over 50 years, indicating that the on-line population is not representative of the UK population. Nearly half (48%) of cases of breast cancer are diagnosed in the 50-69 age group (Cancer Research UK, 2011). Ninety five percent of participants were of white ethnic origin. The majority of women were in a relationship (172/73.2%) and had children (173/73.6%). The deprivation scores for cancer centre 2 were higher than cancer centre 1 and the website although not statistically significant. The deprivation score was unknown in 40 (17 %) of participants (Table 5).

In the UK, the median survival from the time of diagnosis of metastatic breast cancer is between 2-3 years although there is a wide variation in survival of the breast cancer population (Johnston and Swanton, 2006). In this study, the median time from diagnosis of metastatic disease was two years (range from 1 week to 15 years) with 10 (4.2%) women living over five years (Table 5).

**Table 5: Demographic and clinical characteristics of women responding to survey according to place of recruitment (cancer centres and website)**

Characteristic	Centre 1 N= 72 (%)	Centre 2 N= 38 (%)	Website N=125 (%)	Total N=235 (%)	$\chi^2$ test for comparison of place of recruitment p-value
<b>Age</b>					<0.001 <sup>a*</sup>
25-44	9 (12.5)	3 (7.9)	43 (34.4)	55 (23.4)	
45-54	21 (29.2)	9 (23.7)	52 (41.6)	82 (34.9)	
55-64	16 (22.2)	13 (34.2)	26 (20.8)	55 (23.4)	
≥65	26 (36.1)	13 (34.2)	3 (2.4)	42 (17.9)	
Unknown	0	0	1 (0.8)	1 (0.4)	
<b>Marital status</b>					0.24
In relationship	49 (68.1)	26 (68.4)	97 (77.6)	172 (73.2)	
Not in relationship	23 (31.9)	8 (21.1)	26 (20.8)	57 (24.3)	
Unknown	0	4 (10.5)	2 (1.6)	6 (2.6)	
<b>Children</b>					0.74
None	12 (16.7)	8 (21.1)	25 (20.0)	45 (19.1)	
≥1	55 (76.4)	25 (65.8)	93 (74.4)	173 (73.6)	
Unknown	5 (6.9)	5 (13.2)	7 (5.6)	17 (7.2)	
<b>Townsend deprivation index quintile<sup>b</sup></b>					0.78 <sup>a</sup>
1=Most deprived	16 (22.1)	11 (28.9)	12 (9.6)	39 (16.6)	
2	13 (18.1)	6 (15.8)	19 (15.2)	38 (16.2)	
3	12 (16.7)	4 (10.5)	24 (19.2)	40 (17.0)	
4	14 (19.4)	5 (13.2)	21 (16.8)	40 (17.0)	
5=Least deprived	16 (22.2)	8 (21.1)	14 (11.2)	38 (16.2)	
Unknown	1 (1.4)	4 (10.5)	35 (28.0)	40 (17.0)	
<b>Time since diagnosis of metastases</b>					0.65 <sup>a</sup>
<6 months	22 (30.5)	9 (23.7)	32 (25.8)	63 (26.9)	
6-12 months	9 (12.5)	8 (21.1)	28 (22.6)	45 (19.2)	
1-2 years	18 (25.0)	12 (31.6)	33 (26.6)	63 (26.9)	
2-5 years	16 (22.2)	8 (21.1)	29 (23.2)	53 (22.6)	
>5 years	7 (9.7)	1 (2.6)	2 (1.6)	10 (4.2)	
Unknown	0	0	1 (0.8)	1 (0.4)	

<sup>a</sup>Trend test <sup>b</sup> Townsend deprivation index quintiles calculated from total sample with available postcode data

Significance level set at  $p=0.01$  to allow for multiple testing

\*denotes statistical significance

### 3.3.1 Clinical characteristics of women recruited from the cancer centre

While website participants were asked about site of spread, it was not possible to collect accurate details of their breast cancer diagnosis and treatment (detection and treatment regimens). Disease specific data were collected from the medical notes of all

women from the cancer centres (n=110) (Table 6). The majority (93/84.5%) had been treated for early stage breast cancer, while 6 (5.5%) had metastatic breast cancer on presentation. These findings are consistent with the national picture. For those who presented after treatment for early stage disease, the median time interval between the diagnosis of early stage disease and the development of metastatic disease was four years (range 9 months- 23 years). At the time of recruitment 37 (33.6%) had bone metastases alone, 7 (6.3%) had nodal disease only, 18 (16.3%) had a single visceral metastatic site, 47 (42.7%) had more than two metastatic sites and 1 (0.9%) was unknown. The latter was an omission in data collection in cancer centre 2. Site of metastatic spread was determined by investigation results in the cancer centres (such as CT scans, MRI scans, and histology reports).

**Table 6: Clinical characteristics of 110 women from the cancer centres**

<b>Clinical characteristics</b>	<b>Total N = 110</b>
	<b>N (%)</b>
<b>Time between primary diagnosis to metastatic disease</b>	<b>N (%)</b>
<1	13 (11.8)
1-2 years	20 (18.2)
2-5 years	37 (33.6)
5-10 years	21 (19.0)
>10 years	18 (16.3)
Unknown	1 (0.9)
<b>Site of metastatic spread at time of survey completion</b>	
Bone only	37 (33.6)
Nodal disease only	7 (6.3)
Single site visceral disease	18 (16.3)
Multi site disease (two or more sites)	47 (42.7)
Missing	1 (0.9)

### 3.3.2 Medical management

At the time of recruitment the majority of women in the cancer centres were being actively treated with either endocrine therapy (58/52.8%) or chemotherapy (48/43.6%) other than those awaiting investigation results and treatment decisions (4/4.5%) and many had received numerous treatment modalities over time (Table 7). Twenty five women (22.7%) were receiving on-going treatment of Trastuzumab (some in combination with other treatment) and 60 (54.5%) received on-going bisphosphonate treatment. The majority had received prior treatment for their disease (hormone

therapy, chemotherapy or Herceptin). Fifteen (13.6%) were participating in a clinical trial (Table 7).

**Table 7: Number of women receiving different treatment at time of recruitment**

<b>Treatment at time of study recruitment</b>	<b>N (%)</b>
<b>Hormone therapy</b>	
First-line treatment	29 (26.4)
Second-line treatment	18 (16.4)
Third-line treatment	9 (8.2)
Fourth-line treatment	0
Fifth-line treatment	2 (1.8)
<b>Chemotherapy</b>	
First treatment with chemotherapy	30 (27.3)
Second treatment with chemotherapy	11 (10.0)
Third treatment with chemotherapy	4 (3.6)
Fourth treatment with chemotherapy	2 (1.8)
Fifth treatment with chemotherapy	1 (0.9)
<b>Trastuzumab</b>	25 (22.7)
<b>Bisphosphonates</b>	60 (54.5)
<b>Radiotherapy</b>	45 (40.9) <sup>a</sup>
<b>Surgery</b>	1 (0.9)
<b>Recruited into clinical trials</b>	15 (13.6)

<sup>a</sup> numbers represent incidence of treatment per population; some women received more than one episode of a treatment modality

### 3.3.3 Quality of life

Measurement of quality of life by FACT-B showed that women with metastatic breast cancer had low mean scores for overall quality of life in each of the domains (reflecting worse quality of life) when compared with normative data derived from the 295 patient validation sample of women with breast cancer for the FACT-B questionnaire, where 20% of women had distant metastases (Brady et al, 1997), (Table 8) and to women with metastatic breast cancer receiving hormone therapy (Fallowfield et al, 1999). An explanation for this may be that nearly half of the women in this study were receiving chemotherapy and such patients are likely to have a greater disease burden and are also more likely to be adversely affected by treatment related toxicities.

**Table 8: Quality of life scores in comparison to the FACT-B normative sample**

<b>FACT-B quality of life subscales</b>	<b>Total N=235</b> Mean (SD): higher score reflects greater wellbeing	
	<b>Study score</b>	<b>*Normative score</b>
<b>Physical well-being</b>	16.8 (7.4)	22.1 (5.3)
<b>Social well-being</b>	20.1 (5.6)	22.7 (5.2)
<b>Emotional well-being</b>	12.9 (5.3)	16.3 (3.5)
<b>Functional well-being</b>	17.3 (6.2)	20.6 (6.4)
<b>Breast cancer score</b>	21.9 (7.5)	24.1 (6.5)
<b>Total score</b>	89.0 (21.8)	112.8 (20.9)

\*Brady et al (1997)

Univariate analysis of associations between demographic/clinical characteristics and the FACT-B QoL subscales is seen in Table 9.

There was some evidence to suggest that physical wellbeing appeared to diminish with increasing age although this was not statistically significant and that social wellbeing improved with increasing age ( $p=0.002$ ). In addition, there may be some suggestion that emotional wellbeing improved as time increased since the diagnosis of metastatic disease but this was only approaching statistical significance. Women without children had better functional wellbeing than those with children ( $p=0.001$ ).

Those from cancer centre 2 had poorer physical wellbeing ( $p=0.001$ ), poorer emotional wellbeing ( $p=0.001$ ) and lower overall score ( $p=0.001$ ). There was no significant association between deprivation scores and quality of life (Table 9).

**Table 9: Univariate analyses of associations between demographic/clinical characteristics and FACT-B quality of life subscales**

<b>Mean (SD) shown for all subscales</b>	<b>Physical well-being</b>	<b>Social well-being</b>	<b>Emotional well-being</b>	<b>Functional well-being</b>	<b>Breast cancer score</b>	<b>Total score</b>
<b>Age</b>	P=0.04	P=0.002*	P=0.15	P=0.25	P=0.38	P=0.64
25-44	18.2 (6.8)	19.3 (4.8)	12.3 (4.8)	17.3 (5.8)	22.5 (6.6)	89.6 (18.8)
45-54	16.7 (6.8)	19.4 (6.1)	12.3 (5.6)	16.4 (6.7)	22.0 (8.1)	86.8 (23.7)
55-64	16.8 (8.0)	20.0 (5.5)	13.8 (5.0)	17.6 (6.2)	21.6 (7.5)	90.0 (21.0)
≥65	14.9 (8.1)	23.1 (4.8)	13.3 (5.7)	18.4 (5.9)	21.2 (7.6)	90.6 (22.9)
<b>Marital status</b>	P=0.60	P=0.46	P=0.84	P=0.85	P=0.71	P=0.93
In relationship	17.1 (7.1)	19.9 (5.0)	12.8 (5.2)	17.0 (6.2)	21.8 (7.4)	88.8 (21.5)
Not in relationship	16.5 (7.5)	20.6 (7.1)	12.9 (5.4)	17.2 (6.1)	22.3 (8.0)	89.1 (23.1)
<b>Children</b>	P=0.89	P=0.06	P=0.08	P=0.001*	P=0.47	P=0.03
None	16.8 (8.2)	21.6 (4.6)	14.1 (5.5)	20.1 (4.4)	22.6 (9.1)	95.7 (23.1)
≥1	17.0 (7.2)	19.9 (5.7)	12.6 (5.2)	16.7 (6.4)	21.7 (7.2)	87.7 (21.4)
<b>Townsend deprivation index quintile</b>	P=0.82	P=0.31	P=0.44	P=0.65	P=0.45	P=0.51
1=Most deprived	16.1 (7.1)	19.6 (5.8)	12.2 (5.2)	17.3 (6.2)	22.0 (7.4)	86.9 (19.9)
2	17.2 (7.8)	21.6 (4.2)	13.3 (5.4)	18.8 (5.5)	21.0 (8.0)	91.8 (19.3)
3	16.9 (7.9)	19.9 (5.7)	12.6 (5.2)	17.0 (6.9)	21.6 (7.2)	88.0 (23.7)
4	16.6 (7.1)	19.8 (5.4)	12.2 (5.8)	16.5 (6.7)	22.9 (7.3)	88.0 (21.2)
5=Least deprived	16.8 (7.8)	21.8 (5.2)	13.7 (4.6)	17.7 (5.8)	22.5 (8.7)	92.5 (23.2)
<b>Time since diagnosis of metastases</b>	P=0.38	P=0.39	P=0.02	P=0.18	P=0.59	P=0.07
<6 months	16.4 (7.5)	19.7 (6.5)	12.5 (5.6)	16.8 (6.3)	22.3 (7.9)	87.6 (22.1)
6-12 months	17.2 (7.2)	20.2 (5.2)	11.3 (5.6)	16.5 (6.8)	21.1 (6.9)	85.8 (22.2)
1-2 years	15.4 (7.7)	20.1 (5.6)	12.7 (5.1)	17.3 (6.0)	20.4 (7.6)	86.0 (21.1)
>2 years	18.1 (6.8)	20.6 (4.9)	14.5 (4.7)	18.2 (6.0)	23.4 (7.3)	95.2 (21.1)
<b>Site of spread</b>	P=0.90	P=0.09	P=0.70	P=0.91	P=0.39	P=0.46
Bone only	16.9 (7.3)	19.2 (5.4)	12.6 (5.1)	17.3 (6.2)	21.2 (7.4)	87.3 (20.5)
Other	16.7 (7.4)	20.6 (5.6)	12.9 (5.4)	17.2 (6.3)	22.2 (7.6)	89.6 (22.4)
<b>Place of recruitment</b>	P=0.001*	P=0.001*	P=0.001*	P=0.74	P=0.001*	P=0.001*
Centre 1	15.9 (7.3)	21.8 (4.3)	13.7 (5.1)	17.7 (5.8)	20.7 (8.0)	69.1 (15.4)
Centre 2	8.9 (6.4)	21.9 (5.6)	9.2 (4.1)	17.0 (7.4)	16.5 (4.8)	57.1 (8.8)
Website	19.6 (5.5)	18.6 (5.7)	13.4 (5.3)	17.1 (6.1)	24.1 (6.9)	68.8 (17.5)

*P-values shown correspond to F-test from analysis of variance (trend test for age, Townsend index and time since diagnosis).*

*Significance level set at p=0.01 to allow for multiple testing*

*\*denotes statistical significance*

It would have been interesting to explore whether there was a relationship between age and whether or not women had children and quality of life but this could not be determined as numbers within groups were too small.

Considering other elements of FACT-B, there were no statistically significant associations with participant characteristics and FACT-B scores, and no significant associations for marital status and deprivation with any of the subscales.

In multiple regression analysis, social wellbeing was significantly better for older women ( $p < 0.001$ ) and in those with bone metastases only ( $p = 0.002$ ). This may be because younger women and those with visceral disease are more likely to be having active treatment (predominantly chemotherapy). Having to cope with the symptoms of progressive disease and the side effects of treatment may render them less able to maintain their social roles and activity. To support this premise, those receiving chemotherapy had lower functional wellbeing than those receiving hormone therapy ( $p = 0.007$ ). Functional well-being was also significantly higher in women without children ( $p = 0.004$ ) (regression analysis not shown).

### 3.3.4 Symptom burden

Pain and other symptom scores for the women indicated concerns with symptom control, with 81 (34.5%) scoring 'quite a bit/ very much' (the highest two scoring categories) to the statement 'I have certain parts of my body where I experience significant pain'. Those with bone metastases only were more likely to report significant pain (33/75, 44.0%) compared with other metastatic sites (48/158, 30.4%). In addition, lack of energy was reported as 'quite a bit/very much' by 89 (37.9%), nausea by 62 (26.4%), shortness of breath by 63 (26.8%) (Table 10).

**Table 10: FACT-B individual symptoms**

Items	Number (%)
I have certain parts of my body where I experience significant pain <sup>b</sup>	81 (34.5%)
I have a lack of energy <sup>a</sup>	89 (37.9%)
I have nausea <sup>a</sup>	62 (26.4%)
I have been short of breath <sup>b</sup>	63 (26.8%)
One or both of my arms are swollen and tender <sup>b</sup>	64 (27.2%)
I am bothered by hair loss <sup>b</sup>	72 (30.6%)

*Physical wellbeing domain<sup>a</sup> and additional breast cancer concerns domain<sup>b</sup>*

Interestingly, there appeared to be no relationship between time since diagnosis of metastatic breast cancer and symptom burden indicating that uncontrolled symptoms

may be a problem throughout the illness trajectory and not necessarily worsening with disease progression.

### 3.3.5 Experience of care

Just over half (55.5%) of women were dissatisfied with the information and support they received whereas satisfaction with the personal experience of care was higher. Website participants in particular had significantly lower satisfaction with the information and support they received, their personal experience with care and overall ratings of support received than the cancer centre participants (Table 11). It is possible that women accessing the website did so in search of information and support not available outside this medium. Less than half of women were satisfied with this aspect of their care (Table 11).

**Table 11: Responses to experience of care subscales for all survey participants according to place of recruitment**

Experience of care Mean (SD)	Cancer centres N= 110	Website N=125	Total N=235	t-test for comparison of place of recruitment, p-value
<b>Information and advice</b> % of positive responses out of 11 questions [range 0-100]	62.1 (22.4)	49.6 (24.8)	55.5 (24.5)	<0.001*
<b>Personal experience of care</b> % of positive responses out of 10 questions [range 0-100]	78.4 (28.1)	64.2 (31.7)	70.8 (30.9)	<0.001*
<b>Satisfaction with care</b> % positive responses out of 13 questions [range 0-100]	52.4 (37.9)	44.5 (39.1)	48.2 (38.7)	0.119
<b>Overall rating of support received</b> [range 1-10]	7.5 (1.9)	5.0 (2.4)	6.0 (2.4)	<0.001*

*Missing data for satisfaction with care (3), overall rating of support (43)*

*Significance level was set at  $p=0.01$  to allow for multiple testing*

*\*Denoted statistical significance*

In univariate analysis, women aged over 65 years, those with site of spread other than bone and those recruited from a cancer centre were more satisfied with the information and advice they had been given. Older women and those recruited from a cancer centre were more satisfied with their personal experience of care and were also more likely to feel well supported (Table 12). Younger women and those with bone metastases only again appear to have specific need.



In multiple regression analysis younger women were less satisfied with the information and advice they received ( $p=0.003$ ), their personal experience of care ( $p<0.001$ ) and were more likely to rate the overall support they received as lower than older women ( $p<0.001$ ). The association between age and whether or not women had children could not be determined but women with children, who may be younger, were less satisfied with their personal experience of care ( $p=0.007$ ) and less satisfied with the care they received ( $p=0.002$ ) (not shown).

**Table 12: Associations between demographic/clinical characteristics and experience of care subscales for all 235 survey participants**

	<b>Information and advice</b> <i>Mean (SD) % positive responses out of 11 questions</i>	<b>Personal experience of care</b> <i>Mean (SD) % positive responses out of 10 questions</i>	<b>Satisfaction with care</b> <i>Mean (SD) % positive responses out of 13 questions</i>	<b>Overall rating of support received VAS</b> <i>Mean (SD)</i>	<b>Do you feel well supported at the moment?</b> <i>Number (%) responding 'yes'</i>
<b>Age</b>	P=0.01	P=0.001*	P=0.25	P<0.001*	P=0.003*
25-44	53.7 (24.6)	65.2 (30.3)	47.8 (39.0)	5.3 (2.4)	36 (65.5)
45-54	52.4 (25.1)	65.2 (34.4)	45.4 (38.6)	5.6 (2.7)	56 (70.0)
55-64	53.7 (22.8)	75.8 (27.1)	46.0 (37.7)	6.2 (2.3)	40 (80.0)
≥65	66.9 (22.3)	83.1 (24.8)	57.9 (39.3)	7.5 (1.9)	37 (90.2)
<b>Marital status</b>	P=0.73	P=0.76	P=0.64	P=0.84	P=0.82
In relationship	55.8 (23.9)	71.3 (30.2)	47.8 (37.5)	5.9 (2.4)	123 (74.1)
Not in relationship	54.5 (26.5)	69.9 (33.1)	50.6 (41.8)	5.9 (2.9)	43 (76.8)
<b>Children</b>	P=0.26	P=0.04	P=0.01	P=0.24	P=0.08
None	59.4 (22.6)	80.1 (24.1)	61.6 (38.6)	6.3 (2.7)	38 (86.4)
≥1	54.9 (24.6)	69.5 (31.9)	45.7 (38.1)	5.8 (2.4)	121 (72.0)
<b>Townsend deprivation index quintile</b>	P=0.68	P=0.08	P=0.26	P=0.51	P=0.72
1=Most deprived	55.4 (25.9)	61.3 (35.4)	44.2 (41.7)	6.0 (3.0)	28 (73.7)
2	60.0 (23.7)	79.7 (25.7)	55.1 (39.2)	5.9 (2.7)	30 (85.7)
3	52.3 (21.2)	70.0 (32.5)	45.5 (35.3)	6.1 (2.2)	27 (69.2)
4	52.3 (26.5)	64.5 (31.8)	43.0 (38.8)	5.9 (2.4)	29 (74.4)
5=Least deprived	62.0 (21.5)	82.6 (22.6)	61.9 (36.2)	6.6 (2.4)	27 (75.0)
<b>Time since diagnosis of metastases</b>	P=0.10	P=0.20	P=0.04	P=0.19	P=0.50
<6 months	53.0 (23.1)	69.9 (31.6)	43.6 (35.5)	5.8 (2.3)	46 (75.4)
6-12 months	51.7 (27.2)	63.8 (33.9)	42.1 (39.0)	5.5 (2.5)	31 (73.8)
1-2 years	57.9 (24.0)	72.8 (29.8)	49.1 (41.2)	5.8 (2.6)	41 (66.1)
>2 years	58.8 (23.7)	75.0 (28.8)	56.9 (37.9)	6.5 (2.5)	51 (83.6)
<b>Site of spread</b>	P=0.01	P=0.13	P=0.03	P=0.04	P=0.07
Bone only	49.8 (27.7)	66.4 (33.7)	40.1 (39.8)	5.4 (2.7)	50 (66.7)
Other	58.4 (22.2)	73.0 (29.4)	52.3 (37.5)	6.2 (2.4)	119 (78.8)
<b>Place of recruitment</b>	P=0.001*	P=0.001*	P=0.128	P=0.000*	P=0.000*
Centre 1	60.2 (21.4)	78.4 (27.9)	49.6 (36.7)	7.2 (2.0)	62 (89.9)
Centre 2	65.7 (23.8)	78.2 (28.8)	57.8 (40.0)	7.6 (1.8)	31 (88.6)
Website	49.6 (24.8)	64.1 (31.7)	44.5 (39.0)	5.0 (2.3)	76 (61.8)

*P-values for information and advice, personal experience of care, satisfaction with care, and overall rating of support correspond to F-test from analysis of variance (trend test for age, Townsend index and time since diagnosis).  $\chi^2$  test (or  $\chi^2$  test for trend, as appropriate) used for 'do you feel well supported at the moment?'. Significance level set at  $p=0.01$  to allow for multiple testing. VAS = Visual Analogue Scale*

*\*denotes statistical significance*

In regression analysis, those with bone metastases only appear to be less satisfied with the information and advice they received ( $p=0.05$ ), with their experience of care ( $p=0.03$ ), and were less likely to feel well supported ( $p=0.03$ ), although these findings were only approaching statistical significance.

There were no statistically significant associations for marital status and deprivation with any of the experience with care domains.

When considering the individual items within each domain more closely it became clear that those with bone metastases only are a subgroup with specific problems and unmet needs as they are significantly less satisfied with a number of items within the experience of care scale (Table 13).

**Table 13: Items in the experience of care scale showing those with bone metastases experiencing poorer experience of care**

Characteristics	Bone only Mean(SD)	Other metastatic sites Mean(SD)	P value
<b>Information and advice</b>			
I was given enough information about my medication and its side effects	2.5 (1.1)	2.9 (0.9)	$P=0.004^*$
The doctors/nurses gave me practical advice about managing my illness and symptoms	1.9 (1.1)	2.3 (1.0)	$P=0.009^*$
I knew who to contact if I had a problem	2.8 (1.2)	3.1 (0.8)	$P=0.008^*$
<b>How satisfied were you with:</b>			
the thoroughness of the care you received?	2.3 (0.9)	2.8 (0.9)	$P=0.001^*$
the information given to you about your disease?	2.0 (1.0)	2.4 (1.0)	$P=0.005^*$
the reassurance given to you about your disease?	1.8 (1.0)	2.3 (1.0)	$P=0.001^*$
the extent to which you were involved in decisions about your care?	2.1 (1.1)	2.6 (1.0)	$P=0.005^*$
the extent to which your own worries and concerns were considered?	2.0 (1.1)	2.5 (1.0)	$P=0.002^*$
the extent to which your family were considered?	1.8 (1.2)	2.3 (1.0)	$P=0.002^*$
knowing exactly who was looking after you?	2.1 (1.1)	2.7 (1.0)	$P=0.001^*$
the overall care you received?	2.4 (1.0)	2.8 (0.9)	$P=0.007^*$

Significance level set at  $p=0.01$

\*Denotes statistical significance

To explore the relationship between two or more variables multiple regression was used. This established that older women were significantly more satisfied with the information and advice they received ( $p=0.003$ ) and with their personal experience of care ( $p=0.002$ ) and were more likely to give a higher overall rating of the support they

received. Those without children were significantly more satisfied with their personal experience of care ( $p=0.007$ ) and had greater satisfaction with their care ( $p=0.002$ ). To determine if there was a correlation between age and having children cross tabulation was done. There were insufficient numbers in each group to determine a relationship between age and whether or not the women had children on their experience of care.

Again, the findings associated with site of spread highlighted concerns for those who had bone metastases only. There was some suggestion that those with metastatic site other than bone were significantly more satisfied with the information and advice they had been given ( $p=0.05$ ), reported greater satisfaction with care ( $p=0.03$ ) and were more likely to feel well supported ( $p=0.03$ ) but this was only approaching significance.

### **3.3.6 Relationship with healthcare professionals**

When asked which healthcare professional they would choose to see on a regular basis, the majority (146/62.1%) would choose to see their hospital specialist. One hundred and sixty (68.1%) saw their healthcare professional of choice at least once a month (Table 14).

From the free text questions, it was apparent that the nature and quality of interactions with healthcare professionals had an impact on how women coped with their situation. Women appeared to have limited contact with their GPs and with specialist palliative care services, with only 20 (8.5%) choosing their GP and 17 (7.3%) choosing palliative care/Macmillan nurse as the healthcare professional they would want to see regularly (Table 14).

**Table 14: Responses about access to healthcare professionals and support**

	Number (%)
<b>Which healthcare professional would you most like to see regularly? N (%)</b>	
Hospital specialist	146 (62.1)
General Practitioner	20 (8.5)
Palliative care/Macmillan nurse	17 (7.3)
Breast Care Nurse	29 (12.3)
Other (including a combination)	11 (4.6)
Unknown	12 (5.1)
<b>How often is preferred health care professional seen? N (%)</b>	
Once a week	19 (8.1)
Every 2 weeks	60 (25.5)
Once a month	81 (34.5)
Every 3 months	33 (14.0)
Every 6 months or less	24 (10.2)
Unknown	18 (7.7)
<b>Do you feel well supported at the moment? N (%)</b>	
Yes	169 (71.9)
No	58 (24.7)
Unknown	8 (3.4)
<b>Do you receive any help/care at home? N (%)</b>	
Yes	110 (46.8)
No	122 (51.9)
Unknown	3 (1.3)

### 3.3.7 Information and support

The findings of experience of care measure were supported by the responses to the open text questions. There was a strong need to be informed and listened to and to work in partnership with caring healthcare professionals. Many felt they had to work on this relationship in order to gain the information and support they needed to live with their disease. Being informed about their diagnosis, treatment (current and future) and some indication of future expectations was crucial to living and coping in the present. The way information, particularly difficult information, was imparted was important in how participants coped; some felt it was too clinical and dispassionate. How well the delivery of information was done at diagnosis influenced their future perspective and hope.

Relationships with both healthcare professionals and social groups was a strong theme. How others behaved towards them and the effect this had was threaded through almost all the needs the women identified. Some reported a palpable shift in the attitude of healthcare professionals, feeling that their attention waned:

*'Upon receiving my diagnosis of secondary cancer I received very little emotional support in comparison to when I was diagnosed with primary breast cancer. My consultant told me the results, told me there was no cure and treatment could only help prolong my life, arranged for me to see the oncologist the following day and then I was left alone in the hospital corridor. The consultant said he would see me again in six weeks. My breast care nurse left a message for me saying she was sorry but there was no more she could do for me. I had to ask for help before a Macmillan nurse became involved. It was only after seeing the Macmillan nurse that I began to feel better supported. For the days in between times I felt isolated, alone and felt there was no hope left for me. I believe the emotional support required for someone coping with a diagnosis of secondary breast cancer should be available immediately following diagnosis.'* (participant 136, aged 50-54, living with metastases in the stomach for 11 months)

*'The medical staff involved in my care have simply administered all of the correct chemotherapy etc. I cannot complain but I do feel that it would have been good to be seen as a whole person and not just jumble of symptoms.'* (participant 173, aged 40-44, living with lung metastases for 3 months)

Many felt they had to be responsible for the information they needed to feel informed. If they didn't ask, the detail would not be given. The experience of being diagnosed with metastatic breast cancer appeared to compare unfavourably with when they were diagnosed with early stage breast cancer.

*'When I was originally diagnosed in 1999 I came home with carrier bags full of leaflets and booklets, when I was re-diagnosed there was nothing. I wasn't given anything.'* (participant 144, aged 45-49, living with bone and lung metastases for 2 years)

There was an expectation that healthcare professionals should give appropriate, individualised information and support when it is needed, but many women appeared to be primarily seeking reassurance that they were receiving the appropriate and best treatment for them, that their life expectancy would be prolonged by this and that they were doing everything they could to promote their own health.

*'Reassurance that I'm doing everything I can to find the best possible chance of sorting out problems.'* (participant 77, aged 44, living with metastases in supraclavicular nodes for two years)

*'Reassurance that the care I am receiving is appropriate and that I am doing the correct thing to help my health.'* (participant 69, aged 56, living with metastases in supraclavicular nodes and liver metastases for 18 months)

Many women felt that by understanding the impact of diet, nutrition and exercise as a means of promoting maximum health, they could exert some control over their situation. By being informed of what they could do themselves, many felt that by utilising some self-management skills they could take some responsibility and control over their disease.

*'Information about how my disease might progress, symptoms to look for, what can I do to help myself?'* (participant 81, aged 45-49, living with liver metastases for three months)

Some women wanted to know more about their individual cancer and treatment and to have knowledge of possible future treatments. By being informed, they may be able to anticipate the future.

*'I need to be kept fully informed about my condition and long term prognosis and I don't feel this is always done.'* (participant 125, aged 40-44, living with bone and lung metastases for seven months)

Women appeared to be seeking supported self-management approach to care in order to exert some control over their lives.

### **3.3.8 Social support**

From the open text responses women cited partners and family members as their main sources of support. Social wellbeing of the women appeared to be affected by the level of social support they felt able to seek. As the women could live for some time with their disease they felt they could not continually seek support from those around them or sensed that others could not sustain the same level of support over time.

*'Since I have been in this slowly deteriorating state for five years I do not often discuss my anxieties with family or friends. I do not want to seem an illness bore neither do I wish to heighten my family's anxiety. It would be good to occasionally share my feelings with someone outside my life I think.'* (participant 115, aged 72, living with pleural metastases for five years)

*'Sometimes I feel terribly isolated and marginalised, I feel like we are the face of breast cancer no one really wants to see, the story without the happy ending or feel good factor. You can feel very apart and alone, almost as if you are watching everyone through a window at a party from which you have been excluded for reasons you don't understand.'* (participant 118, aged 35-39, living with lung, liver and bone metastases for 14 months)

This detachment appeared to be exacerbated by their life trajectory diverging from those around them.

*'One of the most difficult things is listening to friends talking about their futures with absolute surety - their plans for retirement, relocation, new babies, new businesses and being gracious when listening to them! So my needs? Finding some tools to help me deal with the above.'* (participant 125, aged 40-44, living with bone metastases for 18 months)

*'A few friends have been lost due to the fact that I am no longer the party animal I used to be and unfortunately that seems to upset their lives.'* (participant 124, aged 50-54, living with supraclavicular and mediastinal metastases for 16 months)

As a result the women could feel detached from those around them, and many talked of withdrawing socially as they felt unable to talk to others about living with their disease, which in turn affected their social wellbeing.

### **3.3.9 Finance and employment**

For some there appeared to be considerable financial concerns and the challenge of a potentially prolonged life but with progressive cancer made financial planning problematic. Few women appeared to be clear about the financial assistance they could receive or their employment and pension rights

*'Although work have been supportive, I don't believe I am going to be able to return and that's something which affects me in two ways – worth and finance. I feel the need to continue as normal an existence as possible and that includes work.'* (participant 119, aged 50-54, living with bone and lung metastases for one week)

*'More than anything I need to feel that I am still useful in my employment, to my family and the world in general!'* (participant 5, aged 55-59, living with bone metastases for four years)



Throughout the open text responses, women sought self-management approaches to maximise their health and to maintain some control over their situations in areas such as health promotion, social relationships and employment. The findings of the survey suggest this is done through a backdrop of poor quality of life, uncontrolled symptoms and limited professional intervention.

### 3.4 Summary

Two approaches to recruitment were used; face to face and online aimed to access a wide population both geographically and in treatment and care, as well as those who may have been outside the healthcare setting.

In the absence of an appropriate validated measure of quality of life in psychosocial research, FACT-B was used as the domains covered areas of experience this study sought to explore. FACT-B is a multidimensional instrument developed to measure quality of life in response to clinical trials. In the context of this study, FACT-B has been useful in identifying the problems and concerns of women with metastatic breast cancer as it identified significant concerns about the problems and needs of women.

Those with progressive breast cancer appear to be leading increasingly complex lives from metastatic diagnosis through disease progression, sequential treatments and uncertainty. Overall quality of life (QoL) of women with metastatic breast cancer was poor. Low scores were seen uniformly across all domains of the FACT-B QoL instrument, reflecting the impact of disease and treatment on all aspects of women's daily lives. When compared to normative data (Brady et al, 1997) and to women with metastatic breast cancer receiving hormone therapy (Fallowfield et al, 1999) mean QoL scores in this study were lower. This is not surprising since nearly half the women were receiving chemotherapy; such women are likely to have a greater disease burden and are also more likely to be adversely affected by treatment related toxicities.

The effect of a diagnosis of progressive breast cancer on emotional wellbeing highlights a need to ensure those newly diagnosed have access to psychological support from the point of diagnosis onwards.

Overall experience of care was poor with just over half of women being dissatisfied with information and support and under half being satisfied with their care.

Two sub-groups within the study population appear to have specific unmet needs: younger women and those with bone metastases only. Younger women had lower social wellbeing than those in the older age groups and were less satisfied with elements of their care than older women. As previously stated, younger women may be

more likely to have aggressive disease and chemotherapy and so be more compromised by their disease and treatment and less able to maintain their social roles. These findings may also have been biased by the number of younger women who were on-line participants. It was not possible to determine that younger women with children were a specific sub-group whose needs were not being met, but it is conceivable that younger women with young children may struggle to cope with managing a young family, treatment and progressive disease and maintaining their role in the wider social network.

Those with bone metastases were less satisfied with information and advice they received, elements of their care, felt less supported and rated the support they received as lower. It is likely that this sub-group was managed conservatively with endocrine therapy and bisphosphonates. They may have the occasional fraction of radiotherapy for bone pain but otherwise live their lives outside the healthcare setting. Their only interaction with healthcare professionals may be at their oncology appointments (which were usually every 1-3 months) or when they attend an outpatient unit for bisphosphonate infusions. As this population may have good levels of physical functioning, it is likely that they are continuing their everyday lives and tolerating uncontrolled symptoms with minimal healthcare intervention. By identifying these sub-groups, healthcare providers can consider ways to address their specific needs.

Symptom burden is a significant problem within this population. These findings support earlier work which found that fatigue, pain and sleeplessness are problems for those with metastatic breast cancer (Aranda et al, 2005) and women experience moderate to severe pain with little evidence of healthcare professional intervention (Arathuzik, 1991). In cancer pain, Portenoy and Lesage (1999) state that as many as 90% of patients could attain adequate relief with simple drug therapies, but clearly symptom control is still a problem for those with progressive breast cancer, with many women tolerating uncontrolled pain and unsure where to turn for assistance in managing it.

An explanation for this may be that there was little evidence of GP or palliative care involvement in their care.

A theme from the open text responses was the social separation experienced when women's lives diverged from those around them, leading to a sense of isolation.

Women cited the main source of support to be their partners or family members. Equally, they would feel a sense of isolation when their lives diverged from those around them.

There was a need for adequate information and support but women's experience compared unfavourably with their experience of early stage breast cancer when they were given a considerable amount of information and felt well informed and supported by healthcare professionals. To exert some control over their lives, the women sought ways to self-manage their physical, emotional and social response to progressive disease.

The survey set the scene of the prevalence of problems and needs of women with metastatic breast cancer. The next step in the study sought to explore the women's everyday lives in more depth. Maintaining social relationships and social order to avoid alienation and isolation was central to the women's lives. The exploration of how they did this is the focus of the next chapter.

The findings of the cross-sectional survey have been published in the *Journal of Pain and Symptom Management* (Appendix 7).

## **Chapter 4. Social survival in metastatic breast cancer: mediating the discontinuity between self, body and social order**

This second phase of the study used women's narratives to explore the social consequences of living with progressive breast cancer.

This phase of the study sought to answer the research question:

- What are the social consequences of living over time with progressive breast cancer and how does this affect the self and identity?

As described on page 63, 30 women were interviewed using a narrative approach up to three times over one calendar year.

Women with metastatic breast cancer can live for a number of years with progressive disease. What specifically sets these women apart from many others with metastatic cancers is that they rarely showed any external signs of disease. Unlike many other cancers, they rarely experience weight loss (more often complaining of weight gain due to endocrine therapy) and while some can be physically compromised by their disease it is uncommon to be physically dependent until the very end of life. This means those living with progressive breast cancer can project an image of health and maintain their social roles with little apparent compromise. For these reasons the social consequences of living over time with progressive disease and identity was a central focus for the investigation in this phase of the study.

Using a longitudinal approach, 30 women were interviewed over one calendar year at baseline, six months and 12 months. Twenty two were interviewed three times, six were interviewed twice (two died before the third interview, one was lost to follow-up and one withdrew as she found it too difficult talking about living with progressive disease) and two were interviewed once (both died before the second interview). The average length of the interviews was 60 minutes.

Constructionists argue that our patterns of living begin and are sustained through collaborative relationships (Gergen, 2009). In this phase of the study, women's narratives were used to explore their social roles and relationships and consider the influence of their adopted behaviours and projected identities which enabled them to maintain their social roles within their social groups.

This chapter describes how 30 women with metastatic breast cancer mediated the potential discontinuity between the self, body and social order and how they navigated the oscillations of a life lived with progressive breast cancer. Two key concepts thread through this chapter, *looking well and feeling well* and *looking well and feeling unwell* while living with progressive breast cancer.

We begin with an introduction to the lives and diagnoses of the 30 women who took part in the interview stage. The age range of the women was 25-78 and they had been living with metastatic disease from months to one woman living over seven years. The majority of women were living full lives. Eight had young children, 12 were employed either full time or part time and 13 had retired.

**Table 15: Introducing the interview participants**

<b>Participant</b>	<b>Age</b>	<b>Personal history</b>	<b>Breast cancer history</b>	<b>Site of metastatic spread at recruitment</b>	<b>Time since metastatic diagnosis at recruitment</b>
1. Martha	65	Martha was a retired office worker and lived with her husband in a suburban area. After many years of travelling the world together they had recently settled into a new home near the coast. She had two adult children and was now enjoying time with her grandchildren.	Presented with a breast lump, had wide local excision, radiotherapy and endocrine therapy. Ten years later presented with weight loss, nausea and vomiting, diagnosed with liver and lung metastases.	Bone, liver, lung	4 months
2. Karen	53	Karen lived in the countryside with her husband in a large home they had spent years renovating. She had one adult daughter who lived close by. She worked as a teacher until her diagnosis of metastatic disease. Her breast cancer was hereditary; her mother had died of breast cancer and her sister had been diagnosed with it.	Presented with breast lump, had a mastectomy, chemotherapy and radiotherapy. Two years later presented with right shoulder pain, fatigue and breathlessness. Diagnosed with lung metastases.	Liver, lung, brain	16 months
3. Angela	45	Angela lived with her partner of 20 years in an urban area, and worked as a shop manager almost throughout her illness trajectory, a job she loved. She had three grown children who lived close by and	Presented with a breast lump, had a wide local excision followed by chemotherapy and radiotherapy. Three years later presented with headaches, nausea and right-sided weakness,	Brain	<2 years

Participant	Age	Personal history	Breast cancer history	Site of metastatic spread at recruitment	Time since metastatic diagnosis at recruitment
		was looking forward to her first grandchild.	diagnosed with brain metastases.		
4. Shelley	48	Shelley lived with her third husband and the last of her three children in a bungalow in a suburban area. The other two children were married and lived close by. She worked as an administrator for a large organisation.	Presented with a breast lump and had a mastectomy, chemotherapy, radiotherapy and subsequent endocrine therapy. One year later developed back pain and was diagnosed with bone, lung and liver metastases.	Bone, liver, lungs	<2 years
5. Dawn	46	Dawn lived with her husband of four years and their dog in a suburban area. She worked as a project manager. Since her diagnosis she had adopted a new diet and lifestyle in contrast to the life before where she was doing two or three jobs at one time.	Presented with breast lump, had a lumpectomy and radiotherapy followed by endocrine therapy. Eight years later had recurrent breast lumps and fatigue, found to have bone, liver and lung metastases.	Bone, lung and liver	<18 months
6. Paula	40	Paula was recently separated and lived with her two young sons of school age in a country town. She had recently given up work due to fatigue so she could concentrate her energy on her children.	Presented with a breast lump and underwent a mastectomy, radiotherapy, chemotherapy and subsequent endocrine therapy. Less than one year later presented with anorexia, weight loss and diarrhoea and was diagnosed with lung and liver metastases.	Bone, lung and liver	3 months

<b>Participant</b>	<b>Age</b>	<b>Personal history</b>	<b>Breast cancer history</b>	<b>Site of metastatic spread at recruitment</b>	<b>Time since metastatic diagnosis at recruitment</b>
7. Joan	78	Joan was a widow who lived alone in a large house in the countryside. She had three adult sons who were all married with children and all lived a considerable distance away. She was a retired teacher and very involved in local activities and groups.	Presented with a breast lump, and underwent a mastectomy and endocrine therapy. Three years later developed skin nodules and diagnosed with metastases in supraclavicular nodes, cutaneous metastases and a mass on the ribs.	Supraclavicular lymph nodes, cutaneous metastases and mass on ribs	15 months
8. Joy	50	Joy lived with her husband and two school aged daughters in a small village. She had taken early retirement and enjoyed the freedom of not working so hard. She adopted a healthier lifestyle following her diagnosis of metastatic disease at the same time as primary disease.	Presented with anaemia. Investigated for haematological cancer and bone marrow biopsy found metastatic disease from breast cancer. Diagnosed with bone and bone marrow metastases.	Bone, bone marrow, liver	<5 years
9. Jill	41	Jill lived with her husband and three school aged children in a house in a suburban area. She worked as a counter clerk for a local organisation. Jill enjoyed travelling abroad and regularly organised holidays for up to 30 or more friends and family.	Presented with a breast lump and had a wide local excision, chemotherapy, radiotherapy and subsequent endocrine therapy. Two years later presented with five month history of back pain and diagnosed with bone metastases.	Bone and liver	<6 months
10. Mary	63	Mary was retired and lived with her husband in an apartment on the coast. She had recently given up	Presented with a breast lump, had a mastectomy. Four years later she developed	Bone	<6 years



Participant	Age	Personal history	Breast cancer history	Site of metastatic spread at recruitment	Time since metastatic diagnosis at recruitment
		voluntary work. She and her husband loved to travel and did so as often as they could. She had one adult son who lived close by.	contralateral breast cancer and had a lumpectomy. Nine years after early stage diagnosis presented with back pain and was diagnosed with bone metastases.		
11. Lorraine	55	Lorraine was single and lived alone in a large city. She worked as a consultant in a large corporation. She had a supportive network of friends and attended a cancer help centre support group.	Presented with a breast lump, underwent a lumpectomy then had radiotherapy and endocrine therapy. Within a year she had developed symptoms and was diagnosed with metastatic disease.	Lung and liver	<2 years
13. Alex	43	Alex lived with his partner and had four school age children. Two of the children were from an earlier marriage and the other two lived with him and his partner. Alex worked in a global bank and commuted to London and travelled internationally until the last six months of his life.	Presented with a nipple rash (Paget's disease) and had a mastectomy and chemotherapy. Staging scans showed lung metastases and chemotherapy was changed to a second regime.	Lung	2 months

Participant	Age	Personal history	Breast cancer history	Site of metastatic spread at recruitment	Time since metastatic diagnosis at recruitment
14. Jo	36	Jo was a single mother of two small children. Her ex-boyfriend ended the relationship as he couldn't cope with her illness. Having worked as a shop manager for 18 years, she decided she wanted to follow her dream and train as a care assistant , a new venture she was about to embark on.	Presented with a breast lump, had a mastectomy, chemotherapy and radiotherapy. Developed back pain and was found to have bone metastases and supraclavicular disease. Upset she was no longer eligible for breast reconstruction because of progressive disease.	Supraclavicular nodes and bone	3 months
15. Susan	65	Susan worked as a telephone operator and lived with her husband. She had two adult children and three grandchildren to whom she was devoted.	Presented with a lump, had surgery (nature unknown). Developed back pain three years later: found to have multiple bone metastases.	Bone	<7 years
16. Kylie	25	Kylie was a single mother of a two year old daughter, living in a small community. Her parents lived close by and were very supportive. She had recently started a new relationship which was going well. Kylie stopped work as a receptionist due to treatment and wanting to spend time with her daughter.	Presented with a lump under her arm but due to her young age was misdiagnosed. Adjuvant chemotherapy, lumpectomy and radiotherapy followed by endocrine therapy. Bone scan two years later revealed multiple bone metastases; radiotherapy and changed endocrine therapy.	Bone	11 months
17. Stella	65	Stella lived with her husband and had two adult children and four grandchildren.	Stella had breast cancer 15 years before her metastatic diagnosis. She underwent a mastectomy and had experienced pain on the	Bone	2 years

<b>Participant</b>	<b>Age</b>	<b>Personal history</b>	<b>Breast cancer history</b>	<b>Site of metastatic spread at recruitment</b>	<b>Time since metastatic diagnosis at recruitment</b>
			mastectomy scar. Two years before study recruitment she had a routine mammogram which showed a recurrence on the ipsilateral breast and further investigation found bone metastases. She had further breast surgery and radiotherapy to her hip.		
18. Julie	39	Julie was married with two children under five and two step children in their twenties. She worked as a nanny until her metastatic diagnosis. Her husband worked away from home during the week so Julie had sole responsibility for her young children.	Julie was diagnosed with early stage breast cancer in 1999, while pregnant with her first child, and diagnosed with bone metastases two years later while pregnant with her second.	Bone, liver and brain	< four years
19. Stephanie	70	Stephanie was a retired lawyer. She lived with her second husband and between them they had four adult children and many grandchildren. She enjoyed travelling, which she and her husband did as often as possible.	Stephanie presented with a breast lump and had a mastectomy and radiotherapy in 1986. Radiotherapy left her with brachial plexus injury and left arm paralysis. She had a recurrence in the contralateral breast in 1994 and second mastectomy. She was diagnosed with metastatic breast cancer five years ago	Pleura	< 5 years

Participant	Age	Personal history	Breast cancer history	Site of metastatic spread at recruitment	Time since metastatic diagnosis at recruitment
			and has multiple metastases in her pleura. She underwent bilateral pleuradesis and was prescribed Arimidex which she was still taking.		
20. Jenny	50	Jenny was married and had two teenage children at university. She owned and ran a small business and sold the produce in local markets. .	Presented with a breast lump in 1999, had a mastectomy and breast reconstruction. Two years later she had a routine mammogram and was found to have contralateral breast cancer and had a second mastectomy, chemotherapy and endocrine therapy. Three years after her initial diagnosis she developed enlarged supraclavicular lymph nodes and was confirmed to have metastatic breast cancer and was prescribed endocrine therapy.	Supraclavicular lymph nodes	< 6 months
22. Ayesha	55	Ayesha lived with her husband and had two children who lived away from home. She worked as an office clerk. Ayesha had done a number of events for charity since being diagnosed with metastatic disease such as walking the Great Wall of China and a 12 mile walk.	Presented with a breast lump in 1996, underwent a lumpectomy, chemotherapy, radiotherapy and endocrine therapy. In 2003 developed persistent cough and found to have lung metastases, and treated with endocrine therapy.	Lung	< 6 months

<b>Participant</b>	<b>Age</b>	<b>Personal history</b>	<b>Breast cancer history</b>	<b>Site of metastatic spread at recruitment</b>	<b>Time since metastatic diagnosis at recruitment</b>
23. Nancy	67	Nancy lived with her husband and had five children and 15 grandchildren who all lived close by, many of whom she saw almost daily.	Presented with a breast lump, and underwent a mastectomy and radiotherapy in 1995. Six years later she developed contralateral breast cancer and underwent a second mastectomy. Three years later she developed nodules on her mastectomy scar which were metastatic deposits. These were surgically removed and she dressed them herself daily. Has had radiotherapy to her scar and chemotherapy.	Cutaneous and bone	< 5 years
24. Gladys	70	Gladys lived with her husband and had three grown-up children and several grandchildren. She was a retired market trader.	Presented with a breast lump in 1999, and underwent wide local excision and radiotherapy. A year later developed back pain and was found to have bone metastases. She had radiotherapy to her spine and started on endocrine therapy.	Bone	< 4 years
25. Sylvia	61	Sylvia lived with her husband and had two adult children. She was diagnosed with metastatic disease just as she retired from work.	Sylvia's breast cancer was detected on a routine mammogram in 2003 and she underwent a mastectomy, chemotherapy and radiotherapy. Within a year she developed an enlarged supraclavicular lymph node and was	Supraclavicular and lung metastases	10 months

<b>Participant</b>	<b>Age</b>	<b>Personal history</b>	<b>Breast cancer history</b>	<b>Site of metastatic spread at recruitment</b>	<b>Time since metastatic diagnosis at recruitment</b>
			found to have lung metastases. She had radiotherapy and chemotherapy.		
26. Connie	54	Connie lived with her partner. She had one adult daughter who lived locally. She had recently retired as an office manager for a large organisation as she felt the pain she experienced prevented her doing her job. Until recently she was still playing tennis weekly.	Connie presented with a breast lump in 2000 and underwent a mastectomy followed by radiotherapy and endocrine therapy. Within a year she was diagnosed with primary lung cancer and underwent curative surgery. Five years after her early stage disease she was found to have bone metastases and had radiotherapy and her endocrine therapy was changed. Within months, Connie was found to have liver metastases and her endocrine therapy was changed again.	Bone and liver	6 months
27. Evelyn	63	Evelyn was married and had one adult child and one grandchild. She was diagnosed with breast cancer at the same time as she retired.	Evelyn was diagnosed with breast cancer through mammographic screening in 2003. She underwent a mastectomy, chemotherapy and radiotherapy. Within a year she developed enlarged supraclavicular lymph nodes (SCLN)	Supraclavicular lymph nodes and lung.	< 2 years

<b>Participant</b>	<b>Age</b>	<b>Personal history</b>	<b>Breast cancer history</b>	<b>Site of metastatic spread at recruitment</b>	<b>Time since metastatic diagnosis at recruitment</b>
			and was found to have SCLN and lung metastases. She had chemotherapy and Herceptin.		
28. Gerry	50	Gerry was married and had no children. She had a busy job as a manager which she loved. Conflict at work had caused her much anxiety and dominated the last year of her life	Presented with breast lump in 1997, underwent mastectomy, chemotherapy, radiotherapy and endocrine therapy. Eleven months later, at routine follow-up she was found to have bone metastases. She had chemotherapy and subsequently went on to develop liver and lung metastases.	Bone, liver and lung	7 years
29. Deborah	71	Deborah lived with her second husband. She had two adult children who lived close by. Her pain had reduced her ability to go far from the house.	Presented with inflammatory breast cancer in 1993, had no surgery but had radiotherapy and endocrine therapy. In 2002 developed neck pain and was found to have bone metastases. Had radiotherapy and endocrine therapy. Bone metastases progressed over the years and subsequent treatment was radiotherapy and endocrine therapy.	Bone	5 years

<b>Participant</b>	<b>Age</b>	<b>Personal history</b>	<b>Breast cancer history</b>	<b>Site of metastatic spread at recruitment</b>	<b>Time since metastatic diagnosis at recruitment</b>
30. Kim	61	Kim lived alone but had a partner who lived close by. She had two adult children. Kim worked as a travel writer.	Presented with a breast lump, underwent a mastectomy, chemotherapy and endocrine therapy. Two years later presented with bone pain, found to have metastases in bone and lung. Endocrine therapy changed.	Bone and lung	3 months

*To maintain confidentiality, all participants have been given pseudonyms and in places small details of stories which would have identified women have been change, protecting their anonymity without substantially altering the story.*



## 4.1 Situating the self

All the women appeared to present an identity as a whole person from the very first interview question *'tell me about yourself'*. Almost all began their narrative by defining their social role and presenting an image of themselves before their breast cancer; this allowed them to paint a picture of how they were as an individual before cancer. Almost all the women appeared to situate the self within each biography as worthy, productive and valued within their social worlds. For example, Karen took great pride in detailing her development from a stay-at-home mum to training as a teacher who was greatly valued by her pupils; Jill described a very sociable image as the organiser of a large social group and Jane talked with pride of her high achieving career. They described their place in their social worlds to define their social roles – that they were members of families and social networks. Roles as parent, partner, friend or employee were all described to allow a picture of a whole person to emerge within the narrative, so they were not merely seen as a person with cancer. Describing a cohesive identity which was integral to the social order they lived within appeared to allow a whole person to emerge.

Disruptions in personal continuity could be caused by uncontrolled symptoms, times of disease progression and treatment, as well as uncertainty and the relentlessness of their illness. Charmaz (1991) says when the present is disrupted individuals may seek solace in the familiar foundation of the past, that taking strength from the past assists in the restoration of identity and self-concept. By describing a self-image before breast cancer the women appeared to provide a means to repair the fractured bond between the past self-image and the present. It appeared important to them that they presented themselves as a loved, worthy and valued person who contributed to the world and would leave some form of legacy, or mark on it. Moments of reminiscence were enjoyed by some in the telling of stories when the person before breast cancer was allowed to take centre stage. As the breast cancer narrative was told the women appeared to try to maintain as far as possible the image of a cohesive self which reflected the self-image they had portrayed in their reminiscence.

In contrast, those who were younger and had more aggressive disease (Paula, Jo, Julie) appeared less preoccupied with their past. They were more likely to be embedded in the present as they appeared to need all their personal resources to cope with their current life situation and the implications of disease on their future. All of them experienced some symptoms but showed no external signs of progressing disease.

## 4.2 When the self is dominant

### 4.2.1 Maintaining everyday life

In conversation with the women, accommodating the challenge of progressive breast cancer into everyday life seemed to demand considerable adjustment for them and their social groups. Social identity appeared to shift imperceptibly from the person who *had* cancer to the person *with* cancer, but the women appeared all too aware of the social ramifications of the transition. However, when they *looked well and felt well*, their reality maintenance (Berger and Luckman, 1966) appeared easier to achieve. At times withholding their diagnosis from others seemed to allow them to maintain the social roles they coveted and allowed their social identity to retain a healthy social image and remain a cohesive whole person.

The coexistence of internal and external reality in everyday life was a central concept in their self-evaluation as someone coping with and adjusting to a life dominated by progressive breast cancer. Although the external image was one of health, the internal reality was often one of uncontrolled symptoms and side effects of treatment. For example, despite constant pain Nancy aimed to fill her life with activities she chose, refusing to be compromised by her illness. She had a large family and appeared to remain the matriarch surrounded by children and grandchildren who supported her, but she dictated in what way they were allowed to support her without externalising the limitations her illness imposed on her. This approach allowed her self-image and social roles to remain intact and as a result, retain social order.

*'I try not to let it bother me too much because I think there is always tomorrow and there's something else that's got to be done.'* Nancy

Likewise, Angela gauges her ability to cope and adjust by her ability to maintain her greatly valued role as shop manager.

*'I like my job, I love my job, I live for my job...it's like a medication.'* Angela

Whenever possible, women appeared to maintain daily life and routines which were considered normal and predictable. This was dependent on the physical manifestations of the disease and how much this impacted on their lives, and the balance of normality appeared dependent on the ability to maintain everyday details of life and social relationships, such as the ability to shop for food or collect children from school. When the women *looked and felt well* and were not physically affected by their disease, their internal and external reality worked in harmony, without one dominating the other, and allowed them to maintain everyday life with little or no compromise. The self did not appear to be compromised at these times, the diseased body did not intrude into the

women's lives too much and social order was for the most part maintained. However, the women were still living with the knowledge that they had progressive disease which could at times make them feel detached from the ebb and flow of everyday life. To mediate between their internal reality and their external reality, the women appeared to use a number of different approaches to maintain a social identity they perceived acceptable to their social groups.

Goffman (1963) stated the action of 'passing' – the withholding of information about stigma to others to maintain social order and mediate the disintegration of the relationship between themselves and others in their social groups.

All the women at some time appeared to try to exert some control over a situation to avoid exposing the knowledge of their diagnosis or news of progressive disease to others. These actions appeared to protect their integrity as an equal member of the social group, avoid rejection and at times protect those around them. Jones et al (1984) described six dimensions of stigma: *concealment*, the extent to which the stigma is hidden or visible; *the course*, which describes how the stigma changes the individual and their life over time; the *strain*, which is how the stigma affects relationships; *aesthetic qualities*, which is the extent to which the illness affects physical appearance; the *cause*, which may be inherent or as a result of lifestyle and finally *peril*, the extent to which danger is associated with the stigmatised person. Other than peril, all these dimensions resonated at some point with the women's approach to maintain social order in their lives. The stigma of illness has been the focus of studies into self-concept as a socially constructed perspective (Kleinman, 1988, Franks, 1995) and how bodily functions in illness are rooted in social relationships and social order (Lawton, 2000, Millen and Walker, 2001). Goffman (1963) says that those who are healthy are considered 'normals' and those who are diseased are therefore discredited and believed to be not fully human. In addition, those whose stigma is invisible to others are discreditable but not yet discredited which influences the individual control over the extent of their discreditable condition to mediate the transition from a healthy ('normal') state to an unhealthy, discreditable state (Joachim and Acorn, 2000).

A number of the women chose to 'pass' (Goffman, 1963) at different times in their lives. An example of the desire to avoid being discredited by her disease was Joan, who orchestrated who she told and who she did not. She felt that whoever she told would associate her breast cancer with death and she wanted to avoid the erosion of social relationships and what she felt was inappropriate pessimism. In hospital having cancer was accepted and 'normalised' and she enjoyed the social acceptance of cancer in the hospital social order.

*'The minute people hear you've got cancer you can see their eyes glazing over and they're running through the first verse of Abide With Me, and wondering where their black hat is, and so on, you know. And, erm, you, you really, sort of, have to fight against that. I mean, half of me was inclined not to let people know, well, I didn't let them know to start with. And, the other half is, erm, feels that you ought to say "Yes I've had it and I'm fine" because, erm, it'll, it'll counteract this awful, sort of, doom and gloom atmosphere that people...[pause]. But then, the thing is, when you're in the hospital it's a nice relaxed feeling, it's absolutely normal to have cancer, so what you know, when you don't have to fend off these reactions from people? It can be quite blatant or it can be very subtle, that only perhaps you notice, you know, maybe eye contact or changing to the other side of the street.'* Joan

For Joan, being a hospital in-patient appeared to normalise what has been referred to as social deviance (Parsons, 1951), and allowed a sense of belonging with those who understood a life lived through cancer. But for others the desire to 'pass' as normal (Goffman, 1966) allowed them to enjoy traditional relationships without the compromise of their disease.

Perhaps an extreme example was Jo, a single mother who was in a new relationship which she was enjoying. She was asymptomatic and, at the time, physically uncompromised by her disease. She had not told her new boyfriend she had progressive breast cancer so she could enjoy the social role as partner without compromise. What influenced her decision to withhold her diagnosis from her boyfriend was her previous relationship. Her last boyfriend ended the relationship because of her disease.

*'I was absolutely devastated. "I can't cope with the cancer, I don't want to watch you die", they were his exact words. I really, really cared about him and I have been without...away from the children's father for about three years you see, and it has just been me and the girls and he met, he was the first person to meet them, um so when he rejected me it was like, I don't know I was more angry with myself for letting him.'* Jo

Few took extreme action like Jo, but they commonly mediated the internal reality of their diseased body by a projecting healthy external self-image, concealing the former to reinforce the latter to maintain social order. This was easier to achieve when they *looked well and felt well*.

Charmaz (1983:168) said that 'over time, accumulated loss of formerly sustained self-images without new ones results in a diminished self-concept'. While the majority presented with physical symptoms, such as pain or fatigue, this was rarely visible. The integrity of the physical body of those with progressive breast cancer was disrupted but the external image remained intact. They appeared to continually stage manage their representation of self in their own self-interest and to protect others from their reality to maintain social integration and social order, often very successfully. For example, Stephanie continued to live a busy social life, and those around her, including her husband, compromised very little for her as she chose not to talk very much about her disease and didn't want her self-image to be compromised by illness.

*'Non-medical people feel well you know I had a really rough time in 1999 but you know I have been fine since then, they really don't...[pause] and I don't even think my husband realises this, how much one is hanging by a thread in my sort of state.'* Stephanie (2005)

Stephanie's description of living in silence with progressive disease is an example of how the women could feel apart from those around them and the emotional burden of coping alone over time with the anticipation of progressive disease. To maintain a cohesive sense of self, and mediate the discontinuity of self from the progressive disease and its impact on social order, it appeared that the women chose for the most part to withhold from others the reality of the physical and emotional burden of a life with progressive disease and develop means of projecting a self-image of health to avoid the disintegration of the whole self.

#### **4.2.2 Developing contingent identities**

*'When being discounted is a constant threat, individuals often feel compelled to negotiate their identities, even with family members. They may feel defaced as they no longer perform ordinarily expected activities.'*  
(Charmaz, 1983:185)

In mediating transitions in identity the women appeared to adopt what will be termed as contingent identities. The term contingent identity describes when women adopt an alternative self-representation when faced with threat to their identity to avoid being discredited. For example, contingent identities were often adopted when they were adjusting to new levels of progressive disease or were experiencing uncontrolled symptoms which compromised their ability to maintain everyday life. An example of the process of adoption of a contingent identity would be when the women described times when they were given news of progressive disease. Commonly an internal dialogue appeared to be used to adjust to the news of disease progression, while others

adjusted by talking to another person in depth about the news, the implications and choices involved. Both overt and covert choices appeared to be then made about how to remain within their social worlds, such as who to share the news with and how to integrate the news and its implications in everyday life. As will be described, two different contingent identities were identified; stoicism and absolved responsibility.

#### **4.2.2.1 Stoicism**

The contingent identity most commonly used was one of stoicism. By projecting a combative self-image of positivity that the disease must be faced head on and beaten the women appeared more likely to be accepted back into their social groups with little compromise.

Stoicism appeared to be greatly rewarded by those around them with praise for their strength and fortitude, with the continuity of valued relationships and the ability to maintain the status quo. This projected image was easier to maintain when the women *looked well and felt well* and the disease and its symptoms were not visible. At the point of diagnosis of progressive disease the women often acknowledged fear and internal chaos, searching for hope and stability. Many struggled to adopt a contingent identity initially but quite quickly acknowledged that this was expected of them, by partners, family, friends and even healthcare professionals. Those who had numerous episodes of disease progression understood the process, but equally it became harder to maintain with each episode of progressive disease. Contingent identities were described in numerous ways; the *'barmaid's face'* by Shelley, *'Mum as this stable thing'* by Jane and *'just get on with it'* by Dawn.

An example of a stoic contingent identity was Jill, who continued to work as a counter clerk through most of her disease and treatment. Her manager actually put her forward for an award as a good employee, which she won. He said *'you deserve it, you come in, you keep going'*. She went into work *'even when I don't feel 100%'*. Her friends and family were central to her ability to live with progressive disease. Being rewarded by praise from her colleagues, friends and family for her stoicism was central to her sense of self and identity which in turn allowed social inclusion which she greatly valued.

*'I do feel a big chunk of it is mental, up here as well [touches her head]. I don't know. But that's how I feel personally, how I deal with it mentally. For me it's not going to beat me, well not yet anyway. And I'm determined to fight it as long as possible. But with that comes the support from your friends and your family doesn't it? Because I know I've got them in the background. "Come on Jill".'* Jill

One of the motivational factors in her desire to maintain her social role as employee was to avoid having to spend time alone at home, which gave her time to dwell on her illness, leading her to feeling isolated and low in mood.

#### **4.2.2.2 Absolved responsibility**

The second contingent identity was absolved responsibility. This was when the responsibility for the cancer, its treatment and care was handed to others – healthcare professionals or family members. The progressive disease appeared to be a bodily concern and disconnected from the self. Two women, Shelley and Deborah, appeared to adopt this contingent identity, detaching themselves from the disease as another entity and adopting a passive social role of absolved responsibility. They attended appointments and accepted treatment but the responsibility for their physical body was that of the healthcare professionals and/or family members. In this they followed instruction, took analgesics and anti-cancer treatment but did not acknowledge they were in any way responsible for their physical body other than being the compliant patient. They appeared to take the absolved responsibility further by relinquishing control of their treatment to a family member who was conversant with the treatment regimens (where the women were not) and administered medications. This contingent identity meant the transition from person to patient was permanent and the individual over time withdrew from their social roles and succumbed to the dependent sick role of patient.

Deborah was an example of someone who used the contingent identity of absolved responsibility. During the first interview with Deborah her husband stayed in the next room and was always in ear shot. When Deborah's illness narrative turned to her medical management and treatment she called her husband to come into the room and take over the story. Likewise, Shelley's husband took full responsibility for her medication.

*'If you need my drugs list I will need Martin because he is my drug dealer. I can't even tell you what I am on because he puts them in my little pots.'*

Shelley

In adopting and projecting a stoic contingent identity it could be said that the women were concealing the social reality of their disease. Conversely, by adopting what could be considered a passive social role, those adopting the contingent identity absolved responsibility defined their identity so that others understood the hierarchy of the social order in their life with progressive illness. However, it is difficult in some cases to determine whether the choice was conscious or chosen. It could be considered that the adopted contingent identity was pre-determined by personality or past experience of

coping in adverse situations. For example, Deborah adopted the contingent identity of absolved responsibility but she had experienced many traumatic events in her life. These included a mother who rejected her throughout her life, the death of a child and a physically abusive first husband. It is possible her life events determined how she adapted to a life with progressive disease.

Adopting a stoic contingent identity allowed Jill to remain a central figure in a wide social group which was important for her, and it appeared she would do anything to preserve this. Stoicism was rewarded by her social group and she determined to remain within it, which she did until days before her death.

Contingent identities did not always appear to be sustained indefinitely and most women had one or more people to whom they could talk openly about their thoughts or fears. After these moments of disclosure, they often retreated back into their contingent identity to face the rest of their world. From the women's description of events that challenged their identity, there appeared to be a fear that if they dropped the veil of the contingent identity they would be discredited, face a withdrawal of social support and lose the social roles and order which allowed them to maintain social equilibrium despite progressive disease. Some described events when they knew others avoided seeing and interacting with them. Ultimately it appeared that most had family or friends who were able to support them.

*'I have got a really good core of really close friends and they are the ones that have stuck by me, so and at the end of the day one really good friend is worth what more than 108 mates. So yes, you realise who your real friends are. But no, a lot of people couldn't even look at me. It's frustrating because it is me that is ill not them, it's me that is coping with it not them.'*

Jo

An alternative to adopting a contingent identity would be to completely acknowledge the external and internal reality to others but none of the women appeared to do this through choice. The only time this was done was when their disease dominated their lives and the impact on the self, body and social order was not in their control. As soon as a level of wellbeing was restored, they appeared to restore their contingent identity and so social order.



### 4.2.3 Transitory self-representations in contingent narratives

Ewing (1990) argues that people can project multiple, inconsistent representations of themselves according to the situation they are in. These multiple selves are not necessarily conscious and are often fleeting. This concept is interesting when examining the narratives of the women in this study. They most commonly projected a self-representation of stoicism but this facade could drop or switch to another unconsciously. An example of this was Shelley, who told me with delight that her last scan showed no sign of disease and she was disease free. Later in the same interview she acknowledged she '*was terminal*'. While caution is levelled at researchers to ensure that illness narratives are a true representation of a life biography (Riessman, 1993), Ewing (1990) argues that to experience the temporal flow of experience, individuals redefine themselves in response to internal and external stimuli. So each participant may and did represent themselves in a number of self-images over time.

An example of multiple representations of self in response to internal and external stimuli was in Jane's second and third interviews. As the second interview began, she projected a combative self-image. She wanted to face the disease head on and '*beat it*'. She talked to me, but I said very little throughout the interview. Clearly I was there to listen, even covertly being reprimanded by her tone of voice and a shaken finger when retaining a neutral stance while listening to her talk of the power of complementary therapies to shrink tumours. She spoke of the strategies she had adopted to help her cope, promote wellbeing and increase her survival time: learning meditation, counselling and a healthier diet and lifestyle. Six months later in the third interview she was physically well, but very low in mood, crying and sobbing uncontrollably and extremely distressed as soon as the interview began. The self-image she had been at lengths to project in the second interview had gone.

*E: 'Do you want to do this today? [silence] You don't have to do this; we can sit and talk without the tape on if you want to.'*

*J: 'No, no, I don't mind. No, No, this is part of it and you don't necessarily see this part in the publications and research.'*

*E: 'No you're right.'*

*J: 'But this is... [pause] this is one of the biggest [crying]...and I can't... [crying] and I'm quite a positive person, an optimistic person, but I can't put a face on it any more.'*

*E: 'Do you feel a pressure to put a face on it?'*

*J: 'Yeah [crying]...but I think I probably put that pressure on myself. I don't think anyone else has put it there. You know it's an exhausting way to live.'*

Towards the end of the interview, when she was calmer, her teenage son walked into the room. He asked her when supper would be and she smiled at him and told him 'around 6 o'clock', instantly shifting to the represented image of mother, restoring social order, equilibrium and everyday life. Jane's example demonstrates the effort and 'work' involved for the women in maintaining a contingent identity for themselves and others; the everyday labour of remaining within their social worlds, while feeling slightly apart. This is what Davies and Sque (2002) called *'living on the outside looking in'*.

Representations of self could change fleetingly during interviews: over time, as a relationship grew between me and the women, the representations appeared to become more consistent. The projected image of stoicism in the first interviews was often replaced by representations of women allowing themselves to show sadness, fear, anxiety and helplessness in the second and third interviews, particularly if they had experienced progressive disease or physical decline. At these times, women talked of the cathartic nature of the interview experience, narrating thoughts and fears they had never verbalised. These moments could also be short lived, followed by the restoration of the contingent identity, as if their taped narratives were representations of themselves kept in perpetuity so they wanted to be remembered as stoical, and brave. Karen admitted she wanted *'to be remembered nicely'*.

Likewise, at times the women used humour to entertain me. In doing so, the direction and tone of the interviews remained on safe ground and this appeared to allow them to avoid lowering the façade of stoicism and show the more painful, fearful elements of their breast cancer narrative. Again they used this less in the latter two interviews as we became familiar to each other.

In her final interview Shelley and I discussed her use of humour in her narrative and she talked of using it often as a means to navigate relationships and avoid aligning her internal and external reality, so removing what she termed as her *'barmaid's face'* of the painted-on smile. In using this approach she was able to maintain her chosen self-image of happiness and health and avoid the disintegration of self, which I saw fleetingly in the latter two interviews. This example demonstrates how the contingent identities provided a means to realign the self, body and social order and how they were used to restore the identity the women chose to project and reinforce their desire to be a part of everyday life by aiming to maintain social order.

Joan and Evelyn were the exceptions in that they maintained their stoic identity throughout the interviews. Both were older and used humour and their stoical demeanour to maintain this. Joan quite overtly blocked the conversation if she felt her identity may have been compromised during interviews, at one point stopping

mid-sentence to remark on a small bird in the garden, changing her narrative from an uncertain future to the advent of spring. The ability to mediate the discontinuity of self in the face of progressive disease was easier when the bodily manifestations were minimal and controllable. When the body demanded attention, it appeared harder for the women to maintain their social identity and social order.

### 4.3 The body as dominant

At times of disease progression, or when women experienced uncontrolled symptoms or side effects of treatment, the diseased body could dominate their lives. There appears to be ambiguity in defining the diseased body; either the body is disease free and healthy or it is diseased and ill and malfunctioning. This definition reduces illness to a physical state but it is also a social matter (Burr, 1995). Burr (1995) suggests that the social response to illness is determined by the individual's ability to maintain their usual activities.

#### 4.3.1 The threat of progressive disease

Throughout the illness trajectory there were times when the women's identities were threatened by episodes of disease progression, uncontrolled symptoms and emotional adjustments. At these times they often *looked well but felt unwell*. Where possible they appeared to adopt one of the contingent identities previously described which meant they became performers. They stage-managed their response to threat in order to remain within their social worlds. Threat could be the psychological or physical manifestations of living with progressive cancer. To do this they often went through a period of adjustment, firstly facing and adjusting to the internal reality then choosing a contingent self-image to face the world.

Social order appeared particularly challenged when the women struggled to maintain continuity between body, self and their social world in the face of progressing disease. Subtle shift in relationships not only confronted the women's self-concept but appeared to confront the values and beliefs of those around them. It could be considered that this was influenced by the simple fact that the women looked like the healthy members of the social group but had a life-limiting illness. Their social groups and the wider network appeared challenged and threatened by this unsettling image of cancer, possibly even more so as it was not visible. Adhering to a stoic contingent identity while experiencing symptoms could be rewarded by social affirmation of their strength and fortitude, particularly in the face of pain, almost challenging the women not to lose their contingent identity and thus reveal someone acknowledging advancing cancer and certain death.

### 4.3.2 The shift from discreditable to discredited identity

An example of the impact of the physical manifestations of illness on identity was an experience Ayesha had at work. Ayesha had worked in an office for 15 years. It was a job she enjoyed and over the years she had been given increasing responsibility. She continued to work through her treatment for lung metastases, only taking time off after chemotherapy. She looked well but felt fatigue and had a persistent dry cough as a symptom of her lung metastases. Ayesha made a minor mistake at work and she was instantly demoted. Her manager, who had recently taken over the department, immediately suggested she consider her position and whether she was still able to do her work. She was devastated. When she was well, her work allowed her to maintain the social role of colleague that she greatly valued and when she *looked well but felt unwell*, by adopting a contingent identity of stoicism she felt rewarded with social integration by her colleagues who provided her with social support and friendship. This was until her cough meant her stoic 'healthy' identity was discredited and the social image of health was compromised by a bodily symptom, a symbol of progressing cancer and ultimately death. Ayesha acknowledged her persistent cough was irritating to others, her husband joked as much, but she suspected her manager's reaction was deeper than that. She had been a good employee and had never made a mistake before.

*'I think people find it hard, which I don't understand really, because outwardly I am not ill. I don't look ill, but I think because of this cough which is to do with the tumour in my lungs, is festering and I think every time I cough it reminds everyone that this thing is here.'* Ayesha

The internal reality of Ayesha's cancer became an external reality for those around her and could no longer be hidden from others. These episodes commonly went unacknowledged but others' behaviour indicated that it was acknowledged but not integrated into social relationships, so their social reality diverged from those around them and in some instances, people began to withdraw from them, or in Ayesha's case, remove the discredited body from the social group.

Stephanie found the problem of *looking well but feeling ill* was extended to her oncologist, who denied her the opportunity to make her internal reality an external, acknowledged reality.

*'I go in there and he says to the nurse, "Oh this is Stephanie, she is absolutely, she is the best cancer patient you can possibly have, she has been on this for six years, she is absolutely fantastic". So then when he*

*asks how you are you don't feel like letting him down and saying "well I am not great".'* Stephanie

From the cross-sectional survey it is clear that symptom burden, particularly pain, is a common problem for those living with progressive breast cancer. Many appeared to be tolerating uncontrolled symptoms although this was rarely apparent. Paula came to the end of her second (and last) interview before she winced, and on questioning admitted that she was in constant pain and was only using over the counter analgesia. An added complication for Paula was her fear that stronger analgesia would make her drowsy and affect her ability to retain her role as mother. Likewise, Karen was breathless on exertion but when receiving visitors, including me, she put on make-up and remained seated, which appeared to avoid her projecting an image of ill-health.

At times of disease progression identity was threatened as the women became symptomatic and embarked on new treatment. Their biography was repeatedly disrupted. Often the advent of progressive disease or visible illness heralded referral to formal support services (psychology, community palliative care services). Those who received these on the whole felt the benefit. However, the oscillation of the disease often meant they recovered physically and a level of wellbeing was restored. At other times, the diseased body demanded attention and it became problematic to maintain a cohesive social identity.

## 4.4 Social order as dominant

The dominating central theme of all the narrative was the social pressure from others on the women to maintain the image of 'wellness' and coping. If they could maintain this, they felt able to remain within their social groups, maintain their social roles and protect others from their inner thoughts, fears and concerns. This also allowed them to protect others from the harsh reality of a life with progressive breast cancer.

### 4.4.1 Minimising illness to maintain social identity

Lorraine was compromised by her disease and experienced breathlessness on exertion but maintained her role at work by controlling her activity and underplaying the extent of her illness.

*'I am always mindful when I am going to say what I am going to say to an individual and I am very quick you know, once I tell them you know, I am very quick to say you know "don't worry about it you know, don't worry about it. I feel fine but I am just letting you know".'* Lorraine

As their present and future lives diverged from those around them, the women often appeared detached from the rhythm of everyday life, going through the motions, appearing to maintain their social reality but living with an internal reality of progressive disease and fear of physical decline and certain death in the future. The constant challenge was to maintain equilibrium in the face of progressive disease, and continually be able to adjust, anticipate and manage any discontinuity of self, body and social order.

While the individual living with progressive disease sought to maintain social continuity, those around them appeared to reinforce their need to retain a healthy self-image. By projecting a physical image of health and a self-image of stoicism, they were rewarded by social praise and at times mock disbelief that they were living with cancer. It may be that their healthy social image allowed those around them to deny the reality of the situation, which the women in turn colluded with.

*'People say "well, how are you?" and you say "fine, thank you" [laughs] but you know that you're not, and it's kind of a bit weird!' Dawn*

Many of the women endeavoured to protect others from the realities of their disease, which was easier when they *looked well and felt well*. As many could live for years, they felt they should not talk too much about their disease in order to maintain everyday life and relationships and to protect others from their internal reality of living with progressive disease, constant vigilance, and uncertainty.

*'You don't want to sort of burden your family with how you feel and it's umm... [pause] you just feel that you're being selfish by talking to other people about it... [pause] but I don't really talk to people much about it. It just seems an added complication and there is nothing they can do about it anyway. I just get on with it really. Sometimes I sit and have a cry on my own, but otherwise I just get on with it really.'* Jenny

Jenny felt the pressure within her family to remain strong. On one occasion she was very frank with her husband about her feelings and fears and he was very shocked and distressed, not realising what she was enduring. The invisibility of progressive breast cancer was to her a double-edged sword. She could hide behind it although at times wished it was more visible. Her husband's reaction made her reluctant to compromise her self-concept in front of him again. Jenny was an exception, in that at times her narrative tipped over into anger at the lack of acknowledgement of her situation which meant she had to endure it alone. At other times she acknowledged that by projecting a

healthy external image she made it hard for others to support her as she became adept at deflecting offers of support.

*'I think in a way I would rather have a broken leg, at least you can see somebody has broken their leg. You know when you've got cancer no one really knows.'* Jenny

#### **4.4.2 Dissonance between the internal and external reality**

Despite the physical manifestations of progressive disease, at some point all the women maintained a significant level of physical functioning (as will be demonstrated from the illness trajectories described in the next chapter) and numerous social roles. Angela functioned well as a partner, mother and employee with little compromise until the final months of her life. Her family told her they would not cope if she became confused and did not recognise them and she worked hard to avoid this scenario and protect her family from the harsh reality of her progressive disease; constant pain and fatigue. Angela returned to this potential scenario a number of times in the interviews. When she was diagnosed with brain metastases for the second time she did become confused and did not recognise her family. Her identity as a whole, cohesive person changed instantly and while she recovered well physically, returning to her social roles, she and her family never really recovered; it had been their worst fear and consequently was also Angela's.

*'I have never seen him cry so much, he said he could cope with me being ill, he could cope with me being incontinent anything like that but it was the not knowing him.'* Angela

There was a subtle shift in her relationship with her partner and children. They watched her vigilantly and constantly asked her if she was alright, shifting the social order in the family as she changed from matriarch to dependant. She found the discredited identity difficult and went to great lengths to restore the identity she had before breast cancer, of someone who looked well and was able to undertake tasks and roles which defined her identity before progressive disease. Despite profound fatigue and constant pain, she returned to work, did the catering for 100 people at a friend's wedding and maintained household tasks. However, the family fear of the repeat of the event loomed over them all and threatened her self-concept and the social order she struggled to maintain.

Angela's example describes a family almost challenging a woman to maintain a socially acceptable identity of health by telling her what they could not cope with and events which in their eyes would compromise social order.

While most had no external signs of progressive disease, Joy was an exception. She weathered the oscillations of progressive disease a number of times, with acute episodes and crises requiring hospital admission. When she recovered from a particularly difficult time, her hip fractured and she had to walk with a stick. This caused her no pain or other symptom but her self-concept was compromised, as was her relationship with others and social order. Joy *looked well and felt well* but her social image was compromised.

*'I have to walk with a stick and of course that makes it obvious to other people that I have got something wrong with me, and it has altered my relationship with my husband because suddenly I was almost this little old woman...because he is tall and I was tall and suddenly you know if he gave me a cuddle I was at his armpit you know, we just don't sort of synchronise anymore.'* Joy

Joy was able to function fully but she felt the visual image of walking with a stick compromised her self-image through others' behaviour. Her husband withdrew from her physically and emotionally and while she was surrounded by supportive friends, she felt their behaviour toward her had shifted.

Others felt they had co-constructed social roles for themselves and their social group which they felt pressure to maintain. In doing so they protected others and by taking on these roles in the group hierarchy, maintained social order and remained within the group. Dawn's family all knew she had progressive disease but rarely talked about it. She had been assigned a role within her family as 'the strong one' and from this it could be assumed she would not burden others with her fears and would remain the supporter of others.

*'My mother tells me I have always been the strong one in the family so I suppose I, I ought to a certain extent...[pause] I think well best keep being the strong one then, so it is almost as though I am being strong for everyone else.'* Dawn

#### **4.4.3 The well meaning friend**

A subtle erosion of identity and social role which affected the integrity of self-identity that many appeared to struggle with was the well meaning friend. Well meaning friends and family would inadvertently erode the women's sense of self. During the period of being interviewed, Joy was most often asymptomatic and able to function physically with little compromise. She was also emotionally well but found the shift in her



friendships frustrating and that it eroded her sense of self and social identity. This and her marital problems led to her feeling isolated.

*'...your relationship with everybody suddenly changes. People tiptoe around you a bit which can be a bit irritating at times because I find it patronising, people feeling sorry for me. I have got a friend who has been very supportive in this last year, she says "I'll do the driving", you know I'm not treated on a par any more, I'm treated as though I have a disability, um which I suppose I have but it doesn't stop me driving round. I want to be treated the same.'* Joy

These relationships were difficult to navigate as there was a shift in the balance of social order. When the women *looked well and felt well* despite manifestations of disease becoming visible they didn't want to be treated differently to anyone else in their social groups, particularly not becoming the 'cancer patient'

*'I don't want to be...what's the word?...defined as somebody who's got cancer because there will be plenty of time for that and it's also not very nice because you sort of feel you've lost your identity. You've lost who you were and you're somebody who's got cancer and you know that's horrible. I mean the only difference is that people are terribly (or some people) are terribly nice to me and exaggeratedly [laughs] nice, and sometimes you do feel like saying "come on you, just treat me normally".'* Charlotte

#### **4.4.4 Living with uncertainty over time**

This constant 'identity work' reduced the risk of a disintegrated social reality and a life lived slightly apart from others as the women's future diverged from those around. Other than moments of fatigue and joint pain, Jenny *looked well and felt well* throughout the study but her uncertain future and anticipation of a time when her disease would progress dominated her thoughts almost constantly.

*'I still get quite low. I am not as bad as I was with that. But I still get quite, I guess... [pause] out of my head, I am just waiting for it to happen. I am looking over my shoulder and I am waiting for it to happen. I can't move on beyond it. I just can't put it away enough. I think it's not knowing where it will come back or when it will come back. It's just I find that difficult. If somebody said to me "well it's going to come back on Thursday 15<sup>th</sup> November" I could deal with that. It's the uncertainty of not knowing, and therefore not being able to plan.'* Jenny

Jenny managed her own business and staff as well as a busy family, and did not speak honestly to anyone about her disease outside the interviews. She *looked well and felt well*; her identity appeared intact but she was enduring her fears in silence.

The periods of disease progression, treatment and restoration of wellbeing which will be explored in the next chapter challenged self and social identity. Women found that those around them were supportive and able to marshal resources much like the women at difficult times. But over time, as there was restoration of wellbeing, the support too could wane. This was at times appropriate and allowed the women to re-integrate with their social groups and restore social order. However, it could also mean that their identity within their social groups could shift from health to illness, independence to dependence, and back again. The women continued to live with the reality of life with progressive disease but family and friends resumed everyday life, at times even healthcare professionals withdrew. Those in receipt of palliative care commonly reported being discharged from the service when they no longer experienced physical manifestations of the disease, with little apparent attention to the psychological adjustment and ongoing coping associated with progressive disease.

*'When I was first diagnosed it was as if um, nobody could do enough for me if you know what I mean. I was overwhelmed with people who wanted to help me and um, come and visit me and talk to me but now sort of seven years down the line, I don't get offered anything you know. Nobody says "how are you?" no nurse comes to visit, no Macmillan nurse telephones me to say "how are you doing?" I was a patient of the hospice for three years. My illness has not gone away, my problems have not gone away but it's like all the support has gone away....it's as if I'm back to normal, back to being mum, being grandma again and I am okay, I am fine. I have had cancer you know they don't think...no one seems to think or realise I am still living with it.'* Susan

However, in order to reintegrate back into everyday life after periods of progressive disease and treatment, women often wished to restore some equilibrium and social order for themselves and those around them. In doing so they projected an external reality of health even though the internal reality may have changed in the face of these episodes.

*'We have been through phases when we had lots to talk about, what is going on sort of...try to kind of be honest with each other but again it feels like you can't, you can't go on like that every day because it is too exhausting so um, until something comes up and kind of sets us back, like*

*when I start a new round of chemo, that's the time to kind of talk again about what's happening but um, mostly we go on as normal.'* Dawn

The risk inherent in telling others their diagnosis of progressive disease was the women's emotional response – and a desire not to show this or face the emotional response of others. If faced with rejection, avoidance or distress, the women could become stigmatised by their disease and so face a life outside the everyday life they sought, compromising their social identity. As the disease progressed they faced re-telling many times. Some women talked of a personal sense of failure each time their disease progressed through treatment, as if they were responsible for the disease progression and felt for others when they had to tell them.

The exceptions to the approach to maintaining social order in the face of progressive breast cancer were Mary and Alex. Mary appeared to transcend her illness, even in the face of uncontrolled symptoms. She maintained her social roles as far as she was able and so remained within her social groups. She was always frank with her husband and friends about her disease and how it affected her, both physically and psychologically, and they had open dialogue about her cancer.

*'Went away for the weekend to London, did a lot...ehrm and felt okay but didn't really want to eat, so I find it difficult going to restaurants now but I've decided what I do is I just have the starter while everybody else has the main course and I can cope with that.'* Mary

Mary said she had lived a good and enjoyable life and while she was dying prematurely, she appeared to be resigned to this. When she did appear stoical, this did not seem to be a contingent identity but more a way of being for her. She approached her healthcare management as an active participant, involved in decision making and planning the future. She sought support from, and was supported by, community healthcare professionals with whom she had a good relationship, built over years. Even towards the end of her life, she was included in social gatherings and navigated what was achievable.

*'...you've got to capture these moments, do you know what I mean and it's...I think you find that when you're getting to my stage then every little thing means quite a lot to you, things that you haven't had time to look at before, that sounds a bit dramatic but it is true, I mean I actually, I thought oh my goodness, these lovely butterflies I must have a look. And to me, just to go out there and just smell the lavender and all that, it's very, very relaxing, very nice. Everybody is looking forward to what's happening you*

*know, next year or something. Well when you can't, you can't do that...but you do start to think, look at life a bit differently I think and I keep saying to my son, make sure that you know when you're happy.'* Mary

Alex worked at being as informed as possible about metastatic breast cancer, always seeking the latest information on treatment and discussing it with his oncologist. He felt this allowed him to be informed and forearmed. He felt well supported by his partner, from whom he sought support, and had open communication with his employer and friends.

*'I just get on, maybe you call it a front but I just get on with it, I just every day just um, just a normal day you know we will be going out and I can go out in the evenings, go out for a meal, we just do normal stuff and it is most, mostly lucky that I mean I am never not well enough to be able to plan something and feel like I can actually carry it out, I am not constantly saying oh I don't feel well today, I can't do what we said. I have been fortunate that, that um, you know I haven't actually changed my mindset I suppose just, just carry on as normal and just slow down on the work front, that is almost an excuse to give me more time and energy for the social stuff and that suits me fine, much prefer the social stuff.'* Alex

Both Mary and Alex were exceptional compared to the others in that they appeared to have a level of acceptance and fatalism about their futures and an appreciation of the present. The commonalities of Mary and Alex were that they both had a supportive social network and took an active part in the decision making of their medical management.

#### **4.4.5 Relinquishing social roles**

As their disease progressed over time, some had to relinquish one social role in order to maintain others, choosing between valued social positions or social order where their inability to maintain a contingent identity was more likely to be accepted. Angela struggled to maintain her social roles of partner and shop manager, but each compromised the other. She talked about this in her last interview:

*'I can't do the job properly. I still get tired and really and truly all my energies go to work. I come home and I sleep. I'm no company for John, he's just sat in the chair...[pause] I feel like I've not given him any time...[pause] I'm just wasting my time away, that's how I feel sometimes 'cause I haven't got the energy to do anything. I make myself go out on a Saturday night and I hate it, I hate it.'* Angela

As her disease progressed, she appeared to succumb to losing one of the two social roles she most valued and sought to maintain – that of partner – in order to maintain her role as shop manager. Her world became smaller and she began to withdraw both emotionally and physically.

*'We've always had Saturday nights out me and John, Saturday nights were our night, and I find it such a strain. This Saturday just gone he said "do you mind me going out", I said "no, no you go". So he went out and I just couldn't. I just lay there and slept and slept. So yeah, sometimes I feel my life is go to work all day, come home and sleep. Get up, go to work, come home and sleep and that's how I feel it is. And I got, I have got to admit it has got harder, has got harder but there's not a lot I can do about it'* Angela

Likewise, Paula loved her job and enjoyed her identity as an active, working, single mother successfully balancing these roles in her life. She proudly spoke of a past self-image of a multi-tasker able to survive on little sleep. Paula began to experience uncontrolled pain and profound fatigue while still working full time. As her disease progressed and her social roles were challenged her contingent identity of stoic copier was compromised. Paula *looked well but felt unwell*, and there was a point when she acknowledged she could no longer maintain it. Fatigue began to take its toll on her ability to do her work, but she fought against stopping work for a long time.

*'I was checking it and there I am checking it and I went like that...[closed her eyes], fell asleep literally fell asleep 'cos I'd sat down on a pallet of empty boxes, folded up empty boxes, and I literally fell asleep on the job. I had to go outside, I had fresh air all the time but I had to go out into like the bright sunshine and wake myself up, and I came back and started again and the same thing happened and that's when I realised I couldn't carry on.'* Paula

For those who were mothers, this always appeared to be the last role they would choose to relinquish and the one that was fiercely held on to, with the women often resting when the children were out of the home or at school in order to maintain a contingent identity when they were present. While some did prepare their young children for their death, their uncertain illness trajectory and oscillations of their disease made this challenging. In reality this meant in most cases young children appeared not to be prepared for their mother's death and the contingent identity was maintained for them, often until days, even hours before death.

Alex was an exception in that he relinquished his job as a business man who travelled internationally to be a full-time father. When we first spoke he was proud of his pressurised, fast-paced job and career achievements and that he was able to continue his work commitments, including foreign travel, despite treatment for progressive disease. However, over time, as his disease progressed, he was symptomatic with fatigue and breathlessness. He looked well but felt unwell and was happy to relinquish his career in favour of the role of father. Doing the school run and helping with homework brought him much satisfaction, even to the point of acknowledging his disease had made his relationship with his young children closer. Breast cancer is not common in men (300 a year as opposed to 46,000 women a year (Cancer Research UK, 2011)). As the only man in the study, it was difficult to determine the gender specific nature of his change to become a full-time father in the absence of other men with progressive breast cancer. The women with young children already saw their children as central to their lives.

#### **4.4.6 Projecting into the future**

All the women at some point referred to the end of life, even though for some this was only a fleeting acknowledgement that they had a life-limiting illness. It appeared easier for them to perpetuate the idea that there were many treatment options and the possibility of new treatment in development. Discussing the finiteness of their lives focused on unfulfilled roles such as parent or growing old with a partner, foreign travel, enjoying retirement, and the preparation for and nature of their death.

The central fear was of the loss of identity and relinquishing control in their final days. Dying as a cohesive whole person was what those who talked about the end of life sought. During interviews when this was discussed the tables often turned and I was asked questions about the end of life, predominantly whether death was sudden and traumatic or peaceful and serene. The latter was obviously the desired death of a cohesive bounded self, body and social identity at the end of a continuum of life and dying.

In early interviews relinquishing social roles was feared but for those who were closer to death, there appeared to be a slow 'letting go' of physical tasks that they could no longer do. When we last met two weeks before her death Karen's sister was clearing out her kitchen cupboards and her husband was working hard to complete gardening tasks she wanted to do before she died, although no one had acknowledged why they were doing these tasks and that she was dying. She was never alone, which to her meant she felt she had to maintain her contingent identity so that she did not upset others.

*'...because I have always got people around me I am always holding it in, um, you know I can't break down or have great sobs because I upset everybody else so much and they would take a lot longer to get over it whereas I might sob and cry and feel fine then they will be reacting to it for weeks afterwards, so. You wouldn't believe how many visitors I get, I have so many visitors and if I haven't got visitors then the phone is going, I don't actually get a lot of time. Sometimes I would like more space than I get.'*

Karen

Lawton (2000) refers to the social death of people at the end of life, when the loss of self is determined by the loss of social relationships as people avoided the dying person. This 'social death' was not apparent in the women's narratives, perhaps because I did not see them at the end of life, or when I did they were not aware they were so close to the end of life. However, as the failing body began to dominate identity, the loss of self and identity became more apparent and women had fewer opportunities for social interaction. This did, however, allow some of them to maintain their contingent identity and leave a memory of a cohesive self, body and social identity. They would not be seen by members of their social group (outside immediate family) as a disintegrating self but remembered as whole person, maintaining a cohesive self, body and social order.

There was not a category of *looking unwell and feeling unwell* as this was not apparent through the interviewing process. Although I saw or spoke to two women within weeks of their death, while they were physically compromised by their disease they did not look unwell and continued to present themselves in a healthy image with little external indication of their internal reality.

For the most part, the women appeared able to mediate any potential disorder between the self, the body and social order by projecting a social identity which allowed them to remain integrated within their social groups. However, to maintain it in the face of progressive disease and declining health meant constant 'work'. In so doing this, at times this meant they could live slightly apart from those around them as their lives and potential futures diverged, heightening a sense of isolation.

## 4.5 Summary

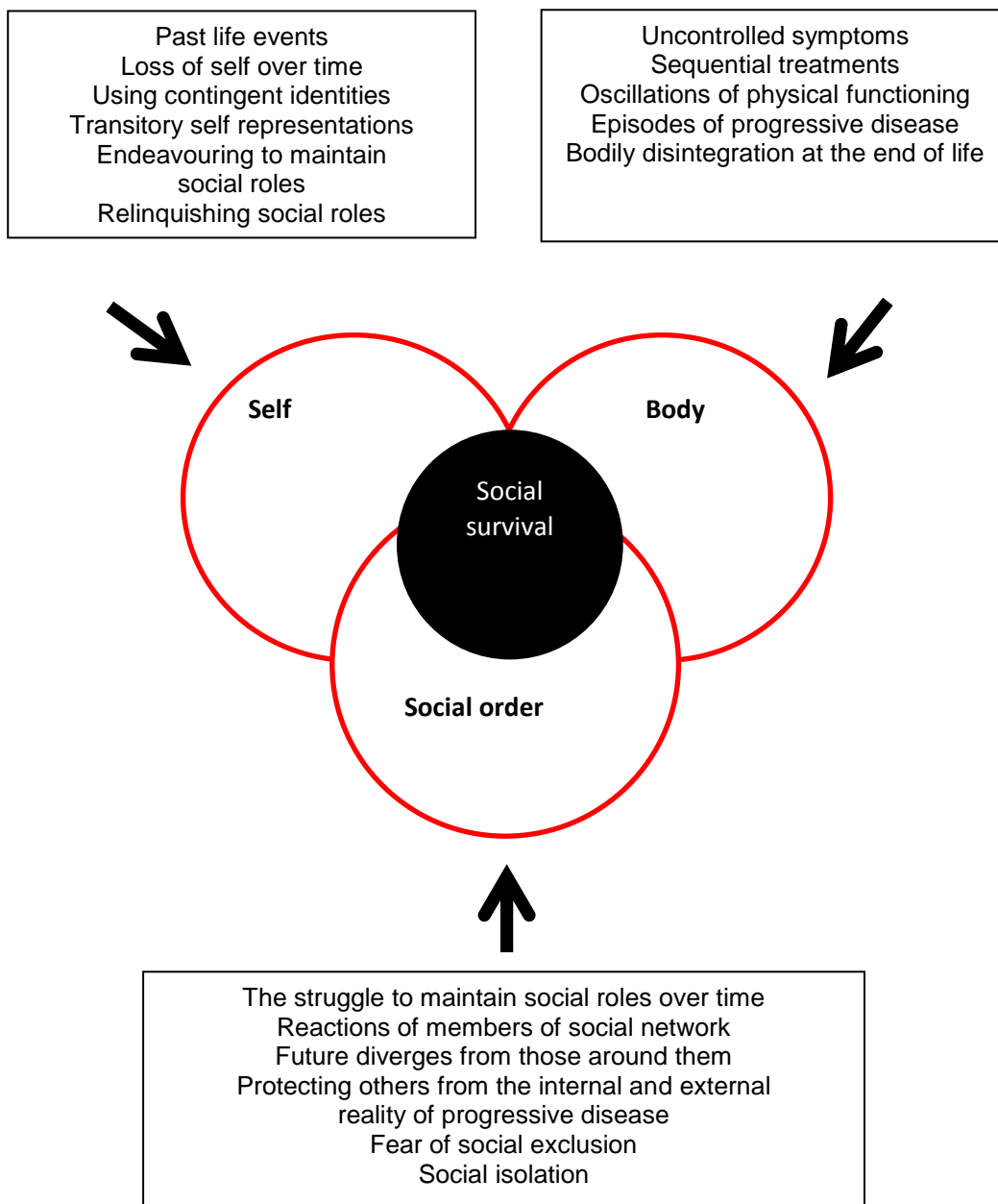
The women faced threats to their identity (Figure 5) and sought ways to maintain their social identity by mediating any discontinuity between the self, the body and social order. By situating the self in the narrative as a cohesive whole person, they drew on their past, healthy self-image to reinforce the present self-image they wished to project.

When the women experienced progressive disease or uncontrolled symptoms their bodily needs dominated their lives and they sought ways of mediating the body's effect on their social identity. Two contingent identities were identified – stoicism and absolved responsibility. As most commonly breast cancer does not have external indications of progressive disease, this was possible to achieve but it also meant the women could be detached from the ebb and flow of their everyday social lives as theirs diverged from those around them. When they looked well and felt unwell, they could maintain their contingent identity but when they were physically compromised, for example by a symptom, their illness was exposed and their projected identity could be revealed so the continuity of the self, the body and social order was disrupted.

Social order appeared to determine the women's projected identity. The women were often rewarded by projecting a self-image of stoicism. Even those using absolved responsibility allowed their social position to be understood in the social order of their groups: illness was allowed to be integrated into their social groups but not openly acknowledged. However, most of the women did have one person (or more) to whom they could talk honestly, but frequently cloaked themselves in their contingent identity to maintain social order in the wider social groups.



**Figure 5: Threats to identity experienced by women with progressive breast cancer**



The oscillations of progressive breast cancer over time meant the women had to weather fluctuations in their health and illness and adapt their social identity accordingly. At difficult times, they appeared to use internal dialogue to adapt and assimilate progressive disease and treatment into their lives. Commonly they were rewarded with praise for their ability to do this, so maintaining social order.

As their disease progressed, the women fought to project the social identity they felt would be socially acceptable. Even close to death the deteriorating body was not necessary acknowledged and, for the most part, the contingent identity and social order were maintained close to the end of life. Where activity associated with end of life

was apparent, it was often acknowledged silently, with little or no open discussion about approaching death.

From both phase 1 and phase 2 the trajectory of progressive breast cancer and the phases women may go through were ill-defined. Throughout, women navigated the social context of life with progressive disease and worked to live with and around it. To develop a closer understanding of the metastatic breast cancer illness trajectory it became important to map women's lives in detail to understand events which punctuated them, such as progressing disease, treatment and other life events.



## Chapter 5. Defining the illness trajectory framework of metastatic breast cancer

This third and final phase of the study aimed to define the illness trajectory of metastatic breast cancer and answer the research question:

- What does the illness trajectory of metastatic breast cancer look like and by mapping this, what does it add to the understanding of the experience of living with progressive breast cancer?

The concept of a trajectory has been described by Strauss et al (1984:64) as ‘a central notion for illuminating the experience and problems of the chronically ill and those who participate in their care.’ The course of illness is shaped by the individual, events which occur throughout an illness trajectory and the physical and emotional response to those events by the individual and the response of those around them.

This chapter describes the illness trajectory of ten women from the point of their metastatic breast cancer diagnosis. The Corbin and Strauss Chronic Illness Trajectory (1998) will be applied to these trajectories as a framework for analysis. In applying this framework Strauss et al (1984) felt the course of illness could be managed with the aim of anticipating and managing events and maximising quality of life. The main concept of this framework is ‘*trajectory*’.

A sub-sample of ten women was selected to map and understand the illness trajectory of metastatic breast cancer. The ten women were selected as their medical and nursing documentation was the most complete. Triangulation of women’s narrative from interviews and documentation collected from their medical notes (including oncologist annotations of appointments, nursing notes, correspondence between healthcare professionals, investigation results and researcher field notes) aimed to map the illness trajectory of metastatic breast cancer alongside physical functioning measured on the Karnofsky scale, as previously described on page 72. Over one calendar year eight women were interviewed three times; two women were interviewed twice but died before the final interview.

All narratives were analysed in their entirety using Lieblich (1998) framework (page 66). Categorical analysis determined overarching themes and sub-categories generated within these (Creswell, 2003).

This phase of the study developed during data collection and was not part of the original study design. I had to retrospectively revisit a set of medical notes of one

participant in the survey for disease data not originally collected. In their entirety, her medical and nursing notes described the oscillations of a woman who in the beginning was physically well, planning a trip to Australia, to progressive disease, uncontrolled symptoms, treatment and physical dependence then recovery. Later in her illness trajectory she was hospitalised, physically dependant and depressed. The oscillations of her life led me to look at other women's illness trajectory. As there had been no previous investigation into the illness trajectory of metastatic breast cancer I considered it important to map this; it would facilitate an understanding of a complex problem and add significant knowledge to assist in the development of services in what was an ill-defined care pathway.

## 5.1 Illness trajectory framework

The Corbin and Strauss (1998) Chronic Illness Trajectory Model was used as a framework to describe the illness trajectory of metastatic breast cancer and to consider ways in which the phases, transitions, problems and needs could be addressed in the management of those living with it.

Strauss et al (1984:64) used 'trajectory' as a concept in understanding the experience of those with chronic illness. They make the point that an illness trajectory is not only the biomedical course of illness but also '*the total organisation of work done over that course, plus the impact on those involved in that work and its organisation.*' They go on to say that when an illness trajectory is uncertain the preparation – physical, emotional and social – can be out of alignment. For those with a life-limiting illness the pattern of 'decline-relieve-decline-relieve-decline to death' renders expectations uncertain and arrangements and plans unpredictable (Strauss et al, 1984:66). The Corbin and Strauss Chronic Illness Trajectory Framework is perhaps the most well known and used framework in healthcare. It is based on extensive enquiry in illness and dying (Glaser and Strauss, 1965, Glaser and Strauss, 1968). It has been widely applied in nursing care (Woog, 1992) and to a lesser extent, research (Robinson et al, 1993) and is built around a concept that chronic illness has a course which can fluctuate and change over time. In applying a framework Strauss et al (1984) feel the course of illness can be managed with the aim of ameliorating events, such as uncontrolled symptoms, and maximising quality of life.

Corbin updated the Chronic Illness Trajectory Model in 1998 in response to developments in healthcare provision, health technology and medical advances. The updated model acknowledges that these developments prolong lives and as such the biographical and social consequences are complex. The updated model aims to consider these developments (Table 16).

The individual with an illness and those around them, including healthcare professionals, will have predetermined impressions of the future course of illness. Strauss et al (1984) refer to this as '*trajectory projection*', the anticipation of the trajectory idea and how it will unfold. Lastly, the '*trajectory scheme*' is the plan put in place to shape the illness trajectory and manage symptoms. It may involve many players and therapeutic approaches.

**Table 16: Definitions of the Corbin and Strauss Chronic Illness Trajectory Model phasing**

Phase	Goal of definition	Goal of management
Pre-trajectory	Genetic factors or lifestyle behaviours that place an individual or community at risk for the development of a chronic condition.	Prevent onset of chronic illness.
Trajectory onset	Appearance of noticeable symptoms, includes periods of diagnostic workup and announcement by biographical limbo as person begins to discover and cope with implications of diagnosis.	Form appropriate trajectory projection and scheme.
Stable	Illness course and symptoms are under control. Biography and everyday life activities are being managed within limitations of illness. Illness management centres in the home.	Maintain stability of illness, biography and everyday activities.
Unstable	Periods of inability to keep symptoms under control or reactivation of illness. Biographical disruption and difficulty in carrying out everyday life activities. Adjustments being made in regime with care usually taking place at home.	Return to stability.
Acute	Severe and unrelieved symptoms or development of illness complications necessitating hospitalisation or bed rest to bring course under control. Biography and everyday life activities temporarily placed on hold or drastically cut back.	Bring illness under control and resume normal biography and everyday life.
Crisis	Critical or life-threatening situation requiring emergency treatment or care. Biography and everyday life activities suspended until crisis passes.	Removal of threat.
Comeback	A gradual return to an acceptable way of life within the limits imposed by disability or illness. Involves physical healing, limitations stretched through rehabilitative procedures, psychosocial coming to terms, and biographical re-engagement and adjustment in everyday life.	Set in motion and keep going the trajectory projection and scheme.
Downward	Illness course characterised by rapid or gradual physical decline accompanied by increasing disability or difficulty in controlling symptoms. Requires biographical readjustment and alterations in everyday life with each major downward step.	To adapt to increasing disability with each major downward turn.
Dying	Final days before death. Characterised by gradual or rapid shutting down of bodily processes, biographical disengagement and relinquishment of everyday life and activities.	To bring closure, let go and die peacefully.

*Corbin (1998)*

Similarities and contrasts between the lives of the ten women as they live over time with and around progressive disease will be described. Three distinct trajectories have been identified. These will be described and explored to understand how these specific trajectories unfold and the implications for practice in defining the differing trajectories. Applying the Corbin and Strauss Chronic Illness Trajectory aimed to give structure to an ill-defined illness course and define the metastatic breast cancer illness trajectory.

This chapter concludes with a summary of the illness trajectory of metastatic breast cancer and identifies ways the typical and atypical illness trajectory of metastatic breast cancer can be managed to improve the quality of life and experience of care for this population. The chapter begins by introducing each woman and her illness trajectory.

## 5.2 Introducing the ten women

### 5.2.1 Joan

Joan was a 78 year old widow who lived alone in a country town (Figure 6). She was a retired teacher and very involved in activities and volunteering locally. In 2003 Joan presented with a breast lump and underwent a mastectomy and hormone therapy. Three years later she developed skin nodules and was diagnosed with metastases in supraclavicular nodes, cutaneous metastases and a mass on the ribs. She was treated with endocrine therapy.

When we first met in June 2005 Joan was well and asymptomatic – almost apologetically so. Her main health concerns were high cholesterol and blood pressure which were being monitored by her GP. Since her metastatic diagnosis she had experienced one episode of profound fatigue. It was found that this was a side effect of the first endocrine therapy which significantly compromised her quality of life. She underwent cardiac investigation but a switch to another endocrine therapy resolved the fatigue and restored a good quality of life. When we met for the second time in December 2005 and the final interview in June 2006, she was feeling very well and her narrative indicated that she was not compromised by her disease in any way.

Over the three years since her metastatic diagnosis she had had two endocrine treatments and one chemotherapy regime. She remained well until the onset of symptoms three and a half years after her diagnosis of metastatic disease. These symptoms resolved after chemotherapy.

Joan felt that being older her needs were not as urgent as those who were younger. She felt her past life experiences of being investigated for cancer when she was a young mother (which was not cancer) and living through the Second World War meant



she had faced her own mortality and in some way this prepared her for living with progressive breast cancer. In addition, Joan nursed her husband for a number of years after he experienced a stroke which rendered him immobile, completely dependent and aphasic. She did not wish to experience the same level of dependence or prolonged illness herself.

Joan lived in a small community which was supportive although she chose not to divulge her diagnosis to more than a few close friends as she did not want pity or sympathy. Her narrative focus was a projected image of stoicism and resignation to cancer at her age.

When she was diagnosed with progressive disease and embarking on chemotherapy for the first time she contacted me to tell me she anticipated that she would die very soon. In the event she responded to chemotherapy well and her symptoms resolved.

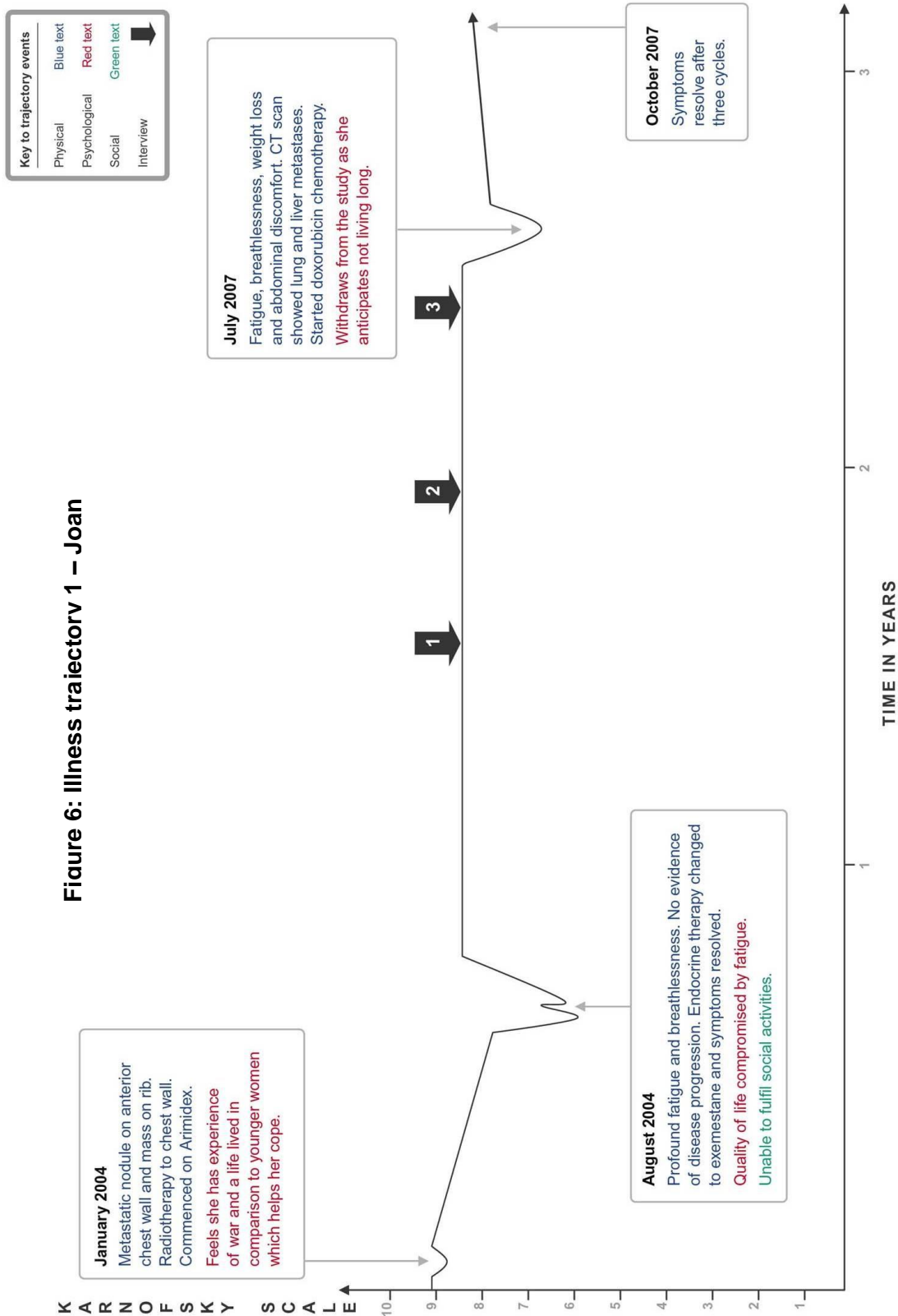


Figure 6: Illness trajectory 1 – Joan

### 5.2.2 Dawn

Dawn was a 46 year old woman who lived with her husband of four years in a suburban area and had four adult step children (Figure 7). Dawn worked as a project manager. She presented with a breast lump in 1996; she had a lumpectomy and radiotherapy followed by endocrine therapy. She was diagnosed with metastatic disease eight years later in 2004 when she presented to the breast care nurse with recurrent breast lumps and fatigue. She was found to have bone, liver and lung metastases.

I first met Dawn in February 2006 when she was undergoing her second cycle of chemotherapy. Central to Dawn's story was the rejection of her lifestyle before progressive breast cancer – three jobs and working 50 hours a week and an unhealthy diet – and the adoption of a new healthy lifestyle and strict dietary regime. Dawn felt this was what she has to do for herself to maximise her health, be better able to tolerate treatment and increase her survival time.

She had two episodes of disease progression over the illness trajectory of four years and four months, three different endocrine therapies, two chemotherapy regimens, Herceptin, monthly bisphosphonates and a bilateral mastectomy due to nodular disease in both breasts. She had one unplanned admission for chemotherapy-related side effects. Other than the initial fatigue she was asymptomatic for most of the trajectory other than the side effects of treatment.

When we met for the second interview in August 2006 Dawn talked of finding the uncertainty of her trajectory difficult to cope with and suffering from bouts of rage. She had a previous history of clinical depression and worked hard not to become depressed. She had counselling but didn't find this useful. When she was between treatments, she feared a recurrence of her disease and felt she had to be vigilant in listening to her body. At night she didn't sleep well and often felt her body to see if there were any changes. She said she was a person who had a lot of internal dialogue which allowed her to rationalise what was happening to her.

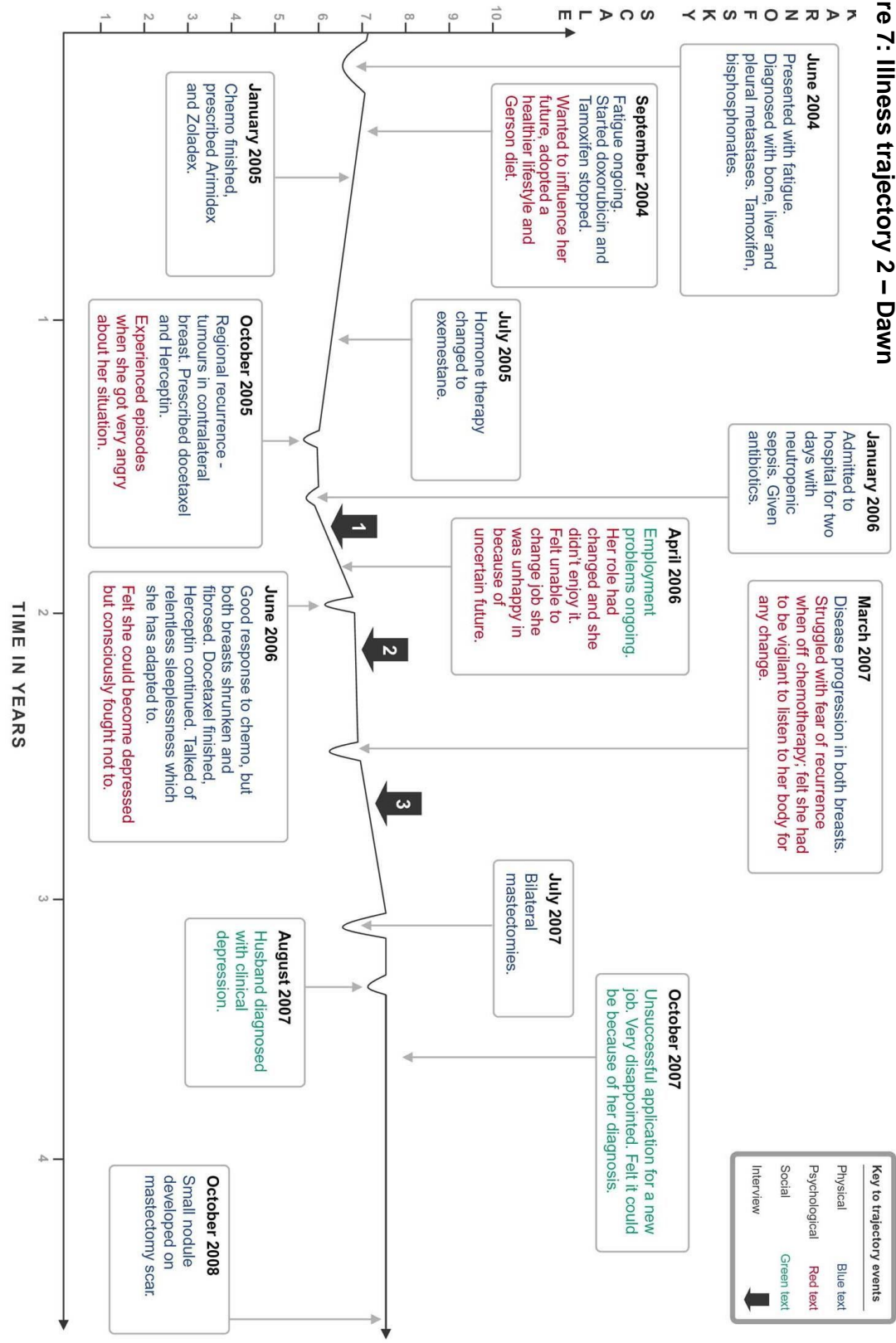
Dawn's progressive disease meant her future ambitions were restricted. She felt unable to change her job and when she applied for a new job she was unsuccessful, which she attributed to her illness and the fact that her uncertain illness trajectory meant she may be an unreliable employee.

When Dawn's husband was diagnosed with depression three years after her metastatic diagnosis, the focus of care was transferred to him and she felt in some way responsible that it was her cancer and uncertain future which precipitated his

diagnosis. Dawn and her husband were able to talk honestly with each other but she felt that constantly talking about the cancer could be exhausting and as she had lived for some time with metastatic disease it would not be good for them always to talk about it.

The last time we met in February 2007 she had developed small nodules on her mastectomy scar and what appeared to be progressive disease. She was still asymptomatic, working four days a week and following her diet and lifestyle regime.

Figure 7: Illness trajectory 2 – Dawn



### 5.2.3 Angela

Angela was 45 years old: she had been married and divorced twice and now lived with her long-term partner of 15 years (Figure 8). She had three grown-up children and worked full time as a shop manager.

Angela was diagnosed with early stage breast cancer in 2001 and had a wide local excision followed by chemotherapy and radiotherapy. Two years later in October 2003 she developed weakness in her arm while on holiday and on her return was diagnosed with brain metastases. Over her illness trajectory she had her brain metastases surgically excised twice. She had seven episodes of disease progression, surgery for abdominal metastases and formation of a colostomy, two chemotherapy regimens, bisphosphonates monthly for three years, Herceptin for 18 months and three radiotherapy treatments. She had two unplanned admissions for pain. As well as increasing fatigue, Angela had uncontrolled pain for most of the four years and two months she lived with progressive disease.

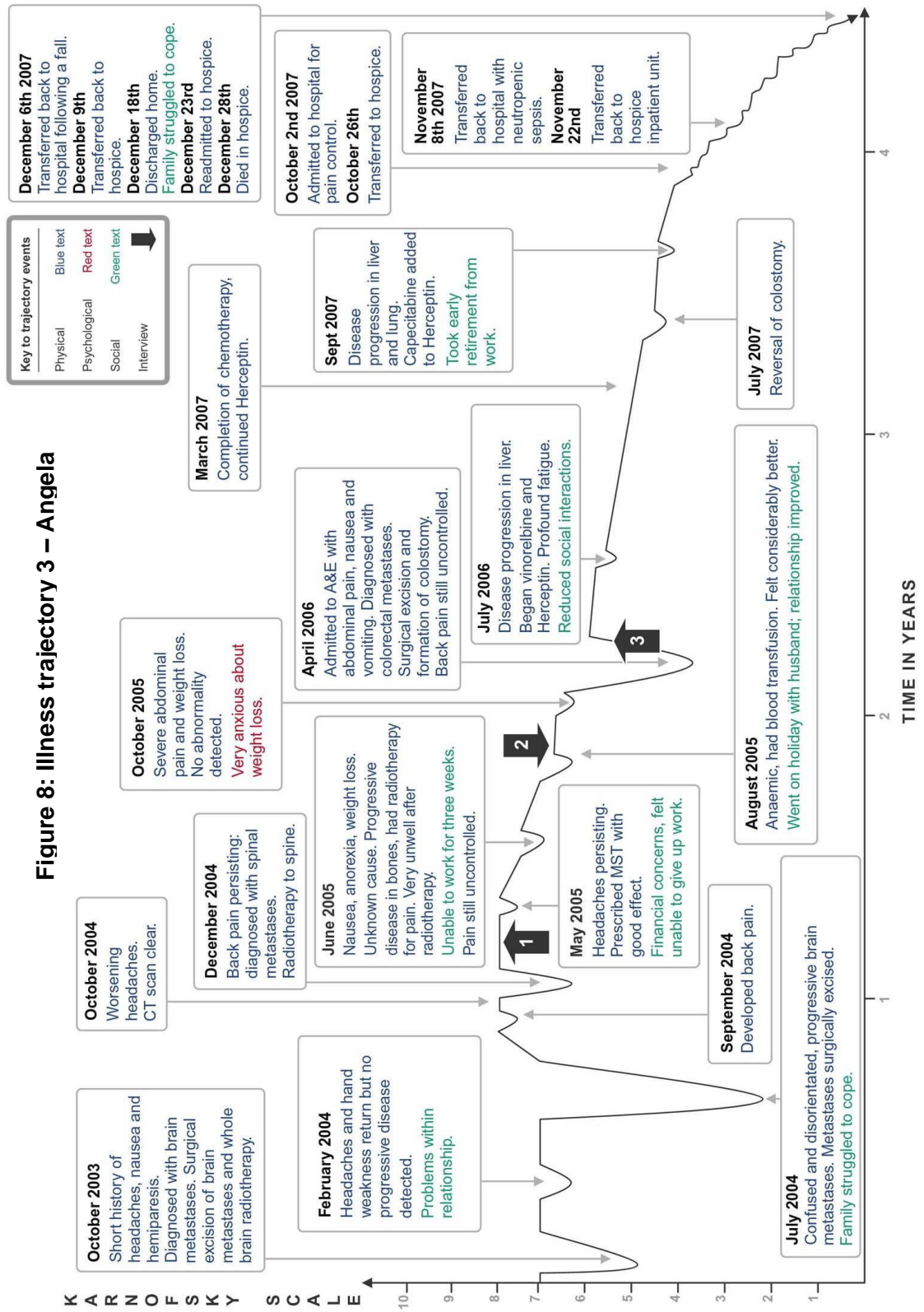
The first interview with Angela was in March 2005: she was back at work but still had ongoing problems with uncontrolled pain. Her GP and oncologist had prescribed analgesia but there was no ongoing assessment of its effectiveness so her pain persisted.

Throughout her illness Angela continued to work. Her job and her ability to do it were the focus of her narrative. She gauged her ability to live with progressive breast cancer around her ability to work. She loved and lived for her job and needed the money from it. Angela's partner struggled to cope with her progressive disease. When they went on a 'make or break' holiday she felt their relationship had deteriorated to patient and carer. The holiday allowed them to talk about their fears and anxieties and brought them close together again. Her partner and family all struggled to cope when she presented with brain metastases and she feared they would struggle if she was confused or unwell in the future. When we met for the second interview in September 2005 they had just returned from their holiday and she was feeling happier about their relationship.

At the final interview in April 2006 Angela had lost weight and was recovering from abdominal surgery. Her ability to perform her role as shop manager had been compromised and she began to acknowledge that she could not work effectively and that as her world became smaller, she felt unable to continue her job. Despite this, she continued to work until three months before she died.

In the last months of her life Angela was admitted to hospital for pain control. She was transferred to and from the hospital and the hospice five times, accounting for 50 days as an in-patient. When she was finally discharged home, her family struggled to cope; she was readmitted to the hospice in early December and died four days later. The time between her last treatment and her death was approximately six weeks.

Figure 8: Illness trajectory 3 – Angela





#### 5.2.4 Shelley

Shelley was 49 years old and lived with her third husband (Figure 9). She had three adult children, one son and two daughters. She worked full time as an office worker which she loved for the social interaction.

Shelley presented with a breast lump in 2000 and had a mastectomy followed by chemotherapy, radiotherapy and subsequent endocrine therapy. Three years later in 2003 she developed back pain over some time and was diagnosed with metastatic disease in her bones, liver and lungs. Over the course of her metastatic illness trajectory she had four episodes of disease progression, four chemotherapy regimens, one endocrine therapy, two radiotherapy treatments and monthly bisphosphonates. She had two unplanned hospital admissions for symptom control and chemotherapy side effects.

The first interview with Shelley was in February 2005. Her main concern was uncontrolled back pain and she was being supported in this by a community palliative care nurse. Shelley had uncontrolled pain almost throughout her illness trajectory due to a non-cancer back problem which improved after surgery. When we met for the second interview in August 2005 she was distressed as due to a clerical error she was not on the list for back surgery and was waiting for a date to be admitted. Throughout her illness trajectory she had periods when she was very well and able to maintain her social roles and work full time and periods when she was housebound and dependent. At this time she was in considerable pain with limited mobility. By the third interview in February 2006 she was recovering from spinal surgery and her quality of life had improved considerably. Within seven months, however, she was clinically depressed and was prescribed anti-depressants.

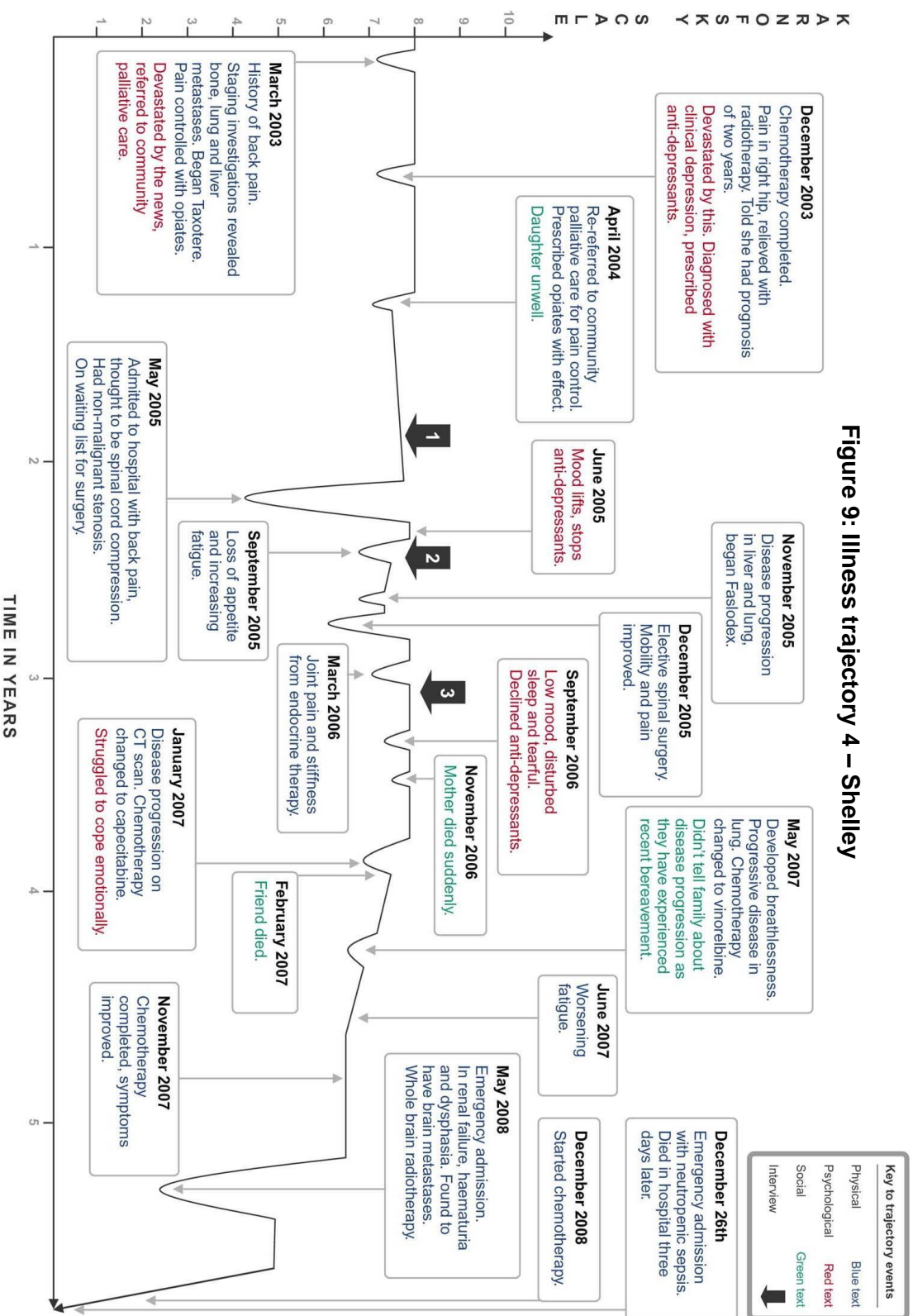
Communication within her family was difficult as she was unable to talk directly to her parents and siblings about her progressive disease which she found hard. Her husband, however, was very supportive. When Shelley had disease progression she adopted a coping strategy of indirect communication. She usually withdrew within herself and did not communicate for up to two weeks. Then slowly, as she assimilated the news, she talked to her husband and eventually her friends. In communicating with her parents, she wrote letters to her sister, who talked to her father, who told her mother. Her father contacted her to ask how she was but she did not go into detail. Her mother only referred to Shelley's progressive disease once before she died suddenly in November 2006, just over a year before Shelley died.

Other family events affect Shelley's ability to cope. Her daughter had a miscarriage, a family friend died of cancer and she had to support her youngest daughter through

bereavement while acknowledging her daughter was anticipating the loss of her mother too.

Shelley was treated for clinical depression once as well as having periods of mood disturbance. She received psychological support from a community palliative care nurse with whom she has a good relationship over four years; although when she was physically well she was discharged from the service.

Shelley died in hospital three days after an emergency admission for chemotherapy side effects. The time from beginning her last chemotherapy regimen to her death was under four weeks.



### 5.2.5 Jill

Jill was married to Ronan and had three children – two boys aged 13 and 15 and a 10 year old daughter (Figure 10). She worked as a counter clerk. Jill loved the social side of work and was the organiser of a wide social network, organising holidays and events for around 30 people.

Jill presented with a breast lump in 2002 and had a wide local excision, chemotherapy, radiotherapy and subsequent endocrine therapy. Two years after her diagnosis and treatment of early stage breast cancer Jill had a five-month history of back pain. She was diagnosed with a spinal fracture which was treated with radiotherapy, endocrine therapy and bisphosphonates. The pain resolved. Nine months later she had progressive disease in her bones and liver. Over her illness trajectory Jill experienced six episodes of disease progression, two different endocrine therapies, three different chemotherapy regimens and radiotherapy three times.

Jill's first interview was in December 2005. She had been recently diagnosed with progressive disease in the liver and started on her first regimen of chemotherapy for metastatic disease. From October 2005 until March 2007 her life was dominated by sequential chemotherapy other than one six-week period in 2006. She had one unplanned admission for chemotherapy side effects. When we met for the second time in July 2006 she had endured two episodes of disease progression in the previous six months but was feeling well, though shocked that her disease had progressed as she felt so well and was continuing to live her life around it. She had lymphoedema in her left leg which impeded her mobility for the last two years of her life. She lost her hair three times.

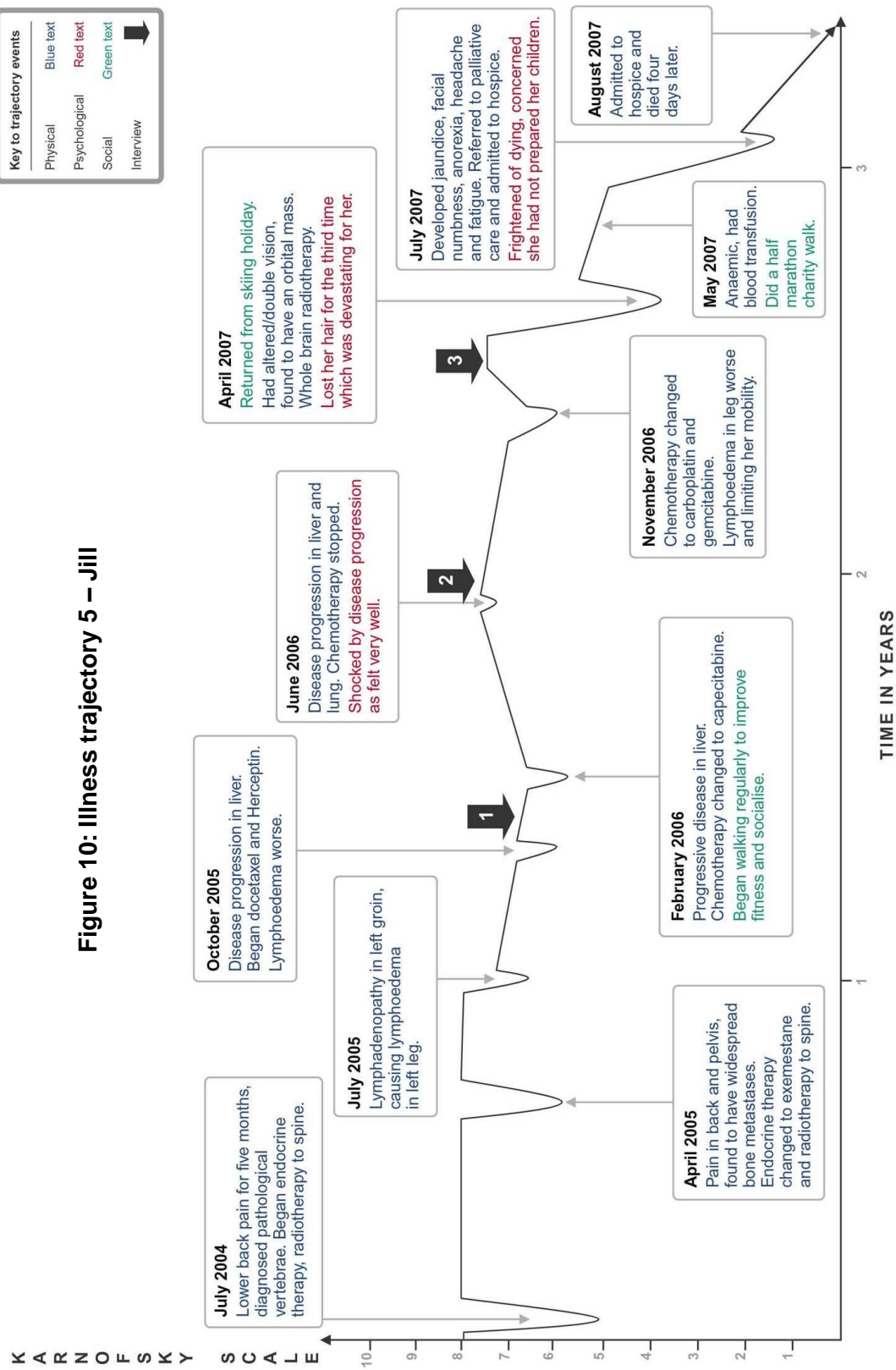
Jill went from extremes of illness when she was very compromised by her disease to having a significant level of wellbeing restored as a result of chemotherapy. The central focus of her life was her family, which meant attending to, protecting and caring for her husband and children. She vigilantly watched how they weathered the oscillations of her illness trajectory and protected them from the harsh reality of it. The unpredictability of her illness trajectory meant she didn't talk to her children about her dying in case she lived for years after telling them, so causing them premature anxiety and distress.

When we met for her last interview in February 2007 she had experienced further disease progression and was on her third regimen of chemotherapy. The loss of the future as a mother was what drove her to accept sequential treatments.

When she had disease progression Jill followed a process of adaption. Firstly she sought isolation, then indirect communication (sending friends texts) and after a week

or so she was able to reintegrate into her social group. This approach allowed her to retain her public persona of optimism and resilience, so allowing her to remain within the social network which was very important to her.

Jill's last episode of illness was an acute admission to the hospice with a number of symptoms. She was frightened and unprepared for her death as were her husband and children. She died four days after admission, five months after her last chemotherapy.



### 5.2.6 Joy

Joy was a 50 year old married woman with two teenage daughters (Figure 11). She worked as a carer until her metastatic diagnosis.

She was diagnosed with metastatic breast cancer at the same time as early stage cancer. Her diagnosis was not straightforward; it took some months of misdiagnosis before she found out she had progressive breast cancer. She presented with anaemia and was investigated for haematological cancer: a bone marrow biopsy found metastatic disease from breast cancer. Joy felt some resentment at the delay in diagnosis and the diagnosis was a huge shock.

Throughout her illness trajectory she had six episodes of disease progression, although these were predominantly within the first three years of her six and a half year illness trajectory. She had five chemotherapy regimens, four different endocrine therapies, an oophorectomy, monthly bisphosphonates and one radiotherapy treatment. Pain and fatigue occurred intermittently throughout her illness. She had one unplanned hospital admission when she was acutely unwell. Joy had periods of time when she was very unwell and recovered so that she was able to have a good quality of life.

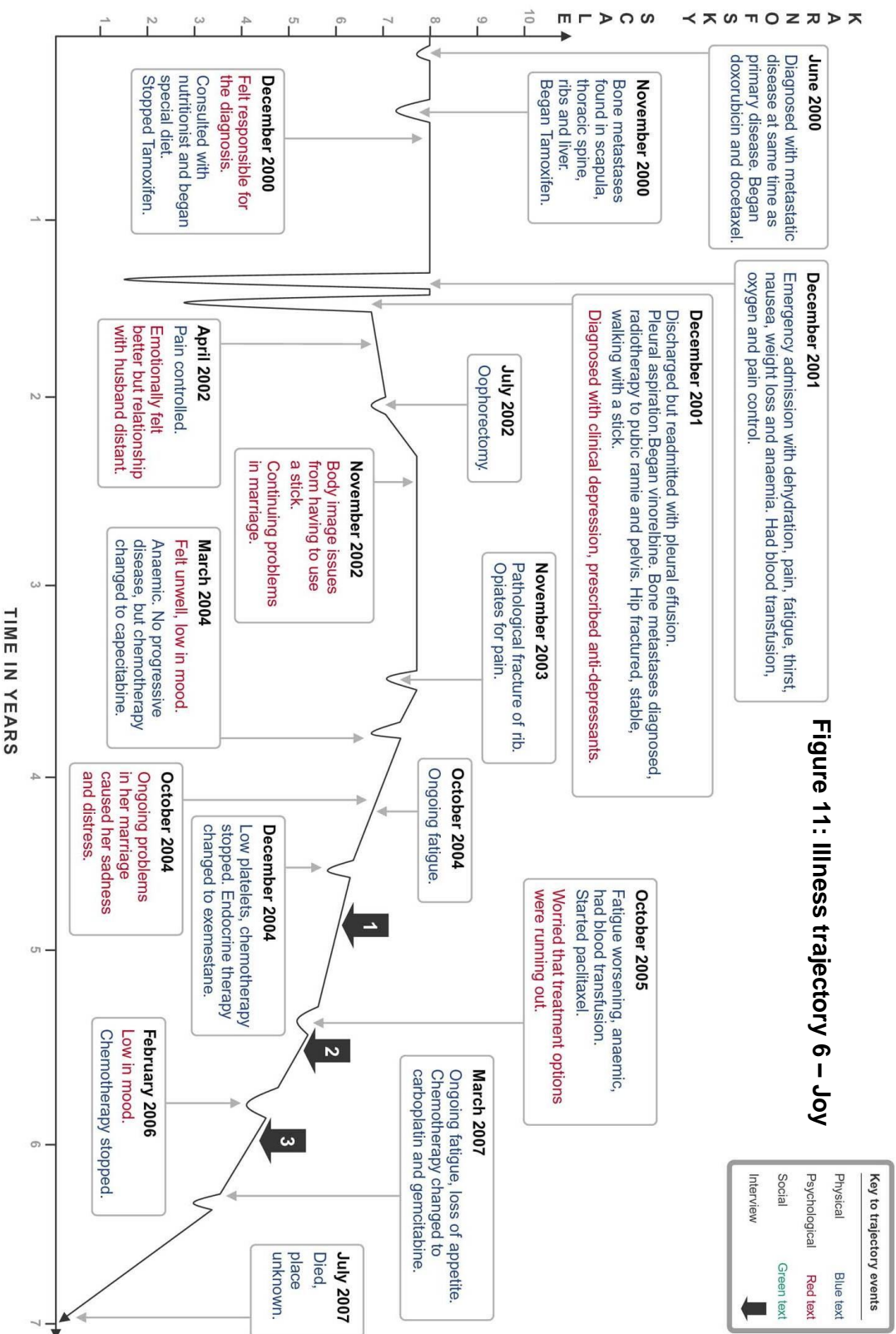
Initially Joy adopted a healthier lifestyle with a strict diet and health regime as she felt her hectic lifestyle prior to her diagnosis contributed to her illness. When she was admitted to hospital in 2001, she was very unwell and contributed her deterioration to her diet which she then modified considerably.

Joy's first interview was in May 2005, five years after her metastatic diagnosis, so the majority of her narrative was retrospective. She had been on one chemotherapy regimen for two years and had begun to have side effects which may have indicated a change in treatment. When we met for the second time in November 2005 she had just started a new chemotherapy regimen and was anticipating hair loss for the second time. Joy experienced times when she struggled to cope and was treated for clinical depression once and assessed with low mood once. She recalled having panic attacks and felt suicidal while in hospital. The main focus of her narrative was the erosion of her social roles and in particular the disintegration of her 20 year marriage which caused her great distress. In addition, a fractured hip meant she had to walk with a stick which significantly affecting her body image and her relationship with her husband. She felt that the oscillations of her illness meant her husband had anticipated her death a number of times and he struggled to cope with anticipatory grief, uncertainty and the responsibility of becoming lone parent. In addition, Joy felt shifting behaviour towards her from others in her social group and that she was treated differently, which at times heightened a sense of social isolation. The last time we met

was in May 2006 and she had endured four cycles of chemotherapy and an episode of low mood. Her marriage had reached a point when she and her husband were planning a separation.

The period between her last chemotherapy starting and her death was five months. Where she died is not known.





### 5.2.7 Karen

Karen was a 53 year old woman who lived with her husband (Figure 12). She had one daughter who lived close by. As an adult she went back to college to train as a teacher, an achievement she was very proud of. Her narrative situated her as someone who overcame difficult events and met problems face to face.

Karen presented with breast lump in 2002; she had a mastectomy, chemotherapy and radiotherapy. Six months after her treatment for early stage breast cancer was complete she developed a new pain around her ribs, was found to have liver metastases and began chemotherapy. She had eight episodes of disease progression over two years. Despite tolerating chemotherapy well she experienced profound fatigue. Six months after chemotherapy began Karen suddenly had altered vision and went blind while on holiday. Shortly after this she had a seizure and was diagnosed with brain metastases. She had whole brain radiotherapy.

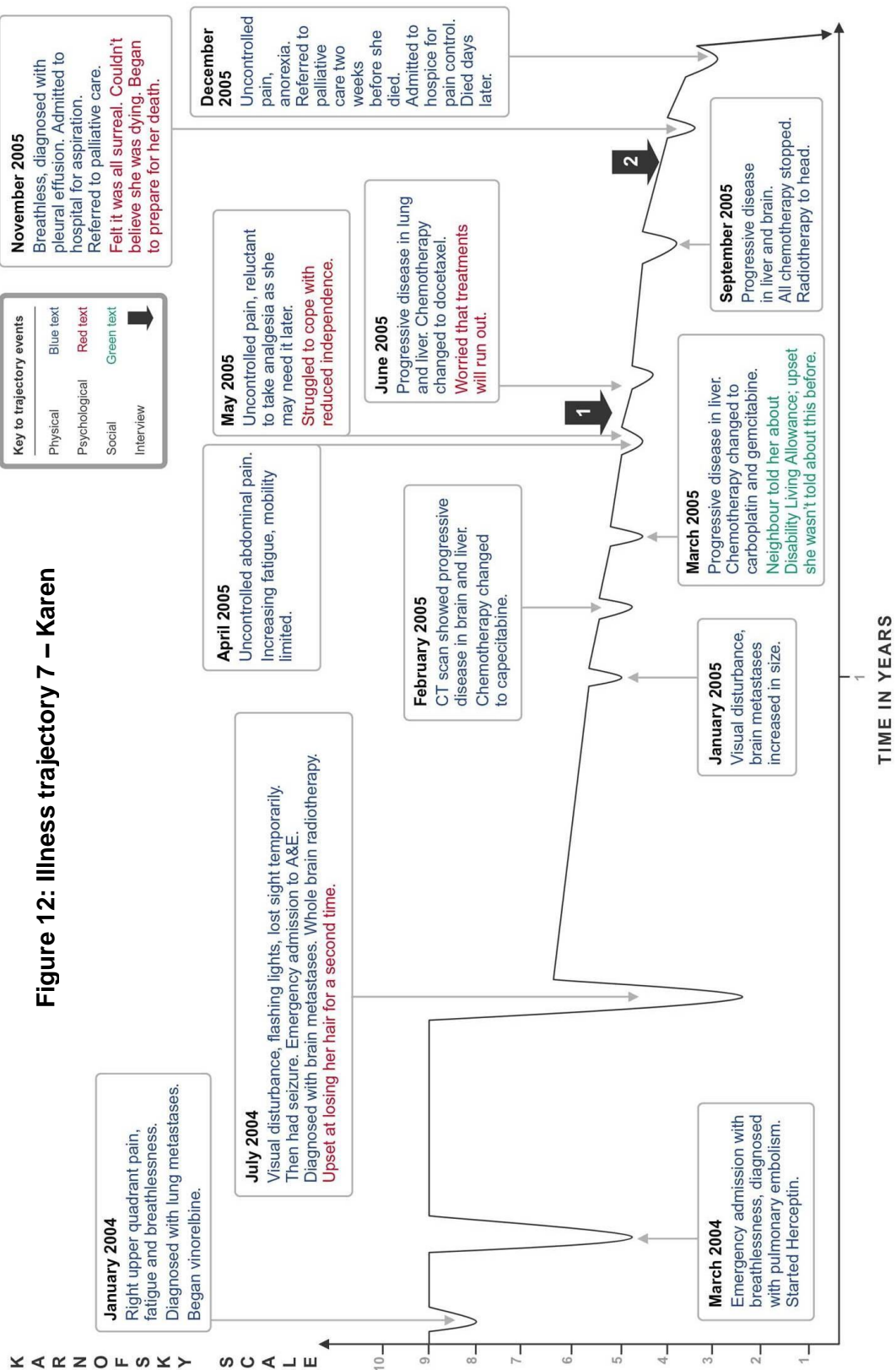
One year later a scan showed progression of the liver metastases. From this time her life was dominated by treatment. She had four chemotherapy regimens, Herceptin, one endocrine therapy and radiotherapy to her head twice. She also had two unplanned admissions for a pulmonary embolism and cerebral symptoms and a planned admission for a pleural effusion. While the side effects of treatment were hard to cope with she talked of presenting well at clinic so they 'think I am worth saving and they remember me nicely'.

At the first interview in May 2005 Karen was experiencing uncontrolled pain and was about to embark on her fourth chemotherapy regimen in 18 months. At the same time she also questioned the futility of treatment which had little impact on her cancer but compromised her quality of life. The focus of Karen's narrative was the need to maintain some equilibrium for those around her in the face of aggressive, progressive disease.

Karen had profound fatigue when we met for the last interview and was dependent on others and unable to perform basic tasks. She admitted she occasionally felt down but tried not to get upset in front of her family. By remaining calm, Karen felt she was able to support those around her to cope. She was rarely alone and tried not to show her fear or distress in order to protect others. She occasionally sought time alone to express her emotions.

The last interview was two weeks before she died. She was admitted to hospital hours after the interview for drainage of a pleural effusion. She could not believe she was going to die. She was referred to the community palliative care service two weeks

before she died, then was admitted to the hospice for pain control and died days later. The time between her last treatment and death was three months.



### 5.2.8 Mary

Mary was 64 years old and lived with her husband (Figure 13). She had been retired for five years. She had one grown up son who was 27 years old and lived close by.

Mary presented with a breast lump and had a mastectomy in 1991. She had contralateral breast cancer four years later and had a lumpectomy. Nine years after her first early stage breast cancer, she developed lower back pain which persisted for some time. An x-ray showed she had widespread bone metastases in the spine, pelvis and other sites. She began chemotherapy and endocrine therapy. Over her illness trajectory she had six episodes of disease progression which were treated with three different endocrine therapies, three chemotherapy regimens and monthly bisphosphonates. She had one unplanned admission for chemotherapy side effects. Pain from bone metastases was fairly constant throughout her illness trajectory and she had four radiotherapy treatments for this. She was referred to a palliative care nurse four years before she died. They developed a good relationship and with ongoing pain management her pain was better controlled.

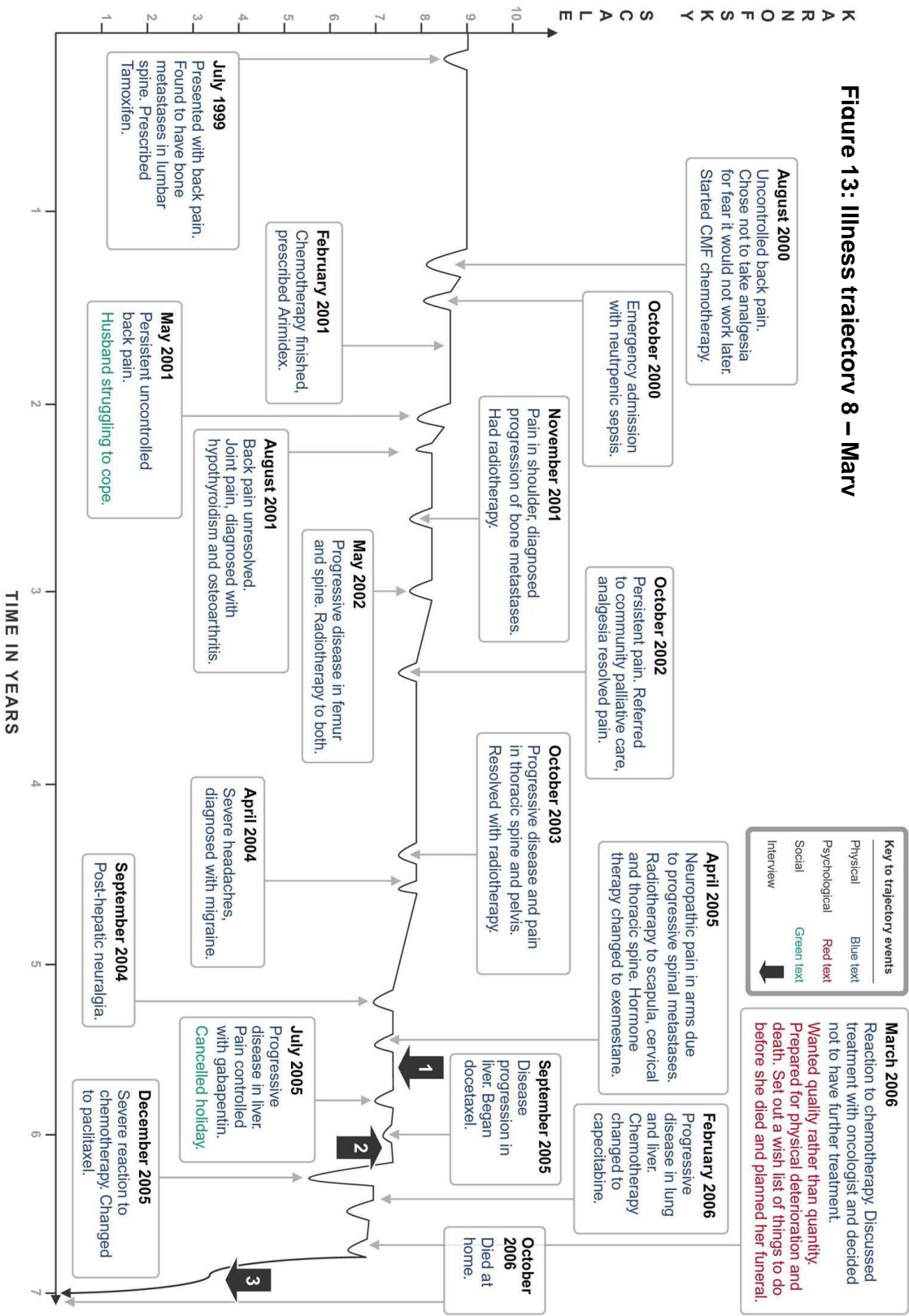
Mary's first interview was in May 2005, when pain was a significant problem for her and she was working with her GP and palliative care nurse to manage this. Mary was accepting of her illness and felt she had lived an enjoyable and productive life. She considered that life events had helped her cope with adversity. Her mother died when she was a child. When we met for the second time in November 2005 the pain was well controlled but she had developed progressive disease and started on her second chemotherapy regimen.

Mary was busy and active throughout the majority of her illness trajectory. Having something to do every day was important, as were her many friends to do it with. Mary coped by deciding to live as full a life as possible with the cancer: she appeared to be able to transcend her illness to live her life around it. She kept a diary to express her feelings rather than burden her husband and friends. She also felt able to talk to her palliative care nurse.

The last time we met in June 2006 Mary had chosen to stop all treatment. The last cycle of chemotherapy was hard to tolerate and her disease was progressing. She had an honest conversation with the oncologist. He told her further treatment would buy her months. She decided it was not worth it and discontinued the chemotherapy. Despite the frank discussion and informed decision she felt a weight lifted from her once the decision was made. Her last treatment was seven months before she died.

In the final months of her life she was happy to be at home and didn't wish to go far or plan anything. She acknowledged this was a shift for her. Mary said she didn't fear death, nor cry for herself. She organised her funeral, the music and readings. Another patient she had become friends with saw her for coffee only a week before she died peacefully at home.

Figure 13: Illness trajectory 8 – Marv



### **5.2.9 Martha**

Martha was a 65 year old retired office worker who lived with her husband in a suburban area (Figure 14). After spending the years of their retirement travelling the world together, they had recently settled into a new home near the coast. She had two adult children and was enjoying time with her grandchildren.

In 1992 Martha presented with a breast lump; she had wide local excision, radiotherapy and endocrine therapy. Thirteen years after her diagnosis of early stage disease Martha developed weight loss, nausea and vomiting, and was diagnosed with liver and lung metastases. Over the next two years she experienced three episodes of disease progression and had two endocrine therapies, two chemotherapy regimens and two radiotherapy treatments for pain. She was referred to the hospice for symptom control and support and attended the day care facility.

From the time of her metastatic breast cancer diagnosis Martha experienced breathless over a five-month period. At this time she also had nausea, fatigue and felt very low in mood. Martha feared she would die during this period and began preparing her husband for her death by teaching him household tasks. During this time Martha talked of her world getting smaller, not anticipating a future, then as her wellbeing improved she began to consider a future and again thought of things like holidays and plans. Equally, she had felt so unwell she was not looking forward to a time when the disease inevitably returned and she felt as unwell as she had previously, as though she had had a glimpse of the future.

Martha began to respond to treatment and her physical functioning improved significantly. She discharged herself from the hospice as she found it depressing seeing others sicker than herself.

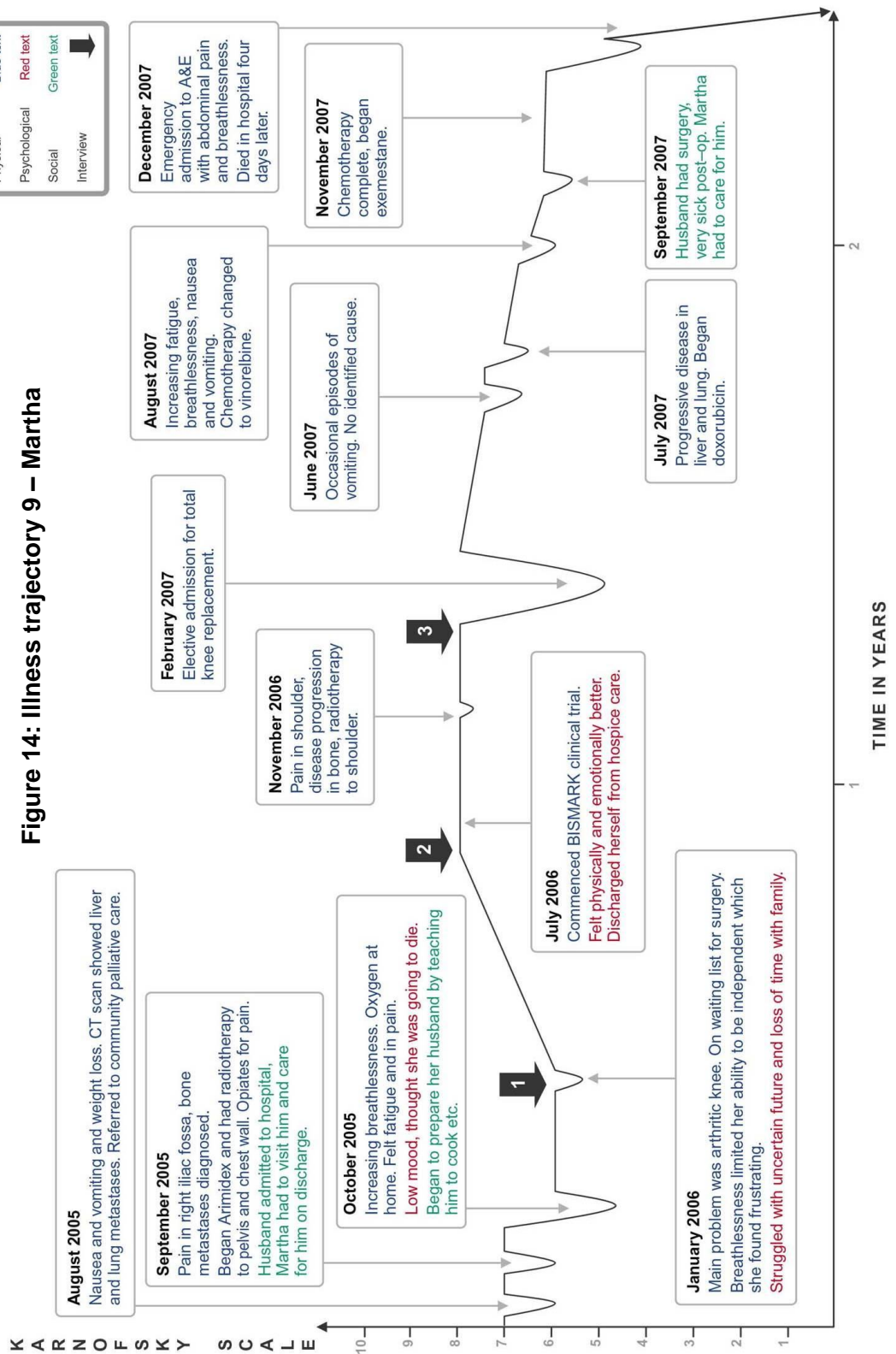
During her illness trajectory Martha's husband was hospitalised twice. On both occasions he was very unwell and she had to care for him at a time when she was unwell herself. On one occasion he was in intensive care and she feared he would die. He was discharged months before she died but continued to have nursing care at home.

At the first interview in January 2006 the main problem for Martha was her arthritic knee which restricted her mobility and caused her significant pain. This was for some time the worst thing in her life. This was resolved when she had a knee replacement 11 months before she died. When we met for the second interview in June 2006 Martha's physical functioning had improved and she felt better than she had done for a while.



This continued and when we met for the final interview in January 2007 she was preparing for elective surgery to her arthritic knee.

While Martha's health improved after the initial diagnosis, in the last six months of her life she endured episodes of disease progression and uncontrolled symptoms which culminated in an emergency admission to hospital with abdominal pain and breathlessness. She died within four days of admission. Her last chemotherapy treatment was one month before her death.



### 5.2.10 Paula

Paula was a 40 year old mother of two school age boys (Figure 15). She decided to separate from her husband shortly before her metastatic diagnosis.

In 2003 Paula presented with a breast lump and underwent a mastectomy, radiotherapy, chemotherapy and subsequent endocrine therapy. Two years after a diagnosis of early stage disease Paula was seen routinely in clinic; she felt fine and well but her oncologist was concerned about her weight loss. A scan showed she had metastatic disease in her liver and lung.

Paula had to stop working in a physically demanding job five months after diagnosis of metastatic disease as she fell asleep while at work due to profound fatigue – a realisation that she couldn't do what she used to do. She was very short of money and worried constantly about providing for her children.

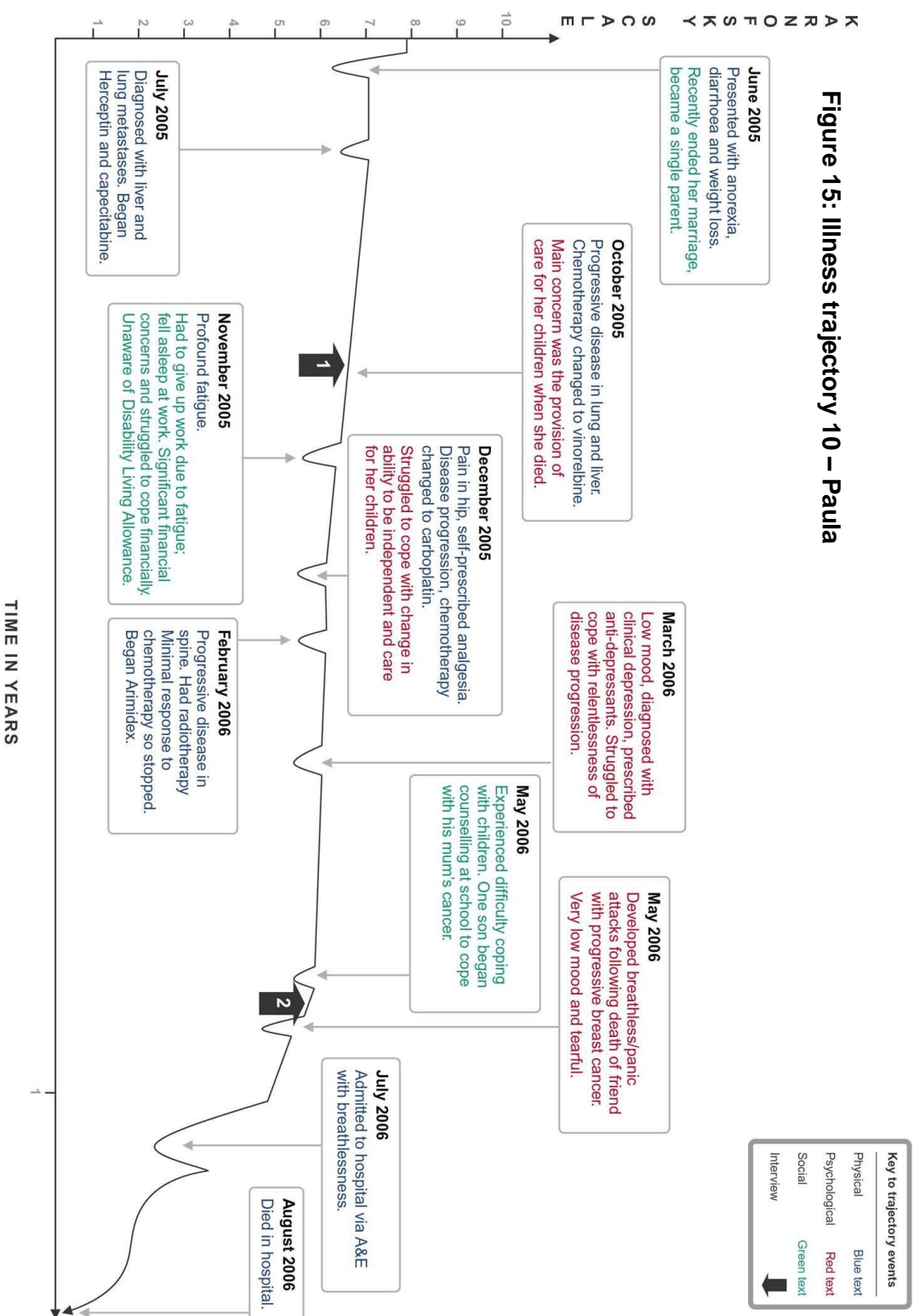
Paula's progressive breast cancer was relentless. Over a 14-month period she had three episodes of disease progression, three different chemotherapy regimens, one endocrine treatment and one radiotherapy treatment for pain. Paula seemed to be caught between having chemotherapy and hoping it would work and tolerating the effects it had on her limited life, both physically and psychologically. She experienced significant pain and fatigue and over the last months of her life breathlessness. In addition, she experienced anxiety and was treated for clinical depression.

The years before her metastatic diagnosis were punctuated with difficult events. Other family members had been diagnosed with cancer and she was coping after the end of her marriage. Although Paula talked of feeling unwell, her life appeared quite hectic; she made jewellery and other things for her friends and the children's school. She had a number of small jobs to supplement her income and looked after her two boys.

At Paula's first interview in October 2005 the focus of her narrative was her children: her concern was that they were looked after and were financially secure, although at the time money was a real problem for her. It seemed her very essence of being was her sons. She admitted that without them she wouldn't go on, but their wellbeing then and in the future was everything to her. Only at the end of the interview when Paula winced did she acknowledge the constant pain she endured in her pelvis and hip, for which she took over-the-counter analgesia. She thought pain was to be expected and did not seek professional support to manage it. When we meet for the second and last interview in May 2006, chemotherapy had been stopped months before and she was taking endocrine therapy. She was low in mood after she found out another patient she

had become friendly with had become breathless and died shortly afterwards. She had not felt prepared for her death and feared she would die soon.

Paula felt supported by friends but had no formal support services. She struggled on, desperately hanging onto her independence: *'I'm not giving in just yet. I don't like people helping me.'* She was admitted to casualty with breathlessness and died in hospital one month after admission. Her last treatment was five months before her death.



## 5.3 Distinct illness trajectories

Three illness trajectories were identified. These could be considered typical in that they were shaped by the nature of the breast cancer.

### 5.3.1 Illness trajectory 1 – ‘*ticking over nicely*’

This illness trajectory was typically long, over years characterised by indolent disease, usually only bone metastases, treated conservatively, predominantly with endocrine therapy. It mostly, though not exclusively, applied to older women. Physical functioning was often good, although considering that those with indolent disease are more likely to be older, comorbidity may compromise physical functioning. An example of this illness trajectory was Joan. Over Joan’s illness trajectory (Figure 7: Illness trajectory 1), she maintained her physical functioning at a high level, and was only compromised by her disease at diagnosis and twice more over three years and ten months. She experienced profound fatigue – a side effect of her endocrine therapy – when she was severely compromised for a short period: *‘if I don’t lie down, I’ll fall down you know, it’s like hitting a brick wall, just breathing is more exercise than I feel like doing.’* This short interlude affected her life and her ability to maintain her social roles. When her endocrine therapy was changed the fatigue resolved, so without this uncommon adverse reaction to treatment she would have lived symptom free for three and a half years. Her medical management until disease progression was focused on her underlying heart disease, angina and hypertension.

Joan felt that being older and retired allowed her to live her life as she wished. She was able to continue to live her life as a 78 year old woman and was very active. Joan may not be typical of an older woman with indolent disease as many may be compromised by comorbidities, but the metastatic breast cancer may not be the main concern and women may be able to live well with progressive disease for a number of years. However, this means they also have fewer interactions with healthcare professionals and less formal support from cancer services. Joan had little interaction with the oncology services as her appointments were every six months, but she felt this was adequate. The findings of Phase 1 of this study should also be considered when addressing the needs of those with indolent disease as those with bone metastases only were less satisfied with their care and experienced more pain than those with visceral disease. The key was Joan’s ability to get access back into the system when she needed it and the support of her GP who she saw regularly.

### **5.3.2 Illness trajectory 2 – ‘*is there no end to it?*’**

In contrast, an illness trajectory of aggressive breast cancer was characterised by a short duration, with a gradual deterioration in physical functioning punctuated by uncontrolled symptoms, episodes of disease progression and treatment with little respite. An example of this would be Paula (Figure 15: Illness trajectory 10), who was young and had aggressive disease. She lived only 14 months after her metastatic diagnosis and her life was dominated by episodes of progressive disease and treatment. She and those around her never caught up with the speed of events. Paula did not get the time or the energy to do everything she planned to prepare herself and her children for her death and her children's life without a mother. Paula was symptomatic but sought no assistance in symptom management. She expected to have pain and until the later months of her illness she was using over-the-counter analgesia with minimal effect. She was not involved with palliative care or any other support services until the admission to hospital with breathlessness. She was never discharged after this admission and died in hospital weeks later.

### **5.3.3 Illness trajectory 3 – ‘*it's a rollercoaster*’**

The most typical illness trajectory was where the duration was longer, from approximately two years to five years or more. Physical functioning could decrease but then recover and, at times, improve to a level higher than that before the event which caused it (see Figure 7: Illness trajectory 2 – Dawn). The trajectory was punctuated by episodes of disease progression and treatment but this may mean that symptoms were then controlled and physical functioning improved, often allowing the women to return to resume activities such as work again. Many of those who weathered the oscillations of progressive breast cancer were able to retain their social roles and few had formal support services despite uncontrolled symptoms, particularly pain, being a significant problem for many of them. An example of this illness trajectory was Joy (Figure 11: Illness trajectory 6), who experienced the oscillations of disease progression, treatment and the restoration of a level of wellbeing, sometimes better than before. She also experienced acute episodes and moments of crisis when the end of life was anticipated by her and those around her, but she recovered and a significant level of wellbeing was restored. This illness trajectory challenged the individual resources of the women to cope with and adjust to what a number of women referred to as a ‘*rollercoaster*’ of illness.

While there were differences in the shape and duration of women's illness trajectories, they all went through similar phases and transitions of their illness experience. The Corbin and Strauss framework is used to describe these (Table 16).

## 5.4 The pre-trajectory phase of metastatic breast cancer

Corbin and Strauss (1992) describe the pre-trajectory phase as a time before the illness course, focusing on the prevention of illness, when no signs or symptoms are present. For those with progressive breast cancer the pre-trajectory phase is a life lived before and after the biographical disruption of breast cancer but before disease progression, incorporating the impact of stressful life events, the diagnosis of early stage breast cancer and the pervasive presence of the fear of recurrence. The pre-trajectory phase in metastatic breast cancer then considers a life lived before a metastatic diagnosis.

### 5.4.1 Past life history

Evidence suggest that the diagnosis of metastatic breast cancer is particularly emotionally traumatic for those with stressful past life events and those with adverse social support. These life stressors can affect the individual's ability to cope with the current stressor of progressive disease (Butler et al, 1999).

Some of the women attributed their progressive disease to their previous life stress or lifestyle. This could lead them to feeling some responsibility for their disease progression. Martha was sure her breast cancer had returned because she smoked, even though she acknowledged there was little evidence to support the association of smoking with breast cancer.

Dawn and Joy felt their diet and excessive working hours prior to metastatic diagnosis contributed to their disease progression. This left them with a sense that they could have prevented their disease from progressing and that they held some responsibility for their current situation.

*' I just kind of thought I had to be superwoman...and that was a really stupid thing to do and I had three different jobs and I was doing between 50-60 hours a week...I just couldn't see the bigger picture and I do think that contributed to, to sort of the speed up of my condition I am sure. I was so stressed and kind of not eating properly and just not coping.'* Dawn

Other life events were stressful to deal with, without a potential diagnosis of progressive disease. For example, Paula was struggling to find some equilibrium for herself and her children following a separation from her husband. She worried how they would cope financially and at the time, she worked full time and did other small jobs to increase her income. Dawn had a previous history of clinical depression a number of years before her diagnosis of early stage breast cancer and felt responsibility for keeping this at bay throughout her life before and after her metastatic



diagnosis. It is important then to consider that progressive breast cancer as a stressor in life cannot be addressed in isolation but must be considered in the wider context of a life biography.

#### **5.4.2 The biographical disruption of breast cancer**

At the end of treatment for early stage breast cancer women have been found to experience a changed identity and have to reconcile the 'new' identity after a breast cancer diagnosis (Fenlon et al, 2010). They commonly live with the ever pervasive fear of recurrence (Oxlad, 2008). In their first interviews all the women were asked 'tell me about your cancer'. Eight of the nine women who had a previous diagnosis of early stage breast cancer began their cancer biography by describing the experience of their initial diagnosis and the impact that had on their lives. In the retelling of their breast cancer story, all the women indicated that their biography was disrupted from the point of early stage breast cancer. However, no one dwelt on the biographical disruption of early stage breast cancer as they had moved into another phase in their breast cancer narrative. For example, Mary described how she found her breast lump, the surgery and treatment, and then said '*so that was that*'. Dawn's description of early stage diagnosis and treatment was similar '*and that was it really*'.

The initial diagnosis of metastatic disease was a pivotal point in the women's illness trajectories but this rarely served as the focus to their story. It was talked about by all the women and often described in distressing terms but only as a means to order the chronology of the illness trajectory. This retrospective narration allowed the women to situate themselves within the narrative and help me to understand the events to date so I could appreciate what they had already endured and the physical and psychological effects of progressive disease to date. It enabled us to focus on the present. The narratives of the women in this study had moved to another level, of facing not only the impact of breast cancer but a life-threatening illness. While the women reflected on the past and projected into the future, their narratives were embedded in the present. Most of the women acknowledged that on reflection they were aware of the ever present possibility of disease progression and had lived vigilantly for many years, although this seemed to wane as time increased since their initial breast cancer diagnosis.

However, there was always a central focus for the narrative that threaded through the interviews. Joy's was her disintegrating marriage, Jill's and Paula's was not being there for their children, Dawn's was her healthy lifestyle and diet. All described their breast cancer from the diagnosis of early stage disease other than Paula. Her breast cancer narrative began in the present chaos of her life with rapidly progressing disease, a

recent separation from her husband and her desire to leave her children well provided for practically and emotionally. Her breast cancer progressed only months after treatment for early stage disease. She never reflected on her early stage disease and she appeared to see only the present. Her projection into the future was of her children's lives without a mother rather than her progressive breast cancer and its impact on her. She only considered herself as someone with progressive breast cancer in the context of being a mother and not meeting her children's needs.

Each narrative sought continuity from a past life history to the present life threatened by discontinuity at any time. The individual narratives highlighted women's endeavour to mediate the biographical disruption of a diagnosis of progressive breast cancer in order to retain identity as a cohesive whole in the present.

## 5.5 The trajectory onset – diagnosis and adjustment to progressive disease

### 5.5.1 Onset of symptoms

Most of the women experienced an insidious onset of symptoms over time. As these commonly continued for some time without a diagnosis of metastatic disease they could be considered to be spanning the pre-trajectory phase and the trajectory onset. During this time some self-medicated or sought services outside the healthcare setting to diagnose and treat this. Others felt the pathway from presenting with symptoms to getting the diagnosis was long and complex, being passed between healthcare professionals, a frightening time as some felt sole responsibility for their declining health. This meant they spent considerable time and money trying to control their symptoms before accessing oncology services again.

*'Having spent really hundreds of pounds at the chiropractor, various other things trying to get my back sorted out...the pain got worse...it never really sort of seemed to resolve and a very long story, after seeing her [chiropractor], she said I think you should go back to the doctor so I went to the doctor and they sent me for an x-ray.'* Jill

Some women presented to their GP but this did not necessarily lead directly to the investigations and a referral back to the oncology services. Dawn made contact with the breast care nurse on the pretext of getting a new prosthesis and mentioned the symptoms in passing.

*'There were signs really that something wasn't right but no one really picked up on them.'* Dawn

The time delay between the onset of symptoms and the first contact with an oncologist was of great concern because of the worry that in the ensuing time their disease would be progressing and had it been diagnosed and treated earlier their quality of life and survival time would be greater.

*'I felt a certain amount of resentment at that time because I had been back and forwards to the breast clinic er with cysts um on about three occasions and I feel now that because I survived so long my cancer must have been there when I went to the breast clinic.'* Joy

These concerns are supported by Turner et al (2005) who found that women felt the delay in their reporting of symptoms and action which led to their diagnosis meant their disease had progressed significantly because of that delay and the failure of healthcare professionals to take their concerns seriously.

Being outside the acute healthcare setting meant the women may no longer have had contact with their breast care nurse or oncologist. They appeared unsure how to re-enter the healthcare system and often took a convoluted path before getting an appointment with the oncology or hospital services. Once within, there appeared no structured pathway to ensure they received appropriate specialist care and support.

### **5.5.2 Communicating the diagnosis**

How the diagnosis was given to the women and how the future outlook was explained was key to how they coped at the time. Allowing some degree of hope was important. When a level of hope was given that treatment aimed to improve symptoms or extend survival time the women felt more confident about the future. However, if the limitations of treatment were emphasised or a time frame was given in bleak terms it had a significant impact on the women's ability to cope and dominated their ability to adjust and assimilate the diagnosis.

Retrospectively some women expressed anger at the way they were told their diagnosis and how their uncertain future was described. Others felt defiance as they lived well beyond their predicted trajectory. Joy was diagnosed with metastatic disease at the same time as early stage disease. For her the diagnosis was shocking, but the delays in diagnosis and the manner in which she was told had a significant impact on her ability to adapt to and assimilate the news.

*'...it was a very dire prognosis. You're not given any hope and of course you haven't read any books...if I didn't have the chemotherapy um, you know I would be gone within months and all this sort of thing. That was very hard to take. I just feel it shouldn't be so definite...you are not given any hope and especially when I am looking back, I survived five years and I am well.'* Joy

In comparison with the experience of early stage breast cancer those with progressive disease do not routinely have access to support from a breast care nurse (Reed et al, 2010). The findings of the survey indicated that the experience of being diagnosed with metastatic breast cancer compared unfavourably with the diagnosis of early stage disease. The women talked of feeling isolated at this time, without access to support and adequate information other than that given to them in their consultation with the specialist.

### **5.5.3 Adaptation and assimilation**

The women had to find some order in the chaos which heralded a disruption to their physical body and how they coped with everyday life and the future. Following the initial phase of diagnosis there was a time of adjustment and assimilation when the women had to acknowledge that their cancer was progressive and could not be cured. They had to begin to develop ways of living with progressive disease. The process of adaptation and assimilation for some took time and was challenged by the physical manifestations of disease such as pain or fatigue and the side effects of treatment. However, for most this was a process they travelled through to reach a level of assimilation and re-integrate progressive disease into their lives. Over time, the process appeared to become an automatic response, and one those around them began to recognise.

*'That night I don't think I slept, and I was trying to think of ways that I could manage it, how I was going to cope with it and you realise you are not going to die tomorrow, you can have a reasonable life.'* Mary

At these transitional moments, the women wrestled to find a way to integrate their disease in their lives; they strived for balance and to restore normality often to protect those around them. In doing so the internal chaos could be at odds with the external image, leading to a sense of isolation. As the women could live for years much went unsaid but the behaviour of others towards them could be covert as they navigated their everyday lives.

*'I am sort of aware that although no one is actually kind of being blatant enough to say "oh if you are going to die soon we'd better spend as much time with you as possible". I am absolutely convinced that is what a lot of people are kind of thinking so I am, I sort of seem to have quite a lot of almost pressure on me to spend time with, with my family and time with my friends and I have got sort of several different groups of friends so I have to kind of try and fit them all in on good days when I am feeling well enough and it, it is almost as though I sort of haven't really got time for me because I am busy spending time with them, um.'* Dawn

Over time, however, moments of disease progression became more demanding and the ability to adjust and assimilate it into their lives became harder. Each time their disease progressed the women had to adjust and assimilate the news. There appeared to be a process to their adjustment each time, which was more marked in some than others. All the women appeared to have a time of quiet reflection about their disease progression, before slowly beginning to talk to those close to them and marshal the resources to adjust and move forward. Shelley talked about '*putting it in the attic and pasting on the barmaid's face*', meaning that she chose to present an image that everything was fine, declined to talk about it, then spent time – sometimes two weeks – only having internal dialogue, crying and struggling to adjust. Then she would talk to her husband, then her family and friends, before re-emerging back into her social network.

*'I thought no this is it, third time it is going to get me this time you know, and so I didn't say anything, went straight back to work, didn't say anything um. He [husband] waits for me.'* Shelley

Another example of this was Jill, who was a central figure in her social network and projected a positive social image which was rewarded with boundless social support. At times of disease progression she used text messaging to tell others about the disease progression and that she didn't want to talk to them. Then she took time to internalise her thoughts and feelings so was able to emerge back into her social network with the positive social image she chose to present. These times were very isolating, when the women felt a sense of being outside their social world. In adopting this approach, the women were able to project a chosen identity and thus remain within their social groups.

From the findings of Phase 1, emotional wellbeing improved with increasing time since the diagnosis of metastatic disease, which indicates that the point of diagnosis is a stressful time when potentially the fears the women have harboured for years are

realised. So the adaption to a diagnosis of progressive disease appeared to evolve over considerable time.

This period of adaption at diagnosis challenged the women's self-identity as a breast cancer survivor to becoming a person with incurable disease and the return of the familiar transition all except one had endured before, that of person to patient. Additionally, in the main the women looked well and identified themselves as feeling well at this time (other than Martha), even though some had presented with symptoms. They now faced the uncertain future they had feared while striving to continue to live their lives as partners, mothers, daughters, friends and employees with little outward indication that they had an incurable diagnosis. Most of the women found it hard to reconcile their physical image with someone with progressive breast cancer, often being shocked when disease had progressed as they felt and looked well. For Dawn, her self-image challenged her ability to acknowledge and believe her diagnosis.

*'Sometimes I think it is a huge joke almost. I mean obviously I know it's not but um, I feel almost like it's the sort of ultimate practical joke because most of the time I feel, I felt...[pause] apart from when I am actually having chemo, since my diagnosis I've felt better than I've probably felt since my teens.'* Dawn

All the women sought information to assist them in adjusting to and coping with the diagnosis. Some searched the internet, while others questioned their healthcare professionals about their disease and treatment options. From the findings of Phase 1, clearly there is an unmet need for information and advice.

#### **5.5.4 Seeking support**

When told the diagnosis, few women appeared to have access to formal support services but they described their main support (mirroring the survey findings) as family and friends. Some sought out a key healthcare professional they could talk to. For example, Mary sought the support of the research nurse she knew when she had early stage disease and who now gave her Herceptin. Most, however, had no formal support at the point of diagnosis and talked about the need to have this and being, as Joy said, *'cast adrift'*. While family and friends were supportive, the women acknowledged the impact the diagnosis had on their partners and social network, thus feeling unable to discuss their inner thoughts for fear of upsetting them.

None of the women knew where to access formal support. Following her diagnosis of brain metastases Angela felt the need for support but did not know how to access this.

She felt she had no one to talk to about her situation, both of progressive disease and how her family were responding to the diagnosis.

*'I don't know what I expected or what sort of care I expected; not knowing what there is to be offered you know? I don't know. Nobody's ever offered anything or said "oh well, we'll visit you" or anything like that...even if it was a little phone call to see how you are because you feel like you're...you've been told, you've been diagnosed, you're sent home and that's it. What do you do about it? That's how I felt. I was just thinking well what do I do about it?'* Angela

While I would challenge that the women were not necessarily on a dying trajectory, they did have a life-limiting illness of unknown duration. In applying Glaser and Strauss's (1968:8) theory of 'death expectation' to the ten women described in this chapter, from the point of diagnosis of metastatic disease the women embarked on a life with progressive breast cancer and of *certain death at an unknown time* (Glaser and Strauss, 1968). At this time the *trajectory projection* – when the women and their healthcare professionals form impressions of their anticipated illness trajectory and how it will unfold – began to emerge (Corbin, 1998).

## 5.6 The phase of living with and around the oscillations of progressive breast cancer (disease progression, treatment and the restoration of a level of wellbeing)

This phase of the illness trajectory incorporated what Corbin and Strauss referred to as *unstable*, *stable* and *comeback* which reflected the episodes of disease progression, treatment and the restoration of a level of wellbeing. Some women experienced *acute* events when they had uncontrolled symptoms or complications of treatment which warranted hospital admission. A small number of the women experienced *crisis* events which were life threatening and required emergency admission and treatment; this was most commonly due to acute onset of symptoms or side effects of treatment. Their lives were disrupted by these events and 'put on hold' (Corbin and Strauss, 1998).

From the time of their diagnosis the lives of the women would be dominated by episodes of disease progression and treatment. They became aware from their own independent searches for information and healthcare professionals that there were many treatments available and that they may have a prolonged illness trajectory but they faced a life dominated by one treatment regimen or another.

### 5.6.1 Weathering the transitions between illness and recovery and back

From the point of metastatic diagnosis the women lived with a certain death at an uncertain time (Glaser and Strauss, 1968). Uncertainty pervaded every element of their lives and they had to seek ways of living with and around this. Time took on a different meaning and was marked by transitions into and out of periods of illness and recovery – the decline, reprieve, decline, reprieve until death (Corbin et al, 1984) – with the ever present fear of a future with disease progression and death.

The continual oscillations between illness and recovery undermined the individual's ability to adjust and repair disruption. While the women welcomed improvements in wellbeing they had to readjust to changes in their physical, psychological and practical reality each time, which could be restoring their physical wellbeing or improving it significantly thus allowing for an upward trend in physical functioning with no external indication of progressive breast cancer. This could be maintained for prolonged periods of time and those around them would expect a reintegration into their life as it was before the disruption. The women continued to live with the uncertain future but often at these times the formal and informal support waned and their sense of isolation heightened.

Conversely the women also wanted to reintegrate back into their lives and social roles, so wanted others to treat them as they had done before progressive disease.

*'And it just makes you slightly alienated in a way from everybody else and slightly alienated because people treat you slightly differently...I suppose it's inevitable umm you know, I'm not working but you sort of...I don't know I feel a little bit miffed in a way even though you're not thinking about getting a job you feel slightly miffed that you are treated differently.'* Joy

The illness trajectories for Joan and Mary were linear for much of their duration and their physical functioning was high, allowing them to fulfil their social roles and integrate within their social network with little visible compromise. On the Karnofsky scale, Mary's illness trajectory plateaued and maintained her performance status at seven or above for six and a half years: Joan maintained a performance status between eight and nine throughout the illness trajectory other than one episode of fatigue and one episode of disease progression. Those with more aggressive disease such as Karen and Paula appeared to have little respite from the cycle of disease progression and treatment: the periods of time between were short. In these instances the participants continually struggled to keep pace with changing events which eroded their sense of self and ability to adjust and adapt to the rapidity of events at the same time as coping with the present and foreshortened future. This led to a lack of control which caused



them stress and anxiety as they struggled to cope with the present and the loss of the anticipated and projected future, at the same time preparing themselves and those around them for when they were unable to function fully and for after their deaths.

Disease progression emerged when the women developed new symptoms which led to investigations to determine the cause, or when they had investigations to determine whether the current treatment was controlling their disease. The approach to appointments to find out the results of investigations was always a very anxious time as they anticipated new treatment when disease progression heralded a new phase and brought death closer. Most commonly the women prepared themselves for bad news but occasionally the news of disease progression was a surprise and the women had to marshal personal resources to assimilate the news and understand the next step on their trajectory.

*'I think you think well, that's another hurdle to get over and then it's a shock when they tell you that one [treatment] isn't working as well as they would have liked, because outwardly I felt so well and I looked alright. He [the doctor] looked at the scan and said "I looked again to check because it wasn't, it's not what you would expect".' Jill*

At times of disease progression the transition from person to patient again was difficult, particularly when the women still felt well. This transitory process, what Turner (1967) called 'betwixt and between', was often a moment of limbo as they anticipated and adjusted to relinquishing the role of person to become a patient again, which could mean time off work, altered social relationships and side effects of treatment.

Those who had access to a community palliative care nurse specialist used this relationship to help them adjust to and cope with progressive disease, although for Shelley contact was made after she had emerged from her time of adjustment. The exception to this process was Mary, who appeared to speak to her palliative care nurse after her appointments and talk the disease progression and subsequent treatment options through with him.

Living through these transitory moments became what was frequently referred to as a rollercoaster.

### **5.6.2 Enduring sequential treatment**

The trajectory oscillations of disease progression, treatment and the restoration of a level of wellbeing became the women's lives. Many became expert patients, searching for information on current and future treatment options and breakthroughs in potential treatments in the future. While many knew the options for treatment were many, they

were also acutely aware that at some point the options might run out and they would be faced with no way of controlling the disease.

*'I just think I'm going to go on like this forever, having treatment, having treatment, having treatment and it's bound to run out soon.'* Karen

Jill's illness trajectory highlights a life with metastatic breast cancer which is dominated by treatment (Figure 10: Illness trajectory 5). She endured nine different episodes of treatment (bisphosphonates, radiotherapy and chemotherapy) and she experienced sequential chemotherapy throughout her illness trajectory. Jill went through cycles of feeling and looking well and living her life to the full to episodes of developing symptoms and feeling unwell, which indicated disease progression. These cycles were present to some degree in all the women other than Joan. When we met in February 2007, two years after her metastatic diagnosis and seven months before her death, Jill reflected on her treatment so far.

*'So we are back to this thing again, that will be the third time I've lost my hair, so when I've finished this cycle I am going to lose my hair again and of course it's going to be through the summer this time. There's a possibility I might have an extra couple of cycles because I've been doing quite well on it. We don't know yet. I mean it's all trial and error...I have been on and off chemo since September 2005 because I went into hospital in the July, came out and popped back in again in August, and that's when we did all the scans and we found out that it had spread and gone to my liver, so I had docetaxel because that's the one that makes you lose your hair isn't it? So I had that up until however long, that cycle lasted for six cycles. Then I had another scan and my levels had started to rise, not that horrendously but they had started to rise, so I had capecitabine and I failed on those. I had an initial response and we did a scan and it looked good, but then I didn't respond very well. So they took me off those which was about May, so that's when I went on to vinorelbine. I've been...[pause] the most I've managed off chemo is six weeks when I was poorly back in December was the longest I've been off, because yes, I sort of basically had chemotherapy and then when that cycle stopped, three weeks later, I've gone onto the next one, it's tied in with the Herceptin and my bone strengthener. So really I haven't been off chemo since October 2005. Other than my six weeks I managed back in November/December just gone.'*

Jill's experience may be extreme in a life dominated by treatment in comparison to others with progressive disease such as Joan. However, it highlights how some women's lives were punctuated by one treatment or another and the disruption this causes in a life lived with and around progressive disease and treatment.

Some of the women had extremes of illness when they were very compromised by their disease. At times Jill was in a wheelchair and unable to undertake simple daily tasks: then having a level of wellbeing restored as a result of chemotherapy, on one occasion she went skiing and on another a cycling holiday. Following a prolonged hospital admission for Joy in 2001, when she experienced uncontrolled symptoms, fatigue, depression and physical dependence, and her partner anticipated her death and bereavement, she recovered; her physical functioning improved so much she decorated her lounge single handed.

Tolerating and anticipating the cycles of treatment was in itself a challenge for Paula, who found the relentlessness of treatment cycles hard to cope with. She had little respite between treatments and was relieved when the chemotherapy was stopped five months before her death.

*'When I'd go for the chemo I would always be a bit miserable the day before. Then it got to two days before. Then it got to three days before. And then the week, it was the weekend and the whole weekend was ruined because I was thinking oh I've got four more days left before I go back to have some more and it was just another vicious circle and, and the chemo wasn't doing what it was supposed to be doing, or as well as they hoped, so they just, they stopped it. And I, I don't think I've got any worse. Because I still think about, you know I've still got to go back for the other treatment but it's, it had got to the stage where I was having probably two or three good days out of three weeks.'* Paula

### **5.6.3 Self-managing physical symptoms**

The physical manifestations of disease and treatment were common problems, in particular fatigue, which all the women experienced, and uncontrolled pain. None of the women other than Mary had access to ongoing pain management and assessment. Most of them tolerated uncontrolled pain and self-medicated. Paula thought it was only to be expected. On a visual analogue scale from 0-10 her pain was 6-7. Angela was prescribed analgesia by the oncologist and her GP but there was no ongoing assessment so her pain remained uncontrolled until she was referred to palliative care services within the last year of her life, which meant she tolerated uncontrolled pain for four years. Again on a visual analogue scale her pain was constantly around six.

A few of the women had involvement with palliative care services, but only one (Mary) maintained this relationship over time. Others (Shelley, Martha) were referred to community palliative care services but when they had no physical symptoms the service withdrew. Shelley felt able to contact her community palliative care nurse if she needed her: Martha referred herself early in her disease, but once her symptoms were controlled she was referred to the hospice day centre for care, felt she didn't fit into this service and discharged herself. Others attending the day centre were very unwell and it distressed her to see both the suffering of others and her potential future in their experience.

When we met in April 2006, 20 months before she died, Angela talked about enduring the pain which she had had since September 2004, although in different sites at different times.

*'It is just, it is just like a, a gnawing pain and it is, sometimes it gets you down because you think God just go away for the day and sometimes I think if only I could have one day where I think oh I feel really good today and it never happens, that, that is what I think gets to you because you just feel so bad all the time especially recently I am now, I am not one for sitting around doing nothing and I am up out doing my job and enjoying my job but recently I haven't been...' Angela*

The side effects of treatment brought other concerns. Hair loss is known to be a concern in women who undergo chemotherapy (Batchelor, 2002), but in those who received sequential chemotherapy, hair loss may have occurred several times, so their hair never returned to how it was before their diagnosis. Hair loss is one of the most common visual images of someone with cancer and in metastatic breast cancer may be the only external sign which challenged the individual's identity and the reactions of others. Some of the women anticipated and feared that the next option for treatment would mean they would lose their hair again.

*'I mean yeah other than losing my hair which was probably...that is one of the hardest things, I think that is probably the worst thing out of all of it for me.'* Jill

Throughout her illness trajectory Jill lost her hair three times (including early stage disease).

#### 5.6.4 Relentless vigilance

Although at times the treatment was difficult to endure, when there were periods of stable disease coping between treatments brought new challenges. The women talked of being very aware of any changes in their body.

Living over time with progressive disease meant the women were constantly aware of their illness and body. While treatment allowed some respite from the symptoms of progressive disease and potentially increased their survival time, living vigilantly with progressive disease appeared exhausting in its relentlessness.

*'It's strange because it's constantly in my head that I am I suppose, seriously ill. You can't kind of get away from it. It's what I wake up thinking about. It's what I'm aware I'm thinking of at night if I wake up, and it's sort of there a lot in my head during the day. It's kind of a constant thing and yet I have to say I kind of feel all right and that's very strange.'* Dawn

*'I hope that every time I have a headache that it's not something come back up there. That's all. You are living on a knife's edge that way. Yeah, waiting for you to be ill or if you do become ill is it just say your normal cold or is it a normal ailment not the cancer, because you just don't know. Every little thing is to do with the cancer all the time.'* Angela

All the women had times when their disease was stable. During this time anticipating progressive disease meant the women lived vigilantly with their bodies. They were always alert to any physical changes which may have indicated progressive disease and lived in a state of constant heightened awareness.

A central theme running throughout the illness trajectory of all the women was that commonly they looked well and felt well, particularly in the earlier stages of their disease. So disease progression was often difficult to anticipate and adjust to.

The oscillations between unstable periods of disease progression and ill health to times when they were stable and asymptomatic with a good level of physical functioning brought different challenges as they projected into their future. The transition from person to patient was reversed and they reintegrated back into their lives, returning to work, resuming full responsibility for the home or the children. But while this transition was welcomed by those around them as a return to health, the women were constantly vigilant in listening to their bodies and being alert to any changes. They commonly endured this in isolation as they were conscious that others enjoyed the normality of life and routine these periods afforded them.

*'Once I came off the chemo there's this sense of kind of waiting. Like I know that I'm on the Herceptin as long as it works but I was kind of thinking is it working, and there's this sense of paranoia that I'm kind of looking every day and feeling and prodding and pushing and thinking "what can I feel?" "What can I see?" "Am I OK or not?" "Am I kidding myself?" I know that's not the way to live, you should just kind of embrace every day and get on with it. I suppose that's going on the whole time really. Then you think, well what happens when I do definitely feel something...you kind of see that day out there in the future and you think, that's going to be a pretty awful day really. So it's having a kind of awareness that it's out there somewhere in the future. Sort of worrying.'* Dawn

*'Well, you're always waiting for something else to happen to knock you back. Funny, you think you know, you go out one evening and you think, oh you look nice, go and do what you're gonna do, if you are going to the theatre or whatever and then you enjoy it. And then you think I'm getting better, I feel a lot better this week, then you get sort of hit again with something else. So you get knocked off your feet.'* Angela

While having chemotherapy the participants were seen by their oncologist every three to four weeks, while when they were between treatments and had stable disease they would usually only have contact with an oncologist every three months. In addition, at times of stability, those who received support from community palliative care services were often discharged as they were asymptomatic and/or functioning well physically. If the women resumed working at this time, it was problematic to see their community palliative care nurse as they worked in the hours the service was available. So while the transition from patient back to person was welcomed by the women and those around them, the reality for the women was that the disease was still present and they continued to live with it, often without feeling able to verbalise their thoughts and fears. By accepting the terms of reference of their social groups they were able to reintegrate back into them, which in itself could lead to a sense of isolation and marginalisation.

#### **5.6.5 Enduring the oscillations of life with progressive disease**

While enduring the cycles of progressive disease, treatment and the restoration of wellbeing the women continued to live their lives with and around their disease. In contrast to the others Joan's life centred less around this cycle and she did not seek a focus in her life with progressive disease, rather she projected an image of stoic acceptance. At the age of 78, she attributed this to her life lived and a strong faith: *'I am a child of the rectory and we all go home in the end.'* Joan had not had to endure many

cycles of treatment and when she did, she tolerated this well, other than one episode of profound fatigue which resolved with a change in her endocrine therapy. She reflected on a number of events in her life which she attributed to a calm acceptance of the present. As a young mother of small children she was suspected of having cancer. She did not have cancer but the fear of leaving small children was a clear memory and she recounted the event as if it was recent. She nursed her husband for years when he was severely disabled and aphasic following a stroke and felt relief that no one would have to do this for her, and she attributed her current coping to having lived through the war, losing people and acknowledging death in her life at a young age: '*You learned anything can happen to anybody.*' She only told a few friends of her diagnosis as she did not wish to court sympathy.

Self- transcendence has been described as moving beyond self-concern without devaluing the self and has been found in women with metastatic breast cancer to be a means to decrease illness-related distress and improve emotional wellbeing (Coward, 1991). Mary was the only person to appear to use self-transcendence as a coping strategy. It is interesting to postulate why this approach helped her to live with and around her illness. She believed that she had experienced a varied and rewarding life and was surrounded by family and friends who remained supportive throughout her illness trajectory. Her palliative care nurse was a constant throughout the majority of her illness trajectory and was influential in controlling her pain and other symptoms. In addition, she retained control of her life and activities and ultimately the decisions around stopping active treatment and her place of death.

Others were not so fortunate and had to maintain social roles such as parent or employee and navigate problems which punctuated their lives outside their breast cancer.

### **5.6.6 Maintaining social roles**

While living with the oscillations of progressive disease the women had to maintain their social roles. Of those with partners, there were often subtle shifts in their relationships. Some women anticipated an erosion or switch of roles and some prepared themselves and others for this. For example, Martha began to teach her husband how to do the washing and to cook, something he struggled with as it meant he too had to acknowledge her disease progression. Paula was very concerned that her ex-husband would honour her wishes for her sons' upbringing after her death, while he struggled to acknowledge her forthcoming death saying things such as '*You'll outlive me yet.*'

The change in social order challenged the participants' identities and the social order to which they were accustomed. The erosion of the social order could make them feel apart from their social groups and at times isolated.

### **5.6.7 Acute episodes**

Corbin (1998) defines an acute phase as events which precipitate hospital admission and the biography of everyday life is placed on hold. Such episodes were as a result of chemotherapy side effects, physical deterioration, uncontrolled symptoms such as breathlessness and cerebral symptoms. Life-threatening situations were rare. Five of the women attended an accident and emergency department at some time for pulmonary embolism and a seizure (Karen), chemotherapy side effects, neutropenic sepsis (due to chemotherapy) and uncontrolled diarrhoea (Mary), physical deterioration and multiple uncontrolled symptoms (Joy), and neutropenic sepsis (due to chemotherapy) (Shelley and Angela).

Other crisis events affected the women's everyday lives. Angela's family struggled to cope with her during the end of her life, resulting, as she had anticipated, in unplanned admissions to hospital and the hospice. In addition, when the women experienced acute events or crises they and their family and friends anticipated their death. This anticipated bereavement became a problem when the women recovered time after time, as partners, family and friends had to readjust to the restoration of wellbeing and physical functioning, and women reclaiming their social roles. For example, Joy endured a number of acute episodes and recovered well. This put a significant strain on her marriage as her husband repeatedly anticipated her death and had to adjust when she recovered.

*'I think he thought I was going to die at that stage so he really gave too much...um and at a later stage he resented that a bit...[pause] all the emotion and effort he put in and you know I recovered. It was as if he couldn't handle the rollercoaster am I going to live, aren't I going to live?'*  
Joy

Crisis events marked the final downward phase for four of the women. All were admitted to hospital via an accident and emergency department; two for uncontrolled pain and two for neutropenic sepsis.



## 5.7 Downward phase

The expectation of the cancer trajectory is that it will have a downward trend at some point (Murray et al, 2005, Pattison, 1977) but this was not necessarily the case in metastatic breast cancer. All the women experienced downward trends in their illness trajectory but unlike other models of illness trajectories in cancer the trajectory of illness in metastatic breast cancer may have a downward trend which recovers again and again, what (Strauss et al, 1984:66) refers to as a pattern of 'decline-remission-decline-remission-decline to death'. So while ultimately the final phase of life will be a downward trend, those with progressive breast cancer may have oscillations which show a downward trend then a restoration of wellbeing to the same or a higher level than before the event which caused the decline. Weathering these oscillations while living their lives, maintaining their social roles and navigating life around breast cancer, challenged the women's individual resources. For all, the final downward trend in physical functioning signalled a step towards the end of life.

### 5.7.1 Convergence of active treatment and the end of life

Eight of the women died during the study. The events leading to Joy's death are unknown. Of the remaining seven, one died at home, three died in a hospice and three died in hospital. Mary died peacefully at home with support from her family, community palliative care team and GP. All those admitted to either the hospice or hospital died within days of admission, other than Paula who died within two weeks.

In those who were receiving chemotherapy at the end of their lives there appeared to be no consensus decision to stop treatment, but of the four who had unplanned admissions leading to their death, two had neutropenic sepsis associated with chemotherapy. From the illness trajectories of these women it appears that they were actively treated up until and including the dying phase of their lives. There was a decision to stop active treatment (chemotherapy) for two women (Paula and Karen) prior to the dying phase, although Karen had whole brain radiotherapy three months before she died. Mary decided to stop treatment in discussion with her oncologist. Most of the women appeared to choose to be treated until treatment was futile, although the definition of futility may have been very different for each individual. However, with the collusion between the women and their clinicians that there were many treatment options, stopping active treatment appeared to be difficult for the women.

All the women alluded to the uncertain future and anticipation of death, but the constant quest for the next treatment and to prolong their lives as much as was possible meant few had support services in place to help them until the end stage of their lives. Some

of the women knew there were support services but associated them (palliative care and the hospice movement) with the end of life and appeared reluctant to access them, perhaps unaware they were approaching their death or unable to acknowledge it. Consequently few had an established relationship with palliative care services before the last year of life, some only days or weeks before death. Two of the three who had an established relationship over years had at times been discharged from the service as they were not symptomatic. It is not possible to know retrospectively what influence palliative care had on these women's lives other than for Mary, who had an established relationship with over time with her community palliative care nurse and died at home, supported by both family and primary care professionals. Others were unaware of where to seek support. As Angela said:

*'You know, no one has ever offered anything, or said oh well we'll visit you or anything like that. The other concern I have got is when it comes right near the end when I am really poorly what do I do? Do I just stay here or do I go into hospital? Do you have to book something? Or that sort of thing... [pause] that I think you really don't know.'* Angela

Angela asked her GP to refer her to a community palliative care team two years before she died and he told her she was not ready for that yet, even though she had endured uncontrolled pain and other symptoms throughout her illness trajectory. She was referred to the community palliative care team in November 2006, just over a year before she died. Although when we spoke they had only met once due to Angela's work commitments, she said *'she's my nurse now'* to indicate that she was establishing a relationship:

*'at least you know you have got someone at the end of the phone that you can talk to if you need to, which yeah, I think that is a good thing... [pause]. It's nice to talk to Julie, she's outside the family so you can talk to her, you can talk about anything.'* Angela

## 5.8 Dying phase

### 5.8.1 Being prepared for death

Mary's death stands apart from the others. Aged 68 she considered she had experienced a good life and although she was very active for most of her illness trajectory, like Joan she appeared more accepting of her illness. At her last hospital appointment, when a CT scan showed her disease had progressed despite the treatment, she decided not to have any further treatment; as she said *'quality was*

*better than quantity*’. She spoke about the last time she left the doctor’s office and the hospital.

*‘The funny thing was when I walked out of the room from seeing the specialist I felt as if the weight had been lifted off my mind, which sounds peculiar but I think you feel right, well you’ve done everything you possibly can, you can’t do anymore, you know, go out there and live your life every day. And that’s what I plan to do.’*

Mary organised her funeral and spent her last few months completing her wish list, a holiday in the country, an Italian opera and spending time with people she loved. The support and presence of her social network never waned and she was well supported by her community palliative care nurse and GP. While it cannot be claimed that the role of supportive palliative care services and GP had an influence on Mary dying at home, this illness trajectory was the exception, and the support services Mary received as well as good social support were almost certainly influential in this.

### **5.8.2 Not being prepared for death**

The final interview with Karen was in the last two weeks of her life, hours before she was admitted to hospital for the drainage of a pleural effusion. She was very weak and had begun to prepare for her death. She said this phase of her life felt surreal, although she still looked well and presented well. While she acknowledged that she was experiencing physical deterioration which may have indicated the final phase of her life, neither Karen nor I realised her death was so close.

*‘It feels like it’s not you, I’m acting it out really. I mean my sister is out there now; she is going through my cupboards... [pause] I want to leave it all clean and tidy so you haven’t got anything to worry about. If I can’t get that done then I get edgy. It doesn’t upset me; it doesn’t feel like it is happening to you really [cries]. Sorry I’m a bit down.’*

Later Karen recounted a discussion with her specialist about dying.

*‘Well I asked him sort of what, what’s going to happen you know when, when you do die. How do you die sort of thing and do you... [pause] is it violent or just withers away or whatever and he said you just fade away. I think that’s all I need to know, I find it quite a nice way to go.’*

In all the women who died there was a rapid decline towards the end of their lives, and for Angela, Jill, Shelley and Martha the end of their lives appeared to illustrate disintegrated dying, where the events are chaotic and the end of anti-cancer treatment

overlaps with the end of life. Consequently there appeared to be little preparation for the event so admission and subsequent death occurred within a short time period. While the women talked about the anticipation of their deaths and some preparation for this, such as memory boxes for children, funeral arrangements and preparing others to live without them, they commonly ended these discussions with talk of hope for more treatment, miracles and scientific breakthroughs around the corner to reassure themselves they may yet have their lives extended even further. The awareness of many treatment options available gave them hope that there would always be one more to try. This may be an explanation for the lack of acknowledgement of the nearness of death and end of life care. Those who had considered planning the end of their lives did not know how to do this or who would assist them.

The last few months of Angela's life appeared to resemble everything she was hoping they would not. While it stood out as particularly chaotic, having learned when we first met her fears that her partner and family would not cope with her when she was dependent and confused it was not surprising. She talked of wanting to plan for the end of her life but was unsure how to do this. She knew her partner's worst fear was that she would not recognise him and would be confused and disorientated at the end of her life. Angela had four unplanned admissions to hospital in the final three months of her life, which were interspersed with transfers to and from the hospice, accounting for approximately 50 days. The reasons for these admissions were uncontrolled pain, neutropenic sepsis and a fall; the final admission was following a second fall when, as she predicted, her family felt unable to cope. She died in the hospice five days after that final admission.

My last interaction was with her partner. I had arranged to speak to Angela once more, and unaware of recent events I called her as arranged and her partner answered. Angela had died the week before. She had been discharged just before to spend Christmas at home but had a fall and went back into the hospice, where she died. Her partner was relieved that it was all over and she had died peacefully at the very end. This period of her life had been traumatic for him. He told me her last few months, punctuated with pain, confusion, weakness and repeated admissions with periods of time at home were '*horrendous*', and he felt considerable relief that she was no longer suffering.

Another example of chaotic dying was the end of Jill's life. Jill returned from holiday with a number of symptoms: she was referred to the palliative care service for the first time and admitted to the hospice. Her anxiety at this time (according to the medical notes) was that she had not prepared her children for her death, having only told her eldest, her 16 year old, that this was a possibility. She had talked about her reluctance

to tell her children many months before. She and her husband had rowed as he felt they should be told more about this possibility and she didn't. She wanted to protect them from the harsh reality of her illness. Jill appeared unaware of the nearness of her death and often spoke of the many treatments available if the next one failed. I met her husband briefly after she died and he and the children had no idea she was as close to death as she was. Their young daughter, who had no memory of her mother without breast cancer, assumed Mummy would have more treatment and have some restoration of wellbeing, as she had done numerous times before.

These examples highlight that there appears to be little time for the acknowledgement of impending death or to prepare the women and those around them for the event. Consequently the end of life for the women who died appeared chaotic with little control or planning around the end of treatment, care at the end of life and place of death. All the women alluded to the end of their lives but clear plans for their end of life care and place of death appeared not to be considered by any of the women other than Mary.

## 5.9 Applying the Corbin and Strauss Chronic Illness Trajectory Framework in metastatic breast cancer

Considering the Chronic Illness Trajectory Framework from the perspective of metastatic breast cancer, it does appear to be useful in understanding the trajectory of progressive cancer in a structured approach. However, for those with metastatic breast cancer, breast cancer has already caused a biographical disruption (Bury, 1982) of their lives since their initial diagnosis of early stage disease, and the long-term effects of the initial diagnosis, physical and psychological, may already have had an impact on the cancer survivor. While the model does consider the pre-trajectory phase (before the illness begins, the preventative phase, no signs or symptoms present), it does not accommodate the transition from early stage disease to metastatic disease. In addition, while it does consider the oscillations of an unpredictable illness trajectory and in particular that it may plateau, what is unclear is the consideration that there may at times be an upward trend, adding weight to Smeltzer's (1992) argument that the Chronic Illness Trajectory Framework does not address the needs of those who are symptom free or whose disease is progressing slowly over years.

The updated model considers a more comprehensive holistic approach to care and uses a pragmatic problem-solving approach. Corbin (1998) believes nurses should be the central figure in the care of those with chronic illness and as such influence the approach to care. In operationalising the model, nurses should first gather data on the physical, emotional, psychological, functional, social and economic problems of the individual then prioritise these as a means of goal setting. The goal setting should be

based on the illness state and biographical needs and must be realistic and achievable, reflecting the individual's abilities and motivation. It needs to be flexible to accommodate the fluctuations of illness and the phases each individual may inhabit. The individual must be integral to the development of goal setting for the model to work.

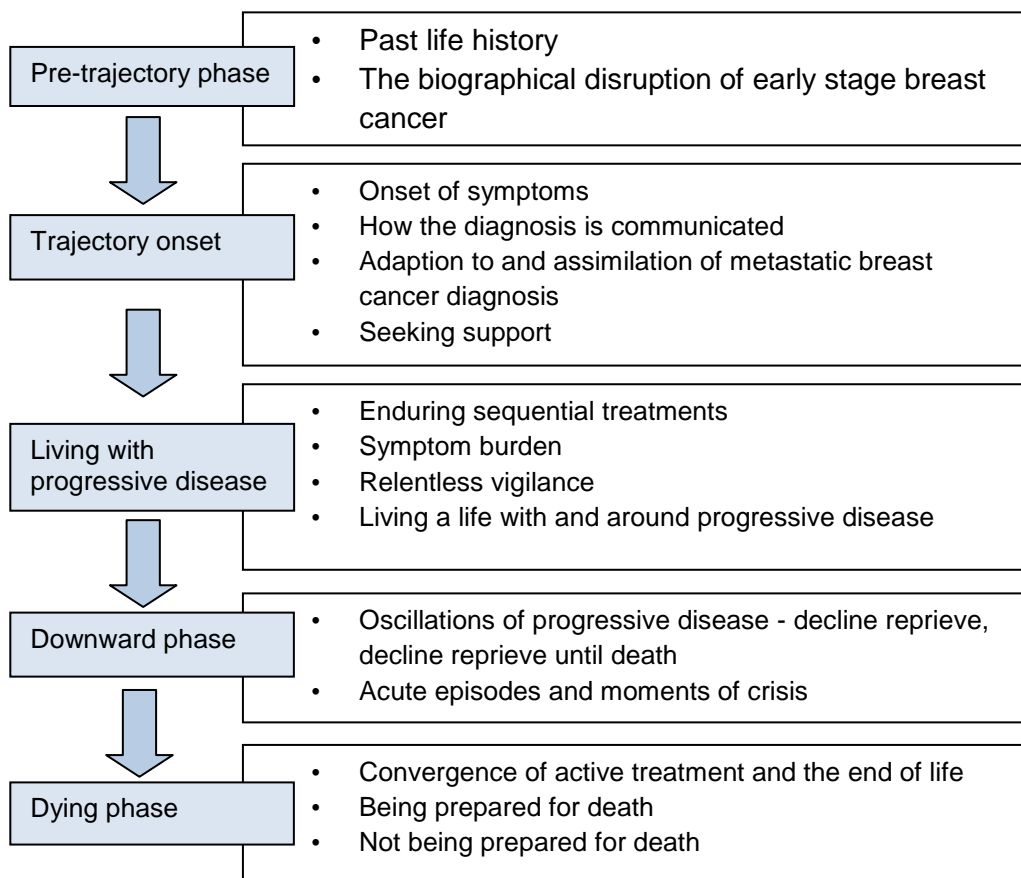
The practical implementation of the model is then determined by identifying who is responsible for which actions and how the plan of care will work in practice. The plan should also consider the phases the individual may go through. Finally, the problem-solving process needs to be an ongoing one which is continually assessed to consider the changes in the biographical, everyday life or illness state which may alter the phase the individual is in. Ongoing evaluation is essential to the model's success. This model is probably a seminal work in the understanding and care of those with chronic illness and it is appropriate to consider it in the illness trajectory framework in metastatic cancer. The framework allows for living over time and the oscillations of this, whereas those considered in cancer care (Kubler Ross, 1970, Pattison, 1977, Copp, 1999), while having some essential components of care, focus primarily on the dying trajectory with little application in cancer survivorship.

## 5.10 Summary

Applying the Corbin and Strauss framework to the trajectory of metastatic breast cancer alongside the mapped illness trajectories allowed a greater understanding of the temporal experience of living with progressive breast cancer. Three distinct trajectories were identified: *ticking over nicely*, which described an indolent disease trajectory; *is there no end to it?*, which described the trajectory of those with aggressive disease which is of short duration, with a rapid decline and little respite from episodes of disease progression and treatment; *it's a rollercoaster*, which was the most typical trajectory, describing a long duration punctuated by episodes of disease progression, numerous treatment regimens and the restoration of a level of wellbeing, at times better than previously indicating that the oscillations of progressive breast cancer can be unpredictable. Phases women appeared to go through were: the pre-trajectory phase, which considered the biographical disruption of early stage breast cancer and other life events; the trajectory onset, which described the onset of symptoms, which were commonly insidious with the path back into oncology services unstructured and convoluted. Within this phase, the women experienced a process of adjustment to progressive disease and how to assimilate this into their lives. The phase of living with and around the oscillations of progressive disease, which considered the transitions from person to patient and back, enduring sequential treatment and uncontrolled

symptoms and the relentless vigilance which would be a constant part of their lives and the time when navigating the social context of progressive disease affected their relationships and identity. The downward phase, which was not necessarily the indication of the end of life as they could have a restoration of wellbeing following treatment, however active treatment and the final phase of life appeared to converge making the distinction between living with progressive disease and the oscillations they had come to expect and dying problematic. Finally the dying phase, which few appeared prepared for, commonly punctuated by acute episodes and emergency admissions, with little apparent preparation for the end of life. Chaotic dying was predominantly the experience at the end of life (Figure 16).

**Figure 16: Metastatic breast cancer illness trajectory phases**



By applying the Corbin and Strauss model, the metastatic breast cancer illness trajectory is given form, with typical and atypical trajectories and phases (Table 16). This approach allows those responsible for the care of women with metastatic breast cancer to assess need and service provision and care.

## Chapter 6. Discussion

This was the first study to explore in detail the everyday lives of women with metastatic breast cancer in the current context of multiple treatment modalities and potentially prolonged survival. As such it offers a significant contribution to the body of knowledge showing that women's quality of life is poor, with many experiencing uncontrolled symptoms throughout the illness trajectory rather than only associated with the end of life, poor experience of care and inadequate professional intervention and support. Prior to this study the illness trajectory and phases and life course of women were ill defined. This study reveals for the first time the illness trajectory of metastatic breast cancer and the oscillations of living with progressive disease through the sequential treatments which dominate women's lives. The study findings highlight the problems and needs of women, the lack of care provision and, in particular, the dissonance between active treatment and palliation which sometimes leads to a disintegrated dying process with little planning for end of life care and place of death.

While the impact of social support on women with metastatic breast cancer has been previously investigated, this is predominantly measured by statistical prevalence, correlation and association. This is the first time a sociological approach to investigating how women navigate social relationships and work to mediate the discontinuity between self, body and social order has been undertaken.

Overall, it appears that women are being cared for predominantly in the outpatient setting by their oncologist. There is little evidence of GP or palliative care involvement: indeed any involvement of palliative care services is at best sporadic and at worst absent. The majority of women appear to only access these services when they are at the very end of life and arguably too late to establish productive relationships and patient-focused care. Women fall between acute care and palliative care with neither discipline meeting their needs.

The purpose of this study was to explore the emotional, practical and physical effects of living with metastatic breast cancer and to identify the prevalence of problems and needs of women as well as practical measures that might be taken to meet them. The study aimed to yield information to improve women's lives by informing those living with metastatic breast cancer, policy makers and care providers.

The aim was to first 'set the scene' of what the experience of living with metastatic breast cancer was like for the wider population and to understand the prevalence of problems and concerns in the context of present day healthcare through a cross-



sectional survey, then to explore in more detail the everyday lives of those living with it through biographical narrative interviews.

The following research questions set out to achieve this.

- What is the prevalence of problems and needs of people with metastatic breast cancer and to what extent does current service provision meet their needs?
- What are the social consequences on identity of living over time with progressive breast cancer?
- What does the illness trajectory of metastatic breast cancer look like and by mapping this, what does it add to the understanding of the experience of living with progressive breast cancer?
- What measures could be taken to improve the wellbeing and experience of women with metastatic breast cancer?

To answer the research questions the study was undertaken in three phases. The first phase used both quantitative and qualitative approaches – a cross-sectional survey of 235 women measuring quality of life and experience of care and open text questions about their problems and needs and where they turned for support. The second phase of the study used the narratives of 30 women over one calendar year to explore the social consequences of living with progressive disease on identity. The third and final phase used women's narrative over one calendar year triangulated with documentation and a measurement of physical functioning to map the illness trajectory of ten women in order to identify typical metastatic breast cancer trajectories and describe the phasing of a life with progressive breast cancer.

In order to recruit a wide population of women with different experiences of treatment and care for the cross-sectional survey, two approaches were applied. First, all women attending two cancer centres were approached to take part in the study, and second, simultaneously women accessed the same survey online through Breast Cancer Care's website. This allowed recruitment to include women who were being treated in different healthcare settings and those who may be outside the healthcare setting.

While on-line surveys have increasingly become common methods of recruitment in research, when this study began they were rarely used and there were no reports of using them to explore the experience of those with progressive cancer. There has been some concern that those with progressive breast cancer accessing the internet may be vulnerable to exploitation in their quest for alternative therapies and second opinions (Pereira et al, 2000). For this reason it was anticipated that recruitment to on-line surveys for those with progressive cancer might not reap many responses. In the

event, the on-line survey received 50 responses within five weeks whereas recruiting the same number in one cancer centre took nine months. There were calls to Breast Cancer Care's helpline and emails thanking the organisation for highlighting the needs of those with metastatic breast cancer. As this population is considered marginalised (Davies and Sque, 2002) it could be argued that the response rate indicated that rather than feeling vulnerable and reluctant to take part, those with progressive breast cancer wanted their voices to be heard.

In total 235 women completed the survey (cancer centre = 110 and website = 125). The women's ages ranged from 25-84. The median time from diagnosis of metastatic disease was two years (range from 1 week to 15 years) with ten (4.2%) women living over five years. The majority of women were receiving some form of treatment and many had been previously treated for their progressive disease.

The cross-sectional survey revealed that women with metastatic breast cancer have poor quality of life. Low quality of life scores were seen in all the FACT-B domains reflecting the impact of living with progressive disease and treatment on all aspects of their everyday lives. Quality of life scores (FACT-B) in this study were significantly lower than the normative sample of which 20% had metastatic disease (Brady et al, 1997) and than women with metastatic breast cancer being treated with endocrine therapy (Fallowfield et al, 1999). Women's overall experience of care was poor with just over half being dissatisfied with the information, support and care they received.

There was some suggestion that emotional wellbeing improved as time since the diagnosis of metastatic disease increased. Women who had been diagnosed recently reported poorer emotional wellbeing, indicating that at the time of metastatic breast cancer diagnosis women are in need of support (although this was only approaching significance). These findings were supported by the open text responses which indicated that women's experience of care at metastatic diagnosis compared unfavourably with their experience of early stage disease when they felt informed and supported. The fear of recurrence is an enduring concern for women who have had a diagnosis of early stage breast cancer (Spiegel, 1983, Northouse et al, 2002), which implies that for them, the diagnosis of metastatic breast cancer is a fear realised. However, the study findings support other evidence which suggests there appears to be inadequate provision of care and support at the point of metastatic breast cancer diagnosis (Reed et al, 2010).

Younger women and those with children appeared to have specific needs. Younger women had worse functional and social wellbeing and were less satisfied with elements of their care. An explanation for this may be that younger women are more

likely to have aggressive disease and so experience more episodes of progressive disease, symptoms and sequential treatments (chemotherapy). To support this premise, those receiving chemotherapy had lower functional wellbeing than those receiving hormone therapy. Active treatment compromised their everyday lives and their ability to manage their responsibilities and social roles such as partner, mother or employee. In addition, those with children appeared to have worse quality of life. These findings may have been biased by the number of younger women who were on-line participants but are supported by the open text responses indicating that social wellbeing is an enduring concern.

Those with bone metastases were a second sub-group who appeared to have unmet needs. They were more likely to report significant pain, were less satisfied with the information and advice they received and with elements of their care, felt less supported and rated the support as lower than women with other metastatic sites. Those with bone metastases only also appeared to have a higher symptom burden.

All women, irrespective of age, appeared to feel a detachment from the everyday lives of others. This led to a sense of isolation and few knew where to turn for support, citing family members as the people from whom they most commonly sought support.

The findings from the survey suggest that symptom burden is a significant problem within this population. The apparent lack of symptom management for women appears to persist throughout the illness trajectory. There was no relationship between time since diagnosis of metastatic breast cancer and symptom burden, indicating that inadequate symptom control was a problem throughout the illness trajectory and not just associated with the end of life. There was little evidence of GP or palliative care involvement in women's care, with the majority (61.1%) choosing to see their oncologist regularly above other healthcare professionals. Only 8.5% would choose to see their GP and 7.3% a palliative care nurse. These findings suggest that care is given predominantly in the outpatient setting by an oncologist.

From the findings of the cross-sectional survey it is clear that women can live for a number of years with progressive breast cancer and experience complex multidimensional needs throughout the illness trajectory which are not met by current care provision and are not solely associated with the end of life.

All those who took part in phase 1 were asked if they would like to take part in the second phase: narrative interviews. A sub-sample of 30 women from the two cancer centres and website were invited to participate in the longitudinal interview study. Use of a sampling matrix aimed to select the women purposefully to ensure they were as

representative a sample as possible. Using a biographical narrative approach, women were interviewed three times over one calendar year.

A framework for analysis of the narratives was developed using Lieblich et al's (1998) holistic-form and holistic-content analysis approach in order to use the interviews in their totality to determine the plot and story over time while analysing the content (page 66). How women mediated the discontinuity between the self, the body and social order was a focus of the narratives; revealed through this analytical approach it became the central theme.

Narrative analysis revealed that living over time with progressive breast cancer challenged women's personal resources and could erode their sense of self. Wherever possible, women chose to maintain their everyday lives and routines that were considered normal and predictable. At difficult times such as uncontrolled symptoms or progressive disease they were thrown out of reality maintenance (Berger and Luckman, 1966) and had to seek ways to live with and around progressive disease.

*Looking well and feeling well* and *looking well but feeling unwell* were concepts which threaded through women's narratives. When the women *looked well and felt well* their external and internal realities worked in harmony and it was easier to maintain their social roles and social order; when *they looked well but felt unwell* they had to seek ways to realign their internal and external realities. This study identified that in mediating transitions in identity, women adopted contingent identities. Two contingent identities were identified – stoicism and absolved responsibility. Stoicism was most commonly used. By projecting an image of coping and positivity women appeared more likely to be accepted in their social groups with little compromise. However, while this approach allowed women to maintain social inclusion and social order they could still feel isolated and detached from the ebb and flow of everyday life as their lives diverged from those around them. The second contingent identity was absolved responsibility. Using this, women handed responsibility of the physical body to others (healthcare professionals or family members). The diseased body was disconnected from the self and the transition from person to patient was permanent. By adopting the contingent identity of absolved responsibility women indicated to those around them a different social order, shifting to one of dependence.

When projecting forward into the future, a central fear was loss of identity and relinquishing control in the final days of life. Having struggled to maintain a cohesive sense of self and identity, maintaining this until death was the desired end to their lives.

The third and final phase of the study aimed to define the illness trajectory of metastatic breast cancer. In order to consider the care needs of women, it was necessary to apply a theoretical framework to give structure to an ill-defined pathway. All the work looking at illness trajectories in illness predominantly considers a biomedical model, while those in cancer (although some acknowledge the more holistic need) are focused on the dying trajectory. Literature on chronic illness underpinned the qualitative approach to this study and chronic illness theories were drawn upon to develop both the study design and analysis. The key theories of loss of self (Charmaz, 1983), biographical disruption (Bury, 1982) and biographical reconstruction (Williams, 1984) informed understanding of the concept of the illness trajectory. A framework to define the temporal experience of progressive breast cancer was not available in the cancer literature as the focus of those available was predominantly on recovery, survivorship or end of life care and the dying trajectory. In the absence of a framework in cancer Corbin and Strauss' revised Chronic Illness Trajectory Framework (1998) was applied to the trajectory of metastatic breast cancer. This conceptual model allows the trajectory to be shaped and defined, the typical trajectories to be identified and the problems and illness course to unfold within it.

From the ten women three distinct trajectories were described. The first was '*ticking over nicely*' which described a long trajectory characterised by indolent disease and a high level of physical functioning with occasional periods of disease progression. '*Is there no end to it?*' described the trajectory of aggressive disease characterised by a short duration punctuated by episodes of disease progression, sequential treatment and uncontrolled symptoms with little respite. Physical functioning gradually declined over time. '*It's a rollercoaster*' was of longer duration, with the oscillations of progressive disease, treatment and the restoration of a level of wellbeing, sometimes achieving higher physical functioning than before the progressive disease. Navigating social roles and relationships could be problematic as those around them weathered the oscillations of the trajectory with them.

By triangulating the women's narratives and documentation, this is the first study to consider the detail of the whole illness trajectory over time, with the physical, social, emotional and practical problems and needs alongside a measurement of physical functioning. This approach tested the survey findings and reinforced the multidimensional problems and needs identified such as uncontrolled symptoms, sequential treatments and the need for a structured care pathway. The illness trajectory suggests that women with progressive breast cancer go through a number of phases which make up the projected trajectory. The *pre-trajectory phase* incorporates the biographical disruption of early stage breast cancer and the influence of a past life

history on the illness trajectory. The *trajectory onset* describes the onset of symptoms, how the diagnosis is communicated and the effect this has on women's ability to adjust and cope, how women adapt to and assimilate metastatic breast cancer diagnosis into their lives and how they seek support. The phase *of living with and around progressive breast cancer* considers how women weather the transitions between illness and recovery and back (which may include acute and crisis events), endure sequential treatments and the symptom burden described in the survey, the relentless vigilance of being aware of any changes in their body, the possibility of future disease progression and how they live everyday lives with and around progressive disease.

All eventually experienced downward trends in their illness trajectory. At times recovery meant the trajectory could go up, a process Corbin et al (1984:66) called 'decline, reprieve, decline, reprieve to death.' Ultimately the final phase of life would be a downward trend.

The *downward phase* towards the end of the illness trajectory marked the physical decline, as well as acute episodes and moments of crisis, and lastly the *dying phase* when there may be a convergence of active treatment and dying within which the women may or may not be aware that they are dying or prepared for death. The end of life in those who died appeared chaotic with little planning or coordination, resulting in disintegrated dying.

Social wellbeing was a constant theme throughout all phases of the study, with women's central concern being to retain social roles and maintain social order. The cross-sectional survey found social wellbeing to be an enduring concern. The narratives revealed that women worked hard to maintain a cohesive sense of self and identity but threats to this were constant through the oscillations of progressive illness, demonstrated by the illness trajectories of episodes of progressive disease, uncontrolled symptoms and living with an awareness of certain death at an uncertain time (Glaser and Strauss, 1968). Younger women had lower social wellbeing and lower functional wellbeing than those in older age groups. Younger women are more likely to have aggressive disease and be living the illness trajectory '*is there no end to it?*'. This illness trajectory demonstrated rapidly deteriorating physical functioning punctuated with episodes of progressive disease, uncontrolled symptoms and sequential treatment with little respite – an unrelenting decline, reprieve, decline reprieve until death (Corbin, 1984).

While the relationship between age and whether women had children on quality of life could not be determined, it is likely that younger women with younger children would struggle to cope with their everyday role as mother and the prospect of leaving children

when they die. The narratives revealed that the social role of mother was the last women would relinquish. Support to assist mothers in coping with the psychological burden of caring for and preparing themselves and their children did not in the main appear to be available in healthcare services. Although these are more readily available in palliative care services there was little evidence to suggest these were accessed.

Conversely, those living through the illness trajectory of '*ticking over nicely*' were found to have unmet needs. They would be more likely to be older, have indolent disease with bone metastases only and be treated more conservatively. Consequently, these women are more likely to be seen less frequently by a healthcare professional. The survey revealed that those with bone metastases only had a significant symptom burden and were dissatisfied with the information and support they received and other elements of their experience of care. These findings indicate that those with very differing illness trajectories have unmet care needs and current models of care appear not to be meeting the needs of those with metastatic breast cancer.

Despite the multidimensional problems and needs of women identified in the literature and reinforced by this study there was little evidence of formal support for women and their experience of care was poor. Care appeared to be given predominantly in the outpatient setting with little evidence of GP or palliative care services. This may explain why uncontrolled pain has been a consistent problem in the literature since 1983 (Spiegel, 1983), to the present time, a 29-year timescale. Both the cross-sectional survey and women's narrative indicate that symptom control is still a significant problem for those with progressive breast cancer, with many women tolerating uncontrolled pain and unsure where to turn for assistance in managing it. To support these findings the women's illness trajectories reveal that pain and other symptoms are an enduring problem, with many experiencing significant pain over a long period of time, even years, with little intervention. To align their internal reality of uncontrolled symptoms with their external reality which showed little evidence of illness the women had to constantly 'work' to maintain their identity, social roles and social order to avoid being discredited. The constant work involved in mediating the discontinuity between self, the physical body of uncontrolled symptoms and social order meant a relentless struggle to avoid being discredited with little evidence of professional intervention and support, which could lead to social isolation.

Evidence suggests that 90% of those with cancer pain could attain adequate relief with simple drug therapies (Portenoy and Lesage, 1999). Challenge could be levelled at palliative care services that they have the expertise in the management of those with advanced cancer but are not providing care for the metastatic breast cancer population

who are living with unmet physical, social, functional and psychological needs. Instead they are focusing care on a short phase of the metastatic breast cancer trajectory, as emphasised by the mapped illness trajectories. While there may be some validity in this argument, in reality women chose to remain under the care of their oncologist and rejected the premise that services outside this setting offered anything they needed. By choosing their oncologist as the healthcare professional they would see on a regular basis, women appeared to think they would be under the care of someone who had knowledge of the individual's breast cancer and the latest knowledge on available treatments. When discussing palliative care, women associated these services with the end of life and for the most part, as inappropriate for them. Many women knew there were many treatments available through their oncologist or independent internet searches. So it could be argued that the collusion between healthcare professionals and the women that the treatment options were plentiful meant the women sought one more reprieve, one last treatment which may control their disease. Consideration of the end of life was only fleeting, with preference given to focusing on active treatment. Women's desire to remain under the care of their oncologist and reject palliative care influences the care they receive, particularly around the end of life. These findings support earlier research by Gagnon et al (2004) who found that for women with breast cancer, care is predominantly given in the outpatient setting by oncologists and there is little evidence of general practitioner involvement or palliative care. The authors conclude that their findings explain high hospital death rates and low home death rates in their study.

The illness trajectories and women's narratives indicate that there was a convergence of active treatment and the end of life. There was little evidence of a process of decision making to end treatment when it was futile. Consequently, the convergence between active treatment and the end of life phase meant women and those around them appeared ill prepared for the end of life and death, with evidence to suggest they had become accustomed to the decline, reprieve, decline, reprieve, decline process and were expecting another reprieve. Women appeared to be focused on living – on seeking one more treatment – rather than acknowledging dying and consequently were ill prepared for their death.

Those who died did so within days of admission and predominantly in a hospital bed; by facilitating transition from active treatment to end of life care, women could prepare themselves and their families and friends for the end of life. In addition, an established relationship with palliative care professionals may influence both the physical and psychological transition and acceptance of the end of life phase and place of death. Central to women's fears about the end of life were loss of identity, relinquishing control



and an unbounded body (Lawton, 2000). Towards the end of life it appeared that some women used social isolation to maintain a cohesive identity by avoiding social interaction and the potential discrediting of a cohesive identity. Access to information and support at the end of life could facilitate women's decision making around treatment choices and care which may influence identity, self-representation and social order, for example, being able to openly discuss the fear of discredited identity with healthcare professionals. And with professional support for themselves, their family and friends, women may be able to consider strategies to maintain their contingent identity and mediate the discontinuity between self, the body and social order in the dying phase of their illness.

The dying phase for women appeared to be chaotic, often associated with uncontrolled symptoms, adverse reactions to treatment, acute events and unplanned admissions. There appeared little preparation for the place of death or death itself. When alluding to the end of life and dying, women sought to maintain a cohesive sense of self and identity, but maintaining this while experiencing disintegrating dying challenged women's ability to mediate the effects of progressive disease on self-representations. There appeared to be little evidence of support for women in coping with the chaos and disintegrated dying until too late in their illness trajectory. Consequently the women and those around them were ill prepared for the nature of their dying and death.

Two women had acute admissions for side effects of treatment and subsequently died in hospital. There appeared to be little consensus over stopping treatment where it could be considered futile. Only two women had this discussion with their oncologists. Consequently few were prepared for their deaths, had established relationships with palliative care services or their GP or had discussions about place of death and care available.

Those who had accessed palliative care services could find it problematic if they were still living active lives as they were unavailable in office hours. In addition, because they were leading active lives they were not considered suitable for palliative care services. An example of this was Angela, who continued to work until just months before her death but experienced pain over years. When she requested referral to palliative care her GP told her she was '*not ready for that yet*'. Those who did access palliative care services were often discharged when they had no physical symptoms. Consequently care was given predominantly in the outpatient setting by an oncologist with little evidence of GP, palliative care and nursing care involvement.

In the absence of formal support services, women's apparent need to seek ways to live well with progressive breast cancer was a strong theme, both in managing the

manifestations of progressive disease but also in promoting health and wellbeing and self-managing their physical, psychological and social response to illness, in everyday life and at difficult times such as disease progression.

Evidence suggests that controlling the extent to which illness was recognised allowed women some social control and autonomy. Wellbeing has been found to be dependent on the individual's ability to control the illness experience (Luoma, 2004) which influenced women's self-concept and in turn could influence how they cope and respond while navigating changes to their identity (Vilhauer, 2008). This study demonstrates that seeking ways to self-manage allowed women to feel empowered but barriers in maintaining this were uncertainty, symptom distress, problems accessing adequate information and support, and lack of knowledge about the illness trajectory. Schulman-Green et al (2011) found that transitions prompted changes in how actively women self-manage. The central theme running through the findings of this study is women's desire to exert control over a trajectory which is ill defined and unpredictable.

The study findings indicate that women themselves are in some ways ahead of the game, seeking means to self-manage and live as well as possible with their progressive disease. It may be that to meet women's needs it is necessary to look towards the management of and services developed for early stage disease. The National Cancer Survivorship Initiative (NCSI) (2010) vision was that individuals managed their cancer in partnership with the healthcare professionals responsible for their care. It identified three ways to facilitate this: self-management education and training programmes, skill development programmes for healthcare professionals and institutional support for service redesign (National Cancer Survivorship Initiative, 2010).

In its totality, the evidence presented by this thesis indicates that current care provision for those with metastatic breast cancer is inadequate. Women fall between acute and palliative care services with neither currently configured to meet their needs. Both policy makers and care providers need to consider novel approaches in order to help women live with their disease from diagnosis until death. This leads to the last research question:

What measures could be taken to improve the wellbeing and experience of women with metastatic breast cancer? To address this question I return to the Corbin and Strauss Chronic Illness Trajectory Framework which considers the goal of management (1998) (page 142).

## 6.1 Trajectory schema for metastatic breast cancer

### 6.1.1 Pre-trajectory phase

Corbin (1998) consider this phase as prevention of illness, although in metastatic breast cancer there is little women can do to prevent progressive disease developing. However, some women feel they may have contributed to their disease progression through lifestyle choices. This should be considered in assisting women to adapt to and assimilate progressive disease into their lives. After treatment for early stage disease women should be given advice and information to assist them in the transition from active treatment to survivorship, which may promote a self-management approach to health and wellbeing. Written information needs to include the signs and symptoms of progressive disease and how to re-enter the healthcare system.

### 6.1.2 The trajectory onset

A structured pathway should begin at this point, with a defined 're-entry' point at which multidisciplinary care begins. At the onset of symptoms there should be one point of access back into the healthcare system which initiates a structured pathway, through whichever healthcare professional women approach. This should be the multidisciplinary team who meet regularly and where all new referrals are discussed. It is standard practice that those newly diagnosed with early stage breast cancer are reviewed by a multidisciplinary team for the discussion of their treatment plan. This operational policy is subject to the peer review programme. More recent guidance supports that a multidisciplinary approach to care should be applied to those with progressive disease (NICE, 2011). As multidisciplinary care is considered good practice in breast cancer, it is no longer acceptable for those newly diagnosed with metastatic breast cancer not to receive the same approach to their care.

Multidisciplinary care that included palliative care professionals as equal participants would influence the care pathway and the decision making process through consensus and if the true outcomes of proposed treatment were discussed it may be that futile treatments would give way to palliation and supportive care when the outcomes may be similar. Professionals supporting each other in the acceptance of ending treatment would be beneficial to women. This approach to the care of women with metastatic breast cancer should be subject to the peer review process.

An integrated oncology and palliative care approach to care and decision making in a hospital setting may ease the transition to the appropriate cessation of active treatment and the acknowledgement and preparation of women and those around them for the end of life. Holistic assessment of needs should also be undertaken at key times such as diagnosis, disease progression and other occasions women have interactions with

healthcare professionals in accordance with national policy (NICE, 2004). Despite this NICE guidance on supportive and palliative care, this is not current practice.

Consensus decision making of the multidisciplinary team (including palliative care) would begin to consider appropriate treatment and management, including assessment, ongoing symptom control and psychological wellbeing. Holistic assessment of need using validated tools should be done at diagnosis to determine individual need. At diagnosis of metastatic breast cancer, the clinical characteristics would allow clinicians to form an appropriate trajectory prediction. While an understanding of the trajectory prediction is central to appropriate management, competency in imparting this to women is essential as the study found that women need a level of realistic hope to allow them to assimilate progressive disease in their lives and consider their futures. At this point, designation for each woman of a 'key worker' – a healthcare professional with core competencies – would facilitate access to information and support throughout the illness trajectory. This would allow for ongoing symptom management and psychological support. Breast care nursing has historically only provided care for women at the point of diagnosis and through adjuvant treatment: it has not been providing care for those with progressive disease (Reed et al, 2010). With a now significant body of evidence suggesting that the provision of breast care nursing for women with metastatic breast cancer is inadequate, breast care nursing teams need to consider how they provide care and look to reconfigure their workforce to ensure they meet the needs of all those with breast cancer, whatever their stage of illness.

### **6.1.3 The phase of living with and around progressive breast cancer**

Appropriate treatment and support aims to stabilise the illness and allow women to live well with progressive breast cancer. To achieve this, a holistic assessment at moments of disease progression, in treatment and at the end of each treatment regimen would assist in appropriate action being taken to address those concerns women identified, such as coping with assimilating progressive disease into their lives and telling others of the progressive disease. This acknowledgement and support alongside the oscillations of progressive disease is key to offering services, not only when there is a physical need but to support women through times when they are physically well and functioning but living with relentless vigilance in silence and striving to maintain social roles and social order. At these times, assisting women to navigate social relationships and supporting those around them may also be necessary.

While the women weather the oscillations of progressive disease, those around them have been found to experience significant levels of traumatic stress (Butler et al, 2005)

but appear to experience less stress when a relationship is rated as cohesive (Giese-Davis et al, 2000). In considering the needs of those with progressive breast cancer, the needs of those around them should also be considered as they are inextricably linked. This may facilitate communication between women and those around them when their lives diverge.

The aim of the Corbin and Strauss model (1998) is to ameliorate problems and anticipate need to resume normal life and everyday biography. While women with progressive disease may not be able to resume their everyday biography, the use of contingent identities indicates that women seek ways to live with and around their progressive disease and how to self-manage these with adequate information and support. There is a need to develop supported self-management interventions to assist women to be more effectively informed and supported so that they can live well with and around progressive disease.

With the NCSI guidance, novel ways to support women may be developed in the primary care setting led by palliative care professionals and GPs. These may include open access clinics based in palliative care services, self-management educational programmes or service redesign. This would transfer the focus of care from the acute setting, develop palliative care services beyond end of life care and begin to address the needs of women throughout the illness trajectory. By applying the NCSI principles the partnership between women with metastatic breast cancer and the healthcare professionals responsible for their care may begin to allow women's needs to be assessed and care to be focused around these. This novel approach may give women the knowledge and tools to live well with their disease. Those women who chose the contingent identity of absolved responsibility, however, may be less likely to seek ways to self-manage. In planning care it is important to consider both the typical and atypical to ensure all women's needs are met.

This phase considers acute events and crises. Appropriate medical management at these times would perhaps consider if another regimen of treatment was the correct action in ameliorating uncontrolled symptoms and consider when this may be futile, reducing acute events and crises which can herald physical decline and hospital admission. These undesirable events should be considered when planning treatment and care.

#### **6.1.4 Downward phase**

This phase is described as assisting women to adapt to increasing disability and each major downturn. This study suggests that as women can have many treatment regimens they are ill prepared for dying and death and that active treatment appears to

converge with the dying phase of life. The myth that there are many treatments to try may give women false hope that the decline, reprieve, decline, reprieve is unending and death is in the far distance. The aims of active treatment need to be clear at this time. Palliation of uncontrolled symptoms may be achievable without active anti-cancer treatment and increased survival time measured in weeks. If this is not communicated to women, how can they be involved in treatment decision-making as part of their care? Not acknowledging and preparing for death does women a disservice. Assisting women in the transition from active treatment to palliation would help them acknowledge and face the beginning of the end of life. These transitional moments require time and sensitivity from healthcare professionals with good communication skills at a time when women may seek yet another reprieve on a continuum of repeated reprieves. If palliative care professionals are involved in the care of those with progressive breast cancer throughout the illness trajectory it is possible that the transition from active treatment to palliation would be smoother as care is being provided by professionals familiar to women.

### **6.1.5 Dying**

Corbin (1998) describe this phase as a time to bring closure, let go and die peacefully. While the women may have been aware that the end of life was nearer, few were prepared or had adequate support at this time. Many maintained their contingent identities until close to the end of life. Few appeared to be able to speak openly about their fears or wishes for their dying and death, including how it would happen and where. This was indicated in the study through the few women who asked me about the dying phase, trying to prepare for how they would die and whether they would retain a cohesive identity until the end. With access to ongoing palliative care, women and their families could be supported to cope at this time and the desired place of death established. As the role of mother is so central to those with children, the involvement of palliative care professionals may also allow women to prepare their children for their death and their bereavement, for example through creating memory boxes or photo albums.

Applying the Chronic Illness Trajectory Framework (Corbin and Strauss, 1989) and identifying phases through which women with progressive breast cancer pass allows healthcare professionals a structured pathway to begin to design models of care. This study demonstrates that oncology services are not addressing the needs of women with metastatic breast cancer as they have past experience of early stage disease when they felt informed and supported and can compare these experiences. While palliative care services have the knowledge and expertise to assist in the support and palliation of symptoms, there is little evidence of their involvement in the care of women

with metastatic breast cancer until the final phase of their lives. These services provide care for those with cancer at the end of life, but as treatment improves and lives are extended, those with progressive breast cancer are living predominantly outside the healthcare setting and their experience could be likened to chronic illness. In view of this evolving change in the experience of living with progressive breast cancer, it is necessary to consider how services can develop to care for and support this growing population living prolonged lives with and around progressive disease.

The involvement of healthcare professionals with core competencies to meet the needs of this population has been described by Breast Cancer Care (2008) and requires knowledge of metastatic breast cancer and its treatment, knowledge of the palliation of symptoms and psychological need and end of life care. Alongside this skills are needed in facilitating decision making (Breast Cancer Care, 2008). What is still unclear is who should be providing this service and where. While there are palliative care teams based in NHS Trusts, there is little evidence to suggest they offer ongoing care for women and currently few breast care nurses provide continuity of care for this population (Reed et al, 2010). One approach to address the needs of this population may be an integrated model of care between oncology and palliative care, where palliative care professionals have an active on-going role in the outpatient setting (as the place women would choose to receive their care) and work in partnership with oncology teams. This approach may influence and improve symptom control, psychological wellbeing and decision making about treatment. It may also ease the transition of care from the acute care setting to community palliative care.

Clearly current care for those with metastatic breast cancer is inadequate and both oncology and palliative care services need to consider the changing face of those with progressive breast cancer and redesign services to address the multidimensional problems and needs of women to meet their needs.

#### **6.1.6. Summary of recommendations to influence policy and practice**

1. At diagnosis of metastatic breast cancer women should be allocated a key worker who will have core competencies in knowledge of metastatic breast cancer, its treatment and palliative care and will support women throughout the illness trajectory. This need should be subject to assessment in the peer review process.
2. From the point of metastatic diagnosis a multidisciplinary approach to care should begin including palliative care professionals. This should be subject to assessment in the peer review process.

3. Palliative care services need to develop beyond offering only end of life care and consider novel models of care which are available throughout the metastatic breast cancer illness trajectory.
4. Palliative and primary care services should develop supportive self-management models of care such as open access clinics and educational programmes to support and give tools to women to live well with progressive disease.
5. The findings of the study will be published in peer review journals with a breast oncology and palliative care readership.
6. Publications from this thesis will be presented at breast oncology and palliative care conferences.
7. Publications will be sent to the National Cancer Action Team and other interested parties to inform them of the findings.
8. Publications will be presented to the All Party Parliamentary Group for breast cancer.

## Study limitations

Using an online survey the aim was to recruit participants from around the UK who were being treated in a variety of different settings, including women who may not be attending hospital follow-up. This approach was reliant on self-reported disease and treatment information. Recruitment bias is problematic to assess in online surveys, but the survey was introduced to participants as exploring the experience of living with metastatic disease and not specifically looking at satisfaction with care, which aimed to reduce the potential for response bias (Reed et al, 2009).

Access to the internet may be less in older age groups or among those from different backgrounds which biases the sample to a predominantly white British, younger age group.

The FACT-B quality of life measure is a biomedical scale designed for use in clinical trials in assessing quality of life and is not designed for psychosocial research. In addition, women may report their quality of life to be higher than it is to ensure healthcare professionals continue to treat them.

When measuring women's experience of care individuals may be less likely to be critical of the care they have received for fear of this influencing their present and future care and treatment.



The Karnofsky scale is used to measure physical functioning: it is designed as a biomedical tool to assess a patient's performance state for treatment and should be used face to face in a clinical setting. It was used in the absence of any other means to map the physical performance of the women in this study.

More research needs to be done to explore the needs of younger women with metastatic breast cancer, particularly considering the impact of different treatment modalities and having children.

Women's narratives are a retrospective account of their experience and as such may be influenced by the memory of events or altered to give a different account of events.

The Chronic Illness Trajectory Model has some limitations in that it characterises women's illness experience through a biomedical model, limiting the ability to demonstrate the psychological and social impact of progressive disease over time. However, it did assist in the development of trajectory phasing and so provided insights into women's relatively high level of physical functioning until very late in the course of their illness while also experiencing high symptom burden and intense and frequent cycles of cancer treatment. This has not been revealed before. The framework assumes that professional care provision is established and the application of the framework gives this established care definition. However, for progressive breast cancer the care pathway is ill defined and provision of care limited, making application challenging in the current care context. By applying the Corbin and Strauss (1998) guidance for management, the illness trajectory of metastatic breast cancer is given definition and informs how care may be planned, implemented and evaluated in future.

The study is limited to insights gained from women at a single time point in the course of their metastatic disease and therefore cannot reflect the variability in quality of life and satisfaction with care that individual patients may experience during the course of their illness.

Retrospective narratives are dependent on memory and the re-telling of events as well as the individual choice of self-representation.

The illness trajectories of ten women may not be generalisable to the whole metastatic breast cancer population.

## Recommendations for future research

- Longitudinal data exploring women's quality of life and experience of care over time are needed to build a more detailed picture of the challenges of living with metastatic breast cancer.

- Those with bone metastases only appear to have more unmet needs: further investigation into this sub-group, their symptom burden and patterns of care is needed.
- Symptom control is a concern and needs further investigation in this population.
- Intervention studies into integrated models of oncology and palliative care are need to determine whether this approach improves care provision, quality of life, psychological wellbeing, palliation of symptoms, treatment decisions and end of life care.
- Supported self-management programme intervention studies for women with metastatic breast cancer
- Dyadic and/or family interventions would add significantly to understanding when support to couples and families may improve the social context of living with progressive breast cancer.
- A retrospective exploration of end of life care needs to be done, considering events leading to death, the convergence of active treatment and the end of life phase, care provision and place of death.

## Conclusion

Women with metastatic breast cancer can have what Sontag (1978) described as ‘dual citizenship’ – when they live both in the healthy world and the sick world and have to navigate through both. In the current context of multiple treatment modalities and prolonged life expectancy, women with metastatic breast cancer live increasingly complex lives.

These findings indicate that current models of care are not meeting the needs of women with metastatic breast cancer and pose interesting questions to cancer and palliative care services that may need to adapt to a changing population of patients with progressive disease who are living predominantly outside the healthcare setting. In particular the study challenges the configuration of palliative care services that focus on the end of life, when an increasing number of those with metastatic cancer are considered survivors who may live for years with progressive disease (Corner, 2008). This study suggests that current models of care are inadequate to meet the needs of those with progressive disease and challenges current services to adjust and develop to consider a changing population.

By turning to the management of chronic illness, models of care incorporating approaches to supported self-management could be developed in the primary care setting where women spend most of their time. These could better address the needs of those who are living over time with progressive disease and seeking ways to promote their health and wellbeing. This change may have positive cost benefits for healthcare provision through, for example, more appropriate use of analgesics and anti-cancer treatment and a reduction in unnecessary hospital admissions.

The pressure on both oncologists and women to promote active treatment, even when this may be futile, is doing women a disservice. By perpetuating the myth that another treatment will prolong survival without a frank discussion of what this means in terms of time and quality of life, women will continue to seek one more treatment, one more reprieve. Good communication and the introduction of support services such as palliative care in the medical management and decision making process should inform women not only of the true expected outcomes of treatment but also that this acceptance does not mean to the exclusion of other means of support and management. Oncologists and nurses from both breast cancer and palliative care disciplines need to develop partnership working to adequately meet the needs of women from the point of diagnosis throughout the illness trajectory.

The personal cost of inadequate care on women's multidimensional lives permeated every aspect of their existence, for example through uncontrolled symptoms, side effects of treatment and the relentless vigilance of a life with progressive disease. This influenced women's identity and ability to maintain their social roles and social order, which in turn appears for some women also to be an economic burden, such as when they cannot maintain employment due to uncontrolled symptoms or are unaware of financial assistance available. Services need to be more flexible and remain available and accessible though the oscillations of progressive illness when women are having active treatment and between these episodes of treatment. By defining the illness trajectory, key times in the phases indicate a requirement for assessment of need, such as disease progression and the start of new treatment. Equally, accessible care should be flexible enough to address need throughout the illness trajectory.

Current models of care and cancer care pathways are no longer fit for purpose in managing individuals with chronicity to their disease. In particular, palliative care services need to consider the development of alternative models of care for those living with and around progressive disease, rather than only addressing the final phase of the trajectory which the findings of this study indicate is too late to be wholly effective.

By considering the evidence from the study in its totality, innovative approaches to care through integrated palliative care and oncology models and by applying a self-management approach to care, women's needs may begin to be addressed.

This study aimed to yield information that may be used to improve the experience of living with metastatic breast cancer by informing those living with it, policy makers and those responsible for providing treatment and care. The findings have already influenced the development of nursing provision in the UK. Current policy and campaigning work undertaken by Breast Cancer Care has used the publication of phase 1 to highlight the inadequacy in care provision and work with NHS Trusts in developing services to meet the needs of women with metastatic breast cancer. Lay reports of the findings of the study will be available for women through Breast Cancer Care's website and subsequent academic publications will be promoted through the print and social media to inform women. If women's lives improve through the publication and dissemination of the findings the work involved in undertaking the research and writing the thesis will be reward enough.



## Appendix 1: Literature review

Psychosocial literature on the experience of living with metastatic breast cancer							
	Reference	Sample	Aim of study	Study design	Outcome measures	Main findings	*Score
1	Aranda S et al (2005)  Australia	105 women with metastatic breast cancer	To identify support and information needs commonly experienced by urban women with metastatic breast cancer and to identify patterns of support and information needs by demographic and disease characteristics.	Survey	Demographic and medical data. European Organisation of Research and Treatment of Cancer Quality of Life Q-C30.  Supportive Care Needs Survey	Poor global health status. Highest levels of unmet need were in the psychological and health information domains. Identified need for counselling and support services. Recommends regular monitoring of personal needs and quality of life.	9/9
2	Arathuzik D (1991)	80 women with metastatic breast cancer	Explore perceptions of pain experienced by women with metastatic breast cancer.	Survey	Modified Pain Intensity Scale developed for this study to elicit perceptions of the concern about pain, coping behaviours, problem solving and emotional regulating coping processes used to deal with pain.	The majority of participants experienced pain >5 with a mean score of 6.75. Most participants were experiencing moderate to severe pain.	9/10

Psychosocial literature on the experience of living with metastatic breast cancer							
	Reference	Sample	Aim of study	Study design	Outcome measures	Main findings	*Score
						Two thirds of participants would have benefited from stronger analgesia on a regular basis. Some tolerated the pain for fear of addiction. Those with negative perceptions associated with their pain were less able to engage in coping responses to deal with it.	
3	Asola R et al (2006)  USA	335 women with advanced breast cancer who had been in contact with the healthcare system due to breast cancer at six months	To assess the intensity of diagnostic testing and cancer treatment during the last six months before death and to compare to practice in earlier decades.	Retrospective data collection from medical records	Individual details of general condition, symptoms, diagnostic and treatment detailed as well as palliative procedures. Zubrod performance status scale. Details of analgesia and other medicines aimed to palliate symptoms.	The number of diagnostic tests increased as death approached. Almost half of tests during the last six months of life were done in the last two months. Endocrine therapy remained stable throughout the last six months of life. 28.1% were treated with third line or more	9/9

Psychosocial literature on the experience of living with metastatic breast cancer							
	Reference	Sample	Aim of study	Study design	Outcome measures	Main findings	*Score
		prior to death				chemotherapy during the last six months. Symptom burden did not decrease in those receiving chemotherapy. Symptoms were a problem throughout the six months before death, worsening over time. Pain was the most common symptom throughout the six months.	
4	Bloom et al (1984)  USA	86 women with advanced breast cancer	To determine the relationship between social support and the psychological wellbeing and social functioning of women with metastatic breast cancer.	Survey Interview	Visual Analogue Pain Scale Coping Response Scale Sense of Power Scale Janis-Field Self- Concept Scale Family Environmental Scale Guttman's Social Activity Scale Profile of Mood States Scale Heimler's Scale of Social Functioning	Predictors of social functioning are coping response, self-concept, outlook on life and social activity. Demographic variables were not related to social functioning. Family support indirectly influences social functioning through its	9/9



Psychosocial literature on the experience of living with metastatic breast cancer							
	Reference	Sample	Aim of study	Study design	Outcome measures	Main findings	*Score
						influence on outlook on life. Fewer avoidance coping methods was associated with better social functioning.	
5	Bordeleau et al (2003)  Canada	235 women with metastatic breast cancer	To evaluate the effect of a standardised group psychological intervention on health-related quality of life.	Randomised control study  Survey	Demographic and medical data European Organisation for Research and Treatment of Cancer Quality of Life-C30	Supportive-expressive group therapy does not appear to influence global quality of life in women with metastatic breast cancer.	8/9
6	Born T et al (2010)	One woman with metastatic breast cancer	To illustrate the effects of an exercise programme on the quality of life of a patient with incurable cancer	Case study	RAND 36 QoL measure Six minute walk test measured at the beginning and end of nine week programme	Able to attend seven of the nine sessions. Improvement in functional wellbeing and general health evaluation of the RAND-36. Six minute walk test showed improvement of 43% compared to baseline. The participant felt her fitness had improved, and she integrated walking into	10/10

Psychosocial literature on the experience of living with metastatic breast cancer							
	Reference	Sample	Aim of study	Study design	Outcome measures	Main findings	*Score
						her daily routine. Also felt benefit of peer support on the programme.	
7	Butler LD et al (1999)  USA	125 women with metastatic breast cancer	To examine levels of intrusion and avoidance symptoms and their relationship to past life stress, current emotional support, disease-related variables and age.	Survey	Demographic and medical data Impact of Events Scale Life Events Questionnaire (short- form) Positive Emotional Support Scale Aversive Emotional Support Scale Emotional Support Network Size Scale	Up to 50% of women with metastatic breast cancer may experience clinically significant levels of traumatic stress symptoms related to the cancer and current and past life experiences. Participants with larger social networks reported fewer avoidance symptoms. NB: the participants chose to participate in group psychotherapy therefore baseline traumatic stress symptoms may reflect those in need of support. Those using greater	9/9

Psychosocial literature on the experience of living with metastatic breast cancer							
	Reference	Sample	Aim of study	Study design	Outcome measures	Main findings	*Score
						avoidance symptoms may have declined to take part in the study.	
8	Butler LD et al (2003)  USA	59 women with metastatic breast cancer	To examine the course of psychological distress and pain from study entry to death.	Survey	Demographic and medical data Profile of Mood State Scale Impact of Events Scale Centre for Epidemiologic Studies-Depression Positive States of Mind Scale Pain Rating Scale	A significant increase in distress and pain and a significant decrease in wellbeing at the last assessment before death. Neither group psychotherapy, pain nor the passage of time could account for these findings.	9/9
9	Butlow et al (2000) (Abstract)  Australia	99 patients with metastatic breast cancer	To measure cognitive appraisal of threat, coping, psychological adjustment, perceived aims of treatment, social support and quality of life four months after diagnosis.	Survey	Unknown	Patients who minimised the impact of cancer survived longer. Those with visceral metastases survived for a shorter duration.	Not scored
10	Cheville AL et al (2008)  USA	163 community dwelling patients	To characterise the prevalence of physical impairments, to determine whether remedial	Data from medical records Clinician	Electronic medical records sought sociodemographic data, history, diagnostic testing, and disease data.	Over 90% of participants appeared to have a physical impairment that may be ameliorated by	9/9

Psychosocial literature on the experience of living with metastatic breast cancer							
	Reference	Sample	Aim of study	Study design	Outcome measures	Main findings	*Score
		with metastatic breast cancer	impairments receive appropriate treatment and to establish where treatment occurred.	administered testing Survey Semi-structured interview	Clinician administered testing – physical examination, six minute walk Functional Independence Measure Mobility Subscale. Older Americans Resource Study Physical Function-10 Distress and interest in rehabilitation scale Structured interview – to determine pre-existing impairments, rehab service utilisation and interventions. Physician assessment of rehabilitation needs.	standard rehabilitation measures; less than a third of these impairments received treatment. Those in an inpatient setting were more likely to receive rehabilitation services than outpatients. Rehabilitation treatment is under emphasised in cancer care.	
11	Classen C et al (1996)  USA	101 women with metastatic breast cancer	To identify coping strategies associated with psychological adjustment and the use of emotional distress as the measure of adjustment.	Survey	Demographic and medical data Profile of Mood States Scale Courtauld Emotional Control Scale Mental Adjustment to Cancer Scale	Fighting spirit and emotional expression were associated with better adjustment. No association was found between emotional distress and either denial or fatalistic	9/9

Psychosocial literature on the experience of living with metastatic breast cancer							
	Reference	Sample	Aim of study	Study design	Outcome measures	Main findings	*Score
						thinking.	
12	Classen C et al (2001)  USA	125 women with metastatic breast cancer	To evaluate the effect of supportive-expressive group therapy on mood disturbance and traumatic stress symptoms.	Survey  Randomised control study	Demographic and medical data Profile of Mood States Scale Impact of Events Scale	Primary analysis showed treatment effect for trauma symptoms but not mood disturbance. Overall reduction in symptoms in the intervention group was carried by a strong and significant decline in avoidance symptoms.	9/9
13	Coward DD (1991)  USA	107 of women with advanced breast cancer	To examine the relationship between self-transcendence, emotional wellbeing and illness associated distress in women with advanced breast cancer.	Survey	Demographic and medical data Reed's Self-Transcendence Scale Bradburn's Affect Balance Scale Cognitive Well-being Scale Young's Symptom Distress Scale Karnofsky Performance Scale	Self-transcendence decreased illness-related distress but did not have a direct effect on perceived illness distress; instead it decreased perceived illness distress through its effect on emotional wellbeing.	9/9
14	Cunningham et al (1998)	66 women with metastatic	To test the effect of group psychological therapy on survival from cancer	Survey  Randomised	Demographic and medical data	No significant difference was found in survival time between the control	8/9

Psychosocial literature on the experience of living with metastatic breast cancer							
	Reference	Sample	Aim of study	Study design	Outcome measures	Main findings	*Score
	Canada	breast cancer		control study		and intervention group at five years. Those adopting self-management practices may have influenced increased survival. NB: the findings may have been contaminated as some of the control group sought self-help and support groups outside the study.	
15	Davies M and Sque Mal (2002)  UK	Ten women with advanced breast cancer under the care of one hospice	To develop a theory to explain the meaning and experience of living with advanced breast cancer.	Semi-structured interview	Grounded theory approach	A theory of 'living on the inside looking in' integrating five categories: reconciling a different me, time bomb, media effect, professional waning and rescuers. Reconciling a different me was the core variable with an explicatory relationship	9/10

Psychosocial literature on the experience of living with metastatic breast cancer							
	Reference	Sample	Aim of study	Study design	Outcome measures	Main findings	*Score
						to the other categories.	
16	DeSanto-Madeya et al (2007)  USA	84 women with advanced cancer with a life expectancy of less than four months	To detail the daily activity of women with advanced breast cancer.	Analysis of an expressive writing intervention study control group	Feminist theory	Daily activities included maintaining gender and socially constructed roles and responsibility, caring for themselves physically, psychologically and spiritually and managing cancer. Evidence that women experience a decline in physical functioning and had to use strategies to conserve energy to maintain physical functioning to live full active lives. Pain, sleeplessness and nausea were a problem for many women.	

Psychosocial literature on the experience of living with metastatic breast cancer							
	Reference	Sample	Aim of study	Study design	Outcome measures	Main findings	*Score
17	Edmonds et al (1999)  Canada	30 patients with metastatic breast cancer	To assess the effects of a long-term psychological intervention on mood and quality of life and to assess changes in other psychological measures associated with survival from cancer.	Survey  Randomised control study	Demographic and medical data Profile of Mood Scale The functional living Index for Cancer Scale The Duke UNC Functional Social Support Questionnaire Mental Adjustment to Cancer Scale Rationality/Emotional Defensiveness Scale Marlowe Crown Social Desirability Scale	Long term psychological intervention for cancer patients did not significantly improve mood or quality of life, nor were there differences in social support or repression. Anxious preoccupation was significantly greater for the intervention patients than control. Intervention patients reported significantly less helplessness. Survival data not reported in this paper.	8/9
18	Edwards AGK et al (2007)	Randomised control studies of psychological interventions for	To assess the effects of psychological interventions on psychological and survival outcomes for women with metastatic breast cancer.	Cochrane systematic review	Data extraction by two independent reviewers	No strong evidence has been found that support groups can increase survival from advanced breast cancer, or that this and other psychological	9/9



Psychosocial literature on the experience of living with metastatic breast cancer							
	Reference	Sample	Aim of study	Study design	Outcome measures	Main findings	*Score
		women with metastatic breast cancer				interventions can improve psychological wellbeing.	
19	Fulton CL (1997)  UK	44 patients with metastatic breast cancer	To explore levels of anxiety and depression experienced by patients with metastatic breast cancer 1-7 weeks before their death.	Survey	Demographic and medical data Rotterdam Symptom Checklist Hospital Anxiety and Depression Scale	Patients demonstrated high levels of depression (50%) and anxiety (66%) in the last interview before death. A weak correlation between physical symptoms and anxiety and depression. High score in gastrointestinal symptoms and fatigue with pain scoring low.	9/9
20	Fulton C (1998)  UK	80 women newly diagnosed with metastatic breast cancer	To monitor the prevalence and detection of psychiatric morbidity every eight weeks over a 16-month period.	Survey Interview schedule	Demographic and medical data Hospital Anxiety and Depression Scale	No significant differences in mood across the eight interviews although there was a trend over the eight interviews for anxiety and depression to decrease.	9/9

Psychosocial literature on the experience of living with metastatic breast cancer							
	Reference	Sample	Aim of study	Study design	Outcome measures	Main findings	*Score
						Detection in mood problems was extremely low and referral to appropriate services not in evidence.	
21	Fulton C (1999)  UK	80 patients with metastatic breast cancer	To describe levels of anxiety and depression, to describe their rehabilitation status and to ascertain any relationship between mood disturbance and physical rehabilitation status.	Survey Interview schedule	Demographic and medical data Cancer Rehabilitation Evaluation System-Short Form Hospital Anxiety and Depression Scale	Mood disturbance was a significant problem and a positive relationship was found between mood disturbance and physical rehabilitation status.	9/9
22	Gagnon B et al (2004)  Canada	2,291 women who had died of breast cancer	To define the extent to which women dying of breast cancer had access to palliative care during the last six months of life.	Retrospective analysis of medical databases	Demographic and medical data A care orientated profile score comparing age groups of women using a proportional odds ordinal regression model	75% of women had few indicators identifying they received palliative care in the last six months of life, those <50 were less likely to receive palliative care. 69.9% of women died in acute hospital beds and only 6.9% died at home.	9/9

Psychosocial literature on the experience of living with metastatic breast cancer							
	Reference	Sample	Aim of study	Study design	Outcome measures	Main findings	*Score
						Low involvement of GPs and predominant care by hospital specialist in outpatients.	
23	Giese-Davis J et al (2001)  USA	124 women with metastatic breast cancer	To test a hypothesis that repressive-defensive, suppression, restraint and distress would be separable factors in the sample.	Survey	Demographic and medical data Courtauld Emotional Control Scale The Weinberger Adjustment Inventory Profile of Mood State Scale Center for Epidemiology Depression Scale Impact of Event Scale	The constructs of suppression, repressive-defensiveness, restraint and distress are separable enough within the sample to be used to predict psychological outcomes and survival in cancer patients.	9/9
24	Giese-Davis J et al (2002)  USA	123 women with metastatic and 2 women with recurrent breast cancer	To demonstrate the complex distinctions inherent in the emotional expression and processing encouraged in the supportive-expressive model and to reducing repression and testing that emotional self-efficacy would increase over time.	Survey  Randomised control study	Demographic and medical data Courtauld Emotional Control Scale The Weinberger Adjustment Inventory Stanford Emotional Self-Efficacy Scale - Cancer	A significant reduction in the suppression of primary negative effect and greater restraint of aggressive, inconsiderate, irresponsible and impulsive behaviour. Concluding that emotion-focused therapy can help women to become	9/9

Psychosocial literature on the experience of living with metastatic breast cancer							
	Reference	Sample	Aim of study	Study design	Outcome measures	Main findings	*Score
						more expressive without becoming more hostile.	
25	Goodwin et al (2001)  Canada	235 women with metastatic breast cancer with an expected survival time of at least three months	To determine the effect of group psychological support on survival in metastatic breast cancer.	Survey  Randomised control study	Demographic and medical data Profile of Mood State Scale Visual Analogue Pain Scale	Supportive expressive group therapy improves mood and the perception of pain, particularly in those initially depressed, but it does not prolong survival.	9/9
26	Grabasch B et al (2006)	227 women with advanced breast cancer	To report the frequency of psychosocial morbidity and assess quality of life.	Structured interview  Survey	Monash Interview for Liaison Psychiatry EORTC QLQ-C30 and EORTC QLO-BR23	43% of participants had a current psychiatric disorder, 36% had depression, anxiety or both. Depression was present in 6%. Adjustment disorder was the most common problem. Poor social support is associated with and may perpetuate	9/10

Psychosocial literature on the experience of living with metastatic breast cancer							
	Reference	Sample	Aim of study	Study design	Outcome measures	Main findings	*Score
						depression (28%). Psychiatric disorder twice that of normative population.	
27	Gray R et al (1998)  Canada	38 women with metastatic breast cancer	The information needs of women with metastatic breast cancer	Focus groups	Broad questioning within four focus groups	Women have high needs for information, in particular to understand their own cancer history and treatment options. They wish to sustain hope.	10/10
28	Gray R et al (2001)	Six individuals involved in a drama project about metastatic breast cancer including two women living with it	Explore the societal shift for women with metastatic breast cancer	Development of a drama script and supporting documentation  Interviews	Not described	The challenges and difficult reality affecting women with metastatic breast cancer most commonly go ignored or avoided by those around them. They are forced to project identity of hero or victim and live outside everyday life narratives.	5/10

Psychosocial literature on the experience of living with metastatic breast cancer							
	Reference	Sample	Aim of study	Study design	Outcome measures	Main findings	*Score
29	Grunfeld EA et al (2006)  UK	102 women with advanced breast cancer	To examine advanced breast cancer patients' perceptions of the key decision-making consultation for palliative chemotherapy.	Semi-structured interviews	Closed questions were scored on a 5-point scale, a 3-point scale and yes, no answers. Open ended questions were analysed using a simple content analysis approach.	Only eight refused chemotherapy and opted for supportive care. They were excluded from the study. 10% of participants felt their needs for information or involvement in decision making were not met. Women who are being offered first-line chemotherapy seem to ask for more information, involve themselves more in discussion and elicit more explanations yet are more passive in the decision-making process than those considering second-line chemotherapy.	9/9
30	Headley JA et al (2004)	38 women beginning	To examine the effects of a seated exercise	Survey	Functional Assessment of Chronic Illness-Fatigue Version	Seated exercise intervention slows the	9/9

Psychosocial literature on the experience of living with metastatic breast cancer							
	Reference	Sample	Aim of study	Study design	Outcome measures	Main findings	*Score
	USA	outpatient chemotherapy	programme on fatigue and quality of life.	Randomised control study	IV Rating of Perceived Exertion	decline in total and physical wellbeing and reduced increase in fatigue scores starting with the third cycle of chemotherapy.	
31	Hopwood et al (1991)  UK	222 women with advanced breast cancer	To determine the prevalence and persistence of affective disorders.	Survey at baseline and 204 women repeated survey at three months	Demographic and medical data Hospital Anxiety and Depression Scale Rotterdam Symptom Checklist	Twenty one were rated as probable cases of anxiety state. Three months later 13% were persistently anxious or depressed. Findings suggest approx one third of cases had an affective disorder and in one third of these it was persistent.	9/9
32	Karamouzis MV et al (2007)  Greece	200 women with metastatic breast cancer at the point of completion	To evaluate quality of life parameters in patients with metastatic breast cancer and to assess the potential difference between patients receiving chemotherapy	Survey Randomised control study	European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire Quality of Life Questionnaire Breast 23 States Scale Visual Analogue Pain Scale	Quality of life was found to be significantly better in those receiving chemotherapy than those receiving supportive care. Emotional and cognitive	8/9

Psychosocial literature on the experience of living with metastatic breast cancer							
	Reference	Sample	Aim of study	Study design	Outcome measures	Main findings	*Score
		of their last chemotherapy cycle of their current treatment regime and >3 months estimated survival time.	and those undergoing supportive care, adjustment to advanced breast cancer, pain, social support and life stress.		Yale Social Support Index Single Item Measure of Social Support Life Events Scale	functioning scored higher in those receiving chemotherapy. Those receiving chemotherapy had better body image, sexual function and satisfaction and better future perspectives. NB: those receiving chemotherapy were in a better clinical condition. The scales focused on physical functioning and by incorporating social and/or psychological scales may have enhanced the findings of this study particularly for patients who have experienced greater life stress. No relationship was found between social support and pain	



Psychosocial literature on the experience of living with metastatic breast cancer							
	Reference	Sample	Aim of study	Study design	Outcome measures	Main findings	*Score
						intensity. Greater life stress was significantly associated with greater pain.	
33	Koopman et al (1998)  USA	102 women with metastatic breast cancer	To examine the relationship between emotional adjustment to advanced breast cancer, pain, social support and life stress.	Survey  Randomised control study	Demographic and medical data Profile of Mood States Scale Visual Analogue Pain Scale Yale Social Support Index Single Item Measure of Social Support Life Events Scale	Social support can improve patient mood but social stress can worsen it, particularly for patients who have experienced greater life stress. No relationship was found between social support and pain intensity. Greater life stress was significantly associated with greater pain.	9/9
34	Koopman et al (2002)  USA	97 women with metastatic breast cancer	To examine sleep disturbance in women in relation to depression, social support and salivary cortisol.	Survey	Demographic and medical data The 27-item sleep questionnaire Center for Epidemiological Studies Depression Scale Single-Item Measure of Social	63% of patients reported at least one sleep disturbance. Women were at a higher risk of sleep problems if they	9/9

Psychosocial literature on the experience of living with metastatic breast cancer							
	Reference	Sample	Aim of study	Study design	Outcome measures	Main findings	*Score
					Support Scale Salivary cortisol	were less educated, in pain, depressed, had bone metastases or lack of social support and more likely to use night sedation.	
35	Lacetti MS (2007)  USA	68 women with advanced breast cancer	To explore the relationship between patterns of language used in expressive writing text and quality of life.	Survey	Linguistic Inquiry and Word Count Functional Assessment of Cancer Therapy - Breast	No relationship was found between positive affect language and quality of life. No relationship was found between quality of life scores and progressive use of causal or insight language.	Not scored
36	Lemieux LJ (2006)  Canada	235 women with metastatic breast cancer	To establish whether supportive-expressive group therapy lowers health care service resource utilisation.	Survey  Data collection from cancer centres	Demographic and medical data Profile of Mood State Scale Visual Analogue Pain Scale Cost-minimisation analysis Cost-effectiveness analysis	Supportive-expressive group therapy does not lower health care resource utilisation. Cost associated with clinically significant beneficial effects on mood and pain perception were	Not scored

Psychosocial literature on the experience of living with metastatic breast cancer							
	Reference	Sample	Aim of study	Study design	Outcome measures	Main findings	*Score
						acceptable.	
37	Luoma ML et al (2004)  Finland	25 women with metastatic breast cancer	To investigate the meaning of quality of life for advanced breast cancer patients undergoing treatment.	Semi-structured interview	Phenomenological approach	Cancer and treatment limited physical functioning, leading to dependency on others and decreased feelings of autonomy. Predominant feelings of uselessness. Changes in lifestyle affected social functioning and led to isolation. Controlling the extent to which their illness was recognised allowed some social control and autonomy. Global QoL was dependent on the individual's ability to control the illness experience.	10/10

Psychosocial literature on the experience of living with metastatic breast cancer							
	Reference	Sample	Aim of study	Study design	Outcome measures	Main findings	*Score
38	Perez (1995)  New Zealand	109 women with metastatic breast cancer	To determine the acceptability of written information about breast cancer for women with metastatic disease.	Survey	Measuring the amount of information women choose to receive on the biology, symptoms, treatment and prognosis.	18% declined to receive any information, 54% requested more detailed information, 30% found it distressing, but only 5% thought too much was provided. Over 75% felt the information sheet helped them in decision making.	9/9
39	Pinder KL et al (1993)  UK	139 women with metastatic breast cancer	To estimate the prevalence of clinically significant anxiety and depression in this population and to examine the relationship between the psychiatric status and sociodemographic and disease data.	Survey  Interview	Demographic and medical data Hospital Anxiety and Depression Scale UICC performance status Past psychiatric history	35% of patients' HAD score indicated probable anxiety and/or depression and warranted psychosocial intervention. Clinical depression was significantly more likely amongst patients in the lower socioeconomic groups and those with a poor performance status.	9/9
40	Rosenzweig MQ et	Purposeful sample of	To better understand the perceived challenges,	Mixed methods	Symptom Distress Scale	WHI women verbalised that it was not fair to get	10

Psychosocial literature on the experience of living with metastatic breast cancer							
	Reference	Sample	Aim of study	Study design	Outcome measures	Main findings	*Score
	al (2009) <sup>a</sup> USA	86 women with metastatic breast cancer including both white and black women and high and low income ranges (WHI, WLI, BHI, BLI)	barriers and potential influences of race and income on management of symptoms that influence the metastatic breast cancer experience.	prospective design  Survey  Semi-structured interview	Functional Assessment of Cancer Therapy – General (FACT-G)  Grounded theory	a recurrence and were the only group to verbalise annoyance with their healthcare professionals reluctant to discuss prognosis. WLI minimised the self and symptoms as protective or coping strategy and expressed feelings of being 'lucky'. They blamed themselves for a lack of information for not clarifying the situation. BLI women had the highest levels of physical, emotional and social distress and verbalised anger at lack of information regarding their illness and prognosis.	
41	Rosenzweig MQ et	Prospective sample of	To explore how race and income status influenced	Survey	Symptom Distress Scale	The majority of women (of each race and	10

Psychosocial literature on the experience of living with metastatic breast cancer							
	Reference	Sample	Aim of study	Study design	Outcome measures	Main findings	*Score
	al (2009) <sup>b</sup> USA	47 women with metastatic breast cancer	women's experience with metastatic breast cancer.		Functional Assessment of Cancer Therapy General (FACT-G)	income group) reported experiencing faith (relationship with God), hope (for a cure and/or optimistic outcomes of treatment) and progressive loss (health, vitality and womanhood). Physical and symptom distress was more severe in African American women.	
43	Spiegel D et al (1983) USA	87 women with metastatic breast cancer	A systematic examination of the pain experience of women with metastatic breast cancer over time.	Survey Interview	Demographic and medical data Profile of Mood States Scale Pain variables – measured by a Visual Analogue Scale and verbal description of sensation	Mood disturbance and belief about the meaning of pain were the most potent predictors of pain. The combination of bone and visceral metastases measured more pain. There was no correlation with clinical course, time since diagnosis and mortality during the year of follow-up	9/9

Psychosocial literature on the experience of living with metastatic breast cancer							
	Reference	Sample	Aim of study	Study design	Outcome measures	Main findings	*Score
42	Schulman – Green et al (2011)  USA	Purposeful sample of women with metastatic breast cancer, who failed first-line therapy for metastatic disease	To describe experiences of self-management in the context of transitions among women with advanced breast cancer.	Semi-structured interviews	Interpretive content analysis	Participants expressed a range of preferences for participation in self-management including becoming empowered, and creating supportive networks. Barriers to self-management included symptom distress, difficulty obtaining information, and lack of knowledge about the cancer trajectory. Transitions identified were shifts in physical, emotional, and social wellbeing, such as when their cancer progressed and there was a need to change treatment. Transitions prompted changes in how actively women	10/10

Psychosocial literature on the experience of living with metastatic breast cancer							
	Reference	Sample	Aim of study	Study design	Outcome measures	Main findings	*Score
						self-managed and were experienced as positive, negative, and neutral.	
44	Spiegel D et al (1989)  USA	86 women with metastatic breast cancer	The effect of psychosocial treatment on survival of patients with metastatic breast cancer.	Retrospective analysis of a one-year psychosocial intervention  Randomised control study	Analysis of death certificates of patients who took part in the study examining the effects of supportive-expressive group therapy	Survival time was significantly longer (an average 18 months) in the intervention group than control.	9/9
45	Spiegel D et al (2007)  USA	122 women with metastatic breast cancer and three with local recurrence	To replicate earlier findings that intensive group therapy extended survival time of women with metastatic breast cancer.	Randomised controlled study. Intervention group received weekly supportive-expressive group therapy and the control group	Demographic and disease data Survival time	The earlier finding (1989) that supportive-expressive group therapy could extend survival was not replicated.	9



Psychosocial literature on the experience of living with metastatic breast cancer							
	Reference	Sample	Aim of study	Study design	Outcome measures	Main findings	*Score
				received educational materials.			
46	Svensson H et al (2009)	20 women with metastatic breast cancer	To explore psychological reactions and coping at disease progression after first-line chemotherapy among women with metastatic breast cancer.	Semi-structured interview	Content analysis	Three themes and eight subthemes emerged. Before the information (perceptions of signs and symptoms), immediately after the information (emotional reaction, intellectual and emotional awareness, worrying about the future), life after being informed of disease progression (future perspectives, the need for support, coping, hope).	
47	Turner J et al (2005)  Australia	66 women diagnosed with breast cancer within the	To define the key emotional concerns of women newly diagnosed with advanced breast cancer.	Survey  Semi-structured interviews	Demographic and medical data Hospital Anxiety and Depression Scale Impact of Events Scale Cancer Rehabilitation	Younger women (<55) had significantly higher levels of intrusive and avoidant symptoms than women over 55.	9/9

Psychosocial literature on the experience of living with metastatic breast cancer							
	Reference	Sample	Aim of study	Study design	Outcome measures	Main findings	*Score
		previous six months			Evaluation System Memorial Symptom Assessment Scale	Key themes were: difficulties in communicating with doctors, perceived delays in diagnosis, the emotional impact, concerns about family, feeling about why the cancer developed, other life stress and trauma and the use of non-prescribed treatment.	
48	Turner-Cobb JM (2000) USA	103 women with metastatic breast cancer	To examine the relationship between social support, both quantity and quality, and neuroendocrine function.	Survey  Salivary samples	Demographic and medical data Yale Social Support Index Salivary cortisol	Stress causes an elevation in cortisol levels and cortisol levels have been used as an index of stress. Greater quality of social support is associated with lower cortisol concentrations in women with metastatic breast cancer which is indicative of healthier	9/9

Psychosocial literature on the experience of living with metastatic breast cancer							
	Reference	Sample	Aim of study	Study design	Outcome measures	Main findings	*Score
						neuroendocrine functioning.	
49	Vilhauer RP (2008) USA	14 women with metastatic breast cancer	To investigate the experiences of women diagnosed with metastatic breast cancer.	Semi-structured interview	Content analysis	Themes were body image, sexuality, worries about effects of stress (fear of progressive disease, fear of dying, practical concerns, loss of future), daily activity (physical symptoms, social constraints, medicalised lifestyle, stress avoidance, financial issues), social support, interrelated concerns.	

Psychosocial literature on people with metastatic breast cancer and their partners/family							
	Reference	Sample	Aim of study	Study design	Outcome measures	Main findings	*Score
50	Butler L et al (2005)  USA	50 partners or spouses of people with metastatic breast cancer (all male except one)	To examine pre and post levels of post traumatic stress symptoms and the relationship of these symptoms to past, current and anticipatory stressors	Randomised control trial group psychotherapy plus education compared to education alone.	Impact of Events Scale Life Events Scale Perceived Stress Scale Anticipation of Loss Inventory	One third of the partners experienced clinically significant levels of traumatic stress during the course of their partner's illness. Partners who felt overburdened in their life generally and who believed they will have difficulty coping with their partner's death may need intervention during their partner's illness. Partner's residual, current and anticipatory stressors were each shown to be a significant predictor of the pre and post loss analysis. Trauma levels appeared in this study to be the	

Psychosocial literature on people with metastatic breast cancer and their partners/family							
	Reference	Sample	Aim of study	Study design	Outcome measures	Main findings	*Score
						partner's individual response rather than mirroring that of the people with MBC. However findings suggest that the women's and their partners' trauma symptoms may be linked to the partners' perceived stress. Those who had high pre-death loss symptoms were most at risk of a traumatic stress reaction. NB: attrition of post participants may limit the validity of the findings.	
51	Coristine M et al (2003) Canada	30 bereaved caregivers of women with advanced	To describe the psychosocial impact on caregivers of caring for women with advanced breast cancer.	Focus groups	Open ended questions to elicit the experiences of caregivers, responses were probed for the contextual factors surrounding action, thoughts and decisions. Content analysis and	Caregivers assume great responsibility in providing care, particularly at the terminal phase. Spousal caregivers have advantages because	10/10

Psychosocial literature on people with metastatic breast cancer and their partners/family							
	Reference	Sample	Aim of study	Study design	Outcome measures	Main findings	*Score
		breast cancer who were within three months of the patient's death			comparison by two primary investigators	living with the caregiver facilitates care giving and patterns of shared decision-making were established before the illness.	
52	Kershaw T et al (2004)  USA	189 patient-family dyads with advanced breast cancer	To compare coping strategies used by patients and their family caregivers and to examine how those strategies relate to patient and caregiver's quality of life.	Survey	Demographic and medical data Brief COPE scale Medical Outcomes Study-SF-36	Active coping was associated with higher quality of life and avoidant coping with lower quality of life. Patient level of symptom distress moderated the relationship between coping and quality of life. A negative relationship between family caregivers' avoidant coping strategies and their mental quality of life was strongest when patients had low levels of symptom distress and	9/9

Psychosocial literature on people with metastatic breast cancer and their partners/family							
	Reference	Sample	Aim of study	Study design	Outcome measures	Main findings	*Score
						weakest when high symptom distress.	
53	Giese-Davis J et al (2000)  USA	125 patients with metastatic breast cancer and a sub sample of 48 patients and partners	To examine mood disturbance among women with metastatic breast cancer in relationship to partner status, relationship quality and partners' coping and mood disturbance.	Survey	Demographic and medical data Profile of Mood States Scale (patient and partner) Ways of Coping Scale (partners) Family Environmental Scale	Patients showed less distress when they rated their relationship higher in cohesion-expression and in conflict and when their partner reported lower mood disturbance.	9/9
54	Grunfeld et al (2004)  Canada	130 women with advanced breast cancer 89 caregivers	To prospectively examine the psychosocial, occupational and economic impact.	Survey at two different time points; the beginning of the palliative phase and terminal phase	Demographic data Karnofsky Performance Indicator (patients) Hospital Anxiety and Depression Scale (caregivers) Medical Outcomes Study 36 item – short form (caregivers) Zarit Burden Inventory (caregivers) FAMCARE	Caregivers experience significant psychological morbidity (anxiety and depression) at the onset of the patient's palliative phase and an increase in caregiver burden and depression at the terminal phase. Caregivers focus so much on the caregiving	9/9

Psychosocial literature on people with metastatic breast cancer and their partners/family							
	Reference	Sample	Aim of study	Study design	Outcome measures	Main findings	*Score
						role they neglect their own medical needs. Caregivers bear occupational and economic burdens.	
55	Mortimer JSB (2005)  USA	34 spouses of women with metastatic breast cancer	To examine how chronicity of stress affects psychological stress responses and depressive symptoms in spouses of women with metastatic breast cancer.	Survey	Demographic data Center for Epidemiological Studies Depression Scale Impact of Events Scale	There was no association between the duration of disease and spousal depression.	9/9



Literature on the psychosocial impact of breast cancer including those with metastatic breast cancer							
	Reference	Sample	Aim of study	Study design	Outcome measures	Main findings	*Score
56	Arman M (2002) <sup>a</sup>  Finland	Four women with breast cancer, three having advanced breast cancer	To obtain a deeper and more profound understanding of the life world of women living with breast cancer focusing on changes in life perspective.	Interview including instruments registering quality of life and coping	Phenomenological approach Demographic and medical data Quality of life measure (not specified) Coping instrument (not specified)	An awareness of patients' increased openness to their own needs and desires is an important resource in the healing and rehabilitative process of breast cancer patients.	10/10
57	Arman M et al (2002) <sup>b</sup>  Sweden	17 women with breast cancer, of whom five had metastatic disease, and their significant others.	To study the experience of suffering among women with breast cancer in different care cultures.	Two interviews with women, with 2-3 week interval. Interview with significant other based on the topics from the interviews	Hermeneutic phenomenological model	The overall theme was 'a field of force' which represented movements of change, adjustment and emptiness.	10/10
58	Arman et al (2004)	16 women with breast	To interpret and understand the meaning of	Interview		The participants wanted to be treated with dignity	10/10

Literature on the psychosocial impact of breast cancer including those with metastatic breast cancer							
	Reference	Sample	Aim of study	Study design	Outcome measures	Main findings	*Score
	Sweden	cancer of whom six had recurrent or metastatic disease	patients' experiences of suffering related to healthcare.			and seen as a whole person by healthcare professionals but suffered from the lack of care and disappointment at a lack of a deeper relationship.	
59	Bender et al (2005)  USA	154 women with breast cancer (26 women with metastatic breast cancer) pooled from three independent studies	To compare the prevalence of symptoms attributable to breast cancer or its treatment and to identify and describe symptom clusters across the phases of the disease.	Survey	Demographic and medical data Profile of Mood States Scale Functional Assessment of Chronic Therapy-Anaemic Fatigue The Symptom Check List Menopause Specific Quality of Life Questionnaire The Kupperman Index The Daily Symptom Diary	Symptom clusters of fatigue, perceived cognitive impairment and mood problems exist across the breast cancer disease trajectory.	9/9
60	Kissane DW et al (2004)  USA	303 women with early stage breast cancer and	A comparative analysis of psychiatric disorder with early and advanced breast cancer	Survey	Demographic and medical data Monash Interview for Liaison Psychiatry European Organisation for	The rates of psychological distress are high across patients with early and advanced breast cancer. Illness	9/9

Literature on the psychosocial impact of breast cancer including those with metastatic breast cancer							
	Reference	Sample	Aim of study	Study design	Outcome measures	Main findings	*Score
		200 women with advanced breast cancer			Research and Treatment of Cancer QLQ-C30 Hospital Anxiety and Depression Scale Affects Balance Scale Mental Adjustment to Cancer Scale Medical Coping Modes Questionnaire	related causes of distress differ. Fatigue and emotional functioning influence the likelihood of psychiatric disorders. Self-image and substantial decrease in sexual functioning challenge self-esteem and relationships when support is important.	

## Appendix 2. Patient letter and information sheet



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BREAST CANCER CARE

### PATIENT LETTER AND INFORMATION SHEET

#### **A study of the experience of living with secondary breast cancer (REC No: 04/Q1704/19)**

Date:

I am a research nurse with experience of caring for people with secondary breast cancer. I would like to invite women with secondary breast cancer to take part in a research study that is being conducted by researchers from Southampton University and Breast Cancer Care. Before you decide, it is important that you understand why the study is being done and what it will involve. This letter and the details on the attached page give you information you need to know before committing to take part in the study.

I will contact you once by telephone within the next two weeks to ask you if you would like to take part in the study. You are under no obligation to take part and can choose not to do so when I contact you by telephone.

Please ask if anything is not clear or you would like to know more. You can call me on 020 7384 2984 or email [lizr@breastcancercare.org.uk](mailto:lizr@breastcancercare.org.uk), or ask your nurse to contact me.

Thank you for reading this letter and for considering taking part in the study.

Yours sincerely

Elizabeth Reed  
Nurse Researcher



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BREAST CANCER CARE

## Patient Information Sheet

### A Study of the experience of living with secondary breast cancer

(REC No: 04/Q1704/19)

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 and discuss it with others if you wish. Ask your doctor or nurse 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.

This information sheet refers to women with secondary breast cancer (when breast cancer has spread to another area in the body) but we acknowledge that men can get secondary breast cancer too, and their involvement in the project is welcome.

Thank you for taking the time to read this.

#### What is the purpose of the study?

Surprisingly little is known about the practical and emotional effects of living with secondary breast cancer or about the support needs of those with it. This study has been designed to explore the emotional, practical and physical effects of living with secondary breast cancer and to identify the support needs of women. The overall aim of the study is to improve the experience of living with secondary breast cancer by providing information to women based on the findings of this study and offering information to those involved in their care.

#### Why have I been chosen?

You have been approached to take part because you have a diagnosis of secondary breast cancer.

#### Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to complete a consent form. If you decide to take part 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?

There are two parts to this study. Firstly, all women known to your specialist with a confirmed diagnosis of secondary breast cancer will be approached to complete a questionnaire. The questionnaire asks how your secondary breast cancer affects you physically, emotionally and practically. It will take at the most, approximately 20

minutes to complete. From those who complete the questionnaire we will invite 30 women to go on to be involved in the second part of the study.

The second part of the study will involve interviewing the 30 women in their own homes (or another convenient place of your choice) to explore their experience further. This approach aims to allow each woman to tell her story of living with secondary breast cancer over a period of one year. This involves being interviewed for around 60 minutes at the beginning, the middle and the end of one calendar year. So the time commitment will be approximately three hours in one year. If you are selected to take part in the interviews, you should hear from me within three months.

You can decide to complete the questionnaire but not be involved in the interviews. Your completed questionnaire would still be important to the study.

Being part of this study does not involve any tests or increased visits to the hospital.

### **What if something goes wrong?**

If being a part of this study causes you any distress, you can choose to withdraw at any time.

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about any aspect of the study, the normal National Health Service complaints mechanisms should be available to you.

### **Will my taking part in this study be kept confidential?**

Any information you share will remain confidential, although if we felt you had a serious problem which needed medical attention, we would ask your permission to discuss this with your doctor or nurse.

Any information about you which is used for the study will have your name and personal details removed so that you would not be recognised from it.

### **What will happen to the results of the study?**

The study will be completed in 2007 and the findings published in medical and nursing journals and presented at conferences. In addition, the University of Southampton in partnership with Breast Cancer Care, aims to inform those responsible for the planning and delivering of breast cancer services of the needs of women with secondary breast cancer from the women's experience of living with it. The findings will be widely publicised through the media and publications most likely to be read by those affected by the disease. The overall aim is to improve the experience of living with secondary breast cancer in the UK.

### **Who is organising and funding the research?**

This study is a partnership between University of Southampton and Breast Cancer Care, the UK's leading provider of information to those affected by breast cancer. The funding is from Breast Cancer Campaign.

For further information, please contact Elizabeth Reed on 020 7384 2984 or email [lizr@breastcancercare.org.uk](mailto:lizr@breastcancercare.org.uk)

If you decide to take part in this study you will be given a copy of this information sheet and a signed consent form.

Date:

## Appendix 3. Website information sheet



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BREAST CANCER CARE

### Website Information Sheet

#### A Study of the experience of living with secondary breast cancer

(REC No: 04/Q1704/19)

Women with secondary breast cancer 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 and discuss it with others if you wish. Take time to decide whether or not you wish to take part.

This information sheet refers to women with secondary breast cancer (when breast cancer has spread to another area in the body) but we acknowledge that men can get secondary breast cancer too, and their involvement in the project is welcome.

This questionnaire will ask you about living with secondary breast cancer. Please take time to decide if you wish to take part, as we recognise that people often use the internet when they are alone and support or someone to talk to may not be readily available. Please consider this before consenting to take part in the study.

Thank you for taking the time to read this.

#### What is the purpose of the study?

Surprisingly little is known about the practical and emotional effects of living with secondary breast cancer or about the support needs of those with it. This study has been designed to explore the emotional, practical and physical effects of living with secondary breast cancer and to identify the support needs of women. The overall aim of the study is to improve the experience of living with secondary breast cancer by providing information to women based on the findings of this study and to offer information to those involved in their care.

#### Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part we would advise you to print a copy of this information sheet and a copy of the completed on-line consent form to keep. If you decide to take part you are still free to withdraw at any time and without giving a reason.

#### What will happen to me if I take part?

There are two parts to this study. Firstly, women with secondary breast cancer accessing the Breast Cancer Care website will be asked to complete an on-line questionnaire which asks how secondary breast cancer affects them physically,



emotionally and practically. It should take at the most 20 minutes to complete. From those who complete the questionnaire we will invite 30 women to go on to be involved in the second part of the study.

Participant No:

The second part of the study will involve interviewing the 30 women on the telephone to explore their experience further. This approach aims to allow each woman to tell her story of living with secondary breast cancer over a period of one year. This involves being interviewed for around 60 minutes at the beginning, the middle and the end of one calendar year. So the time commitment will be approximately three hours in one year. If you have been selected to take part in the interviews, you should hear from us within three months of completing the questionnaire.

You can decide to complete the questionnaire but not be involved in the interviews. Your completed questionnaire would still be important to the study.

Being part of this study does not involve any tests or increased visits to the hospital.

### **What if something goes wrong?**

If being a part of this study causes you any distress, you can choose to withdraw at any time. Sources of where you can get support are listed at the end of the questionnaire.

### **Will my taking part in this study be kept confidential?**

Any information you share will remain confidential, although if we felt you had a serious problem which needed medical attention we would strongly advise you to consult your specialist or nurse.

Any information about you which is used for the study will have your personal details removed so that you would not be recognised from it.

### **What will happen to the results of the study?**

The study will be completed in 2007 and the findings published in medical and nursing journals and presented at conferences. In addition, Southampton University in partnership with Breast Cancer Care, aims to inform those responsible for the planning and delivering of breast cancer services of the needs of women with secondary breast cancer from the women's experience of living with it. The findings will be widely publicised through the media and publications most likely to be read by those affected by the disease. The overall aim is to improve the experience of living with secondary breast cancer in the UK.

### **Who is organising and funding the research?**

This study is a partnership between University of Southampton and Breast Cancer Care, the UK's leading provider of information to those affected by breast cancer. The funding is from Breast Cancer Campaign.

For further information, please contact Elizabeth Reed, Nurse Researcher, on 020 7384 2984, email [lizr@breastcancercare.org.uk](mailto:lizr@breastcancercare.org.uk)

If you decide to take part in this study you should download a copy of this information sheet to keep.

Date:

Participant number:

## Appendix 4. Consent form



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BREAST CANCER  CARE

Study Centre:  
Participant Number:

Date:

Researcher: Elizabeth Reed

### Consent Form for patients

#### **A study of the experience of living with secondary breast cancer (REC No: 04/Q1704/19)**

Please read the following statements. If you are in agreement with them, tick the box at the end of each statement. Please ask if you would like anything explained.

Please tick

1. I confirm that I have read and understood the information sheet for the above study and have had the opportunity to ask questions. ☐
2. 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. ☐
3. If I am interviewed, I give permission for brief extracts from my interview to be used for research purposes (including publications and reports) with strict preservation of anonymity. I understand that the tape will be kept in accordance with University/Trust regulations. ☐
4. I understand the information gathered will be anonymised, so that individuals cannot be recognised, then stored and processed using a computer. ☐
5. I understand that the information I give will be kept strictly confidential. ☐
6. I agree to take part in the above study. ☐

Participant number:

\_\_\_\_\_  
Name of Patient      Date      Signature

\_\_\_\_\_  
Name of person taking      Date      Signature  
consent (if different from  
researcher)

\_\_\_\_\_  
Researcher      Date      Signature

**1 for patient, 1 for researcher, 1 to be kept in patient notes**

## Appendix 5. Participant questionnaire



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BREAST CANCER  CARE

Centre number:

Participant number:

### **A study of the experience of living with secondary breast cancer (REC No: 04/Q1704/19)**

This questionnaire helps us to look at how your cancer affects you in different areas of your life and in particular since your diagnosis of secondary breast cancer.

All the information you give us in this questionnaire will be confidential and no one outside the research team will have access to your responses. Please try not to leave any sections out even if you feel they are not appropriate to you.

#### **Your personal details:**

Age:

Male ☐ Female ☐

Postcode:

Ethnic origin (see attached sheet)

Marital Status:

Number of children:

#### **Section 1**

**Please use the following space to tell us where the breast cancer has spread to in your body and the treatment you have received for this.**

**How long have you had secondary breast cancer?**

**Below is a list of statements that other people with your illness have said are important. By circling one (1) number per line, please indicate how true each statement has been for you during the past seven days.**

PHYSICAL WELL-BEING	Not at all	A little bit	Some what	Quite a bit	Very much
1. I have a lack of energy.....	0	1	2	3	4
2. I have nausea.....	0	1	2	3	4
3. Because of my physical condition, I have trouble meeting the needs of my family.....	0	1	2	3	4
4. I have pain.....	0	1	2	3	4
5. I am bothered by side effects of treatment .....	0	1	2	3	4
6. I feel ill.....	0	1	2	3	4
7. I am forced to spend time in bed .....	0	1	2	3	4

SOCIAL/FAMILY WELL-BEING	Not at all	A little bit	Some what	Quite a bit	Very much
8. I feel close to my friends .....	0	1	2	3	4
9. I get emotional support from my family.....	0	1	2	3	4
10. I get support from my friends.....	0	1	2	3	4
11. My family has accepted my illness.....	0	1	2	3	4
12. I am satisfied with communication about my illness.....	0	1	2	3	4
13. I feel close to my partner (or the person who is my main support).....	0	1	2	3	4
<i>Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please check this box and go on to the next section</i>	<input type="checkbox"/>				
14. I am satisfied with my sex life.....	0	1	2	3	4

**Below is a list of statements that other people with your illness have said are important. By circling one (1) number per line, please indicate how true each statement has been for you during the past seven days.**

EMOTIONAL WELL-BEING	Not at all	A little bit	Some what	Quite a bit	Very much
15. I feel sad.....	0	1	2	3	4
16. I am satisfied with how I'm coping with my illness.....	0	1	2	3	4
17. I am losing hope in the fight against my illness.....	0	1	2	3	4
18. I feel nervous.....	0	1	2	3	4
19. I worry about dying.....	0	1	2	3	4
20. I worry that my condition will get worse.....	0	1	2	3	4

FUNCTIONAL WELL-BEING	Not at all	A little bit	Some what	Quite a bit	Very much
21. I am able to work (include work in the home).....	0	1	2	3	4
22. My work (include work in the home) is fulfilling.....	0	1	2	3	4
23. I am able to enjoy life.....	0	1	2	3	4
24. I have accepted my illness.....	0	1	2	3	4
25. I am sleeping well.....	0	1	2	3	4
26. I am enjoying the things I usually do for fun.....	0	1	2	3	4
27. I am content with the quality of my life right now.	0	1	2	3	4

**Below is a list of statements that other people with your illness have said are important. By circling one (1) number per line, please indicate how true each statement has been for you during the past seven days.**

ADDITIONAL CONCERNS	Not at all	A little bit	Some what	Quite a bit	Very much
28. I have been short of breath.....	0	1	2	3	4
29. I am self-conscious about the way I dress.....	0	1	2	3	4
30. One or both of my arms are swollen and tender.....	0	1	2	3	4
31. I feel sexually attractive.....	0	1	2	3	4
32. I am bothered by hair loss.....	0	1	2	3	4
33. I worry that other members of my family might someday get the same illness I have.....	0	1	2	3	4
34. I worry about the effects of stress on my illness...	0	1	2	3	4
35. I am bothered by a change in weight.....	0	1	2	3	4
36. I am able to feel like a woman.....	0	1	2	3	4
37. I have certain parts of my body where I experience significant pain.....	0	1	2	3	4

## Section 2

**1a. Which one of the following healthcare professionals would you most like to see on a regular basis?**

- |  |                          |
|--|--------------------------|
| Hospital specialist?                   | <input type="checkbox"/> |
| General practitioner?                  | <input type="checkbox"/> |
| Palliative care nurse/Macmillan nurse? | <input type="checkbox"/> |
| Breast care nurse?                     | <input type="checkbox"/> |
| Practice nurse?                        | <input type="checkbox"/> |
| District nurse?                        | <input type="checkbox"/> |
| Other (please specify)                 | <input type="checkbox"/> |

**1b. Approximately how often do you actually see that person?**

- Once a week ☐
- Every two week ☐
- Once a month ☐
- Every three months ☐
- Every six months ☐
- Less than six months ☐

**2. In the following sections we ask you about your views on the care you have received during your consultations or admissions. Please think carefully about each question and answer it as honestly as you can. Please tick one box for each question.**


<b>2a. Information and advice</b>	<b>Strongly disagree</b>	<b>Disagree</b>	<b>Neither agree nor disagree</b>	<b>Agree</b>	<b>Strongly agree</b>
1.The nurses/doctor told me all I wanted to know about my illness					
2. I was given enough information about my medication and its side effects					
3 .I was given enough information about my diet					
4. I was given enough information about social and financial support					
5. I was given enough information about my mobility					
6. The doctors/nurses gave me information just when I needed it					
7. The nurses/doctors gave me practical advice about managing my illness and symptoms					
8. I knew who to contact if I had a problem					
9. I felt comfortable about consulting doctors/nurses if I had a problem between hospital appointments					
10. After talking with the nurses/doctors, I have a good idea of what changes to expect in my health over the next few weeks and months					
11. I did not have enough information about how my hospital appointments were organised					

<b>2b. Personal experience of care</b>	<b>Strongly disagree</b>	<b>Disagree</b>	<b>Neither agree nor disagree</b>	<b>Agree</b>	<b>Strongly agree</b>
1. The doctors/nurses did not seem to understand what I was going through					
2. I saw the nurses/doctors as a friend					
3. The doctors/nurses took no interest in me as a person					
4. The nurses/doctors explained what was wrong with me					
5. The doctors/nurses gave me a chance to say what was on my mind					
6. I felt that my own views of my illness were being fully considered					
7. I felt that the nurses/doctors listened to what was worrying me					
8. I felt able to express myself and ask questions					
9. After talking to the doctors/nurses I felt much better about my problems					
10. I feel the nurses/doctors did not spend enough time with me					



<b>2c. How satisfied were you with</b>	<b>Not at all satisfied</b>	<b>Barely satisfied</b>	<b>Quite satisfied</b>	<b>Very satisfied</b>	<b>Completely satisfied</b>
1. the thoroughness of the care you received?					
2. the extent to which the doctors/ nurses looked into all the problems you mentioned?					
3. the information given to you about your disease?					
4. the reassurance given to you about your disease?					
5. the extent to which you were involved in decisions about your care?					
6. the extent to which your own worries and concerns were considered?					
7. the nurse or doctor's awareness of your needs?					
8. the extent to which your family were considered?					
9. knowing exactly who was looking after you?					
10. the amount that was known about your situation?					
11. the way in which your symptoms were managed?					
12. the way in which the doctors or nurses and GP communicate about your care?					
13. the overall care that you have experienced?					

**Please put a cross on the line to show how you would rate the support you have received overall?**



Dreadful                      Excellent

**3. What do you think your immediate needs are in relation to your physical health?**

**4. Who do you contact first when you are feeling unwell or have unpleasant symptoms?**

**5. Please explain why you contact that person?**

**6. What do you think your emotional needs are at the moment?**

**7. Who do you contact for emotional support?**

**8. Please explain why you choose to contact that person?**

**9. Overall, do you feel well supported at the moment?**

Yes ☐ No ☐

**10a. Do you receive any help or care at home?**

Yes ☐ No ☐

**10b. If yes, in the space below please tell us who provides this for you.**

**11. Describe what areas of practical support you would find useful (for example, childcare, housework, shopping).**

**12. Please use the space below to tell us anything else you feel may be useful in understanding the needs of women with secondary breast cancer.**

**Thank you for completing this questionnaire**

### **Being interviewed**

From the questionnaires that are returned to us, we will select 30 women to go on to be interviewed to explore their experience further. If you are one of the women selected to be interviewed a researcher will contact you within three months. This is to check that you are willing to be interviewed and arrange a convenient date and time. This involves being interviewed for around 60 minutes at the beginning, the middle and the end of one calendar year. So the time commitment will be three hours in one year.

You can decide you do not want to be interviewed or change your mind later.  
You can decide to complete the questionnaire but not be involved in the interviews.  
Your completed questionnaire would still be important to the study.

Would you be willing to be interviewed if selected?    Yes ☐ No ☐

Would you be willing to be contacted by telephone if selected? Yes ☐ No ☐

Your telephone number.....

### **Where you can get further support**

If you have found that completing this questionnaire has caused you to feel upset, the following may be useful in offering you some support.

Your Breast Care Nurse Team - Catherine Walsh, Kye Squire, Emma Bourne, Jan Scott, Southampton NHS Trust.  
Tel: 023 8082 5331 OR 023 8077 7222 Bleep 1134

Wessex Cancer Trust Counselling service, Bellis House, 11 Westwood Road, Southampton, SO17 1DL  
Tel: 023 8067 2200  
Email: wct@wessexcancer.org

The Breast Cancer Care chat forums -  
<http://www.breastcancercare.org.uk/Chat/Forums>

If you have a question which is not answered by the information on the Breast Cancer Care website, you can use the send your question to 'Ask the nurse' at [Nurse@breastcancercare.org.uk](mailto:Nurse@breastcancercare.org.uk)

Breast Cancer Care helpline 0808 800 6000 Monday to Friday 10am to 5pm and Saturday 10am to 2pm.

CancerBACUP helpline: 0808 800 1234  
Freephone helpline open Monday to Friday 9am to 7pm.  
Email: [info@cancerbacup.org](mailto:info@cancerbacup.org)

Elizabeth Reed  
Nurse Researcher, University of Southampton/Breast Cancer Care

Thank you for your time.



## **Appendix 6: Surveying the experience of living with metastatic breast cancer: comparing face-to-face-and online recruitment. *Journal of Research in Nursing* (2009) VOL 14 (1) 43–55**

Reed E, Simmonds P, Corner J

**Abstract:** With its growing use, the Internet offers researchers a novel approach in reaching those they seek to study locally, nationally or globally. The purpose of this paper is to describe our experience of using the Internet as one means of recruiting to a research study exploring the experience of women with metastatic breast cancer and to compare the methodological issues of using face-to-face and online approaches to survey recruitment. The survey incorporated the Functional Assessment of Cancer Therapy-Breast (FACT-B) quality of life measure, a patient experience with care measure and open ended text questions about respondents' physical, emotional and practical needs. Recruitment was done face-to-face in two cancer centres and on the Breast Cancer Care (it is the UK's leading provider of information, practical assistance and emotional support for anyone affected by breast cancer) Website, recruiting 110 people in the cancer centres and 125 from the Website. The age range was 25–84. Website respondents were significantly younger than cancer centre respondents ( $<0.000$ ). They also had significantly lower social well-being on the FACT-B scale and were less satisfied with information and advice ( $<0.000$ ) and their personal experience of care ( $<0.010$ ). Finally, we consider the role of the Internet in research and the methodological and ethical challenges this presents both now and in the future.

**Key words** breast cancer; Internet; recruitment; survey

### **Introduction**

In the UK, Internet use is rapidly increasing. Ofcom (2004) reported that the use of the Internet in the UK has expanded, with 86% of adults accessing it at home, and women aged 25–34 spending over 20% more time online than their male counterparts.

Use is less frequent among older people, but the over 50 s (who make up 41% of the UK population) now account for nearly 30% of all time spent on the Internet. The report also found that home access to the Internet is higher among minority ethnic groups (64%) than the UK population overall (54%) and that minority ethnic groups use the Internet more frequently (14.5 h/week compared with 9.9 for the UK overall). Those on

higher income are twice as likely to use the Internet (91%) than those with the lowest income (39%) although Internet use has grown across all income groups (Dutton and Helsper, 2007).

The Internet offers unprecedented opportunities for health care professionals, service providers and policy makers to gather information on the needs and behaviours of those accessing their services locally, nationally or globally. There is growing interest in undertaking web-based research as it is a cost-effective and time-efficient way of recruiting considerable numbers of responses or observing communities.

### *Cancer and the Internet*

To the novice cancer patient, seeking, understanding and scrutinising breast cancer information on the Internet where there is little regulation of information can be a daunting experience at a stressful time in their lives. Simply typing 'breast cancer' into a search engine yields approximately 503,000 hits and 'metastatic breast cancer' 65,200 hits from UK sites alone (www.google.com). Conversely, privacy and ease of access at any time make the Internet an increasingly appealing medium for accessing health information. Those seeking health information have reported that this method of information seeking removes embarrassing face-to-face or telephone interactions and the amount and type of information is controlled by the person seeking it rather than those involved in their care (Satterlund, et al., 2003; Ziebland, et al., 2006).

Women have been found to use the Internet to seek health information more than men, with 30% seeking health information around once a month; cancer being one of the most searched diseases on the Internet (Satterlund, et al., 2003). To date, studies looking at the use of the Internet in women with breast cancer are predominantly interested in women's search for information (Satterlund, et al., 2003) and their use of online support systems (Fogel, et al., 2002; Hoybye, et al., 2005; Pereira, et al., 2000). One study looking at whether bulletin boards on a breast cancer Website improved quality of life found that there were significant improvements in depression, emotional well-being and overall quality of life as a result of participation in online interaction with other people in a similar situation, although the need for online interaction may wane over time (Lieberman and Goldstein, 2005). However, there is some evidence to suggest that heavy Internet users may be more stressed (Kraut et al., 2002).

The prognosis of metastatic breast cancer has improved over the last 5-10 years as a result of the development of more effective and better tolerated therapies that can be applied to a wider range of patients (Compagnoni, et al., 2008; Conlin and Seidman,

2008; Ross, et al., 2004). As a consequence, women are living longer, with 51% of those diagnosed with metastatic cancer being alive at three years (Acharya, et al., 2008). An online study of the information and support needs of women with metastatic breast cancer found that over half of participants preferred online presentation of information (Mayer and Grober, 2006).

Little is known about Internet use among those with palliative care needs or how their information and support needs are being met by health-related Websites. One study raises the concern that those with advanced cancer, who are frustrated with their care or the limitations of treatment available, are vulnerable to exploitation in their search for alternative treatments and second opinions (Pereira, et al., 2000). Addington-Hall (2002) suggests that palliative care patients are more likely to feel coerced into taking part in research as they are dependent on health professionals for their care and feel unwilling to give honest responses to those who are responsible for their care. The use of the Internet to recruit people with palliative care needs could, potentially, offer a means of excluding some of the ethical concerns identified by Addington-Hall, as the responses of participants are anonymous and fall outside the health care setting.

The purpose of this article is to consider the role of the Internet in research with a marginalised patient group (Davies and Sque, 2002) and describe the methodological issues of using two different approaches to survey recruitment. It will compare online with face-to-face recruitment of women with metastatic breast cancer for a study exploring their experience of care and quality of life, focusing on the methodological issues. Findings of this research study will be reported elsewhere.

## Methodology

### *Recruitment*

Women with metastatic breast cancer were surveyed using two different methods. All medical notes of patients attending breast cancer clinics in two cancer centres were screened, and those with a confirmed diagnosis of metastatic breast cancer were approached face-to-face by the author to participate in the study.

Subject to consent, participants were asked to complete a questionnaire about their experience of living with metastatic breast cancer. They could complete the questionnaire independently while in clinic or return it by post. Concurrently, following national and regional media promotion, those accessing the Breast Cancer Care (it is the UK's leading provider of information, practical assistance and emotional support for anyone affected by breast cancer) Website were asked to complete the same questionnaire. The inclusion criteria were a confirmed diagnosis of metastatic breast



cancer for women recruited in the cancer centres and an accurate description of metastatic breast cancer for those recruited via the Website. To ensure there was only one response from each online participant, post codes were checked for duplication. Where this existed, further data were checked and where present, one of the identical responses deleted.

Participants recruited through the two cancer centres were approached by the author who gave a verbal explanation of the study and a participant information sheet. Potential participants were given the opportunity to ask questions and had a minimum of 24 h to decide if they would like to take part. A consent form was signed by both the participant and the investigator.

For online participants, a link from the Breast Cancer Care Website home page led to a letter from the author introducing the research study. Below the letter were two downloadable PDFs containing the information sheet and a sample of the questionnaire. This meant that potential participants could see the format and type of questions they would be asked before consenting to take part. The sample questionnaire was labelled 'sample' and could only be looked at, not completed. If the person decided to continue, a button labelled 'continue' took them into the consent form.

Although absolute certainty cannot be claimed, we are confident that the online participants were people with a diagnosis of metastatic breast cancer. The completed questionnaires were carefully checked for duplication or inappropriate responses. We are confident that other than those who defined themselves as having metastatic breast cancer but actually had early stage breast cancer or local recurrence (10), all respondents were able to describe the extent of their metastatic breast cancer and the responses to questions were consistent with those who have a knowledge of the disease and experience of living with it.

#### *Outcome measures used for the study of the experience of living with metastatic breast cancer*

Socioeconomic status was measured using Townsend deprivation index derived from postcode data. The Functional Assessment of Cancer Therapy-Breast (FACT-B) was used to assess health-related quality of life. This self administered multidimensional instrument consists of domains measuring physical well-being, social/family wellbeing, emotional well-being, functional well-being and breast cancer specific concerns. The total FACT-B score is calculated by adding the results for each domain. The

questionnaire has a total of 37 items asking respondents to rate how true each one is for the period of the last 7 days. Response scales range from 0 (not at all) to 4 (very much). The questionnaire has been shown to have high internal consistency/reliability and has been well validated (Brady, et al., 1997; Cella, et al., 1993). The experience with care measure included 34 items in three domains (information and advice, personal experience of care and satisfaction with care). To calculate the scores, the percentage of positive responses was calculated for each of the three main domains (information and advice, personal experience with care and satisfaction with care) by grouping the higher two categories (agree/strongly agree or very/completely satisfied) of the five options for each question, as well as an overall rating of the support received.

#### *Statistical methods*

FACT-B subscale scores were calculated using standard methods and summarised according to subgroups of survey participants using mean  $\pm$  standard deviation (SD) and interquartile ranges.

We compared mean scores of the quality of life and experience of care sub-scales between groups using t-tests and one-way analyses of variance and multiple regression analyses. FACT-B and experience with care data were analysed using SPSS (FACIT Measurement Systems, USA).

#### *Free text analysis*

Free text responses were transcribed verbatim and entered into the qualitative software package NVivo. Analysis was undertaken by the author and themes generated verified by a second researcher. Categorical indexing generated the themes from questions on physical, emotional and practical concerns and subcategories generated within these key themes. These findings will be reported elsewhere.

#### *Ethical considerations*

Respondents' rights, dignity and safety should be a primary concern for any researcher, but Internet research challenges these principles. Anonymity cannot be truly guaranteed because a 'hacker' could reveal the identity of participants, particularly if contact details are used. Technically, the Website team involved in design of the online survey and day-to-day management of the Website could have access to the data. In view of this, a confidentiality agreement was signed by them before data collection started.

Although there are technical processes in place to protect the privacy, anonymity and confidentiality of those taking part in online research, the researcher should have an understanding of the collection, processing and storage of the data and the means of protecting them, to be confident that everything complies with data protection regulations (Department of Health, 2005). On submission of the completed survey in this study, data were automatically put into an encrypted Comma Separated Values file that could only be accessed by the research team. The data were transferred to SPSS on completion of data collection. The server was backed up daily. Some researchers advise against requesting email addresses as the risk of others discovering the participants' identity is increased. In this study, email addresses were needed if participants consented to take part in a second phase of the study, which entailed being interviewed. The survey data were stored separately from the contact details to reduce this risk.

Ethical approval was sought from the Local Research Ethics Committee for the main study site. Approval was given with no amendments.

#### *Informed consent*

There are concerns about how informed participants of Internet-based research can be (Cotton, 2003). Because researcher-participant contact is inevitably limited, steps need to be in place to ensure, as far as possible, that those wishing to take part in the research study have full access to enough information to give informed consent. The telephone number and email address of the researcher were available to participants, although it has to be acknowledged that the opportunity to ask questions and clarify concerns about the study could not be as spontaneous as a face-to-face consent. Having read the study information, and having had the opportunity to look at the sample questionnaire, participants had to read each statement and click the computer mouse on a 'button' at the end of each statement to confirm their consent to continue.

The participants were asked to click a final statement 'I agree to take part in the above study' and then clicked on a button labelled 'submit' which took them into the questionnaire. It was not possible to continue with the consent process without agreeing to all statements. As with face-to-face participants, online participants were advised to retain a copy of their consent form. This action took the participant into the questionnaire.

There is some concern that those with metastatic breast cancer may be more vulnerable and isolated by the emotional and or physical manifestations of their

disease. Sleep disturbance has been found to be a significant problem in women with metastatic breast cancer (Koopman, et al., 2002). Asking for their thoughts and feelings on an Internet survey may compound these problems. Of the 125 who completed the survey, nine did so between 23.00 h and 06.00 a.m. It is a concern that access to emotional support, either formal or informal, is limited at this time of night for these participants.

### *Selection bias*

Selection bias needs to be acknowledged when publishing the findings of an Internet survey. In quantitative research, there is some concern that those participating in an Internet survey may not be representative of the wider population and the self-selection of participants may indicate a selection bias (Eysenbach and Wyatt, 2002). For example, 80% of those with breast cancer are over 50 years old (Cancer Research UK, 2008), and in general, Internet users are younger. Website respondents were significantly younger than cancer centre respondents indicating selection bias (Table 1).

Those who are experiencing difficulty coping with their metastatic breast cancer may be less likely to complete a questionnaire which asks them to consider and respond to statements such as 'I am losing hope in the fight against my illness' or 'I worry that my condition is getting worse' (FACT-B). Concerns have been raised that Internet surveys may affect the psychological well-being of participants. They may have an emotional reaction to questions but, unlike those recruited through a face-to-face encounter, those completing an online survey will not have the opportunity of debriefing or support at the point of completion (Kraut, et al., 2002).

### *Incentives*

Flicker, et al. (2004) suggest that when using the Internet to recruit research participants, the lack of face-to-face contact and telephone conversation may lead to difficulties in recruiting adequate numbers, but this was not our experience. Although incentives are often used to recruit participants in online research, we could argue that for a population who have been reported to feel marginalised and unsupported (Davies and Sque, 2002), the incentive was to have their voice heard.

Conversely, these participants may represent those more interested in campaigning for better services rather than a true representative sample of the metastatic breast cancer population.

## *Results*

A total of 234 women and one man completed the questionnaire. In all, 136 patients consented to take part in the cancer centres (72.3% of 188 patients identified with metastatic disease), and 110 completed the questionnaire (a response rate of 88.8%). Reasons given for not taking part were preoccupation with treatment decisions, undergoing further investigations, progressive disease, mood disturbance and finding the questions distressing.

A total of 221 people looked at the online survey and 153 completed it. It is conceivable that this sample could have included people interested in online research and those with an interest in breast cancer as well as those who actually had metastatic breast cancer. However, their responses suggest that they did have personal experience of living with advanced breast cancer, as already stated. Of those who completed the survey, 19 were repeated submissions (people thinking their response had not worked and therefore sent it again) and incomplete responses and a further 10 defined themselves as having metastatic breast cancer but the description of the disease they gave was actually primary or regional recurrence. The final number of Website participants who defined themselves as having metastatic breast cancer and who completed the survey was 125.

The online survey recruited 50 participants in 5 weeks, whereas the same number recruited in one cancer centre took 9 months, indicating that a Website survey is a more cost-effective, time-efficient means of survey recruitment. Overall the majority of responses from cancer centre and Website respondents were complete with only occasional omissions.

## *Demographic data*

In total, 235 people with metastatic breast cancer were recruited to the study. For analysis, it was not possible to combine the cancer centres as this was not a homogenous group. In particular, participants from cancer centre 2 were significantly older.

The Townsend deprivation index was used as an indicator of socioeconomic status. A total of 41% of participants in cancer centre 2 were in the highest quintile (the most deprived) compared with 30% in cancer centre 1. Website respondents had the lowest levels of deprivation with only 20% in the most deprived quintile. These findings support other research indicating that the Internet user population is primarily technologically proficient, educated, white and middle class (Hewson, 2003).

The age range of cancer centre participants was 25–84, with a mean age of 58. Website participants' ages were collected in ranges, therefore the overall mean age score cannot be calculated. However, Website participants were significantly younger ( $<0.001$ ). A total of 42% of Website participants were aged between 45 and 50, whereas 77% of those recruited from cancer centres were over 50. There were similar distributions between the cancer centre and Website participants for all demographic variables other than age (Table 1). The median time since diagnosis of metastatic disease was 2 years and ranged from a number of days to several years, with 10 (4.2%) participants living over 5 years.

The online participants in our study were similar to those in Mayer and Grober's (2006) survey of people with advanced breast cancer, which included 70% aged between 40 and 49, and 74% living with a partner. The authors of this survey acknowledge the limitations of online research, admitting that their sample did not represent minority groups, older and less well educated women, non-English speakers and women from lower socioeconomic groups.

#### *Outcome measures*

When looking at the quality of life domains, online participants had significantly lower social well-being than the cancer centre respondents ( $<0.000$ ) (Table 2). Table 3 shows the individual items within the social well-being domain which were statistically significant. In addition, online participants were less satisfied with their care in all domains: information and advice ( $<0.000$ ), personal experience of care ( $<0.010$ ) (Table 2). Looking at the items within the satisfaction with care domains, website participants' scores are significantly lower than cancer centre participants in 17 of the 34 items (Table 4). These findings suggest that women with metastatic breast cancer may turn to the Internet because of dissatisfaction with the information, advice and support they have received from health care professionals and those around them.

#### *Open text responses*

Both cancer centre and online participants appeared to be committed to answering the open text questions. When asked to 'tell us anything else you feel may be useful in understanding the needs of women with metastatic breast cancer', 118 (94%) of Website respondents answered this question compared with 80 (73%) of the cancer centre respondents. The cancer centre respondents were more likely to write a short response to this question, whereas most of the Website responses were longer (Table 5). This may be because those completing the survey by hand do not have the

opportunity to rewrite their responses, whereas Website respondents may be more likely to spend time crafting their response.

## Discussion

This study supports findings that face-to-face recruitment of people with cancer, and particularly advanced cancer, can be problematic (Addington-Hall, 2002).

Recruitment in the cancer centres was challenging, as participants dealt with their metastatic diagnosis, treatment and unpleasant symptoms along with the emotional adjustment to progressive disease. Although women expressed interest in the study, many felt too preoccupied with the physical and emotional manifestations of their disease and decisions around treatment to take part. The appropriate timing to approach potential participants was key to successful recruitment but for a significant number events changed, such as disease progression after consent was given, which meant they felt unable to continue participation in the study. Cox (2002) highlighted problems with recruitment of patients with advanced cancer to research when interviewing them about their perceptions of early phase clinical trials. She found that altruism was a primary motivation in patients desire to take part, but the patients she interviewed were unclear about their contribution to the clinical trial or the reasons for their participation, requesting information about the trial they had consented to take part in after the event, during qualitative interviews. It could be that reading and understanding information about a research study online, when potential participants are in control of the amount of information they read and the amount of time they take to understand the information in a familiar and possibly less distracting place, may be preferable to doing so in a busy clinic. Conversely the lack of participant-researcher interaction for online participants may affect their understanding and is limited to those able to read English and those who have Internet access.

The demographic profile of the online participants in this study was consistent with other online surveys of those with metastatic breast cancer (Mayer and Grober, 2006). However, online participants in this study had lower levels of social deprivation, had lower social well-being and were less satisfied with the information and advice and care they received from health care professionals than face-to-face survey participants. This may be an indication that some women with metastatic breast cancer turned to the Internet to seek advice, information and support that they failed to get from the health care professionals involved in their care, although further investigation of this issue is needed.

Neither the sample we recruited face-to face nor the online sample can be said to be representative of all patients with metastatic breast cancer. Until access to and use of the Internet is more widely available to the whole population, it will always be inappropriate to use online recruitment alone to seek answers to the needs of a population. It appears, however, that online surveys may be a useful alternative to face-to-face recruitment, overcoming some of the problems inherent in more direct forms of recruitment, as shown in Table 6.

However, despite some limitations, undertaking Internet research also has some advantages (Table 6). It offers unique opportunities for health care professionals, service providers and policy makers' access to information on the needs and behaviours of those accessing their service and is a time-efficient, cost-effective means of survey recruitment.

Studies using mixed modes of recruitment and administration should be undertaken to examine the differences and similarities of Internet versus face-to-face surveys. In addition, further studies into the choice of responses and the characteristics of respondents between online and other survey administration will give a better understanding of the benefits and drawbacks of Internet-generated surveys.

Using the Internet in research poses both ethical and methodological challenges both in the responsibility researchers have to protect their participants' rights, dignity and confidentiality and in the need to ensure that research participation is as inclusive as possible.

That health-related information on the Internet is unregulated is a concern as increasing numbers of people have access and seek this information online with little guidance on seeking reputable, evidence-based information. In addition, unscrupulous researchers could use the Internet to recruit research participants and bypass research governance and ethical approval online. It will be a challenge to the research community to be able to develop guidance and to protect the rights, dignity and safety of those using it to seek information and support. Further work needs to be done on the ethical guidelines in Internet research, both in the UK and internationally.

With access and use of the Internet growing rapidly, unique and exciting opportunities offer researchers a different medium to seek an understanding of the experience, needs and problems of those with health-related concerns. This cost and time-efficient



approach will allow access to a larger, and possibly in the future, a more diverse population than has been possible before.

**Table 1: Demographic and clinical characteristics of women according to place of recruitment**

Characteristic	Centre 1 N= 72 (%)	Centre 2 N= 38 (%)	Website N=125 (%)	Total N=235 (%)	$\chi^2$ test for comparison of place of recruitment p-value
<b>Age</b>					<0.001 <sup>a</sup>
25-44	9 (12.5)	3 (7.9)	43 (34.4)	55 (23.4)	
45-54	21 (29.2)	9 (23.7)	52 (41.6)	82 (34.9)	
55-64	16 (22.2)	13 (34.2)	26 (20.8)	55 (23.4)	
≥65	26 (36.1)	13 (34.2)	3 (2.4)	42 (17.9)	
Unknown	0	0	1 (0.8)	1 (0.4)	
<b>Marital status</b>					0.24
In relationship	49 (68.1)	26 (68.4)	97 (77.6)	172 (73.2)	
Not in relationship	23 (31.9)	8 (21.1)	26 (20.8)	57 (24.3)	
Unknown	0	4 (10.5)	2 (1.6)	6 (2.6)	
<b>Children</b>					0.74
None	12 (16.7)	8 (21.1)	25 (20.0)	45 (19.1)	
≥1	55 (76.4)	25 (65.8)	93 (74.4)	173 (73.6)	
Unknown	5 (6.9)	5 (13.2)	7 (5.6)	17 (7.2)	
<b>Townsend deprivation index quintile<sup>b</sup></b>					0.78 <sup>a</sup>
1=Most deprived	16 (22.1)	11 (28.9)	12 (9.6)	39 (16.6)	
2	13 (18.1)	6 (15.8)	19 (15.2)	38 (16.2)	
3	12 (16.7)	4 (10.5)	24 (19.2)	40 (17.0)	
4	14 (19.4)	5 (13.2)	21 (16.8)	40 (17.0)	
5=Least deprived	16 (22.2)	8 (21.1)	14 (11.2)	38 (16.2)	
Unknown	1 (1.4)	4 (10.5)	35 (28.0)	40 (17.0)	
<b>Time since diagnosis of metastases</b>					0.65 <sup>a</sup>
	22 (30.5)	9 (23.7)	32 (25.8)	63 (26.9)	
<6 months	9 (12.5)	8 (21.1)	28 (22.6)	45 (19.2)	
6-12 months	18 (25.0)	12 (31.6)	33 (26.6)	63 (26.9)	
1-2 years	16 (22.2)	8 (21.1)	29 (23.2)	53 (22.6)	
2-5 years	7 (9.7)	1 (2.6)	2 (1.6)	10 (4.2)	
>5 years	0	0	1 (0.8)	1 (0.4)	
Unknown					

Trend test <sup>b</sup> Townsend deprivation index quintiles calculated from total sample with available data

**Table 2: FACT- B quality of life scale**

FACT-B	Cancer centre 1 Mean (SD)	Cancer centre 2 Mean (SD)	Website Mean (SD)	P value
Physical well-being	15.9 (7.36)	8.9 (6.4)	19.6 (5.5)	<0.000
Social well-being	21.8 (4.35)	21.9 (5.6)	18.6 (5.7)	<0.000
Emotional well-being	13.7 (5.17)	9.2 (4.19)	13.4 (5.3)	<0.000
Functional well-being	17.7 (5.8)	17.0 (7.4)	17.1 (6.1)	
Breast cancer score	20.7 (8.0)	16.5 (4.8)	24.1 (6.9)	
Total score	89.8 (21.7)	73.7 (11.4)	60.9 (15.5)	

Satisfaction with care				
Information and advice	60.2 (21.4)	65.7 (23.8)	49.6 (24.8)	<0.001
Personal experience of care	78.4 (27.9)	78.2 (28.8)	64.1 (31.7)	<0.001
Satisfaction with care	49.6 (36.7)	57.8 (40.0)	44.5 (39.0)	

*\*cancer centres could not be combined due to demographic differences within groups' age and sociodemographic group (see table 1)*

**Table 3: FACT-B quality of life scale**

FACT-B Social well-being items	Cancer centre 1 Mean (SD)	Cancer centre 2 Mean (SD)	Website Mean (SD)	P-value
I get emotional support from my family	3.4 (0.75)	3.4 (0.96)	3.02 (1.1)	<0.005
My family has accepted my illness	3.2 (0.9)	3.3 (1.0)	2.7 (1.1)	<0.000
I am satisfied with communication about my illness	3.1 (0.8)	3.3 (1.0)	2.5 (1.2)	<0.000
I feel closer to my partner (or the person who is my main supporter)	3.5 (0.9)	3.5 (0.9)	3.0 (1.3)	<0.007

**Table 4: comparing significant differences in satisfaction with care between centres**

Information and advice	Cancer centre 1 Mean(SD)	Cancer centre 2 Mean(SD)	Website Mean(SD)	P- value
The nurse/doctor told me all I wanted to know about my illness	3.0(0.7)	3.1(0.7)	2.5(1.24)	<0.000
I was given enough information about my medication and it's side effects	2.9(0.9)	2.9(0.7)	2.7(1.13)	<0.002
The doctor gave me information just when I needed it	2.7(0.8)	2.8(0.7)	2.2(1.2)	<0.000
I felt comfortable about contacting the	3.1(0.8)	3.0(0.9)	2.8(1.2)	<0.002

doctors/nurse if I had a problem between hospital appointments				
After talking with the nurses/doctors I have a good idea of what changes to expect in my health over the next few weeks and months	2.2(1.1)	2.5(0.9)	1.6(1.3)	<0.001
<b>Personal experience of care</b>	<b>Cancer centre 1 Mean(SD)</b>	<b>Cancer centre 2 Mean(SD)</b>	<b>Website Mean(SD)</b>	<b>P-value</b>
<sup>a</sup> The doctors/nurses did not seem to understand what I was going through	1.0(0.9)	1.1(0.9)	1.4(1.1)	<0.005
I saw the nurses/doctors as a friend	2.6(0.9)	2.6(0.8)	2.3(1.1)	<0.003
I felt that my own views of my illness were being fully considered	2.8(0.8)	2.8(0.6)	2.5(1.1)	<0.000
I felt that the nurses/doctors listened to what was worrying me	2.9(0.8)	2.9(0.7)	2.7(1.0)	<0.000
I felt able to express myself and ask questions	3.1(0.7)	3.0(0.5)	2.8(1.0)	<0.000
After talking to the doctors/nurses I felt much better about my problems	2.8(0.9)	2.8(0.8)	2.5(1.0)	<0.016
<sup>a</sup> I feel the nurses/doctors did not spend enough time with me	1.0(1.0)	1.0(1.0)	1.6(1.3)	<0.000
<b>How satisfied were you with</b>	<b>Cancer centre 1 Mean (SD)</b>	<b>Cancer centre 2 Mean (SD)</b>	<b>Website Mean (SD)</b>	<b>P-value</b>
the extent to which you were involved in decision making about your care	2.5(0.5)	2.7(0.8)	2.3(1.2)	<0.000
the extent to which your own worries and concerns were considered	2.5(0.9)	2.6(0.8)	2.2(1.2)	<0.001
knowing exactly who was looking after you	2.5(0.9)	2.7(0.9)	2.4(1.4)	<0.015
the amount that was known about your situation	2.3(0.9)	2.6(1.0)	2.1(1.2)	<0.021
the way in which the doctors or nurses and GP communicated about your care	2.3(1.0)	2.6(0.9)	2.1(1.2)	0.025

<sup>a</sup> Lower score means higher satisfaction as negatively skewed statement

**Table 5: Examples of website responses to Q 12**

'Metastatic breast cancer is like a dance, sometimes the music is up-tempo and sometimes it is not, but you have to keep on dancing whether you like the music or not because you worry about the consequences if you stop.....'

'I sometimes feel terribly isolated and marginalised, I feel like we are the face of breast cancer that nobody really wants to see, the story without the happy ending or feel-good factor. You can feel very apart and alone, almost as though you are watching everyone else through a window at a party from which you have been excluded, for reasons which you do not understand'.

**Table 6: Advantages and disadvantages of Internet surveys**

**Advantages**  
Time efficient  
Cost effective  
Easy to manage on line  
Anonymity – outside care setting so responses not influenced by contact with care givers  
Access to large numbers of people locally, nationally or internationally  
Ease of access at any time  
Access to groups difficult to recruit such as those housebound  
Potential to offer more dynamic, interactive, visual or animated surveys

**Disadvantages**  
Data protection – a knowledge of the collection, storage and protection of the data is essential  
Ensuring informed consent – no opportunity to ask researcher spontaneous questions  
Security – anonymity cannot be truly assured because a 'hacker' could reveal respondents identity  
Respondents' IT confidence and competence  
Volunteer effect  
Selection bias, that is, age  
Potential fictitious responses  
Limited access to emotional support

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## **Appendix 7. Quality of Life and Experience of Care in Women with Metastatic Breast Cancer: a Cross-sectional Survey. *Journal of Pain and Symptom Management* (2011) (Epub ahead of print)**

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### **Introduction**

Despite the implementation of screening and advances in the management of breast cancer, a significant number of women will go on to develop metastatic disease, although the actual number is unknown as these data are not collected. In the UK a significant proportion of the 550,000 women estimated to be alive with a diagnosis of breast cancer will be living with metastatic disease<sup>1</sup>. The needs of those with metastatic breast cancer are increasingly receiving both national<sup>2</sup> and international attention<sup>3</sup>. Evidence suggests that the provision of care for women with metastatic breast cancer is inadequate<sup>4</sup> and the focus of clinical teams and breast care nurse specialists has predominantly been on supporting those with primary disease<sup>5</sup>.

The prognosis of metastatic breast cancer is improving as a result of the development of more effective and better tolerated therapies that can be applied to a wider range of patients sequentially over time<sup>6, 7</sup> and for many it may become a long-term illness. Women presenting with visceral metastases may have a relatively short life expectancy whilst those presenting with skeletal metastases and no other site of metastases have an average life expectancy of approximately 24-36 months. Those with more indolent disease may live for many years (10-15 years in some cases)<sup>8</sup>. Considering the potential long-term nature of metastatic disease, those living with it are now considered to be cancer survivors rather than necessarily at the end of life<sup>9, 10</sup>.

Since the focus of specialist palliative care teams is on end of life care, many women with metastatic breast cancer are not deemed to be in the end of life phase of illness and they often do not receive palliative care input until the last weeks of life. This may be some years after advanced disease is first recognised.



Quality of life among women with breast cancer has been extensively studied but there is a paucity of research exploring the quality of life and wellbeing of women with metastatic disease outside clinical trials of new treatments. To date there has been little information available to suggest whether women with metastatic breast cancer have unmet needs. The prevalence of problems and needs and the experience of care received by women have not previously been described in the current context of increased treatment options and prolonged life expectancy.

While extensive data on the incidence and mortality of breast cancer have been routinely collected for a number of years, there are gaps. In particular, data relating to diagnosis of metastatic breast cancer have not been collected. We are not aware of any country worldwide that collects national data on the incidence of metastatic breast cancer. This means that the natural history of metastatic breast cancer, for example duration of survival after metastatic disease is recognised by the number and types of treatments received, service use or quality of life; how this changes over time following the development of metastatic disease is unknown.

The prevalence of metastatic breast cancer and the longer illness trajectory for many women have potential implications for health service provision and the cost of treatment and care. It is therefore imperative that the needs for support and the impact of ongoing treatment for metastatic breast cancer on women with the disease are understood.

The objective of this study was to assess the quality of life, experience of care and need for support services for women with metastatic breast cancer and to identify whether there were particular groups of women with greater need for support. For example, it was hypothesised that women with visceral disease would have a poorer quality of life and higher symptom burden than women with bone metastases and no visceral disease since the former is deemed to be more aggressive and advanced. A secondary objective was to identify whether there were other sub-groups of women who may have greater needs for support.

This paper reports the first detailed data focusing on the quality of life and experience of care for women with metastatic breast cancer in the UK outside clinical trials.

## Methods

To ensure participation of a large number of women with metastatic breast cancer in the study, a cross-sectional survey using quantitative methods as well as open and closed free text questions was used. Women were identified in local cancer centres as well as by recruitment through a national on-line recruitment campaign.

Women with metastatic breast cancer attending for treatment or follow-up in two cancer centres in the South East of England were recruited over a 24-month period. Concurrently women responding to a media campaign about the study were invited to complete the survey using the website of a UK-wide breast cancer charity.

### Sample size

It was estimated that around 300 women in total may be available to be approached from the cancer centres. Assuming a contact, consent and response rate to the survey of 60% we aimed to yield a sample of 180 women from the cancer centres. The number of likely cases from the website was unknown, but the target sample size was set at 100. The sample size was determined by availability of women rather than by statistical power. However, a total sample of at least 220 women split approximately one-third to two-thirds for bone metastases versus visceral metastases would provide 80% power to detect standardised differences of 0.4 between the two groups in terms of the FACT B and experience with care subscale scores.

### Participants

All women attending breast cancer treatment and follow-up clinics in the two cancer centres were screened by searching their medical notes. All those with a confirmed diagnosis of metastatic breast cancer were identified and approached by the author in one cancer centre and a research nurse in the second to participate in the study. Some women were identified but not approached at the time due to a number of reasons such as the fact that they were receiving information about disease progression and were distressed by their situation at that time or were felt to be in the midst of making decisions about their treatment. In these cases, they were approached at a later, more appropriate time. All women approached were given the study information sheet and at least 24 hours to consider study participation. Subject to consent they were asked to complete a questionnaire either face to face or to return it in a pre-paid envelope.

Concurrently, the same survey was placed on the website of a UK-wide breast cancer charity. The author undertook media promotion about the study on national radio, news websites and local radio stations to call for women with metastatic breast cancer to take part in the on-line survey.

Ethical approval was granted by the Southampton and South West Hampshire LREC.

The inclusion criteria were a confirmed diagnosis of metastatic breast cancer for women recruited in the cancer centres and website participants were asked to describe the extent of their metastatic disease.

To avoid duplication, postcodes were checked to ensure none had taken part in both the cancer centre and website survey or submitted more than one response to the website survey.

Subject to consent, women were asked to complete questionnaires about their quality of life, personal experience of care and support needs and how they sought support to address these.

## **Outcome measures**

The functional assessment of cancer therapy – breast (FACT-B), a self-administered questionnaire, was used to assess quality of life and symptom burden. This multidimensional instrument was chosen because it consists of domains which the study aimed to investigate, measuring physical wellbeing, social/family wellbeing, emotional wellbeing, functional wellbeing and breast cancer-specific concerns.

The total FACT-B score is calculated by adding the results for each domain. The questionnaire has a total of 37 items asking women to rate how true each one is for the period of the last seven days. Response scales range from 0 (not at all) to 4 (very much). The FACT-B questionnaire has been shown to have high internal consistency/reliability and has been well validated as a patient-reported outcome measure<sup>11, 12</sup>.

The experience with care measure incorporated 34 items in three domains (information and advice, personal experience of care and satisfaction with care) with each individual item rated on a five-point Likert scale, as well as an overall rating of support received<sup>13</sup>. The 'information and advice' domain consisted of 11 items which considered the level of information and advice given and whether the women knew where to seek further

assistance. The 'personal experience of care' domain consisted of 10 items and considered the quality of communication with healthcare professionals, and whether the participant felt valued and heard. The 'satisfaction with care' domain consisted of 13 items relating to the thoroughness of care and whether the women's needs and concerns were addressed. Ratings of level of support received were assessed on a visual analogue scale from 0 -10.

For women from the cancer centres, clinical data relating to breast cancer diagnosis and treatment were collected from their medical notes.

Socio-economic status was measured using the Townsend deprivation index<sup>14</sup>, derived from postcodes.

Open text questions explored the experience of living with metastatic breast cancer, specifically the women's physical, emotional and social problems and needs and where they sought support for these. Access to support services was determined using specific questions about which healthcare professional the women would choose to see regularly and why.

## **Statistical methods**

FACT- B subscale scores were calculated using standard methods and summarised according to subgroups of survey participants using mean and standard deviation (SD). For the experience of care data, a positive response was defined for each item in the questionnaire by grouping the higher two categories (agree/strongly agree or very/completely satisfied) out of five options. Then for each woman the number of positive responses was summed separately within each of the three domains (information and advice, personal experience with care, and satisfaction with care). The number of positive responses in each of the three experiences of care domains was then converted to a percentage out of the number of questions in each domain in order to facilitate comparisons between the domains, since they were based on a different number of questions. These percentages represented the proportion of items within an experience of care domain for which an individual participant gave a positive response. Mean (SD) percentages of positive responses for each domain of the satisfaction with care questionnaire were used to summarise across groups of women. Although the distributions of the satisfaction with care subscales were skewed, it was not possible to find a suitable transformation to normalise the data; results were checked using non-parametric methods, which made very little difference so have not been presented.

Where there were missing items, FACT-B subscales were calculated on a pro rata basis according to the number of items in a scale which were completed (providing at least 50% of the items were available), as recommended in the FACT-B scoring manual (there was no item with less than 50% data available). Since no similar guidelines exist for the satisfaction with care module, no adjustment for missing data was done for these subscales.

Analyses were carried out to assess how self-reported quality of life and experience of care varied according to a number of pre-specified demographic and clinical characteristics including age, marital status, whether or not the woman had children, socioeconomic status, time since diagnosis of metastatic disease, and site of spread.

In order to account for multiple testing, a more conservative cut-off of  $p=0.01$  was taken to indicate statistical significance.

We compared mean scores of the FACT-B and experience with care measures subscales between groups using t-tests and one-way analyses of variance for the univariate analyses. In order to take into account associations between clinical and demographic characteristics all factors were entered into multiple linear regression analyses to determine independent associations with the FACT-B and experience with care subscales. The chi-squared test was used to test associations between categorical variables, such as patient characteristics with place of recruitment and some elements of the experience with care questionnaire. Trend tests were used where appropriate.

FACT-B and experience of care data were analysed using SPSS. Open text responses about support needs were transcribed verbatim and analysed by the author using the qualitative research software NVivo. Categorical indexing was generated from the original themes of the open questions, and sub-categories generated within these identifying the key themes<sup>15</sup>. Themes generated from the analysis were verified by a second researcher.

The survey was piloted face to face and online and appeared to yield broadly consistent responses from each method of recruitment.

## **Results**

### **Participants**

In total 235 women with metastatic breast cancer completed the study questionnaires. One hundred and thirty six women consented to take part from the two cancer centres (72.3% of the 188 women identified with metastatic disease) and 110 completed the questionnaires (a response rate of 80.8%). Recruitment of two women was considered inappropriate by their oncologist. One woman had poor cognitive ability and one was close to the end of life.

A total of 221 women looked at the on-line survey, 135 completed it and 125 correctly described themselves as having metastatic breast cancer. Nineteen website responses (17.2%) were repeated submissions of questionnaires so were excluded and a further ten (9.9%) women who described regional recurrence were excluded.

The age range of cancer centre participants was 25-84 with a mean age of 58. Website participants' ages were collected in ranges, therefore the overall mean age score cannot be calculated. Website participants were significantly younger ( $<0.001$ ). Forty two percent of website participants were aged between 45 and 55 compared with 27% from the cancer centres, whereas 35% of those recruited from cancer centres were over 65 years compared with 2% from the website. Participants from both cancer centres were recruited from urban and rural areas. There were similar distributions between the cancer centre and website participants for all demographic variables other than age. The sociodemographic profile of each cancer centre was similar. Ninety five percent of participants were of white ethnic origin. The median time since diagnosis of metastatic disease was two years (range 1 week - 15 years) (Table 1).

Within the whole study population ( $n=235$ ), 75 women (31.9%) had metastatic disease confined to bone, whilst the remainder had visceral disease with or without bony metastases (159/67.7%) (one unknown) (Table 1).

### **Clinical characteristics of cancer centre participants**

It was not possible to collect accurate clinical characteristics from the online participants. Of the cancer centre participants ( $n=110$ ), six (5.5%) had initially presented with metastatic breast cancer but the majority 93 (84.5%) were treated for early stage disease (for the remaining 10% this datum was unknown). For those

women developing metastatic disease after primary breast cancer treatment the median time interval between primary diagnosis and development of metastatic disease was four years (range 9 months - 23 years) (Table 2).

Of the cancer centre participants 37 (33.6%) had bone metastases only, seven (6.3%) had nodal disease only, 18 (16.3%) had a single visceral metastatic site, 47 (42.7%) had multiple metastatic sites (two or more) and 1 (0.9%) had unknown site (Table 2).

At the time of recruitment to the study the majority of women were receiving hormonal therapy or chemotherapy, in some cases in combination with trastuzumab and in over half with bisphosphonates (Table 2).

### **Quality of life**

The mean scores for overall quality of life and for each of the domains were low (reflecting worse quality of life) when compared with normative data derived from the 295 patient validation sample for the FACT-B questionnaire, where only 20% of women had distant metastases<sup>12</sup> (Table 3).

Pain and other symptom scores for the women indicated concerns with symptom control, with 81 (34.5%) scoring 'quite a bit/ very much' (the two highest scoring categories) to the statement 'I have certain parts of my body where I experience significant pain'. Those with bone metastases only were more likely to report significant pain (33/75, 44.0%) compared with other metastatic sites (48/158, 30.4%). In addition, lack of energy was reported as 'quite a bit/very much' by 89 (37.9%), nausea by 62 (26.4%), shortness of breath by 63 (26.8%). Interestingly, there was no relationship between time since diagnosis of metastatic breast cancer and symptom burden, indicating that uncontrolled symptoms may be a problem throughout the illness trajectory and not necessarily worsening with disease progression. There was a small association between time since diagnosis and pain (worsening as the disease progresses) but this was not statistically significant.

Univariate analysis of associations between demographic/clinical characteristics and the FACT-B QoL subscales is seen in Table 4. Having children was associated with lower functional wellbeing. There was some evidence to suggest that physical wellbeing diminished with increasing age and that social wellbeing improved with increasing age although this was not statistically significant. There was also some suggestion that emotional wellbeing improved as time increased since the diagnosis of

metastatic disease but again this showed only borderline significance. There was no significant association between deprivation scores and quality of life (Table 4). In multiple regression analysis, social wellbeing was significantly better for older women ( $p<0.001$ ) and in those with bone metastases only ( $p=0.002$ ). Functional wellbeing was significantly higher in women without children ( $p=0.004$ ). There were no statistically significant associations with the breast cancer or total FACT-B scores, and no significant associations for marital status and deprivation with any of the subscales. Unsurprisingly those receiving chemotherapy had lower functional wellbeing than those receiving hormone therapy ( $p=0.007$ ).

### **Experience with care**

Just over half of the women highlighted dissatisfaction with the items related to information and advice (Table 5). Satisfaction with their personal experience of care was higher (mean positive responses 71%), whereas for satisfaction with care the mean percentage of positive responses was less than 50%. The mean overall rating of support received was only 6.0 (SD 2.4), measured on a visual analogue scale from 0-10 (Table 5).

In a univariate analysis, women aged over 65 years, those with site of spread other than bone and those recruited from a cancer centre were more satisfied with the information and advice they had been given. Older women and those recruited from a cancer centre were more satisfied with their personal experience of care and were also more likely to feel well supported (Table 6). There was some indication that those with bone metastases only were less satisfied with their care, felt less supported and rated the support they received as lower although these findings were only approaching statistical significance. These findings highlight that younger woman and those with bone metastases only may have poorer experience of care.

Multiple regression analysis supports these findings with younger women being less satisfied with the information and advice they received ( $p=0.003$ ) and their personal experience of care ( $p<0.001$ ) and more likely to rate the overall support they received as lower than older women ( $p<0.001$ ). Women with children were less satisfied with their personal experience of care ( $p=0.007$ ) and less satisfied with the care they received ( $p=0.002$ ).

Again, multiple regression analysis suggests that those with bone metastases only may be less satisfied with the information and advice they received ( $p=0.05$ ), with their experience of care ( $p=0.03$ ) and less likely to feel well supported ( $p=0.03$ ) in



comparison to those with metastatic disease in sites other than bone although these findings are only approaching statistical significance.

There were no statistically significant associations for marital status and deprivation with any of the experience with care domains.

Open text responses aimed to elicit reasons for dissatisfaction with the experience of care. Women revealed that the experience of being diagnosed with metastatic breast cancer compared unfavourably to the experience of the primary diagnosis. They highlighted dissatisfaction with the provision of information and support from healthcare professionals in comparison to their experience of being diagnosed with early stage disease when the participants described feeling well supported and in receipt of adequate information.

### **Relationships with healthcare professionals**

The women appeared to have limited contact with their general practitioners (GP) and with specialist palliative care services, with only 20 (8.5%) choosing their GP and 17 (7.3%) choosing a palliative care nurse as the healthcare professional they would want to see regularly. When asked which healthcare professional they would choose to see on a regular basis, the majority indicated this was their hospital consultant, 146 (62.1%). The reasons given were being confident in their knowledge and expertise, the specialist's familiarity with the individual's cancer and treatment, and ease of access. The choice of healthcare professional was also determined by their perceived qualities such as trust, mutual respect, approachability, empathy, ease of access, and the ability to act effectively on the individual's behalf.

Responses to the open text questions indicated that the nature and quality of interactions with healthcare professionals had an impact on how women coped with their situation. When the women established a good relationship with the healthcare professionals involved in their care, they felt respected and treated as an individual. Thematic analysis of free text questions relating to the experience of metastatic breast cancer revealed insights into some issues that are important to women living with progressive disease. The majority (162, 68.9%) felt that their main source of psychological support was from family and friends while a small number (33, 14%) felt unable to burden those close to them so spoke to no one. Those who received formal support services felt these were beneficial but a significant number did not know how to seek formal support.

## Discussion

The women in this cross-sectional survey reflect the heterogeneity of women with metastatic breast cancer. Half the women had been living with metastatic disease for at least two years at the time they completed the survey and nearly one third had metastatic disease to bone only, a clinical subgroup with disease that is known to behave more indolently and thus have a better prognosis. Thus although the women in this study had significant disease burden from a life-limiting illness, few were necessarily at the end of life stage of illness.

Our findings unsurprisingly show that the overall quality of life of women with metastatic breast cancer is poor. Low scores were seen uniformly across all domains of the FACT-B instrument reflecting the impact of disease and treatment on all aspects of daily life. Scores appeared to be influenced by women's age and whether or not they had children. Younger age was associated with poorer social wellbeing and having children was associated with worse functional wellbeing. While we were unable to determine the association between these two variables, it could be considered that younger women are more likely to have aggressive disease, sequential treatments and may struggle to maintain their social roles, particularly in caring for children. This may be a sub-group of women with breast cancer who need particular attention.

Just over a third of women indicated that they were experiencing significant pain and among women with bone metastases, nearly half reported significant levels of pain suggesting that symptom control was inadequate. Given that these women were in regular contact with the cancer centres where there was also ready access to specialist palliative care services it would appear that women are not currently accessing the support they need.

We hypothesised that those with visceral disease would be more likely to have chemotherapy, have a greater disease burden, and so be more likely to have uncontrolled pain and other symptoms. So the finding that those with bone metastases and no visceral disease were more likely to have uncontrolled pain is interesting and significant. There was some indication that those with bone metastases only had poorer experience of care but these findings only bordered on significance and further research comparing site of metastatic spread and experience of care is needed. A possible explanation for these findings is that in contrast to those with visceral disease, who may be more likely to have chemotherapy and regular follow-up, those presenting with bone metastases alone are managed conservatively, commonly with hormonal

therapy and bisphosphonates, and may thus be seen less regularly by the clinical team than those receiving chemotherapy, resulting in fewer opportunities to seek information, support or symptom control. Again this may be a sub-group with specific unmet needs which are not addressed within current service provision.

The experience of care of women who participated in this study compared unfavourably with that reported by patients receiving treatment for advanced lung cancer<sup>16</sup> albeit in the context of a randomised controlled trial comparing nurse led follow-up with conventional clinic follow-up.

It appears from this survey that for women with metastatic breast cancer their main interaction with the health system is with their specialist oncologist. Few participants cited palliative care services or their general practitioner as the healthcare professional they would choose to see regularly. These findings are consistent with a previous study describing the care received by women with breast cancer during the last six months of life which found little evidence of GP or palliative care service involvement with women with advanced breast cancer, even when the patient is nearing death. The authors surmised that a low rate of deaths at home and a high rate of emergency admissions and subsequent deaths in acute care beds occurred as a result of care being delivered predominantly by hospital-based specialists in outpatient clinics<sup>17</sup>.

A possible explanation for the apparent lack of symptom management in our study may be that women with metastatic breast cancer are being actively treated throughout their illness trajectory. Therefore they are either not referred to palliative care services or are themselves reluctant to access palliative care services, associating these with end of life care.

## **Conclusion**

The findings from this study highlight that the multidimensional problems and needs of those living with progressive breast cancer are largely unmet. Living with metastatic breast cancer challenges the personal resources of the individual and poses interesting questions about how healthcare professionals provide information, effective symptom control and emotional and practical support to women with a significant disease burden where the illness trajectory is becoming increasingly unpredictable and complex due to life-prolonging cancer treatment and who may not be receiving support from palliative care services. We surmise that while much has been done to improve survival, insufficient attention has been paid to the wellbeing of those living with metastatic

breast cancer. These findings suggest that the quality of care for women with metastatic breast cancer has not kept pace with the development of life-prolonging treatment although further research specifically exploring this is needed. Improvements in symptom control, psychosocial support and information provision for women with metastatic breast cancer may improve their health and wellbeing and their experience of care.

In the UK, breast cancer clinical nurse specialists provide care for women with primary breast cancer from the point of diagnosis through their treatment and survivorship. However, provision of breast care nursing for women with metastatic breast cancer is currently inadequate<sup>18</sup>. To support service development for this population, core competencies and standards of care have been identified to assist in the development of support services for women with metastatic breast cancer<sup>19</sup>. While there is national guidance on the palliative and supportive care of those with advanced cancer<sup>20</sup>, clearly these services are not currently meeting the needs of this population. Palliative care services need to consider novel means of identifying those with metastatic breast cancer and ways in which they can work more closely with oncology services to address unmet need.

Longitudinal data exploring quality of life and experience of care over time are needed to build a more detailed picture of the challenges of living with metastatic breast cancer. Further research is also required to explore whether alternative models of service delivery can result in improvements in quality of life and experience of care.

Additionally, further research is needed exploring the relationship of site of metastatic disease with quality of life and experience of care.

## **Limitations**

The study is limited to insights gained from women at a single time point in the course of their metastatic disease and therefore cannot reflect the variability in quality of life and experience of care that individuals may go through during the course of their illness.

While neither the cancer centre nor the on-line participants can be said to be representative of all those with metastatic breast cancer, recruitment of women via the website enabled us to collect information from a group who were being treated in a variety of different settings, including women who may not be attending hospital follow-up. However, we acknowledge that it was reliant on self-reported disease and

treatment information and may have been subject to ascertainment bias and the volunteer effect.

Data were equivalent for the two sources of women though a younger and less socially deprived group of women responded to the on-line version of the survey. As the use of on-line surveys become increasingly popular, future research is needed to explore whether face-to-face and on-line surveys yield equivalent findings.

It is not currently possible to derive population numbers through cancer registries which would have allowed us to access a diverse population of women with metastatic breast cancer in the UK.

Despite these caveats we feel that this study reflects the experience of many women receiving treatment for metastatic breast cancer in the UK.

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**Table 1: Demographic and clinical characteristics of survey participants according to place of recruitment**

Characteristic	Cancer centres N= 110 (%)	Website N=125 (%)	Total N=235 (%)	$\chi^2$ test for comparison of place of recruitment p-value
<b>Age</b>				<0.001 <sup>a</sup>
25-44	12 (10.9)	43 (34.4)	55 (23.4)	
45-54	30 (27.3)	52 (41.6)	82 (34.9)	
55-64	29 (26.4)	26 (20.8)	55 (23.4)	
≥65	39 (35.5)	3 ( 2.4)	42 (17.9)	
Unknown	0	1 ( 0.8)	1 (0.4)	
<b>Marital status</b>				0.21
In relationship	75 (68.2)	97 (77.6)	172 (73.2)	
Not in relationship	31 (28.2)	26 (20.8)	57 (24.3)	
Unknown	4 ( 3.6)	2 ( 1.6)	6 ( 2.6)	
<b>Children</b>				0.96
None	20 (18.2)	25 (20.0)	45 (19.1)	
≥1	80 (72.7)	93 (74.4)	173 (73.6)	
Unknown	10 ( 9.1)	7 ( 5.6)	17 ( 7.2)	
<b>Townsend deprivation index quintile<sup>b</sup></b>				0.54 <sup>a</sup>
1=Most deprived	27 (24.5)	12 ( 9.6)	39 (16.6)	
2	19 (17.3)	19 (15.2)	38 (16.2)	
3	16 (14.5)	24 (19.2)	40 (17.0)	
4	19 (17.3)	21 (16.8)	40 (17.0)	
5=Least deprived	24 (21.8)	14 (11.2)	38 (16.2)	
Unknown	5 ( 4.5)	35 (28.0)	40 (17.0)	
<b>Time since diagnosis of metastases</b>				0.45 <sup>a</sup>
<6 months	31 (28.2)	32 (25.8)	63 (26.9)	
6-12 months	17 (15.5)	28 (22.6)	45 (19.2)	
1-2 years	30 (27.3)	33 (26.6)	63 (26.9)	
2-5 years	24 (21.8)	29 (23.2)	53 (22.6)	
>5 years	8 ( 7.3)	2 ( 1.6)	10 ( 4.3)	
Unknown	0	1 ( 0.8)	1 ( 0.4)	
<b>Site of spread</b>				0.73
Bone only	37 (33.6)	38 (30.4)	75 (31.9)	
Other	73 (66.4)	86 (68.8)	159 (67.7)	
Unknown	0	1 ( 0.8)	1 ( 0.4)	

<sup>a</sup> Trend test

<sup>b</sup> Townsend deprivation index unknown for 40 participants

**Table 2: Clinical characteristics of cancer centre survey participants at the time of recruitment**

Clinical characteristic	Total N = 110 (%)
<b>Time from primary diagnosis to metastatic disease</b>	
<1 year	13 (11.8)
1-2 years	20 (18.2)
2-5 years	37 (33.6)
5-10 years	21 (19.0)
>10 years	18 (16.3)
Unknown	1 ( 0.9)
<b>Site of metastatic spread at time of survey completion</b>	
Bone only	37 (33.6)
Nodal disease only	7 ( 6.3)
Single site visceral disease	18 (16.3)
Multi site disease (two or more sites)	47 (42.7)
Unknown	1 ( 0.9)
<b>Treatment at time of study recruitment</b>	
<b>Hormone therapy</b>	58 (52.7)
<b>Of those receiving hormone therapy:</b>	
First treatment	29 (50.0)
Second treatment	18 (31.0)
≥ Third treatment	11 (19.0)
<b>Chemotherapy</b>	48 (43.6)
<b>Of those receiving chemotherapy:</b>	
First treatment	30 (62.5)
Second treatment	11 (22.9)
≥ Third treatment	7 (14.6)
<b>Trastuzumab</b>	25 (22.7)
<b>Bisphosphonates</b>	60 (54.5)

**Table 3: FACT-B quality of life results for all 235 survey participants**

FACT-B quality of life Subscales	Total, N=235	
	Mean (SD): higher score reflects greater wellbeing	
	Study score	*Normative score
<b>Physical well being</b>	16.8 (7.4)	22.1(5.3)
<b>Social well being</b>	20.1 (5.6)	22.7(5.2)
<b>Emotional well being</b>	12.9 (5.3)	16.3(3.5)
<b>Functional well being</b>	17.3 (6.2)	20.6(6.4)
<b>Breast cancer score</b>	21.9 (7.5)	24.1(6.5)
<b>Total score</b>	89.0 (21.8)	112.8(20.9)

*\*Brady et al: Reliability and validity of the Functional Assessment of Cancer Therapy – Breast Quality of Life Instrument. Journal of Clinical Oncology, Vol 5, No 3 (March) 1997, pp974-986.*

*Missing data for social well being (2), emotional well being (1), functional well being (1), breast cancer score (1), total FACT-B score (3).*

**Table 4: Results of univariate analyses of associations between demographic/ clinical characteristics and FACT-B quality of life subscales for all 235 survey participants**

<b>Mean (SD) shown for all subscales</b>	<b>Physical well being</b>	<b>Social well being</b>	<b>Emotional well being</b>	<b>Functional well being</b>	<b>Breast cancer score</b>	<b>Total score</b>
<b>Age</b>	P=0.04	P=0.002	P=0.15	P=0.25	P=0.38	P=0.64
25-44	18.2 (6.8)	19.3 (4.8)	12.3 (4.8)	17.3 (5.8)	22.5 (6.6)	89.6 (18.8)
45-54	16.7 (6.8)	19.4 (6.1)	12.3 (5.6)	16.4 (6.7)	22.0 (8.1)	86.8 (23.7)
55-64	16.8 (8.0)	20.0 (5.5)	13.8 (5.0)	17.6 (6.2)	21.6 (7.5)	90.0 (21.0)
≥65	14.9 (8.1)	23.1 (4.8)	13.3 (5.7)	18.4 (5.9)	21.2 (7.6)	90.6 (22.9)
<b>Marital status</b>	P=0.60	P=0.46	P=0.84	P=0.85	P=0.71	P=0.93
In relationship	17.1 (7.1)	19.9 (5.0)	12.8 (5.2)	17.0 (6.2)	21.8 (7.4)	88.8 (21.5)
Not in relationship	16.5 (7.5)	20.6 (7.1)	12.9 (5.4)	17.2 (6.1)	22.3 (8.0)	89.1 (23.1)
<b>Children</b>	P=0.89	P=0.06	P=0.08	P=0.001	P=0.47	P=0.03
None	16.8 (8.2)	21.6 (4.6)	14.1 (5.5)	20.1 (4.4)	22.6 (9.1)	95.7 (23.1)
≥1	17.0 (7.2)	19.9 (5.7)	12.6 (5.2)	16.7 (6.4)	21.7 (7.2)	87.7 (21.4)
<b>Townsend deprivation index quintile</b>	P=0.82	P=0.31	P=0.44	P=0.65	P=0.45	P=0.51
1=Most deprived	16.1 (7.1)	19.6 (5.8)	12.2 (5.2)	17.3 (6.2)	22.0 (7.4)	86.9 (19.9)
2	17.2 (7.8)	21.6 (4.2)	13.3 (5.4)	18.8 (5.5)	21.0 (8.0)	91.8 (19.3)
3	16.9 (7.9)	19.9 (5.7)	12.6 (5.2)	17.0 (6.9)	21.6 (7.2)	88.0 (23.7)
4	16.6 (7.1)	19.8 (5.4)	12.2 (5.8)	16.5 (6.7)	22.9 (7.3)	88.0 (21.2)
5=Least deprived	16.8 (7.8)	21.8 (5.2)	13.7 (4.6)	17.7 (5.8)	22.5 (8.7)	92.5 (23.2)
<b>Time since diagnosis of metastases</b>	P=0.38	P=0.39	P=0.02	P=0.18	P=0.59	P=0.07
<6 months	16.4 (7.5)	19.7 (6.5)	12.5 (5.6)	16.8 (6.3)	22.3 (7.9)	87.6 (22.1)
6-12 months	17.2 (7.2)	20.2 (5.2)	11.3 (5.6)	16.5 (6.8)	21.1 (6.9)	85.8 (22.2)
1-2 years	15.4 (7.7)	20.1 (5.6)	12.7 (5.1)	17.3 (6.0)	20.4 (7.6)	86.0 (21.1)
>2 years	18.1 (6.8)	20.6 (4.9)	14.5 (4.7)	18.2 (6.0)	23.4 (7.3)	95.2 (21.1)
<b>Site of spread</b>	P=0.90	P=0.09	P=0.70	P=0.91	P=0.39	P=0.46
Bone only	16.9 (7.3)	19.2 (5.4)	12.6 (5.1)	17.3 (6.2)	21.2 (7.4)	87.3 (20.5)
Other	16.7 (7.4)	20.6 (5.6)	12.9 (5.4)	17.2 (6.3)	22.2 (7.6)	89.6 (22.4)
<b>Place of recruitment</b>	P<0.001	P<0.001	P<0.001	P=0.74	P<0.001	P<0.001
Centre 1	16.0 (7.4)	21.9 (4.3)	13.7 (5.2)	17.8 (5.8)	20.8 (8.0)	89.8 (21.8)
Centre 2	8.9 (6.4)	21.9 (5.7)	9.3 (4.2)	17.0 (7.4)	16.5 (4.9)	73.8 (11.4)
Website	19.6 (5.6)	18.6 (5.8)	13.4 (5.3)	17.1 (6.1)	24.2 (6.9)	93.0 (22.4)

*P-values shown correspond to F-test from analysis of variance (trend test for age, Townsend index and time since diagnosis)*



**Table 5: Responses to experience of care subscales for all survey participants according to place of recruitment**

<b>Experience of care Mean (SD)</b>	<b>Cancer centres N= 110</b>	<b>Website N=125</b>	<b>Total N=235</b>	<b>t-test for comparison of place of recruitment, p-value</b>
<b>Information and advice</b> % of positive responses out of 11 questions [range 0-100]	62.1 (22.4)	49.6 (24.8)	55.5 (24.5)	<0.001
<b>Personal experience of care</b> % of positive responses out of 10 questions [range 0-100]	78.4 (28.1)	64.2 (31.7)	70.8 (30.9)	<0.001
<b>Satisfaction with care</b> % positive responses out of 13 questions [range 0- 100]	52.4 (37.9)	44.5 (39.1)	48.2 (38.7)	0.119
<b>Overall rating of support received</b> [range 1-10]	7.5 (1.9)	5.0 (2.4)	6.0 (2.4)	<0.001

*Missing data for satisfaction with care (3), overall rating of support (43)*

**Table 6: Results of univariate analyses of associations between demographic/ clinical characteristics and experience with care subscales for all 235 survey participants**

	<b>Information and advice</b> <i>Mean (SD)</i> <i>% positive responses out of 11 questions</i>	<b>Personal experience of care</b> <i>Mean (SD) %</i> <i>positive responses out of 10 questions</i>	<b>Satisfaction with care</b> <i>Mean (SD) %</i> <i>positive responses out of 13 questions</i>	<b>Overall rating of support received</b> <i>Mean (SD)</i>	<b>Do you feel well supported at the moment?</b> Number (%) responding "yes"
<b>Age</b>	P=0.01	P=0.001	P=0.25	P<0.001	P=0.003
25-44	53.7 (24.6)	65.2 (30.3)	47.8 (39.0)	5.3 (2.4)	36 (65.5)
45-54	52.4 (25.1)	65.2 (34.4)	45.4 (38.6)	5.6 (2.7)	56 (70.0)
55-64	53.7 (22.8)	75.8 (27.1)	46.0 (37.7)	6.2 (2.3)	40 (80.0)
≥65	66.9 (22.3)	83.1 (24.8)	57.9 (39.3)	7.5 (1.9)	37 (90.2)
<b>Marital status</b>	P=0.73	P=0.76	P=0.64	P=0.84	P=0.82
In relationship	55.8 (23.9)	71.3 (30.2)	47.8 (37.5)	5.9 (2.4)	123 (74.1)
Not in relationship	54.5 (26.5)	69.9 (33.1)	50.6 (41.8)	5.9 (2.9)	43 (76.8)
<b>Children</b>	P=0.26	P=0.04	P=0.01	P=0.24	P=0.08
None	59.4 (22.6)	80.1 (24.1)	61.6 (38.6)	6.3 (2.7)	38 (86.4)
≥1	54.9 (24.6)	69.5 (31.9)	45.7 (38.1)	5.8 (2.4)	121 (72.0)
<b>Townsend deprivation index quintile</b>	P=0.68	P=0.08	P=0.26	P=0.51	P=0.72
1=Most deprived	55.4 (25.9)	61.3 (35.4)	44.2 (41.7)	6.0 (3.0)	28 (73.7)
2	60.0 (23.7)	79.7 (25.7)	55.1 (39.2)	5.9 (2.7)	30 (85.7)
3	52.3 (21.2)	70.0 (32.5)	45.5 (35.3)	6.1 (2.2)	27 (69.2)
4	52.3 (26.5)	64.5 (31.8)	43.0 (38.8)	5.9 (2.4)	29 (74.4)
5=Least deprived	62.0 (21.5)	82.6 (22.6)	61.9 (36.2)	6.6 (2.4)	27 (75.0)
<b>Time since diagnosis of metastases</b>	P=0.10	P=0.20	P=0.04	P=0.19	P=0.50
<6 months	53.0 (23.1)	69.9 (31.6)	43.6 (35.5)	5.8 (2.3)	46 (75.4)
6-12 months	51.7 (27.2)	63.8 (33.9)	42.1 (39.0)	5.5 (2.5)	31 (73.8)
1-2 years	57.9 (24.0)	72.8 (29.8)	49.1 (41.2)	5.8 (2.6)	41 (66.1)
>2 years	58.8 (23.7)	75.0 (28.8)	56.9 (37.9)	6.5 (2.5)	51 (83.6)
<b>Site of spread</b>	P=0.01	P=0.13	P=0.03	P=0.04	P=0.07
Bone only	49.8 (27.7)	66.4 (33.7)	40.1 (39.8)	5.4 (2.7)	50 (66.7)
Other	58.4 (22.2)	73.0 (29.4)	52.3 (37.5)	6.2 (2.4)	119 (78.8)
<b>Place of recruitment</b>	P<0.001	P<0.001	P=0.17	P<0.001	P<0.001
Centre 1	60.2 (21.5)	78.5 (28.0)	49.6 (36.7)	7.2 (2.0)	62 (89.9)
Centre 2	65.7 (23.9)	78.3 (28.9)	57.8 (40.1)	7.7 (1.9)	31 (88.6)
Website	49.6 (24.8)	64.2 (31.7)	44.5 (39.1)	5.0 (2.4)	76 (61.8)

*P-values for information and advice, personal experience of care, satisfaction with care, and overall rating of support correspond to F-test from analysis of variance (trend test for age, Townsend index and time since diagnosis.*

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